

Eye Donation Awareness and Conversion Rate in Hospital Cornea Retrieval Programme in a Tertiary Hospital of Central India

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ABSTRACT

Introduction: Corneal blindness accounts for 6–8 million blinds in the world. In India, it is estimated that there are approximately 6.8 million people who have vision less than 6/60 in at least one eye due to corneal diseases.

Aim: This study was done to assess the awareness about eye donation amongst attendants of critically ill and deceased patients, their willingness to donate eyes, the efficacy of grief counselling by Eye Donation Counsellors (EDC), its impact on the conversion rate and the reasons for poor donation rate.

Materials and Methods: This prospective hospital based study was done in 554 participants (guardians of critically ill and deceased subjects) to understand the awareness of eye donation. Factors related to willingness for eye donation that influenced conversion to actual donation were evaluated. Data was analysed with tests for statistical significance: Chi square

test; $p < 0.05$ at 95% confidence interval was set as significant.

Results: Awareness index particularly in males <40 years, was found to be statistically more. In participants who were partially/fully aware of eye-donation, time taken for motivation remained less than 12 hours, which was statistically significant (Chi square=106. $p < 0.001$). Subject who were aware, willing for donation in comparison to those who were unaware in a ratio of 2:1. Grief counsellors (57.5%) had the most influence among the causes that were facilitators of donation.

Conclusion: Utilizing the services of eye donation counsellors is a promising way to motivate the guardians of deceased. Increasing the awareness in society, rendering simple assistances to next of kin and speeding the medico legal formalities can go a long way in increasing the conversion rate and hence actual donation.

Keywords: Corneal blindness, Corneal transplantation, Eye donation counsellors, Retrieval rate

INTRODUCTION

Globally, approximately 6 to 8 million people are blind due to diseases affecting cornea [1]. In India, approximately 6.8 million persons are having vision less than 6/60 in at least one eye due to corneal diseases and both eyes are involved in approximately one million persons [2,3]. By 2020, India will have approximately 10.6 million cases of unilateral corneal blindness [3]. National Programme for Control of Blindness (NPCB) data shows that currently 1,20,000 persons are affected due to corneal blindness with an addition of 25,000-30,000 cases of corneal blindness every year [4]. To address this high prevalence of corneal blindness, approximately 2,50,000 corneas are needed per year as against total number of corneas donated per year of 25,000. Therefore, there is a huge backlog of 2,25,000 donated corneas every year. To tackle this high incidence of corneal blindness, corneal transplantation has emerged as the main sight restoration procedure which is mainly dependant on voluntary eye donation by suitable donors [1].

Despite increased public awareness about eye donation over the years, there is tremendous shortage of donor corneas and there is a waiting period of more than six months for corneal transplantation in patients at most hospitals across the country.

Looking into this tremendous dearth of corneas for transplantation, an adequately planned approach is the need of the hour which can have a significant impact on donation rate and it may be worthwhile to study the causes and reasons for this meager donation rate which can be beneficial in preparing strategies to increase the donation rate.

Pledged corneas cannot be retrieved without the consent of the family and almost always it is the decision of the attendants of the critically ill or brain dead patients with no hopes of survival that decides the

fate of cornea retrieval. However, at the time of death, in the midst of grief and confusion and also improper knowledge regarding the facts of eye donation, even the best of intentions may not lead to an actual eye donation. Main source of cornea retrieval till now has been voluntary eye donation. An important way to increase donation can be done by making general population aware and motivated to help increase the donation rate. Hospital Cornea Retrieval Programme (HCRP) has proven to be an effective technique for eye donation in various secondary and tertiary hospitals which cater to critically ill/brain dead patients with no hopes of survival. These potential donors if counseled adequately and effectively can constitute a substantial number of eye donors. There have been many studies in past which have reported the awareness and willingness for eye donation amongst general public [5-9] However, there have been very few studies which have reported the willingness for eye donation with reference to HCRP [6,8].

