

3.04 CHILD WITH MEDICAL COMPLEXITY

Introduction

Children with complicated special health care needs, termed children with medical complexity, currently account for 10% of pediatric admissions and 40% of all pediatric inpatient expenditures. Advances in intensive care practices, technological devices, and improved survival continue to increase the number and complexity of these children cared for both in the hospital and at home. Many of these children require some form of technological device to compensate for loss or impairment of one or more vital functions and to improve or sustain life. Commonly used devices include gastrostomy and jejunostomy tubes with and without fundoplication, ventricular shunts, baclofen pumps, indwelling central venous catheters, tracheostomies, and various forms of non-invasive and invasive ventilation. When these children are hospitalized, they require acute stabilization, long term care planning, and care coordination in the hospital and for transitions of care to home. The importance of these issues is reflected in the work of national agencies and advocacy groups such as the National Center of Medical Home Initiatives for Children with Special Needs and the American Academy of Pediatrics. Pediatric hospitalists frequently encounter these children with medical complexity and therefore must be able to address and help coordinate their acute and chronic needs across the continuum of care.

Knowledge

Pediatric hospitalists should be able to:

- Discuss the impact of the increasing prevalence of children with medical complexity in the inpatient setting, including hospital and post-hospital care resource needs, access to care, and burden to patients and the family/caregivers.
- Summarize how common acute systemic illnesses affect the child with medical complexity from both short- and long-term perspectives.
- Give examples of possible social, emotional, and fiscal impacts of assessment, initiation, or removal of medical devices on patients and the family/caregivers.
- Discuss the indications for and risks and benefits of initiation and removal of chronic respiratory support, including interventions such as bilevel positive airway pressure, continuous positive airway pressure, tracheostomy, chronic positive pressure ventilation, and others.
- Review the importance of shared decision-making and assessing the values and beliefs of patients and the family/caregivers, including those regarding goals of care and quality of life, prior to placement of any device intended for long term use, especially chronic respiratory support devices.
- Discuss the indications for and risks and benefits of placement and removal of common enteral feeding devices, such as nasogastric feeding tubes, nasojejunal feeding tubes, percutaneous gastrostomy tubes, surgically performed gastrostomy tubes with and without fundoplication, and gastro-jejunal tubes.

- Discuss the goals and utility of differing evaluations for feeding disorders, including occupational and/or speech therapist assessment, developmental assessment, radiographic evaluations, and others, and review the importance of timing of these related to placement or removal of enteral feeding devices.
- Describe the indications for and risks and benefits of placement and removal of common modes of long-term intravenous access, including externally implanted, totally implanted, and percutaneously implanted catheters and ports.
- List the indications for and risks and benefits of placement and removal of common modes of cerebrospinal fluid shunting (such as ventriculoperitoneal shunts and others).
- Discuss the benefits of use of short term enteral, vascular, or respiratory devices during acute episodes of clinical decompensation, including the importance of communicating the goals of these interventions to patients, the family/caregivers, and the healthcare team.
- Cite the common acute problems related to specific medical devices, such as enteral feeding tube dysfunction, central venous catheter infection, ventilator-associated pneumonia, and others, including the diagnostic evaluation and treatment for each.
- Compare and contrast nosocomial infection risk in patients chronically dependent on technology from those with acute, limited technology device use.
- Discuss the increased risks for non-ambulatory patients, such as skin ulceration, deep venous thrombosis, osteopenia, sarcopenia, and others.
- List the indications for and common side effects of commonly used medications for this population, including those for spasticity, anti-epileptics, sialorrhea aides, and others.
- Compare and contrast the utility of commonly used assessment tools for pain, anxiety, fear, and depression for this population with other hospitalized children.
- Discuss the benefits and limitations of providing homecare for this population, attending to access, care networks, home environment, availability of the family/caregivers in the home, and other issues.
- Review commonly encountered issues that may prompt an ethics referral, attending to disagreements with the plan of care between and among the family/caregivers and healthcare team.
- Summarize the benefits of early referral to palliative care services and list indications for hospice referral.
- List the community and educational resources for children with medical complexity within the local context.
- State the importance of creating and maintaining the Medical Home for this population.

