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Awareness, knowledge and Attitude among general public in North Indian regarding Eye donation

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Abstract:

Background: Aim of the study was to assess the awareness, knowledge and willingness to donate eyes among general public in North India

Methods: A cross sectional population-based survey used a semi structured questionnaire on awareness, knowledge and willingness for eye donation. Stratified multistage cluster random sampling method was used with a sample size of 1100 adults >18 years based on, estimated awareness of cataract 70%, assuming an expected rate of 85%, design effect of 1.5, margin of error 4% with 95% confidence interval with 25% from urban areas and 75% from rural areas. Having heard of eye donation was defined as awareness and having knowledge of the ideal time to donate the eyes was considered as knowledge. A pilot study was conducted to validate the questions used in the main study. Statistical package SPSS (version 25) was used for analysis to calculate logistic regression and odds ratios for gender, age, education and urban-rural areas.

Results: A total of 1000/1100 (90.9%) subjects participated in the survey with females 46.5%. 802 subjects (80.2%) were aware of eye donation. 451subjects (45.1%) were willing to donate eyes. The 395 subjects (49.3%) were aware of the ideal time for donation after death.

Conclusions: Awareness of eye donation was high among the general public but the willingness to donate eyes was poor. There is a need to identify barriers for eye donation to increase the voluntary donation of the eyes to combat corneal blindness.

Keywords: Awareness, Knowledge, Willingness, Eye donation, General public

Introduction

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Vision is an essential sense that plays a vital role in an individual's quality of life, independence, and social participation. The loss of vision, particularly due to corneal blindness, significantly impairs a person's daily functioning and quality of life. In developing countries like India, corneal blindness is a major cause of visual impairment and is second only to cataract in terms of preventability and reversibility (1). Corneal transplantation is the only effective treatment for restoring vision in patients with damaged or diseased corneas. However, the success of corneal transplantation depends entirely on the availability of donated corneal tissue.

India has an estimated 6.8 million people suffering from corneal blindness in at least one eye, and of these, about 1 million are bilaterally blind (2). It is estimated that to meet this demand, approximately 150,000 corneas are needed annually, yet only around 50,000 are donated each year, highlighting a significant shortfall (3). This stark gap between demand and supply is largely due to a lack of public awareness, negative attitudes, myths, religious beliefs, and emotional resistance towards eye donation. These factors have impeded the development of a robust eye donation culture in India.

Awareness about eye donation and willingness to donate eyes are key components in addressing the shortage of donor corneas. Several studies in different parts of India have revealed that although people may have heard about eye donation, a significant proportion lack adequate knowledge and harbor misconceptions about the process (4,5). This gap between awareness and actual registration or willingness to donate indicates the importance of targeted awareness campaigns and education.

In the context of North India, with its diverse socio-cultural, religious, and educational background, understanding the level of awareness and attitude towards eye donation is critical. Previous research suggests that awareness levels in North India remain relatively low, particularly in rural and semi-urban populations (6). Furthermore, factors such as age, education level, religious beliefs, and influence of family and peers play a pivotal role in shaping an individual's attitude towards eye donation (7).

Educational institutions, mass media, and healthcare professionals are major sources of information regarding eye donation, yet their effectiveness depends on how well the message is delivered and accepted. Studies have shown that people are more likely to donate or consider donation if they receive accurate information from trusted sources, such as doctors or community leaders (8). Additionally, societal influences, such as family decisions and religious beliefs, often determine whether a person consents to eye donation, either during life (by pledging) or posthumously (by family members).

One of the challenges in increasing eye donation is the presence of misconceptions and cultural myths. For instance, many individuals believe that removing the eyes after death will lead to bodily disfigurement, or that it is not allowed by religion, despite most major religions supporting organ and tissue donation as a noble act (9). Moreover, emotional barriers, such as grief and denial at the time of death, often prevent families from consenting to donation, even when the deceased had pledged their eyes during life.

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Efforts by government and non-governmental organizations (NGOs), including National Eye Donation Fortnight and Eye Donation Awareness campaigns, have contributed to improving public understanding, but their reach remains limited, particularly in rural areas (10). The Eye Bank Association of India (EBAI) and other regional initiatives have emphasized the need for a sustained and culturally sensitive approach to eye donation awareness that considers regional beliefs and language barriers.

