Pediatric Hospital Care for Children with Life-threatening Illness and the Role of Palliative Care

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KEYWORDS

- Pediatric • Child • Palliative care • Chronic disease • Life-threatening illness • Hospitalization • Hospital care • Health care reform

KEY POINTS

- Hospitals are challenged to provide high-quality care to an increasingly complex group of children with life-threatening illness (LTI) who sometimes receive suboptimal care.
- All medical providers have the potential to improve care for hospitalized children with LTI by understanding and maintaining competence in palliative care practices.
- Health care reforms led by the Patient Protection and Affordable Care Act and Medicaid and state-based initiatives are broadening access to palliative care for children with LTI and their families.

OVERVIEW

The landscape of hospital care for children is changing. Hospital providers are challenged to provide high-quality care to an increasingly complex group of children with life-threatening illness (LTI). These children often have disabling comorbid conditions that worsen over time through acute exacerbations and chronic relapses. Hospitalizations for children with LTI are prevalent, lengthy, and costly. Often children with LTI experience suboptimal care that is characterized by fragmented and

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uncoordinated decision making, poor health information management, reactive care planning, overmedicalization, and inadequate involvement of family caregivers.[1–3]

Incorporation of pediatric palliative care for children with LTI throughout the course of their lives may improve the quality of care these children receive. For hospitalized children with LTI, pediatric palliative care is ideally delivered when integrated concurrently with disease-directed therapies. However, the workforce of pediatricians who specialize in palliative care is not sufficiently large to care for all hospitalized children who have palliative care needs. Pediatric hospital providers of all kinds (eg, hospitalists, specialists, surgeons, nurses, social workers) are increasingly being required to provide basic pediatric palliative care. These hospital providers should understand and maintain competence in palliative care practices.

Hospitals may also benefit from a better understanding of how children with LTI, pediatric palliative care, and health care reform are related. Emerging evidence suggests that palliative care is associated with improved quality of care and decreased hospital use for patients with LTI.[4–6] National health care reform efforts such as the Patient Protection and Affordable Care Act (ACA) and state and Medicaid-based initiatives are enabling early palliative care for children with LTI. In time, investigations of these reform efforts and others will help determine the most effective way to deliver palliative care to children with LTI and to optimize their health and well-being.

PART 1: THE CURRENT LANDSCAPE OF PEDIATRIC HOSPITAL CARE

Case Vignette

At birth, Jonathan's parents thought he was healthy. However, within days they noticed that his muscles were floppy and that breastfeeding was a challenge for him. Jonathan's doctors were concerned about him too. Magnetic resonance imaging of his brain revealed lissencephaly, a rare congenital malformation of the brain with a poor prognosis. The doctors told Jonathan's parents that he would not develop like a normal child and he would not survive as long either. Jonathan's parents were devastated to hear this news.

Over the following 2 years, Jonathan developed disabling comorbid conditions, including oromotor dysfunction, gastroesophageal reflux, and hip dysplasia. He developed pneumonia often and was hospitalized 5 times. Each time Jonathan was hospitalized, a new team of hospital doctors and nurses cared for him and they consistently sent Jonathan and his family home with more things to do in an effort to keep him healthy, such as more suctioning, more nebulizer treatments, more oxygen, and more medications. His parents were not sure whether these treatments were helping him.

During Jonathan's sixth hospitalization, his doctors recommended a Nissen fundoplication and gastrostomy tube to help with his gastroesophageal reflux and difficulty feeding. His family agreed. His surgery was complicated by postoperative agitation, which required 2 extra weeks in the hospital. The agitation never fully went away after the surgery, but Jonathan and his family left the hospital because there was nothing else the hospital team could do to help. A week after being home, Jonathan was readmitted to the hospital with a skin infection around his gastrostomy tube. The infection worsened his agitation. Jonathan's parents noticed that he was becoming increasingly weak and less interactive. They were frustrated and worried about him.

Hospital providers are challenged to provide high-quality care to an increasingly complex group of children with LTI. Children with LTI have chronic illnesses such as cancer, cerebral palsy spastic quadriplegia, congenital heart disease, cystic fibrosis, metabolic disorders, and sickle cell anemia.[7,8] Although many chronic illnesses in