Caring for Children with Special Health Care Needs (CSHCN)

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Our Home......

Home Away From Home????
Objectives

- Identifying and understanding care needs of Children with Special Health Care Needs
- Determine the physiologic and unique needs of CSHCN with medical complexities
- Identifying strategies to promote developmental care and enhance family coping
- Understanding and promoting optimal education of CSHCN pediatric patient and their family

Disclosures

We are fans

Children with Special Health Care Needs (CSHCN)

- What is CSHCN?
  - Children with special health care needs are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally. (AAP February, 2011). (Cohen, E., et al. Pediatrics 2011; 529-540)
  - Have developmental needs, but the accomplishment of these tasks is made more difficult by an extra set of demands and hardships associated with the chronic condition
Children with Special Health Care Needs (CSHCN)

- More than 9.4 million children in the US have an special health care needs
- 13-18% children considered to have special health care needs
- Considerable variation in medical complexity, functional limitations, and resource needs

CSHCN

- Children with Medical Complexity (CMC)
  - Children with characteristic patterns of needs, chronic conditions, functional limitations, and health care use.
- Small percentage of CSHCN are CMC
  - Increased Prevalence
    - Increased survival rates in pre-term infants
    - Increased survival for congenital anomalies
    - Improved technology and treatment for acute care (ex.: ICU and oncology)
  - Impact of suboptimal care effects on child’s health, family well-being, and health care system

Children with Medical Complexities
### Children with Medical Complexities

#### Needs
- Increased needs for medical care, specialized therapy, and educational needs
- Significant impact on family
  - Time devoted to care, frequent appointments and hospitalizations, financial burden
- Goal: Family Centered care with access to health care services/information that empowers families

#### Chronic Conditions
- Medically fragile
- High morbidity/mortality
- Goal: Sufficient knowledge, understanding, and decision making support at community and tertiary levels

#### Functional Limitations
- Technology Dependent
- Special adaptations necessary
- Goal: Ensure availability of support for maximizing functions
Children with Medical Complexities

- Health Care Use
  - High Utilization of health care resources
  - Frequent, prolonged hospitalizations
  - Multiple subspecialists
  - Goal: Utilize a high quality and efficient system through enhanced care coordination

HANG IN THERE

Meet Jena
Jena’s History

- Born: October 7, 1997
- Normal Term Delivery
- Wt.- 3,725 grams
- IVH at 1 week age
- Spontaneous IVH
  - Severe CP
  - Chronic Lung Disease
  - Seizure Disorder
  - Neurogenic Bladder
  - Panhypopituitarism

Understanding the Child with Medical Complexities

Samantha & Serena
Understanding the Child with Medical Complexities

• What about all that technology?!

Where’s the baby?

- Be knowledgeable while recognizing the family may be the experts with the home equipment and their child
- Nursing consistency in care and equipment important to the family

Vesicostomy

- Creating an opening from the bladder to the outside of the body, allowing urine to flow freely with no backup to the kidney
- Complications-
  - yeast infection
  - UTI’s
CSF Shunt

- Drains excess cerebral spinal fluid from the ventricles to maintain normal pressure within the brain
- Potential Complications: Brain infections, shunt obstruction, shunt malfunction, Peritonitis

Potential Complications:

- Headache
- N/V
- Irritability
- Altered mental status
- Lethargy
- Fever
- Bradycardia or other arrhythmias
- Seizures
- Apnea

Signs and Symptoms of Shunt Complications

Interventions for a Child with Shunt Complications

- ABC’s
- Oxygen and
- Elevate head of bed to decrease increasing intracranial pressure (ICP)
- Anticonvulsants for seizure activity
- Follow PALS guidelines for arrhythmias
Central Venous Catheters

- A catheter inserted through the skin into a central vein and advanced to the junction of the superior vena cava and the right atrium
- May be single, double, or triple lumen

Central Venous Catheter (CVC) Emergencies

- Bleeding at catheter entry site
- Interventions to control complication; direct pressure, assess and treat respiratory distress, assess and treat hypoperfusion, estimate blood loss

