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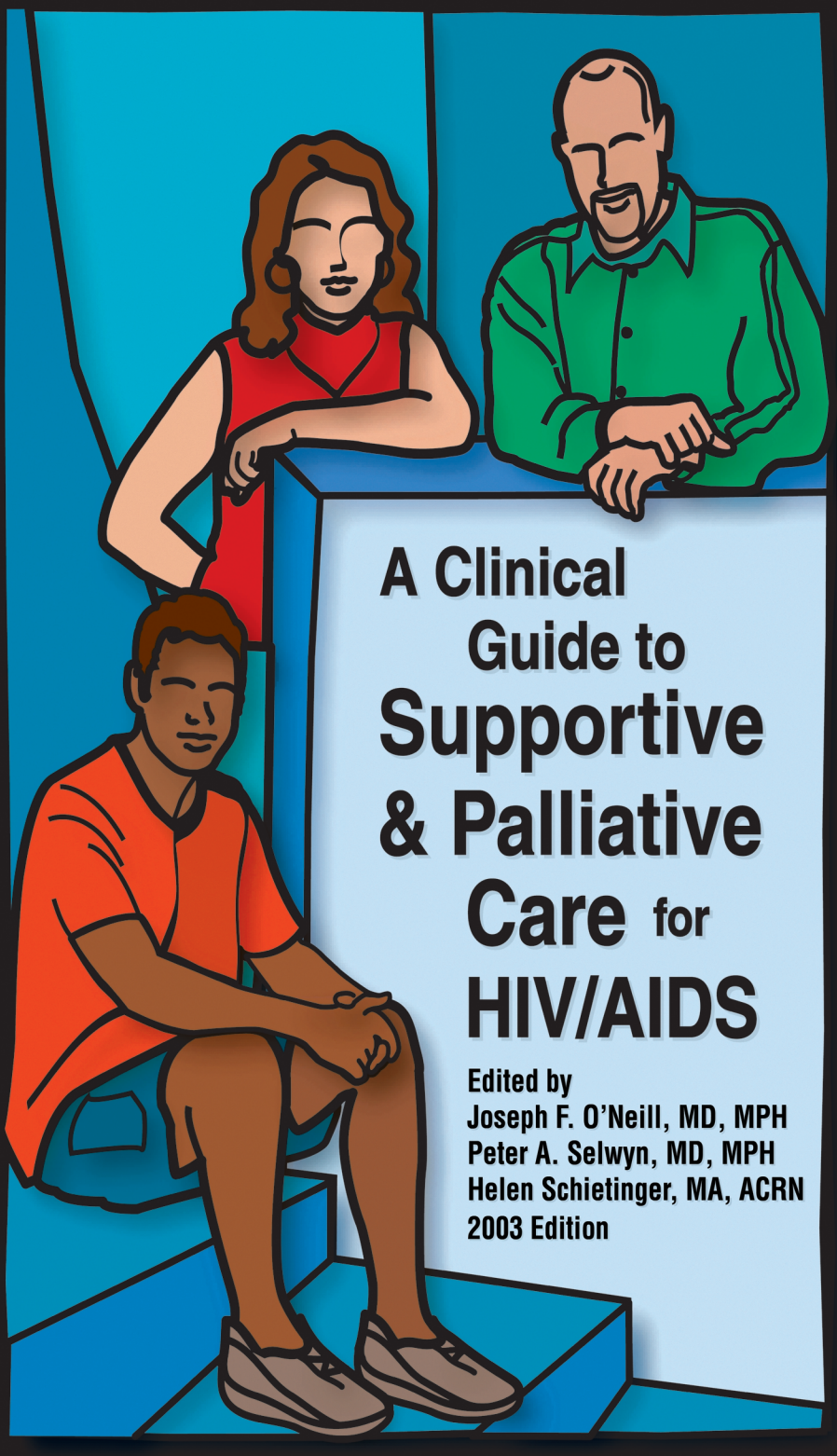

A Clinical Guide to Supportive & Palliative Care for HIV/AIDS

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Chapter 12.

The Care of Children and Adolescents

Nancy Hutton, MD, and James M Oleske, MD, MPH

INTRODUCTION

■ All HIV clinicians, whether they care for adults or children, need to understand the basic issues and needs of children and adolescents in order to provide palliative care. Pediatric HIV providers must have the knowledge and skills to provide palliative care to their patients throughout the disease trajectory. They must also be cognizant of the palliative care issues that affect the family members in a child's life. Providers for adults with HIV must understand the needs of children and adolescents in the lives of their adult patients, especially as they relate to palliative care and care at the end of life.

This chapter first describes the developmental continuum of children and adolescents, and then addresses pain and symptom management. Finally a range of issues related to caring for children with advanced disease is discussed, including prognostication, several aspects of decisionmaking and communication including disclosure of HIV status, and support of affected children including permanency planning.

HIV Is a Family Disease

HIV is a family disease in every sense. In pediatric HIV infection, there are usually at least two generations of the family infected: mothers (and often fathers) and children. Parents continue caring for sick children as their own disease progresses. Families living with HIV often include several people with HIV, increasing the disease's impact on each individual almost exponentially. When multiple adult siblings are infected, substantial caregiving burden falls to their aging parents. If those adult children have children themselves, caregiving responsibility for sick mothers and sick children often falls to grandparents or other elderly family members.

Children and Adolescents Infected with HIV

Young people with HIV/AIDS require high quality care throughout the continuum of their disease, including high quality palliative care. The advent of highly active antiretroviral combination therapies (HAART) has not made palliative care obsolete. In fact, it helps refocus our goals. As symptom management is an important component of palliative care, managing the symptoms associated with antiretroviral therapy should be an integral component of initial HIV management in a newly diagnosed patient.

HAART has not cured HIV. A cohort of children has survived into adolescence on serial mono and dual therapies. These young people, now in their mid-teen years and often in non-parent care, are grappling with the failure of medical treatment to stem the progression of their disease.

