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ORIGINAL ARTICLE

Childhood Blindness In India – Regional Variations

MADGULA I

ABSTRACT

Background: Childhood blindness (CB) has far reaching implications for the affected child in educational, employment, personal and social aspects. In India, the overall prevalence is estimated to be a dismal 0.8/1000 children, ranging from 0.3% in well-developed states (like Kerela) to 1.5% in the poorer states.

Aim: To identify and compare the aetiology of blindness in children in two geographically different areas of India and to assess the impact of the social and rehabilitative measures available to them.

Materials and Methods: A total of 254 students in three blind schools, each in Delhi and Madurai were examined and the data was analysed.

Results: No difference was noticed in age, gender and in the rehabilitative and social support system, but for increased consanguinity in the south (47%). Causes of blindness were anomalies of the globe (32.8% vs. 30.8%), Retina (20% vs. 24%), lens and cornea (15% each vs. 10% each), optic nerve (7% vs. 15%) and others (10.2%), with significant regional variation among children of similar visual status. The social acceptance of the blind was gratifying. More than 80% of the students were fluent in Braille, extracurricular activities and vocational skills training in both parts of the country.

Conclusion: This study showed significant regional variations in the patterns of childhood blindness in India that may require different strategies to tackle the problems in these areas.

Key words: aetiology, childhood blindness, Regional variations,

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Background

Prevention of childhood blindness has been prioritised in the World Health Organization's (WHO's) VISION 2020 – The Right to Sight programme[1]. It aims to reduce the incidence of childhood blindness from 0.75 per 1000 children to 0.4 per 1000 children by the year 2020 [1]. Childhood blindness (CB) has far reaching implications for the affected child in educational, employment, personal and social aspects. The numbers of blind years suffered by the child are much more than those suffered by their geriatric counterparts [2]. The aetiology is multifactorial and is influenced by socio-economic status, available health care services and geographic locales [3].

Treating children with visual problems requires special expertise that is not always available in many remote areas of the developing world. Many causes of CB are avoidable or treatable, which underlines the need for more resources to meet this challenge.[2],[3].

It is estimated that there are 1.5 million blind and severely visually impaired children in the world [4]. The incidence of childhood blindness varies, ranging from 1.5/1000 children in low-income countries to 0.3/1000 in high-income ones [1],[5]. In India, the overall prevalence is estimated to be a dismal 0.8/1000 children, translating to a staggering 2.7 lakhs children who are blind. This ranges from 0.3% in well-developed states (like Kerala) to 1.5% in the poorer states [3].

There is significant regional and urban rural variation in the prevalence and pattern of childhood blindness in our country. This underscores a need to develop strategies that cater to the needs of that particular segment[3].

Aim Of The Study

To identify and compare the aetiology of blindness in children in two geographically separated areas of India and to assess the impact of social and rehabilitative measures available to them.

Methods

The study population was derived from special schools for the blind and visually impaired. The study was approved by the ethics committee of the department and permission was obtained from the principals of the schools. They were visited by the author (IM) during Aug 2001- Jan 2003. Three schools were in the national capital of New Delhi (North India), while the other three were situated in and around Madurai (in south India). Blind schools in both cities admit children from large segments of the regional population. Delhi (national capital) admits children from various north Indian states, while similar schools in Madurai cater to a huge segment of the rural Tamil population. All children underwent an anterior segment examination with a torch and a magnifying loupe. Intraocular pressures were not measured routinely. Posterior segment examination was carried out with a direct or indirect ophthalmoscope after dilatation with 1% tropicamide. Visual acuity was assessed using the illiterate Snellen E chart, with the current spectacle correction. Navigational vision was assessed by the ability to move around chairs unaided and by the ability in recognising faces. Children requiring further examination and assessment were referred back to the respective regional ophthalmic institution.
Those with a best corrected visual acuity in the better eye, less than 3/60, were recorded as blind, those between 3/60 and 6/60 as severely visually impaired and those with 6/18 to 6/60 as visually impaired as per the WHO classification [1].Sociodemographic data, visual acuity, anatomical site of blindness/ diagnosis and rehabilitative measures were entered in a questionnaire based on the WHO/PBL form. This was later analysed using descriptive statistical methods.

