ORIGINAL RESEARCH PAPER

Volume-8 | Issue-1 | January-2019 | PRINT ISSN No 2277 - 8179

INTERNATIONAL JOURNAL OF SCIENTIFIC RESEARCH

AETIOLOGICAL STUDY ON BILATERAL BLINDNESS AND CURRENT STATUS OF REHABILITATION AMONG THEM.

Ophthalmology

Baidya K. P (MD,DNB,FRCS) Regional institute of ophthalmology, Medical college,Kolkata – 73, India

Kumari E* MS Regional institute of ophthalmology, Medical college,Kolkata – 73, India
*Corresponding Author

ABSTRACT

Purpose : To study the etiology and burden of incurable blindness and to know the status of rehabilitation measures among the blind individuals.
Materials and Methods: A population based prospective study among 1000 participants who were blind (BCVA less than 6/60) and conducted from January 2016 to July 2017 in the retina department of a tertiary eye care centre, Kolkata, India.
Results: The study identified 550 incurably blind individuals. Congenital malformations 279 (50.72%) aside the leading cause of incurable blindness, a significant number 231 (42%) were preventable if timely action had taken. A total of 67 (12.18%) were children below 10 years. Sixteen (2.9%) among them received blind school education. Four hundred and sixty two 462 (84%) are not using low vision aids (LVA). Four hundred and eighty (87.28%) are unemployed and dependent for livelihood. Four (0.72%) received vocational and Community Based Rehabilitation (CBR) training.
Conclusion: Preventable causes of bilateral blindness are highly rampant in our community till now. Economically weaker section, women and children are more neglected. Hardly, blinds are using Low vision aids (LVA). Blind school attendance rate is very poor. Majorities are unemployed and have no formal vocational and Community Based Rehabilitation (CBR) training.

KEYWORDS

Introduction:
Blindness is a major public health concern in India which creates a huge burden to our growing economy due to higher rate of unemployment among the blind. A significant proportion of population in our community remains legally blind in spite of our best of efforts and intent, and need rehabilitation. The purpose of rehabilitation of visually disabled individuals is to provide maximum function, a sense of well being, independence, and optimum quality of life but not limited to, the prescription of optical, electronic or other assistive treatment options. The rehabilitation process should be executed with specific plan for individual in compensatory approaches.[1] However; in India the issues related to incurable blindness are not easily addressed at community level. Simultaneously psychological trauma and social ostracism has to be dealt with. With this background, the present study was undertaken with the following objectives.

To ascertain the etiology, prevalence, awareness and current status of rehabilitation of the incurably blind attending a tertiary eye care centre in Kolkata, India.

Materials and methods: The current study was a population based prospective study among 1000 participants who were blind (BCVA less than 6/60) and conducted from January 2016 to July 2017 in the retina department of a tertiary eye care centre, Kolkata, India. The study was approved by the institutional ethics committee for human research. Those who were found to have curable diseases were given appropriate management. All cases were diagnosed after obtaining a detailed history, past medical records, examination and necessary investigations like slit-lamp biomicroscopy, indirect ophthalmoscopy, applanation tonometry, USG-B scan, FFA, OCT, ERG, EOG and VEP. A questionnaire based proforma was filled up for each patient. The questionnaire was developed with a focus on exploring awareness of the subjects on availability & accessibility of facilities and resources in the local community for addressing problem of blindness, rehabilitation, socioeconomic status, age, any gender gap, schools for the blinds, aids for low vision etc.

