Social communicative variation in 1-3 year olds with severe visual impairment

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ABSTRACT

Although the social communicative domain is recognised as being at risk in young children with visual impairment (VI), few tools are available for identifying those most at risk or the aspects that are most vulnerable. A standard parent interview – Social Communication Interview for young children with visual impairment (SOCI-VI), was developed and tested with 55 parents of 17 profoundly, 15 severely VI and 23 normally sighted children; mean age 22 months (range 10-40 months). The 35 item SOCI-VI 35 showed adequate inter-rater and test-retest reliability ($p<0.001$). Thirteen of 35 items discriminated within and between the vision groups (ANOVA p 0.008). The group with profound VI scored significantly lower than the Sighted group on the reduced 13 item SOCI-VI 13 (t test p 0.002), the disparity being greatest for items exploring joint attention. The reduced SOCI-VI 13 showed adequate internal consistency (Cronbach alpha > 0.75) and concurrent validity with the Vineland adaptation questionnaire within a randomised VI subgroup (r 0.8, $p<0.01$). The study reveals trends in early social communicative development in the young VI population and provides preliminary reliability and validity testing for future research within a clinical context.

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Keywords: visual impairment, blindness, preschool, infants, social communication, social development, joint attention. **Abbreviations:** VI: Visual impairment; SVI: severely visually impaired, PVI: profoundly visually impaired; CDPVS: congenital disorders of the peripheral visual system; SOCI-VI: Social Communication Interview for young children with visual impairment; SOC-VI 13: Social Communication Interview (13 items); SOC-VI 35: Social Communication Interview (35 items).

INTRODUCTION

Concern about the social communicative development of young children with congenital visual impairment has been raised by many professional groups (Cass, Sonksen & McConachie, 1994; Keeler 1958, Preisler, 1991, Sonksen, 1993, Recchia, 1997; Rogers & Puchalski, 1984; Rowland, 1983; Urwin, 1983) and include self-centredness, lack of social interest, tactile defensiveness, limited communicative attempts, and difficulties in joint attention. Small sample studies have noted a long term risk of autism in young visually impaired children (Brown et al 1997, Hobson & Bishop, 2003, Parr et al 2010, Pring 2006 , Tadic et al 2010) and larger database studies of preschool children with congenital disorders of the peripheral visual system (CDPVS) have revealed a high incidence of severe 'developmental setback'/ autistic regression (Cass et al 1994, Dale and Sonksen 2002, Sonksen and Dale 2002) and of clinical autism (Absoud et al 2010). The social communicative domain may be especially vulnerable because of the intensity of vision-dependent behaviours such as eye contact, facial expression, gaze monitoring, imitation and gesture.

Although an observational schedule has been recently validated (Absoud et al 2010) there is, to the authors' knowledge, no standard interview tool available with which to detect early social communicative difficulties in preschool children with VI. The need to establish which infants and preschoolers are most at risk and which developmental aspects are most vulnerable is of diagnostic and preventative import. There are no normative measures of social communication development for this population, raising a methodological challenge of tool choice. Existing screening schedules for young Sighted children include vision-dependent behaviours such as gaze, joint visual attention and gesture (e.g., CHAT, Baron-Cohen et al., 2000) and cannot be used reliably with children with VI. As children with VI show one to two years' delay in social adaptation and language compared with Sighted infants (Reynell & Zinkin, 1975; Reynell, 1978), normative scales of social adaptation and communication of the Sighted child (Vineland Adaptive Behavior Scale VABS, Sparrow et al, 1984) are not necessarily valid. Hence, a novel parent interview schedule, the *Social Communication Interview for young children with visual impairment (SOCI-VI),* was designed by our group for this study. The 35 questions all targeted social communicative

behaviour and our aim was to test their reliability and validity and subsequently incorporate those that best differentiated between children with and without social communicative difficulties into the clinician's wider developmental interview with the parent.

The study reported here investigated early social communicative competencies in children with VI aged 10-40 months using the novel *SOCI-VI 35* and subsequently the *SOCI-VI 13.* Parental interviewing was chosen as a cost-effective reliable method for collecting data about early social communicative behaviours because parents have been shown to be highly knowledgeable of these behaviours (Dewart and Summers 1995) and the reliability and validity of parental information on their child's communicative and language development has been demonstrated (Camaioni et al 1991; Dale, 1991). The study aimed to identify areas of strength and weakness in social communicative behaviour in young children with VI. On the basis of previous research on other aspects of development, we anticipated that the children with the most profound VI would be most delayed in this area and most at risk of social communicative disorders though there is likely to be individual variation within this subgroup (Cass et al 1994, Dale and Sonksen 2002, McConachie and Moore 1994, Preisler 1991, Reynell and Zinkin 1978, Tadic et al 2009). A randomised subgroup of the total sample was investigated for reliability and concurrent validity with a standard measure of adaptive behaviour that is not specifically adapted for VI children. This preliminary investigation will provide a platform for wider construct validation of the measure in the future.

