Health Home Care Coordinators Training

Pediatric Chronic Conditions and the PSC-17

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Today’s Presenter

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Objectives

• Present information about chronic conditions for children
  • Types of support needed (medical and home care)

• Review the Pediatric Symptom Checklist (PSC) – 17 and FLACC
  Behavioral Pain Assessment

• Provide Health Promotion: importance of immunizations

• Examine helpful resources for your clients and you

CSHCN: Children with Special Health Care Needs

• Definition
  • Children who have, or are at risk of having, a chronic physical, developmental,
    behavioral or emotional condition and who require health and related services
    of a type or amount beyond that required by children generally.
  • >10 million children in the US meet this definition.

• Subset of CSHCN are **Medically Complex**
  • Substantial health care needs
  • More than one chronic condition
  • Technology dependent
  • Severe neurodevelopmental impairment
Diagnoses Common to Medically Complex CSHCN

Numerous diagnoses but certain categories predominate:
• Preterm birth
• Congenital genetic and metabolic disorders
• Neurologic and Neuromuscular disorders
• Sequelae of severe infection
• Sequelae of severe injury
• Malignancy

Common Scenarios Leading to Pediatric Home Care

• List of potential diagnoses is extensive
• Most children do not have just one disorder
• Typically they have more than one disorder or a single disorder that is so overwhelming that is causes multiple organs to malfunction or fail, creating secondary diseases
Common Scenarios Leading to the Need for Pediatric Home Care (cont.)

- **Overwhelming Neurodevelopmental Impairment:**
  - Hypoxic-ischemic encephalopathy, Near-drowning, Severe brain injury (accidental or non-accidental), Overwhelming infection, Genetic abnormality causing abnormal brain development.

- **Premature infant with extensive sequelae:**
  - Chronic lung disease, Subglottic stenosis with tracheostomy dependence
  - Necrotizing enterocolitis with short gut syndrome
  - Intraventricular hemorrhage with development of Cerebral Palsy
  - Neonatal apnea/ bradycardia

- **Respiratory disorders:**
  - Cystic fibrosis, Central hypoventilation, Severe asthma, other chronic lung diseases

- **Spinal Cord injury**
- **Renal failure**
- **Malignancy**
- **Congenital heart disease**
- **Gastrointestinal disorders**
  - Malabsorption, Severe GERD, Severe Constipation, Liver disease
- **Hematologic disorders**
  - Sickle Cell disease, Thalassemia, Hemophilia and other clotting disorders, disorders associated with increased clotting
- **Endocrine disorders**
  - Diabetes Mellitus, Hypopituitarism
Pediatric Home Health Care- Background- Who and Why?

- Tremendous advances in neonatal, medical and surgical care of infants and children have led to survival of an increased number of Children with Special Health Care Needs (CSHCN)

- Increased emphasis on caring for CSHCN at home, rather than in the hospital

Rationale and Goals for Home Health Care

- **Rationale**
  - Improved psychological health and development of the child
  - Improved family function
  - Decreased cost compared with hospitalization
  - Improvements in technology have facilitated care at home

- **Goals**
  - Optimize health and function of child and family
  - Minimize recurrent or prolonged hospitalizations
Technology Dependent:
Use of medical devices which are necessary to prevent adverse health consequences and/or hospitalization

- Common examples of technology seen in home care:
  - Oxygen
  - Mechanical ventilators
  - CPAP or BiPAP machines
  - Suction machines
  - Indwelling IV catheters
  - Enteral feeding tubes and pumps
  - Colostomy bags
  - Urinary catheters
  - Specialized mobility and seating devices

Examples of situations in which one would encounter use of technology in children at home:

- Osteomyelitis (infection of bone)
  - Indwelling IV catheter used to administer a prolonged course of antibiotics at home

- Respiratory Failure
  - Use of home ventilator and oxygen

- Upper Airway Obstruction
  - Tracheostomy and CPAP or BiPAP and oxygen

- Inadequate Oral Feedings
  - Nasogastric or Gastrostomy tube feedings

- Short Gut Syndrome
  - Total Parenteral Nutrition administered through indwelling IV catheter
Planning for discharge from hospital to home care:

• **Things to consider/ plan for:**
  - Assessment of family and home
  - Identification of Primary Care Provider (PCP)
  - Training of home-caregivers

Planning for discharge from hospital to home care: (cont.)

