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Clientele profile of early intervention services: a focus on eye health

Perfil da clientela de serviços de intervenção precoce: um enfoque na saúde ocular

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ABSTRACT

Objectives: *To describe and analyze the profile of children with developmental disorders treated at early intervention services (IP) and their mothers or caregivers, focusing on aspects related to the child's ocular health.* ***Methods:*** *Quantitative survey, exploratory-descriptive. The data collection instrument consisted of a questionnaire applied with mothers or caregivers of children assisted in IP services. The data were transcribed in Microsoft Excel spreadsheet and analyzed based on simple descriptive statistics. The sample consisted of 273 subjects.* ***Results:*** *There was a prevalence of mothers (84.2%) between 30 and 40 years old (38.8%). The children were between 1 and 2 years of age (34.8%), and, for the most part, with Down's Syndrome (26.7%). The mean age of entry of children in IP services was 7.93 months and the age at first consultation with the ophthalmologist - of those who had already performed (82.8%) - was 6.8 months, with 45,6% presented ophthalmological alterations, predominating strabismus (40.8%).* ***Conclusions:*** *The results obtained allowed the identification and characterization of mothers or caregivers and children attending IP services, especially in questions related to ocular health. Understanding this scenario should support actions aimed at ocular health education, prevention and rehabilitation and should be directed to IP services, managers, families and children.*

Keywords: *Eye health; Early intervention (Education); Developmental disabilities; Child health; Caregivers*

RESUMO

Objetivos: Descrever e analisar o perfil de crianças com alterações no desenvolvimento atendidas em serviços de intervenção precoce (IP) e de suas mães ou cuidadores, dando enfoque a aspectos relacionados a saúde ocular da criança. **Métodos:** Levantamento quantitativo, de caráter exploratório-descritivo. O instrumento de coleta de dados constituiu-se de um questionário aplicado com mães ou cuidadores de crianças atendidas em serviços de IP. Os dados obtidos foram transcritos em planilha do software Microsoft Excel e analisados com base em estatística descritiva simples. A amostra constituiu-se de 273 sujeitos. **Resultados:** Houve prevalência da participação das mães (84,2%) com idade entre 30 e 40 anos (38,8%). As crianças tinham entre 1 e 2 anos de idade (34,8%), e, na sua maioria, com Síndrome de Down (26,7%). A média de idade de entrada das crianças nos serviços de IP foi de 7,93 meses e da idade na primeira consulta com o oftalmologista - daqueles que já haviam realizado (82,8%) - foi de 6,8 meses, sendo que 45,6% apresentou alterações oftalmológicas, predominando o estrabismo (40,8%). **Conclusões:** Os resultados obtidos permitiram a identificação e a caracterização das mães ou cuidadores e das crianças que frequentam os serviços de IP, principalmente em questões referentes à saúde ocular. Compreender o panorama descrito deve subsidiar ações voltadas à educação em saúde ocular, prevenção e reabilitação e devem ser direcionadas aos serviços de IP, aos gestores, às famílias e às crianças.

Descritores: Saúde ocular, Intervenção precoce (Educação); Deficiências do desenvolvimento; Saúde da criança; Cuidadores

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Introduction

There are many causes for visual changes, which may be related to biological, social or environmental aspects[1], whose consequences have repercussions on the family and society, when 80% of cases of blindness and low vision are avoidable.[2] Since eye health must be considered a respectable public health element[3], primary prevention in this field includes actions to identify children eligible for evaluation by the ophthalmologist, followed by the secondary level covering measures of early detection and treatment of visual changes, highlighting the need for effective communication between professionals of different levels of care and the participation of the family to the success of the cases. In addition, actions to promote ocular health and prevent visual diseases are a priority in ophthalmologic community programs. [4]

Because it is the main way of perceiving environmental stimuli, sight is responsible for detecting and identifying environmental information, integrating the other senses, and triggering the necessary motivation for the child to perform movements and actions. Therefore, its deficit has consequences in all aspects of the development of the child and the learning process, especially the need to prevent its changes, early identification and timely intervention.[5-9]

Thus, the association between visual impairment and other disabilities is frequent, and the incidence of changes in people with multiple disabilities is high, occurring to a greater extent when compared to other people. [10-12] However, it is a fact that little attention is paid to the ocular health of people with multiple disabilities, which may be related to the false idea that, when compared to the general picture, ocular health is not that important.[12,13]

Considering the prevention of visual changes as a matter of priority in public health, population-based studies on information regarding the magnitude and nature of visual problems are essential, providing an updated picture of the situation.[14] These studies are carried out in particular by surveys and are of great value for the planning of preventive actions.[2, 4]

The objective of the study was to describe and analyze the profile of children with developmental disorders treated in early intervention services (IP) and their mothers or caregivers, focusing on aspects related to ocular health.

