Childhood disability

G1 CHILDREN WITH NEURODEVELOPMENTAL DISORDERS: PROSPECTIVE STUDY LOOKING AT RESOURCES NEEDED FOR AN ACUTE ADMISSION

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Background: Children with neurodisabilities are surviving longer, but have greater morbidity and are more likely to need acute hospital admission. There is little research in the UK to characterise the resources they need in hospital.
Aim: To characterise the resources needed by neurodisability children for acute admission.
Methods: A prospective observational study was conducted over a 6-month period July to December 2006 at an inner city district general hospital, recording all admissions of children with a neurodisability diagnosis. To compare length of stay, figures were obtained from the coding department for length of stay for other children admitted acutely in the same time period.
Results: In the study period 41 children with a neurodisability diagnosis were admitted 65 times, with a length of stay range of 0–44 days and commonest reason for admission a respiratory diagnosis. For other children acutely admitted there were 701 admissions. Median length of stay for neurodisability children was 3 days compared with 1 day for other children. This was significant (z statistic 5.43 $p<0.001$) on non-parametric testing. In 52% of the neurodisability admissions previous medical information was available to the admitting doctor. Other observational results recording resources showed at least one allied health professional was involved in 46% of admissions, and specialist equipment was needed in 35% of admissions, mainly a nasogastric feed pump. Delayed discharge was rare. Only 6% of admissions had evidence of previous discussion about resuscitation status. 54% of the neurodisability children were previously known to a community paediatrician.
Conclusions: This study confirms that neurodisability children have a longer acute admission length of stay compared with other children. Hospitals and commissioners must be aware of this in the current era of payment by results. However, this study underrepresents the nursing resources needed for this patient group and further research should address this issue. Best practice care must continue to be striven for in all settings for this complex patient group.

G2 THE EFFECT OF EATING BEHAVIOURS ON THE DIETS OF CHILDREN WITH AUTISM

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Introduction: Children with autism demonstrate a wider range of more problematical eating behaviours than the general population. Limited research indicates that although growth may be adequate, the dietary intake of these children is frequently unbalanced. Currently, no research exists studying the effect of individual eating behaviours on adequacy of diet.
Aims: To assess the distribution of eating behaviours and relationship to balance of diet; the extent of parental worry regarding nutritional well-being; the reasons contributing to problematical eating behaviours; the growth of children with autism and relationship to eating behaviour; awareness and current practice of healthcare professionals.
Methods: 50 children (48%) were recruited from a community-based cohort of 105 3–11 year olds (mean age 7 years 7 months, 44 males) with autism. Questionnaires including the food frequency questionnaire, 24-h dietary recalls and adapted brief autism mealtime behaviour inventory were completed during home visits. Medical notes were reviewed and growth measurements collected. Community paediatricians recorded their current practice.
Results: Problematical eating behaviours are highly prevalent (one sample t test $p<0.001$) and significantly affect dietary patterns of children with autism (reduced variety of vegetables $p = 0.001$ and protein $p = 0.003$). Such behaviours correlate positively with increased parental worry about balance of diet ($r = 0.53$, $p<0.001$). Behaviours representing ''limited variety'' are most problematical for parents, largely for nutritional reasons, followed by those associated with ''features of autism'' and ''food refusal''. Reassuringly, growth is adequate regardless of behaviour (one-way analysis of variance $p = 0.304$), although management of obesity may need review (mean body mass index SD = 0.81). Excluding worry regarding growth, parental worry is largely appropriate and related to high levels of problematical behaviour. Professional advice and guidelines on managing nutritional issues in autism could be improved.
Conclusions: Findings support the need for the development of appropriate guidelines and specialist services targeted to the behavioural and nutritional needs of children with autism and their families, thus alleviating parental burden.

G3 MAGNETIC RESONANCE IMAGING IN CHILDREN AND YOUNG PEOPLE WITH CEREBRAL PALSY: WHO REPORTS MATTERS

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Aim: To quantify differences between general radiological reporting of magnetic resonance imaging (MRI) scans at a district general hospital with specialist regional neuroradiological reporting for children and young people with cerebral palsy who have had neuroimaging as part of the aetiological work-up.
Method: A cohort of children and young people with cerebral palsy identified from a local database. Information on neuroimaging was collected using the hospital information support system and case notes review.
Results: 166/189 (87.8%) children and young people with a clinical diagnosis of cerebral palsy had documented neuroimaging. 75/166 (45.1%) were reported locally as well as by a regional neuroradiologist (see table 1 and table 2).
Conclusion: MRI is increasingly available as an imaging modality in district general hospitals. Significant differences in reporting were identified in this audit between local general radiology and regional specialist neuroradiology. Properly commissioned, robust expert neuroradiological reporting arrangements are required for all children's MRI scans irrespective of where the scan is done, to ensure the highest possible quality of information is available to inform management and share with families.

