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Pediatric End-of-Life Issues and Palliative Care

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Abstract

Optimizing the quality of medical care at the end of life has achieved national status as an important health care goal. Palliative care, a comprehensive approach to treating the physical, psychosocial and spiritual needs of patients and their families facing life-limiting illnesses, requires the coordinated efforts of a multidisciplinary group of caregivers. Understanding the basic principles of palliative care can aid emergency department staff in identifying patients who could benefit from palliative care services and in managing the challenging situations that arise when such patients present to the hospital for care.

In this article we present the overall philosophy of pediatric palliative care, describe key elements of quality palliative care, and identify additional referral sources readers can access for more information.

Index words

Palliative Care; Pediatric Critical Care

Optimizing the quality of medical care at the end of life has achieved national status as an important health care goal.(1–3) We expect most children to outlive their parents. But in those cases when childhood death occurs, we strive to deliver quality care to our patients and their families. While deaths in the emergency department (ED) account for a minority of all pediatric deaths in the hospital setting, ED physicians frequently encounter patients with life-threatening or life-limiting illness. Compassionate, high quality in-patient care for these patients and their families begins when they enter hospital, either through the ED or when transport teams manage such patients from referring hospitals. The inclusion of a palliative care interest group by the Society for Academic Emergency Medicine and the development of a position statement on end-of-life care in the ED by the Emergency Nurses Association demonstrate the emergency

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medicine community's recognition of this important topic.(4) In this article we present the contemporary concepts of pediatric palliative care, describe key elements of high quality palliative care, and identify additional resources that readers can access for more information.

Epidemiology of Pediatric Deaths

Approximately 55,000 pediatric deaths occur in the United States annually.(2,5,6) In 2003, 52% of pediatric deaths occurred in children under 1 year of age, and two thirds of those were neonatal deaths.(6) Estimates suggest that more than 56% of pediatric deaths occur in the hospital.(2) Within hospitals, most deaths occur in the pediatric (49–59%) and neonatal intensive care units (31–33%).(7,8) At one tertiary urban academic free-standing children's hospital, approximately 6% of all pediatric deaths occurred within the ED.(9)

The causes of pediatric death varies by age group. The top five leading causes of infant mortality in 2004 included congenital malformations (20%), disorders related to short gestation and low birth weight (17%), sudden infant death syndrome (9%), newborns affected by maternal complications of pregnancy (6%), and unintentional injuries (4%).(10) Among children 1 – 19 years old, the overall and age group-specific leading cause of mortality is unintentional injuries, accounting for 44% of deaths. The second leading cause of death in children ages 1 – 4 years is congenital malformations, deformations and chromosomal abnormalities (12%). Malignant neoplasms make up the second leading cause of death for children 5 – 9 and 10 – 14 years of age (18% and 13% respectively). For children 15 – 19 years of age, the second leading killer is assault (14%).(10) The diagnostic categories among pediatric deaths occurring at one hospital included: cardiac (32%); neonatal specific diagnosis (14%); congenital (14%); infectious (13%); oncologic (10%); and trauma (6%).(7) Thus, clinicians must realize the wide array of conditions leading to childhood death beyond malignancies.

Palliative Care: Philosophy and Goals

While palliative care evolved from the philosophy of hospice care, its focus goes beyond caring for dying patients.(11) The World Health Organization defines palliative care as, “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”(12) The absence of words such as “death” and “dying” in this definition merits recognition. In the past, curative care and palliative care were considered mutually exclusive domains, one ended when the other began. The current model of palliative care as applied to children embraces the concurrent administration of curative and supportive care with attention to physical, psychosocial, and spiritual concerns.(1,5,13–15) (See Figure 1.) Such comprehensive care requires input from a multidisciplinary team that includes physicians, nurses, social workers, chaplains, child life specialists, pharmacists, and physical/occupational therapists.

When viewed in its broadest context, this approach recognizes that children with a variety of medical conditions may benefit from palliative care.(11,16) (See Table 1.) In the setting of such diversity, the pattern of death in children can take different forms. In evaluating adults, Lunney et al. described four distinct trajectories of dying which apply to pediatric patients as well. The first includes highly functional people who experience sudden death, such as a trauma patient. The second group comprises high functioning people who acquire a terminal illness, such as cancer patients. The third group consists of people with a diagnosis that results in decreased function and creates cycles of improvement and progressive decline, such as a patient with cystic fibrosis. The final group includes people with significant impairment who have a slow but progressive deterioration, such as a patient with hypoxic/anoxic brain injury.(17) (See Figure 2.)

