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A questionnaire based study on knowledge, awareness, and willingness towards corneal donation among the paramedical staff, public and students from Southern district of Tamil Nadu, India

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ABSTRACT

Background: To determine the knowledge, awareness, and willingness towards eye donation among paramedical health care providers, public and students from schools and colleges around Tirunelveli district, Tamil Nadu, Southern India.

Methods: It was a cross-sectional, observational study conducted from November 2019 to January 2020. A structured questionnaire regarding knowledge (K), awareness (A), willingness (W) for eye donation was used to elicit responses in the age group of more than 16 years. Participants were paramedical health care providers working in tertiary eye care hospital, school and college students, and attenders accompanying patients (addressed as public). Responses were collected from 1803 participants and analyzed statistically.

Results: Most of the participants had knowledge about the facts of eye donation, such as 96.8% knew that it could be donated after death, and 55% knew that eyes were enucleated within 6 hours after death. 56.2% admitted that lack of awareness is the reason for not donating eyes; 23.8% said that the family members are objecting to eye donation. Social media was proposed as the best source of information about eye donation. Subjects with an age of fewer than 30 years were willing to donate (the odds ratio was 1.90). However, they had less knowledge (p value=0.105) and awareness (p value=0.02) about eye donation than more than 30 years.

Conclusions: Even though awareness and knowledge about eye donation and willingness to pledge eyes are there, self-conscience regarding the need for donor corneas to meet the requirement of corneal blindness plays a pivotal role.

Keywords: Awareness, Willingness, Knowledge, Eye donation, South India

INTRODUCTION

Corneal diseases constitute the second most common cause of blindness next to cataract.¹ It is the primary cause of visual impairment and blindness in children and young adults.² The corneal transplant remains the primary source of sight restoration in these patients. According to the National Programme of Control of Blindness, there are currently 120,000 corneal blinds in India.³ Approximately

6.8 million persons have vision <6/60 in at least one eye due to corneal diseases, and both eyes are involved in one million persons. Every year there is an addition of 25,000 to 30,000 corneal blindness across the country. 4 Only 34% of donor corneas are received every year, which is sufficient to correct 28% of the blind persons. 5 Due to this, there is tremendous shortage of donors, and there is a long waiting time for keratoplasty in most of the tertiary eye care hospitals. According to population census 2011, the

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death rate was calculated as 7.2 per 1000 in India. According to the population statistics in Tirunelveli District, the approximate donor rate proportionate to the death rate is 5 per 1000, which is less. The utilisation rate is less and waiting time of patient is long. The understanding of why people do not donate eyes is a critical issue, hence our study aims to determine the knowledge, awareness and willingness towards eye donation among the paramedics, public and students from schools and colleges and to focus on the reason for undersupply of corneas and to design strategies for intervention to improve eye donation in Tirunelveli district.

METHODS

A cross-sectional, observational study was conducted from November 2019 - January 2020 for paramedical staffs (nurses, operation theatre assistants) from private multispecialty hospitals, for students from engineering and arts colleges, for higher secondary school students from Tirunelveli district, and the public attending hospital visits in Aravind eye hospital, Tirunelveli.

A structured questionnaire was presented in their local languages, and the responses were recorded from a total of 1803 participants. The results were statistically analysed. The questionnaire included 13 questions regarding knowledge (K), awareness (A), and willingness (W) for eye donation and its source of information. Privacy was ensured while administering the questionnaire. Inclusion criteria were age group more than 16 years, with the knowledge to read and write in their local languages, old patients with age more than 65 years, ill patients and subjects who did not consent for the study were excluded from the survey. The demographic characteristics such as age, gender, and the categorized groups were analysed for the variables such as knowledge, awareness, and willingness to donate with logistic regression statistical analysis. For this survey, "awareness "was defined as having heard of eye donation, "knowledge" is defined as understanding about eye donation facts and "willingness" involves the voluntary decision of the subjects to pledge their eyes for donation. This study's proposal was approved by the Institutional review board of Aravind eye hospital, Tirunelveli, Tamil Nadu, India. The study was done according to the guidelines of declaration of Helsinki. Participants signed an informed consent after agreeing to participate in the survey, and their information was treated confidentially.

Statistical analysis plan

Summary statistics (mean and standard deviation) were presented for continuous variables and (frequencies and percentages) for categorical variables. Logistic regression analysis was used to find the factors associated with knowledge, awareness and willingness about eye donation. Analyses were performed using STATA 14.0 (Texas,

USA). Statistical significance was set at p<0.05 with two-tailed test.

RESULTS

A total of 1803 participants (1255-females; 522-males) were interviewed, and the data statistically analysed. The mean (SD) age of the participants was 26.65 (14.5) years, with a range of 16–82 years. Demographic details are depicted in Table 1.

