

Role of 'Community Grief Counsellors' in Enhancing Eye Donations

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ABSTRACT

Introduction: Corneal blindness remains a major public health concern, with a persistent shortage of donor corneas despite awareness initiatives. Ambulance drivers and freezer box service providers, due to their close interaction with bereaved families, may influence eye donation decisions; however, their knowledge, attitude, and practices toward eye donation remain underexplored.

Objective: To understand the Knowledge, Attitude and Practice (KAP) towards eye donation among ambulance workers and freezer box service providers.

Methodology: A validated questionnaire containing 19 questions on knowledge, six on attitude and seven on practice patterns was administered to the study population and their responses were analysed.

Result: Mean age of the participants was 37.57 years. Among all, 69% of the study population had received at least secondary school education. The study participants had partial knowledge (mean score: 15), fair attitude (mean score: 5.8) and poor practise (mean score: 2.7) pattern towards eye donation. Using Dunn's pairwise comparison test, it was observed that the attitude scores of freezer box workers were significantly lesser in comparison to ambulance drivers ($p = 0.001$) and owners ($p = 0.017$).

Conclusion: The study brought to light that active awareness campaigns are required in this cohort and there is considerable potential to improve eye donation if they partner with local eye banks.

Key words: Community; corneal blindness; counsellors; eye banking.

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INTRODUCTION

Corneal blindness is a leading cause of blindness in developing world (Gupta et al., 2013). Apart from 120,000 corneal blind population in India, an estimated 25,000-30,000 are added every year, creating an overwhelming backlog (Oliva et al., 2012). National Programme for Control of Blindness (NPCB) had predicted an estimated corneal blind population of 10.6 million by 2020 (Oliva et al., 2012). The COVID-19 pandemic and ensuing scarcity of donor corneas could be expected to have sky-rocketed these numbers. Only 44,806 corneas are collected every year in India, against approximately 200,000 corneas needed (Kakkanatt et al., 2018). Despite awareness efforts by healthcare workers, knowledge does not consistently translate to positive attitudes toward eye donation, even among medical students (Runda et al., 2019). Hence, it is obvious that awareness must be propagated at grassroots level. Awareness among rural public is below par (S and Prasad, 2022). Oftentimes, after death eye donation perceived negatively (Röck et al., 2016). Higher education levels do not necessarily increase donation rates (Patil et al., 2015). Negative community attitudes can discourage potential donors. Non-governmental organisations (NGO) play a key role in increasing eye donations by engaging community (Christy et al., 2022). Collaboration between public and health professionals can increase eye donations (Faal, 2009; Kakkanatt et al., 2018).

Eye banking in India is meticulously operated, multi-level structured unit supported by government and NGO (Tandon et al., 2017; Gupta et al., 2018). Ambulance and freezer box service providers represent an overlooked

community in corneal procurement. Their close association with general population can prove beneficial in propagating awareness and encouraging eye donations. Their direct contact with grieving families can influence relatives' decisions regarding eye donation. This study aimed to analyse existing level of Knowledge, Attitude, and Practice (KAP) towards eye donation among this particular community: ambulance and freezer box service providers.

METHODOLOGY

This was a non-randomised interventional study conducted among the ambulance workers and freezer box service providers of Pondicherry and two neighbouring districts (Cuddalore, Villupuram) in Tamil Nadu during the period 2023 January to 2023 April. The study was approved by the institutional ethics committee (Reference number: AEH/PDY/EC/OA/130/2021; Dated: 2022 January 20) and adhered to the tenets of Declaration of Helsinki.

Participants were recruited from seven medical colleges in Pondicherry and three government hospitals in Pondicherry, Villupuram and Cuddalore. Sample size was determined based on availability of ambulance workers and freezer box service providers at participating institutions during the study period. All eligible workers who consented to participate were included (convenience sampling). A questionnaire on knowledge attitude and practise (KAP) towards eye donation was developed based on existing literature (Patil et al., 2015; Röck et al., 2016) and refined through focused group discussions with volunteers and professionals. A small pilot study was conducted to validate the questionnaire. Additionally, two

subject matter experts verified the face validity of the questions.