Aim of this study was to assess the awareness about eye donation amongst attendants of critically ill and deceased patients and their willingness to donate eyes, to assess the efficacy of grief counseling by EDC and to assess the impact of above factors on the conversion rate. Also, the reasons leading to poor donation rate were evaluated in detail. Hence, the study effectively put forth the efficacy of present strategies of grief counseling indicating any improvisation in technique to increase the conversion rate of eye donation after grief counseling.

MATERIALS AND METHODS

A prospective hospital based study for a period of one year (March 2014 to March 2015) was conducted in a tertiary eye care hospital of central India, relating to awareness of eye donation amongst

attendants/guardians of the critically ill and deceased subjects. This hospital associated with a medical college caters to approximately a total of 1300-1500 patients on outpatient basis per day. A total of 554 participants were included in the study after written and informed consent, mainly attendant/guardians of the deceased and critically ill subjects admitted in intensive care units of various departments (Medicine, Surgery, Paediatrics, Cardiology). Approval to conduct the study was obtained from Gandhi Medical College Institutional Ethics Board and the study confirms to the guidelines of Declaration of Helsinki.

Departments with high mortality rate were specifically targeted for grief counseling under HCRP. The participants answered a structured (closed) questionnaire prepared in the most local spoken language (Hindi) that included demographic profile, awareness of eye donation, knowledge regarding facts of eye donation, and willingness to donate eyes. Information regarding other aspects of eye donation was also evaluated. Various factors related to willingness for eye donation which function as facilitators for conversion to actual donation were evaluated. The data obtained was analysed with tests for significance with appropriate statistical indices: Chi square test; $p < 0.05$ at 95% confidence interval was set as significant. Results obtained adequately reflected the reasons serving as hindrances and facilitators for eye donation.

The study included trained grief counsellors who took detailed rounds of different wards in the hospital daily. These were the emergency medical wards; cardiology wards, surgical wards, casualty and mortuary. During rounds, patients who were critically ill due to any disease including septicaemia, malignancies or those who were on ventilator regardless of duration or brain dead patients due to any cause were identified. Attendants were informed about the utilization of corneas for optical, therapeutic and research purposes. A thorough study of their case records was done to know the clinical profile. The counsellors met the relatives and families of these patients to establish a bonding, to know their problems and to offer help and advice. This bonding often helped the relatives to open up and speak to the counsellors about the problems they were facing. Counsellors followed up the patients over a period of 1-3 days and were able to deliver all possible assistance to the attendants/relatives regarding any treatment related or any medico-legal formalities and any other help. During this period, they gradually and empathetically made the families aware about eye donation, its role in imparting vision to two blind persons and cleared myths related to it. On death of the deceased, the families were counselled and were offered all assistance in medico-legal and other formalities. While doing so, the relative's willingness to donate eyes of the deceased was noted and when positive, they were further convinced to do so.

To maintain uniformity of information regarding the awareness of eye donation, a well thought over questionnaire [BOX 1] was formulated and systematic data was collected. This consisted of sociodemographic profile of the participants with emphasis on socioeconomic and education profile. Closed questionnaire consisted of 10 related questions and each individual was assigned an awareness index depending on the number of questions he was able to answer. For the purpose of statistical analysis, we divided the study subjects into three groups and formulated an awareness index according to number of answers given. Awareness index was formulated for the study and was evaluated for each patient as per the questionnaire design.

The awareness index was defined as:

- (1) **Aware:** Answered 6-10 questions;
- (2) **Partially aware:** Answered 1-5 questions;
- (3) **Not aware:** Answered 0 questions.

Those who were reluctant to donate, a gentle approach to know the reasons for not donating was inquired and evaluated. Any favourably modifiable situation when possible was guided towards donation. However, the relatives were never forced for obligatory donation. All these were carried out keeping in mind the emotional aspects of the

family and relatives of the deceased. Even in cases which did not lead to donation, awareness regarding eye donation was given.

