Families appreciate the honest discussions from the outset and feel they have the knowledge surrounding potential complications. This enables a more informed decision-making on their part and improved preparation for clinical change. Palliative care delivered in parallel with respiratory care (with or without NIV) has resulted in a smoother journey for families with respect to symptom management, advance care planning and end of life care.

**Conclusion** A comprehensive, easy to use resource to provide structure to discussions when NIV is being considered was constructed and piloted. Feedback was collated prior to Region-wide launch with effectiveness confirmed by further feedback.

A multidisciplinary approach to the consideration of NIV use is vital, including professionals who know the child well in settings outside the hospital environment.

**REFERENCE**


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**306 EXPLORING THE PALLIATIVE CARE INPUT PROVIDED TO THOSE BORN WITH EDWARD’S AND PATAU’S SYNDROME IN THE BELFAST TRUST**

Rachel Moore, Anne Haddick, Sarah Kapur. Royal Jubilee Maternity Hospital Belfast

10.1136/archdischild-2022-rcpch.56

**Aims** Edward’s syndrome (Trisomy 18) is rare and associated with a poor prognosis, however 13% of babies live beyond 1 year of life in the UK. The reported incidence of Edwards is 3/10,000 births every year whilst Patau Syndrome (Trisomy 13) is 2/10,000.

The aim of this audit was to look at the incidence of both Patau’s and Edward’s syndrome in the Belfast trust over a ten year period and review documentation around antenatal care planning and postnatal advance care planning.

**Methods** This was a retrospective audit looking at all the cases of Edward’s and Patau’s Syndrome in the Belfast Trust over a 10 year period. Case notes and electronic care records were reviewed and parameters were identified including incidence, method of diagnosis, median survival, clinical features, birth weight and documented palliative care plan were looked at.

**Results** There was an average incidence of 1 in 2320 live births of Edward’s syndrome in the Belfast trust over 10 years. Only 4 out of 20 of these babies were diagnosed antenatally via amniocentesis. Of those who died in first year of life, the median survival was 5 days (range 1-201). We realised that these children can survive beyond the first year with one child surviving until 2 years and 6 months and another still alive at 2 years old who underwent a gastrostomy and oesophagostomy for a tracheoesophageal fistula. 20% and 15% of infants were discharged home and to the hospice respectively.

There was an average incidence of 1 in 9280 babies born with Patau’s syndrome in the Belfast trust. Of the 5 babies born over 10 years with Trisomy 13 only one was diagnosed antenatally. There was a median survival of 2 days, with one patient still alive at 4 years.

Of these babies with Edward’s and Patau’s, 66% had a clear Palliative Care plan documented.

**Conclusion** This audit demonstrates what we already know – that there is a poor prognosis for babies born with Edward’s and Patau’s Syndrome, however, we have demonstrated that there is a broad range of clinical features, surprising survival ages and an alarmingly low number of infants diagnosed with these syndromes antenatally.

We have also highlighted the need for a clear documented care plan from the moment of diagnosis, either antenatally or postnatally, which counsels the parents appropriately, allows them to prepare for the birth of and to grieve for their infant however they see fit, all the while working along with NICU/ labour ward staff to ensure that their infant is kept as comfortable as possible. This is an essential element of the palliative care process for these patients. In conclusion, we have demonstrated potential for further improvement in our unit and are working on implementing changes in the near future.

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**534 PARENTAL ETHICAL DECISION MAKING AND THE IMPLICATIONS FOR ADVANCED CARE PLANNING: RESULTS OF A SYSTEMATIC REVIEW AND SECONDARY ANALYSIS OF QUALITATIVE LITERATURE**

Veronica Neefjes. University of Manchester

10.1136/archdischild-2022-rcpch.57

**Aims** Both clinicians and parents are expected to make medical treatment decisions in the best interests of the child. Typically, the bio-ethical approach of clinicians involves the application of four principles outlined by Beauchamp and Childress. Parental ethical decision making has received much less attention and European research in particular is lacking. Understanding parental decision making is pivotal in advanced care planning, an important tool aiming to improve care for children with life-limiting conditions as engaging parents in these discussions can be challenging.

The aims of this investigation are:

1) To investigate which ethical values European parents use in medical treatment decision making

2) How parents employ their ethical values

3) How parental decision making fits with advanced care planning, in particular when deciding on treatment limitations


**Methods** Systematic review and secondary analysis of qualitative research papers regarding parental experiences caring for children with life-limiting disorders in the Netherlands, Germany and England & Wales published between January 2010 and December 2020.

**Results** Forty-three papers are included; 16 from England & Wales, 18 from the Netherlands and 9 from Germany. In the papers 731 children were discussed by 880 parents.

Parents in the three countries use the same 6 values for medical treatment decision making: protection of life, protection from suffering, being positive, aiming for normality, child deserving the best life, and altruism.

The parental ethical values are mainly in the context of the parental relationship with the ill child. As such, parental decision making can be understood within the Ethics of Care (EoC) framework. Within EoC the aim of ethical decision making is to nurture and preserve the caring relationship. Decisions about what is right and wrong depend on the particular circumstances at the time.

