Function and Disability Journal ISSN: 2588-6304
Original Article

Evaluation of Vision Behaviors in Children with Cortical Visual Impairment Due to Cerebral Palsy (CP)

Fatemeh Riazi[1,2], Abbas Riazi[3*] , Hassan Sori[2,4]

1. *MSc Candidate in Optometry, Department of Optometry, Iran University of Medical Sciences, Tehran, Iran*
2. *The low vision research center, Rehabilitation faculty, Iran University of Medical Sciences, Tehran, Iran*
3. *PhD, Senior Lecturer, Department of Ophthalmology, School of Medicine, Baqiyatollah University of Medical Sciences, Tehran, Iran*
4. *MSc. Lecturer, Department of Optometry, Iran University of Medical Sciences, Tehran, Iran*

Article Info

Received: 2018/07/01
Accepted: 2018/08/13
Published Online: 2018/10/29

DOI:
10.30699/fdisj.01.2.47

How to Cite This Article

Riazi F, Riazi A, Sori H. Evaluation of vision behaviors in children with cortical visual impairment due to cerebral palsy (cp). Function and Disability Journal 2018. Vol:No2:pages: 47-56

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ABSTRACT

Background and Objective: Cortical Vision Impairment in children is one of the visual disturbances which are occurring due to brain disorders. There are not eye disorders as usual. It has been shown that the image processing in the brain has been affected. Among brain disorders, cerebral palsy (CP) is one of those disorders that leads to at least two third of cortical blindness among these patients.

Observation of the vision behaviors is an appropriate way to evaluate the amount of vision as well as provide low vision rehabilitation.

Method: vision behaviors were evaluated by interview with parents of children under 15 years old. Consent was achieved before interview and participants were informed well about the process. Attendance of one of parents was enough to run the interview preferably mother. Semi-structured individual interview was used to discover vision behaviors of children in daily life. The interview was recorded then transcribed verbatim into text word for thematic analysis.

Results: 22 parents of 18 children with CP participated in this study. (Mean age 37.4±2.51). Parents did not have enough information to deal with their children. They needed special education. Rehabilitation programs from occupational therapists were very effective. The most effective one was physical rehabilitation. There are very significant behaviors which were common among children. This behavior is not being observed among visually impaired children with ocular causes.

Conclusion: Parents do not have much concern about vision of their children. They believe physical rehabilitation is much important than vision rehabilitation. Parents need more education to participate in rehabilitation programs for these children.

Keywords: Cerebral palsy, Cortical vision impairment, Vision behaviors, Vision rehabilitation.

Corresponding information: Abbas Riazi, Department of Ophtalmology,School of Medicine, Baqiyatollah University of Medical Sciences ,Tehran, Iran. Email: Abbas.Riazi@gmail.com Tel:+98-21-82162478

Introduction

Reducing visual acuity during childhood has very severe effects on the development of the child. (Schenk-Rootlieb, van Nieuwenhuizen, van Waes, & van der Graaf, 1994). Also it has side effect in terms of economic for family, and country (Meads & Hyde, 2003; Rahi & Cable, 2003). Many factors during childhood cause blindness and poor vision. The most common causes are neonatal retinopathy, cataract, nystagmus, optic atrophy and cortical blindness (Flanagan, Jackson, & Hill, 2003).

Cortical Visual Impairment (CVI) occurs when the brain is injured. The term of CVI is used when the child does not behave from his own eyes although his eyes are healthy and natural. Meanwhile, Magnetic Resonance Imaging (MRI) results show brain abnor-

malities, especially in the cerebral cortex and optic radiations. The naming of these types of visual impairment is still debatable and there is no general consensus (Boot, Pel, van der Steen, & Evenhuis, 2010; Fazzi, et al., 2004). Therefore visual impairment is related to the processing of image information in different parts of the brain at the visual pathways after chiasma (Boot, et al., 2010) . CVI is produced due to malfunction of visual pathway in different parts of the brain such as optic radiation, LGB and occipital cortex. (Lehman S. S, 2011). There is difficulty in coordination between eye- hand as well as eye -foot, body awareness and balance. Visual therapy may be effective on their oculomotor system. The most common cause of motor impairment among children is cerebral palsy (Chokron S, 2016; Coetzee D., 2003). Children with cerebral palsy usually suffer from abnormalities in their motor function. They have developmental impairment in movement, vision and posture. They have problems in their perception, communication behaviors and cognition (Beckung E, 2002).

