

Clinical use of the Insight Inventory in cerebral visual impairment and the effectiveness of tailored habilitational strategies

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ABBREVIATIONS

Beery VMI	Beery-Buktenica Test of Visual-Motor Integration
CVI	Cerebral visual impairment
PedsQL	Paediatric Quality of Life Inventory
WISC-IV	Wechsler Intelligence Scale for Children, Fourth Edition

AIM To investigate the utility of the Insight Inventory (a structured clinical inventory completed by caregivers) for assessment of children with cerebral visual impairment; and to investigate effectiveness of tailored habilitational strategies derived from the responses to the Insight Inventory.

METHOD Fifty-one eligible children (26 males, 25 females; mean age 9y 5mo, SD 3y, range 5–16y) were recruited from Great Ormond Street Hospital, London. They underwent baseline assessment including neuro-ophthalmological and neuropsychological evaluations, and parent- and child-reported ratings on a questionnaire-based measure of quality of life. Parents also completed the Insight Inventory. On the basis of responses to the Inventory, families received individualized habilitational strategies. Follow-up assessments 6 months later included repeating the Insight Inventory and quality of life questionnaires.

RESULTS Correlations were found between the Insight Inventory and the Wechsler Intelligence Scale for Children, Fourth Edition, the Beery-Buktenica Test of Visual-Motor Integration, and the Benton Facial Recognition Test, suggesting that the Insight Inventory is an effective tool to estimate visual-perceptual difficulties. At 6 months follow-up, caregiver reports indicated significant improvements in the quality of life of children below the age of 12 years.

INTERPRETATION The Insight Inventory is a simple questionnaire which covers practical aspects of cognitive visual function in everyday life. It provides in-depth information about the aspects that children struggle with. It can also guide programmes of individualized habilitation strategies, which may enhance the quality of life of younger children.

Cerebral visual impairment (CVI) refers to visual impairment caused by pathology in the retrogeniculate visual pathways and visual association areas of the brain.^{1,2} CVI is the most common cause of visual impairment in children in industrialized countries^{3,4} but evidence about effective assessment and management strategies is lacking.^{1,2}

Standard visual acuity testing is an insufficient method of quantifying CVI in children as it does not detect visual-perceptual or perceptuomotor disorders.⁵ A validated clinical question set, the Insight Inventory, has been developed as a 52-item checklist for structured history-taking, which assesses a wide range of features of CVI.⁶ The questions are clustered into groups covering various domains, including dorsal stream (occipito-parietal) processing and ventral stream (occipito-temporal) processing.⁷ The response patterns tend to indicate potential locations of anatomical disorder and aid characterization of the visual difficulties for planning habilitation. The Inventory is linked to a range of

practical habilitational strategies⁸ so that each child can be given a set of strategies tailored to their difficulties. An example of such strategies would be for children who seem to have weakness of their lower visual fields and struggle going down steps or stairs. Behavioural strategies might include teaching children to stop and look down, bringing their feet into view, wearing brightly coloured trainers, feeling ahead with their feet, or using another sensory contact with the ground such as a trolley or hiking pole. Environmental strategies might include putting a hand rail on the stairs or marking out stair boundaries with masking tape or paint.

The Inventory has been shown to be reliable in a hospital clinic-based study of children with CVI.⁶ Moreover, it has identified significant visual difficulties (confirmed by visual perception testing) in many children born preterm who had previously passed neurodevelopmental screening.⁵ However, the impact of habilitational strategies on functional vision or on quality of life has yet to be evaluated.

The present study aimed to investigate the relationships between responses to the Insight Inventory and standard neuro-ophthalmological and standard neuro-psychological findings, in a mixed-aetiology, hospital-based population of children with CVI. A further aim was to investigate the impact of the tailored habilitational strategies on functional vision and quality of life.

METHOD

Design

This was a prospective uncontrolled interventional cohort study, designed as a pilot study.

Participant recruitment

Eligibility criteria were children aged 5 to 16 years with: (1) a confirmed diagnosis of CVI based on a known medical reason for brain injury or dysfunction, (2) no signs of ocular pathology other than mild optic atrophy (defined by indirect ophthalmoscopy), and (3) binocular visual acuity of at least LogMAR 1.0 (Snellen 6/60). Children who had previously received advice on specific habilitational strategies were excluded. Written patient and caregiver consent was obtained. Ethics approval was obtained from the NRES Committee London and UCL (references 13/LO/0756 and 11NR42)

Procedure

At baseline, participants underwent an ophthalmological assessment and a neuropsychological evaluation. The Insight Inventory was completed by parents, and measures of quality of life were obtained from parents and child, after which the families received a tailored interventional plan based on the Insight Inventory. Participants were re-administered the Insight Inventory and quality of life measures 6 months later. Subjective parent feedback was also collected.

