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Original Article

Perceptions and Struggle of Corneal Donation and Transplants: You can see the World even after Death

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Abstract

Objective: To assess knowledge, opinion and perception of the general population regarding corneal donation and transplantation. Another objective was to investigate desires, fulfilment, battle and results of patient's experiences of Corneal Transplant Surgeries performed at Tertiary Care Eye Hospital.
Study type, settings & duration: A Cross-sectional study conducted at Tertiary Care Eye Hospital over a period of twenty one months from July 2018 till April 2020.
Methodology: The format of the questionnaire was based on previously published studies in the field of corneal transplantation. Our study was divided into two parts. The first part was conducted via structured questionnaire distributed among the general population (n =2090) visiting our hospital as patients and attendants which assessed basic knowledge regarding corneal transplantation and willingness for donation. Next step was interviews of operated patients of penetrating keratoplasty (n =30).
Results: Total 2090 participants responded to questionnaire in our institution with mean age of sample as 36.66±9.00 years. 1693 (81%) had the opinion that corneal donation will help restoring vision of sufferers whereas 300 (14.3%) considered it unethical. 28 (93.3%) of the patients were in good health and prognosis after surgery whereas 2(6.7%) did not have a good outcome. Vision and quality of life of 29 (96.7%) patients' improved.30 (100%) supported the idea of corneal donation and transplantation.
Conclusion: To conclude a noteworthy population can support corneal donation if the government builds up appropriate channels and facilities to promote corneal donation and eye banks.
Key words: Cadaver, corneal transplantation, penetrating keratoplasty.

Introduction

The cornea is the front transparent structure of the eye. Owing to its refractive, power it plays a major role in visual function.[1] Corneal transplant surgeries aim to restore vision when it is affected by severe corneal diseases compromising its transparency. It includes corneal surface disease, scarring, dystrophies and trauma deemed too severe to compromise its anatomy leading to its opacification and thus adversely affecting the quality of life.[2] Conventional corneal transplant surgery is named as penetrating keratoplasty (PKP) from surgical point view.[3] Most of ocular diseases lead to permanent impairment of vision. However there are other diseases that leads to reversible blindness which can be treated with transplant surgery.[4]

With a global success rate of approximately 90 to 95%, it is commonly performed and most successful transplant surgery till date.[5] The miraculous physiology of sight, powerful depth of vision and mankind's deep-seated fear of blindness, humans have always been inclined to innovate and re-innovate surgical restoration of vision.[6] Although corneal transplantation was conceptualized at the end of 18th century but it was until a century before when human corneal grafting was introduced.[7] During the course of its reconstructing history, penetrating keratoplasty has evolved as full-thickness grafting of donor cornea to the recipient.[8] In recent years, layered based lamellar graft has developed through advent in understanding of concepts, instrumentation and skills.[9] Currently, ten

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million people worldwide are suffering from diseases which are curable by corneal transplantation. It is the third leading cause of blindness worldwide after cataract and glaucoma. Although organ transplantation is a complicated enigma of religious and legal issues, the cornea is gifted by various characteristics that make its storage and transplantation relatively easier, however, due to its avascularity, a transplanted cornea does not have a natural strength and this is a major disadvantage for this transplant as it is possible that even years after the transplantation, the cornea can be detached by trauma or physical activity.[10]

Various studies on responsiveness and approach towards cornea donation globally acknowledged that basic knowledge of corneal transplantation as the only adaptable factor associated with increased inclination to donate. We aim to assess in this study, current views of the general population towards corneal donation and to educate the participants on elementary concepts (e.g. what is cornea transplantation) and then more complex ones (e.g. eligibility standards for cornea donation, waiting times and patient contentment after being operated upon) using an interactive online questionnaire and then directly interviewing operated candidates.

Methodology

This study was conducted in Tertiary Care Eye Hospital over a period of twenty one months i.e. from July 2018 till April 2020. The format of the questionnaire was based on previously published studies in the field of corneal transplantation. Questionnaire was validated by a Pilot Study and opinion of experts on the subject. Our study was divided into two parts, which comprised of 13 questions in Part I and 8 questions in Part II. In first phase of study, patients who reported to our institute for eye diseases and decreased vision were included in the study to evaluate level of awareness, whereas in the second phase patients who underwent corneal transplantation were included and directly interviewed.

