

G213(P) END-OF-LIFE CARE DECISIONS: DIFFERING DECISION MAKING PROCESSES

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Aim Parents of children with life-limiting illnesses (LLI) are often required to make decisions regarding what type of life-sustaining treatment, if any, is to be provided and where care is to be delivered at the end of their child's life. This study aimed to explore the experiences of parents in making and revising end-of-life care decisions for their child with a LLI.

Methods Semi-structured interviews were conducted with three bereaved parents of children with LLI between April and July 2014. Data were analysed using Interpretative Phenomenological Analysis. Eligible families were invited to participate by the child's main consultant. Approval for the study was granted from the National Research Ethics Service and written informed consent was obtained prior to the interview.

Results Two parents in the study had received their child's diagnosis at least a year prior to their child's death, whereas the other parent had only received the diagnosis in the final weeks of the child's life. This parent, prior to receiving the diagnosis, had made decisions to treat her child aggressively on the presumption that the illness was curable. Upon receiving the diagnosis, she decided in conjunction with professionals to transition towards palliative care and ensuring comfort for her child. The other parents had been aware of their child's diagnoses for longer and deemed from the start that aggressive treatment would not be appropriate or in their child's best interests.

Conclusion The majority of the literature on the topic of decision making in children's palliative care includes children with both life-limiting and life-threatening illnesses (LTI). Although there may be some overlap in the decision making processes, this study although limited by its sample, has shown that decisions may differ for children with LLI as compared to children with LTI, suggesting that perhaps these populations should be researched separately. More research is needed in order to determine the differences in the decision making processes and whether specific support with decision making is needed between the two groups.

G214(P) BLENDED FOOD FOR ENTERAL FEEDING VIA A GASTROSTOMY

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A blended diet for enteral nutrition is defined as home-made everyday food blended to a smooth "single cream" consistency. Currently blended food is not recommended by the British Dietetic Association as a first choice supporting guidance on enteral feeding from N. I. C. E. However in a UK children's hospice the policy is where possible to replicate the care received at home, respecting parents' wishes. Therefore guidelines needed to be created for its use in the hospice. Benefits in physical and emotional health needed to be balanced against risks in tube blockage, contamination and digestive upsets.

Aim was to gather information and risk assess the processes in order to formulate guidelines on the use of blended food for staff and parents.

The process involved searches for information on the internet and liaising with specialist groups of dieticians and tube manufacturers. For the process of syringing/plunging where there is very little information available a visual demonstration was developed using a plastic box and a gastrostomy button. For issues relating to contamination and food hygiene we used existing guidance on food preparation.

Guidelines were developed and presented to our clinical governance group for consideration and acceptance for use.

Working with local dieticians a package of information including all the considerations and risks were developed to give to parents.

Blended food is not recommended as a primary choice for enteral feed and may not be supported by all those involved in a child's care such as schools or respite unit. Blended diet is used by 10% of the tube fed children using our service. With careful consideration we have been able to develop practical guidelines that support and replicate care given at home whilst respecting the choices made by all our families on how their children are feed.

For the future one UK university has started research to look at the health, social benefits and implications of blended diet. In North America where there are prescription costs and strict insurance schemes many opt for blended food, for others this is simply their preferred method. Here a company has developed a shelf safe product for gastrostomy feeding from "real food" available on Amazon.com

G215 SETTING AND MAINTAINING PROFESSIONAL BOUNDARIES IN PAEDITRIC CLINICAL PERSPECTIVES FROM AN INTERPROFESSIONAL PERSPECTIVE

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Aim This study explored the manner in which paediatric nurses and hospital play specialists set professional boundaries and the challenges they faced in maintaining a therapeutic relationship when caring for children and their families in hospital.

Methods A phenomenological approach was adopted, through a purposive sample of seven paediatric settings within one NHS Trust. Eight paediatric nurses and two hospital play specialists were interviewed. Thematic analysis, using field notes and transcribed tape recorded interviews, was used to identify emerging themes and generate a description of the respondents' experience.