Ophthalmological examination

The examination included age and developmentally appropriate measures to assess oculomotor function, visual acuities, and visual fields. Visual inattention on each side of the field of vision was assessed using simultaneous confrontation. Visual perception and visual guidance of movement were examined using the Lea Rectangle and Lea Mailbox tests.⁹

Neuropsychological assessment

The neuropsychological assessment took place in a quiet room, with minimal distractions. The tests were administered to those children who were able to understand and comply with the basic instructions. The protocol included: (1) the current age-appropriate version of a Wechsler Intelligence Test: either the Wechsler Intelligence Scale for Children, Fourth Edition (WISC-IV) for 6- to 17-year-olds^{10,11} or the Wechsler Preschool and Primary School Scale of Intelligence, Fourth Edition for 5- or 6-year-olds;¹² (2) the Benton Judgment of Line Orientation; (3) the Benton Facial Recognition Test for those aged 7 years and above;^{13,14} and (4) the Beery-Buktenica Test of Visual-Motor Integration (Beery VMI) for children aged 2 years and above.¹⁵

What this paper adds

- Questionnaire scores demonstrate biologically plausible correlations with formal neuropsychological tests of visual function.
- After administration of matched practical habilitational strategies, younger children showed improvement in quality of life and functional vision scores.

Insight Inventory

The Inventory consists of 52 questions that refer to visual-perceptual and visuo-motor difficulties that children with CVI may face in their everyday lives. These questions are grouped into six domains: (1) visual search, (2) visual fields, (3) visual attention, (4) perception of movement, (5) visual guidance of movement, and (6) recognition/navigation. For each item, caregivers rate how often the problem arises for their child on a 5-point scale (0, never; 1, rarely; 2, sometimes; 3, often; 4, always). Mean scores can be calculated for each of the six domains and the total. For analysis, items that were rated as not applicable by 50% or more participants were excluded. Furthermore, mean scores were not calculated for domains if 50% of responses were either not applicable or missing. Thus, mean scores were calculated for domains in which at least 50% of items were scored. Higher scores indicated more frequent problems and difficulties in activities and behaviours associated with the domains.

For each problem rated as occurring either often or always, specific habilitational strategies were generated by the Insight Inventory software, and a printout was given to each family on the day of the baseline assessment (see an example in Appendix S1, online supporting information). Parents were encouraged to share copies with the children's teachers and other individuals involved in their education or leisure activities. All families received a telephone call after 3 months to report experience, implementation and problems, and to receive advice. At this time, 6-month follow-up appointments were scheduled.

Quality of life assessment

Patients' quality of life was assessed through self-report and caregiver-report on standard questionnaires. All children and caregivers were invited to complete the appropriate versions of the Pediatric Quality of Life Inventory (PedsQL).¹⁶ In addition, children aged 10 to 15 years were asked to complete the Functional Vision Quality of Life and the Vision-related Quality of Life questionnaires.^{17,18} All measures were scored according to the manual instructions. Higher scores on the PedsQL and Vision-related Quality of Life questionnaires indicate better quality of life, whereas higher scores on the Functional Vision Quality of Life Questionnaire indicate higher levels of difficulty.

Statistical analysis

All statistical analyses were conducted using IBM SPSS Statistics, version 21 (IBM Corp., Armonk, NY, USA). After appropriate tests of normality, paired *t*-tests were used to determine the significance of any differences

between the baseline and follow-up scores. Unpaired *t*-tests were used for comparisons between subdomains. Bonferroni adjustments for multiple comparisons were applied as required.

Spearman's rank correlation and Pearson's correlation coefficients were calculated to investigate the relationships between the clinical ophthalmological findings as well as the neuropsychological findings with the Insight Inventory scores.

RESULTS

Fifty-one children (26 males, 25 females; mean age 9y 5mo, SD 3y) were recruited for this study and attended for the baseline assessment. For the neuropsychological assessment protocols, 38 were aged 7 to 16 years, and 13 were aged 5 to 6 years.