The questionnaire comprised four sections: (a) demographic and education details, (b) 19 knowledge questions, (c) six attitude questions, and (d) seven practice questions. Responses were scored as: two for correct answers, one for partially correct answers, and zero for incorrect or 'not aware' responses. Maximum knowledge score was 25; participants were categorised as having good (≥ 19), partial (13-18), or poor (≤ 12) awareness. Attitude scores (maximum 12) were categorised as good (≥ 8), fair (4-7), or poor (≤ 3). Practice scores (maximum 14) were categorised as good (≥ 7), fair (4-6), or poor (≤ 3).

Two trained interviewers conducted in-person interviews. Training included developing a standardised script in the local language covering self-introductions, study objectives, and consistent question administration.

Following the interview, participants received informational pamphlets and a 15-minute educational session on eye donation with opportunity for questions. This educational intervention occurred after KAP assessment to avoid response bias.

Demographic characteristics, educational qualifications, and mean KAP scores were summarised as frequencies and percentages. Kruskal-Wallis and Dunn's pairwise comparison tests assessed associations between education level, occupation type, and KAP scores. The p-value of <0.05 was considered as significant. STATA version 14 was used for statistical analysis.

RESULT

The study included 75 male ambulance and freezer box service providers. The mean age of our participants was 37.84 years (range: 21-56 years). Participants comprised 41 ambulance drivers (54.7%), 15 freezer box service owners (20%), and 19 freezer box workers (25.3%) (Table 1). Approximately 69% ($n = 52$) had secondary school education, and 16% ($n = 12$) had completed undergraduate education. Mean KAP scores were: knowledge 15.01 (partial awareness), attitude 5.79 (fair), and practice 2.73 (poor).

Knowledge assessment: Overall, 57% ($n = 43$) were partially aware, 24% ($n = 18$) had good awareness and 19% ($n = 14$) had poor awareness. Common misconceptions included: spectacle use as contraindication to donation (39%, $n = 29$) and cataracts rendering eyes ineligible (37%, $n = 28$). Additionally, 48% ($n = 36$) incorrectly believed age limits existed for donation, and 47% ($n = 35$) that diabetes was a contraindication.

Correct knowledge was demonstrated by 64% ($n = 48$) regarding HIV as a contraindication and 63% ($n = 47$) regarding the 6-hour post-mortem donation window. Most participants (83%, $n = 62$) knew that family consent was required, and 75% ($n = 56$) were aware of local eye banks.

While 76% ($n = 56$) knew about the shortage of donor eyes existing in the country, 40% ($n = 30$) were not aware about whom to approach for eye donation and 72% ($n = 54$) believed eyes can be procured for donation only in hospitals.

Attitude assessment: Overall, 59% (n = 44) had a fair attitude towards eye donation, 28% (n = 21) had a good attitude and 13% (n = 10) had a poor attitude. Most participants were willing to pledge their own eyes (80%, n = 60) and consent to a relative's eye donation (83%, n = 62). Additionally, 57% (n = 43) were willing to collaborate with eye banks and 76% (n = 57) felt confident in counselling bereaved families toward donation consent.

Practice assessment: Most participants demonstrated poor practice (65%, n = 49), while 31% (n = 23) showed fair practice and 4% (n = 3) good practice. Approximately half (52%, n = 39) had pledged their eyes for donation, and

37% (n = 28) had witnessed eye procurement. Similarly, 51% (n = 38) regularly donated blood. Twenty-eight percent (n = 21) reported being approached by bereaved families for eye donation information.

Attitude scores correlated significantly with education level ($p = 0.035$), with higher education associated with fairer attitudes. Using Dunn's pairwise comparison test, it was observed that the attitude scores of freezer box workers were significantly lesser in comparison to ambulance drivers ($p = 0.001$) and owners ($p = 0.017$). No significant associations were found between knowledge or practice scores and demographic variables.

