

A Comparative Study of Awareness and Level of Willingness for Eye Donation between Two Socio-Economic Groups

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Abstract: **Aim:** To compare the awareness and willingness for eye donation between two socio-economic groups among the next of kin of deceased persons at INHS Asvini from January 2015 to June 2016. **Methodology:** During the counselling of the next of kin, the prime representative of the family was asked about his/her knowledge regarding eye donation and willingness for the same. **Results:** Statistically significant difference of awareness about eye donation was present among two groups but difference of the willingness for eye donation was statistically insignificant. **Conclusion:** Higher awareness of eye donation doesn't convert into actual willingness for the same. So in addition to awareness campaigns, development of a strategy which takes care of infrastructural and legislative aspect is mandatory.

Keywords: Awareness, willingness, eye donation, two socioeconomic groups

1. Introduction

Cornea, which provides almost 3/4th power of the eye, is one of the most important structures of the visual system. There is a huge demand of transplantable corneal tissues worldwide to reduce the burden of corneal blindness. The ratio of demand to supply is not satisfactory to meet the current requirements. Approximately 18.7 million people are blind in India. Out of this all, 190,000 people are blind due to bilateral corneal disease. Every year, another 20,000 people add to this list. According to the data of Eye Bank Association of India, the current cornea procurement rate in India is 22,000 per year. There are certain contraindications of the eye donation and even after procurement of the corneal tissues, not all the corneas are considered suitable for transplantation because many donors are sufferers of medical conditions in which transplantation is not considered safe. Based upon our current ratio of available safe donor eyes, we would require 277,000 corneal tissues to perform 100,000 corneal transplants in a year in India.[1] Even after transplantation procedure, many preoperative ocular conditions can lead to graft failure which may eventually leads to repeat transplant and further expansion of the need of corneal tissues. There is a general impression in the community that well educated people are more aware about the eye donation and can be prepared easily for eye donation. But a study which was conducted at forensic medicine department of a tertiary care hospital in India showed that socioeconomic status and prior knowledge of eye donation of next of kin had no correlation with donor corneal tissue procurement.[2] Active counselling by a motivated team can be effective even in families with no prior knowledge and low socioeconomic status.[3] This study is aimed to assess the awareness and willingness of eye donation among two socio-economic groups.

2. Literature Survey

Causes of blindness

A study was conducted in the Indian state of Andhra Pradesh which showed that cataract related blindness attributed 44% to the total cases of blindness, while refractive errors and retinal diseases contributed 16% and 11% respectively.[4] 7% cases of blindness were secondary to the corneal pathologies. If proper intervention is taken at correct time then 95% of the cataract-related and refractive error related blindness and 90% of the corneal pathology related blindness can be prevented.

Eye donation

If any individual or his/her next of kin opt for eye donation then either the whole eyeball or only the corneal tissue is retrieved from the deceased person because corneal tissue is the only part of the eye which can be transplanted to any other individual.

Keratoplasty

Keratoplasty is the surgical procedure where a part or full corneal tissue is replaced with the corneal tissue retrieved from another deceased human being. It can be divided into two types.

1. Full thickness keratoplasty
2. Lamellar keratoplasty

1. Full thickness/penetrating keratoplasty

In this technique full thickness of host cornea is removed and it is replaced with full thickness donor cornea.

2. Lamellar keratoplasty

Instead of the full thickness of the cornea, selective layers are removed from host cornea and only those layers are replaced with donor tissue.

Lamellar keratoplasty is further divided into 2 broad types.

1. Anterior
2. Posterior

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Demand vs supply of cornea:[5]

As per the data of Eye Bank Association of India (EBAI) total number of corneal tissues retrieved in the whole country in the year of 2000 were 18641. Out of the whole collection, more than 50% of the corneas were collected by the states of Gujarat, Maharashtra, and Tamil Nadu. In the year 2000, 4381 optical keratoplasties were done. This number of tissue retrieval kept increasing over the years and reached to 34520 cornea retrievals in the year of 2008. In the year of 2008, total 9509 optical corneal transplants were done. This means rates of tissue retrieval and transplantation procedures almost doubled over 8 years. Looking at this data it is very much obvious that the trends of eye donation and transplant procedures are towards positive side and eye donation rates are increasing but these numbers are still not enough to meet the total need. India needs almost 200,000 cornea retrievals annually to achieve the target of 100,000 corneal transplants a year. Apart from the number of cornea retrievals, India also needs uniformity in the tissue collection as almost half of the tissue retrievals are carried out by 3 states and rest of the 26 states form half of the bulk.