Of these, 48 families (94%) attended the 6-month evaluation visit. There was a history of preterm birth in 51% of participants. Other common systemic or neurological features included hydrocephalus (12%), epilepsy (14%), and cerebral palsy (23%).

Ophthalmological assessment

With regards to the ophthalmic features observed, nearly half of the patients (46%) had corrected near visual acuity both eyes open N4.5 (the smallest font size on a standard reading chart, said to be equivalent to a distance acuity of 0.0 or Snellen 6/6), while median binocular distance visual acuity was 0.18 (Snellen 6/9) (interquartile range 0.08–0.52; Snellen 6/7.5–6/18) with only 4% of the children having corrected distance visual binocular acuity of at least 0.0 (Snellen 6/6). Thirty-eight of the 51 children had quantified distance visual acuities and the remaining 13 were judged by behaviour to have acuity of better than 1.0 (6/6). Visual fields were assessed (mostly to confrontation) in 67% of the participants and abnormalities were observed in 50% of them (15% had right hemianopia, 12% left hemianopia, and 23% inferior field loss bilaterally). Table 1 summarizes the rates of the most common ophthalmological findings in the sample.

Neuropsychological assessment

The findings of the neuropsychological assessment are presented in Table 2. Most children in the 7 to 16 years age range (32 out of 38; 84%) were able to engage with at least some subtests of the intelligence test. In this age group, the mean for the measure of verbal cognitive ability was in the low average range for the population norms (87.84, SD 17.80). In contrast, the mean for non-verbal, visual-spatial cognitive ability was exceptionally low (69.21, SD 16.78). A lower proportion were able to access the specific tests of visual cognition, judgement of line orientation (25 out of 38; 66%), and face recognition (28 out of 38; 74%). Scores for both were below the age-appropriate level, but this was most pronounced for judgement of line orientation.

For the smaller 5- to 6-year-old group, testing rates were lower. An estimate of verbal ability was calculated for

Table 1: Findings of ophthalmic examinations

Ophthalmic feature	Participants, <i>n</i> (%)	Participants assessed, <i>n</i> (%)
Corrected distance visual acuity, both eyes open at least 6/6	2 (4)	46 (90)
Corrected near visual acuity, both eyes open N4.5	17 (46)	37 (72)
Visual field abnormality	17 (50)	34 (67)
Visual inattention	5 (17)	30 (59)
Abnormal smooth pursuit movements	19 (46)	41 (80)
Abnormal saccades	13 (32)	40 (78)
Strabismus	30 (67)	45 (88)
Nystagmus	14 (33)	42 (82)
Lea mailbox task (difficult/cannot do)	7 (15)	47 (92)
Lea pick up task (difficult/cannot do)	7 (15)	46 (90)
Lea staircase task (difficult/cannot do)	22 (48)	46 (90)

Table 2: Summary of neuropsychological tests

Test	Subtest/index	Participants, <i>n</i> (%)	Mean (SD)
WISC-IV (7–16y)	Verbal comprehension	32 (84)	87.84 (17.80)
	Perceptual reasoning	32 (84)	69.21 (16.78)
	Working memory	31 (81)	79.67 (15.54)
	Processing speed	27 (71)	68.37 (17.33)
	Full-scale IQ	27 (71)	69.70 (17.13)
WPPSI-IV (5–6y)	Verbal comprehension	7 (54)	95.00 (15.72)
	Visual-spatial	3 (23)	71.33 (24.83)
	Fluid reasoning	4 (31)	82.25 (18.87)
	Full-scale IQ	6 (46)	89.67 (18.77)
Benton Judgment of Line Orientation		25 (66)	-2.14 (1.53)
Benton Facial Recognition Test		28 (74)	-1.30 (1.49)
Beery VMI	Visual-motor integration	37 (72)	70.35 (18.02)
	Visual perception	33 (65)	75.57 (2.98)
	Motor coordination	33 (65)	63.54 (16.65)

WISC-IV, Wechsler Intelligence Scale for Children, Fourth Edition; WPPSI-IV, Wechsler Preschool and Primary School Scale of Intelligence, Fourth Edition; Beery VMI, Beery-Buktenica Developmental Test of Visual-Motor Integration.

54% (7 out of 13). The resulting mean score was in the average range (95.00, SD 15.72). Measures of visual-spatial and non-verbal fluid reasoning were obtained for only three (23%) and four (31%) participants respectively, and the mean scores were below the expected level for their age and below the mean for verbal ability.

