

Health seeking behavior of the families of children with cataract attending an eye clinic in Rio de Janeiro, Brazil

Perfil de procura dos serviços de saúde pelas famílias de crianças com catarata assistidas em uma clínica oftalmológica no Rio de Janeiro, Brasil

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ABSTRACT

Purpose: To determine the health-seeking behavior of the families of children presenting with congenital and developmental cataract attending "Instituto Brasileiro de Oftalmologia" (IBOL), Rio de Janeiro, Brazil.

Methods: Caregivers of consecutive eligible children were interviewed using a pre-tested questionnaire and medical records were reviewed to collect information about their health-seeking behavior and socioeconomic status in June and July of 2008.

Results: Data from 70 children were gathered, from which 42 (60.0%) had bilateral disease. Fifty-eight (82.9%) cases were considered congenital and 12 (17.1%) developmental. Presentation delay was observed in 33 (47.1%) children. Having insurance (adjusted OR 0.17; 95% CI 0.04 - 0.82) and being the only child (adjusted OR 0.16; 95% CI 0.04 - 0.69) decreased likelihood of late presentation.

Conclusions: Delayed detection and presentation for treatment of non-traumatic pediatric cataract are still significant problems in the state of Rio de Janeiro. Early recognition as well as prompt referral and appropriate treatment have to be improved, especially at the public sector.

Keywords: Cataract/congenital; Cataract/therapy; Child; Health services

RESUMO

Objetivo: Determinar o padrão da procura dos serviços de saúde pelas famílias de crianças com catarata congênita e de desenvolvimento, assistidas no Instituto Brasileiro de Oftalmologia (IBOL), Rio de Janeiro, Brasil.

Métodos: Os responsáveis das crianças foram entrevistados utilizando um questionário pré-testado e seus prontuários foram revisados para obter informações sobre a procura dos serviços de saúde pelas famílias, assim como suas condições socioeconômicas, nos meses de junho e julho de 2008.

Resultados: Dados de 70 crianças foram obtidos, das quais 42 (60%) tinham doença bilateral. Cinquenta e oito (82,9%) casos foram considerados congênitos e 12 (17,1%) de desenvolvimento. Atraso na apresentação foi observado em 33 (47,1%) crianças. O fato de a criança possuir seguro-saúde (OR ajustado 0,17; 95% IC 0,04 - 0,82) e ser filho único (OR ajustado 0,16; 95% IC 0,04 - 0,69) reduziu a probabilidade de apresentação tardia.

Conclusões: A detecção e apresentação tardia para tratamento da catarata pediátrica não-traumática são problemas ainda significantes no estado do Rio de Janeiro. O reconhecimento precoce assim como o encaminhamento imediato e tratamento apropriado tem que ser melhorados, principalmente no serviço público de saúde.

Descritores: Catarata/congênito; Catarata/terapia; Criança; Serviços de saúde

INTRODUCTION

The control of blindness in children is a priority of the International Agency for the Prevention of Blindness/World Health Organizations' (WHO) global initiative, VISION 2020 - the Right to Sight⁽¹⁾. However, control strategies need to vary, as the magnitude and causes of visual loss in children vary significantly from country to country with a far higher proportion of causes being potentially avoidable in poor countries compared with affluent countries. Indeed, under-five mortality rates and infant mortality rates, which reflect levels of socioeconomic development and access to health care, can be used as proxy indicators for the prevalence and causes of blindness in children^(1,2). It is estimated that bilateral cataract is responsible for 15% of all childhood blindness in the world, with an incidence of at least 10 new cases per million people per year⁽³⁾.

In Latin American countries, retinal diseases are the major causes of visual impairment and blindness in children⁽⁴⁻⁸⁾. Nevertheless, cataract still accounts for 6.4% to 12.7% of visual loss among children attending low vision services in Brazil and Chile^(4,6-8).

Surgical intervention is indicated in the majority of total cataract in children. Prompt surgery is even more important in dense congenital cataracts and early developmental cataracts^(9,10). For total unilateral congenital cataract, surgery is indicated by 6 to 8 weeks of life to minimize amblyopia⁽¹¹⁻¹³⁾. Regarding bilateral cases, optimal timing of surgery has to be established since early surgery is associated with higher incidence of aphakic glaucoma but surgery before three months of life is desirable^(9,11,14).

