Review Article

Eye donation and eye banking in India

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ABSTRACT

Corneal blindness is a priority condition under the National Programme for Control of Blindness and an important cause of avoidable blindness in India. A multipronged approach is needed to eliminate corneal blindness. Curable or treatable blindness requires a spectrum of care including medication, optical rehabilitation and corneal transplantation. Corneal transplantation is dependent on the availability of safe, donor eyes; however, there is scarcity of donor corneal tissues in India. To improve the eye banking system, the Government of India supports eye banks through recurring grants for operational costs and non-recurring grants for infrastructure costs. Strategic interventions by the government and non-governmental organizations include awareness by health promotion and education, community participation, sustainable source of donor cornea, quality medical standards, accreditation and endeavours to strengthen eye banking systems and procedures through training and research. A model eye banking system in India can be achieved only when it is linked with the targeted infrastructure proposed under 'Vision 2020: Right to Sight-India'. Considering these targets, there is a requirement of at least 20 eye bank training centres, 200 eye banks with corneal transplant facility (collection of nearly 500 corneas per year) and 2000 eye donation centres in the country. This would become a reality if the Hospital Cornea Retrieval Programme is strengthened at all private and government hospitals, uniform medical standards are made mandatory for all eye banks and eye donation centres and the process of registration and eye donation is simplified to enhance community participation.

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INTRODUCTION

Blindness from corneal disease is a major ophthalmic public health problem in India. Currently, there are estimated to be 1.2 million corneal blind persons in India, to which 25 000–30 000 people with corneal blindness are added every year.[1] The burden of corneal blindness has been reported to be 0.12% (blindness defined as presenting visual acuity of <3/60 in the better eye) by a population-based study done in northern India.[2] The major causes of corneal blindness in the CORE study were post-surgical bullous keratopathy (46.2%), corneal dystrophy and degeneration (23.1%) and trachoma (15.4%).[2] In another population-based study done in Andhra Pradesh, the prevalence of corneal blindness was reported to be 0.1% and prevalence of unilateral corneal blindness was 0.56% (blindness defined as presenting visual acuity of <6/60 in the better eye).[3] The most common causes of unilateral and bilateral corneal blindness reported were keratitis during childhood (36.7%), trauma (28.6%), and keratitis during adulthood (17.7%).[3]

Corneal transplantation is the only viable option for visual rehabilitation of those made blind from corneal diseases. Based on the present availability of safe donor eyes and utilization rates, it is estimated that 270 000 donor eyes are required to perform 100 000 corneal transplants per year in India, an approximately 4-fold increase from the present availability of donor eyes.[4] The wide disparity in demand and supply of donor human eyes in India poses a challenge to public health specialists in particular and the health system, in general.

EYE BANKING SERVICES IN INDIA

A 3-tier community eye banking system has been proposed for India. These are: eye donation centres (EDC), eye banks (EB) and eye bank training centres (EBTC). EBTCs are responsible for tissue harvesting, processing and distribution, creating public awareness as well as training and skill upgradation of eye banking personnel. The middle tier comprises EBs and organizations that comply with all the regulations stipulated by the Eye Bank Association of India (EBAI).[5] EDCs should provide public and professional awareness of eye donation, coordinate with donor families and hospitals to motivate eye donation, to harvest corneal tissue, and collect blood for serology and to ensure safe transportation of tissue to the parent EB.

Presently, there are 435 functional EBs and EDCs in the country involved in collection and distribution of donated eyes as per the National Programme for Control of Blindness (NPCB).[6] This amounts to nearly 1 EB/EDC per 3 million population. However, a majority of these are concentrated in urban regions. Many of them function more like collection centres rather than EBs.[7] Few EBs maintain the required quality and follow the prescribed medical standards as per EBAI.[8] It has been suggested that EBAI should provide all EDCs and EBs with the required infrastructure, equipment and facilities as per the guidelines of the Government of India.[5]

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Cornea collection in the country as per the NPCB in 2016–17 was 63 256; Tamil Nadu among the states contributed the maximum of corneas collected.[9] Cornea collections have shown a steady increase from 38 646 corneas collected in 2007–08.[9] With the demand for quality donor corneas on the increase and the limited supply, it is imperative that the available corneas must be utilized to the maximum. Currently, the utilization rate ranges between 25% and 60%.[10]

