

# Integration of Palliative Care Into the Care of Children With Serious Illness

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## Practice Gap

The 2013 American Academy of Pediatrics (AAP) Policy Statement "Pediatric Palliative Care and Hospice Care: Commitments, Guidelines, and Recommendations" urges broader integration of palliative care into overall medical care plans not only for terminally ill infants and children but also for those with life-threatening or life-shortening illnesses. Despite supportive federal legislation, the AAP recommendations have not been implemented consistently because of inadequate training, lack of funding, entrenched professional attitudes, and lack of an evidence base for assessments and interventions. To overcome these barriers, pediatric health care clinicians should educate themselves, their patients, their practices, and their health care systems on the benefits of earlier palliative care intervention.

## INTRODUCTION

During the past decade the field of pediatric palliative care (PPC) has transformed. Palliative care services, once thought to be suitable only for patients in the last stages of life or reserved for patients engaging hospice services, are now being used much more broadly. No longer restricted to just the provision of end-of-life care, palliative care for children is now best understood as encompassing a combination of medical, psychosocial, and spiritual care that enables children with serious, life-threatening illnesses to maximize quality of life while making medical decisions based on the goals and values of the patient and family.

Integrating palliative care into the overall plan of medical care for children with serious illness is a key therapeutic goal. In 2013, the American Academy of Pediatrics (AAP) published a policy statement entitled "Pediatric Palliative Care and Hospice Care: Commitments, Guidelines, and Recommendations" that aimed to promote the welfare of infants and children living with life-threatening or inevitably life-shortening conditions and their families through the provision of effective curative, life-prolonging, and quality-of-life-enhancing care. The report in particular emphasized the integration of palliative care into the continuum of care, the need for hospitals that routinely care for children who die to have

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## ABBREVIATIONS

AAP American Academy of Pediatrics  
CCC concurrent care for children  
NICU neonatal intensive care unit  
PPC pediatric palliative care

interdisciplinary PPC teams, and the universal preparedness among pediatricians to provide basic aspects of palliative care and to engage specialty PPC services in a timely manner. The report also underscored the importance of providing bereavement services to the siblings of pediatric patients who are gravely ill or who die, as well as to other family members and to health care staff. (1) In addition, the National Quality Forum, (2) the Institute of Medicine, (3) and the National Institutes of Health have identified palliative and end-of-life care as national priorities and have proposed that palliative care be a key component of high-quality medical care for children with advanced illness. (3) In 2009, the American Society of Clinical Oncology voiced support of the integration of palliative care into routine comprehensive cancer care in the United States by 2020. (4)

Despite these recommendations, integration of palliative care into disease-directed care for children with advanced illness is not consistently performed. Barriers cited include inadequate palliative care training for clinicians, lack of funding to support multidisciplinary PPC teams, professional attitudes regarding the appropriateness of discussing palliative care when prognosis is uncertain, and a lack of evidence base for PPC assessments or interventions. (5)(6)(7)(8)(9)(10)(11)(12)

In this article, we describe some of these barriers and use case examples to illustrate how the integration of a palliative care team into the disease-directed care of children with serious illness can benefit patients and families.

## DISPELLING THE MYTH THAT PALLIATIVE CARE IS ONLY FOR DYING PATIENTS

The belief that palliative care is only appropriate for children with cancer or patients at or near the very end of their lives continues to persist, yet the reality is that many different kinds of pediatric patients living with serious illness can benefit from palliative care. The diversity of pediatric patients receiving palliative care services was found in a multi-institutional cohort study featured in the May 2011 issue of *Pediatrics*. (13) The study provides a snapshot of 515 children receiving palliative care from 6 hospital-based PPC teams in the United States and Canada. Slightly more than two thirds of children in the study (69.7%) survived past the 12-month follow-up (Figure). The 2 most common principal underlying diagnoses in this cohort of children were genetic or congenital disorders (40.8%) and neuromuscular disorders (39.2%). The study further highlighted that palliative care for children is principally about how to help children and families live with life-threatening conditions and the value of integrating palliative care services with disease-directed

medical and surgical interventions. The study also pointed out the complexity of the medical care most palliative care patients receive, including a high number of patients with medical equipment at home and, on average, more than 9 medications prescribed per patient.