• **Things to consider/ plan for:**
  - Arrange home care nursing (in some cases)
  - Arrange for educational/ developmental services
  - Arrange for durable medical equipment
  - Deal with insurance coverage issues
Example- Case #1
13 year old female with history of non-accidental trauma in infancy

- **Primary insult:** Severe brain injury
- **Direct consequences of primary insult:** Poor brain growth, global developmental delay, seizure disorder

- **Subsequent consequences:**
  - **GI** - Dysphagia (swallowing problems), Gastrostomy tube dependence, GERD (reflux), Constipation
  - **Respiratory** - Poor control of secretions, Recurrent aspiration pneumonia, Upper airway obstruction, Chronic lung disease
  - **Neuromuscular** - Spasticity, Muscle contractures
  - **Skeletal** - Scoliosis, Hip dislocation, Osteopenia, Fractures
  - **CV** - Poor peripheral circulation
  - **Skin** - Decubitus ulcers

Example- (cont.)
13 year old female with history of non-accidental trauma in infancy

- **Subsequent consequences continued:**
  - **Vision** - Cortical blindness
  - **Hearing** - Neurosensory hearing loss
  - **Urinary** - Incontinence, Incomplete bladder emptying, Recurrent urinary tract infections
  - **Pain** - Various etiologies related to all of the above, often not easy to identify the source

- **Technologies** - GTT, feeding pump, suction machine, BiPAP machine, Oxygen, Nebulizer, Circumferential chest vest, Baclofen pump, Hoyer lift, hospital bed, wheelchair, stander, bath seat, car seat, incontinence supplies
Example- (cont.)
13 year old female with history of non-accidental trauma in infancy

- **Medical providers involved:** PCP, Gastroenterologist, Pulmonologist, ENT, Neurologist, Physiatrist (Rehab), Orthopedic Surg, Physical therapist, Occupational therapist, +/- Opthalmologist/ Audiologist/ General Surg./Urology/ Nephrology

- **Services required:** Durable medical equip provider, Medical supplies provider, Respiratory equip. provider

- **Education:** IEP plan, Special education classroom, Special education bus service, Specific therapies at school.

- **Home health services:** Medicaid personal care assistant, No provision for home health nursing in most cases.

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Respiratory Care Issues

- Improved survival of children with chronic pulmonary and neuromuscular illness has led to increased need for chronic home ventilation.

- Home care optimizes health, psychosocial development, and family well-being and is less expensive.

[http://www.pediatricspecialcare.com/equipment/equipment.htm](http://www.pediatricspecialcare.com/equipment/equipment.htm)
Which Children Go Home on a Ventilator:

- **Children with chronic lung disease:** may see improvement in pulmonary function over time with lung growth and repair.

- **Children with progressive neuromuscular disease:** will eventually progress to respiratory failure. Ventilation prolongs life and may improve life.

- **Children with terminal illness:** goal is to decrease suffering and allow the child to die in relative comfort of home.

- **Children with severe brain injury and persistent vegetative state:** with no hope of improvement or recovery, careful consideration needs to be given to the decision to ventilate

- **Children who benefit from nocturnal ventilation:** examples include children being weaned from ventilation, early stage neuromuscular disease, central hypoventilation syndromes (can willfully breathe when awake/ alert)

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Tracheostomy

- **Reasons for tracheostomy:**
  - Need for long-term ventilator support
  - Neurologic dysfunction causing a floppy airway or inability to clear secretions
  - Abnormal upper airway anatomy