Methods

The research consisted of a quantitative, exploratory-descriptive survey. The participation of the subjects was voluntary after signing the Free and Informed Consent.

Data were collected between February and July 2013, in the IP services of the 18 institutions that authorized the research in the city of Curitiba-PR. The group of subjects comprised mothers or caregivers of the children attended in these services, of both genders, older than 18 years, able to give information about the characteristics and history of the child.

To collect data, a semi-structured questionnaire (Appendix 1) was elaborated, addressing issues related to the characteristics of the respondent, the child and the ophthalmologic follow-up. The instrument went through the pre-test phase (pilot project) and was applied directly to the respondents.

The sample consisted of 273 mothers or caregivers, representing 65.8% of the total number of children attending these services at the time of data collection. This number was due to the difficulty of contacting some families, the absence of children for care and the apparent abandonment of treatment even though they were registered in the IP service.

The data collected were tabulated and analyzed based on simple descriptive statistics with Microsoft Excel software.

Results

The characterization and profile of the sample are described on the basis of relative (%) and absolute (f) tables and graphs. Some questions could have multiple answers, so the relative frequencies were calculated based on the total of respondents, resulting in an absolute total ≥ 273 and relative ≥ 100%.

There was a prevalence of the mothers' participation, totaling 84.2% (f = 230), followed by 7.7% (f = 21) of fathers and 5.1% (f = 14) and grandparents. The other degrees of kinship appeared with frequency ≤1,1% (f = 3). The age distribution of mothers/caregivers participating in the study is given in Table 1.

Table 1
Distribution by age group of mothers/caregivers

n=273

Age	f	%
Less than 20 years	17	6.2
Between 20 and 25 years	46	16.8
Between 25 and 30 years	46	16.8
Between 30 and 40 years	106	38.8
Between 40 and 50 years	47	17.2
Over 50 anos	11	4.0

The mean age of the children entering the IP service is shown in table 2, and the age group of children attending the IP is as shown in table 3.

Table 2
Average age of entry into early intervention service in months

n=273

Average	Standard Deviation	Minimum	Maximum
7.93	7.47	0.2	42

Table 3
Age group of children accompanied by mothers or caregivers

n=273

Age	f	%
Less than 1 years	62	22.7
Between 1 and 2 years	95	34.8
Between 2 and 3 years	67	24.5
Between 3 and 4 years	43	15.8
Over 4 years	6	2.2

According to the perception of the caregivers regarding the initial diagnosis of the children, there was a prevalence of Down Syndrome, with 26.7% of the children. Next, the diagnoses of Cerebral Palsy and Delay in Neuropsychomotor Development appeared, as shown in table 4.

Table 4
Distribution of children frequencies according to the perception of mothers or caregivers in relation to the initial diagnosis obtained*

n=273

Diagnosis	*f*	%
Down syndrome	73	26.7
Cerebral palsy	47	17.2
Developmental delay not specified	47	17.2
Other neurological changes	46	16.8
Ophthalmologic changes	22	8.1
No closed diagnosis	14	5.1
Congenital infections	12	4.4
Other	9	3.3
Other syndromes	8	2.9
Hearing impairment	4	1.5
Couldn't explain	2	0.7

*Possibility of multiple responses

Regarding the follow-up with the ophthalmologist, 82.8% (*f* = 226) of participants stated that the child had already been at an appointment with this professional, 16.8% (*f* = 46) stated that they haven't, and 0.4% (*f* = 1) did not answer the question. Regarding the frequency of follow-up, 54.4% (*f* = 123) had it routinely, 44.7% (*f* = 101) rarely, and 0.9% (*f* = 2) did not respond. The category routinely included those who reported that the child went to the ophthalmologist 3 times or more, and the category rarely included those who only went 1 or 2 times to the appointment. The average age of the first consultation with the ophthalmologist is shown in table 5

Table 5
Average age in months of first appointment with an ophthalmologist

n=223*

Average	Standard Deviation	Minimum	Maximum
6.8	6.35	0.1	48

* Number of people who reported the age of the first appointment

According to the participants, 42.5% of children did not present ophthalmological changes (Table 6). Regarding those who did, strabismus was the prevalent change, followed by refractive errors (Table 7). The grouping used was criated according to the multiplicity of responses of the mothers or caregivers and considering the tables with named diagnosis or clear explanations of the diagnoses. The group "refractive errors" included: myopia, hypermetropia and astigmatism. The group "Optic Nerve Alterations (ON)" included: atrophy of the ON and pallor of the ON. The group "congenital malformation" included: Microphthalmia, palpebral ptosis and Coloboma. The group "Other" included: fixation difficulties, obstruction of lacrimal pathways and retinal detachment.

