

Pediatric Palliative Care: Beyond the End of Life

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"You matter because you are and you matter to the last moment of your life. We will do all we can, not only to help you die peacefully, but also to live until you die." –Cicely Saunders

Death is a relatively rare occurrence in children; of the approximately 2.5 million deaths in the United States annually, only around 50,000 of those deaths are of infants or children (Heron et al., 2010). Although rare, it is important to acknowledge that death occurs in pediatrics, and to provide these children with comprehensive and compassionate end-of-life care within a family-centered and developmentally appropriate context. Such desire has led to the increasing emergence of pediatric hospice and palliative care services throughout the country. The goal of this article is to provide pediatric nurses and providers with an overview of palliative care including a) distinguishing the differences between hospice and palliative care, b) outlining basic principles for providing pediatric palliative care, c) providing information about

Palliative care is an emerging nursing specialty and is developing a dedicated spot in the field of pediatrics. As a specialty, palliative care focuses on quality of life and symptom management for patients who are living with chronic and life-threatening diseases. In pediatrics, advances in health care mean that many children are living longer with these conditions and could benefit from services that focus on quality of life and superior symptom management. Palliative care can be provided concurrently with curative therapies and is philosophically similar yet distinct from hospice services.

palliative care consultation, and d) examining future directions of pediatric palliative care.

Comparing Hospice and Palliative Care

Hospice and palliative care share a similar philosophy, but in many settings, are distinctly different entities (Himmelstein, 2006). The terms are often used interchangeably, but it is important to understand the differences and principles surrounding each of these services.

The hospice movement in the United States emerged in the 1970s in response to death becoming more of a medical event; hospice emphasizes dying at home and the provision of comprehensive care for patients in the last six months of life. The first hospice emerged in 1971, and the first pediatric hospice was founded in Virginia in 1978 (Carroll, Torkildson, & Winsness, 2007). The Medicare Hospice Benefit (MHB) originated in 1984, and current requirements for the provision of hospice are outlined in Medicare guidelines. Although Medicare finances health care for older adults and persons with disabilities, the MHB is important to pediatric hospice care in that the Medicare framework for payment of hospice services has been largely adopted by the Medicaid program in many states, as well as private insurers. The hospice benefit includes support from an interdisciplinary team, physician services (often in collaboration with or

led by a patient's primary care physician), medical equipment and supplies, medications for pain or symptom management, regularly scheduled home visits on top of 24/7 availability, brief inpatient respite care, emotional and spiritual support, and bereavement support after a death. However, hospice services are limited by current guidelines to provide support for patients in the last six months of life, many of whom are dying in the home.

In pediatrics, the hospice model is used most often for those with severely life-limiting conditions at the very end of life. However, many more children have chronic and life-threatening conditions and could benefit from this model of supportive care throughout their disease trajectory. The concept of palliative care developed mostly within academic medicine, with the goals of applying the principles of home hospice care within institutions and providing supportive care more upstream in the health care system from hospice services (Himmelstein, 2006). Palliative care can be provided throughout the disease trajectory, not just at the end of life, and in any care setting (National Consensus Project for Quality Palliative Care, 2009). Most palliative care, however, is often delivered by hospital-based teams who may refer patients to hospice services in their last six months of life but who continue to follow patients throughout the course of their illness. Palliative care teams vary in their ability to provide services based on regulations, staffing, and funding. Some are

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able to follow patients only in an inpatient setting, whereas others can see patients who are cared for on an outpatient basis or even make visits to the home.

The World Health Organization (WHO) definition of palliative care (see Figure 1) allows palliative care to be much broader than hospice care, and emphasizes the primary goals of symptom management and holistic care of a patient and family facing a life-threatening illness. WHO further describes palliative care as it pertains to children:

Palliative care for children is the active total care of the child's body, mind, and spirit, and also involves giving support to the family. It begins when illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease. Health providers must evaluate and alleviate a child's physical, psychological, and social distress. Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited. It can be provided in tertiary care facilities, in community health centers, and even in children's homes (WHO, 2010).

