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REVIEW ARTICLE

Pediatric Palliative Care

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Pediatric palliative care provides benefit to children living with life-threatening or terminal conditions. Palliative care should be available to all seriously ill children. Palliative care includes the treatment of symptoms such as pain, nausea, dyspnea, constipation, anorexia, and sialorrhea. This care can occur in a variety of settings, from home to hospice to hospital, and must include bereavement care and follow up after the death of a child. There are many challenges in pediatric palliative care, but continued research into this important area of pediatrics will lead to improvements in the care of children with life-threatening illnesses.

KEYWORDS: palliative care, pediatrics, review

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INTRODUCTION

There are approximately 50,000 deaths per year in the United States among children under the age of 19, and approximately ten times that number of children suffer from life-threatening conditions.[1,2] The number of children in similar situations worldwide is in the millions. Appropriate palliative care for these children is required. Pediatric palliative care is an evolving discipline in the field of pediatrics, but it is clear that children who live with life- threatening conditions obtain great benefit from palliative care.

DEFINITION

One challenge in the provision of pediatric palliative care lies in clearly defining the entity. The American Academy of Pediatrics (AAP) defines pediatric palliative care as care that enhances the quality of life for children with an ultimately terminal condition. This is accomplished by relieving symptoms and conditions that are distressing and that interfere with quality of life.[3] The Institute of Medicine (IOM) report on pediatric palliative care defines such care as that which tries to prevent, relieve, reduce, or soothe the symptoms caused by serious medical conditions or their treatments as well as maintaining quality of life.[1] This definition also places emphasis on the emotional, spiritual, and practical needs of patients and their families. Finally, a recent American Society of Clinical Oncology (ASCO) review of pediatric palliative care defines it as care which enhances the quality of life and attends to suffering

ABBREVIATIONS AAP, American Academy of Pediatrics; ASCO, American Society of Clinical Oncology; IOM, Institute of Medicine; NCCN, National Comprehensive Cancer Network; WHO, World Health Organization

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through the art and science of child-focused, family-oriented, relationship-centered medical care.[4] This definition, which was developed by ASCO, includes those previously listed and encompasses the broad definition we feel is most fitting for the current status of pediatric palliative care.

PRINCIPLES

The American Academy of Pediatrics has established principles for providing palliative care to children.[3] These principles include respect for the dignity of patients and families, access to competent and compassionate palliative care, support for the caregivers, improved professional and social support for pediatric palliative care, and continued improvement of pediatric palliative care through research and education. Other principles outlined in the IOM report include the provision of timely, accurate and compassionate information regarding diagnosis, prognosis, and treatment options.[1]

A recent ASCO publication outlined recommendations for palliative care in pediatric oncology, which is one of the areas of medicine where palliative care should be a well-integrated component.[5] Recommendations for this specific application of palliative care included combining treatment of the underlying condition with the components of palliative care for patients with advanced cancer, incorporation of palliative care early in the disease process, and palliative care resources used for dying and seriously, chronically ill children.[5] With the current definition of palliative care as enhancing quality of life and attending to suffering, the best principle to be employed in pediatric palliative care is to ensure availability to all seriously ill children.

The American Society of Pediatric Hematology/Oncology has recently issued a statement emphasizing the five most important needs of gravely ill or injured children and their families.[6] These five needs are: 1) access to a comprehensive, interdisciplinary palliative care program that has the resources and skills to treat all forms of suffering; 2) education about the dying process, children's perceptions of death, and palliative care as an acceptable therapeutic option; 3) reimbursement for end-of-life care; 4) community-based support programs for families, including respite care and financial, emotional, and physical support; and 5) an expanded pediatric pharmacopoeia to control symptoms of pain, nausea, vomiting, sleep, and disordered sleep, movement, breathing, psyche, and stamina. These needs are for the most part unmet for most children dying of illnesses; however, by providing good pediatric palliative care, these needs can be fulfilled.

SYMPTOMS

There are a variety of symptoms experienced by children at the end of life, as well as a variety of therapies that can be useful in treating these symptoms. In a retrospective study of parents of children who had died of cancer, parents reported that their dying children suffered from fatigue, poor appetite, constipation, nausea and vomiting, diarrhea, dyspnea, and pain in their last month of life.[7] For care providers caring for children at the end of life, this study suggests that we have an opportunity to alleviate the symptoms of children at the end of life.

Pain

Of the symptoms most commonly reported at end of life, pain is the symptom for which there exists the greatest diversity of treatment options (Table 1). From traditional pharmacologic therapies, of which opioids are the mainstay for treating pediatric pain, to alternative therapies such as acupuncture and aromatherapy, there are an abundance of modalities available to alleviate pain.

