

### G371(P) PRESENTING PHENOTYPE OF CROHN'S DISEASE (CD) IN CHILDREN 2010–13

<sup>1</sup>JJ Ashton, <sup>1,2</sup>T Coelho, <sup>2</sup>S Ennis, <sup>1</sup>A Batra, <sup>1</sup>NA Afzal, <sup>1</sup>RM Beattie. <sup>1</sup>Paediatric Gastroenterology, University Hospitals Southampton, Southampton, UK; <sup>2</sup>Human Genomics, University of Southampton, Southampton, UK

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**Aims** There has been at least a two-fold increase in the incidence of paediatric-onset CD over the last 20 years; there are few recent reports of the presenting phenotype – symptoms, inflammatory markers and disease extent. We report the presenting features of a defined cohort and compare to previous data.

**Methods** Patients diagnosed with CD at University Hospitals Southampton from 2010–2013 were identified from an in-house database. Data were obtained from note review using a standardised proforma and compared to previous UK data.<sup>1</sup> Weight and height at diagnosis are presented as median SDS (95% CI).

**Results** 106 children were included. Median age 13.80 (Range 4.40–17.32 years), 79 male. The most common presenting features are seen in Table 1. The majority of patients presented with ileocolonic disease (51%) or isolated colonic disease (32%). Twenty-eight patients (26.4%) had perianal signs (5.7% abscesses/fistulae).

Inflammatory markers were raised at diagnosis—median CRP 18.0 mg/L (8.9–27.1), ESR 24.0 mm/hr (19.6–28.4); however normal inflammatory markers were frequently seen—normal CRP 26.4%, ESR 18.2%.

Weight SDS was  $-1.088$  ( $-1.35$  to  $-0.83$ ), 52% patients were below  $-1$  standard deviation (SD). Height SDS was  $-0.366$  ( $-0.60$  to  $-0.14$ ). 26.5% of patients were between  $-1$  and  $-2$  SD from the median and 4.8% were below  $-2$  SD.

Family history (3<sup>rd</sup> degree relative or closer) of IBD was seen in 27.6%.

**Abstract G371(P) Table 1** Comparison of data from Ashton (2015) with Sawczenko (2003)<sup>1</sup>

(Percentage with symptom at presentation)

	Sawczenko (UK)	Ashton (Wessex, Southern England)
No. patients	379	106
Abdominal Pain	72%	85.8%
Weight Loss	58%	55.7%
Diarrhoea	56%	78.3%
Triad of Abdominal Pain, Weight Loss and Diarrhoea	25%	41.5%
Perianal signs	7%	(5.7% abscess/fistula)
Joint disease	7.4%	8.5%
Height SDS	(Mean) $-1.06$	$-0.366$ (Median)
Weight SDS	(Mean) $-1.09$	(Median)

**Conclusion** Despite an increase in incidence of CD there does not appear to be an accrual of milder cases of disease. A significant number of patients will present with both normal growth and normal inflammatory markers.

#### REFERENCE

- 1 Sawczenko A. Presenting features of inflammatory bowel disease in Great Britain and Ireland. *Arch Dis Child*. 2003;88(11):995–1000

## British Paediatric Respiratory Society and Association for Paediatric Palliative Medicine and Paediatric Intensive Care Medicine

### G372 PROLONGED INVASIVE VENTILATION IN PAEDIATRIC INTENSIVE CARE: CHILDREN RESIDENT IN ENGLAND AND WALES, 2004–2013

<sup>1</sup>SJ Fleming, <sup>2</sup>CR Lammings, <sup>2</sup>A Evans, <sup>3</sup>KP Morris, <sup>2</sup>ES Draper, <sup>1</sup>RC Parslow. <sup>1</sup>School of Medicine, University of Leeds, Leeds, UK; <sup>2</sup>Department of Health Sciences, University of Leicester, Leicester, UK; <sup>3</sup>Birmingham Children's Hospital, Birmingham, UK

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**Aims** To describe the characteristics of children resident in England and Wales admitted to a paediatric intensive care unit (PICU) who required prolonged invasive ventilation over the last decade and to compare their demographic and clinical characteristics to those who required a shorter period of invasive ventilation.

