RESEARCH ARTICLE

The impact of family history on corneal donation and transplantation attitudes: a survey-based study

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Abstract

Objective: To assess how having a first-degree relative who underwent corneal transplantation influenced people's attitudes regarding corneal donation and transplantation.

Method: The cross-sectional study was conducted between March 15 and April 15, 2023, in the Ophthalmology outpatient department and cornea division of Necmettin Erbakan University Faculty of Medicine Hospital, Konya, Turkiye, and comprised first-degree relatives of patients who had undergone corneal transplantation in group A and controls matched age and gender without family history of transplantation in group B. All the participants filled out a 13-item survey form regarding socio-demographic characteristics and their perspectives on corneal transplantation and donation. Data was analysed using SPSS 20.

Results: Of the 263 subjects, 133(50.6%) were in group A; 78(58.6%) females and 55(41.4%) males with mean age 46.5±15.2 years. There were 130(49.4%) subjects in group B; 70(53.8%) females and 60(46.32%) males with mean age 44.3±15.8 years ($p>0.05$). There were 110(82.7%) participants in group A and 72(55.4%) in group B who knew what corneal transplantation meant ($p<0.001$). In group A, 81(60.9%) subjects wanted to donate their corneas after death compared to 40(30.8%) in group B ($p<0.001$). In group A, 108(83.7%) participants stated that a first-degree relative's corneal transplantation positively affected their view of organ and tissue donation.

Conclusion: Individuals whose first-degree relatives had had a cornea transplant showed higher awareness of cornea transplantation and willingness to donate their corneas.

Key Words: Cornea transplantation, Keratoplasty, Transplant donors, Awareness, Family medical history.

(JPMA 74: 2139; 2024) **DOI: https://doi.org/10.47391/JPMA.11517**

Introduction

Vision problems are among the most frequent public health problems, especially in developing countries. The World Health Organisation (WHO) reported in 2019 that 2.2 billion people had visual impairments, and, of them, 1 billion were affected by preventable diseases.[1] Moreover, corneal opacities affect 4.2 million people.[1] Vision problems and causes of blindness may vary depending on a country's development level, climate and socioeconomic structures. Corneal problems were found to be the second most common cause of visual impairment in patients in Turkiye.[2]

The first full-thickness corneal transplant was performed by an Austrian ophthalmologist in 1905.[3] Since then, corneal transplants have been used in the treatment of corneal blindness, and have undergone continuous development. With the developments in corneal storage solutions and the improvement of immunosuppressive treatments, corneal transplantation has become one of the most frequently performed tissue transplantations in the world. Corneal transplantation can be a full-thickness procedure, such as in penetrating keratoplasty, or a partial-thickness procedure involving the front or back surface of the cornea.

Despite the increasing frequency of application, the awareness of corneal transplantation depends on many factors, and one of the most important limiting factors remains the number and quality of donor corneas. In fact, studies indicate that only one cornea is available for every 70 corneas needed worldwide.[4] It is estimated that 12.7 million people are on the waiting list for corneal transplantation, and the average waiting time is 6.5 months.[4]

One of the best ways to increase the number of donor corneas is to raise awareness about corneal donation and corneal diseases. First-degree relatives of corneal transplant patients have the potential to empathise with transplant patients. The current study was planned to assess how having a first-degree relative who underwent

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Submission complete: 08-01-2024 **First Revision received:** 29-03-2024

Acceptance: 07-09-2024 **Last Revision received:** 21-08-2024

corneal transplantation influenced people's attitudes regarding corneal donation and transplantation. Evaluate people whose first-degree relatives (mother, father, spouse and child) have had corneal transplantation in terms of their awareness of and perspectives on corneal transplantation in comparison with people who do not have a family history of corneal transplantation.

Subjects and Methods

The cross-sectional study was conducted between March 15 and April 15, 2023, in the Ophthalmology outpatient department and cornea division of Necmettin Erbakan University Faculty of Medicine Hospital, Konya, Turkiye. There is an eye bank within the Ophthalmology department, and corneal transplant surgeries are actively performed at the clinic.

After approval from the institutional ethics review board, the sample was raised using non-probability consecutive sampling technique. Those included were first-degree (spouse, child, mother and father), adult relatives of patients who had undergone corneal transplantation surgery and had attended the follow-up examinations. They were placed in study group A. Control group B comprised subjects matched for age and gender who had no history of tissue or organ transplantation, including corneal transplantation, in first-degree relatives. Individuals were excluded from both groups if they had chronic ophthalmic diseases other than refractive error, a history of ocular trauma, chemical eye injury or ocular surgery, a history of, or need for, organ or tissue transplantation, or if they refused to participate.