Results:
A total of 1000 blind were registered with reduced visual acuity (VA< 6/60 with BCVA). Out of them 450 (45%) persons found to be curably and 550 (55%) incurably blind respectively. The median age of incurable and curable blind was 41.49 (+/-17.35) years and 48.45 (+/-18.84) years respectively. Out of 550, the number of males and females were 207 (37.63%) and 343 (62.36%) respectively. Using modified Kuppuswamy's scale for socio-economic status, we found that upper lower section of the society has the more contribution in curable blindness group 178 (39.56%) followed by lower and lower middle class 121 (26.89%). In case of incurable blindness, lower section of the society 213 (38.73%) contributed most followed by upper lower group 167 (30.36%). The relationship with religion was found to be non contributory with other parameters. So far as etiology of blindness was concerned, 279 (50.72%) out of the 550 eyes with incurable blindness were affected since birth or early childhood**.** Fundal coloboma with iris coloboma and microcornea with or without cataract 204 (37.09%) was the foremost cause of incurable blindness. Other major causes were as follows: congenital cataract 46 (8.36%), congenital glaucoma 05 (0.90%), retinopathy of prematurity 04 (0.72%), TORCH related eye diseases 04 (0.72%).The causes acquired in late childhood or adulthood accounted for the remaining 271 (49.27%) out of the 550 blind individuals. A total of 67 (12.18%) out of 550 were children below 10 years. The spectrum is wide for adult etiology like, advanced diabetic retinopathy 102 (18.54%), bilateral corneal opacity 34 (6.18%), retinitis pigmentosa and associated diseases 29 (5.27%), ARMD and macular dystrophy 25 (4.54%), glaucoma 20 (3.63%), high myopia related complications 09 (1.63%), retinal vaso-occlusive disorders (RVO) 07 (1.27%), bilateral retinal detachment 06 (1.09%), optic neuritis and AION 05 (0.90%). Considering the etiology, numbers of preventable cases were 231 (42%) altogether if timely action were taken. In the preventable group congenital cataract, congenital glaucoma, retinopathy of prematurity, infective keratitis, adult cataract and glaucoma, uveitis, diabetic retinopathy, vasculitis and refractive error were considered.

Out of the total of 550 individuals from the incurable group, only 71 (12.90%) M- 40, F-31, were aware of the existence of blind schools. Sixteen (2.90%) M-12, F-4, blind received Braille education in blind schools. Two hundred twenty (M-165, F-55) managed to acquire visually handicapped certificate. Fifty five (M-43, F-13) had some knowledge about rehabilitation related activity of the Govt. and N.G.Os. Twenty eight (5.09%) were receiving some kind of financial help for being visually handicapped for rehabilitation related activities. Only 04 (0.72%) had received community based rehabilitation (CBR) training. Eighty eight (M-60, F-28), are using low vision aids to improve their vision. Four hundred eighty (87.27%) blind are dependent on their family members for livelihood. Seventy (12.72%) bind are economically productive doing small business or part time jobs like telephone operator, hawker, begging , singing , and jobs like candle making , animal firming etc. Five hundred twenty two (94.90%) incurably blind are able to do self-care independently.

Discussion:
There are 39 million blind people worldwide and a quarter of them lives in India.[2,3] The current population of India lies at 122 crores as per the 2011 census.[4] Considering the current population, 75 lakhs (7.5 million) are due to cataract and 46.36 lakhs (4.6million) are affected by other ocular pathology.[5] The survey conducted by Ministry of Health

and Family Welfare (MoH&FW) during the year 2006-07 revealed that the prevalence of avoidable blindness has come down from 1.4% to 1% due to extensive focus on cataract surgery and awareness on glaucoma and refractive error problems.[6] The prevalence of incurable blindness is not well documented in India. Around the world, especially in the developed countries, there has been a considerable amount of attention towards rehabilitation of patients with low vision. There has been a rise of medicine model of vision rehabilitation in the recent years, spearheaded by and within ophthalmology.[7,8,9]

