

BACCH and child development and disability

G149 NATIONAL STUDY OF FIVE YEAR OLD ICSI CONCEIVED CHILDREN COMPARED WITH NATURALLY AND IVF CONCEIVED CONTROLS

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Aims: To investigate the physical and neurodevelopmental wellbeing of ICSI, conventional IVF and naturally conceived controls five year olds.

Methods: IVF and ICSI children were recruited through fertility clinics, naturally conceived children were recruited through schools/nurseries. Children were singleton, first born and caucasian. A paediatrician ascertained a sociodemographic, medical and developmental history and performed a physical examination including visual testing, pure tone audiometry, measurement of growth and ascertainment of congenital abnormalities. A psychologist (who was blinded to conception type) assessed the child using WPPSI-R, McCarthy, and Bene-Anthony family relations test.

Results: 188 ICSI, 159 IVF and 163 controls were assessed. A range of sociodemographic factors, including social class, parental level of education, maternal smoking, and parental drinking were comparable between groups. Mean maternal age of study children, 34.4 years, was comparable to IVF group, 35.2 years, but both were significantly older than naturally conceived controls, 32.0 years ($p=0.0001$). There was no sex bias, but study children, 5.06 years, and control children, 5.02 years, were slightly older than IVF children, 4.96 years ($p=0.01$). Study children were born slightly less mature at 38.6 vs 39.2 weeks for IVF and controls. Height, weight and head circumference were not statistically different at examination. There was no increase in hospital admissions in either group and the causes of childhood illnesses and surgery were no different. Combined major and minor congenital abnormality rates were also comparable (ICSI 13/45, IVF 5/47, control 9/32). WPPSI-R, McCarthy and Bene-Anthony scores were comparable and around the mean for age. IVF children were less likely to be left handed: 5.5% ICSI, 4.8% controls, 3.8% IVF ($p=0.05$).

Conclusions: Evidence to date in this ongoing UK project suggests that when a study is designed to exclude confounding variables (eg prematurity, higher order births), ICSI *per se* appears safe. However, a much larger cohort is required to definitively address the risk of congenital abnormalities.

G150 COMPARATIVE DEVELOPMENT OF TWINS AND SINGLETONS

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Background: Twins are born earlier and have lower birth weight compared to singletons. It is important to determine whether these factors affect subsequent mental development.

Aim: To compare development of twins with singleton children.

Methods: Cohort study of 98 twin pairs and 122 singletons born at Liverpool Women's hospital between May, 1999 and May, 2001. Development assessment was performed on all the subjects in their second year using the Griffiths Mental and Developmental Scales. A neurological examination was performed using Optimality score to exclude children with neurological problems that may directly affect the development process. The scores were adjusted for differences in birth weight (BW) and gestational age (GA).

Results: The general and sub-quotients for all the developmental skills were lower among twins compared to singletons. However after adjusting for GA and BW there was no difference. See table.

Conclusions: Developmental skills are attained at a slower rate among twins compared to singletons. This delay is associated with lower gestational age and birth weight. Further follow-up is needed to determine whether this trend persists in later childhood.

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	Difference in means (95% CI; p value)	
	Before adjustment	After adjustment*
Locomotor	11.3 (7.6-15.0; <0.001)	0.6 (-4.1 to 5.4; 0.8)
Personal-Social	9.1 (6.4-11.8; <0.001)	1.7 (-1.7 to 5.3; 0.3)
Hearing and Language	6.7 (3.9-9.6; <0.001)	0.4 (-3.2 to 4.2; 0.8)
Eye and Hand	10.2 (7.5-12.9; <0.001)	2.9 (-0.5 to 6.4; 0.1)
Performance	10.3 (7.3-13.2; <0.001)	2.4 (-1.4 to 6.2; 0.2)
General Quotient	9.9 (7.5-12.3; <0.001)	1.6 (-1.3 to 4.6; 0.2)

*Adjusted for GA and BW.

G151 A PARENT REPORT MEASURE OF CHILD DEVELOPMENT FOR PRETERM INFANTS

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Background: Parent report may provide a cost and time efficient alternative to standardised assessments for the purposes of measuring neuro-developmental outcome, particularly for large epidemiological or research studies. To date, the validity of parental measures of cognitive development has not been investigated in very preterm infants, and few have reported on the diagnostic utility of these measures. We have adapted a parent report questionnaire of cognitive development for use in very preterm infants, and report validity, reliability, and diagnostic utility.

Methods: Sixty-four two-year-old children born ≤ 30 weeks gestational age were assessed using the Mental Development Index of the Bayley Scales of Infant Development II (BSID-II), and their parents completed the questionnaire. The questionnaire comprised non-verbal cognition, vocabulary, sentence complexity, temperament, and socio-demographic sub-scales.

Results: Mean BSID-II MDI was 81.0 (SD 19.0). Significant correlations between each of the separate and summed cognitive sub-scale scores and MDI scores ($r = 0.54 - 0.68$, $p < 0.001$) indicated good concurrent validity; the strongest correlation was between the parent report composite scores and MDI. Diagnostic utility of the parent report composite score for an MDI < 70 was assessed: the area under the ROC curve was 0.86 and the optimal cut-off produced equal sensitivity and specificity (81%). Discriminant validity and test-retest reliability were also demonstrated. The accuracy of parent reporting was not significantly affected by social factors.