Early identification of cataract and prompt referral for specialized treatment are needed for good visual results. Despite existence of the simple and non-invasive red reflex test for cataract detection^(11,15-18), screening is not a common practice in the majority of countries and most of the time delay detection is made by parents when they notice leukocoria, nystagmus or/and strabismus^(9,10,19,20).

In Brazil, surgery for cataract in children is performed in both private and public tertiary centers, although ophthalmic services differ in terms of availability and quality in these two sectors. Also, socioeconomic development and many health aspects vary from one region to the others of the country⁽²¹⁾.

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"Instituto Brasileiro de Oftalmologia" (IBOL) is a private clinic in Rio de Janeiro and a referral center for eye diseases in Rio de Janeiro state. A local non-governmental organization (NGO), named "Instituto Catarata Infantil" (ICI) was established in 2004 to support children from low income families who do not have insurance but need cataract surgery. The NGO supports cataract surgery at IBOL at a reduced cost and all examinations and surgery are done by the same professionals, using the same infrastructure and equipment, as private patients.

It was sought to describe the health-seeking behavior of families of children presenting with congenital or developmental cataract attending IBOL in Rio de Janeiro, by direct appointment or by ICI, and investigate factors associated with delay in diagnosis and/or presentation for treatment.

METHODS

This cross-sectional study was conducted in June and July 2008, in the pediatric ophthalmic sector of "Instituto Brasileiro de Oftalmologia" (IBOL) with its private patients and those assisted by "Instituto Catarata Infantil" (ICI).

The study population consisted of children aged less than 16 years with unilateral or bilateral cataract who had attended the ICI and IBOL since 1999. New cases and follow-up cases of congenital and developmental cataract were enrolled on the study. Traumatic cases were excluded. The study was explained and an information sheet was read and informed consent obtained from caregivers.

An interview with children's guardians was conducted, using a pre-tested questionnaire. Interviews were conducted either face-to-face or by telephone. Parents were contacted by telephone if their children did not have an appointment scheduled and/or lived far from the hospital. The following data were collected: demographic details, health-seeking behavior, and socio-economic status. The health-seeking behavior sector of the questionnaire included a series of questions related to the steps from the time a problem was first noticed to the first visit to hospital where treatment was started. Additionally, participants' medical records were reviewed to assess information about etiological, perinatal and prenatal factors as well as details of the disease and other associated anomalies.

Economic status of children's families was classified in five major categories (A, B, C, D and E) using the new Brazilian Economic Classification of the Brazilian Association of Research Companies⁽²²⁾. Additionally, household income grouped according to the national minimal salary (MS) and parent's educational level was assessed. The value of Brazilian MS was 415 reais or 259.4 dollars during the study. Concerning their level of education, parents were grouped in 3 categories: 1. Low education, when they did not have any formal education or studied up to the last year of primary education; 2. Medium, if they had completed part or total of secondary school; 3. High, if they had studied further than secondary school.

Those children whose cataracts were noticed when the child was below one year of age were classified as having congenital cataract and those who developed cataract after one year of age were classified as having developmental cataract.

Detection of the cataract was the moment a problem on the child was first noticed by someone. Presentation time to a health worker was defined as the period of time between cataract detection and the first visit to a health worker, and presentation time to treatment as the period between the latter and being seen by specialized ophthalmologist who started treatment. Delayed presentation time to a health worker was considered if caregivers took more than one month to seek for first help. Moreover, delay in presenting to treatment was considered if this period was more than two months. Finally, total presentation time, the time taken from detection to presentation for treatment, was considered delayed when the treatment started four or more months after detection.

All questionnaires were checked at the end of each interview. Epidata was used for data entry. Excel, SPSS and Stata software were used for analysis. Non-parametric tests (Mann-Whitney) were used to analyze skewed data. Chi-squared test measured the association between categorical variables. In addition, risks factors for delay in presentation were analyzed using univariate and multivariable analysis.

Ethical approval from the LSHTM Ethics Committee was obtained. Permission from IBOL and ICI to review medical records and interview children's guardians was also taken in advance.

RESULTS

Data from 70 children were gathered, 38 (54.3%) of whom were boys. The median child's age at the time of interview was 46.5 months (range 1- 124 months; lower quartile (LQ) - 28; upper quartile (UQ) - 81). Thirty-three (47.1%) interviews were conducted by telephone and the other 37 (52.9%) were conducted face-to-face.

