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The Functional Vision for Communication Questionnaire (FVC-Q): Exploring Parental Report of Non-Speaking Children's Fixation Skills Using a Structured History-Taking Approach

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ABSTRACT

This paper explores whether a structured history-taking tool yields useful descriptions of children's looking skills. Parents of 32 children referred to a specialist communication clinic reported their child's looking skills using the Functional Vision for Communication Questionnaire (FVC-Q), providing descriptions of single object fixation, fixation shifts between objects and fixation shifts from object to person. Descriptions were compared with clinical assessment. 24/32 children were reported to have some limitation in fixation. Limitation was subsequently seen in 30/32 children. Parental report and assessment agreed fully in 23/32 (72%). The largest area of discrepancy was object-person fixation shifts, with five children not observed to show this behavior despite its being reported. Findings indicate a structured questionnaire yields description of fixations, which correspond well with clinical assessment. Descriptions supported discussion between parents and clinicians. It is proposed that the FVC-Q is a valuable tool in supporting clinicians in eliciting information about fixation skills.

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Introduction

Cerebral Palsy and Communication

Children with cerebral palsy (CP) and other physical disabilities, which may result in impairments of speech or accurate pointing are at increased risk of communication and cognitive difficulties.^{1,2} Where impairments of movement are more severe, restrictions to parent-child interaction can occur,³ with reduced profiles of activity and participation being more common.⁴ For children whose oro-motor skills preclude the reliable use of speech for communication, the use of augmentative and alternative communication (AAC) strategies or equipment is often considered.⁵ This may include the use of pictures or graphic symbols as vocabulary for selection in high-tech (powered, computer-based) or low-tech (printed, paper-based) systems. Where limb movement difficulties mean that children may struggle to indicate choices by touching or pointing to their AAC system, controlled, deliberate fixation of gaze on a target item may be considered as an alternative vocabulary selection method. In combination with fixation shifts from item to communication partner this strategy may be referred to as "eye pointing."^{6,7} The intentional use of fixation and fixation shifts in a low-tech system, and fixation shifts between target item and communication partner to "show" an object of interest or preference can serve a similar function to finger pointing. The use of controlled fixation is also important when engaging with AAC systems accessed using eye-gaze control – a technology where the user interacts

with a computer using only the movement and rest of their gaze.⁸ Purposeful use of eye-gaze control devices relies on the child shifting gaze and fixating on areas of the screen to select an item or otherwise interact with software. Confidence in observing fixation skills is therefore essential in clinical decision making for many high- and low-tech AAC interventions with this population of children, in order to achieve most effective access and use.^{6,7}

Cerebral Palsy and Vision

The increased risk of ocular and visual difficulty in children with cerebral palsy and other physical disabilities has been well documented, and the benefits of comprehensive evaluation are well established.⁹⁻¹³ Some questionnaire tools have been developed to enable identification of visual difficulties in children with disabilities,¹⁴ but the emphasis is on documentation of visual detection skills (what a child can see), with little guidance on how to structure observations to confirm detection or other looking behaviors relevant to communication and interaction, including eye pointing. Pueyo and colleagues¹⁵ developed a tool, which highlights the crucial interplay between vision and other skills including cognition and social interaction but again there is little guidance on how and what to observe.

Less well documented is the importance of children's functional vision skills, defined as skills related to the use of "vision to perform critical or meaningful tasks."¹⁶ These skills describe