After taking verbal informed consent from al the participant, data was collected using a 13-item survey form. The form was filled by each participant independently and anonymously. Those who were illiterate answered the survey with the help of a relative. The survey consisted of questions about the socio-demographic characteristics, and the awareness level, attitudes and behaviour regarding corneal transplantation and donation. The survey was prepared after a detailed review of the current literature. The survey was pre-tested on ophthalmologists at the hospital for content validity, and on non-medical staff at the university for face validity.

Data was analysed using SPSS 20. Data normality was evaluated using Kolmogorov-Smirnov test. Categorical variables were expressed as frequencies and percentages, while continuous variables were expressed as mean ± standard deviation. Pearson's chi-square test (χ^2) was used to compare inter-group categorical variables, and an independent sample t-test was used for continuous variables. Two-sided p>0.05 was considered statistically significant.

Results

Of the 263 subjects, 133(50.6%) were in group A; 78(58.6%) females and 55(41.4%) males with mean age 46.5±15.2 years. There were 130(49.4%) subjects in group B; 70(53.8%) females and 60(46.32%) males with mean age 44.3±15.8 years. The religion of all the participants was Islam. There was no significant difference between the groups in terms of age, gender and education level (Table).

Table: Demographic characteristics..

	Study Group (n=133)	Control Group (n=130)	p value
Age (years) (mean±SD)	46.5±15.2	44.3±15.8	0.248*
Gender			
Male (n, %)	55, 41.4%	60, 46.2%	0.433**
Female (n, %)	78, 58.6%	70, 53.8%	
Education level			
Illiterate (n, %)	5, 3.8%	2, 1.5%	0.533**
Elementary school graduate (n, %)	43, 32.3%	48, 36.9%	
Middle school graduate (n, %)	21, 15.8%	14, 10.8%	
High school graduate (n, %)	27, 20.3%	31, 23.8%	
University graduate (n, %)	35, 26.3%	31, 23.8%	
Graduate school (n, %)	2, 1.5%	4, 3.1%	

SD: Standard deviation.
* Tested using the independent samples – t test
** Tested using the Pearson's Chi – squared test

There were 110(82.7%) participants in group A and 72(55.4%) in group B who knew what corneal transplantation meant (p<0.001). In group A, 81(60.9%) subjects wanted to donate their corneas after death compared to 40(30.8%) in group B (p<0.001). (Figure 1).

Of the 121(46%) subjects who wanted to donate their corneas to be used after their death, 22(18.2%) had officially registered themselves as cornea donors; 17 (12.8%) in group A and 5(3.8%) in group B (p=0.009).

The reason for willingness to donate the cornea (Figure 2) and the decision by 54(%) participants who responded negatively (Figure 3) were also explored.

While 173(65.8%) participants said they would accept a corneal transplant, if needed, 23(8.7%) responded negatively, and 67 (25.5%) were undecided. Of the 173(65.8%) people who said they would accept a cornea transplant, 19(11%) were unwilling to donate the cornea.

To the question, 'Would you support one of your first-degree relatives if they wanted to donate their cornea?',