Regarding the diagnostic data of the children, it shows that: 35.2% (*f* = 96) presented had disabilities or changes without the association of visual changes; 32.2% (*f* = 88) presented other

Table 6
Distribution of children frequencies according to the perception of mothers or caregivers in relation to the presence of visual change

n=226*

Presence of visual change	*f*	%
Change	103	45.6
No change	96	42.5
Did not know	19	8.4
No closed diagnosis	8	3.5

*Number of children who had undergone ophthalmological appointment

Tabela 7
Distribution of children frequencies who had visual change according to the perception of mothers or caregivers in relation to the type of visual change*

n=103**

Visual change	*f*	%
Strabismus	42	40,8
Refractive errors	19	18,4
Toxoplasmosis	8	7,8
Changes of the optic nerve	8	7,8
Cerebral visual impairment	7	6,8
Nystagmus	6	5,8
Cataract	6	5,8
Retinopathy of prematurity	2	1,9
Low vision	5	4,9
Congenital malformation	4	3,9
Glaucoma	3	2,9
Retinoblastoma	1	1,0
Albinism	1	1,0
Others	10	9,7

*Possibility of multiple responses
**The calculation of the relative frequency did not considered those who did not have closed diagnosis or did not know to inform the type of the visual change

disabilities associated to visual impairment/change; and 6.2% (*f* = 17) had only visual impairment/change. Note that 26.4% (*f* = 72) of children with disabilities or other developmental changes do not have an ophthalmologic diagnosis.

Regarding the participants' knowledge of the need for ophthalmologic follow-up, 70.3% (*f* = 192) said they knew the reason. Of these, 44.8% (*f* = 86) reported reasons related to the initial diagnosis of the child, 37.5% (*f* = 72) related to the ophthalmologic diagnosis, and 31.3% (*f* = 60) reported reasons not related to any of the two diagnoses. Regarding the provider of guidance, 44.8% (*f* = 86) mentioned the pediatrician, followed by the neurologist and self-search for information, with 14.5% (*f* = 28) each. The ophthalmologist and other professionals had the same frequency of 12.0% (*f* = 23) each. Also, 5.2% (*f* = 10) mentioned the institution's professionals as a source of information, and 1% (*f* = 2) did not respond.

Of those who declared having already gone to an appointment with the ophthalmologist regarding the guidance they received about the frequency of ophthalmologic follow-up,

the average interval obtained was 6.77 months. However, 15.9% (f = 36) stated that the ophthalmologist did not advise the continuity of follow-up or did not specify when to return, and 7.5% (f = 17) could not answer.

Regarding guidance about the development of the child's sight during the first months of life regarding how, what and how much a baby sees, 59.7% (f = 163) answered that they did not receive this guidance, and 40.3% (f = 110) stated they did. Of these, 51.8% (f = 57) mentioned the ophthalmologist as a source of information, 22.7% (f = 25) the pediatrician, and 16.4% (f = 18) the professionals of the institutions.

The Red Reflex Test (Negative Eye Test), confirmed by the child's health certificate, was observed in 64.5% (f = 176) of children. It was not possible to confirm the test of 2.9% (f = 8) of children as a result of the child not having a health certificate with records of the period of birth.

Discussion

The mother is often the one to abdicate from other social roles (professional and personal) due to the intensive care of the children. In a study of about the difficulties found by mothers of children with cerebral palsy, 6 of the 10 mothers interviewed were responsible for caring for their children, not having family support for daily care, "[...] thus increasing the burden of responsibilities." [15] In addition, over time mothers continue to be responsible for some care with adult children, making this role of caregiver for life. [16]

The mean age of entry into IP was relatively low. However, it is necessary to highlight two aspects: the entry into these services at a younger age may be a determining factor for the development of children with developmental changes; and studies point to a gap between the age of diagnosis and the age of entry into IP services [17]. For children with developmental changes, it is vital to ensure access to procedures for performance at its maximum potential[18], so that IP should be encouraged as early as possible. [19]

Regarding the diagnosis of children, in 2006 a study identified that the types of disabilities found had the following frequencies: 78.4% - mental; 69.4% - speech; 58.3% - motor; 34.2% - visual; and 7.2% - auditive. [12] In 2011, another study described the incidence of severe mental retardation in 59.4% of the population studied, followed by cerebral palsy and epilepsy with 18.9% each, in which similar frequency was observed in cases of cerebral palsy. Down Syndrome appeared with a significantly lower incidence than in the present study, with a small percentage of 5.4%. [11] The differences between the data found in this study and those described by other authors may be related to the different groups of diagnoses, to the source of data collection - which were informed by the mothers/caregivers themselves - and to the collection contexts.

