The impact of early intervention on a child with vision loss in infancy - A parental perspective

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Purpose: To assess the impact of early intervention services provided to children with visual loss and to report how parents perceive them in terms of a child’s development and the family dynamics.

Methods: A qualitative descriptive study was conducted on a purposively selected sample of 15 children with severe visual impairment, availing early intervention services at a tertiary care facility in Pune, Maharashtra. Data were collected by conducting in-depth interviews of the parents with the help of a semi-structured interview topic guide. Participants were asked in detail about how and whether various components of the early intervention program (EIP) had an impact on their child. The interviews were audio-recorded, transcribed, and translated into English, and the resultant textual data were analyzed using the qualitative research software NVIVO 12 to identify themes and sub-themes under each domain.

Results: A total of 15 children were included in the study, with ages ranging from 13 months to 5 years. All the children included in the study suffered from severe visual impairment in infancy (Vision 3/60 – PL). In the course of this EIP, the majority of the children showed consistent progress in various aspects of child development. According to the parents, the most beneficial components of EIP were visual stimulation exercises, an improvised teaching methodology, and counselling services. Conclusion: Almost all the parents included in the study reported a positive change in the behavior and development of the child as well as improved family dynamics after implementation of EIP.

Key words: Early intervention, infant, parental perspective, visual loss

According to the estimates released by the World Health Organization in 2006, there are 19 million children under the age of 15 with some form of visual impairment (VI), and out of these, 1.4 million are blind.[1,2]

Two thirds of these children live in developing countries of Asia and Africa. India alone accounts for almost 200,000 of them. Although the number of blind children is relatively low, they have a lifetime blindness ahead of them.[3] Considering the average life expectancy of 70 years,[4] the estimated number of ‘blind years’ for these 200,000 children is second only to cataract. Childhood blindness thus has profound human and socio-economic consequences in our society.[5]

Studies have shown that the key sense for learning and the primary source for sensory information input is vision, and the majority of a child’s early learning is gained through this sense.[6]

Thus, these visually impaired infants develop serious cognitive, physical, and social challenges because of their limited sensory development.[6,7] This can lead to emotional, social isolation, and behavioral issues if they do not receive optimal rehabilitation in their early formative years.[6,9]

Although the importance of early intervention programs for visually impaired young children is widely recognized, there is a lack of evidence about the real-world benefits of these programs.[10]

India harbors the largest number of children with visual loss (VI) in the world, and thus, logically, the need for early intervention (EI) services is high. However, not many such programs and services are currently available. Wherever such programs are available, it is difficult to judge their adequacy because the benefit/satisfaction is a vague construct, difficult to define and measure, and varies from person to person. Thus, quantitative data alone cannot uncover the finer aspects of the adequacy or benefits of such a program.

This qualitative study was undertaken to uncover the real-world impact of the EI services and analyze the shortcomings to strengthen the services wherever possible. To the best of the authors’ knowledge, this is the first such study being reported from India.

Methods

This study was undertaken for a period of 1 year from December 2018 to December 2019 in a tertiary eye care center in Pune, having a dedicated pediatric eye care department and an early intervention center (EIC) that caters to a large number
of children with various eye diseases. Prior approval from the Institutional Ethics committee and written informed consent from the participants were obtained. The study adhered to the Helsinki protocol.

An interview topic guide (ITG) form was developed and pre-tested by the authors based on the related literature. It included demographic information and other information such as the patient’s diagnosis, number of siblings, socio-economic conditions, and so on to understand various factors that could affect a visually impaired child’s development.

The study sample was acquired from existing records of the EIC, and children with severe visual impairment, who had enrolled in the EIP during infancy and had completed at least 6 months of follow-up in the program, were selected. Purposive sampling was performed to provide the maximum variation in the study sample. Children of various ages, both genders, with various causes of visual impairment from both urban and rural families were included [Table 1].

The primary caregivers/parents were contacted on phone and were explained the nature of the study. Of the total 21 parents who were contacted, 15 consented to be included in the study.

Face-to-face interviews were conducted by the principle researcher who was not in any way involved with the implementation of the EIP to avoid problems such as positive response bias.