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Children and Adolescents Affected by HIV

Besides the children and adolescents who are infected with HIV, many non-infected children and adolescents are affected by the disease. Children and adolescents affected by loved ones with HIV—including parents, siblings, grandparents, aunts, uncles, friends and lovers—are often called the forgotten children of the epidemic. Although HAART has provided a respite from the multiple deaths of parents and other treasured adults, the losses have not stopped and are beginning to escalate again. The needs of children and adolescents include basic care and protection, nurturing, discipline, and mentoring in order to grow into independent adults. Children also need support in anticipating and preparing for loss and in experiencing healthy bereavement.

DEVELOPMENTAL CONTINUUM

■ The single characteristic that makes children stand apart from adults is their rapid growth and development. Because the changes are so large and so rapid during life's first two decades, any engagement with children and adolescents, whether infected or affected, must begin with a sense of where a child is on his/her developmental trajectory. Health care providers need to understand a child or adolescent's level of development in order to offer appropriate support.

For purposes of description, four streams of development will be presented:

- Physical growth and physiological maturation
- Motor skills development
- Cognitive maturation
- Social and emotional maturation

Some streams may have greater relevance than others to certain situations. However, we must always remember that all four streams are intertwined into the unique whole of each individual child or adolescent.

Physical Growth and Physiological Maturation

Childhood and adolescence are periods of rapid physical growth. Newborns *triple* their body weight in the first year of life. By the age of 15, an adolescent will weigh two-thirds more than he or she weighed as a ten year old. Appetite, diet, and caloric intake increase substantially as a child grows. Clothing and shoes become too small before they are worn out. Basic care requires close supervision and protection by nurturing adults with the means to support the growing child.

Growth, Size and HIV Infection

Growth failure is a common complication of HIV infection. Short stature in adolescents may lead to teasing by peers and inappropriate treatment by adults who think the adolescent is a younger child.

Clearly "one size" cannot "fit all." For children with special health care needs, equipment must be available in appropriate sizes. Blood pressure cuffs, wheelchairs, beds, and walkers come in a range of sizes.

Using safe and familiar items creatively is desirable. For instance, children feeling too weak or tired to walk around or go outside may enjoy rides in a wagon filled with pillows and blankets.

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Medication Dosage for Children and Adolescents

Medications are dosed by body weight or body surface area. Metabolism and excretion of medications change with the maturation of body organs. Early infancy is a time of rapid maturation in hepatic and renal function. There are further changes at puberty that are less well defined. Therefore, chronic medication dosing must be recalculated as children grow or regress (Table 12-1).

Common pediatric medicines such as antibiotics have been studied for safety, efficacy, and optimal dosing in even the youngest patients. Often, children require and tolerate higher total doses than adults. However, many medications that are used to manage symptoms and complications have not been formally tested in children.

Table 12-1: Example Illustrating the Need for Flexible Dosing Formulations: Range of Doses for a Common Antibiotic Prescribed during Childhood and Adolescence

Age	Weight	Dose Calculation	Dose Administered
2 months	5 kg or 11 lb	50 mg/kg/day	85 mg tid
3 years	15 kg or 33 lb	50 mg/kg/day	250 mg tid
9 years	30 kg or 66 lb	50 mg/kg/day	500 mg tid
14 years	50 kg or 110 lb	(equiv to 15-30 mg/kg/day)	250-500 mg tid
Adult	70 kg or 154 lb	(equiv to 10-20 mg/kg/day)	250-500 mg tid

Medication formulations must provide flexible doses in a form that can be easily swallowed. Liquid formulations offer the most flexible dose titration and are the easiest to swallow if the flavor and odor are tolerable. Sustained release preparations can reduce the frequency and number of doses, but must be available in multiple strengths in order to be useful at all with children or adolescents. Transdermal patches, an ideal delivery system, are available only for a limited number of drugs and in adult dose ranges.

Motor Skills Development

Human infants are completely dependent on adult caregivers for all basic care and daily activities until they develop into independent people responsible for their own care. Gross motor skills are the first developmental milestones we see, as infants learn to sit, stand, walk, run, and climb. Fine motor skills include using hands to accomplish increasingly complex tasks such as grasping, carrying, self-feeding, and gaining voluntary control over intake and elimination (chewing, swallowing, bowel and bladder control).

Motor skills influence the extent to which children can cooperate with or perform their self-care or care for others. They are markers of independence and usually great pride. However, adults sometimes assume that physical skills predict cognitive or emotional maturity. This error can lead adults to expect children to shoulder burdens that are not appropriate for their cognitive or emotional level of development.

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The loss of motor skills due to illness or injury is significant physically and emotionally for child and parent alike. HIV can cause progressive neurologic deterioration, with loss of milestones and increased dependency on others for ambulation and self-care. HIV also causes fatigue and weakness that functionally restrict a child's independence. Assessing changes over time, especially the loss of skills, is an important component of care planning for children with chronic and progressive illness.

Cognitive Maturation

A child's developing ability to think is reflected in his or her ability to communicate in written and spoken language, and in the ability to solve problems. *Expressive language* includes the vocalizations, body motions, or writings that a child will use to attempt to express ideas to others. Primitive skills will communicate comfort or discomfort (smiling, crying). As cognition advances, expressions become more intricate and refined, becoming recognizable words, then sentences, then paragraphs and conversations. With patients who are children, our ability to ascertain their experience of physical symptoms or psychological loss is limited by their ability to express these ideas in ways we can understand.

Receptive language skills include a child's ability to hear and understand the spoken word and see and read the written word. All these skills are necessary for children and adolescents (and adults) to participate effectively in decisionmaking. These skills develop gradually as a child matures. Young children understand events concretely while adolescents are better able to think abstractly. Our explanations of what is going to happen and why, or of choices about treatment, can only be shared to the extent that a child has the receptive skills and cognitive processing to comprehend what is being communicated and its implications.

Social and Emotional Maturation

A child's social interaction begins with parents and other daily caregivers. During the first year, infants begin to distinguish self from others, and familiar others from strangers. They begin to remember people even when the people are not physically present. During the second year, children begin parallel play and later become truly interactive in their play. Social interaction with peers becomes important throughout the school years, and takes on greater importance as adolescents become more independent from adults. Table 12-2 presents suggestions for health care providers to use in working with children and adolescents at different stages of social development.