In this context, assessing the awareness and attitude towards eye donation among the adult population in North India becomes particularly relevant. Adults not only form a major segment of potential donors but also influence family decisions and societal norms. Understanding the factors that influence their willingness to donate can help in designing effective community-level interventions, educational programs, and policy measures to bridge the demand-supply gap in corneal donation.

This study aims to evaluate the level of awareness, sources of information, beliefs, and factors influencing eye donation among the adult population in North India. By identifying the knowledge gaps and barriers, the study seeks to provide evidence for policy-makers, healthcare professionals, and public health educators to strengthen eye donation efforts in the region.

MATERIALS AND METHODS

Type of study: Cross-sectional study design

Period of study: May 2019 to October 2019

Study site: Urban areas of Dehradun district Uttrakhand, India

Sample size: Since the prevalence of eye donation awareness among the urban population was not known, Nekar et al (11) estimated prevalence of 50% among college students, n so for general population we were taking nearly 30 % of prevalence with 95% confidence interval and allowable error of 10%, a sample size was 933 taking as round of 1000.

Tools: A total of 1000 eligible participants were interviewed by trained investigators; all the responds were above 18 years of age. A pretested, semi-structured questionnaire was self-administered for collecting the necessary information after obtaining informed consent. The questionnaire contained questions on demographic details, awareness regarding eye donation, reasons for donating and not donating eyes, intention to donate eyes, and sources of information. The data were entered and analyzed using the Epi-info software package, Version 20. Data was expressed in proportion.

Ethics: The study was carried according to the ethical guidelines for biomedical research on human subjects (ICMR 2006).

RESULTS

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Out of sample size of 1100 subjects, 1000 subjects participated in the study (90.9%). The 465 (46.5%) were females. The average age of the subjects is 41.2 years ranging from 18 to 93 years (Table 1), 802 subjects (80.2%) are aware of eye donation. The 451 subjects (45.1%) had corrected knowledge of ideal time for eye donation after death. Responses to the question when the eyes can be donated are presented in Table 2. The source of information for awareness of eye donation was electronic media (41.1%). Of the 1000 subjects, only 451 (45.1%) are willing to donate their eyes. Among the subjects willing for eye donation 51.9 % were ≥ 11th class. With multiple logistic regression about awareness of eye donation with various variables (Table 3), Males had higher awareness of eye donation (OR=1.8, d=l.2-2.6) and also among the educated-l51 to 10th class (OR=1.5, 01.0-2.2), 11th and above (OR=4.1, 02.1-8.0) (Hosmer and Lemeshow test goodness of fit=0.45). Multiple logistic regression about willingness of eye donation with various variables shows that those who are educated 11th class and above have higher willingness for eye donation (OR=1.9 CI=1.2-3.3) (Table 4) rural area subjects less willing for eye donation (OR=0.2, CI=0.1- 0.3) (Hosmer and Lemeshow test goodness of fit=0.001). We chose to remove occupation variable as education surrogate mother of occupation in multivariate analysis.

Table 1: Demographic profile of study participants (n=1000)*

Variables	Agriculture	Business	Student	Employee	Labourer	house-wife	Others	Total
Age group (years)								
18-39	108	53	117	56	133	51	2	520
40-59	94	32	0	77	85	31	0	319
≥ 60	65	4	0	25	43	23	1	161
Gender								
Male	157	43	86	113	132	0	4	535
Female	113	2	42	73	174	61	0	465
Education								
Illiterate	105	0	0	6	143	17	0	271
1-10* class	138	16	13	24	180	65	2	438
≥ 11th class	9	35	89	114	19	22	3	291
Location								
Urban	8	5	50	53	35	57	3	211
Rural	255	2	74	76	319	56	7	789

*Data from two participants missing.

Table 2: Responses to the question: Do you know when eyes are to be donated, (n=802).

Time period	No. of people who are aware of time for eye donation	Percentage (%)
Before death	56	7.0
Within 6 hours	395	49.3
Within 12 hours	141	17.6
Within 1 day	99	12.3
Don't know	111	13.8

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Table 3: Multiple logistic regression showing association between willingness for eye donation and various variables, (n=451).

