Title : **Profile of Pediatric Low Vision Population: A Retrospective Study from Nepal**

Running Title : Profile of Pediatric low vision

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Background: Childhood blindness and low vision have become major public health problems in developing countries. The purpose of this study was to categorize the causes of visual impairment according to it's etiology and provide detailed local information on visually impaired children seeking low vision services in a tertiary eye center in Nepal.

Methods: A retrospective study was conducted of all visually impaired children (corrected visual acuity of less than 6/18 in the better eye) aged less than 17 years seen in the low vision clinic at the Sagarmatha Chaudhary Eye Hospital in Lahan between January 1, 2012 and December 31, 2013.

Results: Out of 558 visually impaired children, the majority were males, 356 (63.7%). More than half (56.5%) of the children were in the 11-16 years old age group. 52.9% percent of the total low vision children were identified as having moderate visual impairment (best corrected visual acuity less than 6/18 to 6/60). Most children were diagnosed with childhood (36.2%) or genetic (35.5%) etiology, followed by prenatal (22.2%) and perinatal (6.1%) etiologies. Refractive error and amblyopia (20.1%), retinitis pigmentosa (14.9%) and macular dystrophy (13.4%), were the most common causes of pediatric visual impairment. Nystagmus (50.0%) was the most common causes of low vision in the 1-5 years age group, whereas, refractive error and amblyopia were the major causes in the 6-10 and 11-16 years age group (17.6% and 22.9% respectively). 86.0% of the children were prescribed low vision aids and 72.0% of the low vision aid users showed an improvement in visual acuity either at distance or near.

Conclusion: Pediatric low vision has a negative impact on the quality of life in children. Data from this study indicates that knowledge about the local characteristics as well as etiological categorization of the causes of low vision is essential in tackling pediatric visual impairment. The findings also signify the importance of early intervention to ensure a better quality of life.

Keywords: Blindness; low vision; Nepal; refractive error; visual impairment

Childhood blindness is a priority area for VISION 2020, a global initiative to eliminate avoidable blindness. Visual impairment (VI) in childhood can affect a child's cognitive, physical, emotional and neurological development and also adversely impacts the child's family and community.[1, 2]

The prevalence of childhood blindness is higher in large parts of Asia, Africa and South America, in comparison to Western Europe.[3] Currently, it is estimated that there are 1.5 million blind children in the world, of which 1 million live in Asia and in more than half of them, blindness is either preventable or curable.[4] There are an estimated 30,240 blind children in Nepal and three times as many children (90,000) with low vision (LV).[5] This accounts for around 120,000 visually impaired children. Blindness in children is unnecessary and is avoidable in more than 50 percent of the cases in Nepal.[5]

An estimated 230,000 people of all ages are reported to have LV in Nepal.[5] Service coverage for low vision at present is less than 1% (1,500 out of 230,000).[5] Half of the low vision service users are children under the age of 16; 35.5% are adolescents and adults between the age of 16 to 39years and just over 12.0% of the users are aged over 40. This is in sharp contrast to the situation in developed countries where LV services are used predominantly by the older population (above 40 years).[5]

The characteristics of VI in a population vary according to accessibility to healthcare services and sociocultural factors; an important cause of blindness in a given region may be of no significance for another and the cause may vary from decade to decade.[6] A few studies have been conducted and they conclude that around a third of the total number of people affected by

LV are children under the age of 15 years.[7,8] Knowledge of the local demographic data of children with VI is critical for planning and delivering services to meet their needs. Knowing the status of pediatric VI helps to form the policy for reducing childhood blindness. is necessary to formulate the policy for reducing childhood blindness.

The Eastern Regional Eye Care Program (EREC-P) in Nepal is a high volume treatment program providing good quality comprehensive eye care services at an affordable cost to a large population of eastern Nepal and northern India. Sagarmatha Choudhary Eye Hospital (SCEH) in Lahan is an integral part of the EREC-P. It started as a small eye unit 31 years ago and in 2001 as per the 'VISION 2020' mandate, started LV services with the goal of enabling LV patients to integrate into mainstream society by training them to use their residual vision to the best extent possible.[9] Due to the high volume of patients attending SCEH, the patient profile is an appropriate representation of the pediatric low vision in Nepal.