Assessment of pain in a pediatric patient can be challenging. If the child is conscious and cooperative, a variety of pain scales geared toward patients of various ages can be used to rate the child's pain. The Wong-Baker FACES scale is one of the most commonly used scales for children ages 3 years and older who can self report. An older child who understands numerical values will be able to rate his/her pain on a scale of 1 to 10, with 10 being the greatest amount of pain the child can imagine.[8-10] Assessment of pain in a child who is less than 3 years of age or who cannot self report is more difficult. The FLACC Scale (Face, Legs, Activity, Cry, Consolability) can be used to generate a pain score in these children, bearing in mind that there will be a degree of subjectivity be-

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Table 1. Therapies for Pain in Pediatric Palliative Care

Treatment	Dosage (Maximum)	Frequency	Route	Side effects
Acetaminophen	10-15 mg/kg (1000 mg)	q 4 hr	oral	none
Codeine	0.5-1 mg/kg (60 mg)	q 3-4 hr	oral, intramuscular	constipation
Fentanyl	0.5-1 µg/kg (none)	q 2-4 hr	Intravenous, subcutaneous	constipation, respiratory depression, urinary retention, nausea
	1-3 µg/kg/hr (none)	continuous	intravenous, subcutaneous, transdermal	
Hydromorphone	0.05-0.1 mg/kg (none)	q 4 hr	oral	constipation, respiratory depression, urinary retention, nausea
	0.015 mg/kg (none)	q 3 hr	intramuscular, subcutaneous	
	4 µg/kg/hr (none)	continuous	intravenous, subcutaneous	
Methadone	0.2 mg/kg (none)	q 6-8 hr	oral	constipation, respiratory depression, urinary retention, nausea
	0.1 mg/kg (none)	q 6-8 hr	intravenous	
Morphine	0.2-0.5 mg/kg (none)	q 2-4 hr	oral	constipation, respiratory depression, urinary retention, nausea
	0.05-0.1 mg/kg (none)	q 2-4 hr	intravenous, subcutaneous	
	10-30 µg/kg/hr (none)	continuous	intravenous, subcutaneous	
Oxycodone	0.2 mg/kg (20 mg/d)	q 3-4 hr	oral	constipation, respiratory depression, urinary retention, nausea

tween individuals generating the pain score.[11] The most commonly used scales in newborns are the Premature Infant Pain Profile (PIPP) and the CRIES (Crying; Requires oxygen; Increased vital signs; Expression; Sleepless) Postoperative Pain Scales.[12-14] Vital sign aberrations are not always a reliable indication of pain. Patients who are chronically treated with opioids will not always demonstrate changes to heart rate and blood pressure, such as would be seen in the opioid-naïve patient. Good assessment often requires input from those who are most frequently at the patient's bedside, usually family members and the patient's nurse. It is good practice to consider pain scores as "the fifth vital sign" and to document them in the bedside chart. Once a pain scoring system has been adopted for use in a particular patient, all providers should utilize that system in order to provide continuity in assessment and care. Pain scores should be regularly and routinely reviewed, appropriate interventions should be made (if necessary), and the process should be repeated.

Initial management of mild pain can sometimes be treated with a non-opioid (such as acetaminophen) or with a weak opioid (such as codeine) in the appropriate setting. For persistent or increasing pain, strong opioids (such as oxycodone or morphine) should be administered until the child is free of pain. Children at the end-of-life can experience significant pain for which strong opioids are the appropriate treatment. Opioids are now considered to be the backbone of pediatric pain management for moderate-to-severe pain. They should never be withheld due to a concern of addiction. Morphine is the most frequently prescribed opioid in children. It is also the opioid for which the pharmacokinetics in children has been extensively studied. Other opioids commonly used in children include oxycodone, fentanyl, hydromorphone, and methadone.[15]

For children who are able to swallow, persistence or escalation of pain can be treated with oral medications. Ideally, good pain control would be established using a long-acting opioid with a short-acting opioid prescribed for breakthrough pain. Frequent need for breakthrough doses should prompt reassessment of the long-acting dose. The effect of increasing the long-acting opioid takes hours to be appreciated by the patient, so clinicians should consider giving a bolus (the breakthrough dose

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can be used) at the same time as increasing the long-acting dose.

