Children with medical complexity are a subset of patients with special health care needs whose “health and quality of life depend on integrating health care between a primary care medical home, tertiary care services, and other important loci of care such as transitional care facilities, rehabilitation units, the home, the school, and other community based settings,” according to Cohen et al. These children are characterized by (1) substantial health care service needs, (2) one or more severe chronic clinical condition(s), (3) severe functional limitations, and (4) high projected use of health resources that may include frequent or prolonged hospitalization, multiple surgeries, or the ongoing involvement of multiple subspecialty services and providers. Children with medical complexity are an important population for pediatric hospitalists, particularly those practicing in tertiary care settings. Recent studies describe the increasing prevalence of complex chronic conditions among all pediatric hospitalizations in the United States.

This article reviews the definitions of children with medical complexity and recent studies describing the changes in hospital utilization for this group. We discuss issues in their inpatient care, including (1) intensive care coordination needs, (2) critical decision-making that occurs in the inpatient setting, (3) common clinical issues that occur with technology dependence (tracheostomies, feeding tubes, and cerebrospinal fluid shunts), and (4) common reasons for admission (eg, perioperative care, aspiration pneumonia, seizures, and feeding intolerance). Finally, we present a few important clinical questions regarding inpatient care for children with medical complexity that will require research in the coming years. [Pediatr Ann. 2014;43(7):e157–e162.]
CLINICAL VIGNETTE

C is a 20-year-old male with cerebral palsy, seizure disorder, intellectual disability with impaired communication, and gastrostomy tube-dependence who presented to his orthopedic surgeon for surgical correction of his severe neuromuscular scoliosis. Because of concerns about C’s multiple medical comorbidities and increased risk for perioperative morbidity/mortality, the surgeon requested a preoperative consultation with a pediatrician hospitalist. Preoperative assessment identified several potential problems: (1) gastroesophageal reflux that resulted in feeding intolerance and poor nutritional status, (2) constipation requiring manual disimpaction on a daily basis by his mother, (3) restrictive lung disease, leading to anticipation of a prolonged postoperative intubation, (4) well-controlled seizure disorder, (5) impaired communication ability, creating challenges with post-operative pain control, and (6) need for wheelchair refitting to permit postoperative use. The medical team initiated an aggressive bowel management program and optimized gastroesophageal reflux treatment, improving C’s feeding tolerance and allowing him to gain 8 pounds preoperatively.

C underwent a prolonged posterior spine fusion surgery. He remained intubated for 2 days in the intensive care unit, with large fluid shifts requiring careful management. C was extubated to room air on postoperative day 3 and transferred to the floor of the orthopedic team with hospitalist co-management. The team managed his pain aggressively and mobilized him in consultation with physical therapy. He developed feeding intolerance that improved after multiple attempts at feeding. He was discharged home 10 days later with home nursing. C’s mother was delighted that C was able to sit upright in his chair and participate in family activities again.

DEFINING CHILDREN WITH MEDICAL COMPLEXITY

As described by van der Lee et al., the lack of an unequivocal definition of the concept of chronic health conditions in childhood has resulted in diverse approaches to operationalizing the measurement of its prevalence. In the 1990s, a noncategorical approach to defining chronic health conditions was promoted in response to diagnosis-based approaches; this new approach focuses on the functional limitations resulting from a given health condition, and thus considers the similar consequences of diverse diagnoses. One of the most prevalent noncategorical definitions for pediatric chronic health conditions, used by the Maternal and Child Health Bureau since 1998, is that of children with special health care needs (CSHCN), defined as “children who have or are at increased risk of a chronic physical, developmental, behavioral, or emotional condition and who also require health care and health care related services of a type or amount beyond that required by children generally.” Among CSHCN, considerable variation exists in the extent of their medical complexity, functional limitations, and need for resources.

Some of the most severely ill CSHCN are frequently cared for in the inpatient setting, and many hospital-based providers recognized a need to better identify this group for programmatic and research purposes. A recent review article proposed a definitional framework for children with medical complexity (CMC), suggesting that for this smaller set of CSHCN, their “health and quality of life depend on integrating health care between a primary care medical home, tertiary care services, and other important loci of care such as transitional care facilities, rehabilitation units, the home, the school, and other community-based settings.”

