The first was a retrospective case series analysis looking specifically at delayed puberty. A possible association between ADHD and delayed puberty mainly amongst males was noted. This was not associated with stimulant treatment. The authors were cautious about their findings as they felt that an association did not prove causality and that the population studied may have lent itself to falsely high positives.

The second was a study looking mainly at growth of 124 boys with ADHD. This concluded that there was no discernible link between ADHD and delayed puberty.

The final two articles were literature reviews which included the information of this second study. Due to this, they came to a similar conclusion but acknowledged the lack of concrete evidence looking at sexual maturation in children with ADHD.

There have also been animal studies showing a negative effect of stimulant medication on testes size in monkeys. However this effect was temporary.

Conclusion There is a lack of research looking specifically at ADHD and puberty and this has led to differing opinions. Further prospective studies would help to determine if there is a link between the underlying mechanism of ADHD and the factors that control the onset of puberty.

Association for Paediatric Palliative Medicine

G35 A REVIEW OF THE OUTCOME OF A COHORT OF INFANTS BORN WITH TRISOMY 18

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Trisomy 18 (T18), Edward's syndrome, is a rare condition with a prevalence of 0.1/1000 livebirths in the UK.[1] The majority of these infants do not survive the neonatal period with up to 10% surviving for a year [2]. Clinicians are faced with difficult discussions regarding outcome. This study stems from questions posed by parents of a baby girl who died at home aged 22 months.

The study was designed to address the parents' questions:

1.What is the likelihood of a baby being born with T18 with no identified antenatal risk factors?

2.What is the prognosis for a baby born with T18?

3.What support should families receive following a diagnosis of T18?

Method Retrospective study of all karyotype confirmed postnatal diagnoses of T18, born between 2000 and 2010 at hospitals within a perinatal network. Patients were identified from genetic databases. Information was extracted from paediatric case-notes to a pre-designed audit sheet.

Results Over 11years, 19 live born cases were identified. Information is available for 18. Nine cases (50%) were suspected antenatally but karyotyping declined until after birth. Nine cases (50%) were not suspected before birth. The median gestation was 38 weeks with range of associated anomalies; cardiac defects being the commonest. 4 babies died before discharge and all babies discharged from hospital had a named paediatric consultant. Survival was 94% at one week, 72% at one month, 39% at 3 months, 22% at 6 months and 11% at one year of age. Community nursing and hospice support was provided for 12 (66%) babies. Clinical genetics input was documented for 16 families; 6 before and 10 after discharge. Evidence of end-of-life -planning was poorly documented in the case notes.

Conclusions Half of the babies in this cohort were not suspected antenatally. Overall survival rate was 10% at one year consistent with previous studies but medium term survival was higher than other published studies. Better documentation of end of life care is required.

G36 PALLIATIVE CARE IN NEONATES WITH ANTENATALLY AND POSTNATALLY DIAGNOSED CONGENITAL HEART DISEASE

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Introduction The RCPCH[1] and BAPM[2] have issued guidance on palliative care for neonates with life limiting conditions. There is no reference to congenital heart disease (CHD).

Methods We reviewed 7 babies with CHD born between March 2010 and December 2012 who received palliative care.

Results Seven babies were identified with a median birthweight of 2690g (1740–3900g) and gestation 40 weeks (35+3–42+0). Five had antenatally detected complex CHD which was confirmed postnatally. In 3 cases palliative care plans were made antenatally and these babies did not receive any medical intervention. Two were discharged and died at home in the community at 3 days of age with support from their general practitioner and the hospice (True Colours Team). One died in hospital at 7 days in accordance with the parents' wishes.

For two babies there were antenatal discussions but no agreed postnatal plans made. One had an umbilical line for a prostaglandin infusion until the decision was made for palliative care at six days of age. She died at home at sixteen days with support. Another baby with antenatally diagnosed severe tetralogy of Fallot with absent pulmonary valve was admitted to NICU. On day three she collapsed and required ventilation and inotropes. After careful discussion intensive care was withdrawn on day 4 and she died in hospital later that day.

Two babies were diagnosed with CHD postnatally. One had a 6mm atrial septal defect as part of Smith-Lemli-Opitz (SLO) Syndrome. After confirmation of the diagnosis of complex SLO, palliative care was instigated. She was discharged home at 10 weeks and died at home at 14 weeks of age. A baby with a large VSD had trisomy 18 confirmed on day 8 and the decision for palliative care was made the following day. She died at home aged 21 months.

Conclusion This case series shows that the local end of life care pathway, introduced in 2011, is effective for complex CHD. Multiprofessional hospital and hospice teams have learnt important lessons, including: supply pain relieving medications at discharge, early involvement of the GP and the importance of an ongoing lead paediatric consultant overseeing care.

REFERENCES

1. Witholding or Withdrawing Life Sustaining Treatment. Royal College of Paediatrics and Child Health. May 2004.
2. Palliative Care (Supportive and End of Life Care) A Framework for Clinical Practice in Perinatal Medicine. British Association of Perinatal Medicine. August 2010. Acknowledgement: East Anglia's Children's Hospices (EACH) True Colours Symptom Management Team.

G37 WITHDRAWN BY AUTHOR

G38 PARENTAL DECISION-MAKING AT THE END OF LIFE IN CHILDREN DYING OF CANCER

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Background When a child with cancer no longer has a realistic chance of cure, the parents are faced with a range of decisions regarding further treatment options, place of care and place of

death. Little is known however, how parents make decisions around end of life care. Better understanding of the parental decision making process could lead to more effective care for families in similar circumstances as well as a better allocation of resources.