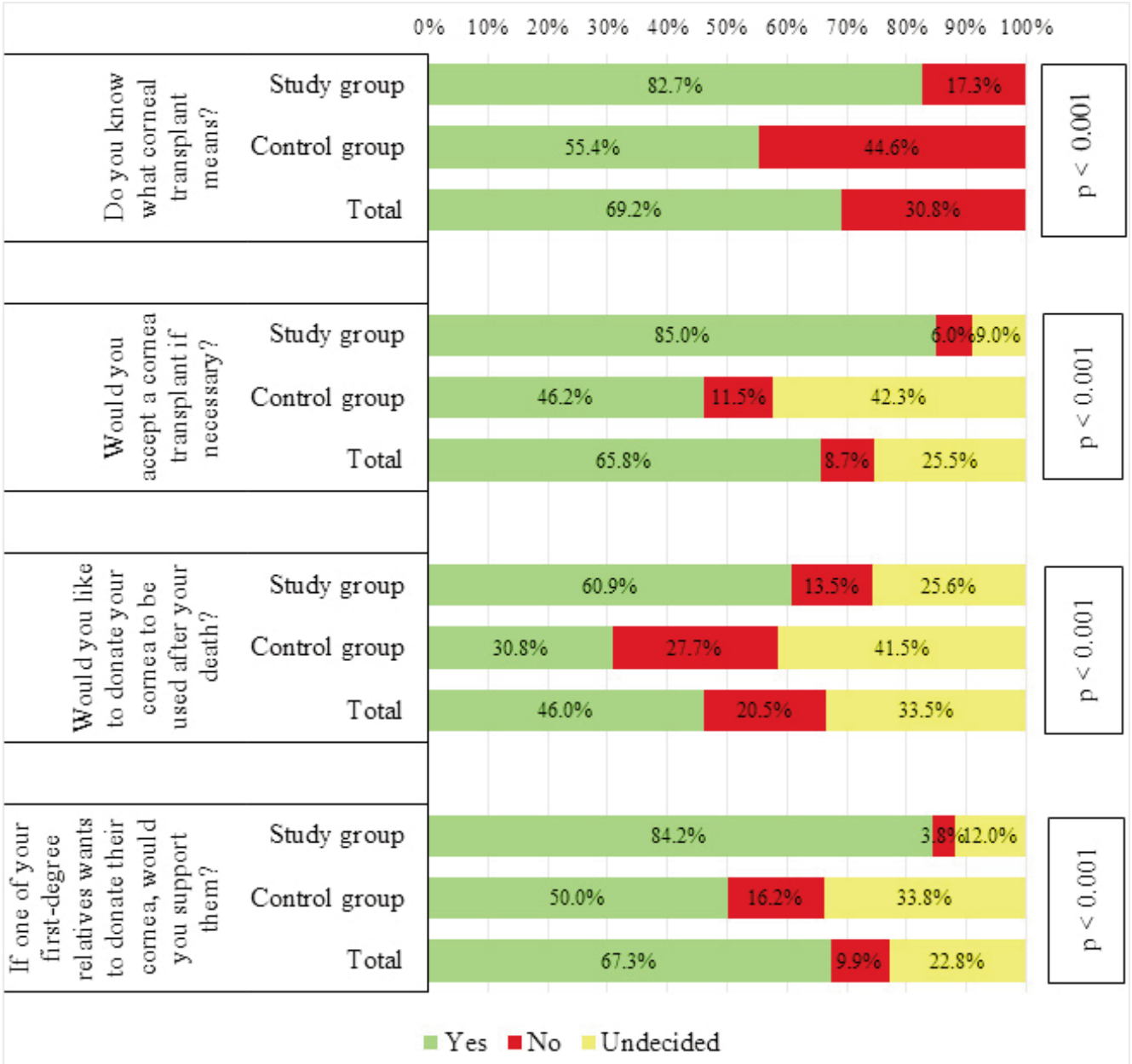

Figure-1: Participants' awareness and perspectives on cornea transplantation and donation.

the intergroup difference in terms of responses was significantly different (p<0.001). Additionally, 108(83.7%) group A participants stated that a first-degree relative's corneal transplantation positively affected their view of organ and tissue donation.

Discussion

The current study, to our knowledge, is the first to focus on the relatives of patients who had undergone cornea transplantation. A survey study was previously conducted focussing on the relatives of patients waiting for transplantation.[5]

Since the main problem with cornea transplantation is cornea supply, informing and encouraging society regarding the benefits of cornea donation is crucial. However, studies show that the desire to be a cornea donor is not uncommon. Even excluding undecided participants, we the current study found that 46% of the participants wanted to donate corneas. This rate increased to 60.9% for those whose first-degree relatives had had a cornea transplant. In a study evaluating publications from 13 countries, the willingness to donate corneas was 52%.[6] In a study in Turkey, the willingness rate was 54.7%.[7]