Different organizations have presented related goals for palliative care. (14,18,19) The Initiative for Pediatric Palliative Care (19) expresses these goals through identification of six domains of high-quality family-centered care. The six IPPC domains include: 1) support of the family unit; 2) communication with the child and family about treatment goals and plans; 3) ethics and shared decision making; 4) relief of pain and other symptoms; 5) continuity of care; and 6) grief and bereavement support.(20,21) We will address these domains by discussing the following key palliative care issues: 1) communication; 2) pain and physical concerns; 3) psychosocial and spiritual concerns; and 4) ethics and legal considerations.

Communication

Communication provides the foundation for determining patient and family needs, assessing the medical team's effectiveness in addressing those needs, and ensuring awareness of participating team members about the patient's and family's progress. Discussing the goals of care with families and patients, if appropriate, provides much of the basis for care. Through compassionate, sensitive conversations with family members, the team aims to define achievable goals that address all aspects of care, physical, psychosocial, and spiritual, in a manner that provides the patient and family with the highest possible quality of life.

In accordance with the American Academy of Pediatrics (AAP) we recommend including patients in discussions of care whenever possible.(14) The notion of discussing death with a potentially dying child may seem daunting to some clinicians. But in a recent study of parents of children who died from cancer, no parents regretted talking to their children about death, but some parents regretted not talking to their children about death.(22) Health care providers and parents can have sensitive and thoughtful conversations with patients without causing harm or additional psychological distress to children with life-threatening illnesses. In approaching such discussions, one should consider the age and developmental level of the child, utilize trained specialists such as psychologists and child-life therapists, and consider using creative approaches, such as art and music therapy.(16)

As previously noted, the team caring for pediatric palliative care patients includes people from many disciplines based in both inpatient and/or outpatient settings. The successful management of these patients depends on adequate sharing of information among the various team members. Poor team communication among pediatric palliative care providers can result in: inadequate symptom management for patients; impairment of patients' quality of life; medication errors; and even misunderstandings regarding families' and patients' advance care plans leading to initiation of unwanted, aggressive therapies, or perhaps worse, a patient's death without the implementation of interventions desired by the family and/or patient. Thus, practitioners must pay careful attention to ensuring good team communication, a fundamental goal of palliative care.

Pain and Physical Concerns

A major component of palliative care involves relieving distressing physical signs and symptoms. In one study, 89% of parents whose children died of cancer reported that their child suffered from at least one bothersome symptom in their last month of life, most commonly pain, fatigue, or dyspnea.(23) Achieving an acceptable quality of life cannot occur in the setting of unrelieved pain, anxiety, nausea, constipation or other burdensome conditions. Thus palliative care practitioners pay particular attention to identifying and treating aggravating symptoms.

Pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage.(24) The experience of pain, a highly subjective phenomenon, depends upon a myriad of factors including developmental stage,

emotional state, cultural background, family functioning, and the underlying organic disease process. The widely accepted pharmacologic approach to relieving pain proposed by the World Health Organization involves an incremental “ladder” of treatment. Therapies begin with mild analgesics such as acetaminophen, ketorolac, and ibuprofen and progress in a step-wise fashion to include gradually more potent opiates such as oxycodone, hydromorphone, methadone, morphine, and fentanyl as well as adjuvant therapies.(25) We refer readers to recent reviews of general issues related to pain management for a more in depth discussion of the topic.(26, 27)

Common concerns among those using opiates to manage pain and other symptoms include potentially hastening death or causing addiction. With regard to the first concern, we will touch on the physiologic considerations here and speak to the ethical issues later. While high doses of opiates are known to cause a dose-dependent depression in respiratory drive, multiple studies show that palliative care patients receiving appropriate doses of opiates for symptom management do not have decreased survival.(28,29) Similarly multiple studies show that appropriate sedation given to palliative care patients does not decrease survival.(28) Appropriate administration of opiates to a well-monitored, *symptomatic* patient is unlikely to stop breathing and hasten death.