[Diagram of tracheostomy and tracheotomy care instructions](http://www.enttx.com/airway-2/tracheostomy-care-instructions)
Risks and Concerns Related to Tracheostomy

• Trachea usually humidifies the air and filters secretions from the airway. This role is disrupted by placement of trach. tube.
• Thick secretions can form and mucous can plug the tube.
• Pressure of the trach tube and suction catheters can irritate and damage the lining of the trachea.
• Overinflated tracheal cuffs can cause necrosis/ scarring/ stenosis of the trachea.
• Significant training of caregivers required.
• Families generally require home-nursing services at least at night so that they can sleep.
• Child will need nurse or trained caregiver (one-on-one) to accompany him/her to school or developmental programming.

Home Oxygen Therapy

• Oxygen therapy is one of the most common services in pediatric home care
• In the past, patients were hospitalized for prolonged periods of time just so that they could receive oxygen
• Home oxygen is usually safe, cost-effective and improves quality of life for patient and family
Home Oxygen Therapy (cont.)

- **Common reasons for O2 Therapy:**
  - Bronchopulmonary Dysplasia (chronic lung disease of prematurity)
  - Cystic fibrosis
  - Other chronic lung diseases
  - Neurologic/ neuromuscular causes

- **Oxygen delivery services:**
  - Nasal cannula is the most frequent low-flow O2 delivery device
  - Tracheostomy patients receive O2 through their trach.
  - Oxygen can be given via ventilator or CPAP/ BiPAP machine

- **Variety of forms of oxygen therapy for home use**

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Ventilation Types

- **Portable Positive Pressure Ventilation via Tracheostomy**
  - Provides ventilation at a set rate to patients via their tracheostomy
  - Requires electricity but capable of battery operation for at least 1 hour
Noninvasive Positive Pressure Ventilation

- CPAP - Continuous Positive Pressure Ventilation
- BiPAP - Bi-level Positive Pressure Ventilation
- Positive pressure via nasal or face mask or tracheostomy
- Either one level of pressure (CPAP) or a different flow rate set for inspiration and expiration (BiPAP)
- Often used only at night and during naps

Diaphragmatic Pacing

- Used for children who have a high spinal cord injury or abnormalities of central (brain-based) control of respiration.
- Uses the diaphragm as a respiratory pump.
- Surgically implanted electrodes stimulate the phrenic nerve.
- Stimulation of the phrenic nerve causes the diaphragm to contract and expand the lungs which draws air into them.

[Images of patients with CPAP and Diaphragmatic Pacing]
Other Respiratory Technologies

- **Pulse oximeter devices** - measure oxygen saturation and heart rate
- **Suction equipment**
- **Aerosol therapy** - home nebulizer machines
- **Airway clearance devices:**
  - Mechanical vibrators used for chest percussion
  - Circumferential chest vests
  - Cough assist devices

The Fully-Loaded, Ventilated Child in Her Medical Stroller
Feeding Issues in Pediatric Home Care

- Oral feeding is the best and most normal means of feeding and should be the goal, whenever it is safe and effective to meet nutritional needs.
- When oral feeding is not possible, other forms of GI (enteral) feeding are possible at home.
- When the GI tract is not function, IV (parenteral) feeds are possible.

Enteral Feeds

- Used for children who are unable to adequately meet their nutritional needs orally but have adequate intestinal absorption and gut function
- Feeding given directly into the stomach (gastric feed):
  - Nasogastric (NG) feed- generally for short term use
  - Gastrostomy (GTT) feed- need for long term enteral feeding
Enteral Feeds (cont.)

- Used for children who are unable to adequately meet their nutritional needs orally but have adequate intestinal absorption and gut function.

(continued)

- Jejunal feeds are used when the stomach needs to be bypassed. NJ (nasojejunal) or GJT (Gastrojejunal) tubes

Considerations in Enteral Feeds

- Need to meet the nutritional and fluid needs of the patient.

- Premature infants, term infants, toddlers, and older children all have different nutritional needs. A nutritionist is often involved in supervising diet and supplements.