The mean age of mothers at the birth of their affected child was 27.8 years (range 14 to 40 years; SD 6.7). Sixty-four (91.4%) children were follow-up cases and only six (8.6%) were new cases; 28 (40%) children had unilateral cataract and 42 (60%) had bilateral cataract. Fifty-eight (82.9%) cases were considered congenital and 12 (17.1%) developmental (Table 1). Surgery was indicated for 65 patients (92.9%).

Mothers (44, 62.9%) or another relative (9, 12.9%) were usually the first person to recognize that the child had an eye condition. In 44 children (62.9%), a "white pupil" (i.e. leukocoria) was the first abnormality detected followed by difficulty in seeing in 11 (15.7%), strabismus in 5 (7.1%), nystagmus in 4 (5.7%), and 6 (8.6%) children had other signs. Health workers detected the abnormality in 17 children (24.3%): 10 (14.2%) pediatricians, 6 (8.6%) ophthalmologists and one nurse (1.4%). The median age at detection was 2 months (range 1-73, LQ - 1; UQ - 8) (Table 1). There was no significant difference between unilateral and bilateral cases.

In those 58 congenital cases, 42 (72.4%) had the problem noticed by the age of 3 months, mostly by parents or relatives (Table 2).

In fifty percent of cases an ophthalmologist was the first health professional parents visited for help. Additionally, the other half (35) of parents relied on pediatricians to make the diagnosis. Presentation time to a health worker varied from less than one week to 69 weeks, median time 2 weeks (LQ - 1; UQ - 4). In only 13 (18.6%) cases caregivers took more than month, the main causes reported were: 6 (8.6%) parents did not know who to look for/where to go, in 3 (4.3%) they thought that was normal of age or not serious, in 2 (2.9%) cases child had more important problems to treat first and 2 (2.9%) people related other causes.

Presentation time to treatment varied from zero to 169 weeks, median time 8 weeks (LQ - 2; UQ - 35). In thirty-one (44.3%) children presentation time to treatment was longer than 2 months. There was a significant difference between the first professional sought for help and delay in presentation to treatment (Table 3). The main causes were: 10 (14.3%) parents did not know who to look for/where to go, 7 (10%) waited for treatment in a public hospital, 6 (8.6%) had difficulties in making an appointment, in 5 (7.1%) pediatricians neither diagnosed the cataract nor referred them and 3 (4.3%) people reported other causes.

The median child's age when treatment was started was 8 (range 1 - 74) months, (LQ - 3; UQ - 24). In the group of children with congenital cataract, the median child's age was 6.5 (range 1 - 48) months, (LQ - 2; UQ - 30). In the other group with developmental cataract it varied from 26 to 74 months, median age 47.5 (LQ - 32; UQ - 57).

Total presentation time varied from less than 1 month to 40 months, median time 3 (LQ - 1; UQ - 10). Thirty-three (47.1%) patients had total presentation delay: 3 (4.3%) at the presentation to health worker, 24 (34.3%) in presentation to treatment and 6

Questionnaire. Cataract in children: health seeking behaviour and cost of treatmentInstitution: _____ Study number

Who interviewed

- 1 Mother
- 2 Father
- 3 Other relative
- 4 Other, not a relative

Demographic details:

Mother's initials: _____

Mother's age when had this child: years

Child's initials: _____

Hospital record number _____

Sex:

- 1 Male
- 2 Female

Ethnic group

- 1 White
- 2 Black
- 3 Mixed black-white

Gestational age Weeks (99 if not known)Weight at birth: kgs (9999 if not known)Total number of siblings No of other children with cataract:

Case:

- 1 New
- 2 Follow up

Type of cataract

- 1 Unilateral
- 2 Bilateral

Child's age when first noticed: monthsAge of surgery: monthsRight eye (999 if not been operated) Date: /____/____ monthsLeft eye (999 if not been operated) Date: /____/____

Aetiology of cataract

- 1 Known
- 2 Unknown

If known:

- 1 Familial
- 2 Toxoplasmosis
- 3 Congenital rubella
- 4 Metabolic disease
- 5 Syndrome
- 6 Other

Other disabilities

- 1 Yes _____
- 2 No

Health seeking behaviourWho first noticed the problem:
(tick one only)