An important point to recognize in palliative care is that it is not an alternative method of care, but instead, a method of care that can co-exist with curative treatments to provide children and families with the best possible treatment. Palliative care can be provided to patients from the diagnosis of their life-threatening illness, and palliative services can have increased involvement in care and symptom management as needed in accordance with the family's wishes. Along with WHO, the American Academy of Pediatrics (AAP) has released a statement in support of pediatric palliative care and outlining recommendations for its provision, including an emphasis on palliative care coexisting with curative therapies (AAP Committee on Bioethics and Committee on Hospital Care, 2000). With a focus on symptom management and quality of life, palliative care is a beneficial model of care for many children and should be offered in conjunction with curative treatments for a chronic, life-threatening, or life-limiting illness.

Figure 1.
WHO Definition of Palliative Care

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.

Epidemiology of Pediatric End of Life

It has been estimated that 13.9% of all children are living with a chronic health condition (Friebert, 2009). The majority of these children are suffering from mild chronic health conditions, with only 2% of children suffering from major or extreme levels of disability (Friebert, 2009). Palliative care can be provided not only to children who are near the end of life, but also to children with these chronic, life-limiting conditions, even when curative treatments are ongoing. According to the Children's Project on Palliative/Hospice Services (ChiPPS), approximately 8,600 children are eligible for pediatric palliative care services on any given day, and palliative care may be an appropriate model of care for 1.5 to 2 million children in the United States living with life-limiting disabilities and illnesses (Children's Project on Palliative/Hospice Services Administrative/Policy Workgroup of the National Hospice and Palliative Care Organization, 2001). On any given day, roughly 5,000 children with chronic childhood conditions are within the last six months of life and may benefit from hospice services (Friebert, 2009).

Although many children and families may benefit from improved end-of-life care, hospice and palliative care services for children are not widely available and are often under-utilized. Although specific to oncology, one survey found that only 36% of Children's Oncology Group (COG) institutions had access to palliative care services (Johnston et al., 2008). Additionally, of the more than 3,000 hospice programs in the United States, only 450 (15%) said they were prepared to offer hospice services to children (ChiPPS Administrative/Policy Workgroup of the National Hospice and Palliative Care Organization, 2001), and more than half of hospice programs that serve children serve only 1 to 10 children per year (Friebert, 2009).

The availability of palliative care and hospice services for children is limited; however, these services are in demand. It has been shown that 82% of children who die are hospitalized, and many of these children are in an intensive care unit (Field & Behrman, 2003). An epidemiological study in Washington State showed that 84% of infants with chronic complex conditions were hospitalized at the time of their death, and 50% of them were mechanically ventilated when they died (Feudtner, DiGiusppe, & Neff, 2003). However, 70% of parents would prefer to have their child die at home if the resources were available (Friebert, 2009). Hospice services can facilitate obtaining resources for death in the home for children and families, and inpatient pediatric palliative care teams can facilitate the transition from a medical environment to home in collaboration with community hospice services.

Basic Principles Of Palliative Care

Emphasis on Quality of Life

The provision of pediatric palliative care should center on a child and family's quality of life. It is important to encourage families to focus on the quality of the child's life and not the quantity of days lived (Kang et al., 2005). Quality of life may be defined differently for each child, but by managing distressing symptoms, providers may be able to not only improve the child's quality of life, but positively impact the course of the child's illness (WHO, 2010). A pediatric palliative care team should be dedicated to "helping children and families live to their fullest while facing complex medical conditions" (Himelstein, 2006, p. 163). Communication is central to palliative care, and speaking with the child and family about their wishes and desires, as well as their definitions of what quality of life means, is important (Ewing, 2009).