Results

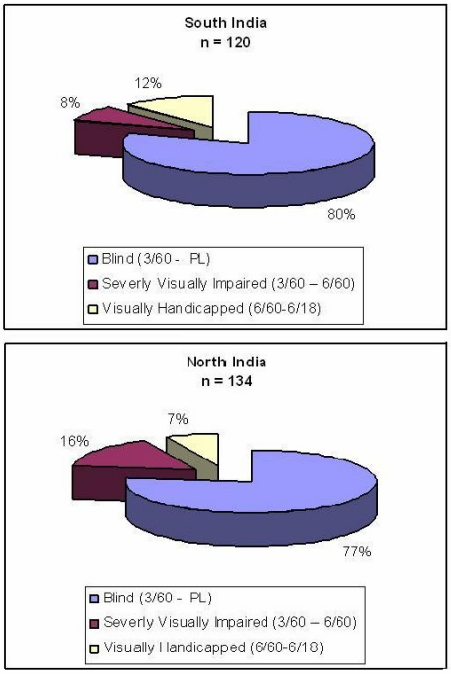
Sociodemographic Data

A total of 134 children (90 M, 64 F) in North India (Delhi) and another 120 (73 M, 47 F) in South India (Madurai) were examined. Their ages ranged from 5-16 years, with a mean age of 10.6 years.
In the North Indian cohort, 61.9% (n=83) hailed from urban areas as compared to 32.5% (n=39) down south, the remaining from rural communities.
The majority of the blind children were Hindus in both parts of the country (94.02% vs 87.5% in north and south respectively).

A significant number of children (47.27%) were born to consanguineous marriages in the south, as compared to the north (5%).
Social acceptance of the blind, assessed by children visiting their native place during holidays, fairs and festivals and similar visits by parents and relatives to the institution, as recorded in the school register, was gratifying (more than 92%) in both the study samples.

More than 80% of the students were fluent in Braille, extracurricular activities and vocational skills training in both parts of the country.

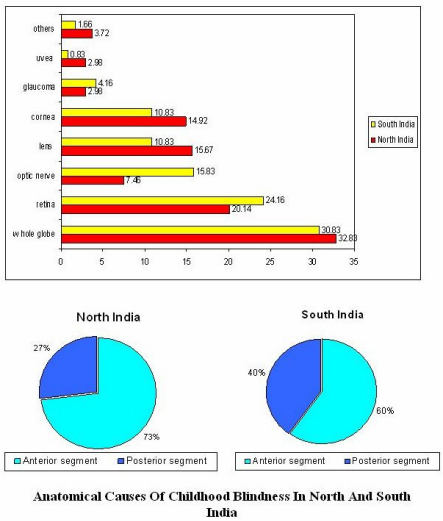
A total of 103 children (76.86%) in the north Indian sample and 96(80%) in the south Indian sample, were blind, 6.71% vs. 11.66% severely visually impaired, the rest being visually impaired [Table/Fig 1].



(Table/Fig 1) Causes Of Childhood Blindness In North And South India

Aetiological Aspects And Anatomical Sites Affected

The major cause of childhood blindness in both the groups was globe anomalies, followed by retinal disorders. Afflictions of the lens and optic nerve anomalies were third in order in the north and south Indian populations, respectively. The anatomical site of blindness in both sections of the population has been shown in [Table/Fig 2].



Anatomical Causes Of Childhood Blindness In North And South India

Preventable causes accounted for 24.6% and 16.66% in the north and south Indian cohorts, respectively. Avoidable causes included cataracts (13.25%), glaucoma and uveitis (1.90% each) and uncorrected refractive errors.

Discussion

WHO defines blindness as less than 3/60 vision in the better seeing eye[1].UNICEF defines a child as an individual who is less than 16 years of age [1].

Data about childhood blindness in the general population is difficult to obtain, as population based surveys are time consuming, cumbersome and expensive. Surveying blind schools is more pragmatic, as a large sample of affected children can be examined in a short duration of time. This method of sampling in these regions is easier and relatively inexpensive. However, the data obtained is potentially biased. It is believed that in developing countries, only 10% of the blind children attend blind schools [1],[2].Ignorance of parents and geographical inaccessibility to the schools are major factors among those residing in remote and poor areas. A culture of mistrust and scepticism exists in some tribal and village communities regarding such centres, which further hinders access. Most blind schools do not admit children below 5 years of age and hence, preschool children are excluded from these studies.