- 1 Mother
- 2 Father
- 3 Grandmother
- 4 Other relative
- 5 Paediatrician
- 6 Nurse
- 7 Family doctor
- 8 General clinician
- 9 Ophthalmologist
- 10 Friend
- 11 Neighbour
- 12 Carer
- 13 Other _____

What was first noticed:
(tick one only)

- 1 White pupil
- 2 Squint
- 3 Difference in size of eyes
- 4 Visual difficulty
- 5 Delayed development
- 6 Nystagmus
- 7 Other _____

Who did you first go to for help?
(tick one only)

- 1 Paediatrician
- 2 Nurse
- 3 Family doctor
- 4 General clinician
- 5 Ophthalmologist
- 6 Others _____

How long did you take to look for help? weeks

If more than 1 month, what was the main reason of delay?

- 1 Difficult to make an appointment
- 2 Fear of diagnosis
- 3 Doctor not available in my town
- 4 Fear of treatment
- 5 The child had others problems more serious to be treated
- 6 I did not know who to seek/where to go
- 7 Others _____

How many ophthalmologists/services did you visit before coming to this service? After been referred, how long did it take to be seen by the specialized ophthalmologist in this service? weeks

If more than 2 months, what was the main reason of delay?

- 1 Difficult to make an appointment
- 2 Fear of diagnosis
- 3 Ophthalmologist not available in my towns
- 4 Fear of treatment
- 5 The child had others problems more serious to be treated
- 6 I did not know who to seek/where to go
- 7 Others _____

(Continuation questionnaire) **Cataract in children: health seeking behaviour and cost of treatment**

How old was the child when treatment recommended by ophthalmologist started? months

Socioeconomic Status

Marital status of mother

- 1 Married and living with husband
- 2 Married but not living with husband
- 3 Divorced
- 4 Single
- 5 Widow

Education

Mother

Father

- 0 No formal education
- 1 Primary only
- 2 Incomplete secondary
- 3 Secondary
- 4 Incomplete tertiary
- 5 Complete tertiary
- 6 Post graduate

- 0 No formal education
- 1 Primary only
- 2 Incomplete secondary
- 3 Secondary
- 4 Incomplete tertiary
- 5 Complete tertiary
- 6 Post graduate

Occupation

Mother _____

Father _____

To be used by researcher

Mother Number _____

Father Number _____

Transport owned by household

Mother

Father

- 0 None
- 1 Pedal bike
- 2 Motorbike
- 3 Car
- 4 Lorry

- 0 None
- 1 Pedal bike
- 2 Motorbike
- 3 Car
- 4 Lorry

Household income per month

- 1 Up to 415 reais
- 2 415 - 1,245 reais
- 3 1,246 - 2,490 reais
- 4 2,491 - 4,150 reais
- 5 4,151 - 8,300 reais
- 6 more than 8,300 reais

- 1 Rented house/flat
- 2 Own house/flat
- 3 Public dormitory
- 4 Other

Housing

No of bedrooms :

No of bathrooms

People living in the household:

Adults

Children

No of color TV

No of radios

Do you have VCR or DVD?

Yes

Washing Machine

No

Yes

Do you have refrigerator?

Yes

No

No

No of employees (salaries)

Actual out of pocket costs of treatment for the family

Travel costs:

No of adults usually accompanying child

Number of visits (outpatient + surgery):

Usual method of transport to eye clinic:

- 1 Walked
- 2 Ambulance
- 3 Bus
- 4 Train
- 5 Motorbike
- 6 Taxi
- 7 Own car
- 8 Friend/relative's car
- 9 Plane

Travel costs for one visit:

| Child | Adult 1 | Adult 2 | Total |
|--|--|--|--|
| Bus <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> Rs | <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> Rs | <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> Rs | <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> Rs |
| Train <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> Rs | <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> Rs | <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> Rs | <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> Rs |
| Taxi <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> Rs | <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> Rs | <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> Rs | <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> Rs |
| Plane <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> Rs | <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> Rs | <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> Rs | <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> Rs |

