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

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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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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
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. 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. Although many chronic illnesses in
children have no cure, advances in surgical, intensive, and home care have enabled many of these children to live longer through control of their underlying illness and related comorbid conditions. Despite constituting less than 1% of the pediatric population, there is also a growing presence of children with LTI in hospitals (Fig. 1). Over the past 2 decades, rates of hospitalizations for children with LTI have doubled. As of 2006, children with LTI accounted for approximately 10% of all hospital admissions, 25% of all hospital bed days, and 40% of all hospital charges in the United States. Between 2006 and 2010, children with LTI and comorbid conditions affecting multiple organ systems were the fastest growing population of patients to use children's hospitals. In 2010 these children accounted for about one-third of patients and one-half of inpatient costs in children's hospitals.

Many hospitalizations for children with LTI are for the treatment of disabling comorbid conditions that tend to worsen over time. For example, nearly 50% of children with severe cerebral palsy develop comorbidities that substantially impair their digestive, respiratory, musculoskeletal, and urinary systems. In recent years, invasive procedures (eg, spinal fusion for scoliosis) and initiation of medical technology (eg, gastrostomy tube for digestive impairment) in the inpatient setting have been increasingly used to treat these comorbidities. In most cases, these treatments do not cure children of their LTI or their related comorbidities. In fact, nearly one-third of children with severe neurologic impairment (eg, those children living in a minimally conscious state) do not survive 3 years after gastrostomy and one-half do not survive 5 years after tracheotomy. Moreover, these treatments are associated with their own complications and adverse events that are also predominately treated in the inpatient setting and that lead to more hospitalizations. Illness categories for various LTI are shown in Table 1.

Many children with LTI experience multiple recurrent hospitalizations because of their fragile health status and substandard hospital discharge and follow-up care. The presence of LTI in a hospitalized child greatly increases the likelihood that their health will worsen after discharge and that an unplanned hospital readmission will occur. Children with LTI such as sickle cell disease, hydrocephalus, or tracheostomy experience 30-day readmission rates at or greater than 25%. Nearly one-quarter of inpatient costs in children's hospitals are attributable to children with LTI who experience 5 or more recurrent readmissions in a year. Hospital discharge care for a child with LTI can be challenging, especially when the hospital providers are unfamiliar with the child and family, and when the child relies on multiple medications.

**Fig. 1.** Epidemiology and health services impact of children with life-threatening illness. (Data from Refs.2,3,10,86)
and medical equipment without sufficient postdischarge community and home care support. Children with LTI are also more likely to experience recurrent hospitalizations when their parents think that their child is not ready to leave the hospital and when their parents are uncertain about how to manage their child’s health after discharge. These remain important areas for research and care improvement initiatives in the future.

At the end-of-life, hospitals are still the usual site for death in children with LTI. About 60% of children with LTI die in the hospital, with one-half of those deaths occurring in an intensive care unit. Cardiovascular, neuromuscular, and oncologic diagnoses are the most common types of LTI in children who die in the hospital. One-fourth of children with LTI who die in the hospital have LTI affecting multiple organ systems and many die after a prolonged hospitalization that includes life-sustaining treatments (eg, mechanical ventilation) or major surgery. Children pursuing curative or restorative treatment such as bone marrow transplantation for cancer or lung transplantation for cystic fibrosis are more likely to die with fewer opportunities to plan for end-of-life care compared with other children with LTI. Hospital teams must attend to the physical, emotional, and spiritual needs of a dying child and their family. Unmet end-of-life needs may have lasting consequences for the bereaved. For example, inadequate relief from pain or psychological symptoms and a difficult moment of death are associated with increased guilt in bereaved parents.

In other care settings many children with LTI experience suboptimal care that is characterized by fragmented and uncoordinated decision making, poor health information management, reactive care planning, overmedicalization, and inadequate involvement of family caregivers. In many cases, these children do not have an outpatient or community provider who oversees their care and is knowledgeable of their overall health status and well-being. Without guidance from such a provider, attending to acute health problems in the context of the child’s overall health is challenging for hospital providers. Adverse events can occur when these providers are unfamiliar with the nuances of the child’s condition and there is poor communication among providers.

