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 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 PEDIATRICS: 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...
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, 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.