- Adequacy of feeding is monitored with frequent weight/growth checks and periodic lab work.

- Children who are fed exclusively enterally will develop abnormalities in oral-motor development: “oral aversion”. They will require feeding therapy (OT/ST).

- Decision about how to administer enteral feeds is often partially dependant on the presence or absence of GERD (reflux).
Gastroesophageal Reflux Disease - GERD

- GERD causes significant problems in children with chronic illness.
  - Pain and irritability from gastric acid burning the esophagus
  - Erosive esophagitis
  - Risk of aspiration of gastric contents into the lungs
  - Risk of gastric contents irritation the larynx and causing obstruction or triggering asthma
  - Poor weight gain because unable to tolerate full volume of feeds

- Feeding options if GERD present:
  - Slow continuous feeds into the stomach (pump feeds)
  - Surgical treatment: Nissen Fundoplication
  - Jejunal feeds – NJ or GJ slow continuous feeds to bypass the stomach

GERD (cont.)

Two older girls receiving enteral feeds:

Total Parenteral Nutrition- TPN

Meeting nutritional needs via intravenous feedings

- **Common reason for TPN**: Short Gut Syndrome- removal of a large portion of the intestinal tract due to some severe injury or malformation of the intestine.

- **Majority of patients should receive at least some portion of their feedings enterally**, even if the majority of calories are coming from TPN.

- **Nutritionist and Gastroenterologist** usually work together to devise the exact contents of the TPN feed.

- **Frequent laboratory measurements** required.

- **Complications can be very serious**: Sepsis, Metabolic derangements, Cholestatic liver disease

- **Least favorable and most potentially dangerous means of providing nutrition** for extended periods of time.
Total Parenteral Nutrition - TPN (cont.)

- **Require Central Venous Access**
- **Options for Central Venous Access**
  - Non-implantable venous catheter (i.e. “Broviac”)
  - Implantable venous catheter (i.e. “Mediport”)
  - Peripherally Inserted Central Catheters – PICC lines

![Implanted venous catheter](http://surgery.med.umich.edu)

http://en.wikipedia.org/wiki/Peripherally_inserted_central_catheter

Central Venous Access for TPN
Complications of Immobility

- **Decubitus ulcers** secondary to pressure, bony prominences, excessive thinness, poor peripheral circulation

- **Osteopenia (weak bones)** and increased risk of fracture related to lack of weight-bearing, immobility, medications, nutritional deficiencies

- **Contractures** related to spasticity

- **Elimination disorders:** constipation, fecal impaction, bladder dysfunction, urinary retention, recurrent urinary tract infections

Pain

- **Chronic pain**- related to known disease process

- **Intermittent unexpected pain**- challenging to identify the source because of communication impairments.

- **Some possible sources of pain:**
  - Ear infections
  - Urinary tract infections
  - Fecal impaction
  - Excessive gas
  - Dental disease
  - Fracture
  - Pancreatitis
  - Gall Bladder disease
  - Skin ulceration etc… (many more possibilities)
FLACC Behavioral Pain Assessment

- The FLACC is an optional screening that may be offered to parents when pain is reported
- It provides terminology to help parents to describe behaviors they are observing to report to the pediatrician

Assistant Technology in the Home Care Setting

- **POSITIONING DEVICES**- equipment used to promote optimal posture and alignment in children who have not achieved head or trunk control
  - **Positioning chairs**- offers an alternative seating arrangement at home (beyond the wheelchair or medical stroller).
  - **Pillows/wedges/inserts**- assists with positioning in chair or bed.
  - **Standers**- support passive standing and facilitate weight-bearing.
Assistive Technology in Home Care

- **MOBILITY DEVICES**
  - **Manual wheelchairs** - used for children with sufficient upper body strength to propel themselves or in cases where patient lacks cognitive capacity to control a power wheelchair.
  - **Power wheelchairs** - used for children with the cognitive ability to control their movement.
  - **Medical strollers** - used for young children who are unable to propel themselves b/o severe cognitive, behavioral, or medical impairment.