In addition, hospital staff may be hesitant to initiate discussions about the child’s

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<th>Table 1</th>
<th>Categories of life-threatening illness and example diagnoses of children who might benefit from palliative care</th>
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<tr>
<td>Illness Category</td>
<td>Diagnoses</td>
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<tr>
<td>Conditions that can be cured but have the possibility of death</td>
<td>Acute leukemia Transposition of the great arteries Severe sepsis</td>
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<tr>
<td>Conditions that have no cure and premature death may be inevitable but whose symptoms can be managed</td>
<td>Down syndrome Sickle cell anemia Diabetes mellitus type I</td>
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<tr>
<td>Conditions requiring intensive medical therapy that are ultimately terminal</td>
<td>Cystic fibrosis Liver transplantation after liver failure Tracheostomy for respiratory failure</td>
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<tr>
<td>Severe neurologic impairments in which complications may lead to early death</td>
<td>Leukodystrophy Severe cerebral palsy Spina bifida</td>
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long-term prognosis and goals of care because they lack prognostic information and long-standing communication with these children and their families. Without these discussions, uninformed decisions to pursue inpatient and postdischarge treatments and procedures that may not benefit the child are more likely to occur. Whenever possible, the child’s end-of-life care should be discussed in advance of the child’s death. Most hospitalists do not acknowledge the possibility of dying with seriously ill patients and focus on the biomedical issues instead. The increasing prevalence of children with LTI and the complex nature of their illnesses implore inpatient health care providers to find better ways to improve care for children with LTI. Early concurrent integration of pediatric palliative care may be one strategy to achieve this goal.

PART 2: THE CONNECTION BETWEEN PALLIATIVE CARE AND HOSPITAL CARE FOR CHILDREN

CASE VIGNETTE

When Jonathan turned 3 years old, he developed pneumonia again. This pneumonia was severe and he was admitted to the intensive care unit for mechanical ventilation. After many weeks, his doctors mentioned placing a tracheostomy tube to help him breathe, clear his secretions, and treat his pneumonia. To Jonathan’s parents a tracheostomy tube was a scary idea.

Over time, Jonathan’s parents connected with his hospital team. Together, they talked about Jonathan’s prognosis and quality of life. They shared their hopes and fears about caring for Jonathan as he got older and bigger. Hospital staff explained to his parents the connection between his lissencephaly and many of the health problems he was experiencing. They explained that, even with a tracheostomy, they could not cure Jonathan’s problems. For the first time, Jonathan’s parents felt like they could understand his health conditions and that their concerns were being heard.

Over the following weeks, Jonathan’s pneumonia resolved and his family decided not to place the tracheostomy tube. Before leaving the hospital, Jonathan’s mother expressed her concerns about what they should expect the next time he became acutely ill and about what medical decisions they might face. The palliative care team was invited to meet Jonathan and his parents to discuss this further. They decided to work together to plan, in advance, for what treatments were best for Jonathan to undergo and forgo when he got sick again.

The palliative care needs of children with LTI are increasingly recognized throughout the course of their lives. A philosophy of care that intersects with the aims of curing and comforting pediatric palliative care is meant to be instituted when “diagnosis, intervention, and treatment are not limited to a disease process, but rather become instrumental for improving the quality-of-life, maintaining the dignity, and ameliorating the pain and suffering of seriously ill or dying children in ways that are appropriate to their upbringing, culture, and community.” Pediatric palliative care seeks to prevent or relieve the harm and distress produced by a LTI and to enable the best life possible for patients with LTI and their families. The focus of palliative care is not to provide more or less care for children with LTI, but rather the right care that is congruent with the family’s goals, preferences, and priorities. Pediatric hospital providers of all kinds (eg, hospitalists, intensivists, specialists, surgeons) are well positioned to provide palliative care to children with LTI throughout the course of their lives- and not just at the end-of-life.

For hospitalized children with LTI, pediatric palliative care is ideally delivered when integrated with disease-directed care rather than delivered as an alternative to it. In this way, treatment of a child’s acute health problems can occur concurrently with practices of palliation. These practices include attention to the child’s comfort, quality
of life, and family support. This type of care is typically delivered through comanage-
ment of a hospitalized child with LTI by a primary team (eg, general hospitalist service) and a consulting palliative care team. Palliative care providers enhance the care offered by the primary team by discussing a family’s understanding of prognosis and treatment options, holistic care plans, and recommendations for advance care planning. In general, families of children with LTI often perceive that their child’s health care needs are more appropriately met with receipt of these care activities.42 Palliative care providers are ideally positioned to assist with a child’s end-of-life because most pediatric clinicians have less expertise in this area.