Methadone has been increasingly used in the pediatric population.[16] In some settings, oral methadone could have some advantages over other opioids. In a study of more than 70 children (aged 8 months to 9 years) who suffered pain mainly from burns or cancer, methadone was given daily for a period of time from several days to greater than a month. No serious adverse effects were observed and significant pain relief was reported.[17,18] A much larger study done on nearly 4,000 patients, of whom 12% were children younger than 17 years of age, found that satisfactory pain relief was recorded in more than 85% of the patients, with no serious side effects reported among patients who received oral methadone.[19] More data are required to fully establish methadone as an alternative to morphine in children. For children who are unable to swallow or for whom the pain is of such magnitude that it cannot be managed with oral medications, the intravenous route may be used, especially if the child has an indwelling central line. Morphine, fentanyl, and hydromorphone are the medications most commonly used. Children who are conscious and capable can often be given patient-controlled analgesia, either with or without a basal infusion. Modifications to patient-controlled analgesia include parent-controlled analgesia and nurse-controlled analgesia. These approaches require that an adult interpret the child's pain experience and bring into question whether the adult is interpreting the child's pain or their own perception of pain, potentially resulting in under- or over-administration of pain medication. Early results on parent-/nurse-controlled analgesia are promising, but more data are required to fully establish these alternatives to patient-controlled analgesia.[20,21]

There are other routes for administration of pain medication. A subcutaneous route is useful if there is no intravenous access. Many of the pain medications given intravenously can also be given by the subcutaneous route. This can be done with single injections or with an implanted subcutaneous line (insuflon). Fentanyl is also available as a patch (transdermal) and as an oralet (oral transmucosal drug delivery system). The patch has been used effectively in children and warrants consideration when developing a pain management plan.[22,23] The fentanyl patch should not be used to treat acute pain. Once pain has been controlled using other routes (e.g., IV, PO), clinicians should consider transitioning the patient to the fentanyl patch. Conversion tables can be found in the package insert, in various pharmaceutical references, and online.[24] Extra precautions regarding use and disposal of fentanyl patches must be provided by clinicians and pharmacists, as there have been a number of deaths and other adverse events reported. Used, unneeded, or defective fentanyl patches should be folded in half (so that the patch adheres to itself) and flushed down the toilet. If the adhesive gel contacts the skin, immediately wash with clear water. The patch should always be used intact —never cut or torn.[24] The fentanyl oralet would be of benefit to prevent acute pain secondary to a procedure and likely has little to contribute to chronic pain in a pediatric patient at the end-of-life. However, it may provide some benefit for dressing changes, replacing NG tubes, and other patient care activities and should be considered.

Careful attention must be paid to side effects when using strong opioids at any dose, but particularly when using large doses. Side effects include constipation, nausea, sedation, urinary retention and pruritus. Constipation, nausea, and sedation are often multi-factorial. Each will be discussed later in this section. Pruritus can develop even with low-dose opioids. Treatment with diphenhydramine, hydroxyzine or promethazine can be utilized to treat this symptom (Table 5). Note that promethazine tablets and suppositories are contraindicated in children < 2 years of age because of the potential for fatal respiratory depression. A wide range of weight-based doses have resulted in respiratory depression in children < 2 years of age. Caution should be exercised when administering promethazine to children 2 years of age and older. Use the lowest effective dose and avoid concomitant administration of drugs that can cause respiratory depression.[26]

For children whose pain is effectively managed by continuous infusion of opioids, low-dose naloxone by continuous infusion can be given to treat nausea and pruritus without decreasing effectiveness of the analgesic. Results of a recent study concluded that small-dose naloxone

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infusion (0.25 μg/kg/hr) can significantly reduce the incidence and severity of opioid-induced side effects without affecting opioid-induced analgesia.[27] If the current opioid is ineffective or a trial of naloxone does not ameliorate side effects, the clinician should consider changing opioids.[24] Urinary retention can be a side effect of opioid administration. Other physiologic causes of urinary retention should be investigated before attributing the problem to opioids. Other medications can cause urinary retention (e.g., medications with anti-cholinergic effects), and these should be carefully reviewed. If the problem can be attributed to opioids, several treatment options exist. Non-pharmacologic (but invasive) options include an indwelling urinary catheter or intermittent straight-catheterization. Pharmacologic options include oxybutynin or low-dose naloxone (Table 5).[28]

