

CHAPTER 18

SUPPORTIVE CARE ISSUES FOR CHILDREN WITH HIV INFECTION

I. INTRODUCTION

RECOMMENDATIONS:

For HIV-infected children, psychosocial issues and HIV-related medical complications should be recognized and addressed as critically important factors to the patients' quality of life.

Collaboration among many providers, including physicians, oral health providers, nurses, physical therapists, social workers, psychologists, child life specialists, and nutritionists as well as members of different religious communities, should be directed to the achievement of the patients' quality of life.

In this chapter, we consider both the recognition of and interventions related to quality-of-life issues of HIV-infected children. With the advances and the benefits of new medical treatments of HIV infection, issues related to quality of life for HIV-infected children must be recognized as critically important. Fortunately, the life expectancy of HIV-infected children has increased. This has resulted in a group of children with psychosocial issues related to a chronic disease as well as issues related specifically to HIV infection. Among these issues are disclosure of the diagnosis to a child, the perceived stigma of the infection, and the illness in other family members. Such issues are particularly difficult in children infected perinatally who are reaching adolescence. New medical treatments require multiple dosing and have potential side effects that can interfere with a child's daily routine, especially school attendance. HIV-related complications can result in physical discomfort requiring pain management. In children with end-stage disease, all efforts must be made to provide adequate palliative care. Discussions with children and their families regarding both medical and quality-of-life issues may occur during patient visits and hospitalizations or in the setting of support groups.

II. MEDICAL ISSUES

A. Nutrition

RECOMMENDATIONS:

In assessing a patient's nutritional status and needs, the first step should be to accurately weigh, measure, and plot the patient on the standard growth charts. The next step should be to calculate whether a patient is consuming adequate calories, protein, vitamins, and minerals.

The ideal body weight in kilograms and not the actual weight should be used for calculation of the caloric needs for an HIV-infected child.

The growth velocity should be monitored regularly to adjust each patient's needs.

When oral intake is inadequate in HIV-infected patients with normal gastrointestinal function, feeding at night while maintaining oral intake during the day should be considered to provide supplemental calories.

Since artificial feeding is a medical intervention, legal issues as well as the patient's or family's desires should be considered before stopping artificial feeding.

Adequate nutrition is essential to the general well-being of an individual (see Table 1). Inadequate nutrition can have severe consequences and lead to wasting syndrome in individuals, especially growing children, with HIV infection. Malnutrition itself, apart from HIV disease, can adversely affect the immune system and, therefore, the host response to infection.¹ Malnutrition in the setting of HIV infection may lead to more severe and frequent opportunistic infections. Although maintaining an optimal level of nutrition remains an important goal in the care of children with HIV infection, maintaining an acceptable level of quality of life while providing adequate nutrition needs to be considered.

TABLE 1
RECOMMENDED DIETARY ALLOWANCES⁴

Category	Age (years)	Weight (kg)	Calories/kg	Protein (g)/kg
Infants	0-0.5	6	108	2.2
	0.5-1.0	9	98	1.6
Children	1-3	13	102	1.2
	4-6	20	90	1.1
	7-10	28	70	1.0

Failure to thrive in patients with HIV infection can result from increased metabolic needs related to HIV infection and intercurrent infections. Grunfeld et al. showed a correlation between HIV progression of disease and resting energy expenditure.² Other factors that contribute to malnutrition include poor dentition, oral ulcers, oropharyngeal thrush, and *Candida* esophagitis, all of which can cause decreased intake due to discomfort in chewing and swallowing. In addition, medications such as antiretroviral agents, including protease inhibitors, can cause anorexia, taste alterations, nausea, vomiting, and diarrhea, which further decreases nutritional intake. Malabsorption is a common manifestation of HIV infection. Yolken et al. in a prospective study³ showed that 53% of HIV-infected children had some form of gastrointestinal dysfunction or malabsorption that could lead to micronutrient deficiencies such as zinc and iron deficiency, which could cause taste alterations⁴ leading to further decreases in oral intake.

Studies in patients with HIV infection have demonstrated severe progressive weight loss in which both body cell mass and body fat are decreased. However, the percentage of muscle loss was much greater than fat loss.^{2,5} Unlike weight loss due to starvation in which fat stores are depleted first, this pattern of muscle weight loss mimics the pattern associated with surgery, trauma, or sepsis. It has been shown in children with HIV infection that their triceps skinfold measurements are within normal ranges, but their mid-arm muscle circumferences are below the normal ranges for a given age. In addition, upon refeeding these children with adequate calories for catch-up growth, they do appear to gain weight but not height.⁶ Miller et al. found that HIV-infected children had less muscle mass than children who seroreverted.⁷ His findings suggested that factors associated with a decline in weight gain in the HIV-infected children might promote preferential muscle wasting over depletion of fat stores. In addition, he found that abnormal oral intake does not account for the weight loss seen.

Growth failure itself may be a subtle prognostic indicator for the progression to AIDS. Brettler et al. observed that growth retardation preceded the onset of AIDS.⁸ In a prospective study, they showed that when weight (see Table 2) or height-for-age had fallen by greater than 15 percentile points on two repeated measurements, it was predictive of symptomatic disease. In addition, these growth abnormalities were preceded by a significant drop in CD4 cell count, another prognostic indicator of progression of disease. In a group of 59 HIV-infected children, the linear growth of children with advanced HIV disease was shown to be more affected than weight gain.⁹ These and other studies suggest that aggressive nutritional support should be instituted

before growth failure is apparent since this is when the benefits of optimal nutrition support are likely to be the most effective.

