

Causes of visual impairment and blindness in children at Instituto Benjamin Constant Blind School, Rio de Janeiro.

Causas de baixa visão e cegueira infantil na Escola para cegos do Instituto Benjamin Constant, Rio de Janeiro

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ABSTRACT

Objective: To determine the main causes of visual impairment and blindness in children enrolled at Instituto Benjamin Constant blind school (IBC) in 2013, to aid in planning for the prevention and management of avoidable causes of blindness. **Methods:** Study design: cross-sectional observational study. Data was collected from medical records of students attending IBC in 2013. Causes of blindness were classified according to WHO/PBL examination record. Data were analyzed for those children aged less than 16 years using Stata 9 program. **Results:** Among 355 students attending IBC in 2013, 253 (73%) were included in this study. Of these children, 190 (75%) were blind and 63 (25%) visually impaired. The major anatomical site of visual loss was retina (42%), followed by lesions of the globe (22%), optic nerve lesions (13.8%), central nervous system (8.8%) and cataract/pseudophakia/aphakia (8.8%). The etiology was unknown in 41.9% and neonatal factors accounted for 30.9% of cases. Forty-eight percent of cases were potentially avoidable. Retinopathy of prematurity (ROP) was the main cause of blindness and with microphthalmia, optic nerve atrophy, cataract and glaucoma accounted for more than 50% of cases. **Conclusion:** Provision and improvement of ROP, cataract and glaucoma screening and treatment and programs could prevent avoidable visual impairment and blindness.

Keywords: Blindness; Visual impairment; Visual disability; Visual disorders; Child health

RESUMO

Objetivo: Determinar as causas de cegueira e deficiência visual nas crianças matriculadas na Escola do Instituto Benjamin Constant (IBC) em 2013, para contribuir na elaboração de estratégias de controle e prevenção de causas evitáveis de cegueira. **Métodos:** Desenho de estudo: observacional do tipo transversal. Os dados foram coletados através dos prontuários dos alunos matriculados na Escola em 2013. As causas de cegueira foram classificadas de acordo com os registros de exames elaborados pela OMS/IAPB. Os dados foram analisados, em crianças com idade abaixo de 16 anos, usando o Programa Stata9. **Resultados:** Entre 355 alunos matriculados no IBC em 2013, 253 (73%) foram incluídos nesse estudo. Dessas crianças, 190 (75%) eram cegas e 63 (25%), deficientes visuais. O principal sítio anatômico, responsável pela perda visual, encontrado foi a retina (42%), seguido de lesões do globo ocular (22%), lesões no nervo óptico (13,8%), cegueira de origem no sistema nervoso central (8,8%) e catarata/pseudofácico/afácico (8,8%). A etiologia foi desconhecida em 41,9% e fatores neonatais corresponderam a 30,9% dos casos. Quarenta e oito por cento dos casos foram potencialmente evitáveis. Retinopatia da prematuridade (ROP) foi a principal causa de cegueira e microftalmia, atrofia do nervo óptico, catarata e glaucoma contaram com mais de 50% dos casos. **Conclusão:** A oferta e melhoria de programas de triagem e tratamento do ROP, catarata e glaucoma podem prevenir os casos de deficiência visual e cegueira evitáveis.

Descritores: Cegueira; Baixa visão; Deficiência visual; Distúrbios visuais; Saúde da criança

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INTRODUCTION

It has been estimated that there are approximately 1.4 million blind and 19 million visually impaired children in the world, of whom 12 million have uncorrected refractive errors.^(1,2) Most of these children live in underdeveloped countries.^(1,3) The prevalence of childhood blindness varies from an estimated 0.3 per 1000 children in high income countries to 1.5 per 1000 children in low income countries.⁽⁴⁾ The control of blindness in children is considered a high priority for the World Health Organization's Vision 2020 initiative: the Right to Sight.

