

## Assessment of Knowledge of Parents of Children with Cortical Visual Impairment: An Interventional Study

Ang Jangmu Lama<sup>1</sup> , Srijana Adhikari<sup>1</sup>, Rojeeta Parajuli<sup>1</sup>

<sup>1</sup>Department of Pediatric Ophthalmology and Strabismus, Tilganga Institute of Ophthalmology, Gaushala, Kathmandu, Nepal

### ABSTRACT

**Introduction:** The cornerstone of CVI management is developing methods to help the kid, caregiver and educator comprehend how the child uses their vision and how modifications may be made to help the child use it more effectively.

**Objectives:** To evaluate caregivers' and parents' understanding of cortical visual impairment and how it evolves after receiving educational materials in the form of video and handout.

**Materials and methods:** This prospective interventional study enrolled all children with CVI at a tertiary eye care center from 2020 February to 2021 January. Parents were interviewed about CVI visual behaviour using a Perkins website consulting interview. They were then sensitised with a Nepali video and handout describing CVI characteristics. A follow-up visit or call was scheduled six weeks later to reassess their knowledge.

**Results:** In the study, 37 parents participated. Before the intervention, 81.1% (n = 30) were unaware of CVI, which decreased significantly to 4.3% (n = 1) after intervention (p <0.001). For the follow-up, 59.4% (n = 22) of parents participated or responded to calls. Initially, 43.2% (n = 16) of parents attributed issues to eye problems, increasing to 90.9% (n = 20) recognising the brain's role after education (p = 0.021). Notice of attraction to bright colors increased from 48.6% (n = 18) to 86.4% (n = 19) post-education. Awareness of children's favourite toys rose from 62.2% (n = 23) to 81.8% (n = 19) in the follow-up. Additionally, noticing better vision in one room over another increased from 24.2% (n = 9) to 40.9% (n = 9) post-education. Movement was reported as good in familiar environments by 81.1% (n = 30), with 70.3% (n = 26) facing issues in unfamiliar ones, consistent in the follow-up.

**Conclusion:** The study found that educating primary caregivers with handouts and videos alone did not effectively improve their understanding of the disease, likely due to factors such as parental literacy and socio-economic status. Consequently, establishing nationwide CVI clinics is urgently needed.

**Key words:** Cortical visual impairment; knowledge; parent education.

**Financial Interest** : Nil

Received : 03.08.2023

**Conflict of Interest** : Nil

Accepted : 03.11.2023

#### Corresponding Author

Dr. Ang Jangmu Lama  
Department of Pediatric Ophthalmology and Strabismus  
Tilganga Institute of Ophthalmology,  
Gaushala, Kathmandu, Nepal.  
E-mail: ang.lama@tilganga.org



**Access this article online**

**Website:** [www.nepjol.info/index.php/NEPJOPH](http://www.nepjol.info/index.php/NEPJOPH)

**DOI:** <https://doi.org/10.3126/nepjoph.v15i2.57263>

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**ISSN:** 2072-6805, **E-ISSN:** 2091-0320



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## INTRODUCTION

Vision serves two primary functions: the first is the ability to perceive objects and their relationship to the world, while the second involves executing visually guided movements. These capabilities are made possible by the intact visual processing that takes place in the dorsal and ventral stream pathways that are responsible for the mental representation of visual space, visual objects, and faces (Zihl and Dutton, 2015). Cortical visual impairment (CVI) in children is a disorder where these retro chiasmatal tracts are involved which leads to an impairment of vision-guided tasks, such as motor planning, in the face of normal ocular findings or little ocular morbidity, and/or visual acuity.

It includes problems with visual attention, visual field, visual perception, visual directed movement, and sensory integration in addition to problems with shape, object, or face identification (Pilling, 2023).