The first part was conducted via structured questionnaire distributed among the general population (n =2090) visiting our hospital as patients presenting with ocular diseases or as attendants of the patients. It assessed basic knowledge regarding corneal transplantation and willingness for donation (Table-1 - part 1). A paper-based questionnaire was used and feedback was received from (100%) participants. With convenience non-probability sampling method, n = 2090 participants were enrolled. The minimum sample size was calculated to be n = 370 with hypothesized % frequency of outcome factor in the population as 40.2%+/-5, margin of error5% and confidence level 95% keeping in view study conducted by Alanazi et al.[11]

Next step was direct interviewing of operated patients of penetrating keratoplasty. (Table-1 - part 2). At the start of the questionnaire, cornea and its transplantation was briefly described. All questions were translated into Urdu.

Data was entered and analyzed by using data management software IBM SPSS (version 23.0). The descriptive statistics of continuous variables were presented as mean and standard deviation, while for categorical data frequencies and percentages were used. Categorical grouped data was analyzed by either Chi-square or Fischer-exact

Table 1: Awareness of general population.

(Part 1)

Are you aware that cornea blindness is reversible by corneal transplantation /Are you aware of corneal transplant surgeries performed in Pakistan

		Are you aware of corneal transplant surgeries performed in Pakistan			*p-Value*
		No	*Unsure*	*Yes*	
Are you aware that cornea blindness is reversible by corneal transplantation	No	696	100	100	<0.001*
	Unsure	398	-	-	
	Yes	199	100	497	

(Part 2)

Do you know corneal donation procedure and eligibility/ If one of your first-degree relatives died would you donate his/her corneas

		If one of your first-degree relatives died would you donate his/her corneas			*p-Value*
		No	Unsure	Yes	
Do you know corneal donation procedure and eligibility	No	497	796	498	<0.001*
	Unsure	-	-	100	
	Yes	99	-	100	

* Significant p-value calculated by Pearson Chi-Square Test

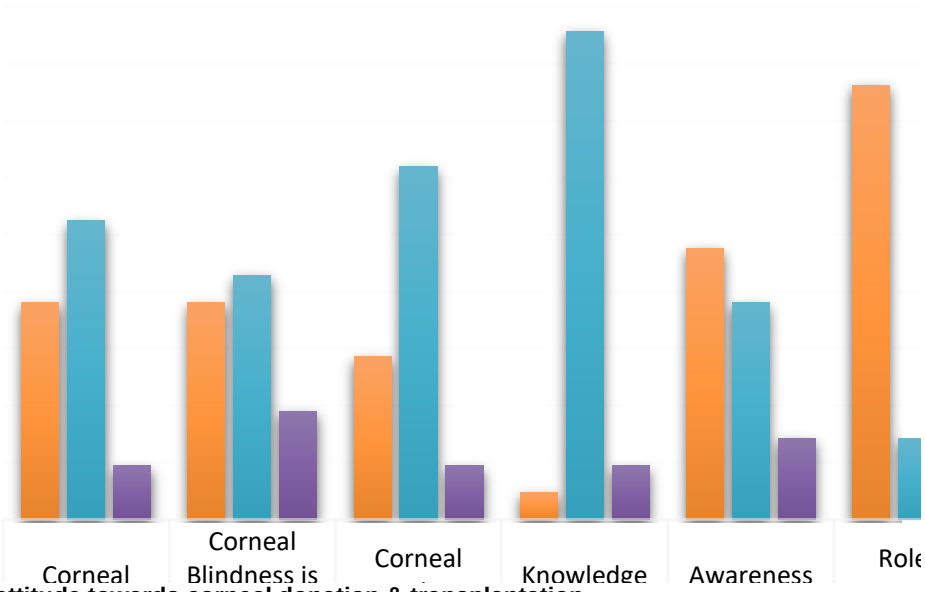

Figure: Knowledge & attitude towards corneal donation & transplantation.

Table 2: Response of patients operated for PKP.