INITIATIVES UNDER THE NPCB

A major proportion of the budget allocation for the NPCB during the 12th five-year plan (2012–17) was allotted to eye banking.[11] Financial support is given to all functional EBs and EDCs in the government/voluntary sector. Full assistance is given to develop new EBs according to quality standards. Training for EB staff, grief counsellors and doctors is also provided under the programme.[12] Despite continuous increase in the number of eye donations over the past few years, there is a huge gap between demand and supply. To address this gap and to create awareness among people regarding eye donation and related issues, the NPCB celebrates the National Eye Donation Fortnight (25 August to 8 September) every year in India.

Capacity building under the NPCB has been initiated; however, it needs to be strengthened, especially at the grassroots level according to the needs of the community. Reorientation training on eye care of government ophthalmic surgeons, medical officers, paramedical ophthalmic assistants, ophthalmic nursing, school teachers and other general healthcare staff including community link workers and village health volunteers is going on under the NPCB.[13,14] Training needs to be imparted at all levels and should benefit the farthest and inaccessible regions of the country.

One area being strengthened with vigour is eye donation and eye banking. The 'Vision 2020: India' team is instrumental in sensitizing people by involving spiritual/religious leaders in advocacy and communication regarding eye donation. The plan is to involve social/developmental non-governmental organizations (NGOs) not associated with the programme but working with the community in health sectors other than eye care.[13] These non-ophthalmic organizations need to be involved to broaden the base for advocacy, communication and social mobilization through a collaborative approach and public–private partnership.

CHALLENGES AHEAD

Eye banking in India is in an evolving phase, ever since EBAI was established.[15] The major challenges include lack of an organized eye banking system, improper regulation and non-supportive legislations. Quality issues such as failure to adopt common medical standards for all EBs, lack of properly trained eye banking personnel and lack of accreditation systems pose additional problems.[16] Other areas of concern are inefficient public awareness programmes and lack of motivation among health personnel, need for consent from relatives and no 'eventual benefit of pledging eyes before death'. All these have aggravated the problems in harvesting an adequate number of quality donor corneas to meet the growing demands, thus creating a gap between demand and supply.

There are 2 ways of overcoming the shortage of donor corneal tissue: one is by encouraging voluntary donation and the other is by exploring newer sources for corneal procurement such as covering deaths in hospitals through the Hospital Corneal Retrieval Programme (HCRP). Voluntary eye donation is a result of realization of one's social responsibility towards people with corneal blindness and is dependent on the willingness of people to donate and pledge their eyes for corneal donation. There are numerous barriers to eye donation and willingness of people to donate their eyes after death.

Awareness about eye donation

Awareness studies on eye donation in the Indian population reveal that illiteracy and rural residence are strong predictors of ignorance about eye donation.[17] Awareness of eye donation in rural and urban populations varies widely from 28% to 80.6%.[18–20] A hospital-based study conducted among relatives of potential donors brought for post-mortem to a tertiary care hospital in northern India, revealed that none of the deceased had previously pledged their eyes.[21] Willingness for eye donation was present in 41.5% of families. The major reasons for not donating eyes were refusal to discuss the issue and dissuasion by distant relatives, legal problems and religious beliefs.[21]

Well-informed nursing and medical students could influence eye donation rates, as they are the future healthcare providers. Eye donation awareness among nursing students of Bengaluru was 96.8% whereas that in first-year medical students of Delhi was 99.4%.[22,23] The perceived reasons for not pledging eyes were lack of awareness (32.7%), objection by family members (27.7%), unsuitability to donate because of health issues (17.7%) and the unacceptable idea of separating the eye from the body (15.5%). A study on knowledge about eye donation of medical and non-medical students found that nearly one-third of them were unaware that eyes should preferably be removed within 6 hours of death.[24] Another study done in healthcare stakeholders including social workers, health assistants, teachers and donor families reported awareness about eye donation to be 93%. The authors were of the view that services of these stakeholders could be channelized effectively to promote awareness about eye donation in the community.[25]