In developed countries, these blind children have other disabilities as well. This condition is on the rise (Nielsen, Skov, & Jensen, 2007; Rahi & Cable, 2003; Swaminathan, 2011; van den Broek, Janssen, van Ramshorst, & Deen, 2006). Over the past 20 years, there has been no consensus on the diagnosis of CVI, and has always been discussed. However, teachers of low vision and blind children have had successful experiences in rehabilitating these types of children and have been able to devise specialized methods for teaching these children. With increasing health facilities, the percentage of children's survival with brain disorders has increased. (Catriona, et al., 2010) The chance of survival of children with cerebral palsy has increased the percentage of children with CVI (Catriona, et al., 2010) . In developed countries, severe visual impairment in children under the age of 16 is 10 - 22 per 10,000. This figure in developing countries is 40 per 10,000 births (Gilbert, Anderton, Dandona, & Foster, 1999). Two-thirds of children with Cerebral Palsy (CP) suffer from severe visual impairment (Schenk-Rootlieb, et al., 1994) . One of the most important causes of blindness in preschool children in developed countries is CVI (Flanagan, et al., 2003). With the knowledge of the characteristics and behaviors of vision in these children, one can obtain an appropriate assessment of their vision. Accordingly, rehabilitation programs for this group of children can also be provided. The aim of this study was to evaluate the visual behaviors of children with cerebral palsy. These children have low vision due to their brain damages.

Materials and Methods

The percentage of patients with cortical low vision is very low, and finding these patients is very difficult. But patients with cerebral palsy can be easily found. Parents of the children also have stated that their child has low vision. Standard eye examination was performed. However, it was not possible to measure visual acuity as usual. Due to the lack of co-operation of children with cerebral palsy in subjective examinations, the method of interviewing with parents has been chosen. At first, written consent was obtained and enough explanations were given to the participants. One parent (preferably mother) was enough for interview.

Inclusion Criteria: Having a child with cerebral palsy, a child under the age of 15 years, definitive diagnosis by providing medical records of cerebral palsy

Exclusion Criteria: Failure to prove cerebral palsy, the presence of any ocular disease leads to poor vision and blindness.

In this study, semi-structured individual interview was used and the interview was recorded (Bryman, 2006; Tashakkori & Teddlie, 1998). The interviewer could ask for more questions if necessary, because the type of questionnaire is open. The interview was initially recorded and then transcribed to text for further utilization and analysis. Any common points, unobjectionable highlights and extras were carefully considered.

Results

A total of 1087 low vision patients visited the Low Vision Clinic during the last three years of 2005-2018, of which 566 were under 15 years old with an aver-

age age of 9±2.5 years old. The reason for vision loss was very diverse, but 45 were diagnosed with cerebral palsy. All parents were invited to participate in this study. However, only 22 of the parents of 18 children participated in the study. Mothers were the most enthusiastic to participate in this study , and only four participants were both parents in the interview. All parents were under 40 years of age. Mean age of parents was 34.72± 5.26

All children were not able to participate in visual acuity measurement. But their objective refraction with radioscopy showed no significant refraction. They had neither strabismus nor nystagmus. They were not able to maintain their fixation. They moved frequently. Due to suffering from brain disorder, they did not communicate during eye examination. Their pupil reflex was normal. There was not any eye disease. Therefore, they were assumed as people with Cortical Vision Impairment.