A personal or family illness will interfere with the normal progression of a child's socialization process. Missing school and other opportunities for age-appropriate play can cause arrest or regression of this component of development.

Emotionally, a child's experience of loss (self, family, friends) will vary according to his or her developmental age. The same loss may be re-experienced in new ways at critical points in the child's development.

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Table 12-2: Interacting with Children and Adolescents at Different Stages of Social Development

Infants (0-12 months)	Communicate to us nonverbally
	Adults should use language, tone, and touch to communicate
	Need physical and emotional nurturing
	Adults should give very simple explanations
	Object permanence develops
Toddlers (1-2 years)	Are learning words
	May have temper tantrums
	Adults should give simple explanations
	Adults should be clear, consistent
	Adults should prepare toddlers for procedures just beforehand
	Adults should be efficient and comforting
Preschoolers (3-4 years)	Have simple conversations, can ask questions
	Can play with others
	Have concerns about body integrity
	Show magical thinking
	Adults should provide concrete information about what is happening and why
Children (5-11 years)	Are curious about own body and own health
	Spontaneous questions are opportunities for adults to tell children the truth
	Learn to read
	Begin to understand cause and effect
	Offering children choices improves their sense of control
Early Adolescents (12-14 years)	Puberty is a period of rapid physical, physiologic, emotional, and social change
	Want to be treated like adults but are still kids
	Struggle with their own vulnerability vs. invulnerability
	Need direct positive adult support
	Peer relationships are very important
Late Adolescents (15-18 years)	Are abstract, existential thinkers
	Can accept active responsibility for own health care
	Can be active in health care decisions, including participation in research
	Still need adult structure and support
	May be shouldering adult responsibilities

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PALLIATIVE CARE FOR CHILDREN AND ADOLESCENTS WITH HIV/AIDS

■ Palliative care is the active total care of patients whose disease is not responsive to curative treatment. Because HIV remains a disease without curative treatment, in some sense, all care is palliative in intent. We must attend to patients' physical problems in order to support further exploration of the emotional, spiritual, and social issues that concern them. We strive to improve the quality of living through HIV-specific therapies and other supportive and preventive therapies.

Symptom Management

This section explores the range of physical symptoms experienced by children and adolescents with HIV/AIDS, management options for these symptoms, and strategies for successfully implementing effective management. Conscious use of this framework for care from the time of diagnosis will help to facilitate the transitions in care that must occur as disease progresses.

The range of symptoms experienced by children and adolescents is similar to that for adults with HIV/AIDS. Some symptoms are caused by the underlying disease and its complications and some are caused by the procedures and treatments that are used to manage the disease (Table 12-3).

Table 12-3: Causes of Symptoms in HIV/AIDS Patients

Symptom	Causes		
	Disease	Procedure	Treatment
Pain	■	■	
Nausea	■		■
Anorexia	■		■
Vomiting	■		■
Diarrhea	■		■
Constipation	■		■
Fatigue	■		■
Fever	■		
Dyspnea	■		
Cough	■		
Bleeding	■		
Seizures	■		
Anxiety	■	■	■
Fear	■	■	■
Depression	■		
Sleep disturbance	■	■	■
Skin lesions	■	■	■

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Managing symptoms follows a logical approach: assessment, treatment, and reassessment. Health care providers should repeat this sequence of actions rapidly until symptoms are controlled and then on a routine basis to assure maintenance of control.

Preventing Iatrogenic Pain and Symptoms

The clinician's first obligation is to prevent the pain and symptoms associated with the tests and treatment provided to patients. This means being conscious of these symptoms and acting preemptively to prevent or control them. The most common procedure-associated symptom is pain due to needle sticks (injections, phlebotomy, intravenous access, lumbar punctures). EMLA cream (eutectic mixture of local anesthetics) is readily available and easy to use for all of these indications. A barrier to its use is a provider perception that there is not enough time for it to work. Usually the lack of time for application of EMLA is a result of providers' failure to anticipate the need for EMLA at the beginning of a clinical encounter. Some families successfully apply EMLA at home prior to traveling to a clinical appointment; again, this is possible when providers anticipate the predictable need for topical pain relief and spend the time and effort ahead of time to implement a strategy for prevention.

Anticipatory fear and anxiety are common procedure-associated symptoms in pediatric patients, as in adults. With children, preparation for procedures using medical play is very effective in reducing fear, improving a sense of mastery and control, and thereby improving the patient's cooperation with procedures. *Child life specialists* are trained professionals who provide developmentally appropriate psychologic preparation and can provide direct support to the child throughout the procedure. Techniques include the use of dolls, medical equipment that the child can touch and manipulate, pictures and books, and role-playing with the child taking the role of the health care professional. Distraction, imagery, relaxation, music, and hypnosis are techniques used during procedures to complement analgesia and preparation.

Many medications have the potential to cause side effects. HAART regimens are common culprits, causing nausea, vomiting, diarrhea, headache, dysphoria, or paresthesia. Children initiating therapy early in the course of HIV disease may feel well until starting medicine and *then* feel sick. For children with progressive disease, medicines may add or obscure symptoms. Whenever possible, providers should minimize treatment-associated symptoms through thoughtful prescribing, patient preparation, and medical management.

Assessing Symptoms

The first step is to determine whether a patient is experiencing any symptoms and, if so, which? Each symptom must be assessed regarding the following factors:

- Onset
- Severity
- Duration
- The presence of precipitating, aggravating, and relieving factors

While this assessment can be challenging with adult patients, it can seem impossible in children.

Direct observation of the child and the report of a parenting adult are essential components to pediatric assessment. In preverbal children, behavioral observation of crying, irritability, withdrawn or depressed affect, tense body position or facial grimacing, and fearfulness may each

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point to underlying pain. Adults who spend a lot of time with the child are able to describe changes or patterns in behavior suggestive of pain. But it is almost never too early to ask the patient directly. Even very young children can provide important information. Their descriptions can be charmingly accurate and to the point. Unfortunately, they also learn quickly that telling the doctor or nurse about a problem may lead to more tests that cause further pain and discomfort, so a child's denial of a symptom that seems likely to be present must be taken in context as well. For instance, a therapeutic trial of analgesia is sometimes the best way to sort out how much pain is contributing to the patient's current condition.