TABLE 2
EXPECTED NORMAL WEIGHT GAIN IN CHILDREN¹⁰

Age	Weight Gain
• 0-3 months	25-35 g/day
• 3-6 months	15-21 g/day
• 6-12 months	10-13 g/day
• 1-6 years	5-8 g/day
• 7-10 years	5-11 g/day

In patients with normal gastrointestinal function, there are many ways, such as nutrient-dense meals, snacks, and milk shakes or dietary supplements in between meals, to provide increased calories. Although the use of appetite stimulants can be considered in HIV-infected individuals, our experience has been that stimulants have limited success. Enteral feedings via nasogastric tube for short-term use or a gastrostomy tube for longer-term use can be considered. Feeding at night while maintaining oral intake during the day should be considered to provide supplemental calories if the oral intake is inadequate. Although bolus enteral feedings during the day are a consideration, their effect on the quality of life needs to be considered. For patients with malabsorption, elemental formulas are available. Parenteral nutrition has been used in adults and children and may be appropriate when the gastrointestinal tract is not functioning normally or if sufficient nutrition cannot be delivered enterally. However, many factors, such as the risk of infection, metabolic imbalances, bypassing the gastrointestinal tract, total parenteral nutrition, cholestasis, and cost, need to be considered. The goal of therapy, benefits, and potential burden should be considered. For example, in a situation in which there is an acute process preventing adequate enteral nutrition, such as pancreatitis, the purpose of parenteral nutrition is to preserve the nutritional status until the patient recovers. In situations in which the patient has end-stage disease without hope of recovery, parenteral therapy may prolong a patient's life causing unnecessary anguish and pain.¹¹ Since artificial feeding is a medical therapy, legal issues as well as the patient's or family's desires must be considered before stopping artificial feeding. In end-stage HIV disease, palliative care may be more important. Bioethical decisions are very complex and should be made as a team in conjunction with an ethicist. This may remove any burden of guilt from withdrawing nutritional support.

B. Pain Management

RECOMMENDATIONS:

Pain management (i.e., recognizing pain, assessing the severity of pain, and developing goals for managing pain in the context of pediatric HIV infection) should be part of the skills of all HIV care providers, but when necessary, there should be consultation with pain management specialists.

In assessments, the characteristics of pain (e.g., intensity, quality, and distribution) should be defined and also triggering factors (e.g., a child's developmental level, a parent's understanding of the child's pain, and the potential for parental guilt and blame) should be taken into consideration.

Children and families should be educated to communicate about pain.

There are many causes of pain in HIV-infected children (see Table 3).¹² Pain can be disease-related, diagnostic intervention-related, or treatment-related. Thus, it is important to recognize the presence of pain, to recognize the underlying cause, and to institute appropriate therapeutic interventions.

Undertreatment of pain in pediatric HIV infection can result from a specific focus on prolonging life (i.e., controlling HIV and treating associated complications rather than alleviating pain and suffering). Health care providers of HIV-infected children may not necessarily be trained in pain management or in the use of analgesics. Furthermore, there is often difficulty in assessing pain in children in general. Families may be resistant to the use of narcotics in their children. Thus, it is important to recognize pain, assess the severity of pain, and develop goals for managing pain in the context of pediatric HIV infection.

In the assessment of pain, it is important to define its characteristics (i.e., the intensity, quality, distribution, and factors that trigger it). Factors that need to be taken into consideration include a child's developmental level, a parent's understanding of the child's pain, and the potential for parental guilt and blame. Children and families need to be educated to communicate about pain. The goals of pain management include the reduction in the incidence and severity of acute and chronic pain by providing adequate pharmacologic pain control with minimal side effects as well as the use of psychological methods.

TABLE 3 POTENTIAL CAUSES OF PAIN IN HIV-INFECTED CHILDREN	
Pain related to diseases of the oral cavity	Oropharyngeal candidiasis, dental caries, gingivitis, aphthous ulcers, and herpetic stomatitis
Pain related to infections of the esophagus	<i>Candida</i> , cytomegalovirus, herpes simplex, and mycobacterial esophagitis
Pain related to diseases of the abdomen	Infectious gastroenteritis due to bacteria, parasites, viruses, fungal agents, pancreatitis, hepatitis, and, more rarely, gastrointestinal lymphoma
Pain related to neuromuscular disorders	Hypertonicity and spasticity, peripheral neuropathies, headache, myelopathy, myopathy, herpes zoster, and post-herpetic neuralgia
Pain related to diagnostic and therapeutic interventions	Venipunctures, tuberculin skin testing, lumbar punctures, bone marrow aspirates, skin biopsies, immunizations, intravenous infusions, and nasogastric tube insertions
Pain related to side effects of therapies with antiretroviral agents and prophylactic antibiotics	Pancreatitis, renal stones, myopathy, and headache

III. DEVELOPMENT OF CHILDREN'S CONCEPTS OF HEALTH, ILLNESS, AND DEATH

RECOMMENDATION:

The child's developmental level should be assessed to identify ways to help the child understand and accept the implications of illness and possible or inevitable death.