CVC Emergencies Cont’d

- Dislodged catheter
- Interventions to treat complication; direct pressure over site, assess and treat respiratory distress, assess for and treat hypoperfusion, estimate blood loss
CVC Emergencies Cont’d
- External broken catheter
- Interventions to treat complication; clamp the CVC closest to insertion site with gauze wrapped hemostats or CVC clamps, assess and treat respiratory distress and hypoperfusion, estimate blood loss

CVC Emergencies Cont’d
- Blood clot or air embolism
- Interventions to treat complication; clamp line with gauze covered hemostats or CVC clamps, assess and treat for cyanosis, sudden changes in respiratory distress and LOC, place child on left side in head down position

CVC Emergencies Cont’d
- Fever
- Interventions to treat complications; recognize high risk for sepsis, assess and treat respiratory distress, assess and treat hypoperfusion
Gastrostomy Tubes

- Types - mushroom-tipped catheter, balloon-tipped catheter, button
- Transport any button adapters to the hospital with the child

Mic-Key

- Contains an internal, inflatable balloon which holds the g-tube in place and prohibits displacement
- The balloon is breakable, so g-tube changes are required more frequently than the Bard
  - The valve is located on the outside of the body
  - Relatively easy to change
  - Has a feeding adapter locking mechanism

G-Buttons Facts

- If dislodged replaced with same size G-button or one size lower Foley
- If replaced and less than 2 months old or insertion is difficult order a contrast study
- A "leaking" G-button can be both a sign of malfunction, need for size increase, or obstruction
  - Each G-button costs about $200
Potential Gastrostomy Tube Emergencies

- Tube dislodged: Interventions to treat complication; place gauze over stoma, assess for and treat dehydration, NPO
- Bleeding at stoma site: Interventions to treat complication; place gauze over stoma, control bleeding
- Broken feeding tube adapter; Interventions to treat complication; clamp tube
- Gastric Distension: Interventions; connect syringe to tube and aspirate until resistance is met

Tracheostomy

- Creation of an opening into the trachea through the neck, with insertion of an indwelling tube to facilitate passage of air or secretions. (Miller-Keane Medical Dictionary)

Why a Tracheostomy

- Provide long term ventilation
- Airway clearance
- Prevent chronic aspiration
Tracheostomy tube should extend at least 2cm beyond stoma, and no closer than 1-2 cm to the carina. (Carina - The anteroposterior cartilaginous ridge in the bifurcation of the trachea which separates the openings of the two primary bronchi.)

Types of Tracheostomy Tubes
- Metal
- Polyvinyl chloride
  - (Shiley)
- Silicone
  - (Bivona)

Tracheostomy Tube Features
- Cuffed vs. Uncuffed
- Fenestrated vs. Nonfenestrated
- Inner Cannula
- Custom tubes
Tracheostomy Tube Emergencies
- Obstruction or Displacement of Tube: Interventions to treat complication; assess and treat ABC’s, suction trach, change trach,
- Equipment Failure: Intervention to treat complications; assess and treat respiratory distress

Suctioning
- Sterile-the use of a sterile catheter and sterile gloves for each suctioning procedure (Always done in hospital)
- Clean-the use of a clean catheter and non-sterile, disposable gloves or freshly washed hands, clean hands (May be done in the home)
- Technique: Twirl
Suctioning Depth

- Shallow suctioning-insertion of catheter just into the hub of the trach tube to remove secretions
- Premeasured Technique- the catheter is inserted to premeasured depth, with the most distal side holes just exiting the tip of the trach tube
- Deep Suctioning-insertion of catheter until resistance is met, withdrawing the catheter slightly just before suction is applied

Premeasured Technique

Tracheostomy Tube Change

- Obtain spare trach from caregivers
- Cut trach ties and attach to trach tube, insert obturator into tube, lubricate tube with NS or water-soluble gel
- Remove occluded trach tube from child
- Gently insert new trach tube, NEVER FORCE THE TRACHEOSTOMY TUBE!
- Remove obturator, secure ties and assess breath sounds
Tracheostomy Tube Change
Cont’d

• If unable to get trach in hold gentle steady pressure on trach at stoma site until child takes breath to see if trach will go in (DO NOT FORCE)
• If still unable to get trach tube in try one size smaller trach tube (if not available may use ET tube)
• If still can’t get trach tube in cover stoma and ventilate through the nose and mouth, if that doesn’t work place face mask over stoma to ventilate (cover child’s nose and mouth)