In discussing addiction, first we must clarify important terms. Addiction refers to behaviors that include impaired control over drug use, compulsive use, continued use despite harm, and drug seeking behavior that result from genetic, psychosocial and environmental factors. This differs from physical dependence, an adaptive state manifested by a drug class-specific withdrawal syndrome produced by abrupt cessation, rapid dose reduction, decreasing blood level of the drug, and/or administration of an antagonist. Both differ from tolerance which occurs when exposure to a drug causes a decreased effect of that drug over time.(30) Children with chronic pain conditions rarely display addiction. On the other hand, physical dependence, resulting from the exposure of cells to opiates over time,(31) occurs in virtually all patients receiving opiates or benzodiazepines for prolonged periods. Patients who no longer have pain and who have received chronic opiate or benzodiazepine treatment require a prolonged, careful tapering of both medications to avoid precipitating withdrawal symptoms. However patients with persistent pain may require increasing doses of the same medication to maintain adequate pain relief due to increased tolerance. Opioid rotation (e.g. changing morphine to dilaudid) can improve pain management in such patients by taking advantage of the incomplete cross-tolerance between opioids.(32)

Some pain responds best to agents other than opiates. Patients with localized or metastatic cancers can have pain referred to as neuropathic pain, often characterized as burning or tingling, related to the effects of the tumor on the peripheral nerve and/or irritation of surrounding tissue and structures. Effective therapies for such pain may include amitriptyline and gabapentin. Consider consulting a pain specialist to optimize treatment in such cases.

Non-pharmacologic approaches to management of pain and other burdensome symptoms can augment medical therapies or in some cases constitute effective therapy alone. One prospective randomized controlled study comparing children treated only with pharmacologic therapies to children treated with both pharmacologic therapies and psychologic interventions showed decreased child and parent distress during procedures in those who received both therapies. (33) Non-pharmacologic interventions include physical measures such as massage, physical therapy, acupuncture, use of heat and cold, or behavior and cognitive techniques such as distraction, play therapy or music therapy, attention to breathing, and guided imagery.(16,32)

Other symptoms commonly seen in children with advanced disease include dyspnea, nausea and vomiting, constipation, itching, fatigue, reflux esophagitis, as well as a variety of

complaints pertaining to sleep disturbances, agitation, somnolence and weakness. Opioids are frequently used to alleviate the symptoms of dyspnea in many patients without precipitating respiratory failure. An excellent discussion and a list of adjunctive medications potentially useful in managing this complex array of symptoms faced by some palliative care patients can be found in a recent review by Himmelstein.(16)

Psychosocial and Spiritual Concerns

In addition to physical symptoms, palliative care aims to assess and treat psychosocial and spiritual concerns. For pediatric palliative care patients, the psychological, emotional and spiritual needs depend upon the child's developmental stage and their extended relations to family and community. Parents and families of patients with potentially life-limiting illnesses also face many challenges such as social isolation, fears about an unknown future, stresses related to making difficult decisions, and addressing the practical concerns of daily life.

To address patient psychosocial needs, one must consider the child's developmental level. Infants and children with limited verbal ability and no concept of death depend upon sensations and a physical relationship to their surroundings. Being held, comforted and soothed provide much of their support. In the pre-school years, children may believe that death is a reversible state. These children may not be able to conceptualize their own death. In addition to parental presence, children at this stage may benefit from clear, unambiguous explanations about what is happening to them. In the elementary school age group children develop more adult-like concepts of death and begin to understand their own mortality. In this stage, important interventions could include supporting a child's efforts to understand the situation, letting the child have control when possible, and allowing the child to participate in medical decisions when appropriate. Adolescents may have an even more sophisticated concept of death as they consider more abstract explanations of death. For teenage patients, reinforcing self-esteem, respecting privacy and again allowing participation in medical decisions are important aspects of care.(11)

Psychosocial support for children extends beyond addressing concepts of death and medical decisions. By focusing attention on age- and developmentally-appropriate personal goals children can maximize the quality of their time with family and friends. For younger children, family activities like taking a trip to Disneyland or getting a shiny new bicycle may fulfill their inner longing and provide a sense of fulfillment. For older children, accomplishing long held ambitions such as going to the prom or obtaining a driver's license may help improve their quality of life and provide a sense of completion.

Psychosocial support for parents and family also can take various forms depending on a family's resources, connectedness to extended family or community, and cultural background. Palliative care programs provide a range of services including counseling or referrals to an appropriate counselor, assistance with the practical concerns of daily life, resources for funeral planning, and bereavement support.

Palliative care providers must also attempt to integrate physical and psychosocial support into each patient's and family's concept of spirituality and/or religion. In facing one's own mortality or that of a loved one, many people rely on cultural, personal spiritual or religious beliefs and values. Studies show that spirituality and religion impact parents' end-of-life decision making and help sustain them emotionally as they face the death of their child. (34,35) But there is no single prescription to address spiritual needs. A patient's spiritual needs are defined by their stage of development and their environment. A parent's needs may be unique to their religion, their interpretation of religion, or their overall spiritual views. Conducting a spiritual assessment can help providers identify important spiritual issues and create opportunities to

discuss relevant concerns.(36) Providing a safe environment for patients and families to explore their own sense of meaning or understanding of the situation can have lasting benefits.

