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Original Research Article

Awareness and post counselling acceptance of eye donation in a tertiary care centre in Northern Kerala

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ABSTRACT

Background: Corneal diseases are among the major cause of vision loss and blindness in the world today. Corneal transplantation remains the mainstay of treatment. Hence creation of awareness carries paramount importance. Aim of this study is to assess the awareness about eye donation amongst attendants of deceased patients, their willingness to donate eyes and the reasons for poor donation rate. To assess the efficacy of grief counselling by Eye Donation Counsellor (EDC), its impact on the conversion rate

Methods: A prospective hospital based study was done in 135 participants (guardians of deceased subjects) admitted in intensive care units, from June 2017 to June 2018. Counsellor accompanied with a junior resident would first screen the cases. Relatives of suitable cases were approached and counselled in a systematic manner following a standard interview pattern. Responses were noted in a predesigned proforma.

Results: Among 618 deceased cases 135 potential donors were identified.57.8% next of kin were aware of the concept of eye donation, but 42.2% were not. After counselling, willingness for eye donation was seen in 54.1%, others refused. Among 57.8% kin who were aware, 51.3% gave consent. Prior knowledge of eye donation, literacy and socioeconomic status did not have any significant influence on willingness. Counselling was found to be the best method to facilitate eye donation.

Conclusions: An active counselling by eye donation counsellor is the main factor which is responsible for eye donation.

Keywords: Awareness, Counselling, Eye donation, Unwillingness, Willingness

INTRODUCTION

According to WHO corneal diseases are among the major cause of vision loss and blindness in the world today. 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 and both eyes are involved in approximately one million persons. ^{2,3}

According to the National Programme for Control of Blindness (NPCB) estimates, there are currently 120,000

corneal blind persons in the country and each year about 20,000 new cases of corneal blindness is added to the existing list.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. To reduce this shortage, raising the level of public education and willingness on eye donation is an important first step.⁵

However, the procurement of donor cornea depends on the availability of suitable donors and requires the consent of the family. Approaching a family for consideration of donation of eyes of their dear ones is never an easy task. This study presents our experience with retrieval of corneas from deceased cases at a tertiary care hospital in Northern Kerala.

METHODS

This was Prospective hospital based study. The study period was from June 2017 to June 2018 at ACME, Pariyaram. Study was conducted among 135 Attendants/guardians of the critically ill and deceased subjects admitted in intensive care units of various departments (Medicine, Surgery, Cardiology), ACME.

Sampling and sampling size estimation

Sample size calculation:

At confidence level 95%

Prevalence conversion (P) = 14.34% ⁶

Minimum sample size,
$$N = \frac{Z 2 PQ}{D 2}$$

Q = 100-14.34=85.66%

D = 7% absolute precision

Z= 2(Standard Normal Value corresponding to 95% confidence level)

$$N = \frac{22 \times 14.34 \times 85.66}{72} = 131$$

Inclusion criteria

Relatives of deceased subjects with healthy cornea other than those excluded.

Exclusion criteria

Relatives of patients <16 years, patients with corneal scarring or any infectious disease in ocular tissue patients with rare invasive brain tumors, Alzheimer's disease or other disease of unknown aetiologia.

Data collection

Departments with high mortality rate were specifically targeted for grief counselling Nursing staffs would inform regarding deaths to counsellor. Counsellor accompanied with a junior resident would first screen the cases. Relatives of suitable cases were then approached and counselled in a systematic manner following a standard interview pattern. Responses were noted in a predesigned Performa.

The religion, level of literacy, socioeconomic status, relationship with the deceased, prior knowledge of eye donation, willingness for eye donation, and reasons for not donating eyes of the deceased were recorded. Consent for donation was obtained when the family was willing

for eye donation. Written consent for donation was always taken from the legal next of kin.

Corneal button was taken from donor under aseptic conditions and were sent to the Eye Bank Association Kerala in Mc Carey Kaufman medium for storage. Preserved corneas were procured from the eye bank as and when required.

Statistical analysis

Descriptive statistical method like mean, standard deviation, frequency and percentage will be used in this study. Inferential statistical tools like chi-square test will be used, a p value of less than 0.05 will be considered significant.

RESULTS

A total of 135 participants were studied. 126 next of kin were men i.e. (93%) and 9 were women (7%) (Figure 1) and Age range was from 31 to 70 years (Figure 2).

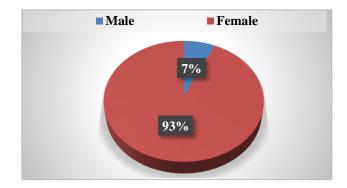


Figure 1: Gender distribution.

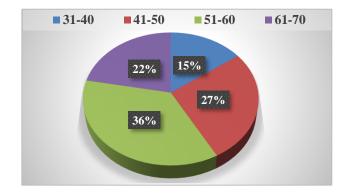


Figure 2: Age distribution.

Out of 135 participants, 78 next of kin were already aware of the concept of eye donation, but 57 were not. (Figure 3). After counselling, willingness for eye donation was seen in 73 whereas 62 families refused (Figure 4).