Humidification

• Upper airway functions to filter, heat and humidify inspired gas; when the upper airway is bypassed, inspired air has humidity deficit
• Goal: To heat and humidify inspired gas to match the normal physiologic conditions at the level of the carina (32-34 degrees C)
• Must consider safety, cost, convenience, and child’s respiratory status when deciding on home humidification

Humidification Devices
Go-Bag

TRACH DISCHARGE CHECKLIST

- Patient has Go-bag
- Osteopenia Precautions addressed
- Medicaid & BCMH, & SSI Application completed and approved
- Nursing Company and Hours established
- Immunizations, Influenza vaccine, Opth, Audiology Up To Date
- Identify follow-up Primary Care Provider and Specialty
- Home Equipment (Respiratory and Enteral) Ordered
- Trach CPR scheduled and completed
- Skills Checklist Completed by both Caregivers
- Caregivers have Air Conditioning, Electrical Outlets, Phone, Car seat, Crib, and Stroller
- Home Equipment delivered to hospital and family trained/ EMS/ Electric Letter
TRACH DISCHARGE CHECKLIST
Continued.....

- Home Equipment Plugged In
- Handicap Parking Pass
- Home Schedule Given to family
- Synagis arranged for home if patient qualifies
- Rooming In completed with home equipment by both caregivers
- WIC Prescription, Formula, Recipe, and Appointment
- Primary Pulmonary Physician Signed off on trach education sheet
- Desat Study 24-48 hours prior to discharge
- Outpatient therapies ordered/Help Me Grow Referral
- Discharge Summary to follow physicians and home nursing company

Education is Key!

Hang In There
Unique Issues

- Chronic sorrow
  - Grief response associated with an ongoing living loss that is permanent, progressive, and cyclic in nature.
  - Grief vs. chronic sorrow
    - Grief is linear and time-bound and ultimately reaches final goal of acceptance and adaptation.
    - Chronic sorrow is a response to ongoing loss. There is a constant reminder of the loss.

- Chronic sorrow
  - Natural reaction
  - Response to ongoing loss
  - Reaction to multiple losses over time
  - Permanent
  - Not depression
  - Most prevalent during times of diagnosis, illness exacerbations, and developmental transitions

- Chronic sorrow
  - Developmental crises:
    - Ages 12-15 months
    - 24-30 months
    - 6 years
    - Onset of adolescence
    - 21 years
  - Other crises:
    - Time of diagnosis
    - When a younger sibling surpasses the child
Unique Issues

- Chronic sorrow
  Differs between Mothers and Fathers

Unique Issues

- Nursing interventions for chronic sorrow
  - Recognize it as a natural reaction
  - Compassionate, EMPATHETIC, sensitive, and nonjudgmental care
  - Assist parents in using effective coping strategies (journaling, counseling, exercise)
  - Provide accurate information and practical care giving tips
  - Identify sources of support and respite
  - Assist parents in maintaining hope and finding meaning in their experience

Unique Issues

- Ethical considerations
  - At some point, children/parents may be faced with making difficult decisions regarding life-sustaining therapies.
  - Children/Parents have a value-based system for making decisions that may differ from the healthcare team.
Unique Issues

- Ethical considerations
  - Parents act in the best interests of their child and sometimes may make decisions which are not consistent with healthcare providers’ value systems.
  - We need to respect their right to do so and understand they have a different perspective.
  - Decision making influenced by the family system, culture, religious and spiritual affiliations, social media, and personal value preferences.

Unique Issues

- American Academy of Pediatrics on Bioethics:
  - The standards for determining the decision-making capacity of minors are the same as those for adults.
    1. The ability to comprehend essential information about their diagnosis and prognosis
    2. The ability to reason about their choices in accordance with their values and life goals
    3. The ability to make a voluntary informed decision, which includes being able to recognize the consequences of various courses of action.
  - Most children do not reach conceptual development maturity until age 11 or 12. (wide variation)

Unique Issues

- Ethical considerations
  - How do we know parents are acting as good decision makers?
    - Commitment to the best interest of the child
    - Demonstration of adequate and appropriate knowledge
    - Emotional stability
    - The ability to make reasoned judgment
  - Beneficence: Doing good
  - Nonmaleficence: Avoiding or minimizing harm
Unique Issues