All the interviews were audio-recorded, ensuring complete confidentiality and privacy of the interviewee. The participants were asked open-ended questions with the interviewer being an active listener, without prompting or passing comments. An experienced EI counsellor was present to write any specific observations (participants’ body languages/emotional reactions) and to provide support if needed.

Qualitative research software (NVIVO 12, QSR International, Australia) was used as a data management tool to perform analysis and to identify themes and sub-themes emerging out of the collected data.

The recorded interviews in the local languages (Marathi/Hindi) were then transcribed and translated to English. Two experienced researchers checked translation to ensure its validity. Each theme, sub-theme, and verbatim quote was coded so as to make it possible to track it to the original interview.

### Results

#### Demographic data

Fifteen children were included in the study, with ages ranging from 13 months to 5 years and a mean age of 2.8 years, with five females (33%) and ten males (66%). Children having a minimum 6 months period of follow-up in the EIC were included in the study. The follow-up period ranged from 6 months to 3 years.

The age at the time of diagnosis ranged from 1 month to 1 year. Of the 15 children, ten were born pre-term. Nine children (60%) had a sibling, and six (40%) were an “only child”. Two parents reported having twin pregnancies. Two children had an additional disability (cerebral palsy).

In the majority of the cases (n = 14), the mother was the primary caregiver. All the mothers in this study had a basic high school education, and 80% had college degrees. In spite of this, they were stay-at-home moms.

According to the Modified Kuppuswamy Classification with a revised income group based on (AICPI), the majority of the families belonged to the lower-middle socio-economic class (n=7). Five belonged to the middle to upper class, whereas three belonged to lower-income classes.

#### Experience around the time of diagnosis and enrolment in EIP

Most parents reported that they found out about their child’s VI within the first few months of birth from the medical staff. They were counseled about the condition and the likely prognosis.

“IT (the diagnosis) came as a shock. By the time she was 6 weeks old, she had to undergo eye surgery.” (3 Y/female, ROP)

Most (10/15, i.e., 66%) parents reported that counseling by the EIP staff helped them accept their child’s condition and that their doubts were discussed in a satisfactory manner.

#### Parental acceptance of the condition

Most parents said that although the diagnosis came as a shock, the counseling services helped them accept the situation and empowered them to tackle it strongly.

Two parents rightly pointed out that delay in acceptance of the situation leads to loss of valuable time. Getting timely advice helped them immensely in tackling this difficult situation at the right time.

“Now I know that accepting this about your child at the earliest is the best thing that you can do for them. It’s important to give the right treatment at the right time. I don’t want her to suffer by even 1 percent because of my delay.” (Mother of 13 months/F with cerebral visual impairment. The mother herself is wheelchair-bound because of paralytic polio.)

#### Milestones achieved

Out of the 15 children, mothers of eight reported that their child had achieved age-appropriate milestones.

“YES she can do all those things, she also recognizes all objects by touch.” (3.5 Y/female with ROP).

### Table 1: Participant details

| Mean age of children | 2.8 Years (range - 13 m to 5 years) |
|----------------------|------------------------------------|
| Gender               |                                    |
| Females             | 5 (33.33%)                         |
| Males               | 10 (66.66%)                        |
| Visual impairment   |                                    |
| Total visual impairment (no pl) | 2 (13.33%)                     |
| Only light perception | 1 (6.66%)                         |
| Partial visual impairment (pl to 3/60) | 13 (86.66%)                    |
| Cause of visual impairment |                                |
| Retinal causes      | 8                                  |
| Cortical visual impairment | 4                                |
| Whole globe anomalies | 2                                |
| Unknown etiology    | 1                                  |
Four children had achieved age-appropriate milestones but lagged in some areas of development. Three children however were noted to have delayed gross motor functions and delayed crawling and walking, but improvement was noted after initiation of physiotherapy.

Navigation and maneuvering
All the mothers except for two reported that their children could navigate comfortably in the house without help. This was because of mobility training.

