

## Abstracts

**Aim** To describe the clinical presentation and current management of FOP.

**Methods** A 7 year old boy with a history of hallux valgus, recurrent painful episodes of soft tissue swelling and new abnormal bone formation, was assessed clinically and radiologically.

**Results** Review of the clinical history and radiographs taken in infancy revealed the diagnosis of FOP. This had not been previously recognised, although he had been seen in a specialist Hallux Valgus clinic as a baby.

**Conclusions** As specific treatments are now becoming available for this life-limiting condition, it is essential that all neonatologists, paediatricians, paediatric oncologists and orthopaedic surgeons consider a diagnosis of FOP if a baby or child presents with bilateral hallux valgus and/or episodes of swelling with evidence of ossification. These children should now be referred to a paediatric metabolic bone clinic to consider genetic testing and for specialist management.

### G206(P) RECOGNISING THE RISK FACTORS: MISSED OPPORTUNITIES TO PREVENT RICKETS

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**Aim** Implementing the NICE guidance published in November 2014 for vitamin D supplementation of at-risk groups, including all children under-five years of age, would help reduce childhood rickets due to Vitamin D deficiency. Whilst awareness of Vitamin D is increasing, we often assume that UK infants have sufficient calcium dietary intake. This case series highlights rickets arising when insufficient dietary calcium compounds the effects of insufficient Vitamin D.

**Methods** We reviewed case-notes, biochemical and radiological data of four children diagnosed with rickets at our hospital during the past 18 months.

**Results** One child presented aged seven months with seizures. She had a prolonged corrected QT interval secondary to profound hypocalcaemia (corrected calcium 1.49 mmol/L), and vitamin D Deficiency (vitamin D <6 nmol/L). The remaining three infants (aged 16–20 months) presented with bony deformities characteristic of rickets, and Vitamin D supplementation had recently been commenced in primary care. Total Vitamin D levels were 26.3, 38.9 and 51.1 nmol/L each with a significant proportion of the total Vitamin D as D2 consistent with supplementation. These three cases had normo-calcaemia (2.3–2.54 mmol/L). Radiology showed rachitic changes. All cases had pigmented skin, were predominantly breastfed and had no vitamin D supplementation during the first year of life. The clinical and radiological rachitic changes were more marked than expected for the levels of Vitamin D. All were cow's milk allergic (confirmed on specific IgE testing) and were slow to wean, with prolonged breast feeding. The children had inadvertently been on low calcium diets without supplementation. All children have made good progress with subsequent appropriate calcium and vitamin D supplementation.

**Conclusion** This series illustrates commonly recognised risk factors for rickets, namely skin pigmentation, exclusive and prolonged breastfeeding, and the lack of Vitamin D supplementation. Undoubtedly the lack of vitamin D was contributory to the development of rickets and appropriate supplementation

could have minimised the adverse skeletal effects. These cases also highlight that a calcium-deplete diet is an additive risk factor for the development of rickets. Infants with cow's milk protein allergy comprise a clinical group in whom it is important to consider the need for calcium supplementation alongside Vitamin D.

### G207(P) TO REVIEW THE OUTCOME OF HIP SCREENING ULTRASOUND SCAN (USS) FOR DEVELOPMENTAL DYSPLASIA OF HIP (DDH) IN HIGH RISK BABIES

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**Aim** The aim of our study was to review the outcome of hip screening ultrasound scan in high risk babies for further evaluation of developmental dysplasia of hip in the district general hospital.

**Methods** This is a retrospective study. We looked at the outcome of the USS hip performed for the period of 18 months from June 2013 to October 2014 in our trust in high risk patient group with breech presentation, family history of DDH, twin deliveries with one of the twin born with breech presentation and on the clinical suspicion after clinical examination of the hip. Data was collected using hospital notes, PACS system was used for USS results.

**Results** In total 553 USS hip was performed for further evaluation of DDH out of which only 4 scans were abnormal. Three of this abnormal scans were in babies born with breech presentation and one was in a baby who's mother had history of DDH needed intervention in past. Out of this 4 abnormal scans 3 scans were Graf Type IIa and one was Graf type D.

**Conclusion** In our experience we have observed a significantly low percentage of clinically relevant USS results for DDH even in selected high risk babies.

## Royal College of Nursing

### G208 REFLECTIONS AND NEW DIRECTIONS IN CHILDREN AND YOUNG PEOPLE'S PALLIATIVE CARE

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In June 2010, the Department of Health (DoH) in the UK released a call to apply for funding to support projects focused on benefiting the lives of children and young people with palliative and complex health care needs and their families. A programme of work was subsequently developed from 2010–2014 including an innovative e-learning programme and important projects seeking to explore issues around competence of care skills and communication challenges in the field of children and young people with palliative care.

**Aims** The aim in this workshop is to share reflections from a recent narrative literature review as part of a programme of work which focused on confidence and competence of care skills. Results of the review will be shared but will provide a platform for critical debate around challenges and new directions in children and young people's palliative care.

**Methods** A narrative review will be firstly shared. Combinations of selected key words were systematically applied to identify research on health professionals' confidence and competence when caring for children and young people's using palliative care services. Articles meeting the inclusion criteria were read and descriptively summarised using data extraction sheets. A narrative synthesis was conducted by examining commonly reported issues which were then condensed into overarching themes.