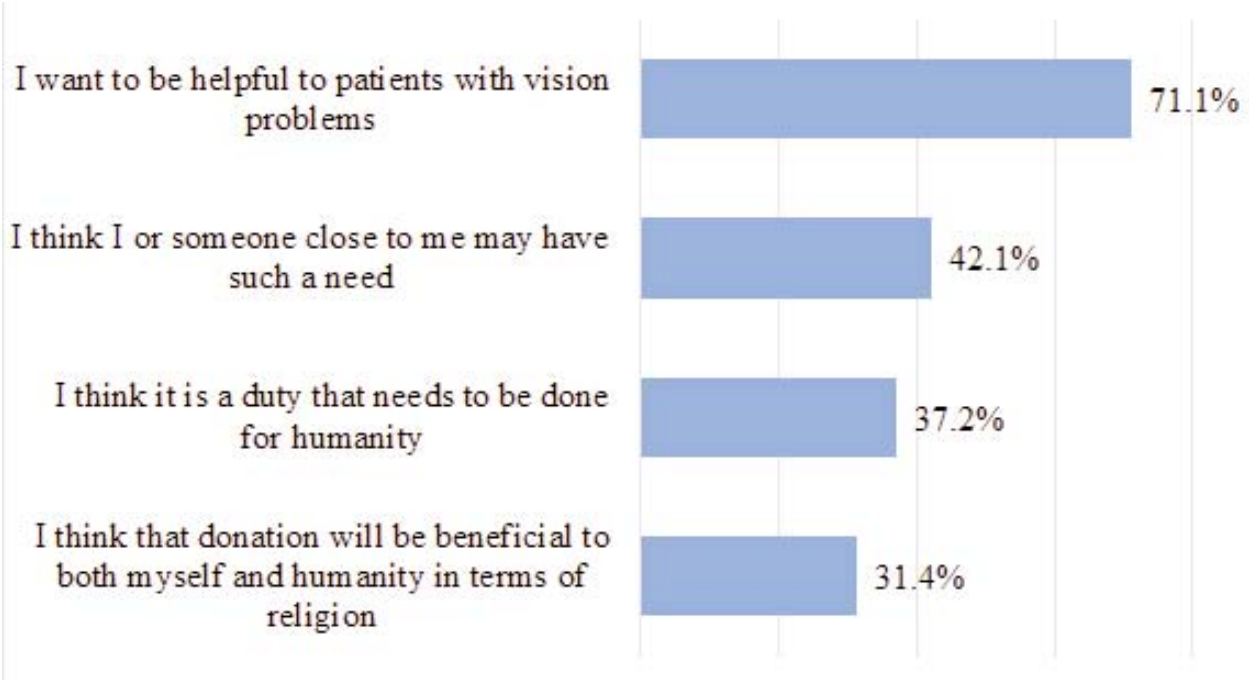

Figure-2: Reasons why the participants wanted to donate their corneas (n=121).

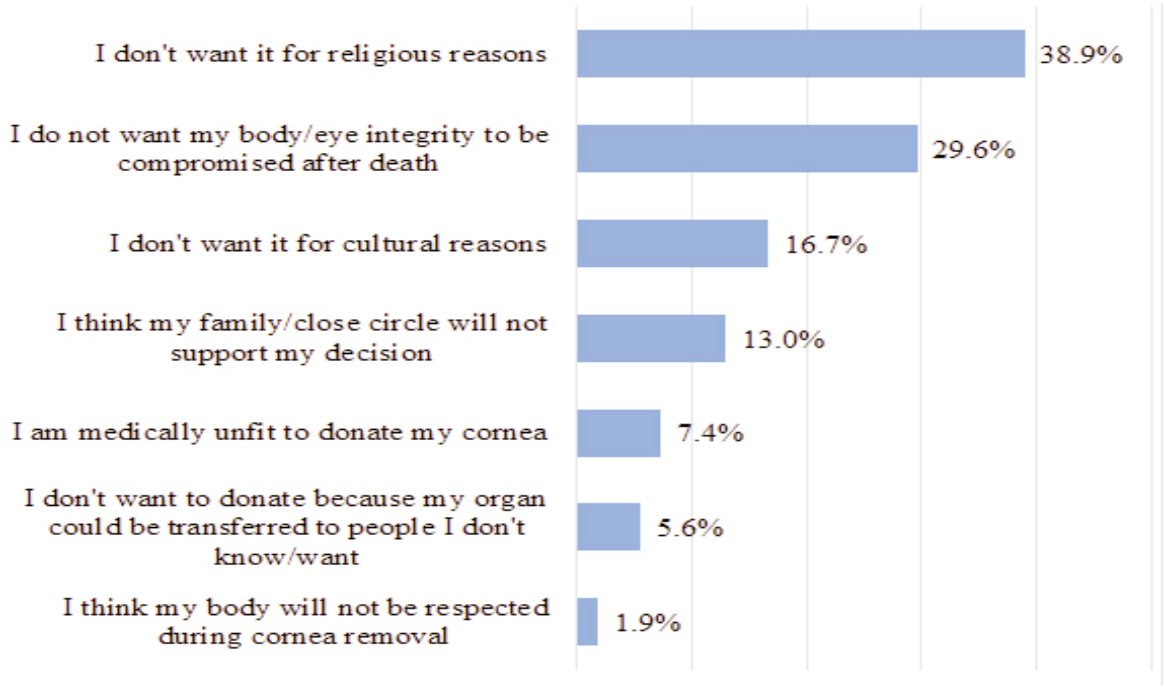

Figure-3: Reasons why the participants did not want to donate their corneas (n=54).