One of the problems that can develop in children who are consistently exposed to strong opioid analgesia is tolerance. Typically, the solution is to increase the dose of the opioid. This strategy can be limited by toxicity and, rarely, by failure to receive adequate analgesia despite increased doses. Occasionally, it may be necessary to rotate to another strong opioid in a different class (e.g., morphine to fentanyl). It is likely that a patient who has developed tolerance to morphine may not have tolerance to fentanyl. This is referred to as "incomplete cross-tolerance". The switch from one opioid to another should include a dose reduction, usually 25%, to allow for incomplete tolerance in the new opioid.[15] In a recent retrospective study looking at the therapeutic value of opioid rotation in a large pediatric oncology center, opioid rotation was found to have a positive impact on managing dose-limiting side effects or tolerance to opioid therapy. This was accomplished without loss of pain control. In this small study (22 children undergoing 30 opioid rotations), favored rotations were morphine to fentanyl (67%) and fentanyl to hydromorphone (20%).[29]

A number of case reports on management of pediatric pain can be found in the literature; intravenous ketamine,[30,31] continuous lidocaine,[32] and propofol[33] have all been effectively used. Intrathecal catheters have been used as a delivery system for pain medicine.[34,35] While not the standard of care for children, novel therapies may have an important role in care for children at end-of-life, especially if conventional treatment has not been effective.

The National Comprehensive Cancer Network (NCCN) has developed the first-ever Practice Guideline for Pediatric Cancer Pain Management.[36] The guideline incorporates pain assessment scales, the World Health Organization's (WHO) three-step "ladder" for cancer pain relief, and algorithms for treating pain at various levels in opioid-naïve and opioid-treated patients. The guideline is a useful reference for care providers taking care of children at the end-of-life.

Nausea

Nausea is a common symptom at the end-of-life in pediatric patients. There are many potential causes and treatments for nausea. One must consider the other medications being given as potential causes of nausea (e.g., opioids, chemotherapy) and consider modifications in these therapies if possible. Clinicians must also consider primary gastrointestinal (e.g., severe constipation, bowel obstruction) or central nervous system processes (e.g., increased intracranial pressure) as causes of the nausea and treat these accordingly.

For a child at the end-of-life who is having nausea, there are a variety of pharmacologic agents available for treatment (Table 2). There may be benefit from one of the 5-HT3 receptor antagonists (e.g., ondansetron, granisetron, dolasetron mesylate). Other anti-emetic agents which may be useful include lorazepam, metoclopramide with diphenhydramine, droperidol, and dexamethasone, but these may have side effects such as sedation which may make them more or less useful, depending on the clinical situation. The evaluation of a child complaining of nausea should also take into consideration the status of enteral feeds. If gastric motility is decreased or absent, enteral feeds should be decreased or discontinued.

Dyspnea

Although infrequent, children at the end-of-life can suffer from dyspnea, and this needs to be treated aggressively (Table 3). Adults describe "the uncomfortable awareness of breathing" as one of the most frightening and distressing symptoms. Measurements of respiratory rate, oxygen saturation, and arterial blood

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Table 2. Therapies for Nausea in Pediatric Palliative Care

Treatment	Dosage (Maximum)	Frequency	Route	Side Effects
Dexamethasone	5-10 mg/m^2 (20 mg)	q 6 hr	oral, intravenous	gastric irritation, glucose intolerance, hypertension, skin atrophy
Dolasetron mesylate	1.8 mg/kg (100 mg)	q 24 hr	oral, intravenous	headache, constipation
Droperidol	0.01-0.06 mg/kg (5 mg)	q 4-6 hr	intravenous	extrapyramidal reaction, hypotension, sedation
Granisetron	10-20 µg/kg (3 mg)	q 12 hr	oral, intravenous	headache, constipation
Lorazepam	0.03-0.05 mg/kg (2 mg)	q 4-8 hr	oral, intravenous, intramuscular	sedation, dizziness, constipation, respiratory depression
Metoclopramide with diphenhydramine	0.5-2 mg/kg (25 mg) with 1 mg/kg (50 mg)	q 4-6 hr	oral, intravenous, intramuscular	extrapyramidal reaction, sedation
Ondansetron	0.15 mg/kg (8 mg)	q 8 hr	oral, intravenous	headache, constipation

gases do not measure dyspnea. Opioids have been demonstrated to provide relief, whether or not identifiable reversible causes exist.[37] In the evaluation of dyspnea, it is important to assess pain, anxiety, and fluid balance and to respond with the appropriate treatment (e.g., increased pain medications, trial of a benzodiazepine, limited fluid intake). Oxygen may also provide comfort, even in a child who has normal oxygen saturation. In the setting of unresolved dyspnea, sedation may need to be increased such that the child's level of awareness would be impaired. Careful discussion with the family needs to accompany any such decision regarding sedation. The NCCN practice guideline for oncology palliative care recommends the use of benzodiazepines for anxiety and opioids for cough and dyspnea.[36] There are studies on the use of inhaled morphine and fentanyl in children with cystic fibrosis with good relief of dyspnea and air hunger.[38-40] There are limited data surrounding the management of dyspnea in children at the end-of-life, suggesting that this symptom is one that would benefit from further study.