In addition, studies have identified children who could benefit from palliative care, including those with neuromuscular disorders, congenital anomalies, and cystic fibrosis. (14)(15)(16)(17)(18)(19) These results were similar to a multicenter, cross-sectional study of Canadian children who received palliative care services during 2002. In this group, diseases of the nervous system accounted for 39.1% of the diagnoses, with combined malignant tumors accounting for another 22.1% of diagnoses. Conditions arising in the perinatal period, including congenital anomalies and prematurity, were the primary diagnoses in 22.1% of children. This study also attempted to estimate the number of children who may have benefited from palliative care services. Using estimates from both the United Kingdom and the United States, they estimated that as many as 3889 children in Canada could benefit from involvement with a PPC service annually. During 2002, only 317 children (8.2%) actually had contact with a formal service. (20)

## EVIDENCE OF THE EFFECT OF PPC SERVICES

Anecdotally, benefits of integrating disease-directed therapies with palliative care include the potential for improved management of pain and other distressing symptoms, gaining a better understanding of the goals and values of patients and families, and improving psychosocial and spiritual support for children and their families as they cope with serious or progressive illness. Studies that document benefits, however, have been sparse, particularly in those not near the end of life. Although many have found that families value palliative care services, correlating specific palliative care interventions with patient and family outcomes has not. Wolfe and colleagues (21) found that an increased focus on palliative care for children treated at the Dana-Farber Cancer Institute and Children's Hospital Boston resulted in improvements in advanced care planning. In addition, parents reported better preparedness for their child's end-of-life course and decreased pain in their children. A recent study compared demographic and clinical features of 24,342 children who died more than 5 days after admission in a sample of children's hospitals, comparing patients who did and who did not receive a palliative care consultation. Approximately 4% of children received palliative care. Palliative care was more common in older pediatric patients and was associated with fewer hospitalization