**Results** Limited research is available that explores health professionals' confidence and competence when caring for children and young people's using palliative care services. Technological advancements, range of conditions/needs; communication challenges/decision-making and resource costs including specialist staff featured as significant themes. Improvements in staff education and training may help to overcome some of the identified issues.

**Conclusion** Debate in the workshop will focus on the implications of this review and programme of work in the current climate. Delegates will be invited to critically discuss potential new directions. Having confidence and being competent in skills is the cornerstone of quality of care and it is important that we reflect to move forward in caring for this specialist group.

#### G209 RELATIONSHIPS AND SEXUALITY IN YOUNG ADULTS WITH LIFE-LIMITING CONDITIONS IN ENGLAND

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**Background** Until recently, surviving into adulthood with a life-limiting condition was rare, and as such, young adults with life-limiting conditions are a unique population about whom it is timely to explore their considerations about intimacy, relationships and sex. Young adults with chronic conditions diagnosed in childhood, especially those who have life-limiting or life-threatening conditions, may want to experience an intimate relationship. This research builds upon the first author's research into the sexuality of young adults with neural tube defects (1<sup>st</sup> Author 2002; 2008) and is the focus of her PhD.

**Aims** This research has explored the following in third sector organisations in England:

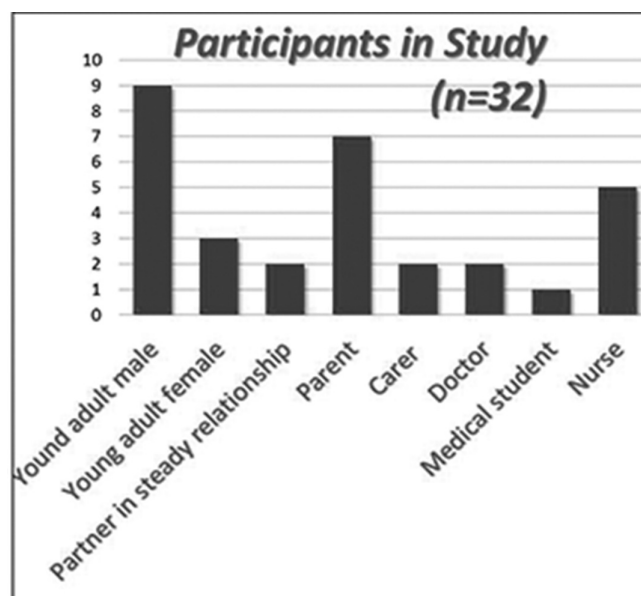
The views, meanings and experiences of young adults with life-limiting conditions about relationships intimacy and sex?

How young adults with life-limiting conditions such as cystic fibrosis, duchenne muscular dystrophy, other neuro muscular degenerative conditions or cancer may be supported in making relationship and sexual choices?

The views of parents/carers and professional staff.

The results from the interim study with 6 young adults with neuro muscular degenerative disorders, 3 parents and 4 care staff will be presented (N = 13).

**Methods** Using purposive sampling and qualitative methods (Figure 1), a face-to face focus group and individual, semi-structured interviews were undertaken with 12 young people with LLCs, (9 males and 3 females) in 2013/2014. The young adults, age 16+, mean age, 26 years, had mental capacity. The young adult participants had cystic fibrosis, neuro-muscular degenerative conditions and cancer. 9 young adults agreed to be interviewed more than once. Partners, parents/carers and care professionals were separately interviewed once (N=20). 5 women who agreed to participate were unwell or died before interviews.



Abstract G209 Figure 1

Following approval from four Human Research Ethics committees (HRECS), the interviews are complete and the main study data is being coded and thematically analysed using NVIVO software. Codes identify similarities and differences between the young adults' perceptions and expectations of their sexuality, compared with parents/carers and care staff.

**Results/Findings** Interim results indicate that the meaning of friendships, relationships, intimacy and sex may vary in young adults with different LLCs.

**Conclusions** Interim findings indicate the importance of parallel planning for young adults with LLCs who may or may not be approaching the end-of-life but wish to live fulfilling lives, including having intimate relationships.

#### G210 CLOSER TO HOME: MEETING THE EDUCATIONAL NEEDS OF NURSES WORKING WITH CHILDREN WITH CANCER

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**Aims** Discussion of an innovative approach to education which meets local need and has evaluated very positively by students.

**Methods** Improving Outcomes in Children and Young People with Cancer (NICE, 2005) recommended that nurses working in this field should be offered appropriate post qualifying specialist education. This has proved challenging for many of the tertiary Paediatric Oncology centres as local Universities cut the number of modules they offer. The Paediatric Oncology Nurse Educators group, within the RCN, have been concerned about the diminishing number of validated modules available for some time.

Recently a 'shared care' hospital approached my University to ask if a validated module about children with cancer was available. Fortunately I had the expertise and knowledge to write such a module at level 6 and 7. I made a case to serve local need and create an option module for the pre-registration nursing programme and successfully developed the module which has recruited 42 students over 3 deliveries.



## G208 Reflections and new directions in children and young people's palliative care

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