Table 1: Demographic of the study participants.

Variable	N (%)
Age	
Mean (SD)	26.65 (14.5)
Range	16–82
Sex	
Female	1,255 (69.8)
Male	548 (30.4)
Occupation	
Paramedical	469 (26.0)
Public	505 (28.0)
College students	524 (29.1)
School students	305 (16.9)

The following are the results of this survey regarding knowledge about eye donation (Table 2).

Table 2: Knowledge about eye donation.

Questions	N	%		
Are you aware that eyes donated after	r death w	vill		
give vision to some one?				
Yes	1746	96.8		
No	44	2.4		
Within how many hour eyes have to b	e enucle	ated		
after death?				
6 hours	992	55.0		
2 hours	619	34.3		
Who has right to give consent for eye	donation	1?		
Next of Kin	131	7.3		
In his own will	935	51.9		
Eye donation card alone written	716	39.7		
Who can donate eyes?				
Diabetes, HTN, asthmatic	108	6		
Age >2 years	868	48.1		
Glaucoma patients	38	2.1		
All the above	648	35.9		
What is the function of an eye bank?				
Buys and sells cornea	160	8.9		
Does tissue processing and storage of	1461	81		
donor corneas	1401	01		
What does eye donation mean to you?				
Service to mankind	243	13.5		
Giving sight to blind	904	50.1		
Donation of one's eye after death	614	34.1		

Within how many hours eyes have to be enucleated after death? (Q2)

Only 992 (55%) subjects out of 1803 knew that eyes have to be enucleated within 6 hours of death.

Who has the right to give consent for eye donation? (Q5)

Most of the participants proposed that consent for eye donation should be on his own will (51.9%), followed by an opinion that consent can be written in eye donation card by 716 participants (39.7%) and next to the kin has a right to give consent was given by 131 participants (7.3%).

Who can donate eyes? (Q6)

Amongst the 1801 subjects who responded, 48.1% felt that donor age should be more than two years, and 35.9% opined that anyone with systemic diseases (diabetics, hypertensive, asthmatics glaucoma patients) could donate eyes, 2.1% felt that glaucoma patients could donate eyes.

What is the function of an eye bank? (Q8)

The majority of the participants (81%) knew regarding the appropriate function of the eye bank as tissue processing and storage of donor corneas for transplantation.

What does eye donation mean to you? (Q11)

50.1% of the subjects explained eye donation as giving sight to the blind, and 34.1% defined it as the donation of one's eye after death; 13.5% thought it is a service to humanity.

The source of information about eye donation obtained from the following questions.

How did you get information about eye donation? (Q3)

Social media (39.1%) was the primary source of eye donation followed by eye donation awareness programs (31.1%) and health care workers in 17.6%, family, and friends in 13.4%.

The following questions give information about the awareness of eye donation (Table 3).

Are you aware that eyes donated after death will give vision to someone? (Q1)

The majority of the participants (96.8%) understood that eyes could be donated after death.

What do you think is the reason for not donating eyes? (04)

Lack of awareness (56.2%) was suggested as the major obstacle in eye donation by the majority of the respondents

followed by an objection from the family members (23.8%), 8.2% were not aware of the contact numbers, 6% consider eye donation as a business, 4.8% believe that corneal transplant yield poor results and 4.6% said religion as a restricting factor for donating eyes.

Table 3: Awareness about eye donation.

Questions	N	%		
How did you get information about eye donation?				
Social media	705	39.1		
Doctors and nurses	317	17.6		
Family and friends	241	13.4		
Eye donation awareness program	560	31.1		
What do you think is the reason for n eyes?	ot donati	ing		
Lack of awareness	1013	56.2		
Objection from family	430	23.8		
Eye donation is business	109	6.0		
Religious restrictions	83	4.6		
Corneal transplant yield poor result	86	4.8		
Not aware of contact numbers	147	8.2		
Can eyes be removed at donors house	itself?	-		
Yes	620	34.4		
No	527	29.2		
Not sure	607	33.7		
Are you willing to take the social responsibility in				
promoting eye donation awareness among public				
and encourage deceased family for eye donations?				
Yes	1326	73.5		
No	316	17.5		
What do you think is the best way to promote eye				
donation awareness among public?				
Self-realisation on the need for donor corneas	490	27.2		
Through public meetings, news paper	325	18		
Through ad, television, radio	629	34.9		
Through internet	400	22.2		

Do you know any of your relatives who have made eye donation? (Q7)

Surprisingly, only 18.6 % of subjects had a relative who has made eye donation.

Can eyes be removed at the donor's house itself? (Q9)

Only 34.35 % of the participants were aware that the eyes could be removed at the donor's house itself; most of them were not sure (33.7%), 29.2% said it can't be removed at deceased house.