Question		*Frequency n = 30*			*p - Value*
		Male (% within group)	*Female (% within group)*	*Total n (%)*	
Emotional State during wait	Cumbersome	25 (92.6)	1 (33.2)	26 (86.7)	<0.001*
	Easy going	2 (7.4)	-	2 (6.7)	
	Unsure	-	2 (66.7)	2 (6.7)	
Outcome matching expectations	Yes	21 (77.8)	3 (100)	24 (80)	.65
	No	3 (11.1)	-	3 (10)	
	Unsure	3 (11.1)	-	3 (10)	
Decision of re-do PKP	Yes	18 (66.7)	2 (66.7)	20 (66.7)	.87
	No	2 (7.4)	-	2 (6.7)	
	Unsure	7 (25.9)	1 (33.3)	8 (26.7)	
Recommend Corneal Donation	Yes	27 (100)	3 (100)	30 (100)	<0.001*

* Significant p-value calculated by Pearson Chi-Square Test

test as applicable. A *p*-value of ≤0.05 was considered to be statistically significant.

The ethical approval was taken from the Ethical Review Committee (ERC) of Armed Forces Institute of Ophthalmology (AFIO). Rawalpindi.

Results

Total 2090 participants responded to our questionnaire. Age range was 24–61 years. Mean age was 36.66±9.00 years. 100(4.8%) participants were of age <25 years, 1791 (85.7%) were between 25–50 years and 199(9.5%) were >50 years.1492 (71.4%) participants were males whereas 598 (28.6%) females. Significance was computed with cross tabulation between genders. We found a low level of knowledge about corneal donation as 1594 (76.25%) participants stated that they were not aware that one pair of eyes is enough to restore vision. 299 (14.3%) said it could restore vision of only one person. 199 (9.5%) said it could restore vision of 2 to 4 person [*p* <.001].1294 (61.9%) stated corneal donation as a good deed,199 (9.5%) had loved one who has seen the agony of blindness, however (28.6%) were unwilling to donate [*p* <0.001].1693 (81%) had the opinion that corneal donation will help to restore the vision of sufferers whereas 299 (14.3%) considered it unethical. In response to a question that whether you will donate corneas of your first degree relative in case of death, (28.6%) said No,(33.3%) agreed and (38.1%) were unsure [*p* <.001].About opinion regarding the establishment of Corneal Donation/ Eye Bank in Pakistan, 995 (47.6%) strongly agreed,497(23.8%) neither agreed nor disagreed, 598 (28.6%) disagreed [*p* <0.001]. 995 (47.6%) believed that Pakistan Government Health Sector should establish an online registration system to

encourage and facilitate donors whereas 497 (23.8%) neither agreed nor disagreed, however, 598 (28.6%) disagreed with the concept (Figure).

Part II of our data included patients who had been through Penetrating Keratoplasty (PKP) at our Institute. It included n = 30 patients of age range between 18–74 years. Gender-wise distribution was 27 (90%) males and 3(10%) females, significant values derived between opinions of both genders. 4 (13.3%) had to wait for 06 months,5 (16.7%) waited for 6–12 months whereas 21 (70%) had to wait for greater than 12 months to get cornea for transplantation [*p* – value .45%]. 28(93.3%) of the patients were in good health and had better prognosis after surgery. 2(6.7%) did not have a good outcome [*p* –value .43]. Vision and quality of life of 29 (96.7%) patients improved [*p* – value .65]. 30 (100%) supported the idea of corneal donation and transplantation. Emotional state during the wait, outcome matching expectations and decision of re-do PKP are enumerated in (Table-2).

Discussion

Consequences of our investigation uncovered that a noteworthy number of individuals will bolster corneal donation in Pakistan if specialists concentrates in this matter. Patients who had experienced Penetrating keratoplasty at our Tertiary Care Hospital have indicated their satisfaction however they had to wait for long time. It can be attributed to an extensive shortage of corneal graft tissue globally with just 1 cornea accessible for 70 patients requiring transplantation. Endeavors ought to be made at the national level to make mindfulness regarding the matter.[12]