STATISTICAL ANALYSIS

The data was then statistically analysed and studied for correlation between various factors that were thought to play an important role. The relationships between awareness of eye donation, willingness to donate eyes and demographic factors such as age, gender, socioeconomic status, education and religion were assessed using the Chi square test and $p < 0.05$ within 95% confidence interval.

RESULTS

With reference to awareness index it was seen, that out of 554 participants, 53 were categorized as aware; 190 as partially aware and 311 as not aware. Awareness Index with respect to age, gender, socioeconomic status, educational status and religion is depicted in [Table/Fig-1,2]. Total of 554 participants were included in the study. These participants were first degree relatives of critically ill or deceased subjects and underwent assessment through a carefully designed questionnaire. The data acquired in the study comprised of: awareness index of patients; Sociodemographic details; Facilitative and hindrance factors for conversion.

After evaluating the socioeconomic status, participants were categorized into upper middle and lower socioeconomic classes as per BG Prasad's [10] classification. Total of 84.03% participants from lower socioeconomic strata were not aware of eye donation and it was seen to be more in higher socioeconomic strata. (Chi square 27.24; $p = 0.0018$). The result is significant at 95% confidence interval. The findings with respect to education also showed

Variable	Aware (6-10)		Partially aware (1-5)		Not aware (0)		Total Statistical significance	
	n	%	N	%	n	%		
Males	33	8.77%	118	31.38%	225	59.84%	376	Chi square= 6.5182. $p=0.038423$. Significant.
Females	20	11.23%	72	40.44%	86	48.31%	178	
Males <40	27	13.04%	98	47.34%	82	39.61%	207	Chi square =78.4213. $p < 0.001$. Significant.
Males >40	6	3.55%	20	11.83%	143	84.61%	169	
Females <40	09	10.46%	35	40.69%	42	48.83%	86	Chi square =0.0999 $p=0.951261$. Not significant
Females >40	11	11.95%	37	40.21%	44	47.82%	92	
Muslim	01	2.38%	01	2.38%	40	95.23%	42	Chi square= 28.3268 $p < 0.001$. Significant
Hindi	52	10.15%	189	36.91%	271	52.92%	512	

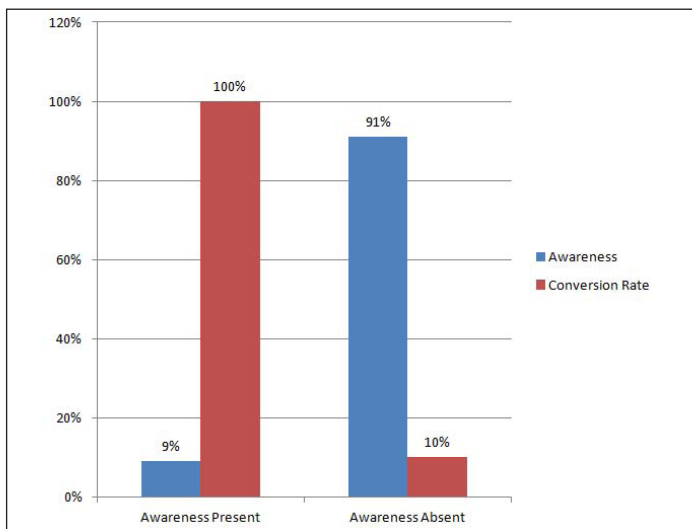
[Table/Fig-1]: Awareness index of participants with reference to gender, age, religion.

Socio-economic Status	Aware		Partially aware		Not aware		Total	Statistical significance
I - II	01	12.5%	01	12.5%	06	75%	08	Chi-square= 27.2438. $p=0.0018$. Significant
III - IV	17	7.11%	23	9.62%	199	83.26%	239	
V	-	-	49	15.96%	258	84.03%	307	
Education								
Primary	-	-	51	22.56%	175	77.43%	226	Chi square =79.0261 $p < 0.001$. Significant.
Secondary	-	-	47	32.41%	98	67.58%	145	
Graduate And above	23	12.56%	11	6.01%	149	81.42%	183	

[Table/Fig-2]: Awareness index with reference to socioeconomic status and education.

