



Abstract G192(P) Figure 2 Post-simulation day confidence

Demographics of participants

| | |
|------------------------------|---|
| Consultant Paediatrician | 1 |
| Level 3 Paediatric Trainee | 2 |
| Level 1 Paediatric Trainee | 2 |
| Broad-based Training Trainee | 1 |
| Paediatric Staff Nurse | 3 |

The group had varied prior experience. 50% had no previous formal training on child death procedures or breaking bad news. A significant proportion (5 of 8) had either no experience or had only been the primary deliverer of bad news on fewer than 5 occasions. Limited exposure to informal training opportunities including observation of such encounters and feedback within the work place were also reported.

The graphs highlight the positive impact of this training with an increase in self-reported confidence (Figures 1 and 2).

Simulated parents were rated as being very useful and being immersed in high fidelity simulation prior to these difficult discussions was viewed as helpful; increasing the realism.

Conclusion We have highlighted an area of practice where self-reported confidence is low as a result of limited opportunities for training and feedback that stem from unexpected child death being an infrequent event. This pilot simulation day was well received and resulted in an increased confidence amongst participants. Plans are in place to further this training and to widen the multi disciplinary team involvement.

British Academy of Childhood Disability and British Paediatric and Adolescent Bone Group

G193

MAGNETIC RESONANCE IMAGING (MRI) SCANS IN CHILDREN WITH NEURODEVELOPMENTAL DISABILITIES: SHOULD A PAEDIATRIC NEURORADIOLOGIST'S OPINION BE SOUGHT?

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Background At our local hospital MRI scans of children with developmental disabilities are reviewed by radiologists who provide the preliminary report. It is the choice of the treating paediatrician to seek further specialist paediatric neuroradiologist's opinion.

Aim Did differences in local and specialist opinion impact on diagnosis?

Method Concurrent MRI scan reports of children with neuro-disabilities from the local radiologist and the neuroradiologist were compared.

Result 63 children had reports from local and specialist radiologist. All had neurodevelopmental difficulties from mild to severe range.

The results were divided into three categories:

Group 1: Where there was significant difference in opinion: 26 reports (41%) Periventricular leucomalacia (PVL) was detected in 11 of which 10 had spastic cerebral palsy. Other cases included the following: antenatal hypoxic Ischaemic encephalopathy (3), thinning or agenesis of corpus callosum (4), disorder of myelination (3). The specialist was more likely to detect disturbances of myelination, (delay, loss or degeneration) The specialist also ruled out (6%) white matter loss (3) and absent corpus callosum (1) reported by the local radiologist.

Group 2: Where there was no difference in opinion: 29 reports (47%) The majority of these children (15) had global developmental delay without spasticity. Other cases included tonsillar herniation (2) Corpus callosum dysgenesis (2) hypoxic ischaemic encephalopathy (1) periventricular leucomalacia PVL (2), Cytomegalovirus infection (2) and hemisphere infarct (1) autism (2).

Group 3: Only subtle differences in report which did not impact on diagnosis: 8 reports (13%) These included arachnoid cysts, aberrant patterns of myelination, age consistent delay in myelination and benign extra cerebral space enlargement.

Conclusion This study showed that a paediatric neuroradiologist's opinion is important and could impact on the diagnosis very significantly. They detected and ruled out abnormalities in 41% of cases resulting in conclusive diagnosis compatible with clinical findings. Periventricular leucomalacia (PVL) was more likely to be detected by the neuroradiologist and was the commonest finding contributing to clinical diagnosis. In children

with global delay with no spasticity the reports were likely to be similar. Subtle white matter abnormalities were also more likely to be detected by the specialist.

G194 VITAMIN D AND VITAMIN D DEFICIENCY: HOW MUCH DO PARENTS KNOW?

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Background Vitamin D deficiency is prevalent among children and the majority are unaware of their low vitamin D levels. Vitamin D is an important component for the optimal health of children, as well as playing a role in reducing the risk of various chronic health issues in the future. This study aimed to gauge the level of awareness and knowledge of vitamin D amongst the parents of paediatric orthopaedic patients.

Study design A retrospective observational study was conducted using a paper-based questionnaire to assess parental awareness. The questionnaire was distributed to parents of children attending paediatric orthopaedic clinics in a single Teaching Hospital Trust over a period of four months.