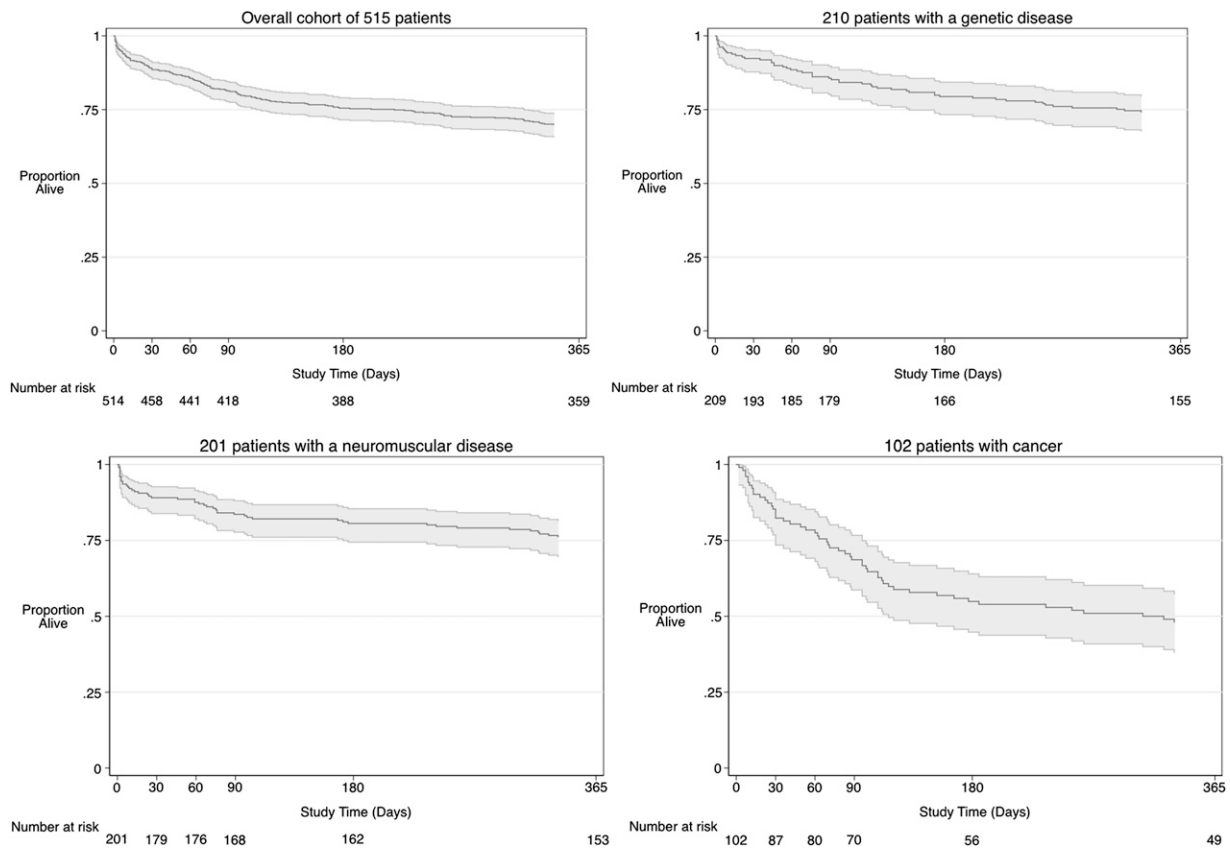


Figure. Survivorship of 515 pediatric patients receiving palliative care. Reprinted with permission from Feudtner et al. (13)

days before death. Children who received palliative care in this study also received fewer medications and were less likely to have invasive interventions or to die in an intensive care unit. (22)

Several studies have examined the effects of palliative care on patients with lung cancer. (23)(24)(25)(26)(27) A landmark study by Temel et al (26) published in the *New England Journal of Medicine* in 2010 randomized 151 patients with newly diagnosed metastatic non-small cell lung cancer to standard oncologic care vs standard oncologic care in addition to early palliative care interventions. Patients receiving early palliative care reported fewer physical symptoms and improved mood in addition to more accurate perceptions of their prognosis. In addition, the palliative care intervention group had a slight increase in survival potentially related to decreased hospitalizations, less aggressive cancer therapies in the last weeks of life, and less major depression. This study is the beginning of further exploration into the benefits of palliative care interventions regardless of prognosis.

Although rigorous randomized clinical trials are absent thus far in the pediatric patient population, a number of studies have documented benefits of palliative care consultation

for children and families, including improved family satisfaction with care, management of distressing symptoms, communication with health care clinicians, and care coordination. (21)(28)(29)(30)(31)(32) Clearly, more research is needed to better establish specific aspects of palliative care that are most beneficial to patients and families.

## INTEGRATION OF PALLIATIVE CARE WITH DISEASE-DIRECTED THERAPIES

Palliative care intervention often occurs late in illness. One of the barriers to full integration of palliative care into the curative treatment has been the stigma that engaging in palliative care services means giving up on the potential for life-extending treatments. Historically, this bias originated in the United States in the provisions spelled out in the legislation passed by the US Congress in 1982 for the newly enacted Medicare hospice benefit that required patients to choose between continuing disease-directed treatments (and some health care services) and receiving hospice services. However, receipt of palliative care services has never entailed forgoing any other form of treatment. Nevertheless,

because many families and clinicians link hospice with palliative care, the bias extends to the palliative care realm.

In 2010, this forced choice provision changed for patients younger than 21 years with the passing of the Patient Protection and Affordable Care Act. This act includes the Concurrent Care for Children (CCC) provision, which requires that programs for children in state Medicaid or Children's Health Insurance Programs allow children younger than 21 years to receive hospice care while still receiving curative treatments. This program has the potential and has already, in many cases, allowed children who meet hospice criteria to continue curative, life-extending treatments, including chemotherapy, dialysis, private duty nursing, and technologic support in the home, such as ventilators. (33) The challenges of implementing CCC across states are just beginning to be explored. (34)(35)

The CCC provision has notable limitations. It does not expand the types of services that are available and is limited to children receiving treatment through Medicaid or Children's Health Insurance Programs. In addition, the CCC does not provide home-based palliative care services to children with life-limiting or life-threatening illnesses whose prognosis falls outside the last 6 months of life should the disease or condition follow its normal course. (34) Despite these limitations, the CCC has the potential to allow children who require home nursing care and technology support at home to also receive hospice services as their condition progresses. These patients with highly complex conditions who once would have been restricted to receiving their end-of-life care in the hospital may now have the option of being at home (Table).

PPC services may be engaged in varying times of illness. Highlighted below are 3 examples of palliative care interventions at different points of illness trajectory. They exemplify the wide range of diagnoses and prognoses that children with these and similar illnesses have in addition to the challenges of prognostic uncertainty that many clinicians and parents face.

