Tubes, Trachs and Technology:
Caring for Medically Complex Children

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Disclosures
I have no relevant disclosures.

The content for this activity, including any presentation of therapeutic options, is well-balanced, unbiased, and to the extent possible, evidence-based.

Goals for this talk
- Review common technologies that your patients may use
- Provide some basic guidelines of what can be done at home, in the office, and in the hospital
- Provide some data on psychosocial aspects of caring for technology-dependent children
- Outline steps primary care providers can take to provide support

Definition
Technology-dependent children:
- Children who need "both a medical device to compensate for the loss of a vital bodily function and substantial and ongoing nursing care to avert death or further disability"
  - U.S. Congress, Office of Technology Assessment, 1987
- 0.10% - 0.25% of children in the U.S.

Common technologies
- Enteral feeding tubes (nasogastric/gastrostomy)
- Long-term central venous access
  - Parenteral nutrition (TPN)
  - IV therapies (e.g. antibiotics, clotting factor)
- Dialysis
- VP Shunts and associated needs
- Respiratory therapies
  - Oxygen therapy
  - Cardio-respiratory monitoring
  - Tracheostomy tube
  - Mechanical ventilation or CPAP

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- Children who need "both a medical device to compensate for the loss of a vital bodily function and substantial and ongoing nursing care to avert death or further disability"
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- Medical device are not necessarily electronic
- Parents provide lots of nursing care
How many patients do you have in your practice with some of these?

1. Zero
2. 1-5
3. 6-10
4. >10

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  - Tracheostomy tube
  - Mechanical ventilation or CPAP
- Nebulizer machine

Enteral feeding tubes

- Indications for home NG
  - Inadequate caloric intake
  - Oromotor dysfunction
  - Aspiration risk

Feeding tube alphabet

- NG tube
- ND tube
- NJ tube
- G-tube / PEG
- GJ-tube
- J-tube

Initial placement and replacement

- Start with the correct tube
  - Feeding tubes are softer than suction tubes
  - Lubricate tube
  - Insert straight back
  - Have the child swallow
  - Confirm placement

How do we confirm placement?

1. Always take an x-ray
2. Listen for stomach bubble
3. pH assessment
4. If the child is comfortable and not coughing it’s probably ok
**Confirming placement**

- pH of gastric aspirate is most common method in the hospital
- X-ray may be used
- Other techniques (used at home)
  - Listen for air bubble
  - Check for gastric aspirate

**Clogged NG tubes**

- First step is to remove and replace
- If no additional tubes are available, or if tube is transpyloric:
  - Coca-cola
  - Clog-zapper
  - Pancreatic enzymes

**Pumps**

![Pumps Image]

**Feeding tube alphabet**

- NG tube
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**G-tube complications**

- Infections
  - Distinguish from granulation tissue
  - Gram positive organisms are most common
  - Usually can feed through the infection
- Dislodgement
  - Immediately replace tube
  - Foley catheter if tube not available

**Changing a Mic-key**

![Changing a Mic-key Image]
Central venous access

- Medium to long-term: Peripherally inserted central catheter (PICC)
- Long-term: tunneled or implanted catheters

Indications:
- IV antibiotics
- Need for extremely frequent access
- Dialysis and chemotherapy

Considerations

- Risks
  - Superficial soft tissue infections
  - CLABSI (central line assoc bloodstream infection)

- Home management
  - Care
  - Heparinization

- Emergency plan
  - Is child prone to hypoglycemia or dehydration?

VP Shunts and associated needs

- Neural tube defects
- Trauma patients
- Neuro-oncology patients
- Neurogenic bladder

VP shunt

Shunt valves

- Pressure regulated vs. flow regulated
- Fixed vs. programmable
Signs of VP shunt infection or malfunction

- Altered Mental Status
- Fever and:
  - Tenderness over shunt or tubing
  - Erythema
  - Abdominal pain
- Higher level of concern with abdominal infections

Clean intermittent catheterization

- Usually every 3 hours during the day
- Clean hands are fine
- Catheters are re-used
- Wash with soap and water
- Dry on a towel or hang-dry
- Ditropan (oxybutynin) is commonly used
  - Relaxes bladder so less reflux