METHODS

Recruitment and sampling

Thirty two children with VI were consecutively identified through the developmental vision clinic at the national paediatric hospital, XXXXXXX Hospital (28/32) and a trawl of paediatricians and ophthalmologists in the region (4/32). The children attending the developmental vision clinic were originally referred for specialist assessment and management of their vision and development. Inclusion criteria for the VI sample were: i) age 10 - 40 months, ii) 'potentially simple' congenital disorders of the peripheral visual disorder i.e. of the globe, retina, anterior optic nerve (CDPVS) and iii) visual impairment in the severe-profound VI range – see next paragraph. An age-matched

Sighted group (n= 23) was recruited from an inner London day nursery, serving a mixed socio-economic urban population. Children with identified motor or hearing impairment or learning difficulties in the first year of life were excluded in the VI and Sighted groups.

Participant identification and characteristics

The participants were 32 children with VI and 23 children with normally developing vision (Sighted). For analysis, the group was classified according to vision level – profound visual impairment (PVI) – light perception or worse (n=17), severe visual impairment (SVI) – basic 'form' vision or higher, according to Near Detection Scale of Functional Vision and Keeler grating acuity (Cass et al 1994, Sonksen, 1983, Sonksen and Dale 2002). The vision of Sighted children was in the normal range for their age. Individual visual diagnoses and visual levels for the VI group are shown in Table 1. The children's chronological ages and vision groups are presented in Table 2 (there was no significant difference in chronological age per vision group F (2,54)=0.341; p= .712). The study was approved through the Great Ormond Street Hospital Ethics committee.

(Insert Table 1 and Table2)

Materials

A draft questionnaire comprising 35 questions was developed by our team, which did not rely on sighted behaviours like gaze and pointing (see Appendix). Initial item selection and content validity was gained through review of the research literature and schedules of social communicative development in Sighted and VI infants (Brambring, Dewart & Summers, 1995; Dobslaw et al, 1987, Seibert et al 1982, Wetherby and Prizant 2002), and through discussion amongst members of our multidisciplinary clinical team who were experienced in assessment and management of young children with VI. The items were phrased in language that would be user-friendly. All questions had forced-choice and open-ended elements (with standard probes in some instances to elicit incidence of behaviour). Incidence was defined as occurrence of the target behaviour in the previous four weeks and was rated on an ordinal measure of 0 (no incidence), 1 (occasional; occurred once or twice) and 2 (well established, occurred regularly). An independent description of

the behaviour for each item was required from the parent, to ensure accuracy of reporting. For statistical analysis, code of 0 and 1 were grouped together as 'no or low incidence' (Code 0) and 2 was rated as 'definite incidence' (Code 1). The questionnaire was piloted with six parents; any questions that proved ambiguous or difficult to understand or to code reliably were modified or discarded by the team. The data from the pilot was not included in the study analysis.

Procedure

Parents (all mothers) were interviewed at home by a trained interviewer who was not informed of the child's level of vision prior to visiting. The interview lasted between 45 minutes to 1½ hours and was audio taped. Test retest agreement reliability was tested on eight randomly selected children with mean interval of 34.3 days (range 28-45) between first and second interview. Inter-rater reliability was examined by comparison of the interviewer and an independent researcher coding the audiotape (110 items, 5 audiotapes).

A randomised subgroup of 27 parents of 10 PVI, 11 SVI, and 6 Sighted children was interviewed with the Communication and Socialisation subscales of the *Vineland Adaptive Behaviour Scale - VABS*) (Sparrow et al 1984). It was hypothesised that there would be a significant correlation of the SOCI-VI with a standard measure of communication and socialisation, but not a total correlation as the Vineland was not designed for, or normed on, a VI sample.