Skills

Pediatric hospitalists should be able to:

- Diagnose and provide basic treatment for commonly encountered acute illnesses and events, such as aspiration pneumonia, line infection, decubitus ulcers, feeding intolerance, seizures, and others.

- Order and adjust commonly used medications and devices, in consultation with other subspecialists as appropriate.
- Provide medical co-management or consultation that optimizes care for these children, particularly for those undergoing surgical procedures.
- Provide basic emergency management of common complications of commonly used devices, such as accidental tracheostomy decannulation, gastrostomy tube extrusion, and others.
- Ensure correct fit and function of devices, attending to the child's age and developmental stage, in collaboration with other subspecialists and hospital staff as appropriate.
- Coordinate care with other subspecialists and the primary care provider, maintaining the medical home model.
- Identify persistent declines from baseline status (such as increasing readmission frequency, need for increasing respiratory support, and others), and communicate changes in prognosis with the patient, family/caregivers and healthcare team.
- Lead end-of-life interdisciplinary discussions between other subspecialists, the primary care provider, healthcare team, patients, and the family/caregivers, and implement this care when appropriate within the local context.
- Write a comprehensive yet succinct summary appeal letter to insurers if medically indicated services are denied.
- Utilize shared decision-making with patients and the family/caregivers to identify and develop discharge plans.
- Lead the creation and implementation of a comprehensive discharge plan, including technology device care, durable medical equipment, formula/feeding equipment, compounded medications, prior authorizations, family/caregiver training, and explicit emergency response instructions for patients and the family/caregivers.
- Coordinate transition of care to the Medical Home upon discharge, ensuring the patient and family/caregivers demonstrate the ability and are empowered to manage care and unanticipated health events.

Attitudes

Pediatric hospitalists should be able to:

- Reflect on the value of coordination of care in providing improved clinical, process, and patient/family/caregivers' satisfaction and resource use.
- Exemplify effective leadership of an interdisciplinary team,

reflecting awareness that hospitalization is a phase of longitudinal care.

- Role model use of shared decision-making and effective communication skills.
- Exemplify professionalism through compassionate care that is sensitive to religious and cultural values of patients and the family/caregivers.
- Advocate for medically appropriate devices and services required to maintain and optimize health for these patients.
- Recognize the need to continually reassess the value of technology and other medical interventions within the context of changes in medical condition, new treatments, and quality of life, considering the perspective of patients and the family/caregivers.
- Collaborate with subspecialists and the primary care provider to ensure coordinated longitudinal care for these children, including organized transition to adult care.

Systems Organization and Improvement

In order to improve efficiency and quality within their organizations, pediatric hospitalists should:

- Lead, coordinate, or participate in the development and implementation of systems within the hospital to ensure comprehensive patient and family/caregiver-centered care for the child with medical complexity.
- Lead, coordinate, or participate in quality improvement initiatives to improve care for this population.
- Collaborate with local, state, and national advocacy groups to educate and champion for equitable access to care for this population, including current technology and specialized testing.
- Collaborate with hospital administration, colleagues, and healthcare leaders to advocate for research funding to enhance the current and future health of this population.

References

1. Berry JG, Agrawal R, Kuo DZ, et al. Characteristics of hospitalizations for patients who use a structured clinical care program for children with medical complexity. *J Pediatr.*2011;159(2):284-290. <https://doi.org/10.1016/j.jpeds.2011.02.002>.
2. Cohen E, Kuo DZ, Agrawal R, et al. Children with medical complexity: an emerging population for clinical and research initiatives. *Pediatrics.* 2011;127(3):529-538. <https://doi.org/10.1542/peds.2010-0910>.
3. Simon TD, Berry J, Feudtner C, et al. Children with complex chronic conditions in inpatient hospital settings in the United States. *Pediatrics.* 2010;126(4):647-655. <https://doi.org/10.1542/peds.2009-3266>.