The association of knowledge of eye donation, socioeconomic status and education with willingness for eye donation was not statistically significant (p > 0.05) (Table 1).

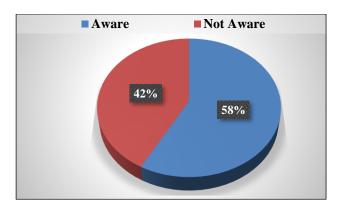


Figure 3: Awareness.

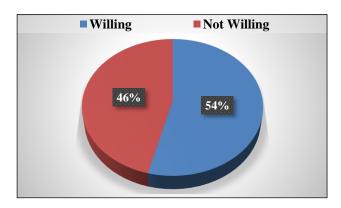


Figure 4: Willingness.

Table 1: Factors Associated to Willingness.

	Not willing	Willing	Total
Knowledge of eye donation			
Aware	38(48.7%)	40(51.7%)	78(100%)
Not aware	24(42.10)	33(57.9%)	57(100%)
Socioeconomic status			
Upper	7(31.8%)	15(68.18%)	22(100%)
Middle	34(53.1%)	30(46.85%)	64(100%)
Lower	21(42.8%)	28(57.14%)	49(100%)
Education			
Primary	17(54.8%)	14(45.16%)	31(100%)
Secondary	30(50.84%)	29(49.15%)	59(100%)
Graduate	15(33.33%)	30(66.66%)	45(100%)

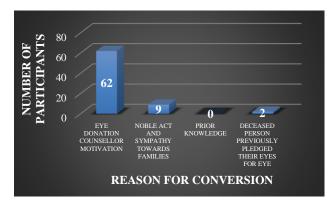


Figure 5: Reason for conversion rate.

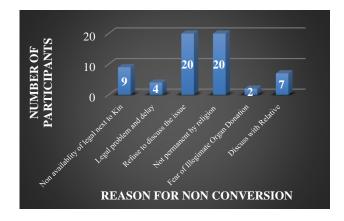


Figure 6: Reason for Non-Conversion

The reasons observed for unwillingness for eye donation by the next of kin were motivation given by eye donation counsellor, considering it as a noble act, previously pledged their eyes for eye donation (Figure 5). The reasons observed for unwillingness for eye donation by the next of kin were refusal to discuss the issue of donation (32.2%), religious beliefs (32.2%), non-availability of the person legally authorized to give consent (14.5%), and dissuasion by distant relatives (11.2%), legal problems (6.4%) and fear of illegitimate organ harvesting (3.2%) (Figure 6).

DISCUSSION

According to World Health Organization corneal diseases are among the major cause of vision loss and blindness in the world today.¹ 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 and both eyes are involved in approximately one million persons.^{2,3}

According to the National Programme for Control of Blindness (NPCB) estimates, there are currently 1.2 million bilateral corneal blind persons in the country and each year about 50,000 new cases of corneal blindness is added to the existing list.⁴ To address this high prevalence of corneal blindness, raising the level of public education and willingness on eye donation is an important first step.⁵ However, the procurement of donor cornea depends on the availability of suitable donors and requires the consent of the family. This study presents our experience with retrieval of corneas from deceased cases at a tertiary care hospital in Northern Kerala.

Of the total 135 families of potential donors interviewed in this study, 57 (42.2%) families were unaware of eye donation. Unawareness of eye donation is one of the major reasons for unwillingness of eye donation, but as demonstrated in our study, the level of illiteracy, lack of prior knowledge of the concept of eye donation or socioeconomic status is not an obstacle for donation if the family is approached by an active counselling team. Our results were also like study conducted by Tandon R et al, concluded that willingness to donate eyes was less (41.5%)

even among relatives of post-mortem cases who were in spite of being aware of eye donation.⁷ 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.⁸

Bhandary S et al, reported that females were more aware of eye donation, like the observations by Krishnaiah S et al., though they were reluctant to donate eyes.^{5,8} In this study female next of kin constituted 9 (7%) of cases, and only 4 were aware but all were willing to donate after counselling. Concern about facial disfigurement after donation has been reported by Lawlor M et al, and Golchet G et al.⁹ In our study fourteen families (10.3%) consented following assurance of no anatomic disfiguration of the face.

The reasons observed for unwillingness for eye donation by the next of kin were refusal to discuss the issue of donation (32.2%), religious beliefs (32.2%%), non-availability of the person legally authorized to give consent (14.5%), and dissuasion by distant relatives (11.2%), legal problems (6.4%) and fear of illegitimate organ harvesting (3.2%) It was seen that certain communities like Muslims had strong beliefs serving as hindrance for eye donation. ^{10,11} This can be overcome by imparting adequate knowledge of eye donation through various media and also through religious leaders. ^{12,13}

CONCLUSION

In this study, literacy, socioeconomic status and prior knowledge of eye donation had no correlation with donor corneal tissue procurement. An active counselling by eye donation counsellor is the main factor responsible for eye donation. Also, formulation of a strategy to overcome emotional, cultural, and religious beliefs may greatly enhance the procurement of the donor corneal tissue.

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Institutional Ethics Committee

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