“Yes she can, if there is any hurdle in the way she removes it, or goes around it. Earlier she would bump into them, but now her walking has improved a lot.” (13 M/female with cerebral visual impairment.).

Child’s journey toward independence
Parents reported positive changes in their child such as increased interest in going out, increased interaction with other children and people, and interest in learning about new things. A few parents recalled certain anecdotes.

A mother of a 3.5 Y/female child with ROP told us

“She is able to recognize many objects now! Her toys, Mamma’s things, if I ask her to get something from the other room she goes and gets it.”

Another mother recounted,

“Now he wants to do all his work such as packing his school bag etc., by himself. He refuses any help (4Y/male with ROP).

Improvement in troubled relationships
Two mothers reported separation from their husband as a direct result of having a visually disabled child. However, after the enrollment in the EIP, positive changes were noted in the child and the husbands re-united with them.

“Things were difficult, it took us a lot of time, we underwent counselling as well. But now that she is able to do certain things like normal children, he has started taking interest in her again. We are living together again.” (Mother of a 3.5 Y/female with ROP).

Most helpful aspects of early intervention
The majority of the parents said that visual stimulation exercises were the most useful service for them, followed by advice regarding special teaching methods such as touch and sound, mobility training, dietary advice, referral services, family counseling, and advice regarding schooling.

“Letting him hold and feel objects and then telling him the names, that has helped us a lot in teaching him things.”

Thoughts about the future
Most parents believed that their children could have a meaningful life ahead. Many of them mentioned that enrollment in the EIP and interaction with other visually impaired working adults during support group meets have helped them gain confidence about their child’s future.

“There are so many examples of people we met here, who are visually impaired yet self-sufficient, at least my daughter can see a little bit. I feel that she can do something meaningful with her life.” (5Y/female with ROP).

Access to the services
Some parents reported that traveling from distant places led to financial strain.

“We come from a village which is 250 km from Pune. It’s difficult for us to spend over 1000 rupees every month just to reach here.” (3.5 Y/male with unknown etiology for VI).

Overall benefits of early intervention
All the parents included in the study said that EI has been beneficial to them and their children.

“Ever since we have started the therapy there is a lot of difference in her. I can feel it myself that she is becoming more and more like other ‘normal’ kids. (5 Y/female with ROP).

Some parents however suggested that they could benefit more from home visits, whereas some suggested a more integrated approach such as in-house referrals for physiotherapy, speech therapy, and neurological and psychological counseling.

Discussion
It is established that the majority of the early learning takes place by the visual sense.[4] These early experiences play a crucial role in the child’s overall development and quality of life. Loss of vision in early infancy can have a profound negative impact not only on a child’s development but also on the family finances and relationships.[10] Early intervention programs can minimize such challenges.[10] However, to the best of authors’ knowledge, there has been no report of whether EIP services indeed help a child. Hence, we conducted this research to report the parent’s perception of the effectiveness of early intervention programs in the life of a child with visual impairment.

In a study conducted in Maharashtra,[17] it was reported that most health care professionals were not aware of the components of the rehabilitation program and felt inadequately prepared to counsel or refer parents to EIP.

The EI program is generally designed to deliver a variety of diagnostic, therapeutic, and supportive services to visually impaired children and their families. It includes assessment and planning, family education and counseling, vision stimulation techniques, speech therapy and audiology, physical therapy, occupational therapy, orientation and mobility practices, referral services, play groups, camps, home visits, nursing services, and parent support groups. Each of the above components may not be required for every child or may be required at different ages.

All the children enrolled in our EIC were given visual stimulation exercises. These comprised showing bright-colored patterns, illuminated checkerboards, and illuminated objects such as toys fitted with light-emitting diodes. These techniques were taught to parents, so they could be easily continued at home. Mothers, who were the primary caregivers in most cases, were asked to wear bright-colored clothes and large bindis when possible to stimulate the children’s vision.

Specialized teaching methods were taught to the parents, which comprise letting a child touch, feel, or smell an object first and then naming it. This helps visually impaired children recognize everyday objects.