Constipation and Diarrhea

Constipation at the end-of-life must be monitored closely. It is often seen in patients who are receiving opioids for pain and is also a side effect of many other medications. Since opioids will decrease bowel peristalsis, a bowel regimen should be initiated at the onset of opioid administration. Use of a stimulant laxative (e.g., senna or bisacodyl) is recommended (Table 4). Stool softeners (e.g., docusate or colace) and osmotic laxatives (e.g., polyethylene glycol) can also be added. Children who are still utilizing oral intake should be encouraged to increase daily intake of fluids and high-fiber foods. If constipation persists, the dose and/or frequency of stool softener/laxative should be increased. In certain settings, enemas may be needed to fully evacuate the bowel. Before administration of an enema, evaluate the child for risk of bleeding, perforation, and infection from trans-location of bacteria.

Diarrhea has been reported as a symptom common at the end-of-life. As with other constitutional symptoms, the etiology may be multi-factorial. Nutritional status, infection,

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Table 3. Therapies for Dyspnea in Pediatric Palliative Care

Treatment	Dosage (Maximum)	Frequency	Route	Side Effects
Inhaled Fentanyl	25-50 µg	q 4 hr	inhaled	
Lorazepam	0.03-0.05 mg/kg (2 mg)	q 4-8 hr	oral, intravenous, intramuscular	sedation, dizziness, constipation, respiratory depression
Morphine	0.2-0.5 mg/kg (none)	q 2-4 hr	oral	constipation, respiratory depression, urinary retention, nausea
	0.05-0.1 mg/kg (none)	q 2-4 hr	intravenous, subcutaneous	constipation, respiratory depression, urinary retention, nausea
	10-30 µg/kg/hr (none)	continuous	intravenous, subcutaneous	constipation, respiratory depression, urinary retention, nausea
	2.5-12.5 mg	q 4 hr	inhaled	headache

and medication use (especially antibiotics) should be evaluated in a child with persistent diarrhea. Medication substitutions should be considered whenever possible. Diets lacking fiber should be supplemented. If diarrhea persists and a cause has not been identified, consider a trial of loperamide (Table 4). Skin care is of critical importance in a child with persistent diarrhea. A barrier cream should be utilized once diarrhea presents. A thorough skin exam should be done regularly and prompt attention paid to any reddened or broken-down areas.

Anorexia

Anorexia is another common symptom and clinicians must take the lead from the child and parents as to how aggressively this should be treated. At the end-of-life, the natural course is that hunger and thirst are decreased. Careful discussions with the patient and family about the likelihood of this happening should be undertaken in conjunction with other discussions. It is important to discuss that the patient's metabolism may be compromised so dramatically that there may be no benefit to nutritional support and that continued efforts at providing feeds can result in fluid overload, infection, and discomfort. For families who are wrestling with withdrawal of food and/or fluids, consultation with an ethicist, pastoral counselor, or palliative care specialist may be helpful.[24]

In some situations, enteral and/or parenteral supplementation is appropriate, especially for children who are alert and interactive, but who simply aren't interested in eating. Occasionally, children will respond to appetite stimulation. Megestrol acetate has been successfully used as an appetite stimulant in children with solid tumors (Table 4). In patients with cystic fibrosis, cyproheptadine has been used as an effective appetite stimulant with minimal side effects (e.g., dry mouth, dizziness. diarrhea, headache).[42] Close clinical monitoring is indicated for children receiving nutritional support. Discontinuation of therapy should be considered at the earliest sign of patient discomfort.

Other symptoms

Sialorrhea (increased secretions) is an uncommon, but nonetheless troubling symptom seen in children at the end-of-life. It arises either as a consequence of increased production of secretions or failure to swallow normal secretions. A simple solution is frequent suctioning. Some children are able to hold the suction wand themselves. Various pharmacologic agents exist which may help reduce secretions including scopolamine transdermal, hyoscyamine sulfate, and glycopyrrolate (Table 5).[24] All three agents are associated with anticolinergic effects such as drowsiness and urinary retention. Therapies are also useful for urinary retention and purities (Table 5).