- Ethical considerations
  - Futility:
    - Clinical intervention reliably expected not to have its usually intended effect
    - Lack of a medical benefit
    - Society: Children should not die  
      - What can be done often shapes what is done
    - Hope always exists...not necessarily hope for survival, but hope for a "good death" or supportive end-of-life care

- Ethical considerations
  - Withholding vs. withdrawing care
    - Ethically equivalent
    - Perception: Not doing something (not intubating) is perceived as more benign than the act of doing (removing vent)
    - Reality: difference between never starting and discontinuing is in the feelings of the individuals
    - An assessment from the child's perspective, of the burden and benefits of offering or continuing treatment is what should count ethically, not whether treatment has begun or not.
    - Just because something can be done, does not mean it should be done

Withdraw or Withhold Life-Sustaining Measures (LSM)

- Persistent Vegetative State
  - No developmental progress, no reciprocal relationship
  - Need for complex support
- No Chance
  - LSM delays death and prolongs suffering
- No Purpose
  - Survival questionable. Quality of Life (ex. HIE)
- Unbearable
  - Progressive and irreversible and further treatment is more than can bear (ex. SMA)

Tobalski J. The legal basis for withholding and withdrawing life-sustaining medical treatment in children. 2006 Journal of Law and Medicine, 14: 244-261
Ethical Considerations

- Guidelines for Pediatric End of Life Decision
  - 1. Withholding versus withdrawing life support
  - 2. Medically supplied food and fluids
  - 3. Use of Opioids
  - 4. Use of paralytic agents
  - 5. Brain Death
  - 6. The dead-donor rule


Guidelines for Pediatric End of Life Decision-Making

- Withholding versus Withdrawal
  - An assessment from the child's perspective, of the burden of and benefits of offering or continuing treatment is what should count ethically, not whether treatment has begun or not.

- Medically supplied food and fluids
  - May prolong dying and near the end of life may cause congestion, excessive bodily secretions, and discomfort. Medically supplied nutrition and hydration are not ethically and legally required in all circumstances. They can be stopped, like all other medical interventions, when their burdens outweigh their benefits

Guidelines for Pediatric End of Life Decision-Making

- Use of Opioids
  - Ethically ok to provide adequate analgesia as long as the INTENT is to relieve suffering and not cause death. Recent research suggests, “if the dosage has been titrated properly, then respiratory depression is rare even when opioids are used at very high levels.

- Use of Paralytic Agents
  - Should never be used at end of life care, NO analgesic or sedative properties. Goal relieve pain and suffering.
Guidelines for Pediatric End of Life Decision-Making

- **Brain Death**
  - Complete cessation of brain function = clinical death. All 50 states. New York and New Jersey—special religious provisions.

- **The Dead-Donor Rule**
  - Uniform Anatomical Gift Act—organs only retrieved from patients who are dead. Excludes permanently unconscious patients.

Unique Issues

- **Ethical Considerations**
  - Guidelines for Decision Making
    - Healthcare providers must provide patient/family with information about therapeutic and diagnostic options (risks, discomforts, S/E, cost, benefits, likelihood of success of treatment)
    - Recommend best option—families may accept or reject

- **Withholding vs. Withdrawing care**
  - Goals at end-of-life:
    - Pain and symptom management
    - Avoiding inappropriate prolongation of dying
    - Achieving a sense of control
    - Relieving burden
    - Strengthening relationships with loved ones
References

- AAP SOHM Sub committee on Complex Care
  ballantine@email.chop.edu – Allison Ballantine – Chair
- AAP Division of Children with Special Needs
  www.aap.org/healthtopics/specialneeds.cfm
- Allen PJ, Vesey JA, Schapiro NA. Child with a chronic condition (9th ed.). Mosby, St. Louis. 2010
- Baylor College of Medicine-Richardo Quinonez, MD, FAAP
  www2.aap.org/sections/hospice/FellowsConference/ChallengesInComplexCare.pdf
- Tidball, J. The legal basis for withholding and withdrawing of life-sustaining medical treatment in children. 2006 Journal of Law and Medicine, 14 244-261