Ethics and Legal Considerations

In pediatrics, where most patients lack decision making capacity, either because of their developmental stage or their medical condition, decisions are made using the best interest standard.(37) The best interest standard means that the decision maker(s) must determine “the *net* benefit for the patient of each option.... The course of action to be followed, then, is the one with the greatest net benefit to the patient.”(38) Arriving at such decisions should result from a shared decision making process that involves the family, the patient when appropriate, and the medical team.(16) For most children in the United States, the legal medical decision makers are their parents or legal guardian(s). In the case of an emancipated minor, the patient himself or herself has the legal decision making authority.

Some of the most challenging and morally driven decisions in pediatrics involve end-of-life decisions, particularly decisions regarding the use of aggressive, potentially life-prolonging but burdensome therapies. The AAP endorses the withdrawing or withholding of burdensome therapies in the interest of maximizing a child’s quality of life. Specifically the AAP states: “Although a child’s life may be shortened by forgoing burdensome interventions or providing adequate sedation in the face of otherwise unrelieved symptoms, the goal of palliative care is to optimize the quality of the child’s experience rather than hasten death.”(14) Moreover, ethicists do not make a distinction between withdrawing (stopping once started) or withholding (not starting) potentially life-prolonging therapies. However, it can be challenging to apply these principles in real-life situations. Studies show that not all medical professionals agree with this accepted ethical concept.(39) Practically speaking, many families may simply perceive a difference between withdrawing vs. withholding a particular therapy. However, providing the best care for a particular patient may include withdrawing or withholding life-sustaining therapies, both ethically supportable practices.

The ED practitioner aims to support life through all possible means unless an advance directive requests otherwise. For patients who present in extremis and whose families later decide to limit aggressive life-prolonging therapies, it may be of some comfort for the emergency physician to remember that withdrawing life supporting therapies, such as intubation and mechanical ventilation, in the intensive care unit or even the ED, is ethically permissible provided that those therapies are not compatible with the best interests of the patient.

The United States legal system also recognizes these ethical principles. The United States courts affirm that a parent should have the option of forgoing potentially futile therapies for his/her child. In 1983 the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research supported a parent’s refusal of medical treatments in most instances. Additionally, the Commission declared that the parent is the person in the best position to make such decisions.(40)

As discussed above, management of palliative care patients often requires administration of opioids or sedative agents to manage pain and other distressing symptoms. In certain situations administering such agents are perceived by some as hastening death and concerns about practicing physician-assisted death may arise. We have already presented data that refutes the notion that administration of opiates and sedatives hastens death. But in looking at the issue from an ethical perspective, the Doctrine of Double Effect provides a helpful framework. The Doctrine of Double Effect states that it is permissible to cause harm as a side effect (the “double effect”) of bringing about a good result given that certain criteria are met. Those criteria include: the treatment must have potential beneficial and harmful effects; the clinician *intends* the beneficial effect; the harmful effect is not necessary to achieve the beneficial effect; and the

beneficial effect must outweigh the harmful effect (proportionality).(28,29) The law supports the obligation of physicians to alleviate pain and suffering and acknowledges the principal described by the Doctrine of Double Effect. In the 1997 United States Supreme Court case, *Vacco v. Quill*, Chief Justice Rehnquist wrote, "It is widely recognized that the provision of pain medication is ethically and professionally acceptable even when the treatment may hasten the patient's death if the medication is intended to alleviate pain and severe discomfort, not to cause death."(40) Thus it is morally incumbent and ethically and legally permissible to administer medications with the goal of providing pain and symptom relief.

Support for Professionals

Medical personnel caring for palliative care patients face mental and emotional challenges. Caring for dying patients may cause a sense of failure or feelings of powerlessness against illness and its associated losses. Caregivers may feel grief, fear of becoming sick themselves, experience self-doubt, or even reconsider working with patients in order to avoid or escape such feelings.(41,42) In addition to caring for our patients and families, we must support professional caregivers who treat patients with life-limiting illnesses and dying patients. Such support can include: providing a professional counselor; organizing regular debriefing sessions during which practitioners can discuss cases; providing collegial support and mentorship to individuals with less experience; and encouraging a compassionate atmosphere where caregivers can openly express their concerns and needs. Personal coping mechanisms for dealing with such emotional and morally challenging situations vary from person to person. Thus, institutions need to provide a diversity of outlets to accommodate individual needs.