CMC are characterized by (1) substantial family-identified health care service needs, such as medical, specialized therapy, and education, (2) presence of one or more chronic clinical condition(s), either diagnosed or unknown, that are severe and/or associated with medical fragility (eg, high morbidity and mortality), (3) functional limitations that are typically severe and may require assistance from technology, and (4) high projected use of health resources that may include frequent or prolonged hospitalization, multiple surgeries, or the ongoing involvement of multiple subspecialty services and providers. One representation of CMC in relation to CSHCN is provided in Figure 1.

HEALTH SERVICE USE BY CMC

Despite issues with the definition, CMC are an important and significant population for pediatric hospitalists, particularly those in tertiary care settings. Recent studies have described the increasing prevalence of complex chronic conditions among all pediatric hospitalizations, as well as those at children’s hospitals, in the United States. Simon and colleagues found that, in 2006, children with complex chronic conditions accounted for approximately 10% of all pediatric hospital admissions, 40% of pediatric hospital charges, and 70% to 90% of technology use.

Hospitalization rates of children with diagnoses of more than one chronic complex condition doubled between 1991-1993 and 2003-2005. In response to this growing demand, many hospitals have established clinical programs that provide care coordination for CMC. Children in
these programs experience repeated hospitalizations, prolonged hospital stays, and 30-day readmission rates of approximately 25%. Recent work using administrative data has identified CMC as those who have one of two hallmarks for complexity: a complex chronic condition and/or the presence of technology. Using this approach in hospital administrative data, Berry et al. found this group experiences recurrent readmission to tertiary children’s hospitals, with 3% of patients accounting for 19% of inpatient admissions and 23% of inpatient charges. Using this approach in a population-based sample in Ontario, Cohen et al. found that CMC experience 30-day readmission rates ranging from 12.6% to 23.7% and account for one third of child health spending in Ontario. Given the emphasis on reducing the costs of health care, we anticipate increased attention to CMC in coming years.12

THEMES IN INPATIENT CARE FOR CMC

CMC require intensive care coordination that often becomes the parents’ or other adult caregiver’s responsibility. Caregivers experience difficulty navigating the health care system, leading to fragmented care and increased monetary expenditures. Ethnographic work conducted among CSHCN suggests that “the system is characterized not only by fragmented services but also by an absence of any efforts to integrate them.”13 Given the number of inpatient subspecialists and outpatient providers participating in the care of CMC, inter-disciplinary teams are crucial for improving patient outcomes and cost containment. In 2002, Children’s Hospital of Wisconsin created the Special Needs Program to improve care coordination and create partnerships between primary care physicians (PCPs) and the tertiary care center for 200 CMC with frequent or prolonged hospital admissions who regularly see multiple subspecialists (average > 7). This program, consisting of an inpatient consultation service and intensive outpatient care coordination, demonstrated significant decreases in frequency of hospital admissions, hospital days, and charges.14 Using a hospital-based, outpatient comprehensive care clinic, Casey and colleagues found similar decreases in inpatient admissions, length of stay, and costs for Medicaid-insured, medically complex pediatric patients. Complex care coordination is not limited to the tertiary care, center-based hospital setting; Cohen and colleagues have been able to translate their successful care coordination model targeting children with technology assistance or having high intensity of care to the community-based settings with reductions in overall costs, inpatient hospital days, and inpatient hospital days at the tertiary care hospital.15

In the absence of dedicated inter-disciplinary teams, other care coordination efforts that may benefit CMC include shared care plans and intense medication reconciliation.16 Care coordination models may benefit from integrating pharmacists to improve accuracy of medication reconciliation and to decrease adverse drug events. Finally, primary care and inpatient providers for CMC can greatly improve their care by coordinating with physical therapy, occupational therapy, and/or school services.