Different from other studies[10, 12], most of the children had already had an ophthalmologist appointment, but 16.8% were still an expressive number of children who had never been with this professional, especially considering the high rate of visual changes in this population. Early diagnosis of visual changes and appropriate treatment can mean an important improvement in the global developmental patterns and a greater response to the therapies to which they are submitted and, consequently, a better quality of life. [11, 12]

In a study on ophthalmological findings in patients with multiple disabilities, a percentage of 56.2% of patients who had never had gone to an ophthalmological appointment was obtained, a result attributed to the lack of information to parents/caregivers regarding the relevance of ophthalmologic follow-up and/or failures in the health system - by the lack of disclosure of the importance of such follow-up or difficulty of access or lack of reference services. [12]

The study of Ventura et al.[10] identified that 56.2% of the population studied (people with multiple disabilities) were having their first ophthalmologic appointment, and could present uncorrected visual changes, making life even more difficult for patients and their relatives. The difficulty of access to ophthalmology services was reported by 51.1% of those who sought this service.

In another study on the clinical and ophthalmologic characteristics of 37 institutionalized individuals, it was observed that most of the individuals had never been to an ophthalmological appointmet, but the incidence of these findings was not described[11]. The discrepancy of the results obtained in relation to the other studies may be due to the fact that it includes institutions aimed at the care of children with visual impairment.

Based on other studies[10, 12], the average age of the first appointment obtained in this study was relatively early. However, considering the perspective that the development of sight in the first year of life is crucial[5, 12, 20, 21], with the first 3 months being key to this process[5], this average represents some risk. Early diagnosis and appropriate treatment of visual changes in children with multiple disabilities improve responses in therapies, leading to evolving global development[11,12], and preventing irreversible vision impairment[11,22]. The early referral of this population to ophthalmology services with adequate human and material resources to care these clients in particular is fundamental.[12] In these cases, ophthalmologic examination should be performed simultaneously with neurological and pediatric assessments.[20]

There is a shortage of referential recommendations regarding the frequency of ophthalmologic follow-up in this age group and with this specific population.[23] It was only obtained that the ophthalmologic follow-up of children with Down's Syndrome should be annual, and that every child should undergo a systematized ophthalmologic evaluation in the first months of life.[19]

The association between disabilities is often described in the literature.[10, 11, 12, 24, 25] Similar indexes of association between visual changes and other developmental changes or disabilities were obtained in other studies, such as 33%[10] and 38.7%.[12] And still, other studies pointed to this association in 50% of cases[20]; 65%[24]; 67.51%[25]; and cases of legal blindness in 41.6% of the individuals evaluated.[11]

Among the most frequent visual changes in people with multiple disabilities are: refractive errors, optic atrophy, nystagmus, strabismus, retinopathy, ptosis, and cataracts[11], as identified in this study. Strabismus is frequently found in the population with cerebral palsy[12], and the incidence may be ten times higher than in non-disabled children, affecting between 30 and 50% of cases.[26] Studies have described this incidence in 25.5%[12], 22.6%[25] and 8.3%[11] of cases.

Ventura et al. [10] identified that strabismus appeared followed by changes in the optic nerve, with 12.6% of incidence, significantly higher than that found in the present study. Less frequently, amblyopia (3.9%), cataract (1%), cicatricial retinocoriditis (0.6%), and retinal coloboma (0.6%) appeared. The reported incidence of cataract was lower than that found in this study. However, the incidence of changes due to toxoplasmosis was higher.

The rates of optic nerve changes found in other studies vary considerably between 4.1%[11], 5.1%[12] and 12.6%[10], some close to that found in this study. Refractive errors are reported with an incidence of 12.5% [11] and 85.6%.[12]

Most of the studies mentioned counted on ophthalmologic examination to reach the results obtained, and the diagnoses in the present study were obtained by the mothers or caregivers report,

and this may be one of the factors for the divergence in the data found.