Child development is a continuum. A child with a chronic illness may regress developmentally. Thus, developmental age may be different from chronological age.

A basic understanding of children's developmental stages regarding issues of health, illness, and death as well as spirituality and religious beliefs is important before discussing the psychosocial issues for HIV-infected children.

A child's developmental stage affects perception of body, illness, and death (see Table 4). Parents may have justifiable concerns that discussing these issues will increase a child's fears. However, giving a child developmentally appropriate opportunities to be knowledgeable about his or her condition does not necessarily heighten death anxiety. Allowing a child to discuss different aspects of an illness may decrease feelings of isolation, alienation, and the sense that the illness is too terrible to discuss completely.¹³ Despite great odds, many children can conquer disabilities and participate in the process of dying.¹⁴⁻¹⁷

TABLE 4
DEVELOPMENTAL STAGES OF CHILDREN'S PERCEPTION OF
THEIR BODIES, HEALTH, ILLNESS, AND DEATH^{15,17}

- **Early Childhood (2-6 years of age):** The child defines health, illness, and death in relation to his or her own experiences as well as the ability to participate in peer group activities. External body activities are identified, although internal functioning is less clear. Stress is reduced by considering the child's immediate sensations, experiences, and feelings. Illness is perceived as something that is "caught." "Magical thinking" may persist, and illness or death may be perceived as a punishment (e.g., a death wish or anger produces death). The child can follow health and safety rules. The child has fears related to his or her own health and safety. Children under 5 years of age do not always see death as irreversible but more as an altered life state in which many normal daily functions are maintained (e.g., sleeping, breathing, and feeling). Death is defined in terms of structure; death is real; there is separation; the deceased person is immobile.
- **Middle Childhood (7-10 years of age):** The child has a better understanding of causal relationships. There is a curiosity and excitement about learning. The child is exposed to ideas and events outside his or her family. Anxiety develops about how external events may affect his or her own life. Awareness increases in regard to how people are different. Personal privacy becomes important to the child. Death becomes specific and concrete; there are both internal causes (e.g., old age) and external causes (e.g., gunshot wound). Death can become personified (e.g., cartoons and fairy tales) and can be seen as punishment for bad behavior. This personification is based on cultural and religious beliefs. Death produces dysfunction and is irreversible.
- **Late Childhood (10 years of age to preadolescence):** The child better conceptualizes processes occurring in the body. Health is influenced by culture, religious beliefs, and personal experiences. The peer group has a strong influence on behavior and decision-making. The concept of ambiguity is better tolerated and reinforces decision-making and assertion skills. Independence from the family increases as the child affiliates with peers and non-family adults. Exposure to sexual activity or illicit drug use occurs. Awareness of serious illness of family members, other adults, or peers occurs. Secondary sexual characteristics may begin during this phase. Death, perceived as it was in middle childhood, is influenced by the child's personal experiences with death and dying. There is recognition that death happens according to certain rules; ideas of universality and permanence are acquired (e.g., the body wears out as does an old car and is no longer able to run).
- **Preadolescence/Adolescence:** The child's peer group becomes a strong influence on behavior and decision-making. Physical changes occur, and how the child compares to peers becomes a matter of great concern. Self-consciousness may be increased in children with chronic illnesses. Increased sexual activity and illicit drug use may occur. There is increased emotional lability. Thought and speculation about death become more abstract. At this stage of development, children may have thoughts of indestructibility and immortality. This form of denial may contribute to exacerbations of the illness and issues of nonadherence with treatments. The art is to acknowledge and accept the adolescent's view of reality while at the same time asserting an adult's view of reality.¹⁸

Children have spiritual lives that are more often social and cultural and that can be different from their religious beliefs. Children, even very young children, have spiritual lives of considerable breadth and depth that shape their understandings of the meanings of their terminal illnesses and pending deaths.¹⁹ The resilience of children's spirituality is apparent from the work with children with chronic conditions. Spirituality is important to the inner life of the child. Spirituality often, but not always, involves beliefs in God or a supreme being.^{19,20}

IV. PSYCHOSOCIAL ISSUES

A. Related to HIV Disease and Treatment

1. Disclosure of Diagnosis to Infected Children²¹

RECOMMENDATION:

Health care professionals should discuss issues regarding disclosure of HIV diagnosis over time, taking into consideration age-appropriate steps in order to enlist the support of the guardians who are searching for ways to tell children about the children's HIV infection.

Whether and when to tell a child about his or her HIV diagnosis are ongoing issues debated among health care professionals along with parents and/or guardians. Some believe that disclosure will help children understand the illness when information is given in an age-appropriate manner. A preschool-aged child may be satisfied to know that he or she has a germ in the blood that the medications help to control. More details can be given as a child matures and has a greater understanding of cause and effect. Providing an explanation can help to enlist a child's adherence in taking medications and make the need for blood tests easier to understand. Others, however, believe that disclosure will cause emotional suffering and ostracism from the community since many adults fear that children will not be able to keep their diagnosis a secret from their relatives, schoolmates, and friends. Biological parents may have guilt about their responsibility in their child's illness, whereas foster and adoptive parents may experience guilt about withholding medical information from their children. Often children know that something is wrong that is a secret and should not be discussed.