The aim of this study on pediatric low vision was to proved detailed local information on visually impaired children seeking LV services in a peripheral tertiary eye center including the causes of VI and the prescription of optical aids.

Methodology

A retrospective study was conducted of all children between 1 and 16 years of age seen in the LV clinic at SCEH in Lahan, Nepal between January 1, 2012 and December 31, 2013. This study was carried out in accordance to the tenets of the Declaration of Helsinki and ethical approval was obtained from the hospital research ethical committee.

Visual acuity was measured in all the children with age appropriate test charts. Preferential looking tests were used for infants; the Kay picture and Sheridian-Gardiner tests

were used for pre-school children, toddlers as well as non-verbal children. All school children were tested for visual acuity using a Snellen test . Near visual acuity was measured using a reduced Snellen test where applicable. Distance and near visual acuity was recorded in Snellen units and M notations respectively with preferred lightning condition and working distance. Refraction was carried out both objectively by static retinoscopy and subjectively where possible. In all cases that required a cycloplegic refraction, a subjective refraction was carried out after three days.. A telescope trial was performed for distance magnification for suitable patients and visual acuities with the telescope were noted. Near visual acuity was noted along with near magnifier preference. The optical low vision aids (LVAs) were prescribed as per the patient's preference. All the different types of LVAs issued for each patient during the one year period from 2012 to 2013 were included in the results. Data were entered into the statistical program SPSS 17.0 and analyzed.

The World Health Organization (WHO) defines a person who needs low vision care as "someone who has an impairment of visual functioning even after treatment and/or standard refractive correction, and has a visual acuity of less than 6/18 to light perception, or a visual field less than 10 degrees from the point of fixation, but who uses, or is potentially able to use, vision for the planning and/or execution of a task."[10] The WHO has classified the visual status of a person in four categories as shown in Table 1.

This study used the etiological classification given by Gilbert et al. (1993). Gilbert recommended two ways of classification for causes for childhood VI: the anatomical classification (cornea, lens, retina, optic nerve, and other) and the etiological classification (genetic, prenatal, perinatal, and childhood).[11] The purpose of etiological classification is to record the disease or other conditions causing visual loss, which are categorized according to the

time of onset of the con dition. Based on the major anatomical site of visual loss, the etiology is recorded for each eye and then for the child. If these differ between the right eye and the left eye, the etiology of visual loss for the child should be that of the major anatomical disorder for the child.

Data on the age distribution, gender, nationality, the etiologies of visual loss and the types of LVAs issued were gathered from the departmental LV database. The WHO working definition of low vision (BCVA of <6/18 to light perception) was used in this study. Bilateral blindness was defined as best corrected visual acuity of less than 3/60 in both eyes, and unilateral blindness was defined as best corrected visual acuity of less than 3/60 in only one eye. All patients were seen by an ophthalmologist before referral to the LV clinic.

Whenever there were multiple disorders mentioned in the patient's record, WHO recommendation was adhered to, i.e. the most avoidable or preventable cause was chosen or, alternatively, the cause that led to the last event rendering the individual sightless. This principle was also used to classify the causes of blindness in unilateral cases when multiple causes were recorded in single eye; for example, in a child with retinitis pigmentosa (RP) and nystagmus, both were recorded but RP was considered the primary diagnosis. Etiological classification as given by Gilbert et al was used to categorize children into four main diagnostic groups: genetic, prenatal, perinatal, and childhood.[11]