Results The study revealed that paediatric nurses had difficulty in defining the concept of professional boundaries, therapeutic relationships and self disclosure. Although no clear definition was given for professional boundaries, respondents agreed that they were important. Paediatric nurses could recognise when boundaries were being broken but lacked the confidence to address boundary violations. Using self disclosure was seen as a balancing act which could lead to boundary crossing and boundary violation. Nurses felt unsupported by senior colleagues particularly when faced with "manipulative families" and found their code of conduct¹ helped guide their practice. Hospital play specialists had a greater understanding of therapeutic relationships than paediatric nurses.

Conclusions Health care professionals can recognise professional boundaries and boundary violations but they need support to

address violations – especially in the paediatric intensive care environment.

REFERENCE

- 1 Nursing and Midwifery Council. The code: Standards of conduct, performance and ethics for nurses and midwives. NMC. London; 2008

G216

DEVELOPING NATIONAL GUIDANCE ON SPECIALIST AND ADVANCED PRACTICE FOR CHILDREN AND YOUNG PEOPLE'S NURSES

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Aims To explore what is meant by advanced practice in CYP nursing.

To clarify the distinction between advanced practice, and the roles of nurse specialist, advanced nurse practitioner and nurse consultant.

To promote the professional and educational guidance in this 2014 UK document.

Methods A review of the professional literature and a range of national and professional policy documents was undertaken in order to define and establish the competencies and standards for advanced practice in children's nursing, and recognise the value of specialist roles across the UK.

A group of expert children's nurses from a range of specialist and generic child health services, worked together to identify the distinction between advanced practice, and the roles of nurse specialist, nurse practitioner, and nurse consultant.

Results The guidance document developed through this project is directed at both commissioners and service providers. It promotes a shared understanding of what is meant by both advanced, and specialist nursing practice, alongside an explanation of the different roles and titles used by nurses and their employers. This is illustrated by the use of real life exemplar nursing roles and services.

The document sets out the characteristics of the robust clinical governance framework required to ensure safe and effective care when developing specialist roles and advanced levels of practice. This incorporates accountability and competence frameworks, and educational preparation.

Conclusion The development of innovative nursing roles, working at an advanced level of practice, requires a planned approach to the commissioning and development of services, and of the workforce that is able to deliver them. The guidance document to be discussed in this presentation brings clarity to the concept of advanced practice in child health nursing. It sets out the need for robust, flexible and accessible educational programmes, and the development of comprehensive career frameworks.

This presentation will explore the roles of advanced and specialist children and young people's nurses in the UK and promote the professional and educational recommendations of this key document.

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TRANSFORMING CHILDREN'S NURSING WITHIN A HEALTHCARE ORGANISATION THROUGH AN INNOVATIVE LEADERSHIP APPROACH

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Introduction Nationally, high quality, translational research that has a tangible impact on lives and outcomes is demanded by service users, commissioners and research funders (NIHR, 2013). However, without strong leadership firmly embedded within health organisations the impact on children's nursing remains limited in reaching its potential.

Aim This presentation will critically review the experiences of employing an innovative leadership approach to progress children's nursing research and evidence-based practice (EBP) culture, capacity and capability within a children's hospital, situated within a large NHS Trust.

Methods Despite demonstrable commitment from the senior nursing management, local implementation of the nursing research vision remained under-developed. Consequently, a local strategy that engaged key stakeholders and PPI was devised during 2013/4 to operationalise the vision within the children's hospital. An innovative approach was employed to fulfil this multifaceted and diverse remit.

Results Outputs to date included identifying research areas that aligned to local and national service priorities; the appointment of a clinical-academic children's nurse; the implementation of a training programme in knowledge translation and scholarly activities; and a funded partnership between a senior children's nursing research leader/professor and the healthcare organisation. Opportunities have been sought with potential for national multi-centre studies with other specialist children's health settings. Post graduate students have been identified and supported.

Conclusion The strategy employed contributes to transforming the children's nursing research and EBP culture within a healthcare organisation in the UK through an innovative leadership approach. This visionary strategy will be shared with delegates with the rationale for appointments and support, and there impact on organisational culture, outlined. Challenges and successes will be discussed including early exemplars and high level impact results. The results and presentation will be useful for all delegates in supporting and developing the culture of nursing research within healthcare organisations.

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THE CONTRIBUTION AND IMPACT OF SPECIALIST AND ADVANCED CHILDREN'S NURSING PRACTICE TO CONTEMPORARY HEALTH CARE

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