However, the workforce of pediatricians who specialize in palliative care is not sufficiently large to care for all hospitalized children with LTI who have palliative care needs. Consultative support from pediatric palliative care providers is not always available and nearly one-third of children’s hospitals do not offer pediatric palliative care services and many programs are underresourced.43 As a result, many children with LTI and their families are making life-altering treatment decisions in the hospital with non–palliative care providers.42,44 Therefore, pediatric hospital staff should understand and have competency in palliative care practices.45,46 Keeping the palliative care philosophy in mind may influence several key processes of inpatient care for children with LTI at the time of admission, during their hospital stay, and at hospital discharge. Proficiencies in palliative care for pediatric hospital providers are described below and summarized in Box 1.

Assess the short-term and long-term prognosis as well as the quality of life of hospitalized children with LTI. Understanding the trajectory of the child’s health and quality of life in the context of their admission heavily influences the approach to the child’s care during hospitalization.47–49 Projecting prognosis accurately for children with LTI is challenging, even for clinicians trained in palliative care.50 Without an active dialogue with the child’s family and their outpatient care team, hospital providers who observe the child only in the setting of an acute illness may underestimate or overestimate the child’s quality of life.51 Higher parent ratings of physician care are associated with providers giving clear information about what to expect during the course of a child’s illness.52 Feudtner and Blinman’s44 surgical palliative care core tasks can help guide this dialogue. Although some parents may not share the same perceptions of prognosis as the inpatient care team and they may find discussions of prognosis about

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most parents desire as much information about their child’s prognosis as possible.\textsuperscript{53} Ensure that children and families are involved when making decisions about hospital treatments for a child with a LTI. Conversations about treatment goals, options, risks, benefits, and outcomes are absent, limited, or delayed for children with LTI and their families.\textsuperscript{49} Such conversations take time, are challenging to initiate, are emotionally charging to sustain, and can result in distress or loss of hope.\textsuperscript{53–56} Moreover, these conversations can reveal unrealistic parent expectations for treatment, differences in clinician and patient/family perceptions of care goals, and lack of parental readiness to discuss prognosis.\textsuperscript{57} Many families report that hospital care for children with LTI is confusing and that hospital providers are sometimes uncaring when discussing treatment options,\textsuperscript{58,59} which emphasizes the importance of compassionate and consistent communication with families of children with LTI throughout their hospital course.

Maximize families’ understanding of their child’s health and well-being. Families of children with LTI must be given ample time to reflect on, respond to, and convey their understanding of their child’s illness with their care teams.\textsuperscript{60} Parents’ comprehension of their child’s health may be hampered by unrealistic visions of treatment, inaccurate health information, anxiety about their child’s health status, and limited health literacy.\textsuperscript{61–64} Hospital providers should pay attention to these issues and do what they can to overcome them. Separate conversations with the family outside of morning hospital rounds and return visits to the bedside may be necessary. It may take multiple

| Box 1
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<th>Pediatric palliative care tasks for hospital providers</th>
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<tr>
<td><strong>Task 1: Assess the child's short-term and long-term prognosis and quality of life at every admission</strong></td>
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<tr>
<td>- Recognize when a child has a chronic life-threatening illness</td>
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<td>- Understand how primary diagnosis and comorbidities contribute to prognosis</td>
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<td>- Assess pain or other symptoms that are not well controlled</td>
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<td>- Converse with other providers who know the child best</td>
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<td><strong>Task 2: Ensure that families are fully involved when making decisions about hospital treatments</strong></td>
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<td>- Recognize the full range of benefits and burdens of treatment options</td>
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<td>- Create time and space for discussing treatment options with families</td>
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<td>- Involve the child and members of the family's support network when appropriate</td>
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<td>- If helpful to the family, offer a medical recommendation that incorporates the family's goals, values, and preferences</td>
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<td><strong>Task 3: Maximize the family's understanding of their child's health and well-being</strong></td>
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<td>- Ask families what they understand about their child's illness and prognosis</td>
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<td>- Ask families to elaborate on quality of life, hopes, and fears</td>
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<td>- Consult pediatric palliative specialists if appropriate</td>
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<td><strong>Task 4: Address factors that could influence the child's well-being and care planning after discharge</strong></td>
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<td>- Assess feasibility and effectiveness of contingency plans</td>
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<td>- Assess caregiving burden needed to keep the child safe and healthy</td>
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<tr>
<td>- Assess postdischarge providers' comfort and competency to care for the child</td>
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conversations before hospital providers and families can agree. Teach-back, a question-and-answer activity during which families verbalize, their child’s health issues, can serve to verify understanding and elucidate any misconceptions about care plans. Hospital education methods using teach-back have been associated with increased health literacy as well as better knowledge acquisition and retention of care plans.