Critical decision making for CMC often occurs on a non-elective basis in the inpatient or intensive care settings. The Institute of Medicine has made shared decision-making a research priority, and the literature confirmed parental preference for a shared decision-making model in varied care settings. In the context of difficult decisions without clear answers, shared decision-making between the clinical team and the decision makers may help empower families. Despite efforts to improve shared decision-making, some families contemplating gastrostomy-tube placement report that they feel coerced with limited or no choice in the decision, and state that they receive inadequate information or support during the decision-making process. Hospital-based physicians face additional unique challenges in prognostication, given their decreased exposure to longitudinal illness trajectory and parent/patient outpatient experiences. Nonetheless, because changes in clinical status precipitate admissions,
they provide an opportune time to clarify and alter goals of care.

**CLINICAL ISSUES IN INPATIENT CARE FOR CMC**

**Technology Issues**

CMC have high rates of technology assistance. Children enrolled in complex care coordination services have high rates of gastrostomy tube (56%), cerebrospinal fluid (CSF) shunt (13%), and tracheostomy tube-dependence (12%), with technology malfunction accounting for approximately 10% of all admissions. Additional technology that CMC may also be dependent on includes vagal nerve stimulators, intrathecal baclofen pumps, cardiac pacemakers, and central venous catheters (a more in-depth discussion of this topic is beyond the scope of this article).

Children unable to meet their nutritional needs through oral intake often require percutaneous feeding tubes. Other indications for feeding tubes include aspiration, poor oromotor intake, gastroesophageal reflux, or other feeding intolerance. Three main types of tubes include gastrostomy tube, gastrojejunostomy tube, and jejunostomy tubes. The tubes vary in several ways, including indication for placement, ways to insert, and problems that commonly occur (Table 1). In general, using a gastrostomy tube is preferable, as this provides nutrition in a more physiologic manner, allows for attempts at bolus feedings, and can be replaced at home without an emergency department visit.

Children may develop hydrocephalus due to a variety of congenital or acquired causes. Although the placement of CSF shunts permits children with hydrocephalus to survive, it often causes new medical and surgical problems. The most common shunt apparatus diverts CSF from the ventricles to the peritoneal space (eg, ventriculoperitoneal shunt), although shunts to the atrial (eg, ventriculoatrial) and pleura (eg, ventriculopleural) spaces are also used. CSF shunt failures cause increased intracranial pressure and require hospitalization and surgical revision. Shunt infection, a more serious complication, typically requires two surgeries and a prolonged intravenous antibiotic treatment course. Evaluation of shunts suspected to be failing and/or infected include a shunt series to evaluate the tubing, head imaging to evaluate the size of ventricles and compare with baseline, and consideration of CSF cultures.

Children with chronic respiratory failure or anatomic abnormalities may benefit from tracheostomy placement to improve respiratory status. Despite the benefits of tracheostomy placement, this subset of patients has readmission rates as high as 60% and mortality rates as high as 10% within the first 6 months. Because tracheostomies bypass the upper airway (and its protective effects), these patients have increased risk for infectious respiratory tract infections that may require antibiotic treatment and hospitalization.

<table>
<thead>
<tr>
<th>TABLE 1. Technology Malfunction Among Children with Medical Complexity</th>
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<td><strong>Gastrostomy Tube</strong></td>
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<td><strong>Indication</strong></td>
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<td><strong>Ways to place</strong></td>
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<td><strong>Feeding rate</strong></td>
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<td><strong>If dislodged, how is it replaced?</strong></td>
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<td><strong>Notes</strong></td>
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Diagnosis of lower respiratory tract infections in patients with tracheostomies is difficult, as these patients often are colonized with multiple organisms, including Pseudomonas aeruginosa. Other complications include decannulation, obstruction, and bleeding. As the patient’s respiratory failure progresses, patients may also require initiation of chronic positive pressure ventilation.