The following are the most important findings of this study

Characteristics of Visual Behaviors

Parents said that in addition to having brain disorders, there are certain visual behaviors in their child. In other words, the behavioral responses of these children to visual stimuli are different. For example, to see an object, they need to move that object so that they can visualize themselves. "*He did not have an interest in watching television. Now he is watching the cartoon. I even bought a cartoon CD, he hears it on a laptop and a computer, and he is very close to them, now he can recognize people.*"

Delay in observing an object and responding (they will not respond fast). It's as if they should look at them much longer to see. "*Motion-and-speech impairment and a very limited perception of learning slowed him down and made education harder*."

Meanwhile, in a crowded environment, their visual problems get bigger or they do not seem to have eyes. In other words; if an object is complex or in a crowded field, it would have less visual perception. "*In crowded places, he cries out and makes a lot of noise, and he provokes and dashes - because he does not see*"

Another important thing is that they are having difficulty seeing new objects, but they see things that have already been seen. "*They only communicate with people who have seen and huddled, they do not even look directly at others.*" "*Skill the new ones, which according to his age are resisting and hard to learn*"

Other important finding through interview which are not directly related to visual behaviors of children

Familial Marriage Knowing about the Consequences!

Many parents were family members. In other words, they are married after knowing that their child may has genetic disorders! "*Unfortunately, despite the warnings that genetic counselors gave us during the marriage, we married and got twin children with a genetic syndrome*"

This is unfortunate situation that many parents who have familial marriage know that they are faced to have disable child, but still they want to do this marriage.

Necessity of Initial Education

Parenting and special teacher are essential in early childhood education. Because, children learn the verbal and motor skills in the first two years with the help of the teacher. In fact, the path to progress is much faster. "*Indeed, I think of private education because public schools and children's centers do not include all children at the same level, and may stop the same way we went, so I would prefer ourselves (my wife and I) and private tutor to train our kids*".

It is important to provide enough education for parents before marriage as well as how to do parenting.

Effective Education

The child is more involved in talking and playing, especially if the exercises are shaped. Therefore, it is possible to train child with play. "*I used to read the book of the story from the years before, along with poetry, I was very interested in poetry, and I was looking for books that included poetry. I myself put all my work and my life along with him and followed him*"

Effective education is very important for parents of

child with CVI because these kinds of education are very special and there are not many institutions that can provide these services.

Parent Educational Requirements

As parents spend most hours with the child, they must learn special courses about working with these children. "*We would be more in touch with well-being and coaches and to attend classes that are specially designed for children with cerebral palsy and provide special exercises that educate parents to train and to take the child to the doctor for examination regularly*"

Parent's Agreement

Unfortunately, many of the responsibilities of these children are left to the mothers. "*I wanted to have his father's cooperation, but he did not help. I think it was a big problem. I read more story and story book and I was interested in what he likes. I wanted to go to the consultation, but I did not have the cooperation of his father again. We would work with the expert, even the advice would not come with me*."

In developing countries mothers are the most responsible person in case of parenting. Therefore, it is important to share this responsibility between parents.

Non-Visual Problems and the Role of Health Care

Many parents said that the physical and mental problem is more annoying. For example, poor physical strength and imbalance often impede the development of skills. Not paying attention to the surroundings and not paying attention to learning are side effects of mental problems. Almost all parents have reached the level of experience that physical and mental health work is very effective in developing the learning and education of these children. "*I wish I could do my home mental rehab for my child*."

This finding indicates that parents are more concerned about non-visual problems of their children which can be compensated with occupational therapy services.

The following finding has been stated by majority of parents

More than 80 percent of parents have stated that their children are not able to recognize the faces, or sometimes they recognize some faces, and only 20 percent of these children are able to recognize faces more often or always.

More than 60% of parents have stated that their children are more likely to be able to recognize forms and objects, and they are also able to identify moving objects better than constant objects.