### PEDIATRIC PALLIATIVE CARE IN THE NICU

In the last decades, survival rates for very preterm and critically ill infants have been increasing. This increase has raised complex issues for both parents and health care clinicians who face the challenges of making complex medical decisions in an increasingly high-technology environment. Certainly, the need for palliative care services in the neonatal intensive care unit (NICU) can be emphasized by the large number of neonatal deaths compared with older children and young adults. (36) Nevertheless, comprehensive interdisciplinary palliative care services are not universally available,

TABLE. **Highlights of Concurrent Care for Children**

- Enacted on March 23, 2010, when the Patient Protection and Affordable Care Act was signed into law
- Concurrent Care for Children provision in section 2302
- Requires that programs for children enrolled in state Medicaid or Children's Health Insurance Programs must allow patients to receive *hospice care* while still receiving curative treatment
- Allows pediatric patients with life expectancies of 6 months or less if the disease follows its normal course (and thus hospice eligible) to transition more smoothly from disease-directed therapy to care focused on comfort and quality of life
- Patients are able to continue elements of disease-directed medical treatments, such as chemotherapy or hemodialysis, while receiving the benefits of hospice services
- Does not expand services for children with life-limiting illnesses whose prognosis falls outside the last 6 months of life
- Only applies to patients younger than 21 years

and the medically intensive environment of the NICU is one where clinicians are comfortable with and focused on a cure-oriented, life-extending interventional approach to care. In a recent survey, neonatologists expressed the belief that palliative care can enhance the treatment of critically ill newborns with life-limiting illness or poor prognosis. Most surveyed had no formal training in palliative and end-of-life care but felt confident in their abilities to provide care. Previously known barriers, including lack of time and private space to have conversations with families, were not considered barriers by those surveyed. (37) There have been efforts to educate clinicians and enhance the family-centered care given to families in the NICU. Protocols to develop palliative care programs in the NICU have been endorsed by professional organizations that seek to incorporate palliative care into the care of these infants and their families. (15)(38)

In an intensive care unit environment, often the palliative care team provides assistance with communication and coordination of information for the family. For many infants with complex medical issues, multiple specialists are involved in addition to the primary team. For these infants, clinicians change frequently. The palliative care team provides continuity and is able to focus on the family throughout the disease course. (39)

### CASE 1: PALLIATIVE CARE IN THE NICU

Emily is a full-term infant born via emergency caesarean section because of placental abruption. Nonresponsive in the

delivery room, her resuscitation required chest compressions, intubation, and multiple doses of epinephrine. She was transferred to a tertiary care medical center for hypothermia treatment and was found to be in status epilepticus. Magnetic resonance imaging revealed global hypoxic ischemic encephalopathy. Her seizures were controlled with phenobarbital, and she continued to receive ventilatory support. Given the high likelihood that Emily will have a poor neurologic outcome, the NICU team would proceed with withdrawal of ventilatory support if the parents agreed. The NICU team requests a palliative care consultation.

In Emily's case, how can involvement of a palliative care team be of assistance?

- Explore the parents' hopes and goals for their child.
- Optimize management of physical symptoms.
- Help the family envision the current problem and implications of medical decisions.
  - If the family decides to withdraw ventilatory support, what happens next? What would things look like if Emily were able to breathe without the ventilator for a period? What if that time was extended?
  - If the family chooses to continue ventilatory support and Emily is unable to wean from the ventilator, would they feel comfortable with a tracheostomy and long-term ventilatory support? What would this look like at home? Would they consider a long-term skilled nursing facility?
- Offer psychosocial and spiritual support regardless of parental choices in medical management.
- Assist with support for Emily's 2 siblings to help them cope with their sister's serious illness and provide bereavement support if needed.

### **PEDIATRIC PALLIATIVE CARE FOR CHILDREN WITH PROGRESSIVE ILLNESSES**

Many genetic, metabolic, and neurologic disorders carry a wide range of symptom burden and can progress at varying rates that cannot often be predicted. Families of children diagnosed as having enzyme deficiencies, mitochondrial diseases, neuromuscular disorders, or illnesses marked by neurologic deterioration with an undefined cause struggle with uncertainty. Some disorders, such as metachromatic leukodystrophy, have more prognostic certainty because they can be diagnosed in infancy, childhood, or young adulthood with some well-documented symptom patterns. For example, children affected with the late infantile form of metachromatic leukodystrophy typically present with difficulty walking during the second year of life. Other symptoms include muscle wasting and weakness, muscle rigidity, developmental delays, progressive loss of vision leading to

blindness, seizures, difficulty swallowing, paralysis, and dementia. Most children with this form of metachromatic leukodystrophy die by age 5 years.