Are you willing to take the social responsibility in promoting eye donation awareness among the public and encourage the deceased family for eye donations? (Q10)

One thousand three hundred twenty-six subjects (73.5%) out of 1803 showed a willingness to take social

responsibility in promoting eye donation awareness among the public and encourage the deceased family for eye donation.

What do you think is the best way to promote eye donation awareness among the public? (Q13)

According to the responses, the best way to promote eye donation would be through television, radio (34.9%), self-realization (27.2%). The promotion through the internet was considered best in only 22.2%.

Question number 12 gives information about the willingness of the participants in the survey (Table 4).

Table 4: Willingness to donate.

Q12	N	%
Yes	1053	58.4
No	214	11.9
Not sure	481	26.7

Are you willing to donate your eyes? (Q12)

58.4% of individuals were willing to donate eyes, 11.9% said no to donate their eyes, and 26.7% were not sure of eye donation.

Logistic regression analysis was used to describe data and explain the relationship between willingness, knowledge, and awareness with variables such as age, gender, and various groups. Participants less than 30 years have better social responsibility and willingness to donate eyes compared to more than 30 years age group (odds ratio of 1.90, 95% CI, 1.19 to 3.04, p value=0.007). The willingness for eye donation does not significantly (P= 0.140) vary among males and females. After comparing the willingness to donate, among public 68% (OR=0.32, 95% CI, 0.18 to 0.56, p value<0.001), college students 75% (OR=0.25, 95% CI, 0.15 to 0.42, p value<0.001) & school students 82% (OR=0.18, 95% CI, 0.11 to 0.32, p value<0.001), all of them have less willingness than paramedical staffs, among them public have better willingness compared to college and school students.

Age and gender of all the participants were not significantly associated with knowledge about eye donation. Compared to Paramedical staffs, the public 87% (OR=0.13, 95% CI, 0.08 to 0.20, p value<0.001), college students 89% (OR=0.11, 95% CI, 0.07 to 0.17, p value<0.001) and school students 94% (OR=0.06, 95% CI, 0.04 to 0.10, p value<0.001) have less knowledge about eye donation (Table 3).

Subjects of age less than 30 years were 34.0% (OR=0.66, 95% CI, 0.47 to 0.93, p value=0.02) not aware about the eye donation. The gender difference exists on awareness about eye donation, females were 1.36 times more aware than male (OR=1.36, 95% CI, 1.03 to 1.79, p value=0.03) and the awareness among the public 86% (OR=0.14, 95% CI, 0.09 to 0.20, p value<0.001), college student 94% (OR = 0.06, 95% CI, 0.04 to 0.08, p value<0.001) and school student 91% (OR=0.03, 95% CI, 0.02 to 0.05, p value<0.001) were less compared to paramedical peoples.

Table 5: Groups versus willingness to donate eyes – analysis by Chi-squared test.

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Groups	Yes (%)	No (%)	Not sure (%)	Total (%)	P value
College students	286 (27.16)	64 (29.91)	163 (33.89)	513 (29.35)	
Paramedical personnel	389 (36.94)	25 (11.68)	48 (9.98)	462 (26.43)	د0.001
Public	216 (20.51)	74 (34.58)	178 (37.01)	468 (26.77)	<0.001
School students	162 (15.38)	51 (23.83)	92 (19.13)	305 (17.45)	
Total	1,053	214	481	1,748	

DISCUSSION

Corneal blindness continues to be the major public health issue in developing countries.⁵ A Hyderabad population-based study identified the average age for blindness caused by cataract was 68 years and for corneal blindness was five years; hence it is evident that the corneal blindness is going to add, long term socioeconomic burden for the country every year.¹ Hence, addressing the problem with limited tissue availability becomes the prime factor in treating corneal blindness. Our study analyzed the awareness, knowledge, and willingness to donate among paramedical staff, students, and the public around Tirunelveli district to provide some strategies to improve the awareness and willingness in our locality.

Many authors have conducted similar studies involving the general population, students from medical colleges, nursing colleges, dental colleges. We have included the general population, paramedical staff, and students from higher secondary schools, arts colleges, and engineering colleges since they are the future care providers to society. Ours was the largest study (n=1803) next to Krishnaiah et al with 7775 participants. 6

Awareness in our study was 96.8% from the southernmost part of the country. In the most extensive study by Krishnaiah et al from Andhra Pradesh, the awareness was only 28%. Kauret from Haryana observed 76.9% awareness in the general group of 360 adults attending routine clinics of tertiary care hospitals.^{6,7} Similarly,