how a person uses their vision for functional, goal-directed tasks such as making choices or signaling attention, as distinct from descriptions of visual functions, which are measurable aspects of how the eye functions, for example visual acuity or refractive error.^{17,18} Whilst recognizing that impaired visual functions impact on a child's functional vision, Deramore Denver and colleagues¹⁸ have highlighted the need to extend assessment of vision beyond impairments occurring within the ICF domain of "Body Structure" to ensure that assessment of skills allied to the domains of Activity and Participation are also considered. Comparatively, little attention has been paid to specifying the functional impact of the difficulties identified during ocular and visual assessment^{18,19} or the modifications of play and communication materials which can help. In contrast to impairments of the structure or function of the eye, observations of functional vision do not require a specialist eye clinic or full ophthalmological examination. The observation of these skills by "non-vision specialists" is encouraged as part of communication and AAC assessment,⁶ in order to provide insight into how best to support children to use their gaze skills. Whilst there could be many different reasons for children presenting with particular profiles of functional vision skills, the underlying causes are not the focus of the work discussed in this paper. Children with visual impairment (defined as a reduction in visual acuity, or clarity of vision, measured using tests appropriate to the child's age and skill level) may present as having comparatively little difficulty using their vision functionally, whereas children whose visual acuity is within normal range may have significant difficulties. In this paper, the authors seek to explore the use of a structured history-taking approach to gain useful reports of children's functional vision skills which can help structure assessment.

Reporting and Description of Functional Vision Skills

When considering functional vision skills for communication, observation of what the child looks at and when they look, assumes importance not only for caregivers and communication partners but also for therapists and teachers during assessment and intervention. Showing objects or symbols is a common way of providing tangible vocabulary options for communication. The clinical experience of the authors,²⁰ indicates that spontaneous descriptions of a child's looking skills are rarely given in clinical history taking of communication skills, even where the child is reported to be using eye pointing as a communication or response modality. Previous work by the authors has shown, however, that parents can provide important insights into their children's looking skills particularly when supported to think about specific aspects of functional vision, such as fixation or eye contact. Parallels exist for this in other areas: parents of typically developing children can reliably report language skills,²¹ although this may be more complicated in atypical development.²² Miller and colleagues²³ provided some evidence that parents can reliably report language skills in young children with ASD and suggest that a combination of parent report and direct assessment may be most informative.

- Does your child look directly at a toy/object when this is placed directly in front of him/her?
- Is your child slow in looking at the object placed in front of him/her?
- Does your child need an additional prompt to look at the object or toy? (please tell us what: e.g. sound, movement)
- If two or more objects are in front of your child, does s/he look at each toy in turn, inspecting each toy? This is sometimes called shifting gaze.
- If there are 2 or more objects in front of your child, is it easy to tell which object your child is looking at?
- Does your child shift gaze between an object and a person (that is, does your child look at an object and then look at a person, or the other way round)

Figure 1. Questions from the FVC-Q that relate to fixation responses.

To this end, a structured history-taking approach was devised by the first author for administration during assessment of communication in children for whom intelligible speech and directed pointing are not possible. The *Functional Vision for Communication Questionnaire* (FVC-Q), described here, aims to elicit detailed, qualitative descriptions of functional vision skills relevant to communication during clinical history taking. The questionnaire breaks down functional vision for communication into components that can be more readily observed and reported on by non-vision specialists, including parents. The full FVC-Q comprises 18 questions, of which six relate to a child's fixations (Figure 1).

This retrospective case note audit investigates whether structured history taking can yield detailed parental descriptions of functional visual skills for communication, and compares these parent descriptions with the clinical assessment findings of a specialist pediatric communication clinic.

Methods

The work was registered (ref: 19BI03) with the Joint Research & Development Office at Great Ormond Street Hospital for Children NHS Foundation Trust and UCL Institute for Child Health.

Participants

All children whose data was included in this study were referred to a specialist pediatric, multidisciplinary communication clinic over a two-year period by a clinical professional, typically a pediatrician or speech and language therapist.

Review of the clinic's records for this period indicated that the FVC-Q was used with 32 children. Reasons for use of the questionnaire were: 1) referrals contained explicit descriptions of eye pointing or the current use of functional vision for communication or, 2) uncertainties were expressed regarding how the child's vision impacted on decisions about communication support or technology use, including the suitability of eye-gaze access technology.

Table 1. Participant characteristics.