It is beneficial to have conversations about quality of life early in the course of a child's illness, when older patients may be able to participate in discussions and families are not under the stress of making immediate decisions (Kang et al., 2005). Conversations about the inclusion of palliative care in a child's care team can occur at diagnosis of a life-threatening illness, or it can be brought up when a patient experiences progression of the illness exhibited by abnormal blood work, imaging scan, or a change in clinical symptoms. However, it is recommended to have these conversations earlier in the disease process, for example, at diagnosis instead of with a third relapse. When conversations about prognosis and goals of care occur earlier in the disease process, children have been shown to receive better palliative care and experience decreased suffering (Wolfe et al., 2000). Even for children who are not at the end of life but experiencing a chronic illness earlier in the disease process, palliative care teams provide an outlook focused on quality of life that can improve the family's experience with a chronic illness. This quality-of-life focused care includes improved symptom management and improved communication between families and providers, as well as between providers. All patients with life-threatening illnesses can benefit from improved communication, symptom management, and quality of life throughout their disease process, not only at the end of life.

A good palliative care program can improve both the patient's and family's quality of life by providing appropriate symptom management throughout the course of a life-threatening illness, compassionate end-of-life care, and support for the family in bereavement (WHO, 2010). Families have reported that important aspects of palliative care include honesty, access to staff, good communication and care coordination, emotional support from staff, being able to maintain the parent/child relationship, and respect for their faith (Meyer, Ritholz, Burns, & Truog, 2006). Addressing all of these issues and emphasizing an environment of open communication can lead to improved quality of life for patients and families throughout the course of a life-threatening illness as well as at the end of life.

Symptom Management

Although palliative care incorporates careful assessment and treatment of any symptom, four categories of symptoms are most distressing to pediatric patients and their families receiving palliative care: a) pain, b) dyspnea, c) gastrointestinal disturbances, and d) neurological changes. Assessment and treatment of symptoms should be done in the least invasive way possible and should not cause more distress than the original symptom (Kang et al., 2005). It is "applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life...to manage distressing clinical complications" (WHO, 2010). Symptom control should be offered to all patients (Harris, 2004), including those who are suffering from life-limiting illnesses and those at the end of life.

Pain is one of the most commonly reported symptoms at the end of life and is often a significant fear for patients with life-threatening illnesses. Effective pain management involves frequent assessments, knowledge of pain medications, adjunct medications, and therapies, as well as communication with the patient and family. Several valid and reliable pain rating scales exist that are appropriate for children. Some examples of these pain scales are the numeric pain rating scale (Connelly, 2010), the Wong-Baker Faces scale (Tomlinson, von Baeyer, Sanson, & Sung, 2010) and the FLACC pain rating scale (Voepel-Lewis, Zanolli, Dammeyer, & Merkel, 2010). Providers, patients, and families are encouraged to use the pain scale that provides a consistent, accurate way to measure and treat the child's pain. When children are unable to report their pain, either because they are preverbal or nonverbal secondary to illness, observation of pain behaviors, identification of potential causes of pain, and proxy reports, especially from parents, should be used (Herr et al., 2006).

The WHO ladder provides a three-step approach with pharmacologic recommendations for managing acute pain and is a good place for providers to start when addressing pain (Kang et al., 2005). The use of opioids for relief of pain should not be avoided, and children with advanced disease or those who have developed a tolerance may require high doses of opioids to achieve ade-

quate pain relief. Tolerance to these opioid drugs is not the same as a psychological addiction; some children may require very high doses to experience relief from pain, but when used for pain relief and administered as prescribed, the risk of addiction is very low. Nurses should be aware that many children who require chronic pain relief, especially at the end of life, may be on exceptionally high doses of pain-relieving drugs. Providers should discuss pain management goals with patients and families to determine their goals for achieving a balance between pain management and sedation when using these medications. Some patients may wish to have relief from pain as a priority, whereas others may be willing to live with pain to be more alert. In addition to opioids, other methods for managing acute and chronic pain include medications, such as gabapentin for neuropathic pain and steroids for pain related to inflammation (Aiello-Laws et al., 2009). Non-drug modalities that can be employed for pain relief include acupuncture, massage, and radiation therapy, as well as distraction, positioning, and hot and cold applications.