Cortical Visual Impairment (CVI) stands as the most prevalent reason for visual impairment among children in developed nations (Ozturk et al., 2016). Incidence of CVI is also on the rise in developing countries as seen in a study done in India which showed CVI as a leading cause of visual impairment among young children aged less than three years (Pehera et al., 2019). The cornerstone of CVI management is figuring out how to help the kid, caregiver and educator comprehend how the child utilises their

vision and how to make accommodations or habilitations to help the child use it more effectively. Research indicates that initiating interventions at an earlier stage leads to more significant improvements in visual function (Huo et al., 1999). The clear communication of information to families and teachers has been recognised as a pivotal factor in closing the gap between health care and education (Hyvärinen et al., 2012).

There is no formalised program designed specifically for children with CVI in Nepal's ophthalmic services. The fact that most CVI resources on the internet or in books are written in English makes this scenario much more difficult for parents. In order to fill this gap, the author produced a handout in Nepali that lists the 10 visual traits of CVI. The details given were an exact translation of the characteristics found in several CVI resources (Cerebral Visual Impairment Society of Scotland, 2023; Christine Roman-Lantzy, 2018). A video explaining the facts given in the handout was created since some parents might find it difficult to understand the specifics offered in the handout.

The purpose of this study was to assess the knowledge of parents and caregivers about cortical visual impairment and how it changes following education with these informative materials.

## MATERIALS AND METHODS

This was a prospective interventional study. All consecutive cases of children

diagnosed with CVI who presented to the pediatric ophthalmology clinic at a tertiary eye care centre from February 2020 to January 2021 were included. Using the convenience sampling technique all consecutive cases of CVI were enrolled. Parents who failed to provide a written consent were not included the study. The parents were interviewed regarding the visual behaviours using a CVI consulting interview available on the Perkin’s website (Perkins). The parents were then sensitised with a handout and a video in Nepali describing the visual characteristics

of CVI (CVI in Nepali, 2021). A follow up visit or call was scheduled six weeks later and the same questions regarding the visual behaviour were asked. Data were collected using a proforma in and entered in Microsoft Excel Sheet Year. Using IBM SPSS Statistics for Windows, version 20 (IBM Corp., Armonk, N.Y., USA), every statistical analysis was completed. The McNemar test was performed to determine the difference for pre-post categorical data. The p-value <0.05 was considered as statistically significant variable.

**Table 1: Cortical visual impairment consulting interview (Perkins,2020)**

	BEFORE		AFTER	
	YES	NO	Yes	NO
<b>KNOWLEDGE</b>				
1. Have you heard of Cortical Visual Impairment (CVI) before this interview or not?				
2. Do you know what caused CVI in your child?				
a. Disorder of the brain				
b. Disorder of the eye				
3. Do you know that children with CVI have specific visual characteristics?				
4. Does vision improve in CVI?				
<b>ATTITUDE</b>				
1. My child’s vision impairment is associated with issues with the brain				
2. My child’s vision issue will eventually improve				
<b>PRACTICE</b>				
<b>Colors</b>				
1. Attracted to bright colors eg. Red or yellow				
2. Does your child have a favorite toy?				
i. If yes what is it:				
3. Does the child recognize shapes? Objects?				
4. Can the child name colors?				

<b>Movement</b>				
1. Is the child's vision drawn to people /objects moving around the room?				
2. Does the child move their head from side to side?				
3. Does the child enjoy rides in any vehicle?				
4. Does the child see better if they are moving themselves?				
5. Does the child eat food from only one side of the plate?				
<b>Complexity</b>				
1. Does the child see better in one room over another?				
2. Can the child move well around the house or familiar environment?				
3. Can the child move well around the unfamiliar environment?				
4. Does the child see objects on a patterned rug/ carpet?				
5. Does the child see things better if they are held up close?				
6. Does the child see solid objects better than patterned or multicolored objects?				
7. Does the child see better if the background is solid in color and pattern?				
8. Does the child seem to look through you?				
9. Does the child look at the face especially the eyes?				
10. Does the child look at you when he/she talks?				
11. Does the child recognize you before you speak?				
12. Does the child recognize other family members? Friends?				
13. Does the child recognize you from photographs?				
14. Does he/she recognize himself/herself in photographs?				
15. Does the child see better in a quieter environment?				
16. Does the child seem less able to concentrate in a busy, noisy room?				
<b>Light gazing</b>				
1. Does the child stare out windows and glass doors?				
2. Does the child look at overhead lighting?				