Of the whole sample, 37 (72%) completed the Beery VMI, and most of these also completed related measures of visual shape perception and fine motor coordination. Scores were all consistent with a degree of impairment.

Insight Inventory

Ninety-four per cent of the caregivers answered all items of the Inventory, allowing for calculation of all domain scores.

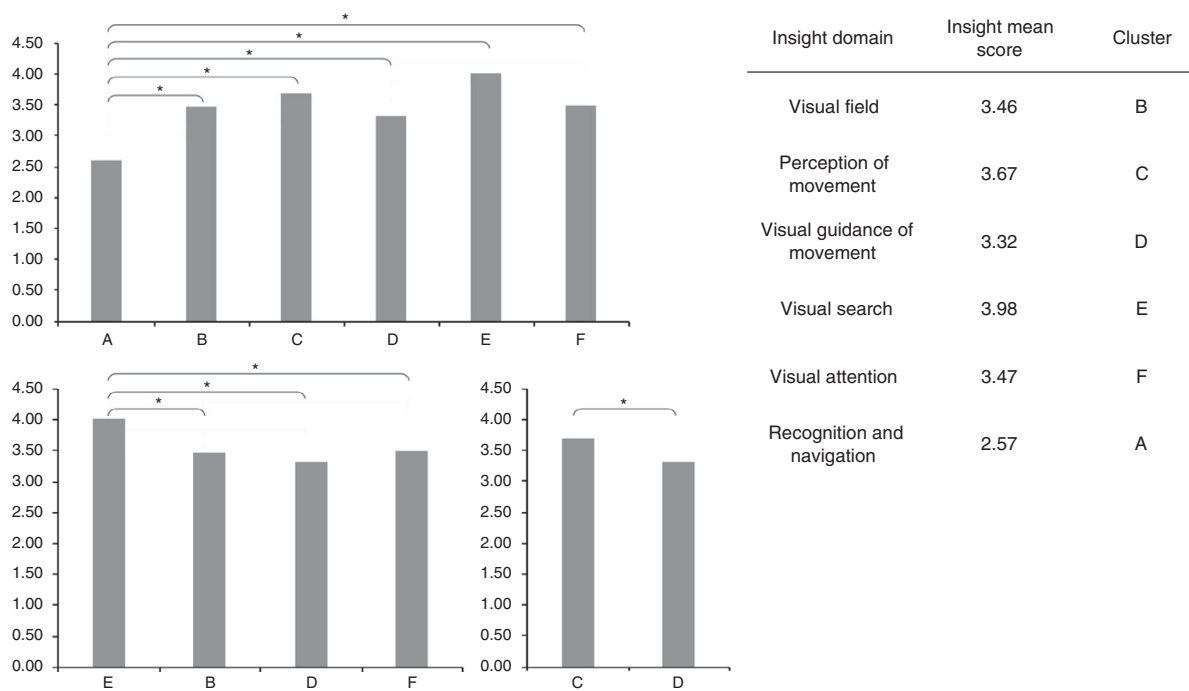


Figure 1: Sum of the Insight Inventory mean scores and statistically significant differences between the mean scores of the inventory's domains. On the bar charts, the x axis represents the Insight domains and the y axis represents the mean scores for each domain. Asterisks indicate significant differences for pair-wise analysis.

Statistical analysis (Fig. 1) revealed that the mean score for impairment in the 'recognition and navigation' domain (mean 2.57, SD 0.71) was significantly lower (less impaired) ($p < 0.001$) than for the 'visual fields' (mean 3.46, SD 0.66), 'perception of movement' (mean 3.67, SD 0.92), 'visual guidance of movement' (mean 3.32, SD 0.63), 'visual search' (mean 3.98, SD 0.68), and 'visual attention' (mean 3.47, SD 0.72) domain scores.

The mean score for the 'visual search' impairment was significantly higher (more impaired) than for 'visual fields' ($p < 0.01$), 'visual guidance of movement' ($p < 0.01$), and 'visual attention' ($p < 0.01$). Lastly, the mean score for 'perception of movement' impairment was significantly higher than the 'visual guidance of movement' domain score ($p < 0.01$).

Insight Inventory score correlations

These are presented in Table 3. With regards to the neuropsychological assessment, the Insight Inventory perception of movement domain was correlated with the Benton Facial Recognition Test, all three domains of the Beery VMI, and the processing speed and perceptual reasoning domains of the WISC-IV. The insight total mean score was also correlated with all the domains of the Beery VMI as well as the perceptual reasoning domain of the WISC-IV. As expected, the insight visual guidance of movement domain was also correlated with the visual-motor integration as well as the visual perception domains of the Beery VMI. Altogether these data suggest that high scores in specific domains of the Insight Inventory, which express

increased difficulty in these particular domains, are significantly associated with low performance in domains of the WISC-IV, Beery VMI, and Benton tests.