In the current study, the most common answer to the question about the biggest source of motivation for cornea donation was, 'I want to be useful to people with vision problems'. Similarly, in a study on ambulance drivers, the desire to help blind people was stated as the most common reason for the willingness to donate.[8]

People's sources of information change along with advancements in technology. When people are asked about their sources of information about cornea

donation, social media comes first.[8] However, new methods could be tried to increase awareness about cornea donation. Tsigkos et al. reported that a five-minute survey conducted via mobile phone significantly increased individuals' willingness to donate corneas.[9] Additionally, informational videos can be beneficial to patients.[10] By popularising and promoting mobile phone applications for organ transplantation, it can be easier to convince people to become donors.

In the current study, the most common reason among those who refused to be a cornea donor was religious beliefs (38.9%). All of the participants in both groups were Muslims. In a study in Singapore, non-Muslims were willing to donate corneas at a higher rate.[11] In another study, 12.5% of the respondents stated that they would not donate organs due to religious reasons.[12] Some studies show that this situation is similar for other religions. According to a study evaluating the attitudes of Jewish individuals with corneal transplants regarding organ transplantation, Judaism was found to be negatively associated with becoming an organ donor.[13] In the same study, 29% of corneal transplant recipients were registered donors themselves, and most were non-religious.[13]

The second most common reason for refusing to be a cornea donor was people's concerns about the deterioration of their body integrity after death, which was also reported by earlier studies.[8] Although religious reasons may cause some individuals to feel negatively about becoming a cornea donor, religion motivated almost one-third of the current participants. These findings indicate that myths about becoming a cornea donor are persistent, and more efforts are needed to dispel them.

In the current study, more people were willing to accept cornea transplantation when needed than to be a cornea donor. The difference in the willingness to be a recipient but not a donor was perhaps due to people's inability to empathise with others in need of a corneal transplantation.

The literature has revealed a significant difference between individuals' stated willingness to donate their corneas and the actual act of donating their corneas. In a study in India, the willingness to be a cornea donor was 44.9%, but only 1.9% of the participants were registered cornea donors.[14] In the current study, the willingness to be a cornea donor was 60.9% among people whose first-degree relatives had had a transplant, the rate of those who officially registered to donate their corneas was 12.8%. The rate was 3.8% in the control group. The difference in the donor rate in the current study was higher than that reported by other studies examining the issue.[5,15] The most important factors regarding cornea donation were attitude and age.[5] The fact that the rate of registered cornea donors in the current study was higher than that in similar studies is promising.

The difference between individuals' willingness to donate corneas and the number of registered cornea donors means that potential cornea donors cannot be evaluated for various reasons. The most common reason people do not become donors is that they do not know how to do so. Indeed, a study showed that only 14.9% of those who wanted to be cornea donors were aware of the procedures for donating.[5] In other studies, this rate has been as low as 11%.[16]

The current study has some limitations. The most important limitation is that all the participants were Muslims. Consequently, the findings do not reflect the attitudes and behaviours of people of other religions. Additionally, first-degree relatives living far from the patients were not included. The controls were relatives who came to the hospital with the patients. Because they spent more time with the patients and saw what the patients experienced, they were more likely to form a stronger bond and have more empathy than other first-degree relatives. This may have affected their attitudes and behaviours compared to other first-degree relatives.

Conclusion

Individuals whose first-degree relatives had had a cornea transplant showed higher awareness of cornea transplantation and willingness to donate their corneas. Educating all members of society on the issue is of critical value.

Disclaimer: None.

Conflict of Interest: None.

Source of Funding: None.