Obstacles to eye donation

In certain medical conditions cornea can not be retrieved even if the family of the deceased is willing to do so.

Contraindications of retrieval of cornea[6]

- Acquired immunodeficiency syndrome
- Active viral hepatitis
- Creutzfeldt-Jakob disease
- Active viral encephalitis or encephalitis of unknown origin
- Rabies

It is not merely various contraindications to the cornea retrieval, the only major cause which contributes to the decreased number of donations but various other logistical factors also contribute to the same. Lack of coordination between staff, lack of dedicated people involved in the transplantation process are few of these factors.

A study was done in a French hospital to point out various logistical issues hampering corneal donation.[7] Over the study period, hospital's coordination team was able to trace only 40.5% of all patients who died in the hospital. This means 59.5% of deaths went unnoticed. When relatives of the deceased person were counselled for the cornea donation by the coordination team, their consent to cornea donation was received in 71% of cases. By simple calculation, it can be concluded that if it would be possible for coordinating nurses to meet the relatives of all potential donors, the number of corneal tissues collected in the same period would be multiplied by a factor of 2.63.

One of the possible reasons for such a low traceability may be inadequate staff dedicated for donation procedures. One study was done in Germany to know whether appointment of dedicated staff can increase the number of eye donations or not.[8] The study period was 14 years in which for initial 7 years one ophthalmic resident was appointed for corneal procurement procedures on part time basis as he was also handling his ward works. For rest of the 7 years of study, one ophthalmic resident was appointed on full time basis.

On evaluation of results, the cornea donation rate in first half was 4 donors per 100 deaths and the whole team managed to collect 181 corneas in 7 years. While in second half, cornea donation rate was 12.3 donors per 100 deaths and the total number of corneas which were retrieved during those 7 years were 711, which was almost more than 3 times higher than first half. For the whole 14 years of period the rest of the eye bank team remained same which consisted of chief of the eye bank, deputy chief of the eye bank and a technician. The only difference in the team was part time vs full time resident who was in charge of the donor screening and interviews.

Reasons for excessive demand of corneal tissue for transplantation

There are certain conditions in which corneal transplantation can not be done even after retrieval of the tissue.[6] These contraindications are:

- Death of unknown cause
- Active meningitis or encephalitis
- Active septicemia
- Hepatitis B surface antigen positive donor
- Hepatitis C seropositive donors

Apart from these contraindications, graft survival following the keratoplasty is also a major issue. Survival of the graft depends upon many factors.

Post operative rise of intraocular pressure and failure to control it adequately can lead to graft failure and it is one of the major causes of graft failure too. One study found the occurrence of post keratoplasty glaucoma to be 34% over the follow up period of 39 months.[9] Most of the cases of post keratoplasty glaucoma were diagnosed within a year following penetrating keratoplasty. Post keratoplasty glaucoma can occur after any keratoplasty procedure but some indications of keratoplasty are more prone to develop this complication. They are pseudophakic bullous keratopathy, corneal perforation and previous graft rejection. Another study also showed similar findings that preoperative indication for keratoplasty is the most important factor deciding graft survival.[10] The indications with high chances of graft failure were previous history of graft failure, bullous keratopathy, adherent leucoma and corneal clouding secondary to miscellaneous causes which includes congenital conditions and glaucoma. Apart from the preoperative diagnosis, other variables which were also found to play the role in graft survival were socioeconomic status, vascularisation of host cornea, age and quality of donor cornea. In this study total 1389 first time corneal transplantations were studied and long term graft survival was observed. The 1, 2 and 5 year graft survival rates were 79.6%, 68.7% and 46.5% respectively. After accounting for the other risk factors of graft failure, the single most important factor determining the graft survival was socioeconomic status. Lower socioeconomic status was associated with high rates of graft failures. This can be accounted to improper compliance to the postoperative care of the transplants in this socioeconomic group.

Approach to reduce gap between demand and supply[11]

Various possible ways to reduce the gap between demand of organ and availability of the tissue are

- 1) Reduce the requirement of transplantation by preventing the progression of the disease so that it does not reach to an end-stage.
- 2) Make more donor organs available for transplantation by increasing the level of realisation of the importance of organ donation in general population.
- 3) Making the best use of resources and boosting the infrastructural facilities.
- 4) Apply modified transplant procedures to make best use of available donor organs like lamellar keratoplasty which makes possible to use single tissue for 2 recipient.
- 5) Improve graft survival rate and ensure adequate compliance to follow up and post operative medications to avoid the need for re-transplantation.