### **CASE 2: PALLIATIVE CARE FOR METACHROMATIC LEUKODYSTROPHY**

Jane is a 20-month-old previously healthy girl brought to her pediatrician when her parents noted she was walking much less than before. Her initial physical examination revealed mildly decreased muscle tone, and magnetic resonance imaging of her brain revealed white matter changes. She was referred to a pediatric neurologist at a regional children's hospital who confirmed the diagnosis of the late infantile form of metachromatic leukodystrophy. During the next 6 months, Jane's parents observe many troubling symptoms, including upper extremity weakness and stiffness, speech that was more difficult to understand, loss of the ability to self-feed, coughing while eating, and fragmented nighttime sleep. The palliative care team was invited to meet Jane and her family as part of a follow-up visit in the neurology clinic to assist with symptom management and establish goals of care.

In Jane's case, how can a PPC team be of assistance to her and her family?

- Optimize management of physical symptoms, including spasticity, sleep disturbance, irritability, seizures, and progressive dysphagia.
- Help the family envision current problems and develop approaches for management of progressive symptoms.
  - If their child has recurrent episodes of aspiration or increasing dysphagia, when is feeding by mouth no longer possible? What are other feeding options that should be considered?
  - For episodes of respiratory compromise from pneumonia or aspiration, what would the family's wishes be for aggressive interventions or resuscitation?
- Offer psychosocial and spiritual support regardless of parental choices in medical management.
- Support the family through the journey of genetic testing while simultaneously caring for their affected child.
- Assist with support for Jane's siblings to help them cope with having a sibling with a serious illness and provide bereavement support if needed.
- Facilitate home-based hospice care for aggressive symptom management and psychosocial, spiritual, and bereavement support for the family.

Children with these types of progressive disorders often have significant symptom management issues, including spasticity, seizures, agitation, sleep disturbances, progressive

weakness, and feeding difficulties. Families witness ongoing physical and sometimes neurologic deterioration of their previously healthy infant and must provide increasing levels of care for their children in the home. For some, advances in respiratory management allow for children with progressive weakness to survive longer with both noninvasive and invasive ventilatory support. With this support, however, comes increasing care needs at home and increased risk of hospitalizations for routine childhood illnesses. In addition, multiple subspecialists are often involved in the child's care, making care coordination and consistent communication with families a significant challenge. These issues have increased the interest and necessity of incorporating palliative care into the care of these children and their families.

### PEDIATRIC PALLIATIVE CARE FOR CHILDREN WITH ADVANCED CANCER

In the United States, more than 12,000 children each year are diagnosed as having cancer. Despite advances in cancer-directed and supportive therapies, more than 2000 of them will not survive. (40) Studies have found that children with advanced cancer experience high degrees of symptom burden and distress from physical and emotional causes. In addition, there can be a great deal of prognostic uncertainty with many forms of cancer. Integrating palliative care into the routine care of patients with advanced cancer is a concept that is increasingly supported by the oncology community. (41) In pediatric oncology, however, availability continues to be major barrier because only 58% of Children's Oncology Group institutions report having a PPC team. (42)(43) A recent study found some pediatric oncologists reluctant to integrate palliative care teams early in diagnosis because of concerns it may alter the relationship oncologists have with patients and families. In addition, the authors found some conflicting philosophies about whether palliative care is consistent with curative therapy. (42) Nonetheless, studies have indicated that palliative care intervention for patients with advanced cancer can have numerous benefits, including improved management of distressing symptoms, better communication, earlier recognition of prognosis, and reduced hospitalizations. (10)(21)(23)(28)(44)(45)(46)

### CASE 3: PALLIATIVE CARE FOR ADVANCED CANCER

Jeremy is a 16-year-old who was diagnosed as having a high-grade glioma of the brain at age 15 years. He underwent surgery to remove the tumor followed by radiation to his brain and chemotherapy. He had severe chemotherapy-related

nausea and vomiting that was treated with several different antiemetics, but the symptoms remained severe enough that he required additional hospitalizations for dehydration and intravenous medications to control his nausea and vomiting. After 6 months of treatment, his tumor recurred. It was determined then that surgical resection was not an option and that further radiation would not be indicated. His parents were interested in experimental therapies, but Jeremy was reluctant because of the adverse effects he remembers from his prior experience with chemotherapy. The palliative care team was invited to meet with Jeremy and his family to facilitate conversations about the intersection of goals of care, quality of life, and experimental therapies.

In Jeremy's case, how can a PPC team be of assistance to him and his family?