Alternative therapies

A host of complementary and alternative therapies are available at the end-of-life. Unfortunately, literature searches reveal few studies that demonstrate statistical significance and of those few, even fewer have been done in children. A recent Phase I investigation of the

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Table 4. Therapies for Constipation, Diarrhea and Anorexia in Pediatric Palliative Care

Treatment	Dosage (Maximum)	Frequency	Route	Side Effects
Constipation				
Bisacodyl	5-15 mg (30 mg)	qd	oral	cramps, nausea, vomiting
Docusate sodium	10-100 mg (none)	q 6-24 hr	oral	cramps, diarrhea
Lactulose	2-30 mL (none)	q 6-24 hr	oral	cramps, diarrhea, nausea, vomiting
Polyethylene glycol	25-40 mL/kg (none)	Continuous or prn	oral	cramps, nausea, vomiting
Senna	2.5-10 mL (10 mL)	q hs	oral	cramps, diarrhea, nausea
Diarrhea				
Loperamide	1 mg if 13-20 kg 2 mg if 20-30 kg 2 mg if > 30 kg	tid bid tid	oral	abdominal pain, nausea, vomiting, constipation, dry mouth, fatigue
Anorexia				
Megestrol acetate	1-2.5 mg/kg (400 mg)	q 6-24 hr	oral	gynecomastia, hyperglycemia
Cyproheptadine	2 mg if 2-6 yr 4 mg if > 7 yr	q 8-12 hr	oral	dry mouth, dizziness, diarrhea, headache

feasibility and acceptability of acupuncture and hypnosis for chronic pediatric pain supported a combined acupuncture/hypnosis intervention. There were no adverse effects. Both parents and children reported significant improvements in children's pain and pain-related interferences in functioning following treatment.[43] Though limited preliminary data are described, the results are promising and warrant consideration in the palliative care planning for children at the end-of-life. There are a number of studies done in adults using acupressure for reduction of post-operative nausea, pregnancy-associated nausea, and chemotherapy-associated nausea.[44-46] The published data are promising. Children at the end-of-life would benefit from further study in this area.

CARE

Pediatric palliative care occurs in different settings, ranging from home to hospice to hospital. There are many benefits to having a child receive terminal care at home.[47-50] Some of the reasons families choose to care for their dying child at home include the child's wish to be at home, easier access to family and friends, freedom from the hospital, less disruption of family life, and ease of care for the siblings as well.[47] The effect of having a child die at home has been researched, and one of the early studies examining families after a child's death in the home versus in the hospital, found that families of children who died at home had a more rapid return to normal social functioning and a decrease in parental guilt when compared to parents of children hospitalized for terminal care.[48] In a follow-up study, investigators found that parents who cared for their dying child at home had decreased feelings of helplessness, greater feelings of control, and increased opportunity for family communication.[49] This study also found that parents of patients who died in the hospital were more anxious, depressed, and defensive. They also found that siblings of patients who died in the hospital showed fewer emotions, were more withdrawn, and were more fearful. A study of sibling adjustment showed the benefit of home care for the sibling of a dying child.[50] It was found that siblings of children who died at home adjusted much better compared to

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Table 5. Therapies for Sialorrhea, Pruritis, and Urinary Retention in Pediatric Palliative Care

Treatment	Dosage (Maximum)	Frequency	Route	Side Effects
Sialorrhea				
Glycopyrrolate	20-100 mg/kg 2.5-10 mg/kg	q 6-8 hr q 6-8 hr	oral, intravenous, intramuscular	drowsiness, urinary retention
Hyoscyamine	0.0625-0.25 mg (0.75 mg/d)	q 4 hr	oral, intravenous, intramuscular, subcutaneous	drowsiness, urinary retention
Scopolamine	6 µg/kg (0.3 mg)	q 6-8 hr	oral, intravenous, intramuscular	drowsiness, urinary retention
Pruritis				
Diphenhydramine	1 mg/kg (50 mg)	q 4 hr	oral, intravenous, intramuscular	drowsiness, constipation
Hydroxyzine	0.5-1 mg/kg (100 mg)	q 6 hr	oral, intramuscular	drowsiness, dry mouth
Naloxone	1-5 µg/kg/hr	continuous	intravenous	nausea, vomiting, narcotic withdrawal
Promethazine	0.5-1 mg/kg (50 mg)	q 4-6 hr	oral, intravenous, intramuscular, rectal	sedation, extrapyramidal reaction, urinary retention
Urinary Retention				
Oxybutynin	0.2 mg/kg (5 mg)	q 8 hr	oral	dizziness, dry mouth, constipation
Naloxone	1-5 µg/kg/hr	continuous	intravenous	nausea, vomiting

siblings of children who died in the hospital, and this was thought to be due to more opportunity for anticipatory mourning and gradual preparation, making the death less frightening to them. There are disadvantages to caring for a dying child at home, and the most often cited concern is the heavy responsibility assumed by the parents and primary care team, who may not feel they have the capability to care for both the dying child and the rest of the family.[51] Some other problems encountered in caring for their dying child at home include watching the decline, fears of what would happen, the nursing responsibility, and care for the other siblings.[49]

