Measurement of visual ability in children with cerebral palsy: a systematic review

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ABBREVIATIONS

COSMIN	Consensus-based Standards for the Selection of Measurement Instruments
CVI	Cerebral visual impairment
ICF	International Classification of Functioning, Disability and Health
ICF-CY	International Classification of Functioning, Disability and Health for Children and Youth

AIM To identify and evaluate measures of visual ability used with children with cerebral palsy (CP).
METHOD Eight databases were searched for measures of visual ability. Key selection criteria for measures were: use with children with CP; focus of visual ability measurement at the Activities and Participation domain of the International Classification of Functioning, Disability and Health (ICF). The Consensus-based Standards for the Selection of Measurement Instruments (COSMIN) Checklist was used to assess psychometric properties.
RESULTS From 6763 papers retrieved, 25 were relevant and 19 measures of visual ability were identified. Only 10 measures were supported with evidence of validity or reliability. No discriminative measure analogous to existing CP functional classification systems was found. No outcome measure valid for evaluation of visual abilities of children with CP was found.
INTERPRETATION Vision impairment is recognized as relevant to the functioning of children with CP; however, measurement of vision is most often focused at 'Body Function' levels, for example visual acuity. Measuring visual abilities in the Activities and Participation domain is important in considering how a child with CP functions in vision-related activities. The lack of psychometrically strong measures for visual ability is a gap in current clinical practices and research.

Cerebral palsy (CP) is a prevalent physical disability in childhood.[1] Its definition has been revised to identify the possibility of secondary impairments relating to vision:

> 'Cerebral palsy describes a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour, by epilepsy, and by secondary musculoskeletal problems.'[2]

Impairments additional to the motor disorder contribute to the developmental and performance challenges faced by children with CP,[3] and evidence suggests that disturbances to vision can be especially challenging for children.[4] There is a growing body of literature reporting the relationship between vision impairments and various aspects of functioning for children with CP, including gross motor, communication, cognition, self-care, and daily functioning skills.[5–11]

Being able to describe the visual abilities of children with CP, and targeting interventions to promote visual abilities, are important areas for practice and research, and valid and reliable measurement is required to establish efficacy for interventions targeting visual abilities or 'useful vision'. The 'Classification of Cerebral Palsy'[2] specifies that accompanying impairments, including vision, should be classified as either present or absent, and that if present, the extent to which they interfere with the individual's ability to function or participate in desired activities and roles should be described, but no specific guidelines are provided for this. It is recommended that vision be assessed, and measures of visual impairment (corrected vision in each eye) are accepted.

THE CHALLENGE OF TERMINOLOGY WHEN MEASURING 'VISION'

The definition of visual impairment in the World Health Organization's International Statistical Classification of Diseases and Related Health Problems (ICD-10)[12] is based on 'best corrected' vision. A level of vision impairment is obtained by measuring visual acuity with best possible

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refractive correction, and results are categorized from 'mild or no visual impairment' (visual acuity equal to or better than 6/18) to 'blindness' (no light perception, light perception, or visual acuity worse than 3/60). A recent systematic review and meta-analysis of the rates of co-occurring impairments and functional limitations in children with CP used this definition in its finding that one in 10 children with CP has a severe visual impairment or is blind.[3] These findings suggest that impaired vision is a significant problem for some children with CP; however, the authors of that review identified a lack of consistency among studies in the recording of information about vision impairments, and were consequently not able to include all vision impairment data in their analysis. Other 'visual impairments' included refractive errors, myopia, hypermetropia, astigmatism, and strabismus, in addition to the reporting of children with 'some impairment' or 'functional blindness'.

A definition or measurement of 'visual impairment' only describes the eye or visual functions being assessed, and these results, although valuable, do not specifically tell us how a child with CP functions in vision-related activities (their 'visual ability'), particularly in the presence of other comorbidities such as gross motor limitations or cognitive impairments. Children with CP may be diagnosed with visual deficits that are of ocular (eye) or cerebral (brain) origin, or a combination of both, and recognition of vision impairment resulting from damage to the brain is a rapidly growing area of research.[13] Visual impairments that result from damage to the brain may be referred to as cortical, cerebral, or neurological visual impairment. The visual abilities of a child can be impacted by impairments at any point along the primary visual pathway (eye, optic nerves, thalami, optic radiations, and primary visual cortices), in the visual association areas, or the oculomotor system.[14]

Measurement of visual impairments, at the eye or brain level, does not directly provide information on functional limitations in daily life resulting from visual dysfunction, and does not provide information on the 'positive aspects' or 'ability' levels found in children with CP. Whereas some children with CP may have a visual impairment that limits performance and restricts participation in daily life, for other children visual ability may be considered a strength.

The measurement of visual abilities is complex. Unlike visual acuity, where a count or measure of the finest detectable visual detail can be made, providing direct counts or observations of how vision is used in daily life is less straightforward; the assessor is confronted by parameters in addition to vision. Measurement of visual functioning requires conceptualisation of what constitutes the variable 'visual ability', for inferences to be made from observations.[15] The distinction between commonly used terminologies such as 'visual function' and 'functional vision' must be clarified, because the measurement of these apparently similar terms can describe very different aspects of vision-related functioning.[16] The absence of clearly defined measurement concepts is likely to lead to errors in measurement, in the interpretation of results, or both.[17]

What this paper adds

- A clear conceptual definition and framework for measuring visual ability is critical in furthering our understanding of the topic.
- No valid evaluative measures of visual ability were identified.
- There is no currently available measure of visual ability for children with cerebral palsy analogous to existing cerebral palsy functional classification systems.