Distance viewing				
1. Does not recognize you when you stand further away?				
2. At what distance can the child recognize you without hearing the voice in a group of parents? -at 3 feet    at 6 feet?    at 12 feet?				
3. Does the child see familiar things in the environment and move towards them or wander then play with what they find?	MOVE	WANDER	MOVE	WANDER
4. Does the child see a novel thing in the environment and move to get it?				
Novelty				
1. Does the child ignore new toys?				
2. If a new toy comes into the environment, does the child take a while to get used to it?				
3. Does the child look at familiar faces?				
Visual reflexes				
1. Does the child react to a threat to his eyes?				
Visual Motor				
1. Does the child reach for objects?				
2. Does he/she look while he/she reaches?				
3. Does the child maintain gaze until he grasps the object?				
4. Does the child look, look away then reach? Yes/ No				
5. Does the child play without looking				
6. Does the child stop at changes of ground surfaces, at rug edges, at shadows, depth changes?				
7. Does the child hit their body on doorways or walls? (Rule out motor issues.)				
Latency				
1. Does it take a while for the child to turn to look at toys?				
2. Does it take a while for the child to focus on the eyes when you are holding him/her?				
Visual field				
1. Falls frequently over clearly visible objects ?				
2. Does the child seem to see things better on the right or left?				
3. Does the child seem to ignore things in the lower field?				

## RESULTS

A total of 37 parents participated in the study. The average age of patient was 5.7 years. Out of them, 45.94% (n = 17) were female and 54% (n = 20) were male. Majority of the parents (81.1%, n = 30) had not heard of CVI before the interview and it was decreased to 4.3% (n = 1) after intervention. This change of awareness is statistically significant ( $p < 0.001$ ). 59.4% (n = 22) parents participated in the follow-up or responded to calls.

Initially, 43.2% parents (n = 16) believed eye problems caused the issues, but after education, 90.9% (n = 20) recognised the brain's responsibility ( $p = 0.021$ ). 48.6% (n = 18) noticed attraction to bright colors which changed to 86.4% (n = 19) post-education. 62.2% (n = 23) were aware of their children's favourite toy, which changed to 81.8% (n = 19) in the follow-up. Additionally, 24.2% (n = 9) noticed better vision in one room over another, which changed to 40.9% (n = 9) post-education. 81.1% (n = 30) reported good movement in a familiar environment, whereas 70.3% (n = 26) faced issues in an unfamiliar environment, consistent in the follow-up.

Concerning visual perception, 40.5% (n = 15) noticed difficulty with patterned backgrounds, but only 45.5% (n = 10) reported this behaviour despite education. 70.3% (n = 26) observed better vision when objects were held up close, increasing to 77.3% (n = 17) post-education. 21.6% (n

= 8) noticed better perception of solid objects than patterned, with 31.8% (n = 7) reporting this behaviour in the follow-up. Better vision with a solid background was noticed by 40.5% (n = 15).

73% (n = 27) reported their children not looking at their faces, especially the eyes, and 54.1% reported not looking at faces while speaking, with similar results in the follow-up. Additionally, 51.4% (n = 19) mentioned their child taking time to focus on eyes when holding, while 40.5% noticed better vision in a quieter environment, increasing to 59.1% in the follow-up.