With regards to the ophthalmological assessment, visual acuity was correlated with the insight perception of movement ($r = 0.47$, $p < 0.01$), visual search ($r = 0.47$, $p < 0.01$), and total mean score ($r = 0.42$, $p < 0.01$), whereas visual field deficits were correlated with the visual search domain ($r = 0.41$, $p = 0.01$).

Effect of the interventional plan on children's quality of life

Responses from all children and caregivers on outcome measures are presented in Tables 4 and 5. Missing entries on questionnaire domains refer to behaviours that parents and children 'did not know' how to address and left unanswered. Some participants did not have the developmental level required to understand and respond to such questions.

Parent-reported outcome measures

As shown in Table 4, parent-reported scores for all PedsQL questionnaire domains across all age groups increased from the baseline to the 6-month evaluation visit for all patients, but paired t -test analyses indicated that none of the changes were statistically significant.

Following parent feedback that the strategies seemed most useful for younger children and that parents of older children wished they had received them earlier, the data were re-analysed for children below 12 years of age.

Table 3: Correlation analysis between the Insight Inventory domains and the Benton, Beery VMI, and WISC-IV tests

Test	Visual fields	Perception of movement	Visual guidance of movement	Total
Benton Facial Recognition Test		$R=-0.47, p=0.01$		
Beery VMI visual-motor integration	$R=-0.61, p<0.01$	$R=-0.55, p<0.01$	$R=-0.48, p<0.01$	$R=-0.52, p<0.01$
Beery VMI visual perception		$R=-0.53, p<0.01$	$R=-0.42, p=0.01$	$R=-0.41, p=0.02$
Beery VMI motor coordination	$R=-0.41, p=0.02$	$R=-0.58, p<0.01$		$R=-0.42, p=0.01$
WISC-IV processing speed		$R=-0.53, p<0.01$	$R=-0.41, p=0.03$	
WISC-IV perceptual reasoning		$R=-0.50, p<0.01$		$R=-0.40, p=0.02$

Only statistically significant and moderate to strong correlations are presented (two-tailed significance reported). WISC-IV, Wechsler Intelligence Scale for Children, Fourth Edition; Beery VMI, Beery-Buktenica Developmental Test of Visual-Motor Integration.

Table 4: Child self-report and parent-report on the Pediatric Quality of Life questionnaire at baseline and 6-month follow-up

Domain	n (%)	Baseline mean (SD)	Follow-up mean (SD)	t-test
<i>Child self-report</i>				
Physical health	37 (72)	50.59 (21.70)	56.28 (23.61)	$t(36)=1.61, p=0.11$
Emotional functioning	37 (72)	62.30 (24.62)	63.51 (21.95)	$t(36)=0.30, p=0.76$
Social functioning	36 (71)	64.86 (23.10)	62.08 (24.24)	$t(35)=0.65, p=0.51$
School functioning	36 (71)	57.64 (19.66)	61.25 (22.02)	$t(35)=1.04, p=0.30$
Psychosocial health	36 (71)	61.25 (18.19)	62.22 (18.85)	$t(35)=0.33, p=0.73$
Total	37 (72)	58.28 (17.47)	60.13 (18.33)	$t(36)=0.67, p=0.50$
<i>Parent-report</i>				
Physical health	43 (84)	40.98 (23.36)	41.66 (25.09)	$t(42)=0.35, p=0.72$
Emotional functioning	43 (84)	44.30 (21.35)	46.89 (21.08)	$t(42)=1.01, p=0.31$
Social functioning	43 (84)	43.48 (21.22)	45.14 (19.29)	$t(42)=0.69, p=0.49$
School functioning	43 (84)	43.83 (18.44)	44.33 (17.07)	$t(42)=0.19, p=0.84$
Psychosocial health	43 (84)	43.54 (15.10)	45.37 (15.79)	$t(42)=1.09, p=0.27$
Total	43 (84)	42.38 (15.61)	44.05 (16.52)	$t(42)=1.27, p=0.21$