A FRAMEWORK TO DESCRIBE THE MEASUREMENT OF VISION

The International Classification of Functioning, Disability and Health (ICF) was published by the World Health Organization in 2001 as a framework for measuring health and disability[18] (see Fig. S1, online supporting information), and this was followed in 2006 by the release of the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY), designed to record the characteristics specific to the developing child. In this framework, 'functioning' is a term encompassing all body functions, activities, and participation, and 'disability' is a term encompassing impairments, activity limitations, and participation restrictions. The ability of a child to function is seen as a dynamic interaction between elements of these domains and is powerfully influenced by contextual factors, including environmental barriers and facilitators to functioning, and personal factors. The ICF and ICF-CY provide a common language to describe functioning, and can serve as a connecting framework between assessments and interventions.[19] The ICF framework is now frequently used in clinical and research practice,[20] and there is a growing body of evidence reporting that impairment-based measures can only provide limited information on functional abilities.[21,22]

The ICF framework can be used to define and describe the measurement of vision, and has been used by Colenbrander to differentiate between two types of vision.[23] 'Visual functions' describe how the eye functions, with deficits described as 'visual impairments', and these have been aligned with the Body Functions and Structures domain of the ICF. 'Functional vision' describes how the child functions in vision-related activities, and this has been aligned with the Activities and Participation domain of the ICF. Functional vision is what the current authors term 'visual ability'. Although in this non-hierarchical framework no domain is superior to another, and interaction between domains is highlighted, the ICF framework provides a structure for considering where assessments and/or interventions are placed, and it defines the type of information in each domain.

'Body Functions' are the 'physiological functions of body systems (including psychological functions)', and 'Body Structures' are 'anatomical parts of the body such as organs, limbs and their components'.[18] Vision is most clearly described by the second chapter of the ICF Body Functions and Structures domain. The code b210 'Seeing functions' describes 'sensory functions relating to sensing the presence of light and sensing the form, size, shape and colour of the visual stimuli'.[24] This includes visual acuity,

visual field functions, light sensitivity, colour vision, contrast sensitivity, and the overall quality of the picture. This chapter also includes the functions of structures in and around the eye that facilitate seeing functions, including internal muscles (e.g. accommodation of the lens), external muscles (e.g. muscles to move the eyes for looking in different directions), and the eyelid (e.g. protective reflex). The codes for b210 'Seeing functions' and b2152 'Functions of external muscles of the eye' have recently been included in the ICF Core Set of categories most relevant to children and young people with CP.[25]

Vision involves more than seeing with the eyes, however, and another chapter from the ICF Body Functions and Structures domain is critical to how and what children see. The first chapter, b1 'Mental functions', includes codes for orientation, intellect, attention, memory, psychomotor functions, perception (including visual perception and visuospatial perception), and basic and higher-level cognition. These functions are all relevant and necessary to seeing, and creating useful vision. Vision may also be impaired by damage to structures related to the eye or structures of the brain.

Performance in vision-related activities is captured by the ICF Activities and Participation domain. Activity is 'the execution of a task or action by an individual', and Participation is 'involvement in a life situation'.[18] The domain chapters describe tasks, actions, and life situations where vision occurs: d1 'Learning and applying knowledge', d2 'General tasks and demands', d3 'Communication', d4 'Mobility', d5 'Self-care', d6 'Domestic life', d7 'Interpersonal interactions and relationships', d8 'Major life areas' (including education), and d9 'Community, social and civic life'.[24] There are three codes in the first chapter which are particularly relevant to using vision: d110 'Watching', d160 'Focusing attention', and d161 'Directing attention'. An example of the assessment of vision that references the ICF-CY activity areas is the work of Hyvärinen,[26] where four core areas of functioning have been identified for assessment: orientation/mobility, communication, activities of daily living, and sustained near vision tasks, such as reading.

Visual abilities can be measured for different types of impairment (i.e. ocular or cerebral visual impairment [CVI]), and the type or reason for the impairment is not the relevant factor. In this sense the measurement of vision can be descriptive of current abilities without the need to explain or interpret what is facilitating or inhibiting functioning. A valid measure of visual abilities will provide information about what a child with CP can do in vision-related activities; this is different from information that can be derived from results of measures of the eye/s or visual functions. Activity- and Participation-level measurement is influenced by 'Body Function' parameters such as cognition, visual acuity, and muscle tone; 'Environmental Factors' such as wearing glasses to aid vision, or the presence and quality of lighting and distractions; and 'Personal Factors' such as age and interest in the tasks at hand. This is consistent with the ICF Framework's depiction of these many factors as constituting a dynamic biopsychosocial model, and a report of visual ability is likely to represent an integrated assessment of 'functioning'.

Two qualifiers or constructs within the ICF Activities and Participation domain can further assist with interpreting abilities, including vision. 'Capacity' describes an individual's 'best performance', and 'performance' describes an individual's 'usual activity'.[18] A measure of visual ability that describes performance in vision-related activities would be considered to provide the most useful information on daily functioning,[27] whereas a measure that describes visual capacity provides valuable information on how a child can perform given optimal environmental conditions. Both forms of assessment were of interest in this review, because interventions are often aimed at reducing the gap between these two related aspects of functioning.[28]

MEASUREMENT OF 'VISUAL ABILITY'

The definition of vision that describes a child's functioning at the Activity and Participation domain of the ICF is the focus of the current review, and what has previously been referred to as 'functional vision' is hereafter defined as 'visual ability'. The importance of visual abilities to the functioning of children with CP, and the potential for providing clinical interventions at the Activity and Participation level, together warrant a review of the availability of this type of measure. We have addressed the complexity of defining visual ability for measurement and intervention by applying the ICF framework to this area of practice. The primary objectives of this systematic review were to identify what tools are currently available to classify and/or measure the visual ability of children with CP; and to explore, among the identified tools, the evidence for validity and reliability of visual ability measures in children with CP. The broader research question of whether interventions can be provided to children with CP and their families to improve activity performance (skills and abilities) in vision-related activities, and/or minimize the impact of vision impairment (ocular or cerebral) on daily activities and participation, cannot be answered in the absence of valid and reliable measures. This review is one step towards addressing the visual abilities of children with CP for clinicians and researchers focusing on Activity and Participation level interventions.

