An Emerging Population: The Chronically Critically Ill

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KEY WORDS
Chronic critical illness, care conferences, family support

CASE PRESENTATION

A 15-year-old medically fragile adolescent presented to the emergency department with a 2-day history of rapid, shallow respirations, weak cough, and an inability to expectorate or clear secretions. Although these findings represented an acute change in respiratory status, the parents reported that during the past year the patient had increased difficulty managing secretions.

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HISTORY

The patient was born at 27 weeks gestational age and sustained hypoxic ischemic encephalopathy. The adolescent's history was significant for multiple medical and surgical interventions associated with this syndrome. During his neonatal course, he experienced recurrent episodes of necrotizing enterocolitis, which resulted in short gut syndrome and parenteral nutrition dependence. He was nonverbal, with profound visual impairment as a result of a bilateral optic nerve atrophy, and had a seizure disorder, severe dysautonomia, and global developmental delays. His more recent history was significant for multiple episodes of gram-negative bacterial and fungal sepsis. He had chronic lung disease and during the past year prior to this illness experienced a significant decline in overall health status, requiring monthly admissions to the pediatric intensive care unit (PICU).

REVIEW OF SYSTEMS

When the provider interviewed the family, the mother and father expressed distress that their son's health status was declining. They noted faster, shallower breathing, a weak cough, and an inability to clear secretions. He had recent weight loss, increased fatigue, and increased abdominal distension. The family denied rhinorrhea, fever, change in level of consciousness, bleeding, or increase in tone. He had approximately three 2-minute generalized tonic-clonic seizures per day, which was consistent with baseline.

PHYSICAL EXAMINATION

The patient appeared ill but nontoxic. He was awake, alert, and tracked with his eyes but was nonverbal. All growth parameters measured less than the 3rd

percentile. Current vital signs included heart rate, 95 beats per minute; blood pressure, 115/75 mmHg; respiratory rate, 42 breaths per minute; and oxygen saturation, 88% on room air. In addition, he was afebrile. Nasal flaring, subcostal retractions, and a weak, nonproductive cough were observed. Secretions were pooling in the posterior pharynx, and a weak gag reflex was noted. Upon auscultation, diminished breath sounds were heard in the lung bases bilaterally with scattered coarse rhonchi. The remainder of the examination was unremarkable.

DIAGNOSTIC TESTING

A chest radiograph, capillary blood gas value, and viral nasopharyngeal swabs were obtained to evaluate for pneumonia and other sources of viral illness.

CLINICAL COURSE

The patient was subsequently diagnosed with influenza A (H1N1) virus and was admitted to the PICU. His PICU course was complicated by a significant decline in neuromuscular strength and prolonged intubation as the result of a secondary bacterial pneumonia. Given his chronic lung disease and baseline impaired airway clearance, the care team recommended a tracheostomy to facilitate weaning from the ventilator and transition of care to rehabilitation services.

The pediatric nurse practitioner (PNP) recognized that the family was overwhelmed by the decisions they had to make, such as whether a tracheostomy was the right intervention given their son's airway compromise, and that they were unsure whether the tracheostomy would improve the quality of their son's life or prolong his suffering.

The PNP organized a care conference that elucidated issues and facilitated discussions, which allowed the family to make informed decisions. Some considerations included a tracheostomy, noninvasive positive pressure ventilation, an altered cardiopulmonary resuscitation (code) status, and increased home care support/home nursing. Subsequently, the family made the decision to forego a tracheostomy and agreed to a move into a more palliative mode of therapy with the full support of the multidisciplinary team.

CASE STUDY QUESTIONS

1. How is a patient classified as chronically critically ill?
2. What strategies can a PNP use to address the family's needs?
3. How can PNPs support families who are making decisions about chronically critically ill children?
4. What factors influence the ways in which these discussions happen?
5. What is the role of PNPs in the care of chronically critically ill children and their families?

CASE STUDY ANSWERS

Chronically Classically Ill Classification

1. How is a patient classified as chronically critically ill?

Chronic critical illness is an emerging concept, as children are living longer with complex chronic illnesses, resulting in prolonged PICU stays, fluctuations in care needs, and frequent exacerbations of their illness that require frequent PICU admissions (MacIntyre, 2012). Patients with complex chronic illness who survive an acute critical illness may subsequently experience chronic critical illness, which is characterized by protein depletion, ongoing catabolism, and neuromuscular weakness (Kalb & Lorin, 2002). These patients tend to be more susceptible to nosocomial, antibiotic-resistant infection. Patients may or may not have tracheostomies and be mechanically ventilated (White, 2012). Although experts disagree on the length of time that a chronic care device needs to be in place for the patient to be considered chronically critically ill, the range of cited length of mechanical ventilation is as little as 2 days to as long as 15 years, with an average time cited as 21 days (Boniatti, Friedman, Castilho, Vieria, & Fialkow, 2011; González-Cortés et al., 2011; King, 2012; Nelson, Cox, Hope, & Carson, 2010). Researchers cite a range of 16 to 40 days after tracheostomy placement and intensive care length of stay anywhere from 7 to 51 days as the criteria to be considered chronically critically ill (Carson, 2012).

Unfortunately, most chronic critical illness literature focuses on adults, with little exclusive information on pediatric chronically critically ill patients. However, differences exist in pediatric patients, such as smaller airways, lower cardiac reserve, and increased numbers of comorbidities compared with their adult counterparts (Peterson-Carmichael & Cheifetz, 2012). The estimated prevalence of these children is six to seven per 100,000. Similar to adults, the majority of chronically critically ill pediatric patients are treated for underlying respiratory issues (Peterson-Carmichael & Cheifetz, 2012).

This medically fragile adolescent acutely presented with influenza in addition to his chronic respiratory insufficiency. He was at high risk to become a chronically critically ill adolescent given his numerous comorbidities. This family needed additional support and counseling when making complex care decisions that

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