Hospital Cornea Retrieval Programme

The HCRP was started in 1990, to focus on hospital-based deaths and encourage eye donations using a combined method of motivation and grief counselling. It involves active counselling of relatives in hospitals after death. Trained eye donation counsellors, commonly known as grief counsellors, approach family members of the deceased in the hospital at an appropriate time, share their grief and prepare them to take a positive step towards eye donation on behalf of their loved one.[26] The pivotal role is played by the 'catalysts'; in this case, the grief counsellors, who facilitate the reaction of eye donation. This mechanism of corneal retrieval provided easy accessibility to potential donors, ready availability of a detailed medical history to assess eligibility of the donor for corneal donation, availability of tissues from younger donors, reduction of death to corneal retrieval time and cost-effectiveness. Hence, it improves both corneal collection and utilization rates in an EB. Health professionals, including attending doctors, residents, nursing staff and paramedics, play a major role in the HCRP by counselling and motivating relatives of the deceased and potential donors. For the past 5 decades, the National Eye Bank, All India Institute of Medical Sciences (AIIMS), New Delhi, has been serving as a non-profit centre and has played a leading role in policy-making, research, training and corneal transplantation activities. The HCRP has proved to be the backbone for procurement of human corneas at the National Eye Bank, New Delhi. Health professionals can counsel and motivate relatives of deceased patients in the hospital and play a key role in the HCRP

for eye donation. A study on the knowledge of eye donation among health professionals of Pune found that 12.1% of them had excellent knowledge, 59.2% had good knowledge and 28.6% had poor knowledge about eye donation.[27]

Corneal transplantation procedure: Challenges

In an effort to eliminate corneal blindness, trained corneal surgeons are required for proper utilization of available donor corneal tissue for successful outcome of any transplantation procedure. As emphasis is laid on performing cataract surgery by the private sector including NGOs, there is lack of interest in conducting keratoplasty and maintaining EB by this sector. Factors that contribute to the upsurge of existing lacunae of corneal surgeons at this level are the longer learning curve for keratoplasty surgery, decreased revenue generation for the private sector through this surgery, increased need for infrastructure, human resources and networking to maintain an EB to produce good-quality donor tissue. The non-availability of corneal surgeon training centres and trained corneal surgeons in all regions of India is a major roadblock to decrease the burden of corneal blindness in the country. Another deterrent for keratoplasty is longer surgical time and follow-up compared to that of cataract surgery.

The poor outcome of penetrating keratoplasty in patients with corneal blindness due to ocular trauma and infective keratitis, the most common causes of corneal opacity in India, adds to the problem.[2] The longer surgical time and lifelong follow-up of patients undergoing corneal transplantation poses another challenge. The outcome of penetrating keratoplasty in patients with bilateral corneal blindness was compared with unilaterally blind patients in a tertiary eye care hospital in northern India.[28] The outcome in patients with bilateral blinding corneal disease was poorer than in those who had unilateral blindness. The most common cause of failure was graft infection (40%) in the study group; 70% of the cases belonged to the low socioeconomic strata ($p=0.004$). In a study of 1725 corneal transplants done at a tertiary eye care centre in Hyderabad, the survival rates at 1, 2 and 5 years for all first-time corneal transplants were 79.6%, 68.7% and 46.5%, respectively. Patients with lower socioeconomic status had higher relative risk of transplant failure, as did patients <10 years of age.[29]

Thus, surgical intervention for corneal blindness that has already occurred is rarely successful unless well-trained surgeons and nurses are available in conjunction with modern operating rooms, good equipment, reliable EB facilities and well-established specialty clinical services for long-term follow-up and treatment of graft rejections and other post-keratoplasty complications. Due to non-equitable distribution of such specialized healthcare services in India, timely management may not be available to people in the rural and underserved regions of the country, where the need of treatment and magnitude of corneal blindness may be the greatest.[30]

THE WAY FORWARD

The future of the eye banking system in India seems bright. There is a need to work on the infrastructure, human resource and training and proper utilization of resources to achieve a balance between demand and supply of donor corneas in the country. The eye banking infrastructure should be linked with the targeted infrastructure proposed under 'Vision 2020-Right to Sight' for India. Considering these targets, an EDC should be available at the subdistrict level for every 500 000 population, an EB should be available for every 5 million population and all centres of excellence should be developed as EBTCs. Thus, 20 EBTCs, 200 EBs with corneal transplant facility and 2000 EDCs are required in the country. This will help in improved referral and linkage at all levels of healthcare delivery. Equitable distribution of functional EBs in the country needs to be ensured. At the EBTC, surgical skill development centre and training facilities should be available for all surgeons of that region.