Pain medications are also often used as the first-line treatment for children with acute dyspnea. In addition to pain, dyspnea should be assessed often. Rating scales are available for dyspnea (Ullrich & Mayer, 2007), but are not well studied in the pediatric population and therefore parental, or if possible, patient report of symptoms may be more beneficial. Anxiolytics or benzodiazapines may help minimize anxiety and distress around feelings of breathlessness; however, opioids such as morphine are often first-line therapy for the relief of dyspnea (Kang et al., 2005). These medications all may increase drowsiness. A small number of studies have also shown that nebulized opioids may provide relief for some children, and fentanyl may be more effective than other inhaled options; however, intravenous and oral formulations have still been proven to provide superior pain relief (Kang et al., 2005). If a child has an underlying lung disease, bronchodilators and systemic steroids should be used first to provide dyspnea relief by treating the underlying disease (Kang et al., 2005). Positive pressure ventilation delivered via continuous positive airway pres-

sure (CPAP) or bilevel positive airway pressure (BiPAP) may increase comfort for some children with dyspnea (Ullrich & Mayer, 2007). In addition, some children report the use of fans, air conditioning, and oxygen as useful (Bausewein, Booth, Gysels, & Higginson, 2008).

Gastrointestinal (GI) disturbances, including nausea, vomiting, decreased appetite, and constipation, are not uncommon in children with advanced disease. Whenever possible, it is important to identify and treat the underlying cause of the disturbance. Nausea and vomiting can be relieved with a variety of pharmacologic modalities, including ondansetron, diphenhydramine, promethazine, scopolamine patches, and dronabinol, depending on the child's age and medical condition. Of note, dronabinol is contraindicated in patients with depression (Santucci & Mack, 2007). Small, frequent meals may also be helpful. Interventions that may be helpful for children with an intestinal obstruction due to tumor size, abdominal compression, or intestinal paralyde include venting the stomach, medication (such as octreotide), surgical intervention, or corticosteroids (Santucci & Mack, 2007).

Constipation may be managed with a bowel routine that can include increased fluid and fiber intake and the use of stool softeners or laxatives. Enemas and suppositories may be necessary for immobile children, but these can increase stress for children and families and should only be used when necessary. Caution should be taken when using bulk-forming laxatives in a child with little oral intake because these can increase the risk of obstruction (Santucci & Mack, 2007).

GI disturbances are often a side effect of pain management, and routine bowel regimens started concurrently with pain medication are imperative. Opioid rotation may be beneficial for children with refractory constipation despite good bowel regimens (Santucci & Mack, 2007). A child with decreased appetite is often a difficult experience for families. As with all symptoms, any potential cause should be identified and treated when possible. Appetite stimulants, such as megestrol and corticosteroids, may be useful in children who are still taking food and fluids by mouth, especially if the family is experiencing significant distress related to the loss of appetite (Santucci & Mack, 2007).

Encouraging family members to provide other care for their child during the time that they would have spent feeding them may minimize family distress surrounding loss of appetite; this can include oral care, skin care, and massage. Offering small bites and tastes of food can provide children and families with comfort even if the intake is not enough to offer nutritional benefit.

Seizures, loss of consciousness, and fluctuating cognition can be especially distressing for children and families, and are often unpredictable. It is especially important to identify possible underlying causes of these symptoms, such as metabolic derangements, tumor growth, or ischemic injury, and to treat the underlying cause with appropriate therapies. Anticipatory guidance to families of children that are likely to experience seizures should be provided consistently and frequently. Children may benefit from anti-epileptic medications, although these may increase drowsiness or agitation. A plan should be made for any child who is at risk of experiencing status epilepticus (Wusthoff, Shellhaas, & Licht, 2007). Children who are experiencing restlessness, agitation, and fluctuating cognition may benefit from anxiolytics, but again, these medications can potentiate sedation (Wusthoff et al., 2007). Child and family education and anticipatory guidance are important because seizures and other neurological symptoms can be quite distressing for families. Increased comfort as well as having a plan and resources in place for managing symptoms can help minimize family distress and patient suffering.