METHOD

The methods used in this systematic review were designed according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses.[29] The review protocol was registered online in February 2014 with the International Prospective Register of Systematic Reviews (Registration number CRD 42014006387) and can be accessed online at http://www.crd.york.ac.uk/PROSPERO/prospero.asp.

Eligibility criteria

Populations

The review is focused on the measurement of visual ability in children (aged 0–18y) with CP. A measure that has been

developed for, or used with, children with a disorder of movement and posture was considered a core requirement in the search for valid and reliable measures of visual abilities for children with CP. Studies including children with neurological impairments were eligible for inclusion when participant descriptions were suggestive of CP, for example terms such as hemiplegia, hypoxic–ischemic encephalopathy, periventricular leukomalacia or intraventricular haemorrhage, brain injury or impairment in the first 5 years of life, or where there was mention of a motor impairment (e.g. physical disability). There was no limitation placed on what percentage of participants must be children or have an eligible diagnosis.

Studies were excluded when participants were exclusively described by a diagnosis other than CP (e.g. Down syndrome) or no participants were younger than 18 years old. The paediatric focus was important because of the variations in the activities and participation of adults compared with children, and because the impairments seen in the adult population are different from those seen in paediatric populations. Studies were also excluded if participants were described as having only ocular or 'low vision' impairment – that is, with no mention or exclusion of children with physical or neurological disabilities.

Measures

Studies were sought that included measures of visual ability. 'Visual ability' was defined as 'how someone performs in vision-related activities,'[16] and measures were identified as addressing visual ability when the focus of the vision measurement was at the Activities and Participation domain of the ICF. Any tool designed or described as measuring 'functional vision' was included, and vision-specific subscales of broader tools were included. Tools that assessed components of vision that focused only on the Body Functions and Structures domain of the ICF (e.g. visual acuity, visual perception) are not considered to be measuring visual ability as defined by this review and were excluded. Measures designed for any purpose were eligible for inclusion, that is descriptive, discriminative, evaluative, and predictive measures.[30] A measure was eligible when assessment resulted in a visual ability category, level, or score. Descriptive records or checklists were excluded, as were single item measures with only two categories (e.g. 'functional vision' and 'no functional vision'). Measurement tools were not excluded on the basis of their psychometric properties.

Publication types

Quantitative interventions, diagnostic, prediction or prognostic studies, aetiological assessments, frequency, instrumentation or psychometric studies were included. Abstracts from conferences and unpublished studies were initially included, and further information sought from the authors. Letters to the editor and commentaries were excluded. Only full papers written in English were included. There was no limit placed on the publication dates of studies; it was anticipated that because of advances in technology, recent studies might have a greater focus on the measurement of Body Function elements of vision compared with the older approaches that relied on observation of performance.

Search

The search strategy was conducted in two steps. Step 1 involved the identification of visual ability measures, and Step 2 searched for evidence of validity and reliability of the identified measures. Searches were conducted in the following databases: Medline, CINAHL, PsycINFO, ERIC, A+ Education, Embase, Scopus, and the Cochrane Library. An example of the search strategy used in MEDLINE and modified for other databases is provided in Appendix S1 (online supporting information). Additionally, citations from papers and measures meeting the inclusion criteria were tracked through Web of Knowledge, and hand searching of reference lists of retrieved studies was carried out to ensure additional relevant references were identified. The searches were conducted up to April 2015.

Step 1: Three key concepts were used to guide the first search strategy to identify measures of visual ability: (1) measurement (e.g. classification, assessment), (2) cerebral palsy (e.g. hemiplegia, brain injury), and (3) vision (e.g. vision, blindness). Relevant terms and synonyms from the literature and medical subject headings (MeSH terms) and relevant terms from key literature (in title and abstract) were used to guide the search. Search results were limited to children.

Step 2: The names of the tools/measures found during the first search were used in a complementary search that aimed to identify additional papers with evidence of validity and/or reliability. The second search was conducted using the measure or author name as text words, and then combined with MeSH terms and keywords for validity and reliability. A decision was made not to seek psychometric evidence for measures containing visual subscales where these properties could not be interpreted separately from the whole measurement score.

Study selection

The first author screened all identified papers by title, and irrelevant papers were excluded. Two authors (BDD and EF) then independently assessed the titles and abstracts of papers. Papers potentially meeting the inclusion criteria were retrieved in full text and reviewed independently by the same two authors. Consensus on the inclusion or exclusion of papers was reached using additional input through discussions with a third author (CI) when required. Where papers did not provide descriptive information on a tool, further searching was undertaken and/or authors of papers were contacted as required.

Data collection process

A data extraction sheet adapted from the *CanChild* Outcome Measures Rating Form[31] was developed, piloted, and

used to summarize information from published papers, manuals, and correspondence with authors. Extracted data included: information on papers reporting use of measures; general information on the tool (e.g. name of measure, authors); the focus of measure (ICF domains); clinical utility of the measure (e.g. instructions, format, time, training, and cost); scale construction; standardization; reliability; and validity. The purpose of each measurement tool was determined by the review authors by looking at the aim, content, and use of the measure, and by using established definitions. Measures were defined as 'describing' details of what and how children function; 'discriminating' variations of an issue to identify discrete levels of function; 'evaluating' within-person change over time; and/or 'predicting' some concurrent or future status.[32] Tools were categorized as measuring visual ability at a 'performance' or 'capacity' level by analysing their aim and format of administration.