RESULTS

Properties of the SOCI VI 35 questionnaire

Using a square contingency table and the Chi square distribution for reliability (Joleyami 1990), a satisfactory association between the two interviews (189.8, $p<0.001$ Chi square) and between raters was established (54.6, $p<0.001$ Chi square) suggesting adequate test-retest and inter-rater reliability respectively. . Missing responses were noted on 4 of 35 items; only one item 'Responds positively if parent joins activity' was omitted by 3 parents (3.6%). The remaining pattern of the missing values was negligible (<2%) and non-systematic. Of the 35 items in the interview, there was a ceiling effect on 22 items, indicating a good and wide repertoire of achieved socio-communicative behaviours (e.g. 'Does s/he react differently to yours and to a stranger's voice?'; 'Does s/he respond when you talk to him/her?) by all three groups of children. Only 13 items showed within group variation and were, therefore selected for further analyses.

Internal consistency of the 13 item scale (SOCI-VI 13) was good (combined sample Cronbach $\alpha=.826$; and Cronbach $\alpha= .806$, .801, and .759 for the PVI, SVI and Sighted group respectively). Missing values (1 item for 1 child with PVI and 2 children with SVI, although not the same item) were replaced by the mean of the rest of the items in the scale. The SOCI-VI 13 composite score - indicating total incidence of target behaviours - was derived by adding up the responses on the 13 items and transforming them to a 0 -100 scale; a higher score being indicative of a higher repertoire of social communicative behaviours.

The SOCI-VI 13 composite scores correlated significantly with chronological age for the SVI ($r=.567$, $p<.05$) and the Sighted group ($r=.732$, $p<.001$), suggesting that the interview tapped into a developmental trend for the SVI and Sighted group. However, the correlation with age was not significant for the PVI group ($r=311$, $p=.225$), which appeared to show a more heterogeneous and unpredictable developmental picture.

Social communicative variability: within group comparisons

The between group differences between the three vision groups was examined on the SOCI-VI 13 composite score (means and standard deviations shown in Table 2). 1-way ANOVA revealed a significant effect of vision group ($F(2,52)=5.367$; $p=.008$). Post hoc t-tests (with Bonferroni correction for 3 comparisons) showed that this difference was significant only between the PVI and Sighted groups ($t(38)=-3.295$, $p=.002$). Difference between the PVI and SVI ($t(30)=-1.844$, $p=.075$), and SVI and Sighted groups ($t(36)=-1.026$; $p=.312$) was not significant.

(Insert Table 3)

Table 3 shows the proportions of children showing target behaviours on SOCI-VI 13. In line with the results of ANOVA, the pattern of ability appears to be decreasing with visual level on most behaviours, although some notable similarities can be observed between SVI and Sighted groups e.g. Items 15, 26 and 30. Two items particularly differentiated the PVI group from the SVI and Sighted groups, but there was individual variation within the PVI group. Only 24% of children with PVI were reported to share experience of playing with a toy with their parent (Item 26), compared to over 70% of children in the other two groups. Similarly, compared to children with PVI, twice as many children with SVI were reported to initiate sharing of a focus of interest with their parent (Item 27), with the incidence highest for the Sighted group

Validity of SOCI-VI 13 with standard measure

The SOCI-VI 13 scores were correlated with the VABS scores in the two VI groups (SVI: VABS Socialisation r=.832, p<0.01, VABS Total r=.683, p<0.05; PVI: VABS Socialisation r=.811, p<0.01. VABS Total r=.809, p<0.01) but not in the Sighted (ns).

DISCUSSION

Social communication competencies were identified in young children aged 10-40 months with severe visual impairment, using the newly developed SOCI-VI 35 interview for VI children in the

preschool age range. Both VI and Sighted children were reported by parents to show a range of social and communicative skills across the age range, with a high mean total score and narrow standard deviation. The majority of items were recorded in all three groups, suggesting a similar incidence and repertoire of affective and social skills in the early years. Since most children were near ceiling level in incidence, the full repertoire of social communicative skills of this age range may be underestimated.

The positively reported behaviours included those relating to positive affect, social responsiveness and engagement, attachment behaviour, reactions to strangers, recognition of social games, attracting attention and taking vocal turns (see Appendix). In Sighted children, they would be expected to emerge during the period of 'primary intersubjectivity' during the later part of the first year and in the second year of life (Trevarthen, 1979). In line with the research findings of others, early social reciprocity and responsiveness appears to be successfully organised in infants and young children with VI, thereby via non-visual, as well as visual, sensory channels (Bigelow, 2003; Preisler, 1991, Rowland, 1983; Urwin, 1983;). This finding does not exclude the possibility of more subtle *qualitative* or frequency differences between the groups or differing ages of emergence, but these issues were not addressed by this study.