Prepare the child and family for life after leaving the hospital. This preparation can be accomplished by discussing the hospital course and the possibility of recurrence of a similar acute illness responsible for the child’s admission with the family. Hospital providers can also talk about the expected stability of the child’s comorbid conditions and their functional abilities over time. Because children with LTI have high readmission rates and are at risk for recurrent hospitalizations, discussions with families about the likelihood and nature of subsequent hospitalizations is important. Hospital staff can also get a sense of the child’s home environment, community support, and the family burden of caregiving associated with keeping the child healthy after discharge. Answers to questions such as “How well does the family understand management of the child’s health after discharge?” and “Why might this child experience an unplanned readmission after they are discharged?” can be helpful in care planning with families before they go home. Consideration and planning for the ongoing palliative care needs that the child and family may have will circumvent future hospitalizations and decrease unmet care needs when the child leaves the hospital. Suggested questions to prompt discussions about prognosis, goals of care, and advance care planning with families of children with LTI are shown in Table 2.

PART 3: THE RELATIONSHIP BETWEEN HEALTH CARE REFORM AND PALLIATIVE CARE FOR CHILDREN WITH LTI

Case Vignette

Jonathan was fortunate that he lived in a state that had recently passed legislation to offer community-based palliative care for children who were not necessarily in the last 6 months of their lives. After Jonathan’s hospital discharge, the community-based palliative care team met together with Jonathan, his parents, and his other outpatient health care providers to make sure that Jonathan’s needs were met, that his family was supported, and that plans were in place to keep him out of the hospital, while maintaining his comfort and quality of life should he become sick again.

Hospitals are under increasing pressure to provide high quality of care while containing costs. Hospitals can benefit from considering how pediatric palliative care and health care reform can improve care for children with LTI and their families. At present, hospital care accounts for four-fifths of health care spending for children with LTI. Policy makers nationally are striving to reduce hospital use for these children by avoiding hospitalizations and/or by reducing length of stay and cost during admission. It is possible that improvements in care delivery for children with LTI will result in a substantial reduction of hospital use. To accomplish this, more attention to the overuse of tests and treatments in the hospital setting and consideration of a palliative approach are important.

Emerging evidence suggests that palliative care is associated with improved quality of care and decreased hospital use for children with LTI. In adult patients, receipt of palliative care is associated with lower hospitalization rates, less use of the intensive care unit, decreased length of hospital stay, and fewer readmissions. Children receiving pediatric palliative care similarly experience fewer hospitalizations, fewer
days spent in the hospital, fewer interventions (eg, mechanical ventilation, surgical procedures), and less total health care spending. At the end of life, children receiving palliative care are less likely to experience hospitalization and are more likely to experience death in the home setting.

National health care reform in the ACA enables concurrent pediatric palliative care for children with LTI. One initiative in this reform, the Concurrent Care for Children Requirement (CCCR), has eliminated the requirement that children with LTI forgo curative or life-prolonging medical treatment to receive hospice care in their last 6 months of life. This reform enables access to hospice care for children assisted with life-prolonging technology (eg, tracheostomy and ventilator) near their end of life. Although the provision of concurrent curative life-prolonging treatment and hospice services for hospice-eligible children is now required of Medicaid programs in every state, progress in implementing concurrent care has varied widely.

Although the CCCR may expand access to hospice care for children with LTI who have a prognosis of 6 months or less, it does not address the fact that these same hospice services may benefit children with LTI and their families well before end-of-life. In recent years, state-based initiatives have addressed this gap through efforts of pediatric palliative care coalitions, Medicaid waivers, state plan amendments, and bridging programs of home care agencies that can provide palliative care services.