In middle-income countries retinopathy of prematurity (ROP) is an important avoidable cause of blindness.⁽⁴⁾ In all regions of the world, cataract, retinal diseases, and congenital abnormalities affecting the whole globe are important causes of blindness.⁽³⁾

Brazil is a middle-income country with a population of 201 million, of whom 25% are under 16 years old. It is estimated that there are 6.5 million visual impaired and 582,000 blind subjects.⁽⁵⁾ Socio-economic and cultural factors affect directly both the prevalence and variation of causes of childhood blindness and visual impairment.⁽¹⁾

Since 2002, pediatricians in Rio de Janeiro state should screen newborns for eye abnormalities through the red reflex test (RRT), referring those patients with abnormal RRT to tertiary eye care services.⁽⁶⁾ In 2004, all Rio de Janeiro municipal government neonatal units (NICUs) implemented the ROP screening and treatment program followed by state government NICUs in 2010.⁽⁷⁾

Instituto Benjamin Constant is established since September 17th, 1854 and is the first school for blind in Latin America. It is the Brazilian Reference Center for visual impairment and blindness, located in the city of Rio de Janeiro.⁽⁸⁾ Since 2008, municipal government schools in Rio provide education for children with multiple disabilities, including blindness.

The purpose of the present study is to determine the main causes of visual impairment and blindness in children enrolled at the Instituto Benjamin Constant (IBC), the blind-school in Rio de Janeiro, in 2013, to aid in planning new health policies for the prevention and management of avoidable causes in the city of Rio de Janeiro, Brazil.

METHODS

An observational cross-sectional study was conducted with data collection from medical records of students enrolled in IBC blind-school and examined by IBC Ophthalmology Department.

Ethical approval was obtained from Research Ethics Committees - Universidade Federal Fluminense (UFF) - CAAE: 37719514.0.0000.5243.

Inclusion criteria: students at IBC enrolled in different categories according to age group and level of education: early intervention (0–3 years old), childhood education (4–6 year old), primary education (> 7 years old), and Alternative Educational Program – PREA (7–18 year old with multiple disabilities); aged less than 16 year old presenting blindness and visual impairment according to World Health Organization (WHO).⁽²⁾

Exclusion criteria: students aged 16 years or older, those with visual acuity higher than or equal to 0.3, whose visual field was normal or not performed.⁽²⁾

Patients' data were collected in a standard form based in World Health Organization (WHO) / Program of Blindness Prevention (IAPB) examination record. Data collected were gender, age, age of blindness, family history, other associated disorders,

visual acuity (far and near, with and without correction), anatomic and etiological diagnosis. The score developed by the International Centre for Eye Health – London and WHO – Program of Blindness Prevention was used.^(1,9,10) Visual impairment and blindness were defined based on the WHO international classification of diseases (ICD 10 – 2016 version).⁽¹¹⁾ Collected data were presented as frequencies. The chi-square test was applied to evaluate the difference of proportion between genders by means of the Stata 9 program. A 0.05 significance level was considered.

The causes are classified according to etiology: hereditary (confirmed genetic alterations, congenital retinal diseases and retinoblastoma, aniridia, congenital cataract and congenital glaucoma – family history in first-degree relatives); intrauterine (intrauterine-transmitted maternal infections and maternal use of drugs/alcohol); perinatal (ophthalmia neonatorum, ROP and asphyxia); childhood (retinoblastoma – without family history, childhood glaucoma, acquired toxoplasmosis, high refractive error, optic nerve (ON) atrophy or central nervous system alterations due to infection or asphyxia in such period); and non-determined (all pathologies without possibility of diagnosis regarding the disease appearance phase). In addition, anatomical site was also recorded: whole globe (anophthalmia, microphthalmia, coloboma, and glaucoma/buphthalmos), cornea (corneal scar), lens (cataract, dislocation and subluxation of lens), uvea (aniridia and uveitis), retina (ROP, albinism, scarring due to toxoplasmosis and other causes, retinal dystrophy, retinal detachment and retinoblastoma), optic nerve (atrophy and hypoplasia), normal eye globe (central nervous system alterations, refractive error and nystagmus), and unknown (unknown causes). Causes were classified as preventable (ROP and corneal scar), treatable (toxoplasmosis, cataract, glaucoma/buphthalmos, retinoblastoma and refractive error), non-treatable (albinism, corneal dystrophy, anophthalmia, microphthalmia, coloboma, atrophy and optic nerve hypoplasia, central nervous system alterations, idiopathic nystagmus and aniridia), and unknown (unknown causes) causes.

RESULTS

Students personal details

Among 355 students attending IBC in 2013, 253 (71%) were included in this study (early intervention, childhood education, primary education and PREA). Ten were excluded because their records could not be found and 92 followed the adopted exclusion criteria. Among the students included, the mean age was 7 years and 7 months old (range: 7 months old – 15 years and 11 months old), 133 (52.6%) were male and 120 (47.4%) female (P 0.2481). Most students lived in the metropolitan area. (95.6%)

Categories of visual loss

Levels of WHO categories of vision and age group for the 253 students attending IBC are shown in table 1.