Respiratory Therapies

Home oxygen

- Indications
  - Chronic lung disease
  - Bronchiolitis in some regions, esp high elevations
  - Cystic fibrosis
  - Interstitial lung disease
  - Pulmonary hypertension
- Benefits
  - Decrease in hospitalizations
  - Optimization of physical growth and development
  - Improvement in quality of sleep
  - Prevention of worsening disease

Home oxygen

- Types of delivery
  - Oxygen cylinders
  - Oxygen concentrators
  - Liquid oxygen
- Usually via nasal cannula
- Usually 100% FiO2
- Usually not on home monitors

Home monitors

- Apnea monitors
- Pulse oximetry
**Tracheostomies**

- Indications
  - Airway anomalies
  - Trauma patients (short-term)

- Types of tracheostomies
  - Non-speaking
  - Speaking

**Tracheostomy emergencies**

- Clogged tracheostomy tube
- Dislodged tracheostomy tube

- Can the child be bag-mask ventilated?
- Can the child be intubated?

- Always have a phone available when changing a tracheostomy tube!

**Home ventilation**

- Emergency plan?

**Nebulizers**

**Which of the following is true?**

1. Nebulized albuterol providers more effective drug delivery than MDI
2. Nebulized albuterol is preferred over MDI in the emergency department
3. MDI with Aerochamber can be safely used in infants
4. Children who get admitted for asthma exacerbations should be transitioned to MDI at the time of discharge
Nebulizers

- Are they necessary?
- MDI’s are just as effective for many
  **Includes acute exacerbations**
- Settings where nebulizer may be necessary:
  - Infants or toddlers
  - Severe exacerbations
  - Parental preference
  - Expert consensus (the EPR-3) and evidence-based

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Impact on children

- Emotional impact
  - Prolonged hospital stays
  - Low self-esteem
  - Sense of burden on parents
- Social impact
  - Disruption of social life
  - Less time with peers
  - Very little “alone time”

Impact on children

- School impact
  - Mainstream vs. special ed vs. special school
  - Increased physical demands
  - Lost time from medical treatments
  - Missing school for appts creates additional stress
- Quality of Life impact
  - Overall scores seem to be lower
  - Need to balance against illness

“Many parents struggle with significant emotional strain, the physical and psychological dependence of the child, the impact on family relationships, living with the daily threat of death, and feeling that they had no choice but to agree to the technology dependency because they would never let their child die.”

Mesman et al. 2012, Carnevale et al. 2006
**Impact on family**

- Emotional impact
  - Mood difficulties
  - Sleep disruption
  - Stress from lack of information and education
  - Stress of long hospitalizations
    - Different behaviors in front of staff
    - Time away from other children and spouse
  - Economic burdens

Mesman et al. 2012

- Social impact
  - Disruption of social life
  - Lost friendships
  - Avoid public outings due to embarrassment
  - Need for respite

Mesman et al. 2012

- Family relationships
  - Dual role of parent and nurse
  - Parents may do painful or distressing procedures
  - Medical personnel in the home
  - Siblings emotions:
    - guilt, embarrassment, frustration, jealousy
  - Less stable home life

Mesman et al. 2012

**Advocating for our patients**

- "He only takes those type of patients on certain days"
  - Challenges accessing subspecialty care
  - 50% report at least one unmet medical need
  - Disabled CSHCN have even higher rates of needs and unmet needs
  - Specialty care, therapy services, mental health services, home health, assistive devices, medical supplies, and DME

(CSHCN – children with special health care needs)

**Other things we can do**

- Regular psychosocial assessments with a multidisciplinary team
- Advocacy for a coordinated community-based system of support
- Increased awareness by clinical providers of family impact
- Financial and organizational support for practices
- Support for multidisciplinary clinical models

Mesman et al. 2012

- Disaster preparedness
- Emergency preparedness
Final Notes

- Technology does not have to be complicated
- Technology does not have to be scary
- Primary care physicians are the first line of support for families of CSHCN and Technology-dependent children
- Be aware of psychosocial needs
- Have an emergency plan

References