Level of willingness to pledge the eyes and awareness of eye donation in other studies:

Study which was done in rural population of state of andhra pradesh revealed that awareness of eye donation was 28%. [12] Out of the whole study population only 0.1% had pledged their eyes. Out of the population who was aware about eye donation only 2.9% had knowledge regarding correct use of the donated eye. This was pointing towards inadequacy of media publicity in this population. Females were less willing to pledge their eyes. Awareness of eye donation and willingness to pledge the eyes was significantly higher among the age group of 60-69 years compared to the age group less than 60 years old. According to the study data, literates were more aware about eye donation but very few had actually pledged their eyes. The study did not find any significant association between socioeconomic status and willingness to donate eyes but the people belonging to higher socioeconomic status were more aware about eye donation.

Tandon et al conducted a study at a tertiary hospital to evaluate various factors affecting eye donation. This study concluded that there was no statistically significant difference for willingness of eye donation between higher and lower socioeconomic groups. [2]

Another study which was done among newly admitted first-year medical students in New Delhi showed that 179 (99.4%) out of 180 students were aware regarding the eye donation. [13] Television was the most common source of information about eye donation followed by newspaper and magazines. 157 (87.2%) out of the 180 students were willing to donate their eyes. 155 (86.1%) out of 180 were aware about the use of donated eyes that the donated eyes are used for corneal grafting. The ideal time of cornea retrieval which is six hours after death was known to 74 (41.1%) of 180 students.

Study conducted at a tertiary care hospital among the next of kins of the cases coming for post mortem revealed that rate of awareness regarding eye donation was 55.4%. [2] There was no significant difference in willingness for eye donation according to literacy and socioeconomic status of next of the kins.

European experience with 'presumed consent' [11]

Many countries in the European union have adopted the policy of 'presumed consent'. Countries like Belgium, Croatia, France, Poland and Sweden are maintaining a national non donor registry. Whoever has an objection for organ donation during his life, he has to register himself with this registry. Even in the absence of name in the non donor registry, the families of the deceased are approached, not to sought the consent for organ donation but to find evidence if ever in the past the deceased person had objected to donate his organs.

The 'presumed consent' model has shown encouraging results in Europe. Presumed consent law was implemented in Belgium in 1987. Organ donation rates almost doubled within 2 years of implementation of this law. [14] Organ donation rates in Austria and Belgium, where law of presumed consent is prevalent, are almost twice compared to Germany and the Netherlands. [15]

Spanish model of organ donation [16]

Though this model was not directed specifically for the eye donation, it's outcomes were encouraging. In 1989, total 550 organ donations took place in Spain. This number kept increasing slowly and steadily and reached to 1155 organ donations in 1997. [17] This means number of organ donations doubled in just 9 years. Looking at it's success, many other countries adopted this model for their organ donation programme.

The salient features of this model are:

The whole system operates at three different levels, national, regional and at individual hospitals.

National and regional transplant coordination network is paid by respective national and regional authorities and the coordinators at these 2 levels were the interface between political and professional levels.

The coordinator at the hospital level is a physician who works on part time basis which gives him space to continue his own professional work other than transplant coordination. Hospital coordinator is functionally attached to the regional and national coordinator.

Head office of the whole organisation acts as a central data management centre which maintains waiting lists, transplant registries and various other statistical data.

Transplant coordinators undergo regular training programmes which covers all the aspects of organ donation like donor management and legal aspects of donation.

Periodic awareness campaigns are organised with help of media and other means of mass communication which also includes regular meetings with journalists as well as 24 hours functional transplantation hot line, in case of one is in need of specific information regarding transplantation.

3. Material and methods

General setting of the study

This study was conducted in a tertiary care hospital setting

Place of study

Tertiary care hospital

Study period

January 2015 to June 2016

Study design

Prospective study

Inclusion criteria

Next of kin of deceased at hospital

Exclusion criteria

Deceased person who was suffering from any of the following diseases

- Acquired immunodeficiency syndrome
- Active viral hepatitis
- Creutzfeldt-Jakob disease
- Active viral encephalitis or encephalitis of unknown origin
- Rabies

These diseases are considered contraindications of cornea retrieval so individuals suffering from them were excluded from the study.

Death occurring anywhere in the hospital was notified to central medical inspection room of the hospital and information regarding the death was carried forward to the on call eye bank personnel either from medical inspection room or directly from the ward where death has occurred.