Method This qualitative study used semi-structured interviews with four bereaved parents and subsequent analysis by IPA to descibe the parental decision making process.

Results During curative treatment, the child's consultant was regarded as the main decision maker. At the end of life however, the responsibility for decision making lies solely with the parents (the children in this study were not informed of their impending death). Importantly, all participants describe disagreements with their partner, especially with regards to medical treatment decisions. In all families, the disputes were resolved by the mother acting as the main decision maker.

The most important factor in deciding in favour of further treatment was a belief that further treatment could be successful. The principal argument against further treatment was a concern regarding the quality of life for the child should the treatment succeed. The most important reason to take the child home to die was the parental perception that the child did not like the hospital. However, in deciding the place of death it was very important to ensure continued involvement of family and friends who had been supportive during the treatment. After the death of the child, engagement in altruistic and reciprocal activities was described as most helpful in bereavement.

Conclusion This retrospective pilot study allows some insight in the parental decision making process at the end of life of their child and calls for further study.

G39 DELIVERING OPTIMUM CARE AT JOURNEY'S END: A COMPARISON OF BARRIERS TO END OF LIFE CARE PLANS BETWEEN A PAEDIATRIC ONCOLOGY SPECIALIST CENTRE IN THE USA AND A DISTRICT GENERAL HOSPITAL IN UK

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End of life care is a challenging but vital aspect for children with life-threatening conditions, requiring parental discussion to plan appropriately. Parents express a need for open and honest information, delivered in a sensitive and timely manner. In adults, advanced care discussions (ACD) result in end of life care closer to patient preference, aligning care with patients' wishes. However there is often patient dissatisfaction regarding the timing and content of ACD.

A recent article in *Pediatrics (*Durall et al., 2012), identified barriers to conducting ACD for children in a paediatric oncology specialist centre in the USA. Following two challenging cases in our own unit, we assessed our colleagues' views at a district general hospital (DGH) in the UK, to see if similar barriers were pertinent despite contrasting hospital settings. 27 responses to a 23-item survey, adapted from the above article, were compared with findings from the USA centre. Additionally, we explored differences in perceptions between consultants and junior doctors.

Similarities between the two hospitals were striking, with 5 of the 6 top barriers to ACD at the USA paediatric oncology centre being replicated at the DGH. Key issues in both settings included clinicians not knowing the right time to address issues, and clinician concern about removing hope. Of note, across the two centres, nurses identified lack of clinician time and lack of importance to clinician as barriers whereas doctors did not. For consultant paediatricians, specific barriers to ACD were differences between clinician/parent/patient understanding of prognosis and clinician uncertainty about prognosis. For junior doctors, specific concerns were not knowing the right time to address the issues or what to say.

This study demonstrates that similar barriers to ACD exist internationally. Junior and senior doctors identified particular concerns which could help enhance and target teaching at specific training levels. Findings from nurses suggest that doctors should reflect upon whether sufficient emphasis is given to ACDs and whether priorities should be revised.

REFERENCE

1. Durall A, Zurakowski D, Wolfe J. Barriers to conducting advanced care discussions for children with life-threatening conditions. Pediatrics, 2012(4)e975

G40(P) WHAT DELAYS DISCHARGE IN CHILDREN WITH LIFE LIMITING CONDITIONS? A QUALITATIVE STUDY OF THE PERCEPTIONS OF PARENTS AND MEDICAL PROFESSIONALS

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Background It is important that any family of a child with a life limiting condition (LLC) have the option of where they would like their child to receive care (ACT 2010, DOH 2008) and do not have unnecessary protracted periods of hospital admission.

Aims The aim of the project was to establish the perceptions of professionals and parents regarding perceived delay in discharge of children admitted acutely who had a LLC; also to look at ways to expedite discharge if appropriate.

Methods This study took place in a large tertiary teaching hospital. A qualitative approach was taken – one to one interviews with parents and focus groups with professionals. Inclusion criteria included parents of children with life limiting conditions admitted with acute illnesses.

Results The data was analysed using grounded theory. A model emerged of "separateness of expert knowledge" from the parents, community and hospital teams.

Conclusion This study, although limited in terms of participant numbers, explored the perceptions of parents and professionals around discharge in children with LLC admitted with acute conditions. The main finding was the "separateness of expert knowledge" between parents, community teams and hospital teams. All the groups included valued access to a professional who knew the patient well. Hospital staff and community teams felt that co-morbidities resulted in longer lengths of stay.

The reason for admission was not solely due to the acute diagnosis, but also lack of other adequate services for this group of children out of hours. There was no specific treatment identified that prevented discharge.

A multi-professional approach to the care of these children, with a robust system for discharge planning may enhance the service. A multi-professional out of hours telephone service for families of children with LLC may help reduce admissions.

REFERENCES

1. ACT's manifesto 2010: living matters for dying Children www.act.org.uk/manifesto accessed 15th June 2010.
2. Department of Health 2008. Better Care Better Lives.

G41(P) HANDLE WITH CARE: ADVANCE CARE PLANNING (ACP) IN PAEDIATRIC PATIENTS WITH PALLIATIVE CARE NEEDS: QUALITATIVE STUDY OF EXPERIENCES AND PERCEPTIONS OF PAEDIATRIC INTENSIVE CARE UNIT (PICU) MEDICAL AND NURSING STAFF

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