Results

A total of 558 children out of 600 referred to the LV clinic were identified as being eligible for inclusion in the study. Forty two were excluded due to the main reasons of lack of

cooperation and unwillingness of the parents to give consent for the child to participate.. Pediatric demographic data which included age and gender distribution are summarized in table 2. The age range of the patients was from 3-16 years with the majority of them (56.5%) in the 11-16 age group. There were more males (65.6%) compared to females (34.4%) in the sample. Of the total children, 66.0% were of Indian origin, whereas only 34.0% were from Nepal. Table 3 gives the status of visual impairment in different age groups based on BCVA in the better eye, 52.3% of the total LV children were identified as having moderate visual impairment (MVI) whereas 20.1% of total children had severe visual impairment (SVI). The majority of these visually impaired children were in the 11-16 age group which accounted for 64.0% of MVI and 55.0% of severe visual impairment. A total of 151 (27.1%) children were bilaterally blind. RP (45.6%), macular dystrophy (29.1%) and nystagmus (15.9%) were the most common causes of total blindness. The majority of these were in the 6-10 age group. A significant number of children, 323 (57.9%), had unilateral blindness, although the VI and unilateral blind categories overlapped.

Table 4 classifies the causes of VI by the etiology. Most children were diagnosed with childhood (36.2%) or genetic (35.5%) etiology, with prenatal (22.2%) and perinatal (6.1%) etiologies being less common. Refractive error and amblyopia (20.1%), RP (14.9%) and macular dystrophy (13.4%), were the most common causes of pediatric VI. Nystagmus (50.0%) was the most common causes of low vision in the 1-5 age group. Refractive error and amblyopia (17.6%) was the most common cause of VI followed by nystagmus (14.1%), RP (13.7%) and macular dystrophy (12.8%) in the 6-11 age group children. In the 11-16 age group refractive error and amblyopia (22.9%), RP (16.5%) and macular dystrophy (14.6%) were the primary causes for VI

(Table 4). Nystagmus was a secondary diagnosis in 43.0% of the children and primary diagnosis in 57.0% of all the children with LV in this study.

Out of 558 children in the study, LVAs were prescribed to 86.0% of children, a significant proportion. The most commonly prescribed LVAs were spectacle magnifiers (157, 31.1%) and stand magnifiers (151, 29.9%). 72.0% of the low vision aid users showed an improvement in visual acuity. Improvement was defined by an increase in visual acuity by one or more line on the Snellen chart, either at distance or near.

Discussion

Since 2001, LV services have been provided in SCEH, Lahan. This is before Nepal Netra Jyoti Sangh, a leading non-governmental organization, launched the national LV program in 2005.[12] A high volume of patients are examined everyday at SCEH and good quality comprehensive eye care services are provided at an affordable cost. This has resulted in a large number of people from Eastern Nepal and Northern India benefiting from the services. The majority of children in this study were of India origin. This can be explained by the location of the hospital and its close proximity (162 kilometeres) to the border between Nepal and India. There is also an open border system between the two countries making it easily accessible to the Indian population. Our result suggests a male preponderance with a ratio of 1.9:1.This is consistent with the previous studies in Nepal where the ratio were 2.4:1[9] and 2.8:1[10]. However, the result may be confounded by the widespread gender based discrimination that still exists in this part of the world. Despite progressive policy reforms, human development indicators of Nepalese women and girls, especially from marginalized castes and ethnicities, living in remote areas, remain low and females are at a disadvantage in terms of healthcare, education and social

aspects[13]. Significant gender inequality is evident in the access of LV services. Only a third of all users of LVAs are female, athough they carry two thirds of the burden of blindness.[5] This strongly suggests the need for eye screenings and awareness programs targeting females.

The majority of pediatric LV patients in this study were in the 11-16 years group followed by the 6-11 years group then the 1-5 years group . This is in contrast to the UK statistics where LV was most prevalent in the 4-7 years age group.[14] This can be attributed to the early eye health screening practice in high income settings. Children visit eye care professionals at an early stage in their development, which is different in a low income setting like Nepal where presentation is quite late, and often there is very little that can be done. MVI was the most common category of visual loss followed by blind and SVI. These results are similar to the study in the Brazilian pediatric population by Haddad MAO, et al.[15] Early and mild visual impairment often go unnoticed as they affect day-to-day activities less than MVI and SVI.