In our study, we observed that majority of the blind individuals in the incurable group were from the lower section of the society. This indicates that poorer are more prone to blindness due to poor access for treatment. A majority of our country's rural population does not have access to specialized diagnostic and management facilities for ophthalmic diseases like infective keratitis, trauma , vitamin-A deficiency, chemical injury specially during Holi festival, burn and blast injury from fire crackers during Diwali festival.[10] Inappropriate home remedies and poor quality surgeries are aggravating their woes. We have observed that females are more affected than males (female 543, male 457). Not only that acquiring visually handicapped certificate, uses of low vision aids , knowledge of rehabilitation related activity were seriously low among the females. This analysis reflects that females are neglected than males in our community in this regard. In congenital group developmental anomaly has emerged as a leading cause of blindness. In acquired group, diabetic retinopathy 102 (18.54%) has emerged as a fore most cause of vision loss. We also noted that delay in initiation of treatment resulted in bilateral blindness 231(42%) in many otherwise treatable conditions like congenital cataract and congenital glaucoma, retinopathy of prematurity, infective keratitis, Vit-A deficiency, for children and diabetic retinopathy, keratitis, hypertensive retinopathy, cataract glaucoma, uveitis, RVO, eye injury refractive errors and vasculitis for adults. All these were amenable to timely intervention and thus preventable causes of blindness.

A sizable proportion 67 (12.18%) of incurably blinds are children below 10 years. No special attention had been paid towards the blind children regarding Braille education and rehabilitation. Currently, there are estimated 270,000 blind children in India and their school attendance rate is only 5.56%.[11] There is a serious lack of infrastructural facilities to combat preventable congenital causes of blindness like congenital cataract, congenital glaucoma, retinopathy of prematurity, infective causes and selective cases of retinoblastoma. This in turn adds to the amount of years lived with disability by these children and this accounts for adverse socioeconomic impact for a community. Solution of these can potentially bring down the amount of disability years lived by blind children by a huge extent. These children need integrated education with a holistic approach for their physical, mental and social well being. Ideally, every blind child should get education preferably in normal school instead of blind school in their own villages along with other normal children. Blind children should get training for mobility, activities for daily living, Braille education and low vision aids by a trained teachers. Parents of such children should also be trained so that they can assist their children in this regard. Education for them is still out of reach as blind school attendance rate is very poor 16 (2.9%). Number of blind schools is very limited and schools are situated far away from their home. The awareness level related to blind education, various rehabilitation activities and uses of low vision aids are seriously low among them. Seventy (12.72%) are economically productive and rest are economically dependent on their family members. The number of Community Based Rehabilitation (CBR) or vocational training recipient is very poor 4 (0.72%). The mobility and orientation training is necessary for a blind individual to adapt themselves to their surroundings in a manner so that they can become independent in tasks like walking short distances without much help. Making these people capable enough for carrying out their daily life routine skills like washing, dressing, cooking, and maintaining hygiene and other essential activities can bring out remarkable difference in their quality of life. Orientation and Mobility (O&M) training has a huge impact on employment outcome.[12] Individuals who were using long and white cane had better physical and working ability in terms of independent living.[13] Apart from that, vocational training for suitable and appropriate jobs can even make these people contribute to our growing economy along with being a morale booster and a source of income to them. The aim of economic rehabilitation can be like running small business ventures like animal rearing, specific agricultural works, crafts making (toys, chair, basket, brooms etc). Rehabilitation can even be initiated at home or within the community of these people which can ensure all time active support to these people.