Time taken for conversion	N	%	Average time	Statistical significance
Motivated (106) Prior knowledge	31	29.2%	<12Hours	Chi square =106. p<0.001. significant.
Hospital counselling	75	70.7%	>12Hours	

[Table/Fig-3]: Time taken for conversion with reference to prior knowledge.



[Table/Fig-4]: Correlation between awareness and conversion rate.

Reason of conversion	Number of patients	Percent
Eye donation counsellor motivation	61	57.54%
Assistance in treatment/ investigations / medico-legal formalities	29	47.54%
Noble act and sympathy towards family	23	37.70%
Ambulance service	9	14.75%
Prior knowledge	31	29.24%
Deceased will get good rebirth / heaven	14	13.20%
Total	167	100%

[Table/Fig-5]: Reasons of conversion.

Reason Of Non conversion	No of patients	Percent
Was not aware	217	48.43%
Face will look ugly	17	3.7%
Delay in certifying cause of death	35	7.8%
Hurry to go home	76	16.96%
Other family members / friends did not accept	69	15.40%
Treatment dissatisfaction / No benefit to family	23	5.1%
Not permitted by religion	11	2.4%
Total	448	100.0%

[Table/Fig-6]: Reasons of non conversion.

significant difference (Chi square 79.0261, p<0.001, significant at 95% confidence interval) with graduates being more aware. In people who were either partially or fully aware of eye-donation the time taken for motivation remained less than 12 hours [Table/Fig-3] which was statistically significant at 95% confidence interval. (Chi square=106. p<0.001).

DISCUSSION

Evaluating the data in this study put forth certain important observations regarding eye donation awareness status in first degree relatives of deceased and critically ill patients, and its correlation with various variables which have a significant impact on conversion rate and actual eye donation. Maximum number of subjects 311 (56.13%) were found to have an awareness index of third category i.e., not aware. Despite rigorous drives being undertaken at the

level of government and various hospitals through the medium of eye-donation fortnights, electronic and print media, awareness programmes at various platforms, still the awareness seems to remain low in society, which further calls for more proactive steps to be taken to increase the awareness index in society. Various other studies have reported awareness regarding eye donation amongst varied population groups [5-9]. These studies did not quantify awareness and hence reported the outcome simply as being aware or unaware on evaluating awareness index with respect to age, gender, religion, and socioeconomic status. Similar observations have been reported by other authors [7] as well. Males being exposed to outside world have better knowledge about various aspects of eye donation. It would be important to sensitize the female subjects about eye donation as they can function as important facilitators in families and society. Study done by Bhandary S et al., reported that females were more aware of eye donation, similar to the observations by Krishnaiah S et al., though they were reluctant to donate eyes [6,7].

As per the study, participants belonging to lower and middle socioeconomic strata [10] were not aware of eye donation. Limited conclusion can be drawn because the institute where the study was conducted is largely attended by those belonging to lower strata. The higher prevalence of unawareness in these groups can be considered to be confounded and a more homogenous population based study can be undertaken in future to eliminate this bias. The findings with respect to education showed a little difference. Though maximum unaware were those with only basic primary education, even graduates showed a higher number of unawareness than secondary educated. As per the study by Bhandary S et al., educational status showed a positive impact on the awareness of eye donation but did not show any statistically significant effect on the willingness to donate eyes [6]. Other authors [11,12] have found that knowledge and willingness is more due to the higher educational status.

It was seen that certain communities like Muslims had staunch beliefs serving as hindrance for eye donation. This can be overcome by imparting adequate knowledge of eye donation through various media and also through religious leaders. The effectiveness of teachings of religious leaders for eye donation has been put forth by other studies [11,13-15].