Abs G3 Table 1 Table of results

n = 75 Dual reported	Regional		
Local	Abnormal	Normal	Total
Abnormal	44	01	45
Normal	15	15	30
Total	59	16	75

Scans dual reported abnormal (n = 44)—important discrepancies identified.

Abs G3 Table 2 Table of results

Domain of discrepancy	No (%)
Description only	11 (25)
Aetiology only	3 (6.8)
Timing only	3 (6.8)
Description + aetiology	5 (11.4)
Aetiology + timing	3 (6.8)
Description + aetiology + timing	9 (20.5)
Similar report all domains	8 (18.2)

G4 ARE TIME-USE DIARIES AN ACCEPTABLE WAY OF EXPLORING THE DAILY LIVES OF PARENTS OF A DISABLED PRESCHOOL CHILD?

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Aims: There is increasing evidence to suggest that early intervention for children with disabilities should be through family-focused services that strengthen and enable families in addition to meeting the child's identified needs. This study investigates whether time-use diaries provide an acceptable tool to explore the daily lives of parents with a disabled child, and whether the diaries provide information that can be used to guide service provision.
Methods: A precoded time-use diary divided into 15-minute time slots was designed. Father–mother pairs with a preschool child with either autism (ASD) or technology dependence (TD) were asked to complete a 7-day diary independently but over the same time period. Each parent was then interviewed separately to ascertain their experiences of using the diary. Participants were identified through their involvement with a child development centre and represented a broad demographic with respect to age and socio-economic status.
Results: 26 parents (13 father–mother pairs) were invited to participate in the study. 18 parents agreed to be involved and 16 completed the diaries and interviews. Three father–mother pairs of an ASD child and one father–mother pair of a TD child declined to be involved. One father–mother pair with a TD child withdrew from the study. Of the 18 parents who agreed to participate, 15 found the diaries acceptable and either easy or straightforward to complete. One parent with dyslexia and one who described himself as a non-reader completed the diaries successfully, finding the colour coding helpful. 12 parents found some aspect of their time use surprising. The four who did not were all fathers. Five parents, all mothers, found completing the diaries enjoyable. Parents spent between 10 and 60 minutes a day completing the diaries, with the median 22 minutes. Mothers tended to spend more time than fathers, and parents with a TD child more than a child with ASD. The diaries provided information not only on the total amount of time spent on different activities but also how much time parents spent together, with their other children and at home or elsewhere.
Conclusion: The time-use diaries used in this study were acceptable to the majority of parents and provided useful information about their daily lives. Time-use diaries could be used in a wide variety of situations.

G5 FAMILY SELECTED SCREENING FOR IRON DEFICIENCY, VITAMIN D DEFICIENCY AND *HELICOBACTER PYLORI* IN SCHOOL CHILDREN WITH SEVERE LEARNING DIFFICULTIES

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Children with severe learning difficulties are a vulnerable group of young people who often have problems with feeding and swallowing, which put them at risk of growth problems and nutritional deficiencies. Mobility problems are frequently seen and this in turn may impair normal bone growth and function. Communication problems may limit the child's ability to express feelings such as pain and tiredness that may prompt a family to seek medical attention.

Community paediatricians usually provide a medical service to children attending special schools. In those children who have obvious clinical or family concerns regarding health and nutrition, routine blood tests often pick up previously unknown information about iron deficiency and other nutritional deficiencies such as vitamin D. It is also well recognised that children in residential settings and with special needs in the community have a higher incidence of *Helicobacter pylori* colonisation, which may be clinically significant. Vitamin D deficiency has also been shown to be higher in the chronically ill and disabled child.

Firwood School is a daytime educational placement for children with severe learning difficulties. A letter was sent out to families asking them to consent to a blood test that could screen for iron deficiency, vitamin D deficiency and *H pylori* colonisation. Out of the 90 children attending the school, 55 gave consent to having a blood test. Results showed 17% of children had a low ferritin level, of which six were biochemically anaemic. Of these, nine children were treated with iron supplements for a 3-month period. *H pylori* colonisation was found in 15 children (27%), with two children receiving eradication therapy based on the symptoms they reported. Confirmed vitamin D deficiency was found in four young women who were all of Asian origin. Incidental findings included jaundice in two children of whom one had gallstones and the other had Gilbert's syndrome. In summary, we feel that it is worthwhile offering these tests as routine screening to this select group of school children with severe learning difficulties.