Sociodemographic And Rehabilitative Aspects

There is a male preponderance in the study, the sex ratio being 2:1 in north India and 1.6:1 in the south. The gender bias could be explained by parents wishing to admit their sons with an aim to rehabilitate them and give them vocational training for an economically independent future. Due to the social stigma associated with blindness, a girl child is less likely to have access to blind schools.

The low percentage of rural children in residential care in north India could be due to poor parental education about rehabilitative services and lack of

accessibility to special schools for the visually handicapped.

Aetiological Aspects And Changing Trends

Hereditary aetiologies were a predominant cause of childhood blindness in the present study, irrespective of the geographical location. A significantly high percentage of consanguinity (uncle/niece or first cousin) in south India, could probably explain the increased incidence of hereditary disorders in this community. A similar observation was made in a study conducted in Sri Lanka which has a significant Tamil population[6].This section needs to be a target of health and family education by social and health care workers. In north India hereditary disorders could be the result of an endogamous population in the absence of consanguinity per se.

Globe anomalies (micropthalmos, anopthalmos, cryptophthalmos) contributed to almost 1/3 of childhood blindness in both parts of the country, 32.8%(n=44) and 30.83% (n=37) in north and south India respectively. This trend was also noticed in a study in Maharashtra (Western India) where 41.3% of blind children had globe anomalies[3]. They postulated that globe anomalies may be the result of interactions between genes controlling retinoic acid signalling and maternal VAD during early foetal development, exposure to pesticides, environmental factors (intrauterine infections, recreational drugs, alcohol, hyperthermia and maternal hypothyroidism) or chromosomal anomalies[3]. However, such an observation cannot be explained by any single factor and requires molecular work up and extensive research to identify the cause and define effective prevention strategies.

Retinal afflictions (Retinitis pigmentosa, Retinal dystrophies, congenital rubella or syphilis) form the next important category attributing to 1/5 of the total cases. Retinopathy of Prematurity (ROP) was not observed in our series. In the developed world, ROP accounts for a significant proportion of retinal afflictions (almost half of the retinal causes of blindness)[4]. A high neonatal mortality rate in the developing countries could explain the difference. However, due to improved neonatal care, more cases are being reported, which calls for effective screening of this condition[3],[5].Retinitis pigmentosa and dystrophies have an underlying hereditary cause that can be prevented by genetic counselling. Early eye screening of children for low visual aids and public education to create more awareness may help integrate these children into mainstream education.

Lens anomalies (congenital cataracts, posterior capsular opacities, uncorrected aphakia), potentially treatable causes of blindness contribute to 15.67%(n=21) of childhood blindness in the north Indian sample. In the south, the number was slightly less at 10.83%(n=13). This is indeed sad, as children in blind schools should be examined by an ophthalmologist prior to admission. These children at this stage usually develop dense amblyopia, which is refractory to treatment. Vijaylakshmi P in 1998 made a similar observation during routine screening of children in blind schools in Madurai. Congenital cataract formed a significant cause of treatable blindness while many children were blind due to surgical complications or poor post surgical visual rehabilitation [7].

Down south, optic nerve disorders comprised 15.83% of the cases, the insult mainly being due to optic nerve hypoplasia, optic atrophy, tumours or meningitis. The incidence of such disorders is almost half in the north (7.46%, n=10). Optic nerve problems account for half the cases of childhood blindness in the western world [4]. This inter regional variation could again be due to the high incidence of consanguinity in the south Indian population. Dissuading consanguineous marriages by the local health care workers, religious leaders and social workers in the community may help attenuate this problem in the future. This is a daunting task as deeply ingrained

customs, traditions and belief systems are resistant to change.

Corneal blindness (due to congenital dystrophies, leucomas, keratomalacia due to vitamin A deficiency) was fourth in order in both north and south India, the percentage being 14.92% and 10.8% respectively. This again is amenable to surgical correction with either keratoplasty or optical iridectomy before the development of amblyopia [7].Corneal scarring is preventable by proper immunization, maternal and child health care, health education, good nutrition, essential drugs, clean water supplies and good sanitation, control of endemic diseases and treatment of common conditions which are the essential elements of primary health care [1]. The role of traditional eye medications in causation is difficult to assess due to unreliable history and poor record keeping. The regional variation reflects the success of immunization programs, vitamin A supplementation and primary health care down south. In Ethiopia, cornea was the major anatomical site of childhood blindness (62.4%of total cases). Vitamin A Deficiency (VAD) / measles accounted for 70.1% of corneal scarring/ phthisis, which reflects inadequate immunisation coverage, poor nutrition and health services for children in Africa [8].

