TO TRACH OR NOT TO TRACH? THAT IS THE QUESTION

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THE PAST

- Historically tracheostomies placed for upper airway obstruction
- Airway reconstructions allow decannulation in many patients
THE PRESENT

- over last decade, tracheostomy is performed on younger patients with greater incidence of chronic and complex medical issues
PATIENT POPULATION

• Retrospective review of children who underwent tracheostomy placement between 2001 and 2011
• Define mortality and long-term outcomes of children undergoing tracheostomy
• 426 patients

• Indication
  • ½ Neurologic
  • ¼ Respiratory
  • ¼ Anatomical obstruction

• Medical Complexity:
  • More than ½ discharged on vent
  • more than 2/3 with G tube

Pediatric Pulmonology 52:946-953(2017)
OUTCOMES

• ¼ of patients died during study period
• ½ of survivors were decannulated (median time 5 years)
• Important differences in prognosis based on indication for trach
• Outcomes significantly worse for trach due to neurological condition
  • Mortality
  • Potential for decannulation
• useful in counseling families regarding what to expect over the long term
• Understanding likelihood of decannulation may assist families in decision making
INFORMED CONSENT
CHALLENGES

• Fragmented communication among providers
• Parents receive conflicting and confusing information
• Poor understanding of long-term outcomes and potential for decannulation
WHAT IS THE FAMILIES PERSPECTIVE?

• Qualitative study exploring experiences of family’s with children with SMA Type 1 in healthcare setting to identify gaps in care and opportunities for improvement

• 19 families interviewed (22 children with SMA)

WHAT DO FAMILIES WANT?

- to fully understand available options and make informed decisions about care
- to participate in shared medical decision making to balance quality of life with longevity
- more information about long term outcomes
- additional education to clarify risks and benefits of treatments and lack of known options
- Education focused not solely on trach/vent but progression of disease (immobility, contractures)
- 50% chose proactive care, 50% chose palliative care
GOALS OF CONFERENCE

• Facilitate communication between medical providers caring for medically complex children requiring tracheostomy

• Promote a full understanding of options

• Discuss long term outcomes and potential progression of disease

• Discuss risk and benefits of different treatment types
HOW DOES CONFERENCE WORK?
• Weekly Multidisciplinary Pre-tracheostomy conference to review cases for medically complex children requiring tracheostomy

• Participants include critical care, otolaryngology, pulmonology, nursing, social work, and care management (palliative care, neurology, complex care pediatrics, ethics prn)

• Critical care team identifies patients, completes intake sheet, and presents each patient at conference
MEDICAL HISTORY

- Brief Medical History and Hospital Course
- Neurological Status (Pediatric Cerebral Performance Category Scale)
- Disease Prognosis (static, progressive, potential for improvement)
- Risk of further decline
- Anticipated repeat hospitalizations based on disease process
INDICATION FOR TRACHEOSTOMY

• Loss of upper airway (loss of pharyngeal muscle tone or anatomical obstruction of the upper airway)
• Facilitation of ventilation (need for mechanical ventilator support)
• Inability to swallow oral secretions (aspiration)
• Secretion retention (impaired airway clearance) – to enable suctioning and removal of secretions from lower airway
FAMILY’S PERSPECTIVE

• Parental Values and Goals of Care

• Family’s understanding of disease process (degree of impairment, likelihood of improvement)
FAMILIES ABILITY TO CARE FOR TRACHEOSTOMY

• Care team concerns regarding family’s ability to care for child with tracheostomy:
  • Family’s ability to provide two caregivers?
  • Risk for CPS involvement?
  • Barriers to Discharge Home with Tracheostomy
LOGISTICS

• Has patients care been discussed with patient’s pediatrician?
• Will that provider continue to care for patient post tracheostomy?
• Expected level of nursing support based on insurance carrier
EXPECTATIONS OF CONFERENCE

• Facilitate communication among providers regarding prognosis, potential recovery or progression of disease

• Clarify long-term implications of tracheostomy including mortality, potential for decannulation, potential for independence from ventilator

• Do not make decision for or against tracheostomy
THE END GAME - SHARED DECISION MAKING
COMMENTS/QUESTIONS?