

Rehabilitation services for visually impaired children: early intervention or a long delay?¹

Keywords:

Low-vision; Mothers' perception; Ophthalmologic consultation

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ABSTRACT

The following aspects related to the care of visually impaired children were surveyed in a Low-Vision Stimulation Service in order to contribute to the improvement of the services it offers: age of the child at the first ophthalmologic consultation; person

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responsible for identifying the problem; knowledge of mothers concerning the vision problem of their child; and, age of the child at the beginning of stimulation. Twenty-five mothers of visually impaired children with ages varying from birth to 4 years were interviewed. In a general way, the problem had been identified before the children were 6 months old; however, only 50.0% of them had been attended to up to this age. In the great majority of the cases it was the mother who first perceived the vision problem of her child (48.0%), followed by other members of the family (28.0%) and, physicians (24.0%). Although the mothers disclosed some knowledge on the technical terminology concerning vision problems, they used it incorrectly. The Authors suggest that ophthalmologists should play a more active part in the early referral of visually impaired children to vision stimulation services.

INTRODUCTION

Low-vision is regarded as "the severe loss of vision that can not be reverted neither by clinic nor surgical procedures, nor with the use of conventional eyeglasses". It can also be described as any degree of vision weakening that causes functional disability and diminishes vision performance. However, the functional ability of the eye is not only associated with visual factors but also with the person's reaction to the vision loss and with environmental factors interfering with the individual's performance, as well. (CARVALHO and coll., 1992).

Visually impaired children when not attended to early in life tend to present serious motor, cognitive and, other handicaps that are likely to produce stigmatisation. Early diagnosis of the problem and prompt attendance of any alteration in the child's development contribute to provide a better prognosis in the majority of the cases, diminishing the impact of the seriousness of the disability and consequently altering its consequences. (LEWIS, 1992; GAGLIARDO & GONÇALVES, 1996).

Right from birth, vision plays a predominant role in human life, since it is a triggering stimulus favouring communication and performance of actions. The infant's relationship with the external world is primarily accomplished through vision, particularly through imitation, so that any abnormality in his vision skills is likely to produce difficulties in his future learning, in his social relationships and diminishment in the efficiency of his physical and intellectual activities (BRUNO, 1993; ALVES & KARA-JOSE, 1996).

Deprived of their visual sense, congenitally blind babies or those with severe vision impairment, when compared with sighted-babies, are likely to present a 4-month delay in their global development at the age of 1. Consequently, the importance of having the rehabilitation procedure being started early in life is amply recognised in these cases. Besides the visual aspect, this intervention should also aim at a global stimulation based on the child's psychomotor and perceptual-cognitive development. The first years of life, the most critical developmental period, are even more crucial for those who present one or more impairments. Innumerable children—who otherwise would have benefited from a rehabilitation program— reach pre-school age with already installed disabilities. In these cases, recovery will be difficult and rarely accomplished (HARREL & AKESON, 1987; HYVARINEN, 1988; BRUNO, 1993).

In 1991, the University of Campinas (UNICAMP) Clinic Hospital gave start to an early stimulation service at its Low-Vision Service ward. The Department of Ophthalmology and the Centre for Studies and Research in Rehabilitation (CREPE), both belonging to the UNICAMP, got together in an effort to provide a conjoined attendance performed by occupational therapists and ophthalmologists, giving priority to early intervention. This Service came to be a specialised pole of attendance to which all cases of vision impairment from all parts of the country are referred. This early intervention is accomplished through various phases.

At the first one, after anamnesis, parents are given orientation on the procedures to be adopted with their child. They are required to provide information on their socio-economic circumstances in order that orientation for early stimulation of the visually impaired child could be compatible with the reality they are inserted in. In the whole process of intervention, the parents' participation is that of a continuous evaluation.