2. Adherence to Therapy

RECOMMENDATIONS:

Given the potential for the development of resistant virus due to non-adherence, antiretroviral medication adherence should be an indispensable component of the treatment plan undertaken with the HIV-infected child and his or her family.

Clinicians should be familiar with side effects, adverse reactions, and unpleasant qualities of antiretroviral medications being prescribed and should make parents and children aware of this information before commencing a treatment plan.

Clinicians should foster a collaborative relationship with a family as one of the best strategies for fostering adherence.

To encourage adherence, clinicians should provide child and family with visual aids and educational materials (e.g., written daily schedule) illustrating both doses and times.

A clinician prescribing a complicated antiretroviral medication plan should be available for ongoing support and education (e.g., encouragement, positive feedback when indicated, and telephone support) and should advise the family to phone if there are any missed doses and/or problems administering and/or tolerating medications.

Clinicians should not make assumptions about a family's understanding of their child's medications but should demonstrate use of syringe, pillbox, medicine cup, and/or any other tool to be given and should ask for a return demonstration, including restatement of the name, purpose, dose, and time of each of the child's antiretroviral medications to assess the family's comprehension of the instructions.

Clinicians should communicate that increases in CD4 T-lymphocyte counts and decreases in viral load are important measures of success for an HIV-infected child and family, and clinicians should discuss the function of the immune system, the impact of HIV, and the benefit of antiretroviral medications. Such explanations should be age-appropriate and tailored to a child's knowledge of his or her diagnosis.

Clinicians should utilize the support of other professionals, such as child life specialists, visiting nurses, social workers, and pharmacists.

Advances in the understanding of HIV pathogenesis have resulted in the use of combination antiretroviral drug treatments as the standard of care. Clinicians have recognized the importance of dual and triple-drug medication regimens to decrease morbidity and prolong survival. It is not uncommon for patients with HIV infection, including those with clinically asymptomatic disease, to require 5 different medications per day with complicated dosing schedules. Difficult for adults, such regimens have become even more difficult for children who may need to take medications that are not available in pediatric formulations and/or have poor palatability.

Antiretroviral medication adherence in the HIV-infected child and family is a complex and challenging issue. However, addressing this issue is an indispensable component of the treatment plan, given the potential for the development of resistant virus due to non-adherence, and clinicians should remember that if an unexpected side effect does occur, it is possible that a family will stop the medication without first consulting the clinician.

Clinicians should utilize the support of other professionals, such as child life specialists, visiting nurses, social workers, and pharmacists. Pharmacists, especially, are an integral part of the health care team and serve as an important resource on antiretroviral medications, including potential drug interactions seen with many of the antiretroviral medications. They also have access to information on new medications, doses, and indications for usage. The pharmacist can counsel a parent and child about medications, side effects, and interactions and can reinforce the prescriber's instructions prior to dispensing the medication. The pharmacist also has access to educational materials in foreign languages for non-English-speaking families.

3. Child Life Specialist Intervention

RECOMMENDATION:

Care of HIV-infected children should be recognized as most effectively delivered by programs that have established multi-disciplinary teams that include a childlife specialist specifically for HIV-infected children as an additional resource.

A child life specialist (CLS) provides the multi-disciplinary pediatric team with a unique knowledge of a child's developmental needs. Thus, a CLS can implement interventions that assist children in achieving mastery of coping skills regarding the medical experience.

In the home environment, a CLS aids families by assisting parents in identifying positive parenting skills and developing effective communication skills. A CLS helps a child learn healthy self-expression in order to communicate more effectively with his/her family, peers, teachers, and medical care providers.

A CLS supports an atmosphere of learning during outpatient medical visits by providing a safe environment for children to play, engage with peers, and explore questions and feelings regarding their experiences in a safe environment. A CLS can provide continuity of care by visiting children in an inpatient unit and preparing them for experiences, such as IV insertion, operations, or tests. With proper preparation and an opportunity to learn about the hospital environment, children experience less anxiety and are more cooperative and adherent. The inpatient playroom created by the CLS is a designated area where children are encouraged to play and interact with peers while engaging in safe, supervised activities that allow for self-expression, exploration, and learning. While interacting in the play area, children learn skills that can be carried over into other arenas in life (i.e., interpersonal interaction and problem-solving skills). See Appendix 18-A for specific areas in which a CLS may play an important role in collaboration with the multi-disciplinary team.

B. Related to Normal Childhood Activities

Most HIV-infected children who were infected at birth will attend school. Furthermore, many such children will be entering adolescence and, therefore, will be facing the many challenges associated with this stage of growth. With the increase in life expectancy and advances in treatment, these children will face situations that are far from the normal childhood experiences. It is, therefore, vital to try to make their lives as normal as possible.

1. School Attendance

School attendance is an extremely important part of any child's life. Education provides a child with a foundation that is needed throughout life as well as an opportunity for social interaction, which are both vital for any child. With the advances in medical treatments, the potential for an HIV-infected child to live to adulthood is becoming more of a reality. Thus, it is essential that these children be prepared for their lives as young adults. While some of these children experience developmental and learning disabilities, education can help build the self-esteem needed to face the challenges of living with HIV infection. Education can also prepare these children to make important choices such as attending to their own medical care as they reach adulthood.