Because the intention for the future use of the SOCI-VI is as a quick interview measure that detects social communication variability and 'at risk' preschool children with VI, the 13 items that showed within group variability were selected for more detailed analysis. As predicted in the Introduction, ANOVA on the thirteen items revealed a significant effect of vision level. Again in line with predictions, the PVI group, who had no vision or light perception only, scored significantly lower than the SVI group, and interestingly, the SVI and Sighted groups did not differ significantly from each other. Thus basic levels of 'form' vision present in the SVI appear to confer some early protection and resilience to the social communicative process.

Two questions in particular were found to distinguish between the vision groups. These questions (Item 25 'shares experience with toy', Item 26, 'shares interest in event') related to the sharing and

communicating about the child's experience and interests: Parents of children with PVI were less likely to report that their child was showing these target behaviours, whereas most parents of SVI and Sighted children gave positive reporting. Sharing experience of a toy or an interest in an event is considered to require joint attention abilities, including coordinating attention with another's attention and joint referencing to an external referent, and would be expected to emerge by 11-14 months in normally sighted children (Trevarthen & Hubley, 1978). Our systematic evidence concurs with observations of others that profoundly visually impaired infants and young children may have difficulties in joint attention and sharing interests and experiences with adults, especially during toy play (Preisler, 1991; Recchia, 1997). It also fits with the theory that the mechanisms involved in early joint attention abilities are primarily *vision* dependent, including a shared attention mechanism (Baron-Cohen, 1995) and triadic person-object-person interaction (Hobson, 1993). Lack of behavioural alternatives to 'visual' joint attention may hinder the young preverbal VI child from detecting the referents of their parents' language and acquiring shared meaning and may have a direct or cumulative effect on joint referential attention (Bigelow, 2003, Hobson, 1993).

A third question regarding *Stopping an activity when told 'No'* also differentiated the children with PVI from the other two groups, suggesting a greater degree of self direction and resistance to adult control and direction in this subgroup. Resistance to adult-directed attention shifting has previously been demonstrated in a comparable sample (Tadic et al 2009).

However, the SOCI-VI 13 interview also showed that there was variation within the PVI group and this was not related to age. This finding is in line with other studies showing variation within the PVI group and a distinction between those progressing more steadily and those who are significantly at risk of developmental difficulties, setback' and autistic signs in the early years (Cass et al 1994, Dale and Sonksen 2002, Sonksen and Dale 2002, Parr et al 2010, Absoud et al 2010). This is of clinical interest as it suggests that the interview differentiates those children who are progressing well and those who are having greater difficulty independent of chronological age. Cognitive ability was not measured in this study; it is therefore not known whether these delays were linked to general cognitive impairment or were specific to the social and communicative domain. It is

planned to investigate further the relationship between SOCI-VI 13 and cognitive and language developmental quotients within a prospective clinical sample (study in progress). We are still in the early days of unpicking the pattern of associations between early developmental processes including social competence and language and cognition in children with PVI, but more recent studies are advancing our knowledge base (Tadic et al., 2009).

The findings must be considered within the limits of applied clinical research. Sources of potential bias and limits to generalisation include potential clinical referral bias to a specialist health service. The parent responders may have been inaccurate or misinterpreted their child's behaviour, particularly those with VI children (Fraiberg, 1977). However the SOCI-VI 35 was used within an interviewer-led interview with probes for behavioural description to increase reliability of parent reporting and rating. Although matched in chronological age the vision groups were relatively small. Within these constraints, the SOCI-VI 35 interview was found to have satisfactory test-retest and inter-rater reliability. This differs from the reported low test-retest reliability of the Social-Emotional scale of the Bielefeld Developmental Test for Blind Infants and Preschoolers (Brambring et al., 1987; Tröster & Brambring, 1992), suggesting that the behavioural items of the SOCI-VI 35 are of higher stability and therefore greater developmental significance.

Preliminary reliability and validity analysis suggests that the SOCI-VI 13 shows some psychometric promise for becoming a standardised clinical interview scale. In addition to good internal consistency, the SOCI-VI 13 showed strong positive correlation with the Vineland Socialisation and Communication subscales for both VI groups. As only thirteen items of the SOCI-VI 35 showed within group variation and the remaining items reached ceiling level for the group, it is not known whether the full 35 or reduced 13 scale would be more valid and appropriate for a younger age group (0-24 months). Also the SOCI-VI 13 may be stronger for discriminating variation within the PVI than the SVI and Sighted groups as there were ceiling effects for these groups.