Pain Assessment

Pain comes in many forms. Remarkably, patients may not report pain unless a provider asks whether it is present. Pain is an important symptom for alerting providers to problems that require further investigation and treatment. Pain is also a problem in and of itself for the patient and requires specific management, regardless of its underlying etiology.

Pain assessment logically begins with location. Providers should ask, "Where does it hurt?" "What other pains do you have?" A list of all the pains helps the provider organize an approach to assessment.

Possible pains in children and adolescents include the following:

- Headache
- Stomach Ache or Abdominal Pain
- Chest Pain
- Back Pain
- Ear Ache, Sore Throat, Mouth Pain, or Tooth Pain
- Extremity Pain

Knowing when a child has multiple pains helps the provider address each type of pain with appropriate modalities and allows specific reassessment to assure the patient's optimal response to each intervention.

The severity or intensity of the pain can be assessed using the behavioral rating scale, FACES scale, or the 1-10 scale. (See Figures 4-2 to 4-5 in Chapter 4: Pain.) Pain rating scales help providers to determine when a patient's pain is getting worse and when interventions are providing relief.

The character of the pain may be more difficult to elicit. Some children are able to use adult descriptors that suggest an etiology of the pain, such as aching versus shooting pain. However, many children will simply say it hurts. Some can describe onset and frequency, but others will only be able to tell the provider if the pain is present now and whether it is sometimes not there. Colicky pain may require adult observation of the exacerbation/remission cycle of the pain.

Physical Examination and Verbal Questioning of Children to Assess Symptoms

Physical examination begins with the careful observation of the patient's position, spontaneous movements, and level of arousal/interaction. This phase of the exam is particularly important with children. Children become frightened and start crying even in anticipation of an exam that may cause them further pain. Once a child reaches this state, it is nearly impossible to discriminate areas of tenderness or to complete an adequate exam.

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Simple preparation before touching the patient and respect for a patient's request to stop a portion of the exam will achieve a more informative evaluation than wrestling with a screaming child. Visual inspection (without touching!) of the skin reveals lesions or wounds. Palpation and manipulation helps to discriminate the presence and location of tenderness as well as other aggravating factors. Asking a child to help the examiner by telling him or her as soon as something hurts, so that further hurt can be minimized, helps include the child in the evaluation and promotes cooperation and improved feedback about symptoms.

Neuropathic pains may have associated motor and sensory changes. Sensory neuropathy causes hyperesthetic areas that cannot tolerate even light touch. The pain of nerve root compression may feel deep and aching but not be made worse by direct palpation in the area of referred pain.

The assessment of symptoms other than pain in children is less well studied. We rely on direct observation by parents and health care professionals and the subjective reports of the patients. Behavioral observations can make us suspicious that a child is experiencing a symptom, but may not indicate specifically which symptom. For this, providers need the child's feedback. However, the child's capacity to provide this feedback is limited by his or her developmental level. Adult proxies may not provide an accurate assessment. In addition, we have few reliable severity measures, inhibiting our ability to detect changes in severity over time other than by behavioral improvements in response to specific interventions. Sometimes the provider can only determine the presence or absence of a symptom. (See Table 12-4).

Table 12-4: Sources of Information about Symptoms in Children

Symptom	Presence	Severity
Pain	O, R	R
Vomiting	O, R	O, R
Nausea	R	R
Diarrhea	O, R	O, R
Constipation	O, R	R
Fatigue	O, R	O, R
Anxiety	O, R	O, R
Depression	O, R	R
Skin lesions	O, R	O, R
Anorexia	O, R	O, R
Insomnia	O, R	O, R
Dyspnea	O, R	O, R
Fever	O, R	O
Cough	O, R	O, R
Bleeding	O, R	O, R
Seizures	O	O

O = Direct observation by caregiver or health professional; R = Patient report

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Infants and young children are dependent on adult caregivers for their activities of daily living. These patients are too young to use the bathroom independently, change their clothes, or prepare and eat meals. Therefore the presence and severity of symptoms that require adult attention can be ascertained by asking a parenting adult. This person certainly will know whether a young child is experiencing vomiting, diarrhea, infrequent stools, decreased appetite, decreased activity, disturbed sleep, or fussy behavior.

As discussed above, behavioral observations regarding changes in appetite, activity, sleep, and mood do not necessarily indicate the presence of a specific symptom. For instance, pain or nausea could cause the same spectrum of behaviors; identifying the correct symptom is necessary for effective symptom management.

Providers need to ask older children directly about their symptoms, in addition to asking adult caregivers for their observations. Children may not recognize or accurately use "medical" descriptors. Nonetheless, their reports are critical pieces of symptom assessment. Nausea is difficult to describe or explain. Constipation may be missed because children do not keep track of their bowel movements. Fatigue may be misinterpreted by adults as laziness. Anxiety, fear, and depression can cause behaviors that adults could label as oppositional or "limit-testing" without exploring their underlying etiology.

Treating Symptoms

An effective symptom management plan will include both pharmacologic and non-pharmacologic modalities. Pharmacologic treatment of infants, children, and adolescents entails challenges uncommon in adult medicine. The safety and efficacy of many common medications have not been established in the youngest age groups. Similarly, pharmacokinetics, dosing levels and intervals are unavailable for many drugs. This is particularly true for patients who fall into the two periods of rapid physical growth and maturation: infancy and puberty. Pediatricians often extrapolate information from adult studies, using promising medications in difficult situations and "guesstimating" doses. However, adult medications may not be available in formulations that young children can swallow or doses that young children can take. Some routes of administration may be frightening or painful.

Pain

Managing pain involves identifying and treating any reversible causes of pain (e.g. infections responsive to antibiotic therapy). Specific pain management should complement curative therapies until the underlying problem is resolved and no longer causing pain. Many pains, especially in advanced disease, will elude clear delineation of etiology or be due to conditions for which there is no effective therapy. In these circumstances, specific pain management is the preeminent therapy. (See Chapter 4: Pain.)