Of these children, 190 (75%) were blind and 63 (25%) visually impaired. Ninety four percent of the students aged 0 to 4 years had blindness. This percentage decreases with the increase of age range (81.0% between 5-9 years old and 62.0% between 10-15 years old).

Etiological categories of visual impairment and blindness in children

Etiological categories of visual impairment and blindness in children < 16 years of age are shown in table 2. Neonatal factors, mainly attributable to ROP, accounted for 30.9% of cases. Here-

Table 1

Prevalence of visual impairment and blindness in children less than 16 years of age according to gender and age range

	Male		Female		Total	
	N	%	N	%	N	%
Visual impairment and blindness (PVA* <0.3)						
0–4 years old	34	25.6	25	20.8	59	23.3
≥5–9 years old	31	23.3	40	33.4	71	28.1
≥10–15 years old	68	51.1	55	45.8	123	48.6
Total (0–<16 years old)	133	100.0	120	100.0	253	100.0
Visual impairment: levels 1 and 2 (PVA* <0.3–0.05)						
0–4 years old	4	9.3	0	0.0	4	6.3
≥5–9 years old	5	11.6	7	35.0	12	19.0
≥10–15 years old	34	79.1	13	65.0	47	74.6
Total (0–<16 years old)	43	100.0	20	100.0	63	100.0
Bilateral blindness (PVA* <0.05)						
0–4 years old	30	33.3	25	25.0	55	28.9
≥5–9 years old	26	28.9	33	33.0	59	31.1
≥10–15 years old	34	37.8	42	42.0	76	40.0
Total (0–<16 years old)	90	100.0	100	100.0	190	100.0

*PVA: presented visual acuity.

Table 2.

Distribution of childhood visual impairment and blindness according to gender in children less than 16 years of age

Blindness cause	Male	Female	Total	%
Hereditary	24	15	39	15.4
Intrauterine	13	2	15	5.9
Neonatal	32	46	78	30.9
Childhood	5	10	15	5.9
Non-determined	59	47	106	41.9
Total	133	120	253	100.0

ditary disease, such as retinal dystrophies, autosomal dominant cataract and glaucoma, were responsible for 15.4%. Intrauterine factors, among them toxoplasmosis scars were responsible for 7 cases (2.8%). In a significant number of cases (41.9%), the underlying etiology of visual loss could not be determined. These were mainly cases with phthisis bulbi, optic atrophy, microphthalmos, anophthalmos, and some cases of congenital cataract.

Anatomical causes of visual impairment / blindness in children

In the 253 students aged less than 16 years with visual impairment or blindness, the retina was the most frequent site of abnormality leading to visual loss in 42.6% of cases (Table 3). Retinopathy of prematurity was the most common cause in all age groups (26.4%). Lesions of the whole globe were the second most frequent and were responsible for 22% of cases. Of the 35 children with optic nerve lesions, 26 had optic atrophy and 9 had optic nerve hypoplasia. Microphthalmia was responsible for 10.6% (27 pupils). Glaucoma/Buphthalmos was responsible for 8.8% (22 children) of cases. Unoperated cataract and aphakia/pseudophakia accounted for 6% (15 pupils). Among the 15 chil-

dren with childhood cataract, 93% (14) were operated and 17% (1) were not operated. Central nervous system contributed to 6% (15 cases). In contrast, lesions of the cornea were not frequent and accounted only for 0.4% of cases. In this study, six children (2.4%) had uncorrected refractive errors.

Avoidable causes of severe visual impairment / blindness in children

Overall almost half of all causes of childhood visual impairment and blindness (48.5%) could have been avoided (treated or prevent) being the main causes ROP, infantile cataract, glaucoma, toxoplasmosis and refractive errors (Table 4).