To understand the facts and myths of eye donation, the idea was strategically analysed to see the awareness, willingness and the actual retrieval. Awareness was present in 53 of the total 554 who underwent assessment through the questionnaire. After subjecting to the standard questionnaire and counselling, the conversion rate almost doubled for donation [Table/Fig-4]. However, the actual donation was meagre, so inspite of having 106 willing donors the drop out due to contraindications and other reasons was high. As the contraindications and medical reasons are non modifiable what can help achieve better retrieval of cornea is increasing the awareness and willingness among general populations and targeting deceased where chances of donation are maximum like, road traffic accidents, young adults and other causes of untimely deaths.

Priming and early conversion: We evaluated the importance of prior knowledge of eye donation to the time taken by EDC in achieving actual conversion and it was seen that it had a direct relation to actual conversion. (Chi-square=106. p<0.001). Our findings are consistent with those of Abuksis G et al., who reported that greater public awareness may increase the willingness to donate organs [16]. Furthermore, if any family member is aware about eye-donation, he actually functions as a direct motivator for others in the family and in coordination with EDC facilitates the process. Outcome of EDC can make a significant difference if the family members are already primed about eye donation. It is hence advocated that there should be a zealous and targeted drive for educating the society about eye donation. This can efficiently function as preparing the bed for future conversion.

On evaluating the causes which facilitate donation [Table/Fig-5],

maximum influence was seen of grief counsellors. They were crucial in successfully motivating 61 (57.5%) cases where the willingness come post direct motivation or with ideas that were directed towards helping the blind in the society to regain vision. The help rendered by grief counsellors in managing the hospital formalities of the deceased pertaining to treatment, investigations and medico-legal was a reason seen in 29 (47.5%) such cases. Though it was ensured at all steps that EDC did not help the families solely for the purpose of eye donation rather they worked as social workers willing to help all patients in need and in this process were also educating and motivating them for eye donation. Yew YW et al., concluded that imparting proper knowledge about eye donation can increase the corneal retrieval. Subjects who had been a witness to prior eye donation in family or neighbourhood could be easily motivated for donation [11]. It was observed that one eye donation in a community served as a facilitator of more donations, owing to the fact that other people also become receptive, inspired and motivated. Some attendants in such families are strongly motivated for the cause and they function as catalysts for the purpose. They not only serve as facilitators for eye donation but also function as motivators for other attendants, neighborhood and society.

Inspite of people specifically allotted to counsel and make aware those accompanying deceased, of the role of eye donation in helping people regain vision, 448 out of 554 could not be motivated [Table/Fig-6]. A large figure to be thought and processed over. The reasons of unwillingness were a wide range, most common being lack of awareness about eye donation and hence the hesitation to do so amidst grief and disaster. Participants without any prior knowledge of eye donation out rightly rejected the suggestion of eye donation, since they were in a state of extreme grief and despair so much that they just wanted to complete the hospital formalities and take the body home. In addition, many believed that it may be time-consuming thus would delay the funeral process. A study conducted by BurroughsTE et al., reported predictors of family members' satisfaction with the decision to consent or refuse donation of a dying loved one's organs or tissue [17]. Concern about facial disfigurement after donation has been reported by Lawlor M et al., and Golchet G et al., [18,19]. A study conducted by Ackuaku-Dogbe EM and Abaidoo B in Ghana showed that very few people attending hospital were aware and willing for eye donation and hence there is a need for public education [20]. Along with eye donation counsellors, hospital stakeholders can also play a vital role in motivating a person for eye donation [21].

LIMITATION

Major limitations of the study are: being a hospital based study, results cannot be extrapolated to generalized population: The attendants might not be in a receptive phase owing to their relatives being in a critical condition: Not all cases could be registered in the study due to odd hours of death and delayed communication to our team.

CONCLUSION

Utilizing the services of eye donation counsellors is a promising way to motivate the guardians of deceased. Increasing the awareness in society, effectively utilizing the services of EDC, rendering simple

assistances to next of kin and speeding the medico-legal formalities can go a long way in increasing the conversion rate and hence actual donation.

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