Sushma et al observed 99.2% awareness among 250 medical and paramedical students from Bijapur but Janti et al from Chennai reported 57% of awareness among 300 medical, dental and nursing students, Yew et al from Singapore reported highest awareness (80.7%) among the Singaporeans and Chinese compared to Malaysia, suggesting the region-wide variation is also an influential factor about the awareness. 9-11

In our study, the awareness was high among females (p=0.03), paramedical staff (p<0.001), and in the age group >30 years (p=0.02). Many authors have considered ethnicity and literacy levels as the predictor of awareness. Krishnaiah et al⁶.had observed females (OR=0.7), age group of >70 years (OR=0.2), and illiterates (OR=0.2) to be less aware, similar to Abaidoo et al and Bhandary et al.^{12,13}

Concerning willingness, we observed willingness to donate eyes in 58.4% of the subjects, they were <30 years (OR=1.90) and paramedical staff (p<0.001), gender association does not exist. In another study, age <40 years, males (36.6%), higher literacy level (OR=5.58), middle socioeconomic status (36.2%), Hindus (33.6%) were associated with a high tendency towards willingness. The willingness also varied region-wise (33.3%-Chennai, 80.7%-Karnataka, 59.9%-Ghana, 4.8%-Bijapur, 67%-Singapore and 70.04%-Haryana).^{7,10-12,14}

The reason for unwillingness was given as the lack of awareness (56.2%) in our study group. Many studies had discussed the various reasons for Unwillingness of the subjects to eye donation (Table 6).

Table 6: The percentage of most frequent reasons reported by authors in their study.

Most frequent reason for unwillingness	Authors	%
	Bijapur et al	83.9
Disfigurement	Abaidoo et al	55.81
	Kaur et al	63.86
	Yew et al	73.2
Religion does not permit	Bhandary et al	31
Need more information	Krishnaiah et al	50.6
Refusal to discuss about eye donation at the time of crisis	Tandon et al	45.5
Lack of awareness	Our study	56.2

In our study, the knowledgeable groups about the facts of eye donation, were paramedical staff, followed by the public (OR=0.13), and college students (OR=0.11). Age and gender did not influence the knowledge of eye donation. Similarly, the study by Janti et al, medical students (67.3%) knew better information than nursing and dental students. Sushma et al felt that although 67.2–99.2% of subjects knew the facts of eye donation, the attitude and practice showed mixed responses in 45.6%.

Krishnaiah et al also felt that there is a need to transfer knowledge if more eyes are to be pledged. ⁶

Although vast knowledge and awareness about facts of eye donation were present in our study group, willingness to pledge, eyes were comparatively less. The reasons may be variable; it is imperative for us to improve the awareness and increase the actual eye donation, through several strategies. In our locality, the Source of information about eye donation was less through awareness programs (31.1%), through health care workers (17.6%) compared to social media (television and radio)-39.1% (Table 7). Thus to realize the dream of achieving adequate donors to treat corneal blindness, the ophthalmologists, health care workers, religious leaders, general physicians, nongovernmental organizations have to work together to motivate people to donate eye.

Table 7: The source of information about eye donation reported in different authors in various studies.

Source of information	Authors	%
Social media and television	Sushma et al	60.8
	Janti et al	64
	Krishnaiah et al	79.2
	Kaur et al	19.86
	Our study	39.1
Public campaigns	Priyadarshini et al	40.86
News paper	Bijapur et al	91.4

The strategies that have worked well in other parts of the world, 'presumed consent law' introduced in 1975 in the USA, is a novel idea of improving the donor corneas through legal sanction. Such legislation can be considered in our country also to achieve our dream. Another concept is the 'required request law' wherein it becomes mandatory for all healthcare workers to contact the bereaved families to make a request for eye donation, which can be enacted. Eye donation awareness programs can be integrated with health care campaigns, school health programs, child survival, and safe motherhood programs, cataract camps, entertainment channels, movie theatres.

There is a greater need to educate school students and college students about the importance, facts of eye donation, and preventive measures of corneal blindness in school and college books. Inclusion of facts about eye donation in the education system will increase the social responsibility of the students from a younger age. Frequent surveys conducted on a different group of subjects from various field of occupations is also an approach to improve the eye donation.

Our study's limitation is that the results could not be generalized for the Tirunelveli district since only a few selected groups of subjects were included. A house to house survey would have been a better option for our study. The shortage of transplantable corneas is the bottleneck in reducing blindness due to corneal diseases.

CONCLUSION

This survey has provided insights on understanding the reasons why people around Tirunelveli district are reluctant to donate eyes, and this survey itself has promoted awareness and educates the participants while filling the questionnaires. People are willing to take responsibility for eye donation, but there is a need to broaden the ways for education and information regarding the same. The promotion of suggested strategies with government aid can be an appropriate concept to promote eye donation from pledging to actual donation in the community.

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