	Participants	
	<i>n</i>	% of category
Total	32	100.0
Gender		
Male	18	56.3
Female	14	43.7
Primary Diagnosis		
Cerebral Palsy	25	78.1
Rett Syndrome	1	3.2
Neurodegenerative condition	1	3.2
Spinal Muscular Atrophy	1	3.2
Traumatic Brain Injury	1	3.2
Other Brain Injury	3	9.1
Speech/Expressive Language Ability		
Unable to Speak or Sign	30	93.8
Single Words, Reduced Intelligibility	2	6.2
GMFCS (for cerebral palsy only) ¹		
IV	4	16.0
V	21	84.0
MACS (for cerebral palsy only) ²		
IV	10	40.0
V	15	60.0

¹Gross Motor Function Classification Scale³².

²Manual Ability Classification Scale³³.

Data extracted from the clinical records of the 32 children included in the study showed that 17 (53.1%) were referred with a request for assessment for use of eye-gaze control technology for communication, 14 (43.8%) were reported to be using eye pointing, 10 (31.3%) were reported to use looking as a response modality in choice making situations, 5 (15.6%) were referred with explicit requests for assessment of functional vision for communication and 3 (9.4%) were referred because of uncertainty about their vision. For 15 children, there was more than one indicator for using the FVC-Q.

Characteristics of children included in the study are presented in Table 1. Chronological age ranged from 2 years 11 months to 14 years 6 months (M_{age} 85 months, SD 40 months). Receptive language skills on assessment ranged from no contextual understanding (no understanding of words/phrases accompanied by gesture or environmental clues) to understanding of two information carrying words without additional clues.²⁴ All children had receptive language impairments, which indicated cognitive impairment.²⁵

Structured History Taking

Any concerns about a child's vision or functional visual skills were noted and information given by referrers on the use of functional vision for communication was extracted from referral documents by the clinical team and discussed as part of the structured clinical history taking with the family, which precedes assessment and advice as part of the clinic's standard practice. The FVC-Q was administered for all children ($n = 32$) by the first author, a consultant pediatrician. Responders were parents ($n = 31$) and caregivers. The word "looking" was used rather than "fixation" and the term "gaze shift" was explained as "looking at more than one thing in turn." Six questions addressed fixation responses (Figure 1).

Assessment

Children's functional vision skills were observed during a receptive language assessment and during free play. In this study, the primary goal was to observe children's looking behaviors, using language assessment tools and play objects as ways of eliciting these. Since it is known^{12,13} that children with CP may use a diverse range of response modalities as alternatives to pointing, a range of assessment tools were used to maximize opportunities for child engagement. A speech and language therapist assessed the key word understanding of all children using a standard set of real everyday objects and/or a single word vocabulary subtest from the *Peabody Picture Vocabulary Test – 4th Edition*²⁶ or the *Derbyshire Language Scheme*.²⁴ Both assessments include the presentation of common items such as keys, book, banana, toy car, cup, sock, toy bus, spoon. In both assessments, the child is given a verbal instruction (e.g. "Where is the bus?") and responds using their most consistent or established response mode. Response modes included direct reach/point, speech, gaze fixation or partner assisted scanning. The choice of assessment format was made by the speech and language therapist based on their clinical judgment, history-taking and the presentation of the child in clinic. For children not demonstrating understanding of object labels, a discussion with parents and familiar adults (such as local therapists and educators) was undertaken, coupled with observation of the child playing with both familiar and unfamiliar toys. This was used to judge whether contextual understanding of familiar words and phrases was present, emerging or not evident.

The clinic uses a standard protocol of observations and assessments to document and describe children's functional vision skills. In addition to observations of fixation, all children in the study were assessed for the presence/absence of squint and a resolution acuity assessment was administered using either Cardiff²⁷ or grating acuity cards.^{28–30} Assessment was conducted with children wearing any prescribed spectacles.