Within the field of pediatrics, we have experience with non-pharmacologic approaches such as distraction, relaxation, and breathing techniques for procedure-associated pain. Health care providers treating children and adolescents need to expand and refine the use of these techniques for chronic and complex pain syndromes.

Providers also need to be comfortable with the use of analgesics (Table 12-5). Having a few basic medicines in our armamentarium will go a long way toward relieving patient pain. Understanding their mechanisms of action, dosing options, and potential for synergistic effects, side effects and toxicities reduces the barrier of provider ignorance and discomfort.

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Pediatric pain specialists are available to help manage more complex or unresponsive pains in children.

Table 12-5: Analgesics for Pain Management in Children and Adolescents

Basic oral analgesics	Dose	Formulation
Acetaminophen	10-15 mg/kg/dose q 4-6 hours	Drops (80mg/0.8ml)
		Syrup (160mg/5ml)
		Chewable tab (80mg)
		Tablets (325mg, 500mg)
Ibuprofen	5-10 mg/kg/dose q 6-8 hours	Drops (40mg/ml)
		Syrup (100mg/5ml)
		Chewable tab (50mg, 100mg)
		Tablets (200mg, 300mg, 400mg, 600mg, 800mg)
Oxycodone	0.2 mg/kg/dose q 3-4 hrs	Solution (5mg/5ml, 20mg/ml)
		Tablets (5mg)
Morphine	0.15-0.3 mg/kg/dose q 4 hrs	Solution (10mg/5ml, 20mg/5ml, 20mg/ml)
		Tablets (10mg, 20mg, 30mg)

Source: Adapted from World Health Organization. *Cancer Pain and Palliative Care in Children.* Geneva: World Health Organization, 1998.

Nausea and Vomiting

Provide frequent sips & small meals. If possible, discontinue offending medications. Provide the patient with antiemetics (Table 12-6).

Table 12-6: Antiemetics for Nausea and Vomiting in Children and Adolescents

Basic antiemetics	Dose	Formulation
Metoclopramide	0.1-0.2 mg/kg/dose q 6 hours	Solution (10mg/ml)
		Syrup (5mg/5ml)
		Tablets (5mg, 10mg)
Prochlorperazine	0.1-0.2 mg/kg/dose q 6 hours	Syrup (5mg/5ml)
		Suppository (2.5mg, 5mg, 25mg)
		Tablets (5mg, 10mg, 25mg)

Source: Adapted from World Health Organization. *Cancer Pain and Palliative Care in Children.* Geneva: World Health Organization, 1998.

Diarrhea and Constipation

Dietary fiber helps control both conditions. Laxatives should be prescribed with opioids to prevent painful constipation. Skin care is very important when diarrhea or incontinence threaten skin integrity. (See Chapter 7: Gastrointestinal Symptoms.)

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Anorexia

Appetite can be stimulated using megestrol acetate (200 to 800mg/day)[2] or corticosteroids. However, parents need reassurance that decreased food intake will not cause death; it is to be expected at the end of life. The body has decreasing nutritional requirements as death approaches. Forcing a child to eat or drink can be uncomfortable at this time, causing choking, abdominal pain, nausea, vomiting, or diarrhea. (See Chapter 5: Constitutional Symptoms.)

Fatigue and Sleep Disturbance

Promote sleep through adequate symptom control, a peaceful and comfortable environment, and orders not to awaken the child unless he or she is taking around-the-clock pain medication. Move as quickly as possible to long-acting agents. Offer quiet activities. Encourage the child to play, walk outdoors, and remain awake during the day to promote sleep at night. Stimulant medication (methylphenidate 0.1-0.5 mg/kg/dose) can be prescribed to promote arousal during the day.[1] (See Chapter 5: Constitutional Symptoms.)

Skin Care

Bathing, moisturizing, and massage all promote skin integrity and prevent skin breakdown. Cushion the child's pressure points and change his or her position frequently to prevent pressure sores. (See Chapter 25: Prevention of Skin Breakdown.)

Dyspnea

Several strategies exist to help relieve the sensation of shortness of breath: humidified air, oxygen, nebulized saline or bronchodilators, opioids (systemic or nebulized), positioning, and assistance with ambulation. (See Chapter 6: Pulmonary Symptoms.)

Anxiety and Depression

The value to a patient of another human presence should not be underestimated. Encourage the patient to use both verbal and non-verbal avenues for expression. Anxiolytics and antidepressants have important roles in relieving these symptoms. Drug interactions are common with protease inhibitors and NNRTIs so the choice of agent will depend on the child's other current medications. Lorazepam (0.02-0.04mg/kg/dose q 4-6 hours)[1] can generally be used concomitantly with protease inhibitors. However, midazolam is contraindicated. (See Chapter 10: Psychiatric Symptoms.)

CARING FOR CHILDREN WITH ADVANCED DISEASE

Prognostication: How Do We Know When the End of Life is Near?

Accurate prognostication requires knowledge about disease trajectory, the range of individual variation, and the potential impact of therapeutic interventions. Although we know that HIV is ultimately a fatal disease, there are wide ranges of severity and survival within the pediatric and adolescent age groups. Declining CD4 counts and clinical complications indicate progressive disease.

In the era prior to HAART, we were able to predict moderately well when a child was approaching the end of life. Children experienced recurrent hospitalizations with new and evolving infections and end organ disease. Their recoveries with each exacerbation never returned them to

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their precomplication baselines; the progression of disease was like a roller coaster ride with an overall downward slope. Now we are learning all over again. If a child is deteriorating, we must ask ourselves whether we have provided the best primary therapy for his or her disease. Changing HAART regimens and assuring 100% adherence continue to make remarkable improvements in children and adolescents who have what would otherwise be end-stage disease.

Children and adolescents are very resilient. They tolerate many therapies better than adults do. They recover more quickly and completely from injury or surgical interventions. They sometimes prove our predictions wrong and recover from complications we predicted would be fatal. On the other hand, children and adolescents sometimes die suddenly, unresponsive to full attempts at resuscitation.