The second phase of attendance comprehends a global evaluation of the child's development as well as an assessment of his vision skills, both in charge of the occupational therapist. At this attendance it is recommended that the evaluation tools be constituted of simple objects (sorting and form fitter toys, different sizes of colourful balls, carpets in different textures, dolls, etc.) of easy acquisition or making and able to be employed in stimulation activities with the child. Next, the ophthalmologist enlightens the parents on their child's condition, giving them specific orientation on how to provide their child with vision stimulation.

In general, the parents are required to bring their child for a general follow-up at every three months and, for ophthalmologic consultation, at every six months. When the child needs that a global stimulation be carried out by specialised institutions for the visually impaired, referral is made, preferably, to institutions already existent in the city where the child lives in. When needed, specific orientation on visual stimulation is provided to health professionals of these institutions, by mail or telephone call, in charge of the occupational therapist of the service.

Taking into account the occupational therapist's role in the care of visually impaired children, the present paper aimed at surveying: the child's age at the first ophthalmologic consultation; the person responsible for identifying the problem; the mothers' knowledge on the vision impairment of her child; and, the child's age at the beginning of the vision stimulation. It is hoped that this information will help subside propositions of intervention in the above mentioned university service, aiming at its improvement.

MATERIAL AND METHODS

This study was carried out following a descriptive survey pattern. The target population comprehended mothers of visually impaired children with ages varying from birth to 4 years, coming from different regions of Brazil, being attended to at the Low Vision Service of the State University of Campinas Clinic Hospital.

A non-probabilistic convenience sample, size-25, was composed following the criteria of data collection availability and easy access of the users who were being attended to by the service, in the period from February to May, 1997. The sample included only mothers of visually impaired children whose impairments had already been diagnosed.

Previously to the present survey, at the planning phase, an exploratory study was carried out interviewing 15 mothers of visually impaired children—who were being attended to in the service—aiming at producing a questionnaire that would be adequate to the reality to be studied. These interviews were recorded, by previous consent, and transcribed afterwards. They provided important information on the mother's language and repertory, making it possible for the Authors to have a good grasp of the sociocultural context of these families.

During this exploratory stage, the need for altering the technical terminology of the questions to the daily vocabulary of the families became obvious. The mothers displayed great difficulty in understanding terms such as diagnosis, ophthalmologist doctor, congenital disease and, others. After the needed alterations in the composition of the questions had been proceeded, a structured questionnaire was produced, based on the information gathered.

This questionnaire was submitted to a pre-test, being applied to 10 mothers of visually impaired children who were being attended to in the service. It is worth explaining that these mothers were not part of the present study sample.

Analysing the results of the pre-test, the conclusion was that no changes in the questions would be necessary. The questionnaire comprehended 25 questions. The present paper is based on the following ones:

- Sex of the child attended to in the infant division of the Low-Vision Service.
- Age of the child attended to in the infant division of the Low-Vision Service.
- Age of the child when the vision problem was perceived.
- Who first perceived the vision problem of the child.
- Age of the child when taken to the ophthalmologist for the first time.
- Age of the child when attended to in the Low-Vision Stimulation Service for the first time.
- Knowledge of the mother regarding the technical terminology concerning the child's vision problem.

The questionnaire data were processed using the EPI-INFO program, version 6.0 (DEAN and coll., 1994).

RESULTS AND DISCUSSION

Just from the first weeks of life, the infant has in the vision his main source of information about his surrounding world. Provided this source is either deficient or absent, the child must build his world with information obtained from the remaining senses - hearing, touch, kinesthesia, smell and, taste (HYVARINEN, 1988).

A child is not born ready and finished. On the contrary, his development is accomplished through a slow, continuous and orderly process. When a child is born, he has the ability to become a receptive, participant and interacting human being in relation to the environment that surrounds him. It seems that the potentiality of a child to grow and develop depends on the presence of dedicate adults and a stimulating environment (SHEPHER, 1996).

The present study surveyed some personal characteristics of the children who compound the sample. According to Table 1, in the variable sex, a somewhat equivalence between the sexes can be observed. As to the variable age, it can be seen that 44.0% of the sample presented ages up to 2 years. Taking into account the nature of the service offered (low-vision stimulation), it is hoped that children with this kind of impairment receive specialised care early on their lives. And, indeed, approximately half of the children of this study were referred to this service up to the age of 2.