Fixation Skills

Children's fixation skills were assessed through presentation of materials used in the receptive language assessment. Assessment consisted of a free play "warm up" session, followed by a language assessment using real items. One item was positioned at one end of an opaque board and presented at the child's eye level. The child was observed for evidence of fixation on the single item before a second item was placed at the other end of the opaque board to offer a fixed choice of two items in the receptive language assessment. Spacing of 25–30 cm was used with either a horizontal or vertical presentation of the board.

Each pair of items was presented up to four times, to create sufficient opportunity for each child to look at the items. Each showing of the items was accompanied by a verbal prompt similar to "Where is the..." or "Can you look at the..." A minimum of four different pairs of items was shown to each child to minimize the possibility that un motivating items could impact on fixation responses. Fixation was considered to have occurred if the child's eyes were directed toward the target and held on it for at least two seconds, and

on more than one presentation. Fixation was recorded irrespective of the correctness of the child's responses to the receptive language assessment prompts. Horizontal placement was used initially unless parents reported that vertical placement was more commonly used. If fixations were not observed with horizontal placement vertical placement was then trialed. Fixation was judged independently of responses to receptive language assessment – fixation was still scored even if the child fixated on an incorrect choice in the language task. The opaque board was used so that a second observer, standing behind the tester reported on whether the child fixated to the left or right (top or bottom if the items were presented vertically). The blinding of this second observer ensured their judgments were not influenced by knowledge of the object's location or assumptions about the child's fixation skills or receptive language level. Assessment of fixation concentrated on three key skills: fixation on single targets (single target fixation), fixation shifts between two targets (target–target fixation shifts), and fixation shifts between an object and a person (target-person fixation shifts). Fixations were judged to have occurred if these were observed by both observers.

Data Analysis

Data were collected in an Excel spreadsheet by the lead author and anonymized for review.

Results

Administration of the FVC-Q took 10–15 minutes. Parents often gave detailed and reflective descriptions of their child's skills, such as “We don't show her two things, it would be hard for her to look,” “He just about looks at one thing. It is hard for him to do this. The therapist told us to show him two but he doesn't look at two things,” “Sometimes I have difficulty in telling if he is looking at [the object] - there is confusion and I don't know what is going on with his eyes,” “Her looking is abnormal and I don't show her more than one thing – the direction of her looking is very hard to read,” “His eyes are not there when you are talking to him” and “She doesn't look much at things.” Several parents remarked that they could not recall ever having been asked to describe their child's looking skills before.

Fixation Skills

FVC-Q Fixation Responses

Parents' and caregivers' descriptions of the three key fixation skills under consideration (single target fixation, target–target fixation shifts and target-person fixation shifts) were classified as either “no reported limitations” or as having limitations in one, two, or three key fixation skills. Twenty-four children (75%) were reported to have some limitation in one or more fixation skills. Limitations in single target fixation were reported for only one child, in target–target shifts for 7 children and target-person shifts for 24 children.

Comparison of FVC-Q Responses with Assessment Findings

Of the 32 children included in the study, 30 (94%) were found on clinical observation to have some limitation in their fixation skills.

The comparison between parents' responses to the FVC-Q questions on fixation and the clinical assessment of these skills for each individual child is presented in Table 2. FVC-Q reports and clinical observation agreed fully in 23 cases (72%), partially in 7 cases (22%) and there was no agreement in 2 cases (6%). Where there was partial agreement, this was characterized by parents reporting skills that were not seen on observation – there were no instances of parents reporting a limitation in a skill that was subsequently observed by clinicians. The largest area of discrepancy was item-person fixation shift, with five parental reports of this behavior not seen on subsequent clinical observation. Where there was no agreement between the FVC-Q report and clinical observation ($n = 2$) it was notable that parents reported the child was capable of all three fixation skills, whereas observation could not confirm these skills.