Visual Acuity (VA) at presentation less than 6/60 in the better eye has been referred to as economical blindness in India. [3] The annual economic burden of blindness in India based on the year 1997 estimated around $ 4.4 billion. [14] In economic terms, the cost of blindness depends on the direct cost incurred by the blind person due to loss of productivity and indirect cost incurred by the family to take care of the blind person. The average number of working years lost due to adult blindness is 10 years and in case of blind children it is 33 years. [6]10% of the productive time of one economically productive member of the family of each blind person is lost in taking care of the blind member of their family.[9] Those received Braille method of education had better job opportunity.[15] Structured Discovery Cane Travel (SDCT) approach were more effective and more likely to be employed.[16] SDCT is rooted on non-visual techniques, problem solving skills and confidence building learning experiences. Edward C. Bell demonstrated higher rate of employment and more income among the Braille users and those received training under SDCT approach. [17] One major problem in formulation of effective policies is that there has never been a nationwide epidemiological study on the prevalence and pattern of blindness in our country. There are only few data available in this regard on regional basis. The national survey done during 1986-89 did not include dilated fundus examination and visual field assessment. Hence, retinal diseases and others noncataractous causes of blindness were underestimated. The Andhara Pradesh Eye Disease Study (APEDS) was done to assess the rate and cause of blindness and low vision, risk factors for various eye diseases, effect of visual impairment on quality of life and barriers to access to eye care services.[18] A south Indian based institution initiated community based rehabilitation (CBR) in a rural district of south India. This institute also analyzed barriers for utilization of rehabilitation programs.[19] Only few NGO'S and private institutions are actively running rehabilitation training programs. International agencies like Sight Savers International and CBM International already have focus on promoting community based rehabilitation for comprehensive eye care for the blind individuals. In India, NPCB has been working for a long period to bring down the prevalence of blindness. To achieve this NPCB has adopted intensive IEC (public health prevention program) and has been conducting training sessions for medical officers, eye surgeons, PMOAs and ASHAs for the recognition of all types of ocular ailments. If we look critically at NPCB, cataract related blindness has remained its main target and an equal amount of attention has not been paid for the rehabilitation programs. Many new blind schools have been set up but unable to meet the current demand. The visually challenged persons can excel with a little support from the society. Only rehabilitation activities can create a more equal society for blinds, promotes opportunities for economic empowerment, livelihood security, achieves their full potentials, and enjoy their human rights.

Conclusion

Majority of blind persons are leading to long years of compromised quality of life. Incurable blind persons should be properly linked to social security measures and more emphasis should be provided towards awareness and demand generation for available governmental/non-governmental schemes. Measures should be escalated with extra care for children and women. A nationwide population based epidemiological study is a must to know the exact number of incurably blind persons, nature of rehabilitation required for them, planning and implementing blindness prevention programs and appropriate allocation of resources.

Table-1: aetiology of blindness (Incurable)

Sr. no	Aetiology (Congenital)	Numbers	percentage
01.	Fundal coloboma + iris coloboma + micro-ophthalmos with microcornea with or without cataract	204	37.09%
02.	Congenital cataract	46	8.36%
03.	Congenital glaucoma	05	0.90%
04.	Retinopathy of prematurity (ROP)	04	0.72%
05.	TORCH related eye diseases	04	0.72%
06.	Albinism with nystagmus	02	0.36%
07.	Corneal opacity	02	0.36%
08.	Congenital anophthalmos + crypto-ophthalmos	01	0.18%

09.	Telecanthus with severe ptosis	01	0.18%
10.	Hydrocephalus with microcornea	01	0.18%
11.	Higher centre abnormality	01	0.18%
12.	Sclerocornea	01	0.18%
13.	Leber,s congenital amaurosis	01	0.18%
14.	Persistent hyperplastic primary vitreous(PHPV)	01	0.18%
15.	Others	05	0.90%
	Total numbers	279	50.72%
Sr. no	Aetiology (acquired)	Numbers	Percentage
01.	Advanced diabetic retinopathy and related complications	102	18.54%
02.	Bilateral corneal opacity	34	6.18%
03.	Retinitis pigmentosa and allied diseases	29	5.27%
04.	Age related macular degeneration (ARMD) and macular dystrophy	25	4.54%
05.	Glaucoma	20	3.63%
06.	High myopia	09	1.63%
07.	Retinal vessels occlusion (RVO)	07	1.27%
08.	Bilateral retinal detachment	06	1.09%
09.	Arterial ischemic optic neuropathy (AION)	05	0.90%
10.	Cataract surgery related complications	05	0.90%
11.	Uveitis	04	0.72%
11.	Retinoblastoma	03	0.54%
12.	Corneal dystrophy	02	0.36%
13.	Chemical injury	02	0.36%
14.	Malignant hypertension	02	0.36%
15.	Bilateral central serous chorio-retinopathy (CSR)	02	0.36%
16.	Anterior staphyloma	02	0.36%
17.	Vasculitis	02	0.36%
18.	Head injury	01	0.18%
19.	Brain tumor surgery	01	0.18%
20.	Others	08	1.45%
		271	49.27%