**Methods** Clinical and demographic information on all children resident in England and Wales admitted to a PICU were analysed. Prolonged invasive ventilation (PIV) was defined as receiving invasive ventilation for more than 21 days during a single admission via endotracheal tube or tracheostomy including jet or oscillatory ventilation. The cut-off of 21 days was chosen as it has been previously used in adult studies of prolonged ventilation during intensive care stay.

**Results** 99,818 of 147,709 admissions (67.6%) received invasive ventilation; of these 2,980 (3.0%) required PIV. As a percentage of all invasive ventilation, PIV has increased slightly over the previous decade from 3.1% in 2004 to 3.4% in 2013. PIV was most common in the under 1s (3.6%) and was similar in males (2.9%) and females (3.0%) (chi-squared  $p = 0.35$ ). Children receiving PIV account for over a quarter (26.5%) of all invasive ventilation bed days, median length of ventilation was 32 days (IQR: 26–48 days) and median length of stay was 37 days (IQR: 28–57) in those receiving PIV. Overall, those receiving PIV had a higher Paediatric Index of Mortality (PIM) score on admission (4.1% vs. 2.5% with a score  $>30$ %, chi-squared  $p < 0.01$ ) and an increased in-unit crude mortality (23.6% vs. 5.6%, chi-squared  $p < 0.01$ ). Multivariate logistic regression will be applied to examine whether the effect of demographic characteristics has changed over time.

**Conclusion** Children receiving PIV are only a small percentage of all admissions requiring invasive ventilation but account for over a quarter of all invasive ventilation bed days. A higher percentage of under 1s who receive invasive ventilation require PIV and it is associated with a higher in-unit mortality overall.

### G373 DIFFICULTIES WITH LIMITATION OF TREATMENT IN PAEDIATRIC INTENSIVE CARE – IMPROVING COMMUNICATION IN MULTI-PROFESSIONAL TEAMS

O Akinkugbe, C DeMunter, H Avila. Paediatric Intensive Care Unit, St Mary's Hospital, Imperial College Healthcare NHS Trust, London, UK

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End of life care in Paediatric Intensive Care Units (PICU) is a very difficult process for children, carers and healthcare professionals. Good decision-making and communication is essential. Though Trust DNAR forms are devised to be communication

tools, they are inappropriate for PICUs. We devised an Agreed Limitation of Treatment Form (ALT) for professionals caring for children for whom a decision has been made to withdraw or withhold life-sustaining treatment. We have been using it for 5 years. Recent changes to national guidance have prompted us to review our practice.

**Aims** To evaluate our Limitation of Treatment process by reviewing our current practice, comparing it to professional guidance and to practice in other PICUs.

**Method** We compared children for whom an ALT had been completed to children who died without an ALT.

We reviewed each ALT form and the entries in the medical notes.

We obtained the opinions of staff on our PICU.

We reviewed practice in our PICU against the recent changes to professional guidance from the Royal College of Paediatrics and Child Health and the General Medical Council.

We surveyed practice in other units.

**Results** There were pre-existing severe or life-limiting conditions in 85% of patients with an ALT compared with 46% of those who died without an ALT.

13 out of 16 ALT forms were either not fully completed or not consistent with entries in patient notes.

Nursing and medical staff found the form to be useful as a communication tool but requested some changes to the wording and layout of the form.

Our practice is in line with National Guidance.

There is no uniformity among the different PICUs and only a few use forms.

**Conclusion** We found the Limitation of Treatment forms very useful and consistent with the professional guidance but the quality of documentation needed to be improved. We have made changes to our practice and would suggest that a similar document would be beneficial for all PICUs.

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#### END OF LIFE CARE IN HOSPITAL. SCOPE FOR PAEDIATRIC PALLIATIVE CARE INVOLVEMENT?