Studies indicate that the role of information is paramount to pediatricians. In this sense, more incisive guidelines are required for these professionals regarding the importance of specialized ophthalmologic follow-up in children at high risk of developing ocular changes.[27] However, health education is a heterogeneous field, and its success depends on multidisciplinary applicability. Thus, health, education and social assistance professionals can become important agents of health education. In a contemporary perspective on health education, everybody acts as educators and learners, but professionals and subjects must establish a co-responsibility relationship, playing the first role of mediator of the critical-reflexive process.[28]

Regarding guidance to mothers/caregivers, the lack of information about the children's disabilities, specificities of the clinical condition, technical and functional aspects, and support systems can lead to them to feeling unprepared to deal with the needs of these children and consequent difficulty in understanding and adhering to guidance on care and management of children.[29] Considering that early intervention services are the first rehabilitation services to receive these children, and that the professionals involved in them (health, education or social assistance) have direct contact with these children and their families and caregivers, they are important agents of health and education promotion.

A significant portion of the sample did not undergo the Negative Eye Test, according to the record in the health certificate, which raised two hypotheses: either the test is not being performed or is not being registered in accordance with the State legislation. Paraná is one of the states with legislation to make it compulsory to carry out the test since 2004 (State Law No. 14,601)[30], in which case all children should have been examined and have their test results recorded in the certificate. This number may be due to the difficulties in complying with the law along with the lack of information of caregivers as to the right to perform the test and what it consists of. No data regarding the actual performance of the test were found in other states in which the performance is mandatory. It should be noted that this test may identify some of the abnormalities found in the ophthalmologic diagnoses reported in the present study.[6, 23]

Conclusion

The results obtained allowed the characterization of mothers or caregivers and children attending IP services, mainly regarding ocular health. The relevance of eye health care actions directed to these clients is clear, considering the high rate of visual changes associated with other developmental changes or disabilities. In this sense, it is necessary to direct actions, efforts and resources for educational and training measures in this area of knowledge to the professionals who are directly related to providing services to these clients, institutional managers, as well as to the relatives and caregivers of these children.

Actions to promote ocular health and prevention of visual impairment are among the priorities of public health programs in the field of ophthalmology. However, it is frequently observed that actions in the field of ocular health are directed to school children and the elderly. Attention to the need for campaigns and actions with a focus on under aged children - a crucial period in the visual development - and of vulnerable groups such as children with other associated changes, which present a high rate of visual changes.

Understanding the scenario described should help actions aimed at health education, prevention and rehabilitation, and should be directed to IP services, families and children. It is necessary not only to direct public policies for this purpose, but also to systematize and inspect the implementation of the already existing ones, as in the case of the Negative Eye Test in the state of Paraná.

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APPENDIX 1: QUESTIONNAIRE MOTHERS OR CAREGIVERS

NPM/C*: _____

1) How old is the child you accompany?
☐ Between 0 and 1 year ☐ Between 1 and 2 years ☐ Between 2 and 3 year ☐ Between 3 and 4 years ☐ Over 4 years

2) How old are you?
☐ Less than 20years Between 20 and 25 years ☐ Between 25 and 30 years ☐ Between 30 and 40 years
☐ Between 40 and 50 years ☐ Over 50 years

3) Are you related to the child?
☐ Yes ☐ No

4) If you are related, what is your relationship with the child.
☐ Father ☐ Mother ☐ Grandfahter ☐ Grandmother ☐ Uncle ☐ Aunt ☐ Brother ☐ Sister

5) If you are not related, identify yourself: _____

6) If you are not the child's mother, do you know how old s/he is?
☐ Less than 20years ☐ Between 20 and 25 years ☐ Between 25 and 30 years
☐ Between 30 and 40 years ☐ Between 40 and 50 years ☐ Over 50 years

7) Has the child had an appointment with an ophthalmologist?
☐ Yes ☐ No

8) How many times? ☐

9) What have the doctors said that your child has in their eyes? _____
_____

10) How old was the child when s/he first went to the ophthalmologist? ☐

11) How old was the child when s/he started attending Intervention/Early Stimulation? ☐

12) Have you been guided about the development of child sight?
☐ Yes ☐ No

13) If so, who guided you? _____

14) Did the child undergo the "Negative Eye Test" (Red Reflex Test)?
☐ Yes ☐ No

15) If so, was it done within the first 48 hours of life?
☐ Yes ☐ No

*: Number in the project concerning mother or caregiver.