Taking into account data on Table 2, it can be noticed that the ophthalmologist—who theoretically should be playing an important role in the diagnosis and referral of visually impaired children to a low-vision stimulation service—had little or none influence in the early detection of the vision problem that, in general, was made by relatives (28.0%) and, mainly, by the mother (48.0%). The frequency zero (0) indicated for the ophthalmologist doctor, in Table 2, might be attributed to the fact that mothers do not usually take their babies to an ophthalmologist when there is suspicion of a vision impairment; they take them, ordinarily, to a pediatrician.

If both detection and diagnosis of a vision problem are to be accomplished early in life, it is necessary that family and health personnel have access to a specific kind of knowledge. Therefore, the family of a visually impaired child should be provided with technical-pedagogic and psychological support, integrated to the sociocultural environment, in order to become fully aware of the child's vision problem and its implying future consequences and, this way, be better prepared to accept and participate of the rehabilitation task.

Daily routine experience with rehabilitation attendance has been pointing out that when this does not occur what happens is a series of mutual accusations, incomprehension and even rupture of the family bonds. The impact of discovering that her baby was born with vision impairment might cause a disruption in the

initial stages of development of the special bond that usually occurs between mother and child for interfering with the mother's reaction, which might cause a greater damage than the impairment itself. Shock, frustration, commiseration and a sense of guilty have a profound influence on the mother's attitude towards her baby and on the mother-child interaction, being responsible for failures in the construction of a healthy bond and disintegration of the family dynamics and relationship. (BRUNO, 1993).

The lack of opportunity for discussing the diagnosis of their visually impaired baby is likely to give rise to a situation in which the parents feel themselves completely overwhelmed and unable to evaluate the reality of their child's impairment. Providing the grieving period crystallises, becoming something permanent within the family, the ghost of the desired, anticipated and, healthy baby will continue to interfere with the family's adaptation to the impaired child. (MILLER, 1995).

The availability of the pediatrician during the first years of a child puts him in a unique position as the best choice of a professional to help the family dealing with this kind of problem. (KLAUS & KENNEL, 1992).

The early perception of the vision problem of the child by non-ophthalmologist doctors shows the important role played by the pediatrician in the early diagnosis of the case. (see Table 2).

KARA-JOSE and coll. (1984) recommend that pediatricians should be made aware of the fundamental role that they can and must play in preventing and referring vision impairment. Being the first health professional to enter in contact with the child and his family, he is a key element in the building-up of a preventive mentality in ophthalmology. This same author, in a work carried out in 1980, had already reported that data observed in his research indicated that the pediatrician should be the professional in the best position to provide mothers with orientation and support in such a delicate moment as that of discovering and disclosing to the family the diagnosis of this severe type of vision impairment.

Through the family history, it can be observed that the responsibility for child bearing falls almost entirely on the mother's side; she is in charge of the greatest part of the child's care. (GOMES, 1992).

Taking into account Table 3, the early detection of vision impairment seems to depend, in general, on the mothers, since 84.0% of the visually impaired children were in the age group up to 6 months when it occurred.

As it was observed during the exploratory phase of this survey, the mothers displayed great difficulty in understanding technical terminology. Having no knowledge on the diagnosis nor on the prognosis, it becomes difficult for them to take an active part in the visual rehabilitation process of their child.

Data on Table 5 indicate that, from the 18 mothers of the sample, 7 did not know how to inform the type of vision impairment of their child; 11 (60.9%) indicated incorrectly the type of vision impairment of their child; and, only 7 (39.1%) knew how to indicate correctly the vision impairment of their child. These data bear great importance, since an enlightened mother is able to play a decisive role in the vision stimulation process of her child.