Congenital glaucoma, uveitis, trauma and uncorrected refractive errors add up to the remaining aetiologies with an almost equal distribution in both parts of the country.

The pattern of blindness observed in the present series is midway between the patterns seen in the developed west and developing Africa. In the UK, CNS or optic nerve disorders were the commonest cause of visual impairment (50%), followed by retinal afflictions (36%) and globe anomalies (11%). Corneal opacity and congenital glaucoma was uncommon and there were no cases of congenital cataract [4]. In Ethiopia, the major anatomical site of visual loss was cornea (62.4%), followed by optic nerve lesions (9.8%), cataract/ aphakia (9.2%) and lesions of the uvea (8.8%) [8].

However, VAD that was an important cause of childhood blindness and severe visual impairment in India a decade ago [9] has declined signalling the success of immunization programmes and Vitamin A supplementation programmes launched by the government.

Vijaylakshmi et al have recommended that children with vision better than counting fingers (CF) should be investigated thoroughly and refracted so that they can achieve the best-corrected visual acuity with appropriate glasses. They observed that children with high myopia, macular dystrophy, congenital nystagmus, microphthalmos, albinism, coloboma, cone dystrophies and even optic atrophies, with refraction showed improvement for distant and near vision or near vision alone[7]. Pal N in North India, concluded that 35.3% of children admitted to blind schools (with afflictions like aphakia, coloboma, refractive error and microphthalmos) benefited from spectacle correction underlining the importance of low vision services in this part of the country[10].

Rehabilitative Aspects

Data collected regarding frequency of family visits and child visits to their homes during holidays and the festival seasons -revealed a high level of acceptance by families.

In the present study, Braille was the medium of communication (reading and writing) for majority of the children. The Braille code consists of about 150 shapes and over 250 rules of usage and is difficult to learn[11].Children were also being taught vocational skills like weaving baskets, sewing, candle making etc to make them economically independent when they left school. They were encouraged to participate in extracurricular activities like music, drama and physical education. However, the technology and techniques available to their counterparts in the developed world like CCTV, electronic speech output devices; Information technology and microelectronic technology are distant dream in India[11]. Thus a blind child

with restricted choice in our set up is more likely to have limited opportunities to fully realise his/her potential. The use of advanced technology that would tap the potential of the visually impaired child to the fullest would require large amount of funding from the central and state government – a difficult proposition. Current observation and published data suggest that provision of low visual aids to the seemingly small sector of children in both parts of the country could help them read print. Such reorganization is psychologically more superior and socially acceptable. This will facilitate integration of visually impaired children into mainstream education. It would require a dedicated, specialist and suitably trained workforce familiar with the disorders in children and a working knowledge of low visual aids. The VISION 2020 targets to ensure one paediatric ophthalmologist per 10 million people by 2020 and development of low-cost, high quality, low-vision devices that are widely available in low-income countries[1]. This requires initiative and political commitment from the state and central governments in India. Opportunities, to train the required number of paediatric ophthalmologists and refractionists to tackle the challenge of vision loss in children and provision of proper infrastructure for young ophthalmologists to gain expertise have to be created. Incentives to work with children in rural areas should be high on their agenda, as most experts tend to be confined to the urban cities leaving the rural population greatly at a disadvantage. India is a pluralistic society and local teams of health care workers who understand the customs and culture of the place can probably make a difference in surmounting this problem.

Conclusion

This study showed significant regional variations in the patterns of childhood blindness in India that may require different strategies to tackle the problems in these areas. Discouragement of consanguineous marriages in the south and better primary health care (immunizations, Vitamin A supplementation) in the north may be an answer to the problem locally. A normal vision is an essential pre-requisite for the complete physical, psychological and personal development of the child. It is his fundamental right and our duty to make him/her exercise it to the fullest extent possible.

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