Conclusion: Our questionnaire provides a reliable diagnostic measure of cognitive development in very preterm infants and may be employed as an outcome measure in randomised trials or large population surveys.

G152 USE OF THE INTERNET BY PARENTS AND CARERS OF PHYSICALLY DISABLED CHILDREN

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Aim: The Internet is an increasingly popular source of information. Not surprisingly parents are amongst the growing numbers of users. It is estimated that about half the people with access to the Internet utilise it to seek health information. This study was designed to look at the prevalence of Internet access and usage patterns amongst parents/carers who had a child with a chronic physical disability.

Method: The study was performed using a questionnaire as a study tool. The parents of children who attended Wilson Stuart School, Birmingham, a special school for children with physical disabilities, were asked to participate. Completed questionnaires were analysed using Excel and free text to record the results and further statistical analysis was performed.

Results: Out of a total of 142, 84 completed questionnaires were received, giving a response rate of 59%. Non responders were statistically more likely to come from Asian than non-Asian background. 55% of the responding parents had access to the Internet, mostly in their own home (80%). Half used the Internet frequently, half of parents with Internet access used it to search about aspects of their child's health. Most felt they found information easily (25/26), that it was useful (26/26) and easy to understand (24/25). More than half

shared the information retrieved with other family members, yet less than a quarter shared it with the doctors involved in their child's care. The majority of parents had no help from their clinicians in seeking suitable Internet sites yet most felt this help would have been beneficial.

Conclusion: Families are utilising the Internet to educate themselves about their child's condition. They consider this process easy and useful. Parents feel clinicians have a role in directing them to useful sites. The Internet is here to stay and we must work together as partners with these parents for the benefit of their children.

G153 IS THERE A FRAXE PHENOTYPE? A SYSTEMATIC REVIEW

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Aims: FRAXE was first recognised as genotypically distinct from the more common form of Fragile X, FRAXA, around 10 years ago. The aim of this study was to determine whether a clinical and behavioural phenotype could be defined from current literature.

Methods: A literature search was performed, using "PubMed" and the term "FRAXE" to identify case reports or series describing FRAXE. Those papers in which formal psychometric and behavioural assessment had been performed were examined in more detail to attempt to define the behavioural phenotype.

Results: Sixteen studies were identified, describing a total of thirty-nine cases. In most, cases were identified through screening for "Fragile X" (FRAXA). Common features included: mild to moderate learning difficulties (although in some cases IQ was in the normal range); difficulties with attention, concentration and hyperactivity, sometimes qualifying for a diagnosis of ADHD; symptoms associated with autistic spectrum disorder including poor eye contact, echolalia, poor social integration, rocking, obsessive traits, ritualistic behaviour and need for routine; motor incoordination; and dysmorphic features (mid facial hypoplasia, high arched palate, marfanoid habitus and joint laxity).

Formal psychometric and behavioural assessment was used in only four studies describing 11 children. Amongst these IQ ranged from 40 to 88 (mean 63), 9/11 had significant impairments in attention, hyperactivity and/or impulsivity, 2 reaching DSM 111 criteria for ADHD, and 9/11 had some features of autistic spectrum disorder (ASD), with 3 receiving a formal diagnosis.

Conclusions: This study suggests that people with FRAXE genotype may have a low IQ, associated with features of ASD or ADHD, motor incoordination, and subtle dysmorphic features. With cases generally identified through screening for possible fragile X, however, ascertainment bias may be a significant factor. There is a need for a larger study employing detailed psychometric and behavioural assessments, and minimizing referral bias, to more formally define the phenotype.

G154 NEURODISABILITY AND QUALITY OF LIFE: THE EXPERIENCE OF A FEEDING CLINIC

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Introduction: Prevalence of feeding problems in children with neuro-disability has been reported to be as high as 89%. We present our experience of a patient cohort referred to the multidisciplinary (gastroenterologist, neurologist, speech therapist and dietician) feeding disorders clinic at a tertiary centre.

Methods: Information was recorded for all new referrals to the feeding clinic over six months. Carers' quality of life was estimated using a validated quality of life questionnaire (SF36).

Results: Of the total 84 patients seen, there were 36(42%) new referrals (Median age 18.5 months, Males 19). The median weight and height were on 0.4th and 9th centiles. Thirty-six percent of patients were referred from outside the region. The median GMFCS (Gross Motor Functional Classification based on functional limitation and disability score) was 3. The commonest underlying diagnosis was cerebral palsy (47%). The routes of feeding were oral (19), gastrostomy (16) and nasogastric (1). 16 carers completed the SF36 questionnaire and the significant domain scores were [PEG fed (9) v Oral fed (7)]: Health Transition [66.7 v 42.9 (p=0.01)]; General health [73.3 v 48.6(p=0.02)]; Role limits - Physical [78.5 v 46.4(p=0.02)]; Vitality [55.6 v 25.9(p=0.02)]; Mental Health [68.9 v 42.1(p=0.02)]; Social Functioning [72.2 v 51.8(p=0.03)]. Following assessment the recommendations included gastrostomy insertion (9), removal/revision of a previously inserted gastrostomy (2), further investigations (6) and medical therapy / dietary advice (20).

Conclusion: By having a dedicated multidisciplinary team we are able to provide holistic advice for patients attending this clinic. In our patient cohort there was a trend towards a better quality of life for carers' of children fed via gastrostomy.