Conclusions Trainee neonatologists lack confidence in many areas of palliative care provision on neonatal units. This study is the first to generate a neonatal palliative care curriculum specifically for this group of doctors, who are responsible for the care of a significant proportion of children who die. Local priorities and service provision need to be central in the generation of educational curricula and subsequent training programs. This can be supported by improved integration between neonatal and paediatric palliative care networks nationally.

G357 LEARNING FROM BEREAVED FAMILIES TO IMPROVE CHILDREN'S PALLIATIVE CARE

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Introduction Paediatric palliative care (PPC) endeavours to provide holistic family-and-child-centred care, to children with life-limiting conditions (LLC). Advance care planning (ACP) is widely recommended and is believed to improve outcomes and experience. Practice varies widely within the UK, by geographical region as well as disease.

Aims To explore the experiences of bereaved parents and determine the main factors that influence the experiences of children who die of LLC and their families, including the impact of ACP.

Method This quantitative arm of a mixed-methods study used an anonymous questionnaire offered online and by post to all bereaved parents in the region whose children had died between December 2013 and June 2018.

The responses were analysed to determine the prevalence of ACP and determine factors that impact families' experiences – as measured by variables such as the availability of choice of place of death (PoD) - and various subjective perceptions of care.

Results Thirty questionnaires were returned. 53.3% (16/30) of questionnaire respondents recalled a prognostic discussion at diagnosis - four out of ten families of children with cancer and seven out of nineteen with non-cancer diagnoses. 53.6% (15/28) reported ACP discussion. 10 reported 33.3 documented ACP.

Families who remembered ACP discussions were more likely to have been offered a choice of PoD ($p=0.0107$). Parents who reported access to a PPC team were more likely to report that they had been offered a choice of PoD ($p=0.01$) and that the caring teams respected their wishes and desires ($p=0.05$) than those who didn't. Parents' educational level, diagnosis of cancer or time elapsed between first prognostic discussion and death had no significant effect on ACP, choice of PoD or subjective experiences.

Conclusions Formal ACP and early prognostic discussions are not yet part of routine paediatric practice in the region. Formal ACP and early integration of palliative care may positively impact subjective experiences as well as outcomes such as realisation of preferred PoD.

Limitations lack of statistical power, diagnostic heterogeneity and socio-cultural homogeneity of the sample, potential recruitment and recall bias. Further research should explore a. impact of ACP in different patient groups and b. professionals' perceptions.

G358 COST OF LONG TERM VENTILATION

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Advances in Neonatal and Paediatric Intensive Care have increased the survival of children with life threatening or life limiting conditions. There has been a significant rise in children on long term home invasive ventilation.

High profile cases have been in the media recently with debate on whether such interventions should be implemented focussing on ethics but without evidence of cost benefit analysis.

Children on long term invasive ventilation are a high cost group with complex and varying underlying medical conditions requiring input from multiple teams, including 24 hour carers, medical and multidisciplinary team input as well as recurrent hospital and PICU admissions. In addition, the cost of equipment and drugs makes this a costly intervention.

In any limited healthcare system rationing decisions have to be made: drug and other therapies are subject to health economic analyses. This study aims to assess cost per annum for LTV and an cost benefit analysis.

Objectives

- Identify patients on LTV including comorbidities
- Assess cost of LTV to quantify cost-benefit analysis
- Measure outcomes : death/admissions/recovery

Methods

- Review of patients requiring home long term invasive ventilation July 2009 – July 2019
- Analysis of costs: clinic visits, hospital admissions, costs of equipment; cost of medication
- Outcomes and quality of life: mortality, admissions and length of stay; decannulation, ability to communicate and mobility analysis; ability of parents to work

Results

10 patients:

- 3 died (aged 1 year, 7 years and 15 years)
- 4 decannulated
- 3 ongoing LTV (aged 15 months, 19 and 22 years)
- 5 night package £140,000pa
- accessories £12,000 pa
- replaceables/service £92,000
- average cost home LTV around £350,000pa

Conclusions LTV ventilation is an expensive treatment: its use should be analysed on a cost benefit analysis in a similar way to other available treatments.

G359 DIFFICULT DECISIONS IN PAEDIATRICS: SHARING, CONNECTING AND MANAGING ETHICAL TENSIONS IN PRACTICE

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Difficult Decisions in Paediatrics is a national forum which aims to share, connect and identify ethical issues in paediatrics. The forum was developed following a two part

documentary which aired on Channel 4 in 2018 - My Baby's Life: Who Decides? – which highlighted the ethical challenges in an increasingly technologically capable world. The programme raised issues in the region and demonstrated the need for healthcare professionals working with children with complex needs to draw together. In addition to developing skills in dealing with difficult decisions in paediatrics, the day has provided a bridge between academic work in this area and clinicians. As a result of the Difficult Decisions in Paediatrics forum, the region now has a paediatric Clinical Ethics Committee at which healthcare professionals can discuss cases at the University Hospital. Both the Difficult Decisions in Paediatrics Day and the regional Clinical Ethics Committee have received excellent feedback, and this work has enabled clinicians to move forward with increasingly complex decisions for the benefit of the children they work with.