- **Activities of Daily Living (ADL) devices:**
  - Bath chairs, Shower chairs, Inflatable bathtubs
  - Specialized potty chairs/toilet seats
  - Car seats
Developmental Considerations

Medically complex children have particular educational and developmental needs:

• **BIRTH TO 3 SERVICES (ESIT- Early Support for Infants and Toddlers)**- Provide home teacher, family support, home-based therapies, vision/ hearing specific therapies. Administered through the Department of Early Learning. Web site: [www.del.wa.gov/esit](http://www.del.wa.gov/esit)

• **OVER 3 YEARS OF AGE**- Local public school system will take over and provide developmental preschool until enrollment in kindergarten. Therapies at school. Transportation to and from school.

• **OTHER SERVICES**-
  • Early referral to evaluate for hearing/ vision deficits
  • Use of Physiatrists (Rehab specialists)
  • Use of Developmental pediatricians
  • Use of Developmental optometrists
  • Private/ community-based therapies (PT/ OT/ ST)
  • Infant/ Child/ Adolescent mental health providers
Primary Care – Role of the Primary Care Provider (PCP)

PCP’s play an important role in coordinating and managing the care of medically complex children.

• Even children who are being followed by multiple specialists need to be seen at regular intervals by their PCP’s.
• They need longer clinic visits to address: acute concerns, chronic issues, health care maintenance (well child care), vaccinations.
• They need to maintain detailed lists of chronic medical problems, medications, specialists, equipment providers, home care companies.
• They need to have access to social workers, nutritionists, palliative care consultants and DENTISTS.

Advance Directives/ POLST forms

- **Definitions:**

  - An **Advanced Directive** is a legal document used to provide guidance about what types of treatments an individual may want to receive in case of a future, unknown medical emergency. It also allows for the appointment of a health care power of attorney in the event that an individual is not able to communicate for themselves. It is recommended that all adults, healthy or ill, have an Advance Directive. Parents of chronically ill children may benefit from having an Advanced Directive to plan for surrogate caregivers in the event that they are not able to care for their children either temporarily or permanently.

  - **POLST** – Physician Order for Life-Sustaining Treatment is a medical order for the specific medical treatments an individual wants to receive during a medical emergency. POLST Forms are appropriate for individuals with serious illness or advanced frailty near the end-of-life.

    Resource for POLST - [https://endoflifewa.org/advance-directive/polst/](https://endoflifewa.org/advance-directive/polst/)
1) A chronically ill older child or adolescent may be cognitively and emotionally capable of participating in treatment decisions and may decide to complete either an Advance Directive or a POLST form. *Many chronic medical conditions worsen over time. Children with chronic medical conditions experience repeated hospitalizations, treatments, life-threatening emergencies and pain. They observe the death of friends with similar medical conditions. They are often mature beyond their chronological years. They may have thought a lot about the difficulties and joys of their life and they may have definite opinions about what they are willing and unwilling to tolerate. They may desire the opportunity to put in writing directions for their medical providers and caregivers to be sure that their wishes are respected in the event that their condition worsens to the point that they are not able to communicate. (from "Ethical Issues in Homecare" in Guidelines for Pediatric Home Health Care, AAP, 2009)*

2) The family of a chronically or critically ill child may decide it is time to put in writing their wishes for emergency care of their child. They might use the "Pediatric Starter Kit" from the Institute for Healthcare Improvement to help them in their decision making or they might have discussions with the child’s primary care provider or palliative care specialist. They would then complete a POLST form.
Advanced Care planning - how/ when to bring it up

- Older children/ teens may want to have this discussion but no one has brought it up. Start with questions to allow the teen to discuss their illness, what brings them joy, what they are afraid of, what plans they have for the future, what they are willing and not willing to lose etc...

- For younger children the discussion is with the parents. Discuss the direction of the child’s health and ask questions: do the parents see the child as stable, declining, having more hospitalizations and emergencies, requiring more interventions, experiencing more pain or suffering?