(Continuation questionnaire) **Cataract in children: health seeking behaviour and cost of treatment**

| | | | |
|--|---|----|--|
| Friend/relative's car | <input type="text"/> | Rs | |
| Motorbike | <input type="text"/> | Rs | |
| Own car | <input type="text"/> | Rs | |
| | | | Grand total for all visits: |
| | | | Rs <input type="text"/> |
| Costs with food (each visit) | <input type="text"/> | Rs | |
| Total cost | <input type="text"/> | Rs | |
| Accommodation costs for visits: | | | |
| Number of nights had overnight stay | <input type="text"/> | | |
| Cost of overnight stay | <input type="text"/> | Rs | |
| Total cost of overnight stays: | <input type="text"/> | Rs | |
| Consultation and surgery: | | | |
| Insurance for consultation: | <input type="text"/> 1 Yes <input type="text"/> 2 No | | |
| Insurance for surgery: | <input type="text"/> 1 Yes <input type="text"/> 2 No | | |
| Consultation fee paid by family: | Per visit <input type="text"/> | Rs | Number of consultations <input type="text"/> |
| Total consultation fee(s) paid: | <input type="text"/> | Rs | |
| Examination under sedation | | | |
| Hospital charges paid by family: | <input type="text"/> | Rs | |
| Physicians' payment: | <input type="text"/> | Rs | |
| Total per examination | <input type="text"/> | Rs | No of examinations <input type="text"/> |
| Surgical fee paid by family: | | | |
| Ophthalmologists' payment | First operation <input type="text"/> | Rs | 2 nd operation <input type="text"/> |
| Total paid for ophthalmologists: | <input type="text"/> | Rs | <input type="text"/> |
| | | | 3 rd operation <input type="text"/> |
| | | | <input type="text"/> |
| Hospital charges paid by family: | <input type="text"/> | Rs | <input type="text"/> |
| Total hospital charges paid: | <input type="text"/> | Rs | <input type="text"/> |
| Anesthesiologist's payment: | <input type="text"/> | Rs | <input type="text"/> |
| Total paid for anesthesiologists: | <input type="text"/> | Rs | <input type="text"/> |
| Intraocular lenses | <input type="text"/> | Rs | <input type="text"/> |
| Opportunity costs | | | |
| Lost of income for adults: | <input type="text"/> | Rs | |
| Other costs: | <input type="text"/> | Rs | Specify _____ |
| Other costs | | | |
| Glasses: | <input type="text"/> | Rs | Total spent on glasses (000 = none) |
| Contact Lenses | <input type="text"/> | Rs | Total spent on contact lenses (000 = none) |
| Eye patches | <input type="text"/> | Rs | Total spent on eye patches (000 = none) |
| Low vision devices | <input type="text"/> | Rs | Total spent on low vision devices (000 = none) |
| Medication | <input type="text"/> | Rs | Total spent on medication (000 = none) |
| Other costs | <input type="text"/> | Rs | Specify: _____ |

(8.6%) in both periods. Initially, total delay of treatment was associated with mother's educational level ($p=0.008$), father's educational level ($p=0.018$), household income ($p=0.002$), being the only child ($p=0.001$) and having insurance ($p<0.001$). Using a multiple logistic regression modeling, only the last two factors showed a protective effect after controlling for the other variables. Children without siblings were 84% less likely to have a delay in their treatment compared to those with siblings. Moreover, children whose families had insurance were 83% less likely to have their treatment delayed compared to those without insurance (Table 4).

There is no statistically significant difference in total presentation time between children with congenital or developmental cataract (Mann-Whitney $U=253.50$; $p=0.14$).

DISCUSSION

Cataract remains an important cause of blindness in children as many studies around the world have shown⁽⁴⁻⁸⁾. Prevention is limited

since many aspects of its etiopathogenesis are still unknown. Consequently, early diagnosis and prompt referral for proper treatment are even more important in increasing the probability of these children developing sight.

In the great majority, cataract was suspected by mothers (62.9%); with leukocoria being the main sign which demonstrates how easily detectable is the disease, particularly in more advanced cases. Despite the existence of a law which obliges examination of red reflex of neonates by pediatricians in all maternity units of the state of Rio de Janeiro since the year of 2002, in this study only 7 (12.1%) of the 58 children with congenital cases had their cataract identified by a pediatrician by 3 months of age. This might be a reflex of lack of pediatricians' training in recognizing eye problems. In total, only about 25% of the children (17) had their cataract detected by a health worker. An evaluation of the existent screening program in the United Kingdom showed that 47% of their congenital cataracts had been detected through routine examination by the age of 3 months⁽¹⁸⁾.