Table 5: Insight Inventory report at baseline and 6-month follow-up

Insight domain	n (%)	Baseline mean (SD)	Follow-up mean (SD)	t-test
Visual fields	40 (78)	3.41 (0.67)	3.18 (0.66)	$t(39)=2.74, p<0.01$
Perception of movement	42 (82)	3.63 (0.93)	3.35 (0.77)	$t(41)=3.17, p<0.01$
Visual guidance of movement	43 (84)	3.35 (0.64)	3.10 (0.59)	$t(42)=2.61, p=0.01$
Visual search	41 (80)	3.93 (0.67)	3.70 (0.67)	$t(40)=3.44, p<0.01$
Visual attention	43 (84)	3.52 (0.74)	3.20 (0.72)	$t(42)=2.94, p<0.01$
Recognition and navigation	43 (84)	2.58 (0.73)	2.46 (0.66)	$t(42)=1.60, p=0.11$
Total	43 (84)	3.36 (0.59)	3.13 (0.52)	$t(42)=3.94, p<0.01$

Within this subgroup, the increase in total PedsQL score was statistically significant ($p=0.02$).

In addition, there was a statistically significant increase on the physical health domain score ($t_{13}=2.37, p=0.03$) between the two visits in children aged 5 to 7 years old. It is of note that the changes in social functioning ($t_{13}=2.06, p=0.059$) and total score ($t_{13}=2.08, p=0.057$) domain scores were very close to the cut-off for statistical significance.

Table 5 summarizes parents' responses on the Insight Inventory on baseline and evaluation visits. A statistically significant decrease in the mean scores for almost all domains was observed, suggesting that nearly all domains of visual function improved significantly after the 6 months of the intervention plan in all participants.

Children-reported outcome measures

Mean scores for most domains of the child-reported PedsQL, across all age groups, increased over time.

However, paired t -tests showed that none of the changes were statistically significant. Subgroup analysis in children aged 5 to 7 years revealed that there was a statistically significant increase in the mean score of the physical health domain ($t[10]=3.12, p=0.01$) between the two visits, which was in agreement with parents' response on this domain. School functioning score change was very close to cut-off of significance ($t_0=2.04, p=0.07$), suggesting perhaps a trend for improvement for this domain, whereas the rest of the domains remained stable.

In addition, paired t -test analyses for the Functional Vision Quality of Life Questionnaire showed that there was no significant change ($t_{12}=1.27, p=0.22$) in their mean scores between the baseline (mean 56.15, SD 17.06) and evaluation visit (mean 51.53, SD 16.92). Similarly, paired t -test analyses for the Vision-related Quality of Life Questionnaire revealed that there was no significant change ($t[13]=1.07, p=0.93$) in their mean scores between the

baseline (mean 63.50, SD 16.07) and evaluation visit (mean 63.79, SD 14.00). Of note is that on subgroup analysis, the Vision-related Quality of Life score change between the two visits was very close to the cut-off of significance ($p=0.058$) in children younger than 12 years.

Subjective feedback from parents

The most beneficial strategies reported by parents involved those related to reading and navigating, generally helping the child to be calmer and more cooperative. Some parents of the older age group reported that similar strategies were already in place for their children and they wished they had known about them earlier as it took them years of practice to develop them. Parents across all age groups reported that the formal habilitation plan, whether this included new strategies or strategies already in place, empowered them (and teachers and other caregivers) and improved their confidence in trying to help their children.

DISCUSSION

While most children with CVI will not gain normal visual function, some visual improvement may be seen over time.^{19–22} Some studies suggest that interventions may promote such improvement but evidence is lacking.² A recent study showed that older age at presentation to the neuro-ophthalmologist is associated with lack of vision improvement, suggesting the importance of early diagnosis and intervention.²³ Children with CVI can often be (1) misdiagnosed, owing to the presence of additional issues including communication, cognition, or to visual–motor problems and because paediatricians and paediatric ophthalmologists have lacked a systematic approach for assessing the impact of the visual difficulties in everyday life, and (2) mismanaged, because ophthalmologists lack any practical management strategies on how problems can be ameliorated.

The present study evaluated the utility of the Insight Inventory in the assessment and intervention for a clinical sample of children aged 5 to 16 years with CVI. These children were selected as having visual acuity better than 6/60 so were at the higher functioning end of the CVI spectrum. Most were in mainstream education. Neuropsychological assessment at baseline indicated that the children's verbal abilities tended to be below the expected level for their age, but that visual cognitive and visual–motor abilities were lower still, and consistent with a degree of impairment, as would be expected in a clinical group of children with CVI. The sample also included a proportion of children who were particularly towards the lower end of the age range and who were unable to access standardized psychometric assessments.