Low-vision children present difficulties concerning their global, psico-social and emotional development, which brings a series of implications for the teaching-learning situation. According to JAN, SIKANDA & GROENVELD (1990), low-vision affects all the areas of infant development that are associate with abilities mediated by vision.

Depending on the degree of impairment, the visual deficiency of a child might be verified either soon after birth, at pre-school age, or while attending elementary school. The untimely discovery of the vision impairment puts the child at risk of not being understood or not being sufficiently stimulated.

CARVALHO (1993), in a research carried out in the period from 1982 to 1991, at the same place the present survey was developed, reports that from the 836 cases attended to at the Low-Vision Service 46.0% aged less than 1 year when came to the LVS for the first time, suggesting an earlier detection of vision impairment when compared with data of the presented study.

Blindness in infancy is particularly important, being it by the indices with which it presents itself in developing countries, being it by representing one more aggravating socio-economic burden. (TEMPORINI, 1984). There is a common agreement among

specialists as to the importance vision assumes, since birth, in the learning process as well as to the need for discovery as well as treatment of ocular disorders being made early in life as a way of minimising or even solving such problems. (KARA-JOSÉ & TEMPORINI, 1980).

Socio-economical status is likely to become one more aggravating factor in this already serious problem. Therefore, if on one hand these children are not totally blind to be entitled to the assistance provided by social and rehabilitation services, on the other hand they are not well-sighted enough to lead a normal life.

In this sense, national programs for the blind should create new services for attending the visually impaired population. In developing countries, the already meager resources assigned to the health area should attend multiple and different priorities, not always privileging programs of a preventive character.

On Table 3, in the item related to the child's age at the first ophthalmologic consultation, it can be observed that 20 children were in the age group from 1 day to 6 months. Therefore, one is entitled to say that from the 21 children whose visual impairment had been detected up to the age of 6 months, only one have not had his first consultation at this age.

Programs focusing healthy practices in ophthalmology and blindness prevention at schools have been identifying children with vision impairments (TEMPORINI, 1980). These kinds of campaigns are helpful in making the population, professionals of public and private school networks and medical doctors, in general, aware of the importance of the early referral of visually impaired children to low-vision stimulation services. However, a very serious vision impairment is, in general, already installed before the first year of life. Therefore, if it is detected only at school age, it would be too late for any preventive procedure worth being taken, since the impairment would have already caused damages in the child development.

According to VEITZMAN (1992), early diagnosis and adequate medical treatment assume capital importance in the care of visually impaired children. The delay in referring children either with amblyopia or strabismus to specialised treatment puts their visual prognosis in jeopardy. Therefore, eye examination should play an important role in the general control of the schoolchildren's health. (MACCHIAVERNI FILHO and coll., 1979).

Total or partial lack of vision is likely to interfere with motor skills, fundamental for the process of a child's independence. The first months of life are crucial for the development of vision. LEAL and coll. (1995) emphasise that visual experiences are more copious and detailed than the ones provided by the other senses.

On Table 3, it can be seen that 21 cases of vision impairment (84.0%) were discovered up to the age of 6 months. On Table 4, in this same age group, only 8 cases (50.0%) came for specific attendance at the Low-Vision Stimulation Service. These results might possibly be put on account of a lack of referral on the part of either ophthalmologists or pediatricians.

GREENBLATT (1988), in a study on the interaction between ophthalmologists and visually impaired persons, disclosed that besides the reduced number of referrals to vision rehabilitation services, on the part of ophthalmologists, many of them had no knowledge on the existence of this kind of service in their own community. Once regularly informed about the types of attendance provided by these institutions, there was an increase in the number of referrals. He also emphasised that in the measure in which procedures to get the ophthalmologists more conscious of the importance of an early referral of these cases were taken, more children would benefit from this kind of service.

Therefore, the ophthalmologist's role is decisive for the child's future. The family might not search for a vision rehabilitation service if it were not suggested by the ophthalmologist in a clear and emphatic way. Data on Tables 3 and 4 show that although both detection of the vision impairment and first ophthalmologic consultation had occurred early, only 50.0% of the children whose mothers provided information had their initial attendance at the Low-Vision Stimulation Service within their first 6 months of life. These results are surprising, if one takes into account that this is a well-known service and one professionally respected within the medical community.