Frequent assessment, appropriate management, interdisciplinary collaboration, and communication with families are key concepts for symptom management in palliative care. The provision of palliative care, with an emphasis on symptom management, should start at diagnosis for children with life-threatening or potentially life-threatening illnesses, and continue throughout their care alongside curative therapies and through the end of life.

Communication and Decision Making

"Let us communicate with each other clearly, compassionately, and collaboratively, as we strive to improve the quality of life for chil-

dren including, when necessary, that part of life that is dying" (Feudtner, 2007, p. 583). As with many successful partnerships, communication is key in pediatric palliative care between patients/families and providers, as well as between providers caring for the child. For a successful, skilled pediatric palliative care team to be established, staff working within the institution must be aware of what the team can do, who can contact the team, and what resources are available to patients and staff from the team. Members of these palliative care teams often include physicians, nurse practitioners, registered nurses, social workers, child life specialists, and chaplains, but could also include psychologists and music or art therapists depending on patient and family needs. Staff members who receive education and support from such a team feel more comfortable consulting and collaborating with the team for palliative care and tend to refer earlier (Davies et al., 2008). Communication between providers is important to provide families with a consistent message, and palliative care teams often assist in facilitating this communication.

Children and families depend on consistent, frequent communication about sensitive, often difficult information and may require repetition of facts. It is important to be open and honest with families, and to speak clearly and in simple terms. Often, families need multiple meetings to fully understand a situation and to make decisions for their loved one. Effective therapeutic communication takes skill in conversations, ranging from breaking bad news to planning a family meeting to discussing goals of care (Kang et al., 2005). Supportive colleagues can provide feedback on what went well in addition to what could be improved. As Mark Twain said, "The difference between the right word and the almost right word is the difference between lightning and a lightning bug" (Twain, 1888).

Although finding the right words is important for effective communication, listening and silence are also vital to the process. Families need and desire information, but allowing silence and listening to a patient's and family's wishes are also important aspects of effective, therapeutic communication. It is important to allow for silence in conversations and to be unafraid of having the perfect words.

Sometimes a therapeutic presence is all that is needed, and families may reveal more when given the opportunity, which can only happen when silence is allowed. Silence can be a very important communication tool and must not be underestimated when working with children with chronic and life-threatening conditions and their families.

The Pediatric Consult

In most pediatric settings, palliative care teams operate in a consultative role, although in some cases, they are the primary providers. Involvement of the palliative care team usually begins with a referral, often from a physician or nurse outside the team. Many barriers exist to obtaining a palliative care consult. Multiple studies have shown that pediatric providers may equate palliative care with hospice, are unsure of when to refer to palliative care, are uncomfortable with prognostication, and lack training, comfort, and education in palliative care services (Boldt, Yusuf, & Himelstein, 2006; Davies et al., 2008; Docherty, Miles, & Brandon, 2007; Sheetz & Bowman, 2008; St. Laurent-Gagnon, Duval, & Carnevale, 2008; Thompson, Knapp, Madden, & Shenkman, 2009). For many established pediatric palliative care teams, obtaining a consult from a specialty service, such as cardiology, oncology, or genetics, can be challenging (Ward-Smith et al., 2007). This may be because these specialty providers often focus on cure as opposed to symptom management, and may be uncomfortable providing curative and palliative therapies simultaneously (Foster, 2007; Kang et al., 2005).