Despite relatively good visual acuities, neuro-ophthalmological findings included a high proportion of visual field deficits (and possibly underestimated since testing was by confrontation²⁴) and oculomotor deficits. The latter showed correlations with visual perception as reported in the insight questionnaire showing the importance of

oculomotor function in visual perception, especially in areas of movement perception and visual search.

Insight Inventory findings at baseline

The Insight Inventory was found to identify information about visual–perceptual difficulties, providing valuable information about how children with CVI use their vision in everyday life. The better scores for recognition and navigation compared with other domains suggest that ventral stream processing is more resilient than dorsal stream processing in CVI as has been reported, with visual search and visual perception of movement being particularly affected.

Statistically significant correlations were found between the Insight Inventory and certain domains of the Beery VMI, WISC-IV, and Benton tests, indicating that the Insight Inventory tool is effective in eliciting and estimating visual–perceptual difficulties. By addressing everyday life situations, it yields a different, complementary set of data from formal psychometric tests. No formal neuropsychological training is necessary for such a clinical question inventory to be administered and it can be given to parents, carers, and children in paediatric and paediatric ophthalmology clinics. In addition, because the questions relate to practical everyday issues, the responses lead naturally to recommendations for practical habilitational strategies tailored to the individual child's particular problems, enhancing their learning experiences and enabling them to perform more effectively. We would therefore suggest that the 'Insight' approach may be a valuable additional assessment tool to complement formal neuropsychological assessment, where the latter is possible. We have issued this tool to specialist teachers because it is very practical and functional and enables practical strategies to be recommended and tried without medicalization.

Impact of habilitational strategies

Subjective parental feedback was very positive and borne out by the high attendance for 6-month follow-up (94%).

There was evidence of reductions in impairments as measured by the Insight Inventory at follow-up compared with baseline. This suggested that the strategies generated by the Inventory may have had specific targeted beneficial effects on everyday function.

There were no significant effects on quality of life when the sample was considered as a whole. However, subanalysis of younger children (suggested by the subjective feedback from parents) indicated an improvement from baseline to follow-up in PedsQL and Vision-related Quality of Life. One possible explanation for this could be that young children below the age of 12 years had not yet developed their own strategies compared with older children who had learnt through their own experiences and years of practice how to adapt to a given environment. Another factor may be that, in the younger children, the parents were more in control of implementation of any habilitational strategies.

These results should be interpreted with care, because, in the absence of a comparison group, it is possible that the changes happened by chance or as a consequence of the children's natural development. In addition, as a pilot study, there was no formal sample size calculation so *p*-values therefore need to be interpreted with caution. A randomized controlled trial is now underway on the basis of the encouraging preliminary results.²⁵ Future studies need to investigate the impact of the strategies on children's quality of life, including a comparison group. There may also be room for further refinement or extension of the Inventory and the strategies suggested, to better meet the needs of children aged 12 years and above or children with more complex needs.

In conclusion, CVI is now the most common cause of visual impairment in children in industrialized countries, and evidence-based assessment and management strategies are lacking. The Insight Inventory provides ophthalmologists and other professionals with a practical framework for assessing functional vision, which has been shown to accurately reflect formal measures of visual perception. In addition, it yields practical habilitational strategies. These

preliminary data show encouraging benefits in terms of functional vision in younger patients and, although there are some limitations, this study shows that even small changes in the environment or behaviour can possibly have significant impacts on young children's quality of life. Future studies that can follow these children for longer could perhaps investigate the impact of this structured tailored habilitational plan not only on children's quality of life but also on their cognitive, social, and emotional development.

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SUPPORTING INFORMATION

The following additional material may be found online:

Appendix S1: Examples of tailored habilitation strategies to address visual-perceptual problems related to each of the six domains in the Insight Inventory.