Variables	Willingness, (n)	Odds ratio	P value
Age group (years)			
18-39	271	1.00	
40-59	121	0.883 (CI=0.604-1.291)	0.521
≥ 60	59	0.843 (CI=0.511-1.391)	0.504
Gender			
Male	275	1.00	
Female	176	0.955 (CI=0.683-1.337)	0.790
Education			
Illiterate	82	1.00	
1-10* class	135	1.087 (CI=0.722-1.636)	0.689
≥ 11th class	234	1.968 (Ol.165-3.323)	0.011
Location			
Urban	230	1.00	
Rural	221	0.204 (CI=0.132-0.314)	0.0001

Table 4: Multiple logistic regression showing association between awareness of eye donation and various variables, (n=852).

Variables	Willingness, (n)	Odds ratio	P value
Age group (years)			
18-39	440	1.00	
40-59	264	0.880 (CI=0.58-1.33)	0.546
≥ 60	148	0.867(00.52-1.44)	0.578
Gender			
Male	458	1.00	
Female	394	1.820 (Ol.26-2.64)	0.002
Education			
Illiterate	212	1.00	
1-10* class	378	1.490 (Ol.00-2.22)	0.049
≥ 11th class	262	4.106 (CI=2.10-8.02)	0.000
Location			
Urban	278	1.00	
Rural	575	0.577 (00.32-1.05)	0.073

DISCUSSION

The findings of this study highlight a critical gap between awareness and willingness regarding eye donation among the general public in North India. While 80.2% of the participants were aware of eye donation, only 45.1% expressed willingness to donate their eyes. This disparity

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underscores the need for targeted interventions to bridge the knowledge-action divide and address the barriers hindering eye donation.

Awareness and Knowledge

The high awareness level (80.2%) observed in this study aligns with similar research conducted in other regions, such as Singapore (Yew et al., 2005), but contrasts with studies from South India (Priyadarshini et al., 2003) and Malaysia (Bhandary et al., 2011), where awareness was notably lower. The primary source of information for participants was electronic media (41.1%), emphasizing its pivotal role in disseminating knowledge about eye donation. However, despite the high awareness, only 49.3% of the aware participants knew the ideal time for eye donation (within 6 hours after death). This indicates that while awareness campaigns are effective in reaching the public, they often fail to convey detailed, actionable information.

Willingness to Donate

The willingness to donate eyes (45.1%) was significantly lower than awareness levels. This discrepancy suggests that awareness alone is insufficient to motivate action. Factors such as education level and rural-urban divides played a significant role in willingness. Participants with higher education (≥11th class) were nearly twice as likely to donate (OR=1.968, p=0.011), while rural residents were significantly less willing (OR=0.204, p=0.0001). These findings highlight the influence of socio-economic and cultural factors on donation behavior.

Barriers and Recommendations

The study identifies several barriers to eye donation, including:

1. **Misconceptions and Lack of Detailed Knowledge**: Many participants were unaware of the procedural details, such as the ideal time for donation, which may contribute to hesitation.
2. **Cultural and Religious Beliefs**: Deep-seated myths and emotional resistance, particularly in rural areas, likely deter potential donors.
3. **Educational Disparities**: Lower education levels correlated with reduced willingness, suggesting the need for tailored educational programs.

To address these barriers, the following strategies are recommended:

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- **Enhanced Public Campaigns**: Utilize electronic media more effectively to provide comprehensive information, including procedural details and dispelling myths.
- **Community Engagement**: Involve faith leaders, local influencers, and healthcare professionals to advocate for eye donation, as their endorsement can significantly impact public perception.
- **Targeted Interventions**: Focus on rural and less-educated populations through community-based programs and workshops to improve knowledge and willingness.

Limitations

The study has limitations, including a small sample size and potential bias in responses from illiterate participants, whose answers were recorded by interpreters. Additionally, the study was conducted in urban areas of Dehradun, which may limit the generalizability of findings to other regions.

Conclusion

While awareness of eye donation is high in North India, translating this awareness into actionable willingness remains a challenge. Addressing knowledge gaps, cultural barriers, and educational disparities through targeted campaigns and community involvement is essential to increase corneal donations and reduce the burden of corneal blindness. Future research should explore innovative strategies to enhance public engagement and evaluate their effectiveness in diverse populations.

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