- Ask if anyone has discussed Advanced Directives or POLST. Give them resources if interested.
  - https://theconversationproject.org/starter-kits/

- Understand that they may not be ready to discuss this yet and never push; just provide info and let them know you are willing to assist if/ when they are ready.

- Make sure they understand that all decisions about Advance Planning are reversible.

Advance Care Planning (ACP)

Pediatric Starter Kit


Really excellent resource. Available in English, Spanish and Chinese.

The adult version is available in 11 languages.

Leads families through the stages and process of discussion and advanced planning.

Worth printing out and giving to any interested families.
Immunizations

- WA State Immunization Information System - WSII (previously called Child Profile) A registry of vaccinations received by children in WA state. Data electronically transferred from medical clinics throughout the state. All medical offices should be able to access this system and print out a copy of vaccines that a child has received. [https://fortress.wa.gov/doh/cpir/iweb/](https://fortress.wa.gov/doh/cpir/iweb/)

- Vaccination schedules have become very, very complex. Most clinics have a vaccination nurse who can help the medical provider and family determine which vaccinations are needed.

- The overwhelming majority of children (over 6 months of age) should receive an Influenza vaccine every Fall. This is especially important for children with chronic illness in whom Influenza can be life-threatening.

- Other family members and household contacts should be sure their vaccines are also up to date and they should get an Influenza vaccine every Fall also.

Pediatric Symptom Checklist - 17

PSC 17- a brief screening questionnaire for use in children 4-16 years of age to improve recognition of mental health problems.

- It is not meant to establish diagnoses but rather to encourage referral to the child’s primary care provider or a mental health specialist for further assessment.
PSC-17 (cont.)

• Includes 17 questions – a total score of 15 or higher suggests significant behavior or emotional problems and should lead to the recommendation that the child be seen by their PCP or a mental health specialist.

• The 17 questions are divided into 3 subscales which also have cut-off scores for referral:
  • Internalizing- anxiety and mood disorder, cut-off score of 5
  • Attention- hyperactivity, attention deficit, cut-off score of 7
  • Externalizing – conduct problems, oppositional behavior, cut-off score of 7

PSC-17 (cont.)

Significantly abnormal PSC-17 result (total score of 15 or higher, or any subscale score exceeding the cut-off) should lead to referral back to the primary care provider for further assessment or referral directly to a mental health provider.

The PCP may have additional screening tools that they use and they will likely conduct a more detailed interview with the child and parent. They may choose to provide counseling in the office or they might refer out to a mental health provider. They might prescribe psychiatric medication themselves or they may refer to psychiatry or to a behavioral pediatrician.

A parent can access Behavioral Health services directly without a referral from the PCP. Some BHO’s provide same-day, walk-in intake evaluations, others require an appointment for the intake. After the intake, if there is a significant mental health issue, the child will be assigned a therapist for ongoing care. A psychiatrist may become involved.

For a county by county guide to the Behavioral Health Organizations in WA state go to the DSHS, Division of Behavioral Health and Recovery website and search for Children’s Behavioral Health, and Mental Health Services for Youth.

Behavioral Health Organizations (BHOs)

Information About Children’s Behavioral Health Services

Link to DSHS Behavioral Health Website: https://www.dshs.wa.gov/bha/division-behavioral-health-and-recovery/childrens-behavioral-health
Pediatric Home Care

- Working to improve the lives of children
- With complex medical needs and
- Supporting families and caregivers so they can best enjoy their time together

Bibliography


Resources

Educational Web Links:

Tracheostomy and ventilator education


Gastrostomy tube feeding

PRISM Health Risk Indicators (HRI)

PRISM Report includes:

Health Risk Indicators

Risk Level: 2

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Washington State Department of Health

https://www.doh.wa.gov/YouandYourFamily
Care Coordinators Toolkit

https://www.dshs.wa.gov/altsa/stakeholders/chronic-disease-and-education-materials