About 30 percent of parents said their child was unable to recognize the color, but a significant number stated that their child was sometimes able to recognize the color.

Eighty percent of these children are able to find their own home routes easily and are also able to navigate in some places.

More than 90% of the children experienced a fall down the stairs

Based on behavioral patterns, such as eating and where the plate is empty, it is possible to see the presence of a scotoma in the visual field. More than 60% of parents have stated that this is true for their children

More than 80% of these children get tired of doing everyday activities which is related to vision, for example painting and writing.

Many of these children have had eye deviations and some have undergone surgery.

These findings indicate that using visual behaviors is the best way for interpreting the amount of residual vision in children with cortical visual impairment

Discussion

This study showed that many parents of these children have a history of family marriage. family marriage affects many of the polynomial traits such as height, size, intelligence, and even cardiovascular characteristics (Fareed & Afzal, 2014) . The prevalence of this type of marriage is different based on the traditions of different nationalities and ethnicities, not only in different parts of the world, but also in the different cities and villages of Iran. For example, in Sri Lanka, the percentage of family marriage among parents is reported by about 50% (Eckstein, Foster, & Gilbert, 1995) . In addition, it is common about 28%

in Lebanon, 14% in Saudi Arabia and 16% in China. In Iran, out of 30, 6343 couples from 12 different ethnic groups, 38.6% of marriages are familial and 27.9% of these marriages have occurred between cousins. Of course, among different ethnic groups in Iran, the marriage rate is different (Saadat, Ansari-Lari, & Farhud, 2004). The probability of blindness and diminished vision as a result of these types of marriages seems to be significant. Therefore, raising awareness about the importance of carrying out genetic tests before marriage and the assessment of its potential risks requires special attention. Unfortunately, the high cost of these tests discourages many families from doing so.

It is well known that the vision is not just visual acuity. Vision consists of information processing in the brain. Therefore brain damage has a significant reduction in visual processing (Zihl J & Dutton GN, 2015). Most parents of children stated that the eye examiner looked at the eyes during the infancy and stated that the eye had no particular problem. Many parents say that we have been told that "the problem is from the brain and nothing can be done. Also, because the eye is healthy, nobody suggests that the child might be blind. The golden age is the development of vision at the time of infancy and childhood, and it is time to begin work early. In general, the lack of recognition of this situation will lead to permanent loss of vision, and that golden opportunity will be lost and there will be no return. Unfortunately, many children are not recognized at this time; therefore, no initial measures are taken. These actions, based on timely diagnosis, include step-by-step implementation and planning that will lead to success. For example, by talking and playing, especially if the exercises are shaped, the child cooperates more. Presence of trained educator is essential in early childhood education. Because children learn the verbal skills in the first two years with the help of the instructor (Philip & Dutton, 2014) . Parents also need especial education to deal with these children.

Any assessment of children should start with parents first. Parents are the best specialist about their children. Their information is very useful and should not be overlooked. Parents and other family members are living with these children 24-hour and are fully aware of all the moments and circumstances and conditions. So the first evaluation should start at home. Because parents spend most hours with their child, then they should take special courses about working with these children. "I wish I knew I could do something in my home for mental retardation." Parents also should be in touch with rehabilitation centers and coaches, attend classes that are specially for children with cerebral palsy, and special exercises that educators teach parents. The consistency of family education with educational centers is also important. For example, the trainer takes a long time with self-help training to educate the child to eat independently. The next point is that, unfortunately, many of the responsibilities of these children are left to the mothers. This issue should be taken seriously. Fathers should also be involved in this process.