Out of the 558 chidren with low vision children, 27.1% were bilaterally blind and the majority were in the 6-10 years age group. The high number of bilaterally blind children could be the result of unpreventable causes of blindness as well as lack of eye health-related awareness and poor health seeking behavior of parents. . Anecdotally as well as from study by Jimba M, et al in rural Nepal, reported that when there is moderate or severe illness, healthcare is first sought from traditional healers before visiting other health workers.[16] This highlights the need to establish a suitable referral system to identify those children where early visual rehabilitation can be most effective. The childhood and genetic etiological groups were the most common cause of VI in our study. This is in contrast with the study of visually impaired children of Republic of Suriname where perinatal (21.5%) and genetic (13.8%) causes were found to be more common.[17]

Consanguineous marriages may be the cause of a significant trend in genetic diseases, as such practice is more common in the region.[18]

Refractive error and amblyopia , RP and macular dystrophy , were the most common causes of pediatric VI. This result is in agreement with the study of Thakur et al in which refractive error and amblyopia, RP and globe anomalies were the most common cause of VI in the 0-15 years age group.[9] In another study by Khanal et al from a region closer (115 kilometers) to the current study location, contrasting results were obtained. Nystagmus and globe anomalies were the most common causes in the 0-15 years age group.[10] Our results were also in contrast with the results reported from children in the UK where retinal disorders (18.0%) followed by albinism (11.0%) were the main causes of VI.[14] In this study, refractive errors and amblyopia were the most common causes of VI in the childhood etiological category while RP was the most common cause in the genetic etiological category. These results are in contrast to the study of UK children, where glaucoma was the most common cause of VI due to childhood etiology, and retinal problems (rod/cone dystrophy, retinal dystrophy, excluding RP) were the predominant causes for VI due to genetic etiology. Only the causes in the perinatal etiological category overlapped, where optic atrophy was the most common cause. Community based screening programs are necessary for early identification and management of visual disorders in low income settings such as Nepal. In Nepal, cataract has been the main focus of eye screening programs with refractive error management being of least priority for programs. Effective interventions such as early recognition of children with LV needs should be a priority during community screening programs. This will ensure that these children are managed accordingly and have access to the appropriate LV rehabilitation.

In both the genetic and childhood etiological category, the main causes of VI in this study are different from those in high income settings. An explanation for the childhood causes of VI being different in our study to that of children in the UK can be due to the difference in the attitude and eye health seeking behaviour of parents, non compliance to spectacles as well as the lower socioeconomic status of parents in Nepal.

Nystagmus was the most common cause of VI in the 1-5 years age group. Refractive error and amblyopia, RP and macular dystrophy were common in the 6-10 and 11-16 years age groups respectively. This is in contrast with the study conducted in a blind school in North India where vitamin A deficiency (VAD) was responsible for 12.5% of blindness in 5–8 year olds, 17.8% in 9-12 year olds, and 24.5% in 13–16 years olds.[19] VAD was not the case of VI in any of the cases in this study, this can be attributed to the effective biannual distribution of vitamin A capsules in all the districts of Nepal.

The majority of the children with VI were prescribed with LVAs. The parents of those not prescribed LVAs were concerned about the appropriate handling and use of the devices by their children and decided against it. Spectacle magnifiers were the most commonly prescribed near LVA followed by the stand magnifier and handheld magnifier . Telescopic aids was the only distance LVA available in the center and it was the least preferred amongst all the LVAs. Near LVAs were more preferred over the distance ones as most of the children were of school going age and had most difficulty in reading and writing. The children usually compensate not being able to see in the distance by sitting in the front row in the classroom. Selection of other optical and non-optical LVAs such as closed circuit televisions, telemicroscopes, sheet magnifier, bioptic telescopes etc, were limited due to their availability.