The difference between health care professionals principled decision making and parental contextual decision making explains some of the challenges clinicians experience in
abstracts

advanced care planning, in particular in decisions regarding treatment limitations.

Parents describe a reluctance to make specific decisions in advance and, if agreeing to treatment limitations only do so because they know that they can revoke the decision. Moreover, most parental values described above pull parents in the direction of prolonging life. Only actual (or expected) suffering leads parents to agree to treatment limitations. Consistent with this finding is that parents whose child experienced a prolonged PICU admission feel that not speaking about treatment limitations after their child recovered is a missed opportunity that could have prevented further intensive treatment.


Conclusion Parental ethical decision making is contextual rather than based on principles. It is important to take this into account when engaging parents in discussions regarding treatment limitations.

568 FACILITATING REGIONAL EDUCATION IN PAEDIATRIC PALLIATIVE CARE: A DIGITAL SUCCESS

Charlotte Holland, Alison Pearce, Sue Lakie. Helen and Douglas House Children’s Hospice

Aims To explore the requirements, then create and deliver education in children’s palliative care within the Managed Clinical Network (MCN) for Buckinghamshire Oxfordshire and Berkshire, considering continued restrictions on face-to-face group size due to COVID-19 and increasing need for virtual methods of education that facilitate learning.

Methods Two groups were identified to run pilot education programmes within the region.

The first was a group of three Band 6/7 outreach nurses in paediatric palliative care working towards specialist level/prescriber status through Helen and Douglas House Hospice. A curriculum was devised based on national guidance and self-identified learning needs covering over 20 divided into mini-series of 2-5 sessions. Teaching is delivered weekly for 30-45 minutes, facilitated through a virtual meeting room using Microsoft Teams and interactive worksheets through a Moodle platform course.

The second was the development of a series of five ‘webinar’ style sessions to introduce the concepts of paediatric palliative care, delivered to interested nurses from acute, ward and community teams across the region. This identified learning need came through a local collaboration group comprising paediatric and neonatal intensive care, oncology, hospice and child mortality members. Webinars were run for 1 hour in the evening every 6-8 weeks using Microsoft Teams and PowerPoint with integrated videos detailing family/patient stories and experiences, and a facilitated Q&A session. Further series will be hosted by the neonatal and children’s intensive care teams.

Results Outreach nurses consistently reported 5/5 on a Likert scale of usefulness for each mini-series developed. They enjoyed the mixture of learning styles, including case discussion, communication skills, short videos, interactive elements and using resources to answer specific questions. It was an advantage to get instant feedback on correct or ‘ideal’ answers. They felt that weekly sessions of 30-45 minutes with

group size of 5 or fewer participants was optimal for learning.

About half of those who signed up to the webinar series pilot attended the event in person, with a further percentage accessing recorded material post-event. It was well-received as an introductory series level with 88% giving it a 4 or 5 rating for usefulness, and 84% saying they would be likely to join for further sessions (the remaining 16% were ‘not sure’ depending on specific topic or timings). Attendees enjoyed the ‘chunk-style’ of information rather than a more overwhelming full day, use of patient stories and case discussion. They found the length of session and evening timing acceptable.

Conclusion The project has attracted Hospice UK funding as part of an MCN grant and is being presented as an option for education on a wider regional footprint through NHS South-East England.

Multi-media and innovative approaches enhance the digital education experience for the learner, meaning they are more engaged despite the virtual environment. Targeted paediatric palliative care education can be meaningfully delivered in mini-series delivered in short sessions. Further development of a virtual platform to enable education to a wider reach across the region is desired, with a blended approach of virtual face-to-face and supporting resources.

587 APPROACH TO BLEEDING IN A DYING CHILD

Pravin RR. Cardiff

Aims To discuss the common aetiologies of bleeding in paediatric palliative care, management and to discuss about the decisions made in the approach to bleeding in a child at end of life

Methods This is an educational poster which looked at paediatric palliative care resources for the causes of, management of bleeding in a dying child and discusses the ethics behind transfusions for the dying child.

Results There are many causes of bleeding in a dying child which may be related to underlying malignancy, treatment related, or related to other aetiologies such as liver or renal disease. Management can be tailored to the management of the bleeding episode and adjuvants (non-pharmacological & pharmacological).

Conclusion Bleeding in a dying child is never easy for the parents, the child & the physician. Bleeding can be multifactorial & appropriate treatment according to the reason for bleeding can be instituted. However, thoughtful palliative care needs to be practiced to determine if the child will always benefit from the treatment.

750 SYMPTOM CONTROL WITH PALLIATIVE CHEMOTHERAPY AND RADIOTHERAPY IN PAEDIATRIC PATIENTS WITH CANCER IN A TERTIARY CENTRE

Anne Haddick, Robert Johnston. Royal Belfast Hospital for Sick Children

Aims Radiotherapy and chemotherapy have been used for many years to try and reduce symptoms in palliative cancer patients. Important considerations for Clinicians to consider