<sup>1,2</sup>LA Brook, <sup>1</sup>K Tewani. <sup>1</sup>Specialist Palliative Care Team, Alder Hey Children's Hospital, Liverpool, UK; <sup>2</sup>International Observatory on Palliative Care, Lancaster University, Lancaster, UK

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**Background** End of life care in the setting of choice is important in palliative care. The majority of children die in hospital intensive care where end of life frequently involves withholding/withdrawing life sustaining treatment: many have conditions that may benefit from palliative care. We hypothesised children were dying without specific palliative care support despite a well established paediatric palliative care team and that a proportion of children would be suitable for rapid discharge to the setting of choice for end of life care.

**Method** Casenotes for inpatient deaths from January to December 2013 were reviewed to identify: children with a life limiting condition, whether the end of life occurred following planned withholding/ withdrawing of life sustaining treatment and if so whether the child was stable enough to be transferred to an alternative care setting for end of life care.

**Result** 62 children (31 male) died. Median age at death was 10 ½ months (Q1 6 weeks, Q3 2 years 8 months). Primary diagnoses were cardiac 40%, general paediatrics/neonates 19%, oncology 14%, neurology 11%, congenital malformations 11%. 85%

children had life threatening conditions. 58% children died following planned withholding/withdrawing of whom 39% (N = 14) were stable enough to transfer to an alternative setting for end of life care. Median interval between withholding/withdrawing and death was 30 min but 27 h (Q1 = 4 h, Q3 = 132 h) for those stable enough to move. All 15% (N = 8) children with life limiting conditions known to the palliative care team, but no other children had documented discussion of preferred place of care. Preferred place of care was hospital for 6 and home for 2 of whom both were stable enough to move but not notified to palliative care team until after death.

**Conclusion** Approximately 22% children dying in our institution would have been suitable for rapid discharge, living median of 27 h following transfer to their setting of choice.

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#### CHILDREN WITH LIFE-LIMITING OR COMPLEX CHRONIC CONDITIONS IN PICU; PREVALENCE, WITHIN PICU AND LONG TERM OUTCOMES

<sup>1</sup>LK Fraser, <sup>2</sup>M Van Laar, <sup>3</sup>MM Miller, <sup>2</sup>RC Parslow. <sup>1</sup>Department of Health Sciences, University of York, York, UK; <sup>2</sup>Division of Epidemiology, University of Leeds, Leeds, UK; <sup>3</sup>Martin House Children's Hospice, Wetherby, UK

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**Aims** This study aimed to review the literature to ascertain what proportion of admission to PICUs are for children with Life Limiting Conditions (LLC) or Complex Chronic Conditions (CCC) and what are their within PICU and post PICU outcomes. **Methods:** A systematic review of the literature was undertaken with electronic databases, MEDLINE and Embase searched for studies published in English between 1990 until Aug 2014. Hand searching of reference lists was also undertaken.

The titles and abstracts of all the retrieved papers were reviewed for inclusion by two authors. Data was extracted from the full-texts of all the studies which fitted the eligibility criteria. A narrative synthesis of the included studies was undertaken as the heterogeneity of definitions and therefore the included populations and outcomes did not allow for a meta-analysis to be undertaken.

**Results** The database search retrieved 9439 references. 83 full texts were screened for inclusion and 19 papers were included in the data extraction and synthesis process.

A large US study found the prevalence of children with CCC in PICU to be 53% (range 22.4–70.6%). The smaller study from Greece found a prevalence of 37.8% and a multi-country study found a prevalence of 67%.

The within PICU mortality rates were highest for the haematopoietic stem cell transplant (HSCT) patients (45–69%) with the studies on oncology patients alone having mortality rates of 16–27%.

Four of the studies presenting post PICU mortality data were for patients admitted to PICU post HSCT (mortality rate ranged from 67–85%), three were on oncology patients (mortality ranged from 17–48%) and one was children with severe neurological impairment requiring mechanical ventilation (50% mortality one year post PICU).

**Conclusions** Children with CCC formed a large but variable proportion of PICU admissions in the US and had higher within PICU mortality. Children admitted to PICU post HSCT had very high within and post PICU mortality rates.

There were no studies undertaken in the UK and none using the LLC definition to define their population of interest. There were no large studies which assessed long term mortality or outcome after PICU.