2. Extracurricular Activities

Extracurricular activities, such as sports, scouting, school clubs, and associations, help a child become a well-rounded, confident adult. This is even more important to a child living with a chronic illness. Such activities provide a child with opportunities for normal social interaction in the context of normal childhood experiences. Through participation in extracurricular activities, an HIV-infected child can divert his or her attention from the routine of receiving medical care.

3. Summer Camp

Summer camp programs are available for children with HIV infection. These programs can provide the opportunity for children to meet with other children who experience many of the same problems. Programs allow the children to know that they are not alone and can eliminate the feelings of isolation felt by so many children living with HIV infection.

C. Uninfected Siblings of HIV-Infected Children

RECOMMENDATIONS:

Health care professionals should discuss with the parents the potential developmental and psychological issues that may be experienced by uninfected siblings of HIV-infected children.

Health care professionals should provide uninfected siblings of HIV-infected children with age-appropriate information about HIV disease to prepare the siblings for such issues as bereavement and permanency planning and should when indicated refer uninfected siblings of HIV-infected children for individual and group treatment.

An HIV diagnosis in a family member presents issues not seen in other chronic or life-threatening illnesses, including the perception of the stigma of the disease, issues regarding the illness in parents, other family members or friends, and issues of death and bereavement. Thus, it is important for health care professionals to be mindful of uninfected siblings of HIV-infected children. Uninfected siblings may be HIV-exposed seroreverters, whereas others may have been born before maternal infection; both are at risk for developmental and psychological problems. Uninfected children may have been exposed to other infections such as hepatitis B and C, syphilis, cytomegalovirus, or toxoplasmosis as well as to illegal drugs and alcohol.

Siblings can feel neglected and/or abandoned since the caretakers spend much time accompanying the infected child to medical appointments and attempting to protect the infected child from situations they perceive as dangerous. Siblings may be jealous of their infected siblings; they may also feel guilty that they are not infected. Siblings may react with anger, acting out to gain attention, have lowered self-esteem, withdraw from family and friends, or wish to become ill to receive the attention that is directed to their infected siblings.

V. COMMONLY ENCOUNTERED ADHERENCE PROBLEMS

Commonly encountered adherence issues include reports by parents of children not taking medications, of children disliking the taste of and refusing to take medications, of children becoming nauseous and vomiting after taking medications, of children adhering to their medication treatment plans even as their clinical and immunological status is deteriorating; anxiety on the part of parents that the antiretroviral medications will harm the child; limitations (i.e., medical and/or psychological/cognitive) on the parent required to administer a complicated medical regimen at home; and confusion experienced by the parent about which medications are being given due to multiple names for medications. Appendix 18-B elaborates on the most commonly encountered adherence problems summarized in Table 5.

TABLE 5
SUMMARY OF MOST COMMONLY ENCOUNTERED ADHERENCE PROBLEMS

Problem	Intervention(s)
A parental report of the child not taking his/her medications.	• Obtain a detailed history aimed at identification of the specific causes of this broad complaint. • Conduct an interview incorporating the “what, who, when, why, where, and how” interviewing approach described in Appendix 18-B. • Make available information in the primary caretaker’s language.
A parental report of the child disliking the taste of and refusing to take his/her medicine.	• Offer the child choices when possible on how to take medications (i.e., with juice or water; in a syringe or a medicine cup). • Consult with a pharmacist to discern if alternate dosage forms may be made available through compounding. • Switch to pill formulations if possible.
A parental report of the child becoming nauseous and vomiting after taking medications.	• Administer medications with food if not contraindicated. • Administer medications with 8 ounces of liquid to help reduce gastric irritation. • Request assistance from the school nurse if nausea and vomiting primarily occur in the morning before school. This may only be done with the family’s permission.
A parental report of adherence in the face of a deteriorating clinical and immunological status in the child.	• Obtain refill history from primary pharmacy. • Request home delivery of medications to ensure refills are being ordered on schedule. • Utilize visiting nurse services to assist with adherence assessments. • Utilize directly observed antiretroviral therapy (i.e., shift nursing).
Parental anxiety that the antiretroviral medications will harm the child.	• Provide in-depth counseling and education on HIV disease, the immune system, and impact of antiretroviral medications. • Explore the family’s fears regarding treatment. Discuss these concerns in a non-judgmental manner. • Collaborate with the family when making treatment decisions. Active participation in treatment choices helps decrease anxiety and facilitate self-efficacy. • Refer to a support group for HIV-infected parents to provide a forum for discussion of anxiety. Peer support often proves to be most valuable in these situations.
A parent with cognitive/psychological limitations is the primary caretaker administering the medications.	• Utilize visiting nurse services. A home health aide would also provide substantial assistance to the family. • Provide the parent and child with tools to support adherence such as pillboxes and medication alarms. • Utilize color-coded bottles with a matched color-coded calendar.
A parent becomes confused about which medications are being given due to multiple names for medications.	• Provide parent with a written schedule of all medications. This illustration should include both brand and generic names and some description of the medications. • Request for the primary pharmacy to deliver medications to the clinic at the time of the patient’s clinic visit. This will provide a forum to answer any questions and assess the family’s understanding of instructions.