- Manage distressing symptoms—For Jeremy, headaches, neuropathies, cognitive loss, seizures, and loss of motor function are all symptoms that may develop to varying degrees as his tumor progresses. Anticipating likely symptoms and giving his family the tools needed to manage them are critical to maximizing Jeremy's quality of life. Avoiding unnecessary hospitalizations by anticipating patient needs will allow him to spend more time at home.
- Establish goals of care—Jeremy and his parents will need to discuss the options of continuing cancer-directed therapies. Palliative care teams can help facilitate these discussions with Jeremy's oncology team and ensure that benefits and burdens of experimental and conventional treatments are considered.
- Facilitate discussions with Jeremy about his wishes. Adolescents and young adults should be encouraged to participate in advanced care planning. (47)(48) Palliative care teams can help facilitate these discussions using adapted advanced planning tools and provide the additional psychosocial support needed to manage potential conflicts between the wishes of the parents and those of the patient.
- Offer psychosocial and spiritual support regardless of patient and parental choices in medical management.
- Assist with support for Jeremy's siblings to help them cope with having a sibling with a serious illness and provide bereavement support if needed.
- Facilitate home-based hospice care for aggressive symptom management and psychosocial, spiritual, and bereavement support for the family.

### CONCLUSION

During the past decade, pediatric medicine has made great strides toward integrating palliative care into the overall care of all children with serious illness. The coming decade will

require further changes in health care systems and policies to overcome persistent barriers and marked expansion of the PPC workforce to meet the needs of this increasing population. Every day, though, pediatric health care clinicians should remain alert and recognize that children and families may benefit from earlier palliative care interventions, initiate early conversations about the benefits of integrating palliative care into the overall care of the child, and refer patients for PPC specialty consultation.

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## Parent Resources from the AAP at HealthyChildren.org

- English: <http://www.healthychildren.org/English/family-life/health-management/pediatric-specialists/Pages/What-is-a-Hospice-and-Palliative-Medicine-Pediatrician.aspx>



## PIR Quiz

1. Fourteen-year-old Jeremy has end-stage renal disease. He is undergoing dialysis and has been awaiting a kidney transplantation for 3 years. His physician recommends a palliative care consultation, but the parents are distressed by the implications of this next step. In the ensuing discussion, the physician offers an explanation regarding palliative care. Which of the following is most consistent with what palliative care for children is principally about?
  - A. Helping children and families with bereavement services.
  - B. Helping children and families engaging hospice services.
  - C. Helping children and families with home-based technology services.
  - D. Helping children and families in the last stages of life.
  - E. Helping children and families live with life-threatening conditions.
2. As a pediatrician newly introduced to the palliative care team at your local hospital, you inquire as to which patients would be suitable for your referrals. Studies with similar results to a 2002 Canadian study have identified which group of children as having the highest percentage of pediatric patients receiving or possibly benefiting from receiving palliative care services?
  - A. Children with complex multisystem diseases.
  - B. Children with cystic fibrosis.
  - C. Children with history of prematurity.
  - D. Children with malignant tumors.
  - E. Children with nervous system diseases.
3. In following up your inquiry to the palliative care team at your local hospital, you probe further as to what are the demonstrated benefits of palliative care for children and families. Which of the following is a documented benefit of palliative care consultation for children and families?
  - A. Increased acceptance of long-term hospitalization.
  - B. Increased parent satisfaction with communication with health care clinicians.
  - C. Increased compliance with required bed rest.
  - D. Increased long-term survival.
  - E. Increased use of pain medication.
4. In a study published in 2010 that investigated patients with newly diagnosed metastatic non-small cell lung cancer, which of the following was found in those who received early palliative care interventions in addition to standard oncologic care vs those who received standard oncologic care?
  - A. Improved mood.
  - B. Less accurate perceptions of their prognosis.
  - C. More aggressive cancer therapies.
  - D. Slightly decreased survival.
  - E. Slightly increased number of hospitalizations.
5. You are treating a 10-year-old girl with complex medical issues who might benefit from referral to the palliative care team. Of concern is compliance with the rules and regulations of the Concurrent Care for Children (CCC) provision of the Patient Protection and Affordable Care Act. Which of the following is a limitation of the CCC provision excluding certain patients?
  - A. Patients may not receive services if they are receiving chemotherapy.
  - B. Patients may not receive services if they are receiving dialysis.
  - C. Patients may not receive services of private duty nursing.
  - D. Patients may not receive services if they receiving ventilatory support.
  - E. Patients may not receive services if they are not enrolled in Medicaid.

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## Integration of Palliative Care Into the Care of Children With Serious Illness

Tammy I. Kang, David Munson, Jennifer Hwang and Chris Feudtner

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