Cornea retrieval team consisting of an ophthalmology resident and a medical assistant approached the families of all the deceased person. As in the moments of grief, one becomes more realistic about their own views, the next of kins were asked if they were aware about the concept of eye donation and if yes then various aspects of eye donation. During counselling procedure, the next of kins were represented the fact that eye donation is a noble act which can help to restore the sight of two blind persons. Their queries regarding the procedure were answered satisfactorily.

The name, age/sex, religion, occupation, contact details, education of each family member and per capita monthly income of the family were noted. Families unwilling for the donation were thanked, and all the details regarding eye donation were left with them in case they change their mind. Death certificate and consent for donation was obtained from the family who was willing for eye donation. The corneas were retrieved, stored in McCarey-Kaufman medium and sent for assessment of the tissue.

Assessment of socio economic group

A compound socioeconomic status scale used in earlier studies which was based upon education and family income, was followed.[2] The two criteria of the assessment of

socioeconomic group were per capita monthly income score and family literacy score. Per capita monthly income score of the family and family literacy score both were given equal importance.

Calculation of per capita monthly income score

Monthly family income was divided by total number of family members to obtain per capita monthly income. The per capita monthly income score was assigned as described in the following table.

| Per capita monthly income(INR) | Score assigned |
|--------------------------------|----------------|
| > 50,000 | 30 |
| 49,999-20,000 | 26 |
| 19,999-10,000 | 21 |
| 9999-5000 | 14 |
| 4999-2500 | 11 |
| 2499-1000 | 7 |
| < 1000 | 3 |

Calculation of family literacy score

The literacy of all the members in the family who are above the age of 15 years was obtained. Score was assigned according to the level of education as under described table.

| Level of education | Score of each individual member |
|--------------------|--------------------------------------|
| Class 1-5 | Numerical value of class studied |
| Class 6-8 | Numerical value of class studied + 1 |
| Class 9-10 | Numerical value of class studied + 2 |
| Class 11-12 | Numerical value of class studied + 3 |
| Graduate | 21 |
| Post graduate | 26 |
| Further | 30 |

The scores were added and the final figure was divided by the total number of family members who contributed to the literacy score to obtain family literacy score.

The per capita monthly income score and family literacy score were added, and the median value was determined. The scores were then categorised into 2 groups based on whether the value was greater or lesser than the median value, that is, upper or lower composite socioeconomic status.

4. Results

Table 1: Awareness of eye donation among two groups

| | | Group | | Total | |
|-----------------------------------|-----|----------------|-----------------|--------|--------|
| | | Low(<42 score) | High(>42 score) | | |
| Are you aware about eye donation? | No | Count | 10 | 1 | 11 |
| | | % within group | 27% | 2.90% | 15.30% |
| | Yes | Count | 27 | 34 | 61 |
| | | % within group | 73% | 97.10% | 84.70% |
| Total | | Count | 37 | 35 | 72 |
| | | % within group | 100% | 100% | 100% |

| Chi-Square Tests | | |
|--------------------|-------|--------------------------------|
| | Value | P value (significant if <0.05) |
| Pearson Chi-Square | 8.118 | 0.007 |
| N of valid cases | 72 | |

Table 2: Willingness for eye donation among two groups

| | | Group | | Total | |
|-----------------------------------|-----|----------------|-----------------|--------|--------|
| | | Low(<42 score) | High(>42 score) | | |
| Are you willing for eye donation? | No | Count | 15 | 11 | 26 |
| | | % within group | 55.60% | 32.40% | 42.60% |
| | Yes | Count | 12 | 23 | 35 |
| | | % within group | 44.40% | 67.60% | 57.40% |
| Total | | Count | 27 | 34 | 61 |
| | | % within group | 100% | 100% | 100% |

| Chi-Square Tests | | |
|--------------------|-------|--------------------------------|
| | Value | P value (significant if <0.05) |
| Pearson Chi-Square | 3.313 | 0.117 |
| N of valid cases | 61 | |

Table 3: Reason for willingness for eye donation among two groups

| | | Group | | Total | |
|--|-------------------------|----------------|-----------------|--------|--------|
| | | Low(<42 score) | High(>42 score) | | |
| Reason for willingness for eye donation? | Example to others | Count | 0 | 1 | 1 |
| | | % within group | 0 | 4.30% | 2.90% |
| | To help blind | Count | 3 | 13 | 16 |
| | | % within group | 25% | 56.50% | 45.70% |
| | Inspired by print media | Count | 2 | 2 | 4 |
| | | % within group | 16.70% | 8.70% | 11.40% |
| | Noble act | Count | 7 | 7 | 14 |
| | | % within group | 58.30% | 30.40% | 40% |
| Total | | Count | 12 | 23 | 35 |
| | | % within group | 100% | 100% | 100% |