References:

1. Gormezano SR - Promoting independence through low vision rehabilitation. Optometry 2005; 76: 327-31.
2. Thylefors B, Negrel AD, Pararajasegaram R, Dadzie KY - Global data on blindness. Bull World Health Organ 1995; 73: 115-21.
3. Mohan M. Survey of blindness, India (1986-89): Summary and results. In: Director General of Health Services, Ministry of Health Family Welfare, and Government of India. Present status of National Program for Control of Blindness (NPCB) 1992. New Delhi: Government of India, 1992; 79-100.
4. Population census of India 2011.http//censusindia.govt.in/
5. Quaterly newsletter (NPCB India) - Theme of issue: building up cataract surgical capacity. October -Decmber; 2012.
6. MoH&FW (NPCB) - Rapid assessment of avoidable blindness.India.Report; 2006-07.
7. Gieser DK - Visual rehabilitation: the challenge, responsibility, and reward. Ophthalmology 1992; 99: 1622-25.
8. Fletcher DC - Low vision: the physician's role in rehabilitation and referral. Geriatrics 1994; 49: 50-3.
9. Massof RW, Dagnelie G, Deremeik J - Low vision rehabilitation in the US health care system. J Vis Rehabil 1995; 9: 3-31.
10. Saxena R(1),Sinha R, Purohit A, Dada T, Vajpayee RB, Azad RV- Pattern of pediatric ocular trauma in India. Indian J Pediatr. 2002 Oct;69(10):863-7
11. Community based screening of children for detection of visual impairment in Rajasthan and Uttarpradesh: Blindness control division , Directorate General of Health Services, Ministry of Health and Family Welfare, Government of India, Nirman Bhawan, New Delhi, 2006.
12. Leonard R, D'Allura T, Horowitz A - Factors associated with employment among persons who Have a vision impairment: A follow-up of vocational placement referrals. Journal of Vocational Rehabilitation 1999; 12: 33-43.
15. Aditya RM - A Comparison of two orientation and mobility certifications. A report produced through funding from RSA under grant number H133B010101-03., Washington, DC: National Institute on disability and rehabilitation research (NIDRR), Washington, DC. Retrived from professional development and research institute on blindness, 2004. website: http://www.pdrib.com/pages/researchreports.php.
14. Shamanna BR, Dandona L, Rao GN - Economic burden of blindness in India. Indian J Ophthalmol 1998; 46: 169-72.
15. Ryles R - The impact of Braille reading skills on employment, income, education, and reading habits. Journal of Visual Impairment & Blindness 1996; 90: 219-26.
16. Omvig JH – The characteristics of an NFB orientation centre. Braille Monitor 2005: 48: Retrieved from http: //www.nfb.org/images/nfb/ publications/bm/bm05/bm0504/bm050403.htm
17. Edward C Bell, Natalia M Mino - Employment outcomes for blind and visually impaired adults. Journal of blindness innovation and research 2015; 5(2). http://nfb.org/ images/nfb/ publications/ jbir/jbir15/jbir050202.html
18. Dandona R, Dandona L, Naduvilath TJ, Nanda A, McCarty CA - Design of a population based study of visual impairment in India: the Andhra Pradesh Eye Disease Study. Indian J Ophthalmol 1997; 45: 252-57.
19. Vijayakumar V, Datta D, Karthika A, Thulasiraj RD, Nirmalan PK - Utilisation of community-based rehabilitation services for incurably blind persons in a rural population of southern India. Indian J Ophthalmol 2003; 51: 273-7.