Choice and control are fundamental to parents' coping strategies, and home is generally seen as the place of choice for terminal care of the child.[52] Research examining terminal home care for children with cancer found that this was very feasible; however, this type of care requires the ability to expect and prevent symptoms, to have liaison between the hospital and the primary care team, and to have a family support nurse.[53] In addition, 24-hour access to hospital staff for advice was important. Other studies have reinforced the need for adequate support systems and emphasize that the most important aspect for home palliative care is continuity of team efforts to help the family and to mobilize necessary resources.[54]

Hospice is defined as an organization that helps prepare patients and families for an anticipated death, manages the final stages of an illness according to the wishes of the patient and family, and provides support to families prior to and following the death of a child.[5] An inpatient hospice unit is seen as a valuable option when families no longer want to remain in the hospital and returning home with the child is not a feasible or desirable option.

The hospital is often the place of death for many children who die, and this may be due to the circumstances of the death, such as a death from sepsis, where there is still active medical treatment with the intent for cure, until very close to the time of death. There is still a large role to be performed by a palliative care team in this situation. Families also often choose the hospital as the location for the death of the

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child, due to the comfort level and familiarity of the child and family with the health care team at the hospital. As outlined above, there are some difficulties encountered by families when caring for their terminal child at home, and the hospital must always remain as an option for families who feel they cannot cope at home.

PSYCHOSOCIAL ASPECTS

Parental involvement in the care of pediatric patients is something that clinicians should always strive for, and this involvement is imperative in dealing with palliative care for pediatric patients. In a study examining the quality of pediatric palliative care, parental involvement was felt to be a very important factor, and parents appreciated it when they were actively involved in making decisions about their child's treatment and care.[55]

A major point in the psychosocial dimension of pediatric palliative care is the discussion with the child about their prognosis. There are many issues around talking with children about death and dying, and many views. The issues include whether the child should be told, who should tell the child, and when the child should be told. There are no right or wrong answers to these questions, but there has been research that can direct clinicians and families in their approach.

An important factor in talking to children about death is taking into account their developmental level and ability to understand death. The child's developmental level influences all aspects of their care, including pharmacology of medications they receive, their communication skills, and their understanding of their disease and death.[56] The developmental levels are unique among children, but there are general guidelines regarding their understanding of death.[57] Children between birth and three years of age are unable to differentiate death from temporary separation or abandonment, but by the end of this phase they define death structurally as a state of immobility. Between the ages of three and six years, children may think of death as temporary and reversible and may not realize that life and death are mutually exclusive. They don't understand why people die and may believe they can cause death with thoughts or actions. Between the ages of six and twelve years, children recognize that death is irreversible, the causes of death, the fact that everyone dies, and that dead people don't function. Beyond age twelve, children develop abstract thinking and are able to comprehend death like adults do. These stages are generally achieved at an earlier age in children with life-threatening illnesses.

A recent study interviewed parents of children who died of cancer regarding their discussions with their child about death.[58] The investigators found that none of the parents who talked with their child about death regretted it, while 27% of parents who did not talk with their child about death regretted this decision.

Previous studies regarding telling children about their impending death reinforce that this is the best practice to maintain. Children with terminal diseases are usually aware of their condition but may try to hide this knowledge from those around them.[57] As well, adults who respond with comfort to the questions raised by dying children will help these children to feel more secure and supported.[57] It is also recommended to encourage parents to observe how much their children understand about their illness and to recognize the fact that children know when they are dying, and if they are not allowed to speak openly about their illness and death, then they may feel very isolated.[59] At one center, open and honest discussion with children over age 4 is the practice, and they have found that this greatly facilitates the dying process for children and their families.[60]

Another aspect to consider in pediatric palliative care is care for the siblings of the patient. There are guidelines to aid in care for siblings of children in the terminal phase of illness.[61,62] These include allowing the siblings to participate in all discussions, allowing the siblings choice as to how much they want to participate in the decisions regarding palliative care, providing resources for help with anticipatory mourning and bereavement, and avoiding false protection of the sibling by exclusion. Siblings are often overlooked when another child in the family is dying, and these guidelines should help to ensure they are appropriately involved in the situation.