References

1. World report on vision. Geneva: World Health Organization. [Online] [Cited 2019 October 8]. Available from: URL: https://www.who.int/publications-detail/world-report-on-vision. 2019.
2. Karahan M, Demirtaş AA. Causes of Blindness in Adults in Southern Turkey According to Health Committee Reports. Turk J Ophthalmol. 2021; 51:146-50. doi: 10.4274/tjo.galenos.2020.76301.
3. Zirm EK. Eine erfolgreiche totale Keratoplastik (A successful total keratoplasty). 1906. Refract Corneal Surg. 1989; 5:258-61.
4. Gain P, Jullienne R, He Z, Aldossary M, Acquart S, Cognasse F, et al. Global Survey of Corneal Transplantation and Eye Banking. JAMA Ophthalmol. 2016; 134:167-73. doi:

10.1001/jamaophthalmol.2015.4776.
5. AlRyalat SA, Aburumman R, Taweel L, Al-Rawi H, Dababseh S, Al Bdour M. The impact of having a relative in a need for cornea: the Knowledge, Attitude, and Willingness for Corneal Donation (KAWCD) questionnaire. Cell Tissue Bank. 2022; 23:899-908. doi: 10.1007/s10561-022-10005-9.
6. Williams AM, Muir KW. Awareness and attitudes toward corneal donation: challenges and opportunities. Clin Ophthalmol. 2018; 12:1049-59. doi: 10.2147/OPTH.S142702.
7. Palamar M, Durusoy R, Egrilmez S, Salis O, Yagci A. Public opinion concerning corneal donation and transplant: a survey from Izmir, Turkey. Exp Clin Transplant. 2011; 9:134-8.
8. Joshi RS, Goel P, Adatiya VH, Seth AS, Rasal AV. Eye Donation: Knowledge, Beliefs, Awareness, and Willingness Among Ambulance Drivers in Central India. Clin Ophthalmol. 2023; 17:1263-9. doi: 10.2147/OPTH.S401768.
9. Tsigkos D, Tzelepi A, Kopsini D, Manolakou D, Konistis E, Palioura S. Interactive online survey raises awareness about cornea donation. BMJ Open Ophthalmol. 2020; 5:e000285. doi: 10.1136/bmjophth-2019-000285.
10. Kalayci M, Cetinkaya E, Suren E, Yigit K, Erol MK. Are YouTube Videos Useful in Informing Patients about Keratoplasty? Semin Ophthalmol. 2021; 36:469-74. doi: 10.1080/08820538.2021.1890145.
11. Paraz CM, Truong HT, Sai DK, Cajucom-Uy HY, Chan CL, Kassim SM. Knowledge and attitudes toward corneal donation among Singaporean youth: a cross-sectional study. Eye Vis (Lond). 2016; 3:17. doi: 10.1186/s40662-016-0049-3.
12. Tamuli RP, Sarmah S, Saikia B. Organ donation - "attitude and awareness among undergraduates and postgraduates of North-East India". J Family Med Prim Care. 2019; 8:130-6. doi: 10.4103/jfmpc.jfmpc_206_18.
13. Abuksis G, Orenstein S, Hershko A, Michowiz R, Livne M, Loia N, et al. Cornea recipients: are their opinions and attitudes toward organ donation different from those of the general population? Transplant Proc. 2004; 36:1249-52. doi: 10.1016/j.transproceed.2004.04.093.
14. Dandona R, Dandona L, Naduvilath TJ, McCarty CA, Rao GN. Awareness of eye donation in an urban population in India. Aust N Z J Ophthalmol. 1999; 27:166-9. doi: 10.1046/j.1440-1606.1999.00196.x.
15. Ashraf Jahangeer SM, Rani A, Rehman MA, Meenai EA, Mallick AHH, Masroor L, et al. An assessment of knowledge, attitude, and practice regarding organ donation among students and physicians. J Pak Med Assoc. 2023; 73:480-6. doi: 10.47391/JPMA.5123.
16. Alanazi LF, Aldossari SH, Gogandy MA, Althubaiti GA, Alanazi BF, Alfawaz AM. Attitude, beliefs and awareness towards corneal donation in Saudi Arabia. Saudi J Ophthalmol. 2019; 33:121-9. doi: 10.1016/j.sjopt.2019.02.003.

Authors' Contribution:
BO: Concept, design, data analysis, interpretation, revision and final approval.
SB, MA: Concept, design, data acquisition, analysis, interpretation, drafting and final approval.
EM: Concept, design, data acquisition, revision and final approval.
YD: Concept, design, data analysis, interpretation, revision and final approval.