Outcome of Acuity Assessment

Children's acuity is presented in Table 2. Acuity measures were obtained for 17 children, and these were within normal limits in 3. Of the 14 with reduced acuity, this was mild in 3, moderate in 7 and severe in 4. Nine children had undetermined acuity; of these six showed fixation skills which indicated positive evidence of visual detection or recognition. Visual detection refers simply to the ability to visually detect the presence of a silent visual target. Detection is possible even where acuity reduction causes significant blur, and it can be confirmed in children whose visual acuity is too low to be captured by acuity card testing procedures. In the remaining, three children (P22, P24, P29) evidence of detection or recognition was not obtained. In all three cases, engagement with the child was difficult to establish and neither visual impairment nor cognitive impairment could be excluded.

Six children were found to have very severe acuity reduction (5 with detection vision at best, 1 with no evidence of detection) which was insufficient to support visual discrimination and recognition of communication materials. All six of these children with severe acuity reduction displayed markedly atypical visual behavior throughout assessment, with single object fixation observed in three children, object–object fixation shifts in one and no observations of object-person shift.

Discussion

This retrospective case note study addressed the assessment of fixation in children with significant movement limitations. The study looked at parental report of these skills using the FVC-Q as part of structured history taking, yielding parental descriptions which corresponded highly with subsequent assessment. In many cases (72%), parental report tallied with clinical observation and, where there was a difference between report and observation, this served as a basis for discussion between parents and professionals.

Parents' descriptions were often qualitatively rich, with insightful observations given in response to FVC-Q items that could be used to guide assessment and intervention. Many parents commented that they valued being asked to explicitly report observations that had long concerned them.

Table 2. Comparison of parent report and assessment observations.

	Parent Report (FVC-Q)			Assessment Findings			Agreement	Visual Acuity (LOGMar ¹ Equivalent where obtained)
	Single Object	Object-Object	Object-Person	Single Object	Object-Object	Object-Person		
P01	Y	Y	N	Y	Y	N	FULL	Normal
P02	Y	N	N	Y	N	N	FULL	Severe VI (1.1)
P03	Y	Y	N	N	N	N	PARTIAL	Severe VI (1.17)
P04	Y	Y	N	Y	Y	N	FULL	Unconfirmed – Detects Objects
P05	Y	Y	N	Y	Y	N	FULL	Unconfirmed – Object Recognition
P06	Y	N	N	Y	N	N	FULL	Detection Vision Only
P07	Y	N	N	Y	N	N	FULL	Severe VI (1.1)
P08	Y	N	N	Y	N	N	FULL	Severe VI (1.26)
P09	Y	Y	N	Y	Y	N	FULL	Moderate VI (0.8)
P10	Y	Y	Y	Y	Y	N	PARTIAL	Unconfirmed – Object Recognition
P11	Y	Y	N	Y	N	N	PARTIAL	Moderate VI (1.0)
P12	Y	Y	N	Y	Y	N	FULL	Moderate VI (1.0)
P13	Y	Y	N	Y	Y	N	FULL	Moderate VI (1.0)
P14	Y	Y	N	Y	Y	N	FULL	Mild VI (0.5)
P15	Y	Y	N	Y	Y	N	FULL	Moderate (0.9)
P16	N	N	N	N	N	N	FULL	Unconfirmed – Object Recognition
P17	Y	Y	N	Y	Y	N	FULL	Mild VI (0.4)
P18	Y	N	N	Y	N	N	FULL	Detection Vision Only
P19	Y	Y	Y	N	N	N	NONE	Detection Vision Only
P20	Y	Y	N	Y	Y	N	FULL	Unconfirmed – Detects Objects
P21	Y	N	N	Y	N	N	FULL	Unconfirmed – Object Recognition
P22	Y	Y	Y	Y	Y	N	PARTIAL	Unconfirmed
P23	Y	Y	Y	Y	Y	Y	FULL	Mild VI (0.4)
P24	Y	Y	Y	Y	Y	N	PARTIAL	Unconfirmed
P25	Y	Y	Y	Y	Y	Y	FULL	Normal
P26	Y	Y	N	Y	Y	N	FULL	Normal
P27	Y	Y	Y	Y	Y	N	PARTIAL	Moderate VI (0.7)
P28	Y	Y	N	Y	Y	N	FULL	Unconfirmed – Object Recognition
P29	Y	Y	N	Y	Y	N	FULL	Unconfirmed
P30	Y	Y	N	N	N	N	PARTIAL	Unconfirmed – Detects Objects
P31	Y	Y	Y	N	N	N	NONE	Detection Vision Only
P32	Y	Y	N	Y	Y	N	FULL	Moderate VI (1.0)

