Transition to home of technology-dependent children for end-of-life care (EOLC)

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Disclosures

• Mullaney:
  – I have no financial interests or other conflicts to disclose pertaining to the information presented in this discussion.

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  – I have no financial interests or other conflicts to disclose pertaining to the information presented in this discussion.
Providing Quality End of Life Care in the ICU and Beyond
Is home the best place for a child to die?

- What are the options for a child in the ICU?
Palliative Care in the PICU
Palliative Care in the PICU

• >50% of the approximately 55,000 children who die each year will die in the hospital.

• 30 – 60% of all deaths in PICUs follow an order to either withhold or withdraw life-sustaining treatment.
Synchronization of intensive care and palliative care services is critical

• Families wish to participate in the end of life decision-making process for their critically ill children.
• Informed consent requires a family’s understanding of the full-range of options available
  • Intensive care options
  • Palliative care options
• Location of death is important
  • Calm environment
  • Family present
  • Ability to participate in life-closure activities
Common themes in end-of-life parental decision-making

• Quality of life
• Presence and degree of suffering
• Lack of effective treatments
  • Experience and observation
• Passage of time
• Importance of having options and advice
• Emotional reactions
  – “It’s not fair that this is happening to my child”

Priorities for parents

• Honest and complete communication
• Ready access to staff
• Communication and care coordination
• Emotional expression and support by staff
• Preservation of the integrity of the parent-child relationship
• Faith

• Meyer EC et al. Pediatrics. 2006; 117; 649 - 657
A few case studies...
• 19 y.o female
  – Severe autism
  – Metastatic rhabdomyosarcoma
  – Malignant pleural effusions
  – Respiratory distress
• PICU staff
  • Intubate? DNR?
• Oncology staff
  • Are invasive procedures appropriate?
• Radiology staff
  • Current lab values? Risk?
  • “I don’t want to be the executioner”
• Transport staff
  • Reimbursement? Time frame?
Following Placement

Day of Transport Home
A quiet trip home... ...a promise kept

PICU physician present for transport
• 19 y.o. with neurodegenerative condition
• Long-term trach-vent dependence
• Renal failure with failed access
• Parents decide
  • “If nothing more can be done in the hospital, we want to get home ASAP”
Preparation for the family

• Determine expectations
• Who will be in their home
  • Length of time staff will be present
• Clear description of
  • Process
  • Physical changes they should expect to see in their child
• Long-term plans if the child continues to breathe comfortably
• Medications used and the indication
• Spiritual and cultural needs of the family
• Complete DNR for out of hospital
• Funeral planning
  • Hospice nurse pronounces death; funeral home transports child’s body
Benefits of home extubation

• Privacy, calm, quiet
• Comfortable/familiar surroundings
• Unlimited time to grieve with their child
• Greater autonomy for parents
• Pre-death connection to community agencies that can provide on-going bereavement support

• Reducing wasted use of ICU resources
Barriers

• Lack of care providers with experience
  – ICU technology in a pediatric hospice??
• Difficulties in reimbursement
  – Less common medications
    • Administration guidelines
• Availability of home medical equipment
• Cost of transport
• Legal and ethical concerns
  – Scope of practice
  – Practitioner comfort
Practice Pearls

• A thorough discussion regarding family preferences of *location of death* is paramount.
  – Determine whether transport to home is feasible for child prior to offering to the family
  – Clarify the family’s needs, not what the medical team may interpret those needs to be
  – Death in the hospital should never be interpreted as a failure

• Time and thoughtful preparation of the family may diminish the risk of complicated grief
Questions?