Our EIC counselors have been trained for basic grief and family counseling. Parental counseling was the first and
foremost service provided to the parents upon enrollment of the child in the EIC. Following this, assessment of the child’s overall condition was performed, vision was recorded, any associated disabilities were noted, and a follow-up plan was prepared.

Children noted to have associated conditions/disabilities were referred appropriately. Thus, other aspects of EI such as speech therapy, mobility training, developmental delay, associated syndromes, and so on were addressed by appropriate referral to audiologists, physiotherapists, neurologists, and pediatricians. Parent support groups were formed as well.

In the present study, over two thirds of the children included were born pre-maturely. The association between pre-maturity and visual impairment has been well established. The infant mortality rate has been on the decline in India, and this may mean an increasing number of pre-mature children with visual challenges.

The majority of the parents referred to EIC from outside were sent by their pediatricians or local ophthalmologists. Almost all of them reported being emotionally distraught upon finding out about the child’s VI, but timely counseling helped them to deal with this fact. Allowing them to grieve and then slowly helping them each step of the way is what ensures their active participation and compliance.

Most parents noted that their children became more active and involved in their surroundings after enrollment in EIC. These responses suggest that increasing interaction with these children; exposing them to different stimuli, situations, and environments; and specialized teaching methods can help them get out of their shell and develop their own individual personalities.

Teaching day-to-day things to a visually impaired child is a grueling task, so the advice regarding specialized teaching methods definitely helped them become more confident as parents.

Similarly, the role of neuroplasticity in vision development during early childhood is critical. Vision stimulation exercises can enhance vision if performed within the first 4–5 years of life.

Many said that visual stimulation exercises and specialized teaching methods were the most important aspects of the EIP. Other services they found useful were counseling services, referrals and schooling, and dietary advice.

The Government of India’s policy promotes inclusive education. However, the lack of awareness on the part of parents and shortage of special facilitiespose a barrier for the schooling of these children. Most parents in the present study reported that the guidance regarding education was very helpful for them.

The ministry of family welfare and health has conceptualized and is in the process of establishing a network of district early intervention centers (DEIC) for such young children with various disabilities. The sooner this network expands, the better it will be for the children located in remote rural areas. Until then, potential solutions could be mobile vans, special transport services, and home visits by trained community health workers. Home services can enable observation of these children in their natural environment, making adaptations and modifications appropriate for children and the family characteristics.

As far as financial impact was concerned, almost half of the parents confided having financial strain. Long-term care means regular expenses for a family already drained of resources because of expenditure on investigations, surgeries, and hospitalizations during the course of treatment. Loss of a potential earning member (mother) in order to care for a child with visual disability further compounds this problem.

Having a child with any kind of disability is a hard fact to digest. Understandably, all the parents said that they had a difficult time coping with it. The right kind of advice from the EIC and timely counseling gave them encouragement and hope. This sense of empowerment of parents holds the key to a successful journey of a child with disability.

None of the parents reported any negative aspects of the EIP. The majority of the parents were satisfied with the current EI services.

There are certain limitations of this study. Lived experiences of the children with VI could not be captured because of the fact these children could not articulate. A comparative study between children who received and those who did not receive EI services could help document the differences between these two groups in a precise manner. Certain variations in outcome in terms of level of efficacy were noted. These could be because of variability of compliance with the program, other associated disabilities, and differences in severity of visual impairment.

Our job as an ophthalmologist usually ends with the diagnosis “Nil visual prognosis”. The life of that young child however begins from that moment on. All children with severe visual impairment are candidates for EI services and should be referred at the earliest age. No child is too small if he/she is otherwise medically stable. If established EI centers are unavailable, the primary ophthalmologists could refer these children to pediatric ophthalmology clinics. An assessment of associated disabilities, such as mobility, speech and hearing impairment, delayed milestones, and any other health conditions, should be performed, and appropriate referrals should be provided.

Conclusion
In conclusion, EIP does help these children and their families overcome the challenges associated with early VI. It can empower them to shape their child’s future in a positive manner.

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Conflicts of interest
There are no conflicts of interest.