G6 IMPEDANCE STUDIES IN THE DIAGNOSIS OF GASTRO-OESOPHAGEAL REFLUX: AN INVALUABLE INVESTIGATION IN CHILDREN WITH NEURODEVELOPMENTAL DISABILITY ATTENDING A CHILD DEVELOPMENT CENTRE

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Background: Gastro-oesophageal reflux (GOR) is a common problem in children with an evolving or established neurodisability. The symptoms are, however, often non-specific and a low threshold of suspicion is required. Investigating the condition with pH monitoring has been helpful, but the use of combined pH and multiple intraluminal impedance allows for the detection of both acid (pH <4) and non-acid (pH >4) GOR episodes, as well as tracking how high the reflux bolus movement is travelling up the oesophagus. This is a newer method of investigation that is increasingly useful in our practice.
Aims: To demonstrate the impact of this measurement tool in patients attending our child development centre.
Methods: Impedance with combined pH study results over a one-year period were collected in children attending the child development centre. The impedance pH probe was passed in the ''awake'' stage following calibration of the sensors. The probe was then fixed at a specific measurement estimated via the Strobel formula and a check *x* ray was performed for confirmation of accurate sensor position. The pH sensor was confirmed as 3 cm above the lower oesophageal sphincter. Each child's parent/carer was then asked to document in a 24-h diary: meal periods, lying down periods and symptoms during the study. Each study lasted for 24 h, the probe was then removed and the data downloaded and analysed and checked for accuracy against the patient's diary. Each study was performed and analysed by the same practitioner.
Results: 12 patients were identified from the database out of a total of 93 studies (13%). This patient group showed a range of

ages, symptoms and neurodisabling conditions, which will be presented. The impedance results showed both acid and non-acid reflux and its relation to symptoms. Each test result impacted on patient management.

Conclusions: Impedance studies are well tolerated in this group of patients. Particularly advantageous over pH studies is the ability to measure acid and non-acid reflux, accurate correlation with symptoms, extent of bolus movement and the fact that the patients can continue their GOR treatments during testing.

G7P DRAMA AS A MEANS OF PUBLIC ENGAGEMENT WITH MEDICAL CONTROVERSIES: A TRIAL EXPERIMENT

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Drama provides a powerful tool to explore controversial issues. A play ''A dog with a tail at both ends'' was written about the medicalisation of disability and consumer involvement. Jo, is a dying profoundly disabled adolescent. Under court order she is given a controversial medical treatment, which not only saves her life but restores her to ''normal'' developmental parameters. Unfortunately, Jo ultimately wishes to have her treatment stopped and revert to how she was before..

The play was performed in front of an audience of medical students at Birmingham University. An audience questionnaire was completed after the performance.

36 questionnaires were returned from the audience of 50 people. 27 were medical students, seven were members of the public, one person was from academia and one did not reveal their status.

All but one agreed that scientists should continue to develop new ways to treat long-term conditions. The audience was asked should the treatment have been given, 21 replies were affirmative, 10 replies indicated that the treatment should not have been given and five people were undecided.

There were many common themes for positive responses including ''best interests'', ''helping to advance science'', ''disability being a social construct'' and the issue of patient competence.

All agreed that drama was a useful way of exploring issues of ethics in medical practice.

Specifically written plays can be used as part of a strategy of public engagement by MCRN, to explore ethical, scientific and medical issues and inform/guide the public concerning the challenges and complexities of modern medical science.

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G8P HOW DO ABLE CHILDREN PERCEIVE DISABLED CHILDREN IN A MAINSTREAM PRIMARY SCHOOL IN ITALY?

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Aims: Even though children's views are influenced by the adult world around them, they have their own views, and these make a difference to peer interactions and the experience of childhood. The aim of this research was to explore the views held by primary school children towards their peers with disability (physical and cognitive) and their attitudes towards them.

Methods: The setting was a mainstream primary school in the north of Italy with 200 children, of whom six had a statement. Of these six, three had cerebral palsy and three had autism, learning difficulties and/or behavioural problems. The material was gathered through participant observation in class, semistructured interviews with 20 children, questionnaires given to all children and teachers.