Recommendations for eye banking and elimination of corneal blindness were developed at the National Expert Group meeting in November 2017 at the apex national tertiary eye care centre of AIIMS, New Delhi. Eminent corneal experts and representatives from WHO and the NPCB, India developed an action plan to effectively combat corneal blindness and work towards the goal of universal eye health. It was recommended to initiate exhaustive capacity building and training of all ophthalmologists in Regional Institutes of Ophthalmology and medical colleges in the field of corneal transplantation. At the secondary level of healthcare delivery, registry of all individuals with corneal blindness should be maintained and appropriate referral to higher centres should be ensured. The district ophthalmic surgeons should be trained in management of patients with corneal grafts. They should establish an effective network with the optometrists at the vision centre and with health workers at the grassroots level. At the primary level, village-level health volunteers can mediate between relatives and the nearest EB soon after death to facilitate eye donation.[31] Accredited social health activists (ASHAs) can participate in generating awareness at the community level about eye donation. As they are recruited from the community, they are known and acceptable to the local inhabitants. The optometrists can be trained in corneal retrieval so that home deaths are maximally covered with the help of village-level volunteers. Hence, training needs to be imparted at all levels and should benefit the farthest and most inaccessible regions of the country.

At this expert group consultation, emphasis was also laid on monitoring and quality assurance, an important building block of any health system. Maintenance of registers of those who have corneal blindness, number of district hospitals with a functional HCRP programme at the secondary level, number of corneal transplants performed, surgeons trained at the tertiary level, eye donations facilitated at the primary level can serve as important monitoring indicators for the eye banking system in India. Epidemiological research to generate the national need for donor corneas with mapping of functional EB and corneal surgeons will be useful for future planning and advocacy in this field.

Apart from changes at the level of healthcare delivery and advocacy, we need to facilitate effective eye donation. Current awareness about eye donation has been achieved through publicity campaigns run by various NGOs and other voluntary organizations, supplemented by media campaigns by government agencies. This is probably not effective among the illiterate population. Alternative strategies need to be developed to educate the illiterate and rural population, understanding their barriers and resolving their myths, giving due respect to their religious beliefs. Community participation and behaviour change at the local level are required to improve eye donation rates. Another mode of enhancing eye donation in the hospital is to incorporate a question on willingness of eye donation in the death certificate.[32] In addition, non-ophthalmic organizations can be involved to broaden the base for advocacy, communication and social mobilization through a collaborative approach and public–private partnership.

Home deaths, burial and cremation grounds through priests and faith leaders; road traffic accidents and suicide deaths through casualty medical officers, emergency medical personnel and

police officers should also be covered.[33] A system of catalysts in those crucial hours after death can ensure that eyes are donated after most deaths in the country.[34] There is a need to educate students in all fields, about eye donation so that the younger generation may act as motivators for enhancing eye donation rates in the community.

It is believed that India has no dearth of knowledge, skills and resources to create a world-class eye banking and corneal transplantation network, but a proactive national movement is required.[16] It has been reiterated that India does not lack basic infrastructure and workforce related to eye banking; the need is to strengthen existing strategies such as wide implementation of the HCRP and grief counselling, enabling legislation, public awareness, medical standards, accreditation and continuous training programmes for the personnel involved in eye banking.[3]

In the coming years, the priority in eye banking in developing countries will have to be on increasing corneal procurement, improving quality and better utilization of all donor corneas received and reducing costs. A sustained multipronged approach should be undertaken at all levels of healthcare so that management and follow-up of patients with corneal blindness are easily accessible and affordable to the rural poor. Community-level workers, traditional healers and local practitioners need to be educated and their cooperation must be sought to direct patients to appropriate healthcare facilities and increase awareness about eye donation to control corneal blindness.

Conflicts of interest. None declared

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