G360 MINORITY REPORT: CAN MINOR-PARENTS REFUSE MEDICAL TREATMENT FOR THEIR CHILD

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Infants are unable to make their own decisions or express their own wishes about medical procedures and treatments. They rely upon surrogates to make decisions for them. Who should be the decision-maker when an infant's biological parents are also minors?

M, is a 15 year old girl who has a long-standing needle phobia, she gives birth to B and is assessed to be capable of caring for him. B is discharged into M's care on the second day of life. However, on day 7 the baby develops apnoeas and is brought to hospital by M and her own mother, G, with whom they live. There are signs that B has sepsis. The paediatricians plan to insert an intravenous cannula (IV) and perform a lumbar puncture (LP) to exclude meningitis.

M consents to an IV for B and administration of antibiotics. However, she finds the process so distressing she refuses consent for B to undergo the LP.

The central questions raised by the case are whether minor-parents should make medical decisions on behalf of an infant, and if so, what are the limits to this decision-making authority? In particular, can they refuse treatment that might be considered best for the infant?

We examine different claims to parental decision-making authority; we argue that provided that minor-parents are capable of fulfilling their parental duties, they should have a right to make medical decisions for their infant.

We then examine the limits to minor parents' decision-making authority for their children. We argue that the restricted authority that teenagers are granted to make medical decisions for themselves looks very similar to the restricted autonomy of all parents. That is, they are permitted to make choices, but not harmful choices. Like all parents, minor parents must not abuse or neglect their children and must also promote their welfare. They have a right to make medical decisions for their infants within the same 'zone of parental discretion' that applies to adult parents. We conclude that adult and adolescent parents should have comparable decision-making authority for their infants.

G361 SERVICE EVALUATION OF MANAGEMENT OF CHILDREN AND YOUNG PEOPLE PRESENTING WITH ALCOHOL INTOXICATION TO A PAEDIATRIC EMERGENCY DEPARTMENT IN NORTHERN ENGLAND

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Aims To evaluate management of children and young people (CYP) aged 8–16 years presenting to a Paediatric emergency department (PED) in Northern England with alcohol intoxication and to identify any relevant service improvements.

Methods Retrospective analysis of electronic records of cases coded on Snowmed database as 'alcohol intoxication' or 'toxic effects of alcohol'. Data collected for overall number of PED admissions with alcohol intoxication over 5 years period from June 2013–May 2018. Data analysis for period June 2017–May 2018 included details on demographics, management, medical diagnosis/comorbidities, services referred into and re-admission rate for CYP. Clinical management compared with 'Management of children and young people with an acute decrease in consciousness level'-clinical guideline by RCPCH (Royal College of Paediatrics and Child Health).

Results 338 CYP aged 8–16 years attended PED with alcohol intoxication during above 5 years period. 25% reduction noted in number of admissions in 2017–2018 as compared to 2013–2014. Detailed data analysis undertaken for 60 cases for the period June'17–May'18. Results showed female preponderance (60:40%). Observations and blood sugar levels documented in 100%. Glasgow coma score (GCS) not documented in 15%. Investigations included blood alcohol level (3%), urine toxicology (8%), Paracetamol blood level (13%) and CT brain (23%). 92% had no underlying medical diagnosis. 74% discharged directly from PED, 26% admitted to Paediatric ward. 80% referred to Youth Drug and Alcohol services (YDAP), 15% to CYP services (mental health), 52% had safeguarding liaison forms completed, 16% had Police involvement. 1/3rd of cases had red flags on electronic system (Looked after children, Child protection plan, MARAC). 16.6% re-attended, 60% of these had adverse social factors.

Conclusions Overall management in PED appropriate, agreed to improve documentation on GCS. Consent required for YDAP referrals which may affect referral uptake. Direct liaison with YDAP is important to explore training for Paediatric staff to maximise support for this vulnerable group. Children are recognised to present at younger age (youngest age in our cohort was 11 years old). Use of electronic flagging systems can highlight vulnerable group at increased risk of readmission with alcohol intoxication. This can help explore further targeted interventions for this group.

G362(P) SIMULATION TEACHING AS A MODALITY TO TEACH PALLIATIVE MEDICINE SKILLS IN A GENERAL PAEDIATRIC SETTING

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Aims To assess the role of simulation teaching to teach paediatric palliative medicine (PPM) skills to the multidisciplinary team within a general paediatric setting.