DISCUSSION

Institute Benjamin Constant is a referral school for the blind in the metropolitan area of Rio de Janeiro. It has its own Department of Ophthalmology, which provides an excellent eye care for its students and for the entire surrounding community. This is a particular situation because most studies on causes of visual loss in childhood are carried out in schools for blind or in Low Vision Departments in Eye Hospitals or Ophthalmology Department in General Hospitals.⁽¹²⁻¹⁶⁾

The present study describes the main causes of childhood visual impairment and blindness at IBC. Although blind school studies have the advantage of ease of examining and collection of large numbers of children within a relatively short period by one examiner using standard methods, they are potentially biased. In contrast to other blind school surveys, IBC enroll pre-school children in early intervention and accept multiple disabled children. Most children come from metropolitan area and those from most remote areas of the state may not have access to IBC. Despite the limitations, blind school surveys may provide valuable information

Table 3**Distribution of the main causes of visual impairment and blindness in children less than 16 years of age according to the anatomical site by gender**

Sites	Male	Female	Total	%
Retina			108	42.6
Retinopathy of prematurity	26	41	67	26.4
Albinism	5	5	10	4.0
Toxoplasmosis scar	5	2	7	2.8
Retinal dystrophy	9	4	13	5.0
Scar due to other cause	3	0	3	1.2
Retinal dystrophy due to unknown cause	1	1	2	0.8
Retinoblastoma	3	3	6	2.4
Cornea			1	0.4
Cornea scar	1	0	1	0.4
Lens			15	6.0
Cataract (without surgical correction)	0	1	1	0.4
Pseudophakia	5	2	7	2.8
Aphakia	5	2	7	2.8
Dislocation/Subluxation	0	0	0	0.0
Eye globe			56	22.0
Anophthalmia	1	2	3	1.2
Microphthalmia	14	13	27	10.6
Coloboma	4	1	5	2.0
Glaucoma/ Buphthalmos	11	10	21	8.2
Optic nerve			35	13.8
Atrophy	14	12	26	10.2
Hypoplasia	3	6	9	3.6
Normal eye globe			22	8.8
Refractive error	4	2	6	2.4
CNS*	9	6	15	6.0
Idiopathic nystagmus	0	1	1	0.4
Uvea			6	2.4
Aniridia	3	3	6	2.4
Uveitis	0	0	0	0.0
Unknown	7	3	10	4.0
Total	133	120	253	100.0

*CNS: Central Nervous System.

Table 4**Avoidable causes of severe visual impairment / blindness in children aged < 16 years of age**

Classification	Male	Female	Total	%
Preventable	27	41	68	26.8
Treatable	33	22	55	21.7
Non-treatable	62	53	115	45.5
Unknown	11	4	15	6
TOTAL	133	120	253	100

on the causes of visual loss.

There was no statistical difference between gender distribution among the studied population, in contrast to other studies(17,18) thus reflecting an equal access to school and eye care among boys and girls in the Rio de Janeiro scenario.

Previous investigations carried out at IBC considered broader age range inclusion criteria of the studied population. (19,20) Students up to 26 years old were found in primary school in 2013, possibly due to neurological impairment. The present study

considered data of children younger than 16 years old, following the childhood definition of the WHO criteria, which may difficult comparison with previous studies at IBC.

Categories of visual loss

Seventy-five percent of study population was blind (190 pupils). Instituto Benjamin Constant is a blind school and visually impaired children in Rio might be referred to municipal government schools.

Although 20.8% (59 children) of total population studied was represented by children aged 0-4 years, 93% (55 children) of them were blind. The proportion of blind children in each age group studied was inversely proportional to age, i.e. the youngest age group had the highest proportion of blind children. It may be explained by the fact that families with blind children may seek for an earlier enrollment at IBC than those with visually impaired children.

Etiological categories of visual impairment / blindness in children

In this study, neonatal period was responsible for 30.9% of cases. It may indicate the need of improvement of public policies

directed to pregnant women (early prenatal follow-up of good quality) and neonate's care (appropriate support of neonatologist since the labor room until neonatal units).

Anatomical causes of visual impairment / blindness in children

The main site of blindness found in others Brazilian studies was the retina,⁽¹²⁻¹⁶⁾ being the main cause toxoplasmosis which contributed to 40% of cases^(12,14-16), optic nerve atrophy⁽¹²⁾, cataract^(12,14,16), glaucoma^(13,14,16), inherited retinal disease⁽¹⁵⁾ and ROP in approximately 12% of cases.^(13,15)

In many middle-income countries, ROP is an important cause of blindness.⁽⁴⁾ In this study, ROP was the main cause of blindness and visual impairment in childhood. The improvement of neonatal care, decrease of neonatal mortality, associated to the lack of availability of ROP screening and treatment programs could be responsible for the increase in the number ROP cases. Until 2004, Rio de Janeiro government NICUs had no ROP screening and treatment program, only some isolated initiatives. In 2004, Rio de Janeiro municipal health government implemented a ROP screening and treatment program⁽²¹⁾ followed by state government units in 2010. Until now, coverage is not universal.

