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

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**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
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.

Methods 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 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.

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.

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...