VI. PALLIATIVE CARE

Palliative care presents contradictions and challenges to pediatric practice. The World Health Organization defines palliative care as “care for patients that is focused on the physical, social, and spiritual needs of the patient.” The futility of aggressive treatment for a terminal illness requires a shift toward palliative intent where the goal becomes achieving the best quality of life for patients and their families. However, since remarkable variation exists in defining when a child in care is in transition to a palliative intent, the importance of palliative care should be recognized from the initial diagnosis and continue throughout all phases of the illness, allowing for preventive, pro-active interventions as well as for facilitation of subsequent decision-making. The family is a vital resource to help the child face the potential of death with understanding and dignity. Support continues with bereavement counseling for the family and health care providers.²²

A. Palliative Care and Pediatrics: Uniting Paradigms

RECOMMENDATIONS:

Liaisons with professionals experienced in palliative care should be considered essential for the provision of consistent high-quality palliative care for children.

Collaborative decision-making facilitated by open and honest communication among the parents, the child, and the health care team should be used for identifying when palliation is appropriate.

Although the need for palliative care is widely recognized for adults with terminal illnesses, it is rarely the case that its need is recognized for children. The National Hospice Organization reported that of the children who die each year in the United States, only 0.05% receive hospice services. Estimates indicate that approximately 17,000 children per year could benefit from palliative services.²³ Thus, there is a critical need to define and practice standards of supportive care. Issues of supportive care include pain management, nutrition, child and family psychosocial services as well as spiritual support.^{24,25} Comprehensive medical case management along with community-based health services can provide the necessary continuity. Since providing consistent high-quality care for a relatively uncommon problem is difficult, a liaison with professionals experienced in palliative care is essential.²⁶

Identifying when palliation is appropriate remains a vexing problem. Pediatric health care professionals (i.e., physicians, nurses, social workers, psychologists, child life specialists, and nutritionists) may have different perceptions of a child’s need for palliative care.²⁷ Inconsistency and confusing messages from the health care team can interfere with the goals and specific interventions in the care of the terminally ill child. Collaborative decision-making is facilitated by open and honest communication among the parents, the child, and the health care team.^{27,28}

B. Children’s Understanding of Death and Dying

RECOMMENDATION:

Providers should understand the child’s psychological perception of illness and death in formulating the most meaningful and helpful interventions (or non-interventions) in managing illness and death.

It is preferable that providers respond to a child’s understanding of death and other complex subjects rather than to allow “magical thinking” and unspoken fears to trouble a child’s imagination. Responding can alleviate concerns, calm fears, and correct misinformation. Children with serious illnesses do not always need answers; they may only need comforting.²⁹

The spiritual well-being of the child should be recognized by all professionals caring for HIV-infected children and families. Children have a basic need to feel loved, accepted, and secure. For a child dying from complications of AIDS, who may feel more disenfranchised

than if he/she were dying of another serious illness, making an acknowledgment of spirituality is vital to alleviate fear and anxiety.

C. Parents/caregivers, Siblings, Professionals, and the Dying Child

RECOMMENDATIONS:

Effective communication of information should be stressed between health care professionals and parents.

Professionals should identify their patients' needs in collaboration with the patients' parents.

Communicating information effectively is important for parents and health care professionals. Parents want information conveyed in understandable terms to allow them to participate in decision-making and to give truly informed consent.^{30,31} Professionals must identify their patients' needs in collaboration with the patients' parents.³² This collaborative approach is exemplified in the acronym LEARN³³:

L- Listen with sympathy and understanding to the family's perception of the problem

E- Explain your perception of the problem

A- Acknowledge and discuss the differences and similarities

R- Recommend treatment

N- Negotiate agreement

Parents need to recognize that the child is special while maintaining as much normality within the family's life as possible and retaining the responsibility of parenting their dying child.³⁴

In the palliative paradigm, health care professionals need to find a balance between being supportive and being separate to allow them to perform their functions and not be viewed as "one of the family."³⁵ Health care professionals should begin by examining their thoughts about death and bereavement, their desire to care for others, and the consternation of a child's death.^{36,37} Thus, it is important that health care professionals avoid directive and disempowering relationships that may erode family boundaries and the integrity of the family unit (as well as avoid judgmental attitudes toward a grieving family).³⁰

D. Care of the Dying Child and the Family Home and Hospital

RECOMMENDATION:

Health care professionals and families need not only recognize but also enlist a child's perspective in devising an optimal palliative care plan including advanced directives and will of the child if possible.³⁸⁻⁴⁰

The obstacles to humane terminal care are complicated by the families and their psychosocial environments. The goal should be to maintain the child's comfort and quality of life. There should be discussion and strategies to allow the family to remain in control during crises.

Careful planning and coordination of care with continuous and, ideally, around-the-clock care should concentrate on the issues listed in Table 6.

TABLE 6
PLANNING AND COORDINATION OF CARE ISSUES

- Pain management and non-pharmacologic interventions to assure comfort.^{22,41-44}
- Nutritional support that does not interfere with quality of life.⁴⁵
- Respiratory care (i.e., chest physiotherapy; positioning; oxygen; medications, such as cough suppressants, bronchodilators, and opioids; suction equipment).
- Management of conditions such as convulsions, agitation, cognitive changes, and bleeding.
- Easy access to the hospital.
- Clear communication with hospital staff on palliative care plan.
- Pronouncement of death at home or the hospital, registration of death, and funeral arrangements.
- Discussion about an autopsy, ideally before the child's death.
- Bereavement support for the family and health care team.