Microphthalmia was an important cause in our study, predominantly in students aged 0 to 4 years old; which could be explained due to fact that families of patients with the highest levels of visual compromise sought early care at the IBC, even to early intervention.

Optic nerve atrophy is an important cause of blindness and visual impairment world-wide, including developed countries, due to its severity (non-treatable and hardly preventable).⁽¹⁾ It is very hard to establish a cause for optic nerve atrophy, especially because it can be many times associated with some event during pregnancy, and therefore registrations are incomplete.

In the current study, glaucoma was among the main causes. It can be explained by the possible early diagnosis and treatment delay, disease severity and the several related complications such as corneal opacity and optic nerve atrophy, as well as non-corrected refractive error resulting in amblyopia. The prevention of visual impairment and blindness due to glaucoma is linked to genetic counseling, early detection and treatment and a regular ophthalmologic follow-up (intra-ocular pressure control, frequent refractions, glasses prescription and amblyopia treatment). Therefore, since prevention requires many steps, glaucoma is still an important cause everywhere.^(13,14,16)

In 2002, the red reflex test was implemented in maternity hospitals in Rio de Janeiro. Cataract accounted for 6% of causes in our study compared to over 10% of cases reported by Haddad et al.⁽¹⁴⁾ and de Paula et al.⁽¹⁶⁾ Despite the low contribution of cataract as a cause of childhood blindness in our study, among the 15 children found with vision impairment/blindness due to cataract at IBC, 14 had surgical intervention. It might reflect barriers to access early treatment.⁽²²⁾

Central nervous system causes were had high rates in this paper too, which could be explained due IBC accept multiple disabled children.

Chorioretinitis caused by toxoplasmosis had a low prevalence in this study, unlike the other studies found in Brazil.^(12,14,15,16,19,20) This can be explained by the increase and improvement in early diagnosis and treatment, with consequent fall in cases with severe ocular sequelae that would be inserted in the study population.

Avoidable causes of severe visual impairment / blindness in children

In this study, 48.5% of the children attending IBC had lost their vision because of avoidable (treatable and preventable) causes,

which might reflect barriers to timely access good quality eye care.

The main causes of childhood blindness and number of blind children in the population could vary extensively in each region, and the determining factors include level of socioeconomic development, availability of primary medical care, in addition to childhood mortality rate below 5 years of age. Studies have showed differences among the main causes of childhood visual impairment and blindness in developed, developing, and underdeveloped countries.^(1,23) There is a high prevalence of preventable and treatable causes in underdeveloped countries, whereas developed countries show a higher prevalence of non-treatable causes, thus reflecting a better quality and agility in the early diagnosis and treatment. Developing countries have demonstrated a mixed profile, especially with an increase of ROP cases.⁽²³⁾ The main Brazilian reports in the last 10 years were carried out in Rio de Janeiro, São Paulo, Belo Horizonte and Salvador, mostly in Low Vision Departments. Studies in others regions, mainly North, Northeast and Center-West regions should be performed to increase knowledge about the current situation and contribute to planning service delivery.

The prevention of childhood blindness demands a multidisciplinary effort that involve not only physicians (obstetrician, pediatrician, family doctors, geneticists and ophthalmologists), but also nurses, community agents, social assistants, and teachers. Prevention begins with a prenatal care of quality to identify and treat congenital infectious diseases (toxoplasmosis, herpes, cytomegalovirus, syphilis and more recently Zika virus) and, if possible, to provide a genetic counseling for inherited diseases that affect vision (glaucoma, cataract, retinal dystrophy). At birth and during the first years of life, the main screening strategy is the red reflex test, which should be referred to an ophthalmologist.⁽²⁴⁾

Our results suggest the need to improve prenatal and perinatal care, which would impact on the prevention and treatment of infections, asphyxia (both in the labor room and neonatal unit), pre-term birth as well as improved early diagnosis and treatment of congenital glaucoma, cataract and ROP.

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