Health professionals sometimes have difficulty acknowledging how poor a patient's prognosis is. We generally err on the side of optimism, thinking that our patients have much longer to live than they actually do. Our need to feel that we have "done everything" and not "given up" is magnified when working with young people who have only begun their lives. Although provider optimism feels hopeful and positive, it must not blind us from the work to be done providing excellent palliative and end of life care.

Role of Antiretroviral Therapy in End-of-Life Care

The role of antiretroviral therapy in palliative and end-of-life care is not clearly defined. The advent of protease inhibitor combination therapies caused the same dramatic clinical improvements in children that were observed in adults with HIV/AIDS. And in younger populations we are seeing the same disappointments when HAART does not achieve complete viral suppression.

However, laboratory values do not tell the whole story. We see immunologic benefit in the apparent absence of virologic control. We see clinical improvement in the absence of immunologic improvement. Clearly these changes translate into improved quality and longevity of life for patients with HIV/AIDS. When highly active combination therapies fail to keep a patient feeling well or cause intolerable pill burden or side effects, they should be discontinued. "Suboptimal" regimens can be considered if they offer some slowing of disease progression without undue burden. These regimens would not be considered if decisions were based solely on medication treatment history and genotypic analysis. But in palliative care, we have permission to look to the patient first and offer care that is helpful, even if it is not "standard" in the traditional sense.

Withholding or Withdrawing Life-Sustaining Therapies

A broad range of invasive, high technology therapies are used in pediatrics to support vital functions while a child recovers from injury, surgery, or treatable illness. Interventions such as artificial ventilation play an important role in supporting children with HIV through treatable crises. However, the use of such therapies should not be automatic, just as they should not be routinely withheld. The likelihood of benefit must be considered and balanced against the risks and burdens of the intervention. This balance will shift over the course of a child's disease trajectory.

The values and beliefs of the child and family regarding life, illness, suffering and death form the foundation for their consideration of our medical information and recommendations. Parents and health care providers alike need to know that they have done everything within their power

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to provide the best life possible for the child in their care. We do not and should not "give up" on children. But we must keep in mind that regardless of our interventions, HIV is ultimately fatal. When life-sustaining therapies become death-prolonging, we can support families in deciding to forgo or withdraw such therapies, knowing such decisions are a means toward their goal of providing the best quality of life possible for their child.

Providing Care: Who and Where?

Most care for children and adolescents occurs in the home. Home is a familiar place of comfort where family members come together to love and care for the child. Current practices in pediatric home care and hospice care are based on this foundation. Home care professionals provide in-home assessment and training, permitting parents and other caregiving adults to provide even highly technical and specialized care outside the hospital setting.

Accessing home care or hospice services is sometimes difficult depending on the child's health insurance and health status. Many insurance plans require patients to be "homebound" to receive home care services. Yet the health care provider's goal of keeping children active and functioning in a developmentally appropriate way may clash with traditional definitions of "homebound." Advocating that services should be rendered and reimbursed based on need and least restrictive setting is consistent with pediatric principles of care.

Unfortunately the AIDS epidemic has disproportionately hit vulnerable families who may not meet this pediatric ideal. Some children live with parents who also have progressive HIV disease, with resulting weakness, confusion, repeated hospitalizations, and early death. There may be serial caregivers both short and long term, causing discontinuity in the child's basic care and medical care. Some children live in substandard housing, some without utilities. However, none of these conditions is a contraindication to home care if there are caring adults willing and available to provide care for the child. Palliative care is generally "low tech" and depends more on "high touch." As long as the child is warm, dry, safe, and comfortable, the other aspects of care can be addressed.

In situations where there is no reliable adult and no safe place to live, we need to look to residential and inpatient alternatives. These are in particularly short supply for children. There are almost no pediatric hospices in the United States. Adult hospices are not prepared to accept pediatric inpatients.

Home hospice services vary in their capacity and readiness to provide child-centered services. At a minimum, they need pediatric training and backup to provide pediatric home hospice care. We should look for opportunities for partnership between community-based hospice services and children's hospitals or other pediatric specialty and tertiary care facilities to build the capacity to care for these children and adolescents.

Health Care Decisions

Collaboration with the Family

Making good decisions depends on the collaboration of the patient, family, and health care providers. Each person brings unique information and perspective to the choices posed at points along the disease trajectory. Identifying these key individuals and preparing them to participate effectively is a critical component of palliative care.

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Health care providers are responsible for gathering relevant information about the patient's clinical status and possible treatment and management options. Providers should be able to present all of the different options that exist and to articulate the following aspects of each option:

- What the patient will have to do
- Implications for the patient's daily routine and level of comfort
- Any restriction of activities
- The "downside" of each option such as side effects, need for procedures or hospitalization
- The alternatives, including "doing nothing"

One way to think about this process is to imagine standing at a fork in the road and considering which pathway to take. What is the destination? Do all paths lead to the same or different destinations? What good or bad things might be encountered along the way? Will the path be smooth and flat or steep and rocky? What if there is an unanticipated problem, e.g., a landslide blocks the way, you get a flat tire, the weather turns cold and wet? Can you turn back? Or is there a point of no return? What is unknown?

Providers must have specific knowledge of treatments for specific problems and be able to answer questions including the following:

- Which medicines can be used to treat this problem?
- What are the dose, route and schedule?
- What are the side effects and interactions?
- Can this problem be treated at home? As an outpatient? As an inpatient?
- How long will the treatment last?
- How likely is it to work?
- How will you know if it worked?
- Will the problem recur?
- What will happen if no medicine is given?

These are considerations for each treatment we offer throughout the course of a patient's disease. Practicing conscious consideration of all the relevant issues from the time of diagnosis lays a strong foundation for open consideration of all issues at advanced stages of disease. Which choices are made may change over time as the patient's disease progresses. (See Table 12-7: Health Care Decisionmaking: Case Example.)

It is critical for the treatment team to discuss all the options and come to consensus prior to presenting information to a patient and family. Hearing conflicting and fragmented information causes distress and confusion for patients and families. As HIV disease progresses, it involves more body systems and therefore more specialists. The burden for organizing the input of multiple specialists and making coherent recommendations falls to the primary health care provider. This burden should not be shouldered by the patient and family.