In Brazil, although primary health care is well established and easily accessible, primary eye care is not normally incorporated to it.

Total delay in presentation in our study occurred mostly in seeking the specialized ophthalmologist who started treatment after the child had been seen by another health worker. Considering that half of caregivers sought directly an ophthalmologist as first health worker, a much lower proportion of delay on the second phase should be expected. Instead 11 (31.4%) out of these 35 children had delay at treatment presentation, mostly due to problems in referral or treatment in the public health system. Additionally, other 20 children firstly seen by pediatricians had delay at treatment presentation, half of them (10) by referral problems due to lack of knowledge of specialized centers or difficulty in making appointment mainly in the public health system and also, although much less frequently, in the private sector. Moreover, in other 5 of these 20 cases lack of pediatricians' skills in diagnosing the problem was responsible for the delay.

Applying the same criteria used in this study for educational level to the population of the state of Rio de Janeiro about 17.0% were classified as having low education, 50.0% medium education and 33% high education⁽²¹⁾. In the present study, similar figures were found for the parents' educational level, respectively: 16.4%, 57.1% and 26.4%. This may suggest our sample is representative of the population of the state of Rio de Janeiro. However, the mother's educational level in this setting was not a determinant in late presentation in this study. This finding contrasts with that of a similar study in Tanzania⁽²³⁾. Furthermore, the gender of the child was not deter-

minant in seeking for treatment as it is in some African and Asian settings⁽²³⁻²⁵⁾.

In fact, the only two factors which showed significant negative relation to total late presentation were: having insurance and being the only child. The former was expected by some of the reasons mentioned above as a great number of children whose treatment was supported by NGO had already been seen or even treated in the public system before seeking or been referred to ICI. Comparison of this result is not possible due to lack of similar studies. Furthermore, being the only child as a protective factor against delay in presentation could suggest higher level of parents' attention on their only child. In contrast, Mwendu et al.⁽²³⁾ found that children with congenital cataract who had siblings were 4.40 (95% CI 1.38 to 14.39) less likely to have a late presentation to hospital (after 12 months in their study) compared to only children in Tanzania.

The fact that the study was performed in a specialized hospital could introduce some bias since parents who attend these hospitals tend to be more health concerned or conscious, more likely to have higher socioeconomic status. Moreover, even with the NGO covering most of the costs, expenditure with transportation could deter some families from looking for help. Also, some level of inaccuracy in recalling details of their health-seeking behavior could occur particularly in cases of longer follow-up.

We considered the number of siblings at the day of interview which could not be same of that at the birth of the child. Therefore, association between this variable and total delay in presentation could be underestimated or overestimated.

Table 1. Median age of child at detection by type of cataract and laterality

| | Age of the child at detection (months) | | | | Frequency |
|---------------------------|--|---------|----------------|----------------|-----------|
| | Median | Range | Lower quartile | Upper quartile | |
| Type of cataract * | | | | | |
| Congenital | 1 | 1 - 36 | 1.0 | 4.0 | 58 |
| Developmental | 30 | 18 - 73 | 21.5 | 51.0 | 12 |
| Laterality** | | | | | |
| Bilateral | 2 | 1 - 55 | 1.0 | 9.0 | 42 |
| Unilateral | 1 | 1 - 73 | 1.0 | 4.5 | 12 |
| Total | 2 | 1 - 73 | 1.0 | 8.0 | 70 |

*Mann-Whitney test=7.5; p<0.0001; **Mann-Whitney test=512.0; p=0.34

Table 2. Age of child at detection by who detected her congenital cataract

| Who detected | Age of the child at detection (months) | | Total |
|---------------------|--|----------------|------------|
| | ≤ 3 months (%) | > 3 months (%) | |
| Parents/relatives | 31 (73.8) | 13 (81.3) | 44 (75.9) |
| Pediatrician | 7 (16.7) | 2 (12.5) | 9 (15.5) |
| Other health worker | 4 (9.5) | 1 (6.2) | 5 (8.6) |
| Total | 42 (100.0) | 16 (100.0) | 58 (100.0) |

Pearson $\chi^2=0.3582$; p=0.836

Table 3. Delay in presentation to treatment by first professional sought for help

| Delay | Professional | | Total (%) |
|-------|---------------------|------------------|------------|
| | Ophthalmologist (%) | Pediatrician (%) | |
| Yes | 11 (31.4) | 20 (57.1) | 31 (44.3) |
| No | 24 (68.6) | 15 (42.9) | 39 (55.7) |
| Total | 35 (100.0) | 35 (100.0) | 70 (100.0) |