Results: The analysis of the data indicated that children with disability became known to their able peers quite quickly, with one-third of the children in year 1 already able to identify the children with physical disability as the ''children who couldn't walk and/or talk''. In year 2 between a third and half of them made this identification. By years 3 to 5, the majority of the children would do so. From the children's perspective, both body appearance and performance played a big role in differentiating between children who conformed and those who did not and who then became different. Physically disabled children and those with cognitive disability but without disruptive or aggressive behaviour elicited feelings among their able peers that included pity, sadness, compassion and uneasiness. Children with cognitive disability and aggression tended to elicit negative emotions among their able peers, such as anger and fear.

Conclusion: Children with cognitive and physical disability ''become known'' to their able peers through their daily interaction, mutual observation within the class and outside, as well as through the observation of adult discourse and practices. The findings showed that the majority of the children in the school were well aware of their peers with disability, of their different body and body competences. Children with cognitive disability and aggressive behaviour were more at risk of exclusion from their peers.

G9P A POSSIBLE FUTURE FOR EARLY SUPPORT

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Early support is the national government programme to improve the delivery of services to children under the age of 3 years with special needs and disabilities. This puts into practice principles outlined in the government initiative guidance document ''Together from the start''. Funding of £13 million was provided to promote the implementation of the government initiative, encourage cooperative working between health, social services, education and voluntary services. Funding was given to 45 pathfinder areas to develop the principles of the service and our region was appointed as one of these pathfinders. A multiagency management committee was established, which appointed a project manager, designated keyworkers and non-designated keyworkers (including portage workers) and administrative staff in order to provide training and then run the service, which was formally evaluated.

This evaluation clearly demonstrated that the Early support service measurably improved service delivery to the children and families. Before the introduction of Early support satisfaction with the current service was assessed by families as very good or excellent in 55.4%, improving to 92% subsequently. In all areas there was significant improvement. In total, 95.8% of respondents felt that keyworking improved the services, 87.5% felt that this improved the service ''a great deal''. This success was attributed to effective multi-agency referral meetings, effective keyworking following good training and ongoing management. Pathfinder was discontinued in 2007 but the service continued partly by incorporating the service into the participant's job plans and with some funding from the local authority early intervention service for designated keyworkers. This reduced service has continued to provide effective Early support, which has been re-evaluated, and this evaluation will be presented at the meeting. Our experience confirms the value of keyworking. Also that Early support multi-agency referral meetings and management can be successfully integrated into job plans. Additional funding for designated keyworkers remains problematical but with progress in the development of local authority children's centres it is hoped that Early support training could be given to staff at these centres who will be able to provide locality-based keyworking in the future

G10P THE MANAGEMENT OF 22Q11 DELETION SYNDROME

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This study examines the management of patients with a genetic diagnosis of 22q11 deletion identified by the genetics department of a tertiary paediatric hospital by January 2008. The study assessed management by examining patient case notes retrospectively and completing a questionnaire for each patient diagnosed. When designing the questionnaire professionals from paediatric subspecialties relevant to the management of 22q11 deletion syndrome were asked to contribute. The questionnaire was therefore developed with input from clinical geneticists, cardiologists, immunologists, endocrinologists, community paediatricians, speech and language therapists and nephrologists.

Methods: A database was generated by the genetics department detailing all the patients who had been tested for 22q11 deletion. The case notes were then sourced for the patients in question and the questionnaire was completed according to the data gathered from the individual case notes.

Results: The study resulted in a cohort of 52 patients. The average age of diagnosis is 45.1 months, the standard deviation of this dataset is 65.7 months. The median of the ages is 4.5 months. The majority of referrals for genetic testing for 22q11 deletion are made by cardiologists as shown in previous studies (6). The second highest referrers for the test were found to be the cleft surgeon, indicating the high index of suspicion for 22q11 deletion in patients with a cleft palate. The majority of patients (81%) had had contact with cardiology before obtaining a diagnosis of 22q11 deletion. The proportion of patients referred to immunology was 40%; however, of those who had not been referred to immunology only 48% had a normal lymphocyte count. Fifty per cent of patients were sent for a renal ultrasound. Twenty-nine per cent of the cohort had had hypocalcaemic symptoms including fits, cramps and pins and needles. Ninety-two per cent of patients had their calcium levels checked and 54% of these patients had ongoing monitoring of calcium levels.

Discussion: The aim of the study is to produce guidelines for the management of patients with 22q11 deletion. The hope is to provide coordinated care for patients who present with 22q11 deletion.