'Validity' refers to the accuracy of a measure.[33] This review evaluated the content and construct validity of included measures. Special consideration was given to the development and content of measures, because in considering measurement of a concept like 'vision' it is important first to be sure that the measure is assessing the 'right' thing. Because there is no criterion standard for visual ability measurement, in this review whenever 'criterion' validity was mentioned as a psychometric property it was rated as 'construct' validity, as done previously by de Boer et al.[34] 'Reliability' is the property of measure that shows that it is measuring something in a reproducible and consistent fashion.[31] Internal consistency, interrater reliability, intrarater reliability, and test-retest reliability were considered in this review. Reliability correlation coefficients were described according to the *CanChild* Outcome Measures Rating Form (≥0.8 as 'excellent', 0.6–0.79 as 'adequate', and <0.6 as 'poor').[31] Responsiveness is the ability of a measure to detect change within an individual over time.[30]

Quality assessment

The Consensus-based Standards for the selection of health Measurement Instruments (COSMIN) checklist was used to evaluate the methodological quality of studies investigating aspects of reliability, validity, responsiveness, and interpretability of identified measures of visual ability.[35] Measurement properties were scored on a 4-point rating scale (poor, fair, good, or excellent), and a final rating was determined from the lowest rating of any within the set of items measuring that psychometric property. Pairs of raters including BDD plus one of EF, CI, or SW-G completed the quality assessments independently, followed by discussion to reach consensus on a final rating. Consensus was reached for all ratings without involvement of a third author.

RESULTS

Search results

Search results and study selection processes that led to the identification of 19 included measures are illustrated in Figure 1. Most excluded papers measured vision at the ICF Body Functions and Structures domain – that is, visual acuity, visual field, or visual perception. A list of excluded measures is available on request from the lead author (BDD).

Included measures of visual ability

Table I summarizes the included measures of visual ability. Nine measures focused on visual performance, and were typically questionnaires administered using caregiver report.[36–44] Nine measures focused on visual capacity, and were mostly administered test items or judgment-based therapist ratings.[45–53] One measure addressed both visual performance and visual capacity.[54] Although authors did not articulate the purpose of their measure using defined terminology, it was determined by the review authors that included measures had been developed and/or used to describe, discriminate, predict, or evaluate visual ability, and some measures were intended for more than one purpose. The Atkinson Battery for Child Development for Examining Functional Vision[45] was the most commonly used measure, and the Health Utilities Index – Mark III[40] was the second most common, but most measures were described or used in only a single study. A list of studies using the measures is available in Appendix S2 (online supporting information).

The identified measures used nominal (e.g. yes or no responses in the Preverbal Visual Assessment[41]) or ordinal levels of measurement. No measure used item weighting to calculate a total score, and the level of difficulty for individual visual ability items has not been established in any measure. The scores from measures were used to describe visual skills and abilities,[38] to establish normal or estimated visual development,[41,45–47,51] to describe or predict CVI,[37,42,54] and to make recommendations about follow-up or further assessment and for intervention planning.[36,47–49,52–54]

Psychometric properties of visual ability measures

Table SI (online supporting information) summarizes the studies (n=11) that provided evidence about validity and reliability of the included measures. Studies included children with a range of motor and visual impairments (ocular and cerebral). Many of the included studies recruited participants from sites providing services to children known or suspected to have visual impairments, such as from vision clinics.[37,38,41–43,52,55,56]

Validity and reliability results for the included measures are summarized in Table SII (online supporting information). While construction of visual ability measures included comprehensive reviews of the literature and existing measures, combined with clinical experience of authors, there was no reported inclusion of children or primary caregivers in the selection of items for any visual ability measure. The Functional Visual Questionnaire,[38] Visual Assessment Procedure – Capacity, Attention and Processing,[52] and Visual Skills Inventory[43] used factor analysis and principal components analysis to confirm dimensionality;

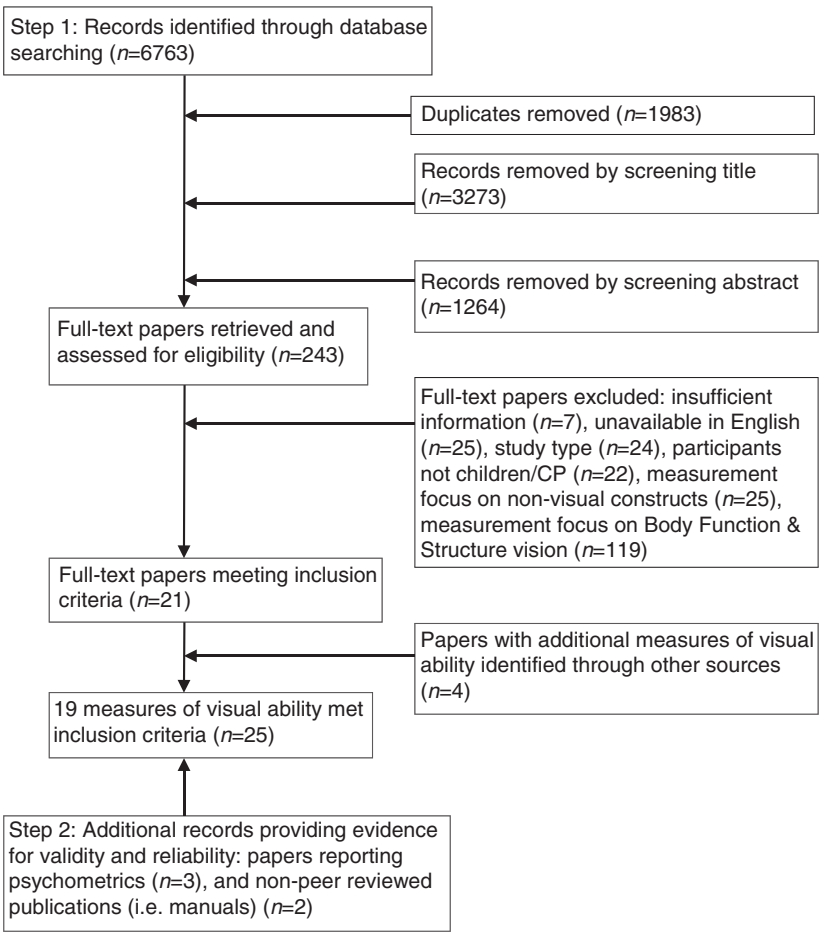

Figure 1: Flow diagram describing selection of relevant papers for inclusion in the review.