Education

In addition to providing emotional support to professional caregivers, we must also provide educational support. Through education, professionals may feel more comfortable and confident as they care for this important patient population. To learn more about education in palliative care we refer readers to some useful online sites which can facilitate personal education and education within an institution.

- **The Initiative for Pediatric Palliative Care (IPPC):** IPPC provides an online curriculum to help health care professionals provide quality pediatric palliative care.
Website: <http://www.ippcweb.org/>
- **Education in Palliative and End of Life Care (EPEC):** EPEC Uses a train-the-trainer approach and now offers a program specifically for members of the emergency medicine community.
Website: <http://www.epec.net/EPEC/webpages/index.cfm>
- **The End-of-Life Nursing Education Consortium (ELNEC):** ELNEC provides training to nurses through courses in palliative care delivered nationwide.
Website: <http://www.aacn.nche.edu/elneec/>
- **Center to Advance Palliative Care (CAPC):** CAPC provides health care professionals with the tools, training, and technical assistance necessary to start and sustain successful palliative care programs in hospitals and other health care settings.
Website: <http://www.capc.org/>
- **American Academy of Hospice and Palliative Medicine (AAHPM):** AAHPM offers a course in palliative care taught by experts in the field designed for a variety of practitioners including emergency medicine physicians.

Website: <http://www.aahpm.org/education/course.html>

Challenges in the Emergency Department

While the medical community acknowledges the importance of providing good end-of-life care in the ED, a number of barriers to success in this setting exist. The core concepts in emergency medicine of diagnosing and treating illness in an effort to cure do not always match palliative care goals. ED clinicians often make rapid decisions in a fast-paced environment allowing little time for discussions of complex issues and challenging medical decisions that require in-depth conversations. ED clinicians have brief and often forced relationships with patients and families during times of unexpected injury or medical crises. Finally, EDs traditionally provide transitional care to patients who are either admitted to the hospital or discharged to home.(43)

Despite such challenges the principals of palliative care can play a role in the ED setting. ED clinicians can help identify patients who may benefit from palliative care and ensure admission of such patients to the appropriate service. Patients who present with burdensome symptoms can obtain initial relief through appropriate therapies in the ED. Direct inquiry of family members and patients about advanced directives and do-not-resuscitate status may avoid unwanted therapies while minimizing patient suffering. Caregivers can give families the option of being present during the resuscitation of their loved one and provide support to families as they witness such events. Through partnership with palliative care teams, emergency medicine personnel can help provide information to families about options for care and create a care plan that appropriately addresses each patient's and family's goals.(4,43–45)

Summary

Palliative care, a comprehensive approach to treating the physical, psychosocial and spiritual needs of patients facing life-limiting illnesses and their families, requires the coordinated efforts of a multidisciplinary group of caregivers. Understanding the basic principals of palliative care can aid ED staff in identifying patients who could benefit from palliative care services and in managing the challenging situations that arise when such patients present to the hospital for care.

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Old model of Palliative Care

New model of Palliative Care

Figure 1. Models of Palliative Care
Adapted from (5)

Figure 2. Theoretical Trajectories of Dying
Adapted from (17)

Table 1

Conditions Appropriate for Palliative Care

Adapted from (11,16)

Description of Condition	Examples of Condition
Curative or life-prolonging treatment is possible but may fail	Advanced or progressive malignancy Malignancy with a poor prognosis Complex and severe congenital or acquired heart disease
Conditions requiring long periods of intensive treatment aimed at prolonging quality of life	Human immunodeficiency virus (HIV) Cystic fibrosis Severe gastrointestinal disorders or malformations such as gastroschisis Severe epidermolysis bullosa Severe immunodeficiencies Renal failure when dialysis and/or transplantation are not available or indicated Chronic or severe respiratory failure Muscular dystrophy
Progressive conditions in which treatment is exclusively palliative from diagnosis	Mucopolysaccharidoses or other storage disorders Progressive metabolic disorders Certain chromosomal abnormalities such as trisomy 13 or 18 Severe forms of osteogenesis imperfecta
Conditions with severe, nonprogressive disability	Severe cerebral palsy with recurrent infection or difficult symptoms Extreme prematurity Severe neurologic sequelae of infectious disease Hypoxic/anoxic brain injury Holoprosencephaly or other severe brain malformations.