The process of decisionmaking is collaborative. Health care providers need to grapple with which option they think is the best for this particular patient at this particular time, recognizing that some patients and families will disagree and choose another option, and some families will look

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to the provider for guidance: "what would you do in my situation?" Health care providers are in a powerful position to influence decisions, even unconsciously, by the content of the information they provide and the manner in which it is provided. We must be vigilant to maintain honesty and truthfulness while providing guidance as needed by the patient and family. We should not abdicate our responsibility as the health care experts to provide our best recommendations.

Table 12-7: Health Care Decisionmaking: Case Example

Situation	Mary is a three-year-old with advanced AIDS and her third central line infection. She has candida esophagitis, wasting, diarrhea, neurodevelopmental delay, and cardiomyopathy. Due to previous difficulty with peripheral and central venous access, her line is currently her only venous access for hydration, antibiotics and parenteral nutrition. Her blood pressure is lower than usual and the house staff are preparing to send her to the ICU for pressor support.
What are the options?	1. Transfer to the ICU for full support 2. Maintain current level of care 3. Arrange home hospice care
Analysis	Any of these options might reasonably be considered. Prognosis and parent-provider collaboration are critical. **Option 1** provides the best chance of fighting her presumed sepsis. But it has its own burdens, such as physical transfer to a new unit, disconnection from familiar care personnel, an increased number of invasive procedures, and a risk of complications. The benefit is not guaranteed. **Option 2** allows her to remain in a familiar care environment, but may not effectively treat her underlying infection. **Option 3** provides the opportunity for the child and parents to shift the focus of care to being home together as a family for the precious time she remains living.

Including Children in Decisions

The ethical tenet of autonomy supports the inclusion of even young children in decisions regarding their health care. There is a strong tradition within the field of pediatrics to talk with children of all ages in a developmentally appropriate way about what is happening. Children are often excellent sources of information for how they are feeling and what they can and cannot tolerate. They are better able to cope with treatments and procedures when prepared and supported for these interventions.

The legal age of majority varies from State to State and with the clinical situation. State law may allow minors to seek care for certain conditions, such as sexually transmitted diseases, repro-

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ductive health, prenatal care, substance abuse, and mental health, without parental consent. Some States allow provider discretion regarding notification of a parent about treatment of a minor. Minors cannot consent to experimental treatment or research independently, regardless of their cognitive maturity.

The maturity of a particular child or adolescent helps determine the level at which they can participate in their care planning. Just as with physical and emotional development, the developing ability to understand, ask questions, consider future implications is a continuum, not a yes/no switch. Hence it is unnatural to assume that a 15-year-old has no ability to decide what care is best for her or him, just as it is unnatural to assume that an 18-year-old no longer needs the support of family or friends when considering life-threatening issues.

Disclosure of HIV Diagnosis to Infected Children and Adolescents

It is assumed in our western culture that adult patients with life-threatening conditions have been informed of their diagnosis and treatment options, and offered some prognosis. This is not true for children and adolescents. Well-meaning adults often try to "protect" young people from the truth. They believe that sharing this information will take away the child's hope and will to live. However, decades of experience in the field of pediatrics support the opposite conclusion. Children with cancer diagnoses, the most commonly studied, are better prepared and less anxious if they receive developmentally appropriate information about what is happening to their bodies and why. Providing developmentally appropriate choices and control over interventions improves a child's ability to cooperate and make choices that best enhance his or her quality of life.

Only the patient himself or herself can say what is most important, what hurts, and what helps. This truth holds, regardless of the age of the patient. If we approach all people as unique individuals and communicate in the most effective and appropriate way for them, we will provide better opportunities for all patients to participate meaningfully in their own care.

With young HIV/AIDS patients, anticipating questions early in the disease process allows information to be shared in stages of increasing complexity and detail (see developmental section above). For most children, information about whether they need blood tests, have to stay in the hospital, or how many medicines they have to take, is most critical. These issues can be discussed in great detail without disclosing the name of the diagnosis. As children's cognition advances, more detailed information about what blood tests are or how medicines work becomes appropriate. Ultimately, describing and naming the child's health condition permits him or her to become a partner in care.

The fear of telling is primarily an adult fear. We fear the reaction we might get. We fear the questions we cannot face answering. We fear our own emotional reaction to the disclosure and project that onto the child. We fear that the secret will be shared with others. Disclosure may force us to face the truth when we would rather brush it aside for another day. But children should not be held captive to our fears. Information and inclusion need to be based on the child's interest and ability to be involved. Information should not be withheld, just as it should not be forced.

There are natural opportunities to disclose information to a child. The time of diagnosis is an obvious one. This is the time when health professional and parent are learning the diagnosis. It makes sense that the person who owns the diagnosis should learn about it as well. Because the time of diagnosis can be fraught with so much emotion among the adult family members, it may

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make sense to approach the child in the context of initiating therapy. In this way the diagnosis is discussed in the context of what can be done to control it and at a time when adults have had some time to adjust to the situation.

For children whose diagnosis and initial therapy occurred when they were very young, natural opportunities arise when they ask questions about why they take medicine or go to the doctor's office more often than their friends do. It is critical at these times that adults tell the truth, including partial truths only if that is all that the adult can provide at the time. For example, it is better to say, "You need to ask Dr. Smith about that" than to lie to a child. Children need to know they can trust the adults in their lives, and this need increases as children enter adolescence.

Another natural opportunity to discuss a diagnosis occurs when therapies need to change, especially when they are becoming significantly more complex. Children will naturally be curious about why this change is occurring. It is respectful to answer this question honestly in a developmentally appropriate way. These natural opportunities are far preferable for discussion of an HIV or AIDS diagnosis to times of crisis, such as hospitalization or admission to the ICU, or the onset of sexual activity.

Sometimes providers encounter parents or guardians who refuse to tell their children even as the children enter mid-adolescence. This is clearly beyond the range of "normal" secrecy or protectiveness and requires active intervention by a health care team in order to prevent harm to the adolescent. Awareness of his or her diagnosis is a prerequisite for including the child or adolescent in decisions about his or her care at the end of life.