however, these factors were not incorporated into the scoring schema or used to aid interpretability of the measures. Internal consistency, test–retest, or interrater reliability were reported for six measures.[38,41,47,51,52,55,56] Clinicians in reliability studies for the CVI Range[54] and Erhardt Developmental Visual Assessment[47] had undergone training programmes in the administration and scoring of the measure, before testing. No measure reported intrarater reliability, and there were no studies of responsiveness. Although seven intervention studies were identified in the search, and six of these aimed to evaluate change in vision ability, none used an assessment tool with evidence to support validity for evaluative purposes.[36,49,53,57–60]

The visual ability subscales identified from the Health Status Classification System – Preschool,[39] Health Utilities Index – Mark III,[40] and 15-Dimension Questionnaire[44] do not allow interpretation of the vision scale separate from the other dimensions of health, and were therefore excluded from the analysis of psychometric information. Five measures had no available evidence for validity or reliability.[36,48–50,53]

The methodological quality of 10 studies reporting psychometric properties was evaluated using the COSMIN.[37,38,41–43,47,52,55,56,61] The results of this analysis can be found in Table SIII (online supporting information). No studies reported evidence for intrarater reliability, measurement error, cultural validity, or responsiveness on any measure. The overall quality of studies is primarily limited by small samples and lack of hypotheses to support construct validation. The statistical methods used in all studies were based on classical test theory. No study used an item response theory model to develop or evaluate the measure.

DISCUSSION

In this review, we sought measurement systems used to describe, discriminate, predict, or evaluate the visual abilities of children with CP, and 19 measures were identified. The need to measure vision at a functional level has been identified previously,[62–64] and this systematic review contributes an important contemporary overview of the field that could be used to inform future developments in alignment with modern approaches to measurement. The findings of this review suggest that visual ability measures are not in common use with children with CP and there is little evidence of ongoing validation of existing measures.

Table I: Summary of visual ability measures

Measure and year published	Aim of measure and target population	Purpose[a]	Measurement constructs	Administration/ response format	Scores and interpretation	Focus[b]
ABCDEFV[45] 2002	To assess functional visual capacities in children with a cognitive age of 0–6y	Descriptive Predictive	Core vision; additional tests	Administered items	Pass/fail score for each test based on normative data (*n*=318 children with typical development);[45] each failed item includes suggestions for further specific assessment or follow-up	Capacity
Alimovic et al.[36] 2011	To assess visual attention and visual communication in children with perinatal brain damage	Evaluative	Visual attention; visual communication	Judgement-based therapist rating[c]	Two scales rating function – visual attention: 'very interested in looking' to 'does not keep attention'; visual communication: 'using vision in communication (looks and response to facial expressions)' to 'does not look at other person at all'	Performance
Callier Azusa Scale[46] 1974	To assess development, including visual development in deaf-blind and multidisability children	Descriptive	Visual development	Observation; administered items	Developmental level for visual skills determined by highest level of achievement, where all lower level behaviours consistently reached; level/score corresponds with a developmental age	Capacity
CVI Questionnaire[37] 2011	To screen for cerebral visual impairment in children suspected of CVI	Discriminative Predictive	Visual attitude (fixation, visual field, visual attention, influence of environment); ventral stream; dorsal stream; complex problems; other senses; associated characteristics	Parent/ caregiver completed questionnaire	CVI characteristics rated as present/not present; sum scores interpreted for CVI prediction	Performance
CVI Range[54] 2007	To assess visual functioning in children with CVI	Descriptive Evaluative	Colour preference; need for movement; visual latency; visual field preferences; difficulties with visual complexity; light gazing; non-purposeful gaze; difficulty with distance; atypical visual reflexes; difficulty with visual novelty; absence of visually guided reach	Interview administered questionnaire; observation; administered items	Two scores: across CVI (level of functioning across behaviours) and within-CVI characteristics (how much each characteristic is interfering with vision, or how much the CVI characteristics has resolved); summary score from 0 (no functional vision) to 10 (typical or near-typical visual functioning)	Performance and capacity
EDVA[47] 1998	To measure visual development in individuals of all ages and cognitive levels (e.g. children with developmental disabilities, multiple disabilities, CP and/or learning disabilities[d])	Descriptive Evaluative	Primarily involuntary visual patterns (reflexive): pupillary reactions, doll's eye responses, and eyelid reflexes; primarily voluntary eye movements (cognitively directed): localisation (visual approach), fixation (visual grasp), ocular pursuit (visual manipulation), and gaze shift (visual release)	Administered items	Skills rated as present, normal and well-integrated; emerging or abnormal; absent; or transitional pattern replaced by more mature pattern; results indicate development level (up to 6mo) for each skill cluster, and indicate gaps in skill sequences, developmentally inappropriate patterns, and specific intervention needs	Capacity
Functional Visual Questionnaire[38] 2011	To assess daily visual performance in children with CP who are difficult to assess (severe motor, cognitive, and communicative limitations)	Descriptive	Basic visual skills; visual function during interactive play and communication situations	Educator completed questionnaire	Items rated 1 (never) to 5 (often >75%) or N/A	Performance