Table 1: Demographics and mean knowledge, attitude, and practice scores of the study population.

Parameters	n (%)
Age	
30 and below	31 (28)
31 – 40	28 (37.3)
Above 40	26 (34.7)
Total	75 (100)
Role	
Driver	41 (54.7)
Owner	15 (20)
Worker	19 (25.3)
Education	
Primary	11 (14.7)
Secondary	52 (69.3)
Undergraduate	12 (16)
Mean score	Mean±SD; Range
Knowledge	15.01 ±3.93; 2-21
Attitude	5.79 ±2.21; 0-8
Practice	2.73 ±2.0; 0-7
Overall score	23.53 ±6.4; 4-33

DISCUSSION

This study assessed knowledge, attitudes, and practices toward eye donation among ambulance drivers and freezer box service providers in Pondicherry and neighbouring districts. It revealed that ambulance drivers and freezer box service providers possess partial knowledge, fair attitudes, but poor practices toward eye donation. While 80% were willing to pledge their eyes and 76% felt confident counselling bereaved families, significant knowledge gaps persisted regarding contraindications and procurement procedures. Freezer box workers demonstrated significantly lower attitude scores compared to ambulance drivers ($p = 0.001$) and owners ($p = 0.017$), and higher education correlated with better attitudes ($p = 0.035$). These findings demonstrate unutilised potential for these workers to serve as 'community grief counsellors,' addressing the critical gap between individual pledges and family consent at death.

The practice of keratoplasty, the solution to the growing burden of corneal blindness, is perpetually plagued by the dearth of corneal buttons and an ever-growing requirement. Efficient eye banking and eye donation practices alone can help bridge the enormous gap between the demand and supply of corneal buttons to eliminate corneal blindness. Over the years, multiple steps have been taken by the government and eye banks to increase the collection and utilisation of donor corneas. Notable mentions include the a) launch of the National Programme for Control of Blindness (NPCB) in 1976 which aimed at bringing down the prevalence of corneal blindness from 1.4% to 0.3% by the year 2020, b) involvement of the Ministry of Health and Family Welfare

(MoHFW) in taking consistent efforts to increase public awareness about eye donations by observing National Eye Donation Fortnight from 26th August to 8th September every year since 1985, c) the establishment of Eye Bank Association of India (EBAI) in 1989 to set regulatory guidelines and standards for eye banks across the country, d) passing of the Transplantation of Human Organs Act in 1994 to enable harvesting of eye anywhere by a registered medical practitioner, and e) perhaps the most fruitful of all was the initiation of Hospital Cornea Retrieval Programme (HCRP) in 1990 in an attempt to increase donor cornea collections (Christy et al., 2023).

The HCRP relied on the potential of secondary and tertiary hospitals in terms of concentrated availability and accessibility of eye donors. A partnership between eye banks and such hospitals enabled an upsurge in the donor cornea collections. Dedicated workers called 'grief counsellors' acted as facilitators and catalyst for such eye donations by motivating the grieving families to choose to donate the eyes of the deceased. The grief counsellors are the key elements in determining the success of the programme owing to their timely proximity to the next to kin of the deceased and gentle assertion to persuade the bereaved families to consent to eye donation (Christy et al., 2022). Drawing from this programme, we came up with the concept of 'community grief counsellors' to carry similar roles outside of the hospital set up. This idea is supported by results of a various studies (Christy et al., 2023; Ganesh-Babu et al., 2019), where it was observed that consenting family members were motivated by volunteers outside the family circle and that a majority of non-donors would have donated if someone had

reminded or encouraged them to do so.