The contradictions and challenges surrounding pediatric palliative care are evident and especially true for AIDS. Palliative care needs to be on a continuum.⁴⁶ In the care of a terminally ill child, the goals become to live for the moment and to appreciate each day. Health care professionals offer support and teaching and assist the family through their knowledge, experience, and skills.⁴⁷ This approach unites everyone in caring for the child with a terminal illness and maintaining a commitment to the quality of a child's life in the circle of care.

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APPENDIX 18-A

SPECIFIC AREAS IN WHICH A CHILD LIFE SPECIALIST MAY PLAY AN IMPORTANT ROLE IN COLLABORATION WITH THE MULTI-DISCIPLINARY TEAM

- **Supplemental psychosocial evaluation of children and families**

A CLS can evaluate a family's needs regarding the psychosocial issues, including disclosure of HIV infection, which can be as great as the medical issues of HIV infection. HIV infection often affects several family members and, thus, has devastating effects on the development of both infected and uninfected children. Uninfected siblings of HIV-infected children could benefit from therapeutic play to address their unrecognized needs such as the stress of seeing their siblings and parents become ill and die.

- **Developmental Observations**

Developmental delays can be more easily identified when a child is engaged in free play with peers. Since all CLSs are trained to identify general developmental milestones, they assist health care professionals by observing and reporting any general developmental delays a child may be exhibiting. Such early identification of delays is essential for a child to achieve his or her maximum potential and receive proper interventions in the school environment.

- **Medication Adherence**

A CLS assists children and their families by identifying and implementing techniques that both support and encourage children and their families to achieve medication adherence. The outcome of medical adherence is not only better health physically but also the promotion of a feeling of mastery and cooperation between families and the medical team.

- **Diversional therapeutic play during an illness or a procedure and/or for pain management**

At routine outpatient clinic visits, children commonly undergo procedures such as venipunctures, administration of immunizations, and tuberculin skin tests. Although the medical team considers these to be minor procedures, children often perceive them as major procedures. During hospitalizations, children may have to undergo a variety of procedures, such as venipunctures, placement of intravenous lines, lumbar puncture, bronchoscopy, and endoscopy.

Children can benefit from engaging in play therapy to alleviate their anxiety. A CLS can assist in the treatment/examination rooms by providing distracting activities, relaxation techniques, and focused support for a child, facilitating a child's development of effective coping mechanisms to be used during future medical experiences in the clinic, home, or hospital. A CLS engages a child in medical play that assists a child in achieving mastery and understanding regarding medical procedures. The sense of mastery promotes a positive self-concept and a feeling of control, helping a child feel competent to the challenges of everyday life (i.e., schoolwork, difficult family and peer interactions, and medical adherence). Anticipation of procedures, painful or not, can be as unpleasant as the procedures themselves. Non-pharmacological relaxation techniques could have a role in easing the actual procedures. During inpatient admissions, a CLS reinforces and encourages children to utilize coping methods developed during clinic visits that promote mastery and provide continuity of care for children and families.

- **Parent Education**

Parents may sometimes utilize ineffective and potentially disruptive parenting techniques (i.e., permissive parenting style and/or inconsistent discipline) that may impede a child's development of social, emotional, educational, and medical adherence skills. A CLS assists parents in identifying and developing appropriate and effective skills that support the parent/child dyad. The opening of effective communication lines not only helps family communication but promotes better communication in other areas as well (i.e., places of employment, school, and various public assistance offices).

- **Staff Education**

A CLS provides assistance and support in implementing developmentally appropriate methods of communication and interaction, which will increase understanding and motivate adherence to therapy on the part of a child and family.

APPENDIX 18-B

ADHERENCE PROBLEMS

A PARENT REPORTS THAT A CHILD IS NOT TAKING HIS/HER MEDICATIONS.

This is a very common but vague complaint. A detailed history as indicated below is most important for discovering the reason and providing a solution. If a parent communicates missed doses of a medication, decipher the facts without making negative judgements. HIV infected/affected families are quite sensitive to both the negative and positive opinions of their medical providers. Families who are penalized for honesty will avoid speaking the truth.

WHAT: Ask the patient which medication has not been taken as prescribed.

WHO: Ask the patient/family who usually gives the medications to the child. Find out if there is a different person administering the missed doses. Make sure that the instructions are available in the caregiver's primary language.

WHEN: Ask the parent or child when missed doses are occurring. How many doses are actually being missed? Is there a specific time pattern to the missed doses? For example, does the missed dose happen every afternoon when the child is tired? Does it occur during school hours, due to inconsistent administration by the child or school personnel?

WHY: Try to uncover why the doses were missed. If there is a specific cause, intervention should be directed at this cause. For example, if a patient reports missing a morning dose of medicine because of nausea, suggest possible administration 1 hour after breakfast.

WHERE: Where are the medications usually given? Where are doses scheduled to be administered being missed? For example, if a family reports missing the 3 PM medications every day, it would be important to learn where the child is at 3 PM. If the child is at the baby-sitter, the parent may miss afternoon medications for fear the baby-sitter will learn the diagnosis.