Table I: Continued

Measure and year published	Aim of measure and target population	Purpose[a]	Measurement constructs	Administration/ response format	Scores and interpretation	Focus[b]
Hoyt[48] 2003	To functionally evaluate vision in research study (children with PVL or infarction of the visual cortex)	Evaluative	Visual function	Judgement-based therapist rating[c]	Scale rated from 1 (light perception only) to 6 (completely normal vision); improvements in vision determined by change in level of function score	Capacity
HSCS-PS[39] 2005	To assess health status of preschool children (2.5-5y of age), including vision	Descriptive	Vision (ability to see)	Parent/ caregiver and/ or clinician completed questionnaire	Five levels of ability – 1 (sees normally without glasses e.g. able to see well enough to recognize small objects and familiar people at distance) to 5 (unable to see at all); vision not interpreted independently of other dimensions of health status	Performance
HUI-III[40] 1996	To measure health status and health-related quality of life, including vision, in people older than 5y in both clinical and general populations	Descriptive	Vision	Parent/ caregiver completed questionnaire or self-report version for ≥12y	Six levels – 1 (able to see well enough to read ordinary newsprint and recognize a friend on the other side of the street, without glasses or contact lenses) to 6 (unable to see at all); vision attribute of health status and health-related quality of life is not interpreted independently of other attributes	Performance
Institutes' Developmental Profile[49] 2006	To evaluate neurological abilities, including visual competency in brain injured populations	Evaluative	Visual competency	Judgement-based therapist rating[c]	Visual competence subscale scored from I (light reflex) to VII (reading with total understanding)	Capacity
Low Vision Checklist[50] 1999	To measure visual function in uncooperative patients (children with low vision, neurological deficits, or both)	Descriptive	Light perception; visual exploration; fixation; following; grabbing; grabbing a moving object; deambulation; optokinetic nystagmus	Administered items	Item success scored yes/no; sum of success scores divided by number administered tests; final visual quotient score ranges from 0 (absence of visual behaviour responses) to 1 (presence of visual behavioural responses to all tests)	Capacity
PreViAs[41] 2014	To assess visual behaviour/visual cognitive abilities in infants <24mo	Descriptive	Visual attention; visual communication; visual-motor coordination; visual processing	Parent/ caregiver completed questionnaire	Visual behaviours rated yes/no; total score for each domain place child within or outside normal range of visual maturation	Performance
Short CVI Questionnaire[42] 2012	To diagnose CVI in children with good visual acuity suspected to have CVI	Discriminative	Dorsal stream; ventral stream	Questionnaire[c]	Presence of problems scored no/yes/ sometimes; sum score not valid predictor of CVI diagnosis	Performance
SoGS[51] 1987	To screen development, including visual skills in children birth to 5y	Descriptive	Function (functional response to visual stimuli); comprehension (interpretation of intact visual function)	Administered items	Achieved skills recorded and summed for total score and plotted against chronological age to produce developmental level; performance two bands below age range is recommended for further investigation	Capacity

Table I: Continued

Measure and year published	Aim of measure and target population	Purpose[a]	Measurement constructs	Administration/ response format	Scores and interpretation	Focus[b]
VAP-CAP[52] 1993	To assess visual functioning (capacity, processing, and attention) in children who are visually impaired	Descriptive	Low vision (visual capacity and basic levels of visual attention – how much the child can see and how visual attention is motivated); visual processing (visual perceptual and visual cognitive abilities and the more complex levels of visual attention)	Administered items	Scoring method unclear; range of response options and interpretation described;[e] highlights areas of visual deficit and areas for intervention	Capacity
Visual Skills Inventory[43] 2007	To evaluate visual skills and responses to familiar situations in children with neurological impairment	Descriptive	Visual skills and responses to familiar situations – visual recognition of food and objects; visual guided behaviours with social content	Parent/ caregiver completed questionnaire	Questions scored yes/no for visual behaviours; additional scores for some items e.g. distance for vision from 6 feet to <1 foot	Performance
Wong et al[53] 2006	To assess functional visual outcome in research study (children aged 18mo–14.5y with central or peripheral visual disorder, and lack of clinical visual recovery for at least 12mo)	Evaluative	Functional vision	Judgement-based therapist rating[c]	Scale from 1 (light perception only) to 5 (completely normal vision); study interpreted positive outcomes as improvement of one level	Capacity
15-D[44] 1994	To measure health-related quality of life, including vision, in adults (aged 16y+)[f]	Descriptive	Vision	Self-administered questionnaire	5 level scale: 1 (I see normally, i.e. I can read newspapers and TV text without difficulty, with or without glasses) to 5 (I cannot see enough to walk about without a guide, i.e. I am almost or completely blind); vision scale not interpreted separately from other health domains	Performance

[a]Purpose of measure (to describe, discriminate, predict, or evaluate) determined by review authors based on aim, content, and use of the measure. [b]Focus of measure (Performance or Capacity) determined by review authors based on measurement aim and format. [c]Administration format interpreted by review authors from limited information. [d]UK usage for mental retardation. [e]The Instructional Video and VAP-CAP Kit which were unavailable may provide additional information on scoring and interpretation. [f]16D (for adolescents aged 12–15y) and 17D (for children aged 8–11y) were developed based on the original 15D. ABCDEFV, Atkinson Battery for Child Development for Examining Functional Vision; CVI, cerebral or cortical visual impairment; EDVA, Erhardt Developmental Visual Assessment; CP, cerebral palsy; PVL, periventricular leukomalacia; HSCS-PS, Health Status Classification System – Preschool; HUI-III, Health Utilities Index – Mark III; PreViAs, Preverbal Visual Assessment; SoGS, Schedule of Growing Skills; VAP-CAP, Visual Assessment Procedure – Capacity, Attention, and Processing; 15-D, 15-Dimension Questionnaire.