Collaboration, in addition to consultation, is important for optimizing utilization of palliative care services, and more importantly, patient and family satisfaction with their child's overall health care treatment (Hays et al., 2006; Hinds, Oakes, Hicks, & Anghelescu, 2005). Families who receive palliative care consults earlier in a patient's disease are more likely to feel supported throughout the child's illness, death, and bereavement period (Mack & Wolfe, 2006; Wolfe et al., 2000, 2008). Studies have also shown that as the number of palliative care consults increases, children are more likely to have "Do Not Resuscitate" orders, receive less aggressive care,

spend fewer days in intensive care, and obtain better pain and symptom management. Families report greater satisfaction with care and decreased emotional distress when they are involved with a palliative care team (Duncan, Spengler, & Wolfe, 2007; Lee & Dupree, 2008; Tan, Totapally, Torbati, & Wolfsdorf, 2006; Wolfe et al., 2008).

In addition to improved patient and family outcomes, non-palliative care providers prefer to have an experienced palliative care team available to assist in the management of complex patients (Sheetz & Bowman, 2008). Many teams have been successfully developed from pain teams (Friedrichsdorf, Remke, Symalla, Gibbon, & Chrastek, 2007) and coexist in institutions with a cure-driven mission (Harper et al., 2007; Kang et al., 2005). The focus of any palliative care team should be family-centered, culturally sensitive care; improved patient quality of life; advanced symptom management; skilled communication with providers and families; support from diagnosis through bereavement; continuing education for team members and colleagues; and awareness of community resources (Brandon, Docherty, & Thorpe, 2007; Center to Advance Palliative Care, 2010; Davies, Collins, Steele, Pipke, & Cook, 2003; Davies, Contro, Larson, & Widger, 2010; Hubble et al., 2009; Jennings, 2005; Meyer et al., 2006; Rushton et al., 2006; Weidner, 2007; WHO, 2010). As these advanced teams continue developing throughout the country and awareness of these teams as expert resources increases, the number of consults will undoubtedly rise, resulting in increased patient, family, and provider satisfaction.

Future Directions in Pediatric Palliative Care

The future of pediatric palliative care will include more pediatric facilities providing inpatient, interdisciplinary palliative care and expansion of these services into the community. These palliative care teams will incorporate physicians, nurses, social workers, chaplains, child life specialists, and other support staff to provide truly comprehensive care to patients and families.

With the creation and expansion of palliative care teams will come increased awareness of palliative care

among pediatric providers, and increased awareness of the resources available for practitioners and families from palliative care teams. Providers will benefit from increased education about the concept of palliative care and the advantages of obtaining a palliative care consult early in the disease process, preferably at the diagnosis of a chronic or life-threatening illness. Families also need more information about the services that palliative care can provide and how to access these services. However, the information provided to families depends on the education of providers distributing the information, and increased awareness of palliative care resources among providers will result in increased awareness and education of families about palliative care services.

The future of palliative care should also involve increased support from insurance companies and governmental agencies to provide increased reimbursement for palliative care and to make billing and reimbursement easier for palliative care providers, particularly advanced practice nurses working in the field. Reimbursement is a complicated process for any consultative service, especially one that wishes to provide consults to families in the inpatient, outpatient, and home settings. Increased financial support from both insurance companies and government agencies may increase the development, compensation, and use of palliative care services.

Children are living longer with progressive, life-limiting illness, increasing the need for pediatric palliative care. Every pediatric provider needs awareness of palliative care services that can be provided in the hospital and community in which they practice. All patients with chronic and life-threatening illnesses should be referred to a palliative care team early in the course of illness to help collaborate with the primary specialists and provide improved quality of life, better symptom management, and skilled communication throughout a patient's disease trajectory, including end-of-life care and bereavement support for family members. The future of pediatric palliative care is aimed at improved recognition, increased utilization, and better reimbursement for palliative care providers. Increased utilization and availability of pediatric palliative care specialists will also increase overall

provider, patient, and family satisfaction within the pediatric health care system for children with complex medical conditions. ■

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