Various studies have also reiterated the need for community participation in bridging this chasm (Faal, 2009; Kakkanatt et al., 2018; Christy et al., 2022). Community contribution is the backbone of voluntary eye donations and efforts targeting the education and motivation of the public to donate eyes are rampant. However, here lies the hitch with this conception. An individual can pledge their eyes for donation but after passing, the right to donate their eyes lies solely with the intended donor's family, in essence rendering the act of pledging futile. Suffice to say, it is the kith and kin of the departed that needs to be focussed on to ensure successful eye donation. This is the point where the 'community grief counsellors' come into play. Essentially, these community grief counsellors would be individuals involved in activities and jobs centred around a grieving family or a funeral. These workers are very much part of the community with no relations to the eye banks or the government, and their opinions can become more relevant to the mourning families. Examples of such workers include ambulance drivers and freezer box service providers. Inarguably, the views and knowledge about eye donation of these workers is of much significance. Propagation of misinformation may influence the families to take misguided decisions, while a sound awareness on the part of these workers might guide the families to consent to eye donation.

On analysing the knowledge of our participants, the major roadblocks we found were certain myths that may deter families from considering eye donation. A considerable number of our participants believed that wearing

spectacles, having cataracts and diabetes were contraindications for eye donation and did not know whom to approach if one is interested in donating their eyes. On the flip side, more than half of the study population was aware of the acute shortage of donor eyes in the country, the time sensitive nature of cornea retrieval, the requirement of the family's consent and did not believe the eye donation process to be disfiguring to the face.

Attitude scores of the study participants were more encouraging. More than 3/4th of the study group was willing to pledge their eyes for donation, willing to consent for a relative's eyes to be donated and were confident of convincing a grieving family to consent to eye donation. About half of the group was willing to be involved in eye bank activities to promote eye donation. This statistic further affirms the importance of these workers in nudging the families towards a positive outlook towards eye donation. A correlation between higher educational and occupational qualification and better attitude scores was also established, signifying a barrier that needs to be broken by boosting better eye donation practices amongst all groups of the society.

In contrast, the practice scores of the study population left much room for improvement. Although about half of the participants had pledged their eyes for donation and had donated blood in the past which highlights their altruistic nature, they did not actively involve in encouraging the process or seek to arm themselves with knowledge regarding the same. However, a quarter of the population admitted to being approached by the families of the deceased for information about eye

donation, further emphasising their significance in the process. The attitude-practice gap may be attributed to various factors like lack of procedural knowledge and absence of structured training and sensitisation programmes. While participants demonstrated altruistic intent through prior blood donation and eye donation pledging, this did not translate into proactive engagement, such as initiating discussions with families or guiding them during critical decision-making periods. This suggests that positive attitudes alone are insufficient to drive practice, and that targeted educational interventions focusing on practical aspects and communication skills are essential.

Furthermore, the exclusively male composition of the study sample limits the generalisability of the findings. Women, who often play key roles in family decision-making and caregiving in many sociocultural settings, may demonstrate different levels of awareness, willingness, and engagement in the donation process. The absence of female participants may therefore underestimate or skew the true practice dynamics within the broader population.

CONCLUSION

Present study's results clearly suggest an untapped potential amongst the ambulance and freezer box service providers to be catalysts in increasing community eye donations. Majority of the study population was sensitive to scarcity of donor corneas, was interested in engaging in activities in improving the current scenario and in being eye donors themselves. Being a part of the community themselves, they have an advantage over various awareness programmes in actually impacting the views of the families in their hour of grief. The most

prudent way to utilise the results of our study would be to sufficiently equip this population with knowledge about eye donation practices and abolish the prevalent myths surrounding the practice.

This study has several limitations. The all-male sample limits generalisability to female workers. Geographic restriction to Pondicherry and two neighbouring districts may not represent workers across India. The relatively small sample size ($n = 75$) and convenience sampling method may introduce selection bias. Additionally, self-reported data on attitudes and practices may be subject to social desirability bias. Future research should include larger, more diverse samples across multiple regions.

The inferences from the study substantiate the significance of the community in improving and increasing eye donation. Practices that might be beneficial to adopt are holding awareness and educational sessions for the community grief counsellors and training them in efficient counselling to bolster their impact. Being equipped with a sound awareness and knowledge would only increase their credibility in the community. Empowering the community and making them privy to these practices can potentially result in a boost in eye donations and contribute significantly to tackling corneal blindness.

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