Table 2
Questions to engage families of hospitalized children with life-threatening illness in palliative care conversations

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<th>Conversation Topic</th>
<th>Example Questions</th>
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<td>Prognosis</td>
<td>What is your understanding of your child’s health problem(s)?&lt;br&gt;How do you see your child’s health over time?&lt;br&gt;How often are you worried or concerned about your child’s health?&lt;br&gt;What are your expectations about your child’s health?&lt;br&gt;What do you think the future may hold for your child?</td>
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<tr>
<td>Quality of life</td>
<td>Can you tell me about your child as a person?&lt;br&gt;What brings your child joy?&lt;br&gt;How does your child communicate with you and with others?&lt;br&gt;How would you describe your child’s quality of life?&lt;br&gt;What is your child’s daily routine?&lt;br&gt;Tell me about how your child’s illness affects your child’s and your family’s lives?&lt;br&gt;What would life be like for your child if his/her health gets worse/better?</td>
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<td>Goals of care</td>
<td>What is the most challenging aspect of your child’s condition?&lt;br&gt;What care needs are not being met for your child?&lt;br&gt;What worries you about your child’s care?&lt;br&gt;Describe the health that you want your child to achieve.&lt;br&gt;Describe the things and activities that are important for your child to be able to do.&lt;br&gt;What are your goals for your child?</td>
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<tr>
<td>Advance care planning</td>
<td>In light of your understanding of your child’s illness, what is most important to you?&lt;br&gt;Although we continue to hope for the best, how can we prepare for other possibilities?&lt;br&gt;How could your child’s health problems impact how long he/she lives?&lt;br&gt;What do you know about treatment decisions that might arise if your child’s health worsens?&lt;br&gt;What are your hopes for your child?</td>
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to children who do not yet meet hospice eligibility criteria. Preliminary results of community-based palliative care in California reveal that such services are associated with less inpatient hospital care and reduced health care costs.\textsuperscript{4} Massachusetts has a state-funded program to provide palliative care for children throughout the commonwealth with LTI who are 18 years of age or younger.\textsuperscript{80} Outcomes of this program on health care use are still being assessed. Another state-level initiative for children with LTI financially incentivizes care management through an enhanced fee-for-service payment arrangement. Some states (eg, Michigan) are incentivizing care management specifically for children with LTI by increasing fee-for-service reimbursement (eg, up to $100 monthly per patient) for care plan oversight, multidisciplinary team meetings, telephone calls, and home visits.\textsuperscript{81}

The Accountable Care Organization (ACO) is another initiative that may help children with LTI by provisioning groups of providers and institutions across the care continuum to join together to provide care for a defined group of patients.\textsuperscript{82} ACO providers and institutions share in cost savings if targets of quality measures and reduction of costs are achieved for their patients. It is hoped that ACOs will align resources and payment with care management processes (eg, care coordination, goal setting) that typically have little or no financial reimbursement in traditional fee-for-service arrangements.\textsuperscript{83}

Health care reform specific to hospital readmission and the meaningful use of electronic health records are also particularly important for hospitalized children with LTI. Under the ACA, the Centers for Medicare and Medicaid Services (CMS) reduces Medicare payments to hospitals with excess readmissions.\textsuperscript{84} In part because children with LTI have an increased risk of hospital readmission, the Pediatric Quality Measurement Program, created by CMS and the Agency for Healthcare Research and Quality, is currently developing hospital readmission measures for use in children with Medicaid throughout the United States.\textsuperscript{85} This standardized measurement allows comparison of pediatric readmission rates across hospitals and may help improve discharge care for children with LTI. Meaningful use requirements are also emerging for the development, documentation, and sharing of care plans in electronic health records. These care plans are intended for longitudinal use and will include patients’ health goals and outcomes, instructions on how to stay healthy, care team members for health system navigation, and advanced directives. It is hoped that these health care reforms will improve the quality of care for children with LTI by more broadly incorporating palliative care practices.

**SUMMARY**

Hospitals are challenged to provide high-quality care to an increasingly complex group of children with LTI. Pediatric palliative care is an essential component of optimal delivery of hospital care for children with LTI and their families. When hospital providers understand and are competent in practices of palliative care, providers of all kind can improve hospital care for children with LTI. By assessing prognosis, focusing on quality of life, involving families in treatment decisions, maximizing the family’s understanding of their child’s health, and making plans to prepare the child and family for life after discharge–hospital providers can deliver high quality care for children with LTI that supports the child and family. Health care reforms enabled by the ACA and Medicaid are designed to improve health care value by broadening the access to pediatric palliative care. Together, these efforts can enhance health for children with LTI and their families by focusing on care that benefits their quality of life and well-being.
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