Including Guardians in Decisions

Guardianship is where many child and adolescent patients are left in limbo. Many have had serial caretakers and the current caretaker may lack a sense of the child's life history and values. The guardianship may not be clear or well documented. The guardian may be a government agency rather than an individual adult with an investment in the well-being of the child.

Providers should take practical steps to determine who should participate in decisionmaking regarding an infected child or adolescent's health care, based upon answers to the following questions:

- How old is the child?
- What is his or her ability to understand the issues at hand?
- With whom does he or she live? Who is the responsible adult? (Is it a parent? Is there a responsible adult at all? Is the role shared, or does it shift around among family members?)
- Is a parent still living. If so, does she or he have parental rights? Has this parent been involved in the child's life?
- Is the adult with whom the child lives a relative? Has that person formally been granted guardianship? The health care provider should ask to have a copy of the court order.
- Is the child in foster care? Living with a family? Long-term? In a group home? Usually a foster parent at best has limited guardianship for purposes of enrolling the child in school and seeking routine medical care. The foster care

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agency or state government may be the legal guardian. A foster parent who has raised a child may be best suited to be the adult proxy decisionmaker for the child. In that case, petitioning the court to bring the legal documents in line with the human relationship may be the best strategy for the child.

- Does the responsible adult with whom the child lives (and/or the guardian) have the competence and capacity to make health care decisions? Many adults with advanced HIV disease experience complications that diminish their capacity, such as dementia (memory loss, confusion). Many children have been raised by grandparents or other senior family members. These seniors may now be facing their own health concerns, which may include dementia.

Supportive Care for Children Affected by HIV/AIDS

AIDS is a family disease. More than any other, this disease tears at the very fabric of vulnerable families, causing illness and death within and across generations in the same family. All family members, whether infected with HIV or not, are deeply *affected* by the illness and loss of others. Grandparents may continue to care for surviving grandchildren with evolving social and emotional needs, even while they are themselves aging and encountering personal health problems. As the elder caregiving generation dies, the children left behind experience another wave of losses. (See Chapter 16: Grief and Bereavement and Chapter 20: Care for the Caregiver.)

One of the most heart-wrenching situations is a dying mother who cannot ensure that her surviving children will be safe, loved, and cared for. Permanency planning is a crucial but emotionally difficult responsibility for parents with life-limiting conditions. Care providers should encourage and support parents to honestly consider the possibility that they may become disabled or die. There are concrete steps that parents can take to plan for their children's futures. Standby guardianship (see Chapter 18: Legal and Financial Issues) was created in response to the AIDS epidemic to enable HIV-infected parents to identify another trusted adult to care for minor children in the event of temporary or permanent disability or at the time of death. For parents living in States with these statutes, this process facilitates seamless transition of legal authority to care for children at a time of crisis. When planning has not been done, children may be placed in foster care. Siblings may be separated. Placements may change repeatedly. These additional losses can be catastrophic for children who have just lost a parent.

Legacy building can occur when families acknowledge the possibility that life will be shortened. Parents can write letters or leave videotapes for their young children to read and view when they are older. Hand molds can be made, regardless of the age of the dying patient, becoming keepsakes for those who survive him or her. Photographs, artwork and poetry can be part of a rich cache of memories. Creating these legacies can be directly beneficial for the person who is dying and are enormously valuable to those whom he or she leaves behind.

Communication

Clear and effective communication is a mandatory component of palliative care. It is so integral to excellent care that commenting on it seems to state the obvious. Yet most of the preventable distress and anger on the part of patients, families, and care providers can be traced to ineffective or nonexistent communication. (See Chapter 21: Patient-Clinician Communication.)

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Communication among care providers must be accurate, timely, and respectful of the interdisciplinary nature of the care we provide. Challenges to effective interprofessional communication can include the following:

- Different care venues
- Different work schedules
- Different views of a patient's health status
- Different views of the options for treatment and care
- Different levels of skill in communication
- A lack of unified or continuous information systems

The benefits of effective team communication among providers include the following:

- Greater efficiency
- Greater satisfaction
- Reduced errors
- More complete assessment of the patient
- More coordinated treatment
- Improved discharge planning

Important communication occurs within family units. In optimal situations, these roles and relationships among family members are clear and supportive of providing the best care for the child patient. Unfortunately, there are families in which relationships are rancorous, sometimes erupting into arguments at the child's bedside. In other families, the breadth and depth of family communication and involvement may be almost invisible to the care team. Asking openly about a family's communication, and supporting ongoing communication within families, will facilitate the best assessment and plan for care for all concerned.

Communication with the child patient is discussed earlier in this chapter but needs reiteration. The child *is* the patient and deserves to be the center of attention. Asking questions, sharing information, and supporting the child's inclusion and involvement in decisionmaking can and should be tailored to the child's developmental and physical capacity as discussed above. Communication between the health care team and the child-family team then has the best chance for success.

Impact on Pediatric Health Care Providers

This chapter is not complete without acknowledging the deep commitment of pediatric health care professionals to promoting the best care for children and adolescents infected and affected by HIV/AIDS. This work is as deeply rewarding as it is remarkably difficult. If we are to provide the best palliative and end of life care, we must know and understand the paradoxical world in which we work.

Death remains the exception in the practice of pediatrics. Just as it is unnatural for children to predecease their patients, so it is unnatural for our child patients to die. Although efforts are now increasing, providers receive little training in how to care for children and families who are dying. This often leaves us feeling incompetent to provide the expert care we know our patients deserve.

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HAART has complicated this emotional dynamic enormously. We have seen dramatic clinical improvements in children with end stage disease who begin HAART therapy. We also see children and families who simply cannot successfully adhere to these complicated regimens. How far should we go to assure that young patients have had the best available treatment to keep them healthy? Do we recommend, or insist on, the placement of gastrostomy tubes for medication administration? Do we recommend, or insist on, a child being removed from a mother's care because her failure to assure medication adherence is medical neglect? How do our answers change depending on where the child is on his or her disease and treatment trajectory? When is enough enough, despite sub-optimal social circumstances? How can we as health care providers feel we have "done everything" we should to control our patient's HIV, and still have the time and wherewithal to provide palliative and end-of-life care? We must continue to engage in this struggle to define a path to walk with our patients and their families.

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