In summary, this study has demonstrated that a non-vision dependent measure of early social development and communication is needed to capture the variation in abilities and difficulties in

social communication of children with differing levels of congenital visual impairment. Our draft measure - the SOCI-VI 35 - which is still in development, can be administered reliably with parents of young children with profound and severe visual impairment. The SOCI–VI 13 illustrated progress of social communication in PVI, SVI and Sighted children and enabled comparisons to be made with respect to incidence of individual behaviours between these groups. The study highlighted key behaviours in the area of joint referential and joint attentional development showing significantly lower incidence in the PVI subgroup and which may be part of the symptomatology of developmental setback and early signs of autism in this subgroup. Analysis of frequency and quality of behaviour in a larger sample may reveal further important trends. Future research to standardise and provide norms for the SOCI-VI 13 with a larger sample of children with 'potentially simple' congenital disorders of the peripheral visual system would pave the way for a scientifically robust tool for future clinical and research application.

Appendix: ***Social Communication Interview for Young Children with Visual Impairment (SOCI-VI 35)***.

NB summary of behavioural items; not actual words

Item

1. Response to verbal approach
2. Social engagement of adults
3. Enjoyment of cuddles
4. Social smiling
6. Social laughter
7. Response to calming behaviour
8. Reaction to separation
9. Reaction to reunion
10. Reaction to physical lifting (stranger)
11. Reaction to voice (stranger)
12. Discrimination of familiar and stranger's voice
13. Showing affection
14. Reaction to novel surroundings
15. Attracting attention
16. Indication wanting action repeated
17. Indication wanting game stopped
18. Taking vocal turns
19. Imitation of sounds or actions
20. Extension of imitation to turn-taking
21. Recognition of social rhyme game
22. Anticipation of social rhyme game action
23. Requesting repeat of social rhyme game
24. Initiation of social rhyme game
25. Social playing with favoured object

26. Sharing experience with toy

27. Sharing interest in event

28. Positive response if parent joins activity

29. Reaction when toy removed

30. Stopping activity when told ‘No’

31. Protesting if thwarted

32. Negative communication (‘No’)

33. Affirmative communication (‘Yes’)

34. Complying with requests

35. Making requests or expressing desires

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TABLES

Table 1: Distribution of visual disorders according to visual level group

Visual disorder	*PVI*	*SVI*	*Total*
Albinism	0	3	3
Bilateral aniridia with glaucoma	0	1	1
Bilateral optic nerve hypoplasia	3	3	6
Familial exudative vitreo retinopathy	0	1	1
Leber's Amaurosis	6	2	8
Anophthalmos and Peter's anomaly	1	0	1
Bilateral microphthalmia	2	2	4
Multiple opacities and scleral cornea	0	1	1
Norrie's Disease	3	0	3
Persistent primary hyperplastic vitreous	1	0	1
Retinal dysplasia	0	1	1
Septo-optic dysplasia *	1	1	2
	17	15	32

**During the course of the study, two children who initially had a diagnosis of optic nerve hypoplasia received the diagnosis of septo-optic dysplasia, putting them in the 'potentially complicated' CDPVS group (Sonksen & Dale, 2002). Analysis run with and without the two children showed similar trends and they have therefore been included in the final report.*

Table 2: Descriptive statistics

	PVI (n=17)	***SVI (n=15)***	***Sighted (n=23)***
Gender ratio			
Male/Female	12/5	8/7	11/12
Age			
Mean	23.7	22.5	21.3
(SD)	(10.6)	(8.5)	(8.7)
SOCI-VI 13 composite score			
Mean %	65.2	80	86.3
(SD)	(24)	(21.1)	(16.6)

Table 3: Percentage of children in each group showing individual SOCI-VI 13 behaviours

Item no	*SOCI 13 items*	*PVI*	*SVI*	*Sighted*
15	Tries to attract attention	88 %	100%	100%
16	Indicates wants action repeated	88%	87%	96%
22	Anticipates rhyme game action	76%	93%	96%
23	Requests repeat of rhyme game	82%	73%	91%
24	Initiates rhyme game	47%	67%	61%
25	Social play with favoured object	47%	60%	65%
26	Shares experience with toy	24%	73%	74%
27	Shares interest in event	29%	64%	78%
28	Responds positively if parent joins activity	76%	85%	100%
30	Stops activity when told ‘No’	56%	87%	87%
32	Indicates ‘No’	94%	87%	91%
33	Indicates ‘Yes’	71%	80%	83%
35	Make requests or show desires	71%	93%	100%