78.4% (n = 29) of children did not ignore new toys, and the majority (62.2%) adjusted quickly to new toys in a different environment. 79.41% (n = 27) of parents reported their child stopping at changes of ground surfaces, and 85% (n = 17) reported this behaviour in the follow-up. 53.1% (n = 17) fell frequently over clearly visible objects, and 27.8% (n = 10) ignored things in the lower visual field, with 45.5% (n = 10) reporting this behaviour in the follow-up interview.

## DISCUSSION

In an ideal scenario, when a child is diagnosed with CVI, it is crucial to conduct a thorough functional visual assessment to gain insight into the child's visual abilities. The main goal of this assessment is to facilitate accessible learning by tailoring educational methods to match the child's visual skills. Subsequently, the child should be provided with appropriate

environmental adjustments and support at home to enhance their learning experience (Perkins, 2023). In a developing country like ours this is easier said than done. With an improved infant mortality rate of 23.37 deaths per 1000 live births Nepal is bound to have an increase in the number of children with CVI (World Bank, 2021). The absence of facilities and adequately trained human resources dedicated to caring for children with CVI in our nation poses a significant obstacle, impeding the comprehensive growth and development of these children with unique requirements.

The interview was conducted using a CVI consulting interview available on the Perkin's website (Perkins). The interview questions assessed whether the parents were aware of presence or absence of visual characteristics in their children. Majority of the parents at the first visit had not heard of the term CVI and thought that visual problems were related to the eye. Parents observed certain characteristics even before formal education, such as a preference for better vision in one room compared to another, difficulties with movement in unfamiliar surroundings, the inability to gaze at their parent's face, holding objects close to their eyes, pausing at transitions between different ground surfaces, and a fascination with bright colors. However only a minority of parents noticed behaviours like solid objects being more visible than patterned, better vision if the background is solid in color and better vision in a quieter environment. Only a few parents noticed that their child

ignored new toys and ignored things in the lower visual field.

Despite being provided with information regarding the visual behaviours of CVI, there was no statistically significant difference seen in the level of knowledge about these behaviours post education. For those who are not well-versed in the workings of the visual system, comprehending the features of CVI might be difficult. Therefore, a significant portion of parents may have found it difficult to understand the complex information provided in both the handout and the video. Several factors might contribute to this outcome. The literacy level of parents, particularly the mother, directly influences the effectiveness of educational information. Additionally, the socioeconomic status of the primary caregiver is connected to the usefulness of educational tools. Understanding the child's visual behaviour may not be a priority for the parents if a family is struggling financially. The results indicated that merely educating the primary caregiver about the disease with informative materials did not sufficiently assist them in comprehending its features. In addition to informative materials, conducting a live assessment of these visual characteristics can help reinforce parents' understanding and knowledge.

Numerous case studies involving mothers of children with CVI revealed a shift in their roles from being caretakers to becoming advocates for their child after receiving the diagnosis. These mothers

took the responsibility of informing their child's educational team about their CVI. However this study was conducted at a children's hospital located in a major city in the United States. The hospital had a dedicated clinic for children with CVI, and these children had access to various services such as occupational therapy, physiotherapy, and vision services (Furze, 2021).

In Nepal's socio-economic situation, creating a facility for CVI that is both comprehensive and customised is an ambitious goal. It is not practical to conduct functional visual assessments and suggest appropriate therapies for children with CVI in a typical pediatrics outpatient department (OPD) setting. As a result, in order to give these kids specialised care, a specific area and a specialist care giver are needed. The first step we can take is to establish CVI clinics across the nation. This underscores the need for eye centers

with pediatric ophthalmology services to prioritise the care of children with CVI.

Only 22 parents participated in the follow-up, indicating attrition. The research is based on a very small sample size of 37 parents. It is possible that the smaller sample size misrepresents the overall population.

## CONCLUSION

This study showed that simply educating the primary care giver with information handout and videos does not help them understand the features of the disease. This could be attributed to various reasons like literacy level of parents and the socio-economic status of primary caregiver. Hence establishing CVI clinics across the nation is a pressing priority.



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