For this review the ICF was used as a conceptual framework to define the measurement of visual ability in relation to a child's level of functioning in vision-related activities. This approach measures vision at the Activities and Participation domain, rather than measuring vision according to the Body Functions and Structures domain, where inferences need to be made about levels of functioning in daily activities. Despite the frequent use of the ICF in rehabilitation research since its publication in 2001, only the authors of the Visual Function Questionnaire made reference to this framework.

The review identified some evidence of measures discriminating between levels of visual ability,[37,42] but there is currently no available measure to discriminate between levels of daily visual functioning analogous to existing functional classification systems for children with CP: the Gross Motor Function Classification System,[65] Manual Ability Classification System,[66] Communication Function Classification System,[67] and Eating and Drinking Ability Classification System.[68] Most available measures of visual ability are descriptive, and there are no measures validated for predictive or evaluative purposes.

Current issues in visual ability measurement

The results of this systematic review highlight a number of problems with the measurement of visual ability. First, a measure should be designed and validated for a specific purpose,[69] but most measures included in this review did not clearly state the intended purpose of the 'assessment'. Analysis of the included measures by the review authors suggests that most existing measures are meant to be descriptive tools.

Second, the items selected for a measure are important, and items in a descriptive measure should include all the characteristics that discriminate between individuals.[33] The absence of children with CP, their primary caregivers, and practitioners in the development of included measures makes it difficult to determine whether all domains of visual ability that are meaningful to the target population have been included. Furthermore, vision is a complex construct and it is important, in establishing validity, to determine whether only visual ability is being measured or whether other factors are also making a significant contribution to the assessment of ability (e.g. motor skills, cognition, or attention). Non-visual factors influence performance in vision-related activities, and therefore probably the measurement of visual ability. For example, the cognitive or learning skills of a child may influence their ability to see and recognize letters. Visual ability has been established as a unidimensional construct for measurement in other populations,[70,71] and therefore it appears theoretically possible to achieve this in a measure suitable for children with CP. When determining the measurement construct it is also important not to be influenced by the name of a measure, but instead to look at the content and items.[32] The Atkinson Battery for Child Development for Examining Functional Vision would appear to consist primarily of tests and items measuring vision at the Body Functions domain of the ICF, and although it includes 'Functional Vision' in the battery name, it may not provide the type of information required by a practitioner interested in the direct assessment of daily visual functioning.

The third problem is that some measures included in this review used the common but problematic approach of adding raw nominal or ordinal scores to determine the 'level' of ability, and the relative contribution of each item to the total score was either not considered or not reported.[33,72] This problem has previously been explained by Massof,[15] and an example from the Functional Visual Questionnaire illustrates the issue. Two items from this measure, 'Looks around when entering a room' and 'Responds to facial expressions', have the same ordered response alternatives that range from 'never' to 'often >75%' on a 5-point Likert scale. Although both items load on the same task-orientated visual skills factor, looking around a room is not likely to require the same level of visual ability as recognizing and responding to facial expressions. Averaging the scores on items such as these to produce a score would not provide a valid measure of daily visual performance, because the items themselves are not equivalent. In measurement systems such as this, the score estimating a person's visual ability depends on the choice of items. The scoring option of 'not relevant' – or an equivalent option that results in no numerical score – was present in a number of the included measures and provides additional compromise to the measurement score.[38,46,50] The degree to which one can assign any qualitative meaning to quantitative scores is also a major limitation of the visual ability measures in this review.

Finally, measures included in this review with evidence of construct validity relied heavily on correlations with, or discrimination from, Body Functions or Impairment-level measures.[37,38,42,43,56,61] This was done in the absence of specific hypotheses for evidence of construct validity. The visual acuity and visual perceptual measures commonly used in these validation studies do not measure the same construct as visual ability or functioning in vision-related activities, and while positive correlations could be expected, a priori hypotheses that specify both the direction and the strength of the anticipated relationships need to be developed and tested to support construct validity.[35]

Implications for practice and research

The focus of this systematic review should encourage practitioners and researchers to consider the possibility of visual impairments (ocular or cerebral) influencing the activities and participation of children with CP. Vision should be considered when gathering information from families, setting goals, and considering the focus for assessment and intervention. The results of this review can be used to guide visual ability measurement in practice and research. Clinical reasoning should include the consideration of purpose, content, and focus of available measures,

and tools chosen must have proven validity and reliability for the intended purpose and population.

Based on the results of this review, five tools have some evidence to support their validity and reliability as descriptive performance measures of daily visual functioning.[37,38,41,43,54] The CVI Range assesses visual functioning in children with CVI, the CVI Questionnaire screens for CVI, the Functional Visual Questionnaire assesses daily visual performance in children with CP who are difficult to assess, and the Visual Skills Inventory evaluates visual skills and responses in neurologically impaired children. The Preverbal Visual Assessment assesses visual behaviour and visual cognitive abilities in infants, although there is only limited evidence of construct validity for children with motor impairments. Until psychometric evidence is available to support the use of these measures in clinical practice, questionnaires can be used to guide information-gathering on areas of daily functioning that are commonly limited by visual impairment. A useful finding of this review is the knowledge that measures using questionnaires to gather information from parents result in information about a child's daily performance, while clinician-administered measures provide information on best performance. There are also six tools with some psychometric evidence to support their use as descriptive measures of visual capacity (best performance).[45–47,51,52,54]

There are currently no valid measures of visual ability for predictive or evaluative purposes. In the absence of valid and reliable evaluative measures, it is impossible to quantify whether interventions are without efficacy or whether we are simply unable to detect clinically important change. The current lack of evidence about interventions to improve the visual abilities of children with CP adds urgency to the need for valid and reliable measures of visual abilities.[73–75] Until valid and reliable visual ability measures are developed, it is recommended that practitioners consider using individualized goal-based measures such as the Canadian Occupational Performance Measure[76] or Goal Attainment Scaling[77] for the evaluation of interventions related to specific visual ability goals. These outcome measures have established validity, reliability, and are sensitive to change.[78]