References
1. Resnikoff S, Pascolini D, Etya’Ale D, Kocur I, Pararajasegaram R, Pokharel GP, et al. Global data on visual impairment in the year 2002. Bull World Health Organ 2004;82:844-51.
2. World Health Organization. Global Initiative for the Elimination of Avoidable Blindness: Action plan 2006-2011. Available from: http://www.who.int/blindness/Vision2020_report.pdf.
3. Frick KD, Foster A. The magnitude and cost of global blindness: An increasing problem that can be alleviated. Am J Ophthalmol 2003;135:471-6.

4. Riley JC. Estimates of regional and global life expectancy, 1800–2001. Popul Dev Rev 2005;31:537-43.

5. Kulkarni S, Gilbert C, Zuurmond M, Agashe S, Deshpande M. Blinding retinopathy of prematurity in Western India: Characteristics of children, reasons for late presentation and impact on families. Indian Pediatr 2018;55:665-70.

6. Thompson SD, Merino S. Visual Impairments in Young Children: Fundamentals of and Strategies for Enhancing Development. Young Exceptional Children. 2018;21:157-69.

7. Dulay MF, Murphy C. Olfactory acuity and cognitive function converge in older adulthood: Support for the common cause hypothesis. Psychol Aging 2002;17:392-404.

8. Murphy JL, Hatton D, Erickson KA. Exploring the early literacy practices of teachers of infants, toddlers, and preschoolers with visual impairments. J Vis Impair Blind 2008;102:133-46.

9. Anthony TL. Family support and early intervention services for the youngest children with visual impairments. J Vis Impair Blind 2014;108:514-9.

10. Sahin C. Increasing the effectiveness of early intervention practices for young children with visual impairment. Int J Learn Dev 2017;7:30-43.

11. Gutek BA. Strategies for studying client satisfaction. J Soc Issues 1978;54:44-56.

12. Gay LR, Mills GE, Airasian PW. Educational Research: Competencies for Analysis and Application. Columbus, OH: Merrill; 1976.

13. Bailey D, Scarborough A, Hebbeler K. Families’ First Experiences with Early Intervention: National Early Intervention Longitudinal Study. NEILS Data Report. 2003.

14. Mitchell-DiCenso A, Guyatt G, Paes B, Blatz S, Kirpalani H, Fryers M, et al. A new measure of parent satisfaction with medical care provided in the neonatal intensive care unit. J Clin Epidemiol 1996;49:313-8.

15. Burton CB, Hains AH, Hanline MF, McLean M, McCormick K. Early childhood intervention and education: The urgency of professional unification. Topics Early Child Spec Educ 1992;11:53-69.

16. Konstantina N, Eleni F, Evangelos K, Paraskevi G, Vasilis T, Maria S. Parental satisfaction with early intervention services for children with visual impairments and multiple disabilities in Greece. J Phys Educ Sport 2014;14:60-5.

17. Kulkarni S, Gilbert C, Kakade N, Dole K, Deshapnde M, Azad R. Habilitation services for children blind from retinopathy of prematurity: Health care professionals’ perspective in Maharashtra. Indian J Ophthalmol 2019;67:928-31.

18. Leung MP, Thompson B, Black J, Dai S, Alsweiler JM. The effects of preterm birth on visual development. Clin Exp Optom 2018;101:4-12.

19. Nagarajan S, Paul VK, Yadav N, Gupta S. The National Rural Health Mission in India: Its impact on maternal, neonatal, and infant mortality. Semin Fetal Neonatal Med 2015;20:315-20.

20. Tailor VK, Schwarzkopf DS, Dahlmann-Noor AH. Neuroplasticity and amblyopia: Vision at the balance point. Curr Opin Neurol 2017;30:74-83.

21. AQ3. Singh JD. Inclusive education in India- concept, need and challenges. International Journal of Social Sciences and Management Studies (IJSSMS).2016;3:3222.

22. Kar A, Radhakrishnan B, Girase T, Ujagare D, Patil A. Community-based screening and early intervention for birth defects and developmental disabilities: lessons from the RBSK programme in India. Disability, CBR & Inclusive Development 2020;31:30-46.