Parents have always had many questions, and most of the time they have not been able to answer them, and they have sometimes been desperate and disappointed. Many questions are arising such as mental development, physical growth, behavioral, evolutionary and educational development, information on disease and its progression, medicine and accessible therapies. The use of specialized words causes parents to be confused. Meanwhile, when parents experience psychological problems from their status, it is not a good time to give them this information. Because, they are more disadvantageous and that may create more troubles and confusion. Such information should be given at the right time and should not expect them to be fully understood by parents. Therefore, any information to be given to parents should be carefully considered, accurate and conducted in a negotiation process to prevent any mistakes made. It should be kept in mind that parents do not have accurate information on events occurring in the child's neurological, perceptual, speech, and motor systems. So the information should be passed on to parents carefully and accurately.

Any deficiency in vision processing may have negative side effects on the learning and development.

Therefore current tools and strategies to improve vision impairment are not effective for CVI (Maria B. C. Martín, 2016). Many parents report that the physical and mental problem is more annoying than eye problems. For example, poor physical strength and imbalance often impede the development of skills. More than 90% of the children experienced a fall down the stairs. More than 80% of these children are tired of doing routine activities, for example, painting, writing, lack of attention to learn from mental problems. But the important finding is that almost all parents found that physical and mental rehabilitation programs are very effective in developing the learning and education of their children. In other words, occupational therapy is a more effective way to reduce difficulties than vision rehabilitation. From the point of view of vision rehabilitation, attention should also be paid to the disability that causes the most harm to the child's life. For example, doing personal work should be prioritized. Training needs to be addressed in order to meet these needs. Another important point is that parents are happy to receive such training and confirm their effectiveness.

Children with cerebral vision impairment need special programs which are provided by an interdisciplinary team. To measure visual outcome also needs special clinic for these group of visually impaired children. Also trained pediatric ophthalmologist and optometrist are needed to assess functional vision of CVI children. Specialized rehabilitation services as well as individualized program is needed (Swetha Sara Philip, 2017). All parents have many wishes for their child, and they also hope that these problems will be resolved. Some parents can quickly get out of this shock, but all parents are still looking for their baby to recover and have a normal life. But experts and teachers have a different perspective, and in their view, there is something else. They look at the barriers, not the wishes of the parents. Therefore, it is necessary to remove parents from these dreams and thoughts, and they were informed that the situation may be worse than this. However, sympathy is recommended to parents and teaches them how their children are capable. These parents should not feel different with other parents; they should feel themselves like others.

It is anticipated that using vision behaviors characteristic is a new way to assess vision in children with cerebral palsy. In other words, how children use their vision to perform daily living activities (Belinda Deramore Denver, 2017). Children with low vision have different visual behaviors compared to normal ones, and their visual behaviors are not normal. Their sight changes in different conditions, in other words, they may look better in one place than elsewhere (Ashworth Jane, 2016). Unfortunately, there is not enough published information about this specification. Some researchers believe that over time, visualization will improve, but it will take several months or several years. Studies and experiments have shown that improved vision has been developed in children who at the time of diagnosis and childhood, and even newborns, have rehabilitation programs implemented compared to those who have not received any program (Lotfi B, et al., 2017).

Conclusion

Since it is impossible to cure vision special rehabilitation programs can be selected for these children. Meanwhile some visual responses develop with delay and can be anticipated. The parents of these children should be trained from the very first days and should be informed as soon as possible after the start of rehab. Power of brain plasticity development at birth will continue to act in such a way that "the sooner the better", so time is of the essence.

Acknowledgments

The authors would like to thank the participants for their time and patience. In addition, no specific fund was provided for this study.

Conflict of interest statement

Authors declared no conflict of interest.