Analysing Table 5, it can be seen that the mothers attribute different names to the vision problem of their child. From the 25 mothers of the sample, 18 (72.0%) stated remembering the name attributed to the vision impairment of their child. However, from these 18 mothers, only 7 (39.1%) did give the correct name. Although not cognisant of the correct meaning of technical terminology such as diagnosis, congenital disease, or pathology, the mothers display interest in relation to the vision

impairment of their child, taking in view that, in the majority of the cases, the mother is the person who first identifies the problem (Table 2).

It was observed that the mothers of the visually impaired children who compound the study sample are lay in the matter and probably present difficulties in understanding technical terminology. Frequently, lay-persons consider professional terminology –even when they understand it– as something stigmatising and threatening. (TELFORD & SAWREY, 1976).

The difficulty of mothers in understanding the correct name attributed to the vision impairment of their child emphasises the importance of the ophthalmologist's role in providing the families a clear orientation concerning his diagnosis of their child's vision impairment.

CONCLUSIONS

Taking in view the results observed in the sample studied, the following conclusions can be drawn:

- The sample was composed of 25 mothers of visually impaired children with an average age of 24 months, indicating a somewhat equivalence between the sexes.
- In general, the child's vision impairment was first perceived by the mother, occurring within the first 6 months of life.
- The first ophthalmologic consultation also happened within the first 6 months of life; however, the stimulation attendance at the Low-Vision Stimulation Service was started, in the majority of the cases, during the first year of life.
- Some familiarity of the mothers with the technical terminology could be observed, although incorrectly employed.

The evinced facts suggest the need for a more active participation of ophthalmologists along with the visually impaired children's family, contributing for the early referral and attendance of these cases.

Table 1.

Personal characteristics of the visually impaired children attended to at the Low-Vision Stimulation Service.

n = 25

Characteristics	<i>f</i>	%
Sex male	14	56.0
Sex female	11	44.0
Age (months)		
1 day - 12	4	16.0
13 - 24	7	28.0
25 - 36	5	20.0
37 - 48	6	24.0
≥ 49	3	12.0

Table 2.

Person who first perceived the vision problem of the child attended to at the Low-Vision Stimulation Service.

n = 25

Person	<i>f</i>	%
Mother	12	48.0
Other family members	7	28.0
Ophthalmologist doctor	-	-
Other Medical Specialists	6	24.0

Table 3.

Perception of mothers of visually impaired children attended to at the Low-Vision Stimulation Service concerning their child's age when his vision impairment was detected and at the first ophthalmologic consultation.

n = 25

Age (months)	<i>f</i>	%
Detection		
1 day - 6	21	84.0
7 - 12	3	12.0
≥ 13	1	4.0
First Consultation		
1 day - 6	20	80.0
7 - 12	3	12.0
≥ 13	2	8.0

Table 4.

Age of visually impaired children at their first attendance at the
Low Vision Stimulation Service.

n = 16*

Age (months)	f	%
Up to 6 months	8	50,0
7 - 12	6	37,5
> 13	2	12,5

* From 25 mothers, 9 did not know how to inform.

Table 5.

Correct and incorrect use, on the part of mothers, of technical terminology
indicating the vision impairment of their child.

n=18*

Denomination Attributed	Correct		Wrong	
	f	%	f	%
Strabismus	1	5,5	3	16,5
Congenital Cataract	2	11,2	1	5,5
Albinism	2	11,2	-	-
Detachment of retina	-	-	2	11,2
Malformation of the eye	2	11,2	-	-
Congenital Toxoplasmosis	-	-	2	11,2
Atrophy of the eye	-	-	1	5,5
Nystagmus	-	-	1	5,5
Eye lesions	-	-	1	5,5

* From the 25 mothers, 7 did not know how to inform.


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Digitopuntura



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