Future directions for research

Several directions for future research have been highlighted by this review. First, further analysis of the conceptual foundations of identified measures is essential, because clinicians and researchers must know whether they are measuring visual ability or some other construct. Linking items from measures to specific chapters and codes of the ICF using Cieza's established linking rules[79] will clarify which content and tools focus at an item level on measuring visual ability. Preliminary analysis of the content of included visual ability measures at a subscale level identifies frequently occurring constructs such as attention, communication and social interactions, visual processing, visual motor coordination, and the role of the environment and other senses (e.g. touch, listening). Further analysis of content may also provide insight into whether vision measured within the context of functional activities is a measure of activity level performance, or whether scoring occurs at the Body Function level.[22]

Second, the review results also suggest the need for a classification system to describe 'levels' of visual functioning in children with CP analogous to existing functional classification systems, for example the Manual Ability Classification System.[66] Third, future research should seek confirmation from children with CP and their families that all characteristics relating to levels of visual functioning, and those that are meaningful, have been identified. Fourth, there is a need for evaluative measures of visual ability for use in intervention studies and clinical practice. Parents and practitioners are likely to have valuable insights on what is functionally important in the daily lives of children with CP, and which abilities are likely to change after intervention.[30] Fifth, the dimensionality of a measure of visual ability needs to be investigated to confirm whether measurement of this construct can be achieved in a single scale. Sixth, a hierarchy for visual abilities should be established using methods such as item response theory, and using interval level measurement. And finally, systems for the qualitative interpretation of scores must also be developed for families, practitioners, and researchers to make use of quantitative scores.

To move this field of research forward, future studies need to consider the spectrum of children diagnosed with CP, including age and functional levels. Researchers are encouraged to select and describe participants using the Gross Motor Function Classification System, Manual Ability Classification System, and Communication Function Classification System. Limiting factors for a number of the included measures in this review are the focus on subsets of the CP population, or not all measurement items being relevant for all children. Children with CP present with a diverse range of functional abilities, including varied levels of motor and cognitive abilities. It is also suggested that – in the future, as a complement to visual diagnoses – measures of visual ability should focus not only on the underlying reasons for impairment (i.e. CVI), but rather on levels of visual ability in daily activities. This approach, focusing on ability, has been well established in other functional measurement systems for children with CP.[27] This review also highlights the importance of good quality psychometric studies. An increasing awareness and use of checklists such as the COSMIN rating system would help in designing and reporting future high-quality studies in support of measurement systems.

Benefits from focusing on the functional impact of visual impairments are likely to include: increased focus on and monitoring of the development of visual abilities; increased analysis of how vision impacts activity performance; and increased focus on visual abilities as facilitators or barriers to participation. Interventions will be developed to target visual abilities, and levels of visual ability may be able to

guide the selection of management options. Consistency in terminology will increase the clarity of communication about vision and visual abilities, and enable comparisons across CP populations and research studies. Research into other areas of functioning (e.g. manual abilities) will also benefit from the ability to stratify participants by level of visual ability. Establishing the validity of visual ability measurement systems for predictive purposes will also assist services and policy makers with planning for future intervention and care needs.

Limitations

There are some limitations to this review. First, studies not published in English were excluded, so some measures of visual ability may have been missed. Second, this review focused specifically on the identification of measurement in children with CP. Although this criterion was established because the primary disability of this population is a movement or posture impairment that is likely to need consideration in item selection, it is acknowledged that measures developed for use with children without physical impairments might also provide valuable information. Future research may include validation studies of other existing measures for children with CP (e.g. CVI Inventory[80]). Third, this review has not reported on clinical utility of available measures, focusing instead on measurement properties.

Finally, although inclusion criteria focused this review on the identification of visual measurement at the Activities and Participation level of the ICF, the extent to which the selected measures met this aim requires further assessment, as some included measures appear to contain both Body Function and Activities and Participation level items. Body Function items are likely to assess different aspects of visual ability from items related to Activities and Participation. While analysis of visual ability measures at an item level was beyond the scope of this review, further exploration may contribute to our understanding of the visual ability construct in children with CP, and provide evidence on the usefulness of existing visual ability measures at an item level.

CONCLUSION

This systematic review used the ICF framework to define, identify, and evaluate currently available measures of visual ability for children with CP. Results show that while visual ability is being measured, there is no consensus on which visual abilities should be measured, nor how, and there is generally a lack of strong psychometric properties. We are currently unable to discriminate the range of visual abilities across the CP population, and there is no valid method to evaluate interventions aiming to change visual ability. While measurement in the Body Functions and Structures domain, such as visual acuity tests for measuring eye function, and cognitive test for measuring perception of vision, will continue to be important, it is hoped that the ICF framework can be used by researchers, practitioners, and policy administrators to understand the inadequacy of relying on impairment measures to describe levels of functioning and disability. In the future, vision measurement should occur at both the Body Function and Activity and Participation levels of the ICF.

The results of this review can be used to develop the ways that visual impairment and daily functioning are considered, and to guide future development of valid and reliable visual ability measurement in both new and existing tools. Although not an easy task, appropriately developed and psychometrically sound measures would have tremendous clinical and practical utility for children with CP because they would promote understanding of the impact visual impairment (ocular or cerebral) can have on daily functioning and other areas of development, and facilitate the development of future interventions targeted at visual abilities.

SUPPORTING INFORMATION

The following additional material may be found online:

Figure S1: International Classification of Functioning, Disability and Health (ICF), as published by the World Health Organization in 2001.[18]

Appendix S1: Example of database search strategies.

Appendix S2: Included studies using a measure of visual ability.

Table SI: Summary of studies reporting data on Validity and Reliability.

Table SII: Summary of results: Validity and Reliability.

Table SIII: Quality assessment of psychometric studies according to COSMIN criteria.

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