REFERENCES

1. Sakki HEA, Dale NJ, Sargent J, et al. Is there consensus in defining childhood cerebral visual impairment? A systematic review of terminology and definitions. *Br J Ophthalmol* 2018; **102**: 424–32.
2. Williams C, Northstone K, Borwick C, et al. How to help children with neurodevelopmental and visual problems: a scoping review. *Br J Ophthalmol* 2014; **98**: 6–12.
3. Mistry D, Bunce C, Wormald R, et al. Causes of certifications for severe sight impairment (blind) and sight impairment (partial sight) in children in England and Wales. *Br J Ophthalmol* 2013; **97**: 1431–6.
4. Fazzi E, Bova S, Giovenzana A, et al. Cognitive visual dysfunctions in preterm children with periventricular leukomalacia. *Dev Med Child Neurol* 2009; **51**: 974–81.
5. Macintyre-Beon C, Young D, Dutton GN, et al. Cerebral visual dysfunction in prematurely born children attending mainstream school. *Doc Ophthalmol* 2013; **127**: 89–102.
6. Macintyre-Beon C, Young D, Calvert J, et al. Reliability of a question inventory for structured history taking in children with cerebral visual impairment. *Eye* 2012; **26**: 1393.
7. Philip SS, Tsherlinga S, Thomas MM, et al. A validation of an examination protocol for cerebral visual impairment among children in a clinical population in India. *J Clin Diagn Res* 2016; **10**: NC01–4.
8. McKillop E, Dutton GN. Impairment of vision in children due to damage to the brain: a practical approach. *Br Ir Orthopt J* 2008; **5**: 8–14.
9. Williams C, Gilchrist ID, Fraser S, et al. Normative data for three tests of visuospatial function in primary school children: cross-sectional study. *Br J Ophthalmol* 2015; **99**: 752–6.
10. Crawford JR, Anderson V, Rankin PM, et al. An index-based short-form of the WISC-IV with accompanying analysis of the reliability and abnormality of differences. *Br J Clin Psychol* 2009; **49**: 235–58.
11. Wechsler D. Wechsler Intelligence Scale for Children—fourth edition. San Antonio, TX: Harcourt Assessment, 2003.
12. Wechsler D. Wechsler Preschool & Primary Scale of Intelligence – fourth UK edition (WPPSI-IV UK). London: Psychological Corporation, Pearson Education, 2013.
13. Benton AL, Varney NR, Hamsher KD. Visuospatial judgment. *A clinical test. Arch Neurol* 1978; **35**: 364–7.
14. Benton AL, Van Allen MW. Impairment in facial recognition in patients with cerebral disease. *Trans Am Neurol Assoc* 1968; **93**: 38–42.
15. Beery KE, Buktenica NA, Beery NA. The Beery-Buktenica Developmental Test of Visual-Motor Integration: administration, scoring, and teaching manual (6th edition). Minneapolis, MN: Pearson, 2010.
16. Upton P, Eiser C, Cheung I, et al. Measurement properties of the UK-English version of the Pediatric Quality of Life Inventory 4.0 (PedsQL) generic core scales. *Health Qual Life Outcomes* 2005; **3**: 22.
17. Tadic V, Cooper A, Cumberland P, et al. Measuring the quality of life of visually impaired children: first stage psychometric evaluation of the novel VQoL_CYP instrument. *PLoS ONE* 2016; **11**: e0146225.
18. Tadic V, Cooper A, Cumberland P, et al. Development of the functional vision questionnaire for children and young people with visual impairment: the FVQ_CYP. *Ophthalmology* 2013; **120**: 2725–32.
19. Khetpal V, Donahue SP. Cortical visual impairment: etiology, associated findings, and prognosis in a tertiary care setting. *J AAPOS* 2007; **11**: 235–9.
20. Matsuba CA, Jan JE. Long-term outcome of children with cortical visual impairment. *Dev Med Child Neurol* 2006; **48**: 508–12.
21. Good WV, Jan JE, Burden SK, et al. Recent advances in cortical visual impairment. *Dev Med Child Neurol* 2001; **43**: 56–60.
22. Huo R, Burden SK, Hoyt CS, et al. Chronic cortical visual impairment in children: aetiology, prognosis, and associated neurological deficits. *Br J Ophthalmol* 1999; **83**: 670–5.
23. Handa S, Saffari SE, Borchert M. Factors associated with lack of vision improvement in children with cortical visual impairment. *J Neuroophthalmol* 2018; **38**: 429–33.
24. Hellgren K, Jacobson L, Frumento P, et al. Cerebral visual impairment captured with a structured history inventory in extremely preterm born children aged 6.5 years. *J AAPOS* 2020; **24**: 28.e1–8.
25. Duke R, Eyong K, Burton K, et al. The effect of visual support strategies on the quality of life of children with cerebral palsy and cerebral visual impairment/perceptual visual dysfunction in Nigeria: study protocol for a randomized controlled trial. *Trials* 2019; **20**: 417.