Care of the Medically Fragile Child with Tracheostomy and/or Ventilator Dependence

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Introduction

• Purpose:
  • Discuss the complexities of global care for and treatment of a medically fragile child with tracheostomy and/or ventilator dependence

• Objectives:
  • Describe populations affected by need for tracheostomy and/or ventilator support.
  • Discuss interdisciplinary intervention and management for children with tracheostomy and/or ventilator dependence.
  • Identify interdisciplinary interventions that facilitate development, function, and family inclusion.
  • Describe techniques for transition to the community targeting interdisciplinary aspects of care.
Types of patients that require airway and/or respiratory support

- **ENT patients with anatomical/physiologic issues**
  - examples: stenosis (including critical airway), malacia, trauma

- **Patients with parenchymal lung disease**
  - examples: Bronchopulmonary Dysplagia, chronic aspiration

- **Neuromuscular disorders causing severe weakness**
  - examples: Spinal Muscular Atrophy (SMA), myopathies (Nemaline Rod, Centronuclear, etc.)

- **Disorders of control of breathing**
  - examples: Congenital Central Hypoventilation Syndrome (CCHS), cervical Spinal Cord Injury (SCI)

Why sub-acute hospitalization?

- “Discharges for children associated with long-term mechanical ventilation require substantively greater inpatient resource use than other children with complex chronic conditions.” 1
Upon admission: establishment of discharge criteria:

- **Medical**: absence infection, criteria based on specific diagnoses, follow-up plan clear
- **Respiratory**: predictable respiratory support needs
- **Nutrition**: predictable nutrition regimen
- **Developmental**: often diagnosis-dependent; optimize function, access
- **Equipment**: seating/mobility, splints/braces, stander, compression garments
- **Community**: Home Choice, Help Me Grow, WIC
- **Home**: SW home assessment, electrical capability, accessibility,

**Services unique to post-acute care**

- Frequent family team meetings
- Interdisciplinary morning rounds: including families, therapists, social work, care managers in addition to medical, nursing respiratory
- Every child provided with PT/OT/SLP/RT evaluation
- Every child provided with Care Management services
- **Environment**:
  - Central monitoring for patients at the nursing station
  - Play and dining areas on the divisions
  - School classrooms
  - Multiple therapy locations including large treatment areas and smaller more private rooms
  - Several outdoor courtyards and playgrounds
Therapy Services

- PT/OT/SLT/RT/MT
- Seating and positioning
  - In room and on the unit
- Groups – Socialization + Stimulation
  - Play group, Music group, Infant group, Movement group, Toddler group, Spoon group, Story time, Music with Robin
- Speaking valve
- Assistive technology consult
- Multiple therapy locations: gyms, small treatment rooms, sensory rooms, aquatics, ADL room
- Community Integration

Therapy, cont’d.

- Aquatic therapy
- Sensory experiences
- Discipline collaboration:
  - Off-unit treatment
  - Tolerance of handling – consult medicine, respiratory, etc.
  - Achievement of clinical goals
  - Timing of interventions
  - Family education
Transition to Community

- Overall discharge plan – ongoing review
  Asses: did we address everything?
- Provider-to-provider hand-off for transition
- Role-modeling with family and caregiver(s)
- Continuity of care form – SW and PCM
- Home assessment
- Home nursing
- Transitional overnight with parents providing 24 hour care

Transition to Community, cont’d.

- Therapy
  - Equipment
  - Outpatient therapies – environment considerations based on community
  - Community integration
  - Feeding – Infant Feeding and Nutrition Clinic, Pediatric Feeding Disorders Program, outpatient OT/SLT
  - Education – role-modeling, home programs
  - Fresh Air Camp
Case Study 1: Baby I.

- 2 month old female
- Diagnosis: Congenital Central Hypoventilation Syndrome (CCHS) requiring tracheostomy and ventilator support
- Considerations:
  - Dysautonomia
  - Need for long term respiratory support/mechanical ventilation
  - Genetics, ophthalmologic, GI
  - Long term support with unique family education parameters
  - Medical complexity did not greatly affect development
- Therapy — monitor development, speaking valve/expression

Case Study 2: Baby J.

- 10 month old female
- Diagnosis: non-immune Hydrops Fetalis
  - 31 week twin gestation
- Considerations:
  - Poor tolerance for stimulation & handling
  - Prolonged NICU stay/procedures
  - Global developmental delays due to prematurity and respiratory issues
  - Significant increases in developmental gains post-discharge (family very involved)
Baby J.: Before & After

Case Study 3: N.

- Admitted at 8 months old and discharged at 3.5 years old
- Diagnosis: 25 weeks premature, global developmental delay, supraglottic/glottis/subglottic stenosis (“critical airway”), tracheomalacia, tracheostomy dependence
- Considerations:
  - Staged surgical procedures over time to reconstruct airway, granulomas,
- Therapy/Social -
  - Psychology, Behavior Plan, and Daily Schedule
  - Music Group – socialization and peer-to-peer interaction
  - Initiate potty training
  - Community re-integration outings to home, multiple settings
  - School – IEP
  - Feeding
  - Role-modeling and bonding opportunities with mother
- Discharge Recommendations – outpatient PT/OT/SLT, Feeding Team, subspecialties
Baby N., cont’d.

References


References, cont’d.


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- Amy Fuhrman, CTRS
- Shannon Wemple, PT, DPT
- Ashley Torgerson, CTRS
Questions?