Pearson $\chi^2=4.6898$; p=0.03

Table 4. Characteristics associated with total delay

| | Total presentation time | | OR (95% CI) p value | Adjusted OR (95% CI) p value |
|--|--------------------------|--------------------------|----------------------------------|---------------------------------|
| | ≤ 3 months n = 37 (%) | > 3 months n = 33 (%) | | |
| Gender of child | | | | |
| Male | 24 (63.2) | 14 (36.8) | 2.50 (0.95 - 6.58) | |
| Female | 13 (40.6) | 19 (59.4) | p=0.06 | |
| Mother's age at child's birth | | | | |
| < 30 years | 20 (51.3) | 19 (48.7) | 0.87 (0.34 - 2.23) | |
| ≥ 30 years | 17 (54.8) | 14 (45.2) | p=0.77 | |
| Laterality of cataract | | | | |
| Bilateral | 21 (50.0) | 21 (50.0) | 0.75 (0.29 - 1.96) | |
| Unilateral | 16 (57.1) | 12 (42.9) | p=0.56 | |
| Family history | | | | |
| Negative | 30 (51.7) | 28 (48.3) | 0.77 (0.22 - 2.69) | |
| Positive | 7 (58.3) | 5 (41.7) | p=0.68 | |
| Number of siblings | | | | |
| One or more siblings | 18 (39.1) | 28 (60.9) | 0.17 (0.05 - 0.53) | 0.16 (0.04 - 0.69) |
| Only child | 19 (79.2) | 5 (20.8) | p=0.001 | p=0.014 |
| Marital status of parents (at recognition) | | | | |
| Married | 33 (56.9) | 25 (43.1) | 2.64 (0.71 - 9.76) | |
| Other | 4 (33.3) | 8 (66.7) | p=0.15 | |
| Who first noticed the problem | | | | |
| Relatives | 26 (49.1) | 27 (50.9) | 0.53 (0.17 - 1.63) | |
| Health workers | 11 (64.7) | 6 (35.3) | p=0.26 | |
| Mother's educational level | | | | |
| Low (primary/none) | 3 (27.3) | 8 (72.7) | 1.00 p=0.008 χ^2 trend=6.95 | 1.00 |
| Medium (secondary) | 19 (48.7) | 20 (51.3) | 0.39 (0.91 - 1.71) | 0.74 (0.14 - 3.99) p=0.725 |
| High (tertiary) | 15 (75.0) | 5 (25.0) | 0.12 (0.02 - 0.66) | 2.35 (0.17 - 33.17) p=0.53 |
| Father's educational level | | | | |
| Low (primary/none) | 4 (33.3) | 8 (66.7) | 1.00 p=0.018 χ^2 trend=5.58 | 1.00 |
| Medium (secondary) | 20 (48.8) | 21 (51.2) | 0.52 (0.14 - 2.02) | 1.17 (0.24 - 5.73) p=0.85 |
| High (tertiary) | 13 (76.5) | 4 (23.5) | 0.15 (0.03 - 0.79) | 1.32 (0.15 - 12.06) p=0.80 |
| Economic category | | | | |
| Class A+B | 18 (66.7) | 9 (33.3) | 2.53 (0.89 - 7.10) | |
| Class C+D | 19 (44.2) | 24 (55.8) | p=0.68 | |
| Household income | | | | |
| ≤ 3 minimal salaries (MS) | 16 (38.1) | 26 (61.9) | 1.00 p=0.002 χ^2 trend=9.82 | 1.00 |
| 4 - 6 MS | 10 (66.7) | 5 (33.3) | 0.31 (0.09 - 1.06) | 0.74 (0.14 - 3.83) p=0.72 |
| > 6 MS | 11 (84.6) | 2 (15.4) | 0.11 (0.02 - 0.57) | 0.17 (0.01 - 2.79) p=0.21 |
| Insurance | | | | |
| No | 13 (33.3) | 26 (66.7) | 0.15 (0.04 - 0.43) | 0.17 (0.04 - 0.82) |
| Yes | 24 (77.4) | 7 (22.6) | p<0.001 | p=0.027 |

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