HOW: How are medications usually taken? Are medications given with milk, water, or sucking candy or on empty stomach? Is a medication cup, pillbox, syringe, or spoon used? How are the medications that are being missed administered?

A PARENT REPORTS THAT THE CHILD DISLIKES THE TASTE AND REFUSES TO TAKE THE MEDICINE.

The parent needs to be counseled that the child can be offered some choices regarding how he or she takes the medications. For example, does the child want juice or water with the medicine? Does the child want the medicine in a medicine cup or in a syringe? If possible the parents need to be counseled that tasting the "dreaded" medication and discussing the child's concerns are ways to both empathize with and acknowledge the child. In addition, the primary pharmacy may be able to compound the medication into a more palatable formulation. This could include flavoring the medication or compounding it into a powder form, so it may be mixed with various foods or drinks, although the ability to compound any given medication would depend on the pharmacokinetics of the particular drug. Finally, another option is to change from liquid formulation to pill formulation if the child is able to swallow pills.

A PARENT REPORTS ADEQUATE ADHERENCE TO THE PRESCRIBED ANTIRETROVIRAL MEDICATIONS, WITH CLINICAL AND IMMUNOLOGIC DETERIORATION OF THE CHILD.

The dispensing pharmacist may be phoned to verify if the child is receiving the medications on a regularly scheduled basis. The pharmacist has a complete record of the patient's medication profile, including the time interval between refills. Collaboration with a pharmacy that offers an adherence program would provide substantial support to the family. Direct home delivery of medications with monthly telephone consultation can also be helpful. An additional tool to foster adherence is a small alarm system that sounds every time the patient is due for a medication dose. Last, the support of a home health care agency that offers a variety of therapeutic options to assist the family with adherence is invaluable in these situations. One such intervention is directly observed antiretroviral therapy, provided by shift nursing. This intervention should not be implemented as a punitive and/or controlling strategy to force a family into adherence. Instead, directly observed antiretroviral therapy should be presented as an educational and supportive therapeutic intervention with the primary short-term goal being for the child and family to comprehend the value of adherence and with the long-term goal being for successful independent maintenance of the antiretroviral regimen.

A PARENT WITH MEDICAL AND/OR PSYCHOLOGICAL/COGNITIVE LIMITATIONS IS REQUIRED TO ADMINISTER A COMPLICATED MEDICAL REGIMEN AT HOME.

The use of color-coded bottles matched with a color-coded calendar may provide substantial assistance to a parent who is illiterate or intellectually limited. Home care services such as a home health aide and/or a visiting nurse are invaluable in these situations.

THE PARENT REPORTS THAT AFTER TAKING MEDICATIONS THE CHILD BECOMES NAUSEATED AND VOMITS.

Administration of a medication with food may help to prevent nausea. If co-administration with food is contraindicated, administration of the medication with an 8-ounce glass of water will help reduce gastric irritation and may relieve nausea. If nausea and vomiting primarily occur in the morning before school, assistance from the school nurse should be requested to help alleviate this problem provided the family grants permission, the child assents, and school authorities guarantee confidentiality.

A PARENT IS FEARFUL THAT THE ANTIRETROVIRAL MEDICATION WILL HARM THE CHILD IN SOME WAY.

This is one of the more difficult challenges that a clinician will face. The difficulties in this situation arise from two different and often opposing belief systems. The goal for this problem should be directed at a win-win solution. The family should possess an understanding of the recommendations and rationale for treatment plan, and the clinician should attain an understanding of a family's mistrust and anxiety. Only from mutual empathy and collaboration can both belief systems be challenged to evolve and change. Patience, perseverance, and neutrality are essential attitudes to be maintained by the health care team.

Collaboration with the HIV-infected child and family is a fundamental component of the antiretroviral treatment plan. Collaboration will not only facilitate adherence to medication schedules but will also improve patient self-esteem and, ultimately, quality of life. Collaboration implies choice, in contrast to adherence which suggests passivity. Clinicians must also remember to collaborate with other health care professionals, including pharmacists and home care nurses.

A PARENT BECOMES CONFUSED ABOUT WHICH MEDICATIONS ARE BEING ADMINISTERED BECAUSE OF MULTIPLE NAMES.

A written illustration of the medication regimen tailored to the cognitive level of the parent proves to be most valuable in this situation. Such an illustration would list the names of the medicines, including both generic and brand names as well as some description of each medication to facilitate easy identification by the parent. The clinician should specify the time of medication dosing as opposed to giving a parent general dosing times, such as 3 times a day or every 12 hours. An example of a specific medication dosage regimen would be: nelfinavir (Viracept)— give 3 blue tablets at 7 AM, 1 PM, and 7 PM. Finally, when commencing a new treatment plan, a clinician should ask the primary pharmacy to deliver the medications to the clinic at the time of the patient's visit. Clinicians may test the effectiveness of written illustrations by asking parents to demonstrate what medications they will administer and when they will administer these medications. This is a valuable measure of a parent's comprehension of both medications to be administered and the clinician's instructions. It also serves as an important forum for clinicians to answer any questions about the medicines while the parent and child are present.