Gain et al. did a global survey of corneal transplantation and eye banking. Ranking order as per their statistics, highest was the United States of America (199.10−6) in corneal transplants per capita, next in order was Lebanon (122.10−6) followed by Canada (117.10−6), whereas the median of 116 countries conducting transplant surgeries was (19.10−6). However, only 82 countries were doing procurement of corneas. The United States of America (USA) and Sri Lanka were among notable cornea exporters. It's worth mentioning here that our institution previously used to receive corneas from these two prime cornea donating countries .There is (53%) global deprivation of corneal transplantation.[13]

Williams et al studied awareness and attitudes versus challenges and opportunities towards corneal donation. They gathered results for awareness of corneal donation from 55 published studies of 13 countries. Participants presented positive attitudes toward eye donation when compared with an actual number of donations received. The most commonly stated reason for small number of registration was awareness about eye donation.[14] We also found a low level of knowledge about corneal donation. 1594 (76.25%) participants stated that they were not aware that one pair of eyes was enough to restore vision.

Haddad et el analyzed public attitudes and perceptions toward corneal donation in Jordan. Total 500 participants completed the questionnaire. About 67.2% of the study participants showed their willingness for corneal donation whereas 32.8% were not willing to do so. Main intention for for corneal donation was doing a good deed by helping others. According to our trial results 1294 (61.9%) participants stated that donating cornea was a a good deed. In the same study fear of the body being maltreated was the main reason for unwillingness to donate cornea and in our case 99(14.3%) considered it unethical.[15]

Ackuaku-Dogbe et el did research on awareness and willingness about corneal donation among patients visiting a Tertiary Eye Center in Ghana. Awareness of subject and willingness for corneal donation after death were illustrated in 45 (8.40%) and 321(59.90%) of participants respectively while in our study the knowledge and awareness of corneal donation was even much less(4.80%).[16]

Paraz et al performed a cross-sectional study to determine knowledge and attitudes toward corneal donation among Singaporean youth. Paraz found that 31% of study participants were willing to donate cornea. Somewhat similar (33.30%) proportion of our study population were for corneal donation. The proportion of the unwilling (22.2%) Singaporean youth to donate cornea is also comparable to the unwillingness (28%) population of this study sample. However the proportion of people not sure of their willingness to donate cornea was less (38.10%) in this study as compared to those (46.8 %) reported by Paraz et.al. Factors favoring willingness to donate were older age group, non-Muslims and sound knowledge.[17]

Noopur et al conducted a population-based study to figure out attitudes and perception towards Eye Donation in patients with corneal disease.As per their results awareness was 46.4% (n = 205 of 442) and 52.3% (n = 462 of 884), in cases and control groups respectively (P = 0.044). Reasons for not pledging eyes were lack of willingness (36.7%) and knowledge (15.3%). Educational caliber had significant influence($p < 0.001$).[18]

Fasolo et al. inquired about health status and patient satisfaction after corneal graft. As per

their results, 83.1 % patients were satisfied with the outcome of the graft, The result are comparable with our cornea contenders as 80% of patients who underwent corneal transplants were satisfied with the outcome and 100% recommended corneal donation. Transplantation improved patients' quality of life and mental health in terms of social interaction and emotions with minor issues such as limitation and pain.[19]

Therefore because of studies conducted worldwide on the general population and patients operated upon, the results of our study were applicable and relevant with global endeavors of exploration and analysis on the matter of corneal donation and transplantation. The patients have to wait for an extensively long period before the corneal gifts from USA and Sirilanka are available. Additionally the pandemic of COVID – 19 has been an experience and a realization of self-reliance and to reducing our dependencies on foreign aid in the health sector.

We ought to edify, persuade and encourage individuals to advance 'corneal gift' with the goal that we can carry expectation and light to those battling through the haziness. Public campaign strategy via social and electronic media can be generated to sensitize the masses regarding corneal donation. If Public is sensitized and awareness created about the importance of corneal donation, then it would be not be difficult to establish an eye-bank as a matter of fact great deal of the charity work in Pakistan is contributed by its citizens.

To conclude, a noteworthy population can support corneal donation if the government builds up appropriate channels and facilities to promote corneal donation and eye banks. Keeping in view the ongoing pandemic of Covid-19, establishing our own banks for corneal donation will eradicate our dependency on its import as global transport chain is disrupted. Self-reliance in corneas can not only ease out provision but also number of beneficiaries can be enhanced.

Conflict of interest: None declared.

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