¹LOGMar = Logarithm of the Minimum Angle of Resolution. Positive scores on this scale represent a degree of visual impairment, with normal vision represented by a LOGMar score of 0. Scores ≤ 0.5 are considered a mild visual impairment, ≤ 1.0 are considered moderate visual impairment and >1.0 indicates a severe visual impairment³⁴.

Although infrequent, reasons for poor agreement between parental description and clinical assessment warrant consideration. In all cases of disagreement, skills were reported by parents that were not seen on clinical observation. It may, of course, have been the case that the child did not respond to assessment, due to a variety of factors (fatigue, discomfort, motivation). A further and important possibility relates to previous eye clinic visits. When a professional in such a clinic reports that a child has no eye problems, this may relate to eye examination, refraction, and basic fixing and following skills only. Parents may understandably assume that no vision problems are present when reassurance of “normal” eyes is given.

The assessment used a standard range of test materials and play objects. It is possible that children may have shown different responses to familiar objects, or to their own toys, however it was decided to use standard materials and objects wherever possible to minimize variation between children. Only children who were not able to respond to standard materials might have benefitted from further assessment with familiar items and in such cases, their responses were informally observed as part of initial observation and history taking.

The results obtained in this study can be seen as a starting point for dialogue between parents and professionals about how children’s fixation skills are assessed and reported. The findings indicate that it is clinically just as important to know

where there is a mismatch between report and observation as it is to know when they are aligned. It is the basis for the discussion that is important, rather than complete alignment between parental report and professional observation.

The assessments in this study were not recorded, the use of video recording and subsequent review may offer an interesting area of future investigation, with teams of parents and professionals evaluating recordings of children’s fixations to advance discussion or to ensure agreement on the behaviors that are being described.

Six children were found to have severely reduced acuity, which resulted in significant limitations of their functional use of vision. This did not appear to impact on agreement between FVC-Q report and clinical observations of fixation. Vision at this level of reduced acuity requires substantial adaptation and limited reliance on visual materials.^{11,31}

The FVC-Q can be seen as a tool which could be used alongside descriptive measures such as the *Eye-Pointing Classification Scale* (EPCS).⁷ Eye pointing may be used as a response modality or selection method in the context of assessment where pointing with hands or other body parts is not reliable. When discussing eye pointing for communication, it is important that observers are confident of the distinction between purposeful eye pointing to signal a selection or choice and the child simply “looking” to investigate, explore or resolve an object.⁶ Because eye-

pointing involves gaze shifts between another person and the item of interest, reporting of this behavior can be affected by the familiarity of the child and their communication partner. The FVC-Q asks parents to describe their child's fixations in a way that does not presume any level of social or linguistic ability, complimenting the EPCS by providing insight into how parents feel their children's fixations are used generally, beyond the clinical setting. This provides clinicians with a greater scope of insight on which to base clinical discussions about children's use of fixation and eye pointing. The results of this study suggest that the questionnaire may be useful in eliciting responses about these component skills from parents/caregivers by asking for descriptions of their child's usual responses.

Conclusion

A structured clinical history eliciting details of patterns of fixation can provide useful descriptions which can inform communication assessment. Therapists and teachers may find such a tool useful, both to elicit parental descriptions and to structure observations during assessment and therapeutic work. This study suggests that a tool such as the FVC-Q may be a helpful way to support non-vision-specialists in starting discussions around how children use their vision and the impact of this on communication. A combination of careful history taking, structured observation and assessment is proposed to address questions about how children use vision in communication. The FVC-Q supported parents and clinicians in this study to collaborate in exploring children's looking skills.

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