Results 220 parents responded to the questionnaire. 85% of respondents believed vitamin D to be important for the health of a child. 65% said they knew what vitamin D was. 40% of all parents asked were unable to write a brief statement of their basic understanding surrounding vitamin D. 17% give their children vitamin D supplementation. 2% of the respondents' children have been told they are vitamin D deficient.

The participants were asked what they believed to be good dietary sources of vitamin D. 64% of respondents could identify oily fish or eggs. However, 46% believed dairy products to be a good dietary source of vitamin D.

The questionnaire asked respondents whether GPs have provided education or advice about the importance of maintaining adequate vitamin D levels in children, only 9% of parents said that they had received information from their child's GP.

59% of respondents to the questionnaire wanted more information about vitamin D and vitamin D deficiency. This information was sent to each of those respondents as a short leaflet.

Conclusion Parental awareness of vitamin D and deficiency is poor. There is a need for increased levels of parental education to ensure children have a better chance of maintaining adequate vitamin D levels.

G195 WHAT ARE THE LONG TERM CLINICAL OUTCOMES OF SPINAL DYSRAPHIAS IN CHILDREN?

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Background Spinal dysraphia is a non-fatal foetal anomaly comprising a range of spinal canal fusion abnormalities. There have been recent advances in the diagnosis, treatment and prevention of this condition. The longer term outcomes currently vary within the literature and are based historic cohorts prior to more recent advances in care.

Aims Review the long term outcomes and symptomatology in a current cohort of children with spinal dysraphia.

Methods Retrospective review of medical records of patients with diagnosis of spinal dysraphias. Children were excluded if there was other genetic abnormality or syndrome.

Results We identified 70 children (mean age 10.7, SD 7.1, 41% male). There was 100% survival at 1 year of age and 68 (97%) children were still alive at time of the review. Mortality in both children was secondary to meningitis. Diagnosis was made antenatally in 37%, and postnatally in 63% with 3 children (5.7%) being diagnosed at school age. 51 (73%) were symptomatic and 22 (31%) had evidence of neuropathic bladder and bowel. Antenatal diagnosis ($p = 0.047$), higher level of lesion ($p = 0.044$) or shunts *in situ* ($p < 0.001$) were all predictive of greater symptomatology. If a patient was found to be symptomatic in one area, they were significantly more likely to also have other symptoms ($p < 0.001$) supporting the need for regular review in these children. There was a high incidence of urinary symptoms (11.7%) constipation (37%) and orthopaedic problems (such as scoliosis or lower limb abnormalities) (48%) in the absence of neuropathy. Mental health issues were documented in 4 children (5.7%).

Conclusions Spinal dysraphia is associated with high rates of morbidity (73%) with a significantly lower mortality (3%) and incidence of mental health issues (6%) when compared to previous studies. The current follow-up of patients with spinal dysraphias varies, therefore further studies are needed to develop appropriate follow-up strategies for this high risk patient group; including the evaluation for comorbidities and psychosocial complications.

G196 WHAT DO CHILDREN AND YOUNG PEOPLE WITH LEARNING DISABILITIES WANT FROM HOSPITAL SERVICES?

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Background Children and young people (CYP) with learning disability (LD) have more hospital admissions and greater lengths of hospital stay than children without disabilities. Yet, few researchers have sought to understand the hospital experience from the perspective of these patients, which means we have little evidence of how to improve hospital services in order to meet their needs. Limited research has been conducted with parents of CYP with LD to ascertain what it is like for them and their child to receive hospital services, which largely reveals parental concerns about staff members lack of confidence and knowledge to care for their child with LD.

Aims Our study sought to understand the hospital related needs and experiences of CYP with LD, their families and hospital staff. Reported here is data collected through observation, interaction and communication with CYP.

Methods An ethnographic approach was used to observe, in detail, the everyday life of 9 CYP with LD and their families during one or more episodes of hospitalisation, over a 12 month period. The use of arts based methods facilitated 4 of these CYP to share what was important to them. 135 staff consented to be observed during this time frame. Interviews with 27 staff, not reported here, were also conducted. Data were analysed using the Framework Approach.

Results Data revealed that despite sharing a label of LD, this population of patients are not all the same and can want different things from hospital services. The key to getting it right is ensuring that their non-medical needs are identified, understood