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BEREAVEMENT CARE

Bereavement is defined as the situation of having experienced a loss through death, and grief is used to describe the feelings and behaviors in response to a death.[1] Bereavement care in pediatrics is the support given to family members after the death of a child. The death of a child is recognized as one of the most stressful life events.[63] In pediatric oncology, the recommendations for bereavement care include: bereavement counseling for parents and siblings with the physician to discuss the care given to the child as well as the surviving family members' needs, follow-up and counseling sessions for surviving siblings, professional psychological help to parents who feel the need, and encouragement of bereaved parents and siblings to initiate self-help groups.[61]

Bereavement care is very important in pediatric palliative care. The death of a child is associated with an overall increase in mortality from both natural and unnatural causes in mothers and an early increased mortality from unnatural causes in fathers.[64] There is also an increased risk of anxiety and depression among bereaved parents compared to non-bereaved parents, and this risk has been found to be higher in the period 4 to 6 years following the death compared to 7 to 9 years following the death.[65] Psychological stress has been found to be higher among bereaved mothers, and there is an increased risk of psychological distress with the loss of a child age 9 years or older.[65] This information reinforces the need for bereavement care to families following the death of a child.

A case report on sibling grief recommended the following guidelines for working with bereaved siblings:[66] adjust interventions to the developmental level of the child, determine the child's thoughts and feelings about the death, help the sibling to correctly understand the circumstances around the death, give the sibling permission to grieve, promote expression of feelings, encourage expression of grief through play, and identify any magical thinking that could lead to inappropriate feelings of guilt. These are excellent guidelines to follow when providing bereavement care to siblings.

CHALLENGES

There are many challenges in providing palliative care to pediatric patients. One challenge in pediatric palliative care is the timing of the institution of palliative care. One problem in instituting palliative care is the recognition by both the family and the patient of the lack of chance for cure of the child. A recent study found that considerable delay exists in parental recognition of no chance for a cure for their child.[67] This study also found that earlier recognition of this situation resulted in a stronger emphasis on treatment directed at lessening suffering. There has also been an identified need to create a unified evidence-based set of minimum standards and guidelines for clinical practice in pediatric palliative care,[68] and this has not yet been done.

Other barriers to care that have been identified include technical advances making death seem a misadventure rather than natural disease process, legal decisions impeding decision making by health care providers, difficulty in meeting the eligibility requirements for palliative or hospice services, and difficulty in the assessment and management of symptoms in pediatric patients.[68]

There is literature regarding the symptoms experienced by children with cancer at the time of death, and they suffer from significant pain, dyspnea, and other symptoms.[7,69] Also, in a recent survey among Canadian institutions, only 15% of pediatric oncology patients utilized palliative care services at the time of death,[70] and in an American publication only one in 10 children at the end of life had access to hospice.[5] Involvement of a palliative care team and palliative care services are paramount to help relieve the symptoms and suffering for children with life-limiting conditions.

Palliative care teams are not always available at centers caring for dying children. A recent 2002 survey of Canadian pediatric institutions found that a palliative care team was available in 88% of the tertiary care pediatric centers across Canada.[70] In a 1997 ASCO survey, a palliative care team was rarely or never available to 48.3% of pediatric oncologists.[71] One can hope that in the 5 years between these 2 surveys there was increased availability of a palliative care team in pediatric oncology

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centers, although there is no recent survey to compare the availability in the United States versus Canada to determine if there is indeed a difference in service availability between the 2 countries.

Home care needs to be an option for pediatric palliative care, but parents of children who died at home report inadequate home and community based care at the end of life.[55] There need to be adequate services available as well as adequate training for health care personnel who are providing pediatric palliative care. Furthermore, there must be adequate reimbursement to the health care personnel for the provision of pediatric palliative care.

RECENT AND FUTURE RESEARCH

Recent publications in pediatric palliative care are mostly descriptive, and very little research has been published in the last few years in the area of pediatric palliative care. Some of the most recent research in this area includes comparison of telephone and bedside consultation which demonstrated that bedside consultations had more value.[72] In addition, there was a recent comparison of strong opioids to WHO guideline pain management in terminal cancer patients. The investigators found that strong opioids were useful as first line agents in this setting.[73] There are also many publications in pediatric palliative care looking at symptoms[7,74] experienced by these patients. Currently, within the Children's Oncology Group, the Palliative Care Committee is working on many studies designed to advance the science of pediatric palliative care.

CONCLUSIONS

Pediatric palliative care is an expanding field that enhances quality of life and attends to the suffering of children with life-threatening conditions. This care must include controlling the variety of symptoms experienced by these patients. It must also encompass the psychosocial aspect of palliative care and include bereavement follow up. By accomplishing these goals, the benefits of end-of-life care for pediatric patients can be maximized.

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