5. Discussion

Corneal blindness leads to poor quality of the life of that particular person and increases the social and economical burden to the society. To overcome the problem of corneal blindness to some extent, India requires increased number of eye donations to many folds.[5] But the problem lies in the eye banking facilities in India which is still at an emergent stage. Apart from the eye banking facilities, level of general awareness about the eye donation and lack of realisation of the various aspects of eye donation are also other issues.

Statistically significant difference of awareness about eye donation was present among two groups in our study. Awareness about eye donation in higher socioeconomic group of our study was 97%. Only one person among total 35 people belonging to higher group, was unaware regarding the concept of eye donation. While awareness about eye donation in lower socioeconomic group of my study was 73%(P value 0.007)

Krishnaiah et al conducted a study to evaluate the awareness among the population of the state of Andhra Pradesh. The study found that awareness of eye donation was more prevalent in the individuals having higher income and who were more literate.[12]

Statistically insignificant difference of willingness regarding eye donation was present among two groups in our study. In our study, 67% of the people belonging to higher socioeconomic group were willing to donate their eyes

whereas willingness was present in 44% of the people belonging to lower socioeconomic group. (P value 0.117)

Tandon et al conducted a study at a tertiary hospital to evaluate various factors affecting eye donation. This study concluded that there was no statistically significant difference for willingness of eye donation between higher and lower socioeconomic groups.[2]

Study conducted by Krishnaiah et al revealed that statistically significant difference for willingness of eye donation was present between illiterates and literates but there was no statistically significant difference for willingness of eye donation between higher and lower income group.[12]

Among the people who were willing for eye donation, most common reasons of their willingness were the realisation of the fact that eye donation is a noble act and intension to help blind. While among the people who were not willing for eye donation, most of the people were not having any particular reason for their non willingness among both the groups.

During my study, many of the family members of deceased person were refusing eye donation because according to them the eyes of their beloved one were not useful as they have underwent cataract surgery. This implies poor knowledge regarding the part of the donated eye which is used for the transplant procedure. Collectively all this points point toward inadequate awareness campaigns.

As media remains the most effective and common way to increase the awareness about eye donation, the lower socioeconomic group has relatively lesser access to the same. As per the study, awareness was found to be low in the lower socioeconomic group compared to the other group, the effective awareness programme is more essential for the lower group. This problem can be overcome by unconventional campaigning like street plays in the areas dominated by lower socioeconomic group individuals. Apart from unconventional ways, the media campaigns also need to be more informative and detailed which cover all aspects of eye donation. This is important to vanish various myths and to improve knowledge regarding all facets of eye donation in both higher as well as lower socioeconomic group. The awareness campaigns should include the following details in minimum.

- (a) When the eyes can be donated
- (b) Procedure to become a pledged eye donor
- (c) How this pledge can be converted into an actual eye donation
- (d) Importance of discussing the willingness for eye donation with family members
- (e) Importance of signing a donor card for eye donation
- (f) The procedure should ideally be carried out within 6 to 8 hours of death
- (g) Eye donation can be taken at home and
- (h) Eye donation does not causes any facial disfigurement

As per the data of this study, higher awareness is not converted into higher donation rates, so apart from the awareness campaigns boost to the infrastructural facilities and enforcement of the proper laws are also mandatory.

Many countries in the world have legislative provision to support the organ donation activity.[11]In these countries each individual is considered as 'presumed organ donor' unless he/she has specifically expressed the unwillingness to do so during his life. For example, in USA the 'Presumed Consent Law' was introduced in 1975. This concept has legal provision that if any deceased person has not registered any objection to donate his/her organs while alive, consent is presumed and eyes can be removed as required. As India is not having this type of legislative support for organ donation, we are solely dependant on the awareness of population regarding this issue.

6. Conclusion

Though awareness regarding eye donation remains higher in the higher socio-economic group, level of willingness for eye donation shows no significant difference between higher and lower socio-economic group. Apart from awareness campaigns, if appropriate laws,adequate infrastructure and dedicated and trained staff are made available then it is easier to fill the gap between demand and supply of transplantable corneal tissues.

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