**Common Reasons for Admission**

Major reasons for inpatient admission among CMC enrolled in clinical programs that provide care coordination included major surgery (47%), respiratory tract problems (29%), medical technology malfunction (9%), seizure (6%), and vomiting/feeding difficulties (3%). Technology malfunction is discussed in the previous text and in Table 1. The clinical vignette at the beginning of this article highlights the importance of perioperative management of CMC. Despite the majority of pediatric hospitalists reporting that they provide surgical comanagement services, little research evaluates surgical comanagement of CMC. Preoperative management may focus on general medical clearance, evaluation of cardiopulmonary status, and optimizing nutritional status (as malnutrition is associated with poorer outcomes in complex pediatric patients). In one large pediatric hospital, 72% of patients undergoing spinal fusion for neuromuscular scoliosis had specific recommendations made on medication or nutrition changes, as well as further diagnostic work-up after evaluation by pediatric hospitalists. The limited studies on postoperative comanagement of patients undergoing posterior spinal fusion suggest that hospitalist comanagement may decrease overall length of stay, decrease use of parenteral nutrition, and decrease the number of postoperative laboratory tests completed, although these findings are not consistent and may be limited to select groups of patients. The limited data available highlight the need for rigorous research on hospital comanagement of CMC undergoing surgical procedures. In early 2014, a new American Academy of Pediatrics (AAP) surgical care subcommittee was chartered under the AAP Section on Hospital Medicine with one goal being “to advance a research agenda in collaboration with our hospitalist, surgical, and other partners to inform the care of surgical patients.”

Aspiration pneumonia, a common admission diagnosis for CMC, is defined as clinical signs of a lower respiratory tract infection (eg, cough, increased tracheostomy secretions, fever, and hypoxia) associated with a witnessed or suspected choking or vomiting event. Diagnosis of aspiration pneumonia is challenging given that aspiration events may not be witnessed, that this patient population is at increased risk for community-acquired pneumonias, and that these patients often have underlying lung disease. Bacterial causes include a mixture of gram-positive and anaerobic bacteria. Evaluation may include routine laboratory studies (complete blood count with differential), tracheostomy cultures (if present), and chest radiographs. Common antibiotics used in treatment include penicillin-based antibiotics (eg, piperacillin/tazobactam, ampicillin/sublactam, amoxicillin/clavulanic acid) and clindamycin. Complications of aspiration pneumonia include development of lung abscesses or empyema. Research needed in this area includes a better understanding of risk factors for pneumonias and development of evidence-based treatment guidelines for pneumonias in patients with neurological impairment and/or tracheostomy.

Seizures are another frequent reason for admission for CMC. A detailed seizure history can be helpful, as at times it can be challenging to differentiate between increased seizure activity and similar movements (eg, myoclonic jerks). The differential for changes in seizure is broad, and can include concurrent infection, subtherapeutic medication doses (including lack of ketosis if on ketogenic diet), impaired enteral absorption of seizure medication, CSF shunt malfunction, electrolyte abnormalities, and new central nervous system injury. Evaluation is tailored to the suspected cause, and may include complete blood count, basic chemistry, urinalysis with cultures, drug levels, head imaging if shunt is present, consideration of CSF studies if febrile, beta-hydroxybutyrate levels if on ketogenic diet, and consideration of electroencephalogram. The primary treatment includes treatment of the underlying cause, and increases in seizure medications may be necessary.

Feeding intolerance is the inability to tolerate a home-feeding regimen, as demonstrated by emesis, abdominal distention, or pain. Causes of feeding intolerance include infections (eg, acute gastroenteritis, Clostridium difficile), infection-associated ileus, small bowel obstruction, superior mesenteric artery syndrome, pancreatitis, feeding tube misplacement, and/or constipation. Evaluation includes a careful history and physical examination, screening labs, and abdominal radiographs (including contrast tube studies). Treatment is directed at the underlying cause. An important research question is the optimal feeding modality for neurologically impaired children with gastroesophageal reflux that is refractory to medical management (gastrostomy tube with Nissen fundoplication versus trans-pyloric feedings).
CONCLUSION
Children with medical complexity are an important and growing population for pediatric hospitalists. CMC will continue to be a focus of clinical and research efforts given the increased use of inpatient and outpatient resources, challenges associated with care coordination, and the variety of medical conditions that affect CMC. Intensive inpatient (and outpatient) care coordination clinics and targetted interventions may reduce future health care utilization and hospital readmission for CMC. Ample opportunities are available to improve the evidence base for common inpatient clinical issues through additional health services research and multicenter research trials.

REFERENCES