Limitations

A retrospective study such as this has certain limitations. The main one being measurement error between different practitioners when recording data. In this case, there is also subjective judgment involved when deciding if a child is suitable for LVAs assessment and which LVAs to prescribe. When doing a clinical audit, it is also difficult to ascertain any missing data as sometimes, the practitioner may not be there anymore or there is the chance of recall bias. Data may also be recorded in a manner which does not allow the analysis of specific variables. In this study, we are unable to separate the refractive error and amblyopia data. These children are referred from the LV clinic to the optometry clinic for examnination. This segregation would further help to plan services and is now being collected at the clinic as a standard.

Conclusion

Pediatric low vision has emerged as a major challenge in low and middle income countries and it is detrimental to the quality of life of children. This study provides local demographic data and the status of pediatric visual impairment in a large LV clinic as well as data categorized by etiology. The findings from this study suggest that early intervention can provide effective visual rehabilitation and is essential in reducing pediatric VI. A large number of these children benefit from access to LVAs. Furthermore, the findings of this study provide a basis for formulating a comprehensive approach needed for the prevention and treatment of pediatric blindness and VI, including providing LVAs and accessibility to services for such children. In addition, the evaluation of service provision and demographic data in this part of the world can be a useful adjunct in combating pediatric VI at a global level.

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Table 1 *WHO classification of visual status*

BCVA	**Visual status**
Better than or equal to 6/18	Normal
Less than 6/18 to 6/60	Moderate VI
Less than 6/60 to 3/60	Severe VI
Less than 3/60	Blind

Abbreviations: BCVA, Best Corrected Visual Acuity; VI, Visual Impairment

Table 2 *Distribution of pediatric low vision patients, according to age and gender*

Age (years)	**Male (N)**	**Female (N)**	**N (%)**
1-5	11	5	16 (2.8)
6-10	152	75	227 (40.7)
11-16	203	112	315 (56.5)
Total (%)	366 (65.6)	192 (34.4)	558 (100.0)

Table 3. Prevalence of visual impairment by age group (based on BCVA)

Age(years)	**MVI (N) (Better eye)**	**SVI (N) (Better eye)**	**Bilateral Blind (N)**	**Unilateral Blind(N)**
1-5	8	5	3	9
6-10	97	45	85	113
11-16	190	62	63	201
Total (%)	295 (52.9)	112 (20.0)	151 (27.1)	323 (57.9)

Abbreviations: MVI, Moderate Visual Impairment; SVI, Severe Visual Impairment; N, Number

All the figures are presented considering BCVA.

The visual impairment category and the unilateral blind category overlapped.

Table 4. *Etiological classification and causes of low vision in different age groups.*

Etiologies/ Causes	**Age groups**		
	1-5 (n=16)	**6-10 (n=227)**	**11-16 (n=315)**
Genetic (35.5%)			
Albinism	0.0%	2.2%	1.9%
Macular dystrophy	0.0%	**12.8%**	**14.6%**
Retinitis pigmentosa	0.0%	**13.7%**	**16.5%**
Stargart's diseases	0.0%	1.3%	2.5%
Corneal dystrophy	0.0%	4.9%	2.2%
Prenatal (22.2%)			
Cataract	0.0%	2.6%	3.2%
Nystagmus	**50.0%**	**14.1%**	5.4%
ON hypoplasia	0.0%	1.8%	0.6%
Coloboma	18.8%	2.6%	1.0%
Microphthalmos	12.5%	3.5%	1.6%
Aniridia	0.0%	4.9%	2.2%
Perinatal (6.1%)			
Optic atrophy	0.0%	6.6%	3.5%
Cortical VI	6.2%	1.8%	0.0%
ROP	12.5%	0.4%	0.0%
Childhood (36.2%)			
Glaucoma	0.0%	0.9%	1.9%
Myopic degeneration	0.0%	2.1%	5.4%
Retinal detachment	0.0%	3.1%	8.9%
Corneal opacity	0.0%	3.1%	5.7%
Refractive error and amblyopia	0.0%	**17.6%**	**22.9%**

The figures in bold indicate the frequency (in%) of the causes that have a higher prevalence in different age groups.

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