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Function and Disability Journal ISSN: 2588-6304

مقالهٔ پژوهشی

بررسی رفتارهای بینایی در کودکان مبتلا به اختلال بینایی کورتیکال به علت فلج مغزی

فاطمه ریاضی[۱،۲]، عباس ریاضی[۳*]، حسن سوری[۲،۴]

۱. دانشجوی کارشناسی ارشد بینایی‌سنجی، دانشکده بینایی‌سنجی، دانشگاه علوم پزشکی ایران، تهران، ایران
۲. مرکز تحقیقات کم بینایی، دانشکدهٔ توانبخشی، دانشگاه علوم پزشکی ایران، تهران، ایران
۳. دانشیار، گروه چشم پزشکی، دانشکده پزشکی، دانشگاه علوم پزشکی بقیه الله، تهران، ایران
۴. استاد، گروه اپیدمیولوژی، دانشگاه علوم پزشکی ایران، تهران، ایران

اطلاعات مقاله

تاریخ وصول: ۱۳۹۷/۴/۱۰
تاریخ پذیرش: ۱۳۹۷/۵/۲۲
انتشار آنلاین: ۱۳۹۷/۸/۷

نویسندهٔ مسئول:
عباس ریاضی
گروه چشم پزشکی، دانشکده پزشکی، دانشگاه علوم پزشکی بقیه الله، تهران، ایران

پست‌الکترونیک:
Abbas.Riazi@gmail.com

تلفن:
۰۲۱-۸۲۱۶۲۴۷۸

چکیده

زمینه و هدف: اختلال بینایی کورتیکال Cortical visual impairment (CVI) یکی از مهم‌ترین عوامل نابینایی در کشورهای توسعه‌یافته در دورهٔ کودکی است و زمانی رخ می‌دهد که مغز آسیب دیده باشد؛ به‌طوری که دو سوم از کودکان مبتلا به فلج مغزی Cerebral palsy (CP)، به اختلال شدید بینایی و میدان بینایی مبتلا هستند. علت اصلی این نوع نابینایی و کم‌بینایی به پردازش اطلاعات تصویر در قسمت‌های مختلف مغز مربوط می‌شود. ازاین‌رو هدف مطالعهٔ حاضر مشاهدهٔ رفتارهای بینایی به‌عنوان راهی مناسب در بررسی میزان بینایی در کودکان مبتلا به فلج مغزی است تا بتوان از این طریق امکانات توان‌بخشی کم بینایی را فراهم کرد.

روش کار: رفتارهای بینایی با روش مصاحبه با والدین کودکان زیر ۱۵ سال بررسی شد. ۲۲ نفر از والدین ۱۸ کودک در این مطالعه شرکت کردند (میانگین سن والدین ۲/۵۱ ± ۳۷/۴ بود). بیشتر والدین دربارهٔ مشکلات کودک خود اطلاعات کافی نداشتند و به آموزش‌های خاص نیاز داشتند. والدین باید آموزش‌های لازم و کافی دریافت کنند. توان‌بخشی مشکلات غیرچشمی با روش‌های کاردرمانی بسیار رضایت‌بخش است. رفتارهای خاصی در این کودکان دیده می‌شود که منحصربه‌فرد است و این رفتارها در کم‌بینایان با علل چشمی دیده نمی‌شود.

یافته‌ها: ۲۲ نفر از والدین ۱۸ نفر از کودکان مبتلا به فلج مغزی در این تحقیق شرکت کردند (میانگین سنی ۲/۵۱ ± ۳۷/۴) والدین اطلاعات کافی برای برخورد با فرزندانشان نداشتند. نیاز به آموزش ویژه داشتند. برنامه‌های توانبخشی گروه کاردرمانی بسیار تاثیرگذار بود موثرترین آنها توانبخشی فیزیکی بود. رفتارهای مهمی میان بچه‌ها مشترک بود. این رفتار در میان بچه‌های مبتلا به اختلال بینایی دیده نشد.

نتیجه‌گیری: والدین خیلی نگران وضعیت چشمی کودکان خود نیستند. آنها بیشتر نگران مشکلات جسمی کودک خود هستند و معتقدند تمرینات کاردرمانی خیلی موثر است. والدین این کودکان به آموزش های خاص در مورد توانبخشی کودکان خود نیاز دارند.

واژه‌های کلیدی: فلج مغزی، کم‌بینایی و نابینایی مغزی، رفتار بینایی، توان‌بخشی بینایی