

Introduction to the Curriculum

What is the goal of this curriculum?

The goal of this curriculum is to improve the quality of care that patients with HIV/AIDS receive throughout the illness and at the end of life. This is accomplished through increasing the capacity of the AIDS Education and Training Centers to train clinicians in palliative care, and through increasing the HIV/AIDS care skills of palliative care clinicians. This curriculum is designed to provide the materials which medical educators need to deliver effective training sessions on a number of palliative care topics.

What topics does this curriculum cover?

The curriculum is divided into modules, with educational materials related to the following topics:

- ▶ Overview of HIV/AIDS Palliative Care
- ▶ Advance Care Planning
- ▶ Communicating with Patients & Families
 - Communicating with Patients & Families about End-of-Life Care
 - Giving Bad News
- ▶ Cross-Cultural Issues in HIV/AIDS Palliative Care
- ▶ Pain and Symptom Management
 - Assessing & Managing Pain in HIV/AIDS
 - Palliative Management of Dyspnea in HIV/AIDS
 - Complementary Medicine and HIV/AIDS Palliative Care
 - Symptom Management in HIV Disease
 - Pain Management for Patients with a History of Substance Use
- ▶ Psychosocial & Psychiatric Issues
 - Helping Patients to Have a Good Death
 - Psychiatric Issues in HIV/AIDS Palliative Care
 - Spiritual Issues in HIV/AIDS Palliative Care
- ▶ Pediatric HIV/AIDS Palliative Care
- ▶ HIV/AIDS Palliative Care in Corrections
- ▶ HIV/AIDS and Hepatic Failure

What are the components of the curriculum?

Modules include:

- Learning objectives
- PowerPoint slide presentations with accompanying slide notes
- Skills building and interactive exercises
- Sample agendas
- Evaluation forms
- Suggested handouts
- Resource lists

In addition, 7 video trigger tape segments are included, and these may be used with several of the modules.

How and why was this curriculum developed?

Anti-retroviral therapies have transformed AIDS from a progressively fatal disease to a chronic illness; Clinicians providing care to patients with AIDS need palliative care education designed specifically for this clinical context. In addition, improved palliative care is important in AIDS because, despite advances in highly active anti-retroviral therapy (HAART) and sharp declines in mortality rates, AIDS remains a leading cause of death among Americans aged 25 to 44 years.

In a unique collaboration between the Health Resources Services Administration (HRSA) and the Robert Wood Johnson Foundation (RWJF), the University of Washington's Northwest AIDS Education and Training Center (NW AETC) was contracted to develop curricula for the National AETCs and their medical educators. The Center for Palliative Care Education was formed to be a national resource on HIV/AIDS palliative care. This HRSA/RWJF collaboration was forged with the dual intent of increasing the capacity of the AETCs to train clinicians in palliative care, and of increasing the HIV/AIDS care skills of palliative care clinicians.

These curriculum modules were developed by clinicians with expertise in HIV/AIDS and in palliative care. The modules were piloted, evaluated, reviewed, and revised before being made publicly available here.

Who can use this curriculum?

These materials can be used in training sessions for health care professionals, including physicians, nurse practitioners, physician assistants, nurses, mental health providers, social workers, and other palliative care clinicians. Although the materials include information specific to care for patients with HIV/AIDS, clinicians who do not work in HIV/AIDS care will find the information useful.

How can this curriculum be used?

The materials can be adapted to the needs of your training session participants, to your time frame, and to your training format. The materials can be used intact, or individual elements can be selected, modified, and used as needed. You may wish to review resource materials listed for each topic for additional background to help you prepare for delivering training sessions.

We've piloted this curriculum and based on these experiences, we have culled some survival skills and tips for educators to help create successful learning sessions. In general, an interactive small group format is most effective for learning about these topics. However, these materials may also be used in a didactic, large group setting. You may wish to review the *Resources for Trainers* section to prepare for delivering training sessions.

Acknowledgements

Funding:

Health Resources and Services Administration
Robert Wood Johnson Foundation

Partners:

Northwest AIDS Education & Training Center
University of Washington Center for Health Education & Research

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Special Thanks:

Ann Downer, EdD, UW CHER Executive Director, for starting it all.
Bernadette Lalonde, PhD, NW AETC Director, for support and advocacy.

Palliative Care for People with HIV/AIDS:



Developed by: The Center for Palliative Care Education, www.uwpallcare.org
A Project of the Northwest AIDS Education & Training Center
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Palliative Care for People with HIV/AIDS:

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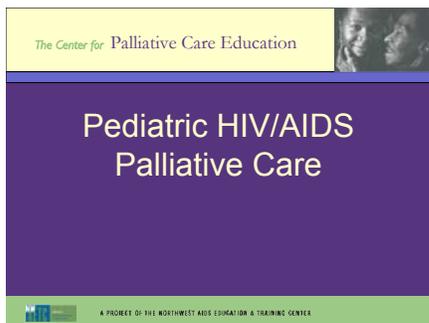
Learning Objectives

At the end of this presentation, participants will be able to:

- Consider how HIV/AIDS palliative care for children differs from that for adults
- Discuss issues related to communication with pediatric HIV/AIDS patients and their families
- Describe assessment skills related to palliative care needs for pediatric patients
- Be familiar with management options for symptoms in pediatric patients, including pain, anorexia, fatigue, sleep disturbance, dyspnea, and psychiatric symptoms

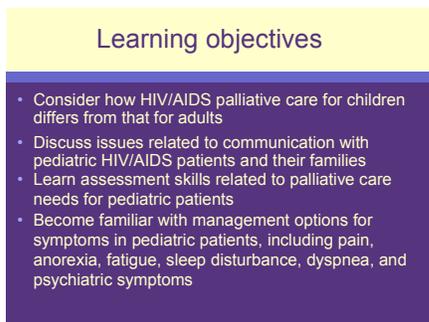
Pediatric HIV/AIDS Palliative Care

PowerPoint Notes



Trainer Suggestion

Introduce yourself and go over the agenda for the session. If there is time and the group is small, you may want participants to introduce themselves and talk about what they would like to get from the session. Learning objectives, on the next slide, could be revised based on participant interest.



- Consider how HIV/AIDS palliative care for children differs from that for adults
- Discuss issues related to communication with pediatric HIV/AIDS patients and their families
- Learn assessment skills related to palliative care needs for pediatric patients
- Become familiar with management options for symptoms in pediatric patients, including pain, anorexia, fatigue, sleep disturbance, dyspnea, and psychiatric symptoms

Slide Note

The objectives for this module are to understand how to provide palliative care for children and adolescents who are living with HIV/AIDS. There are many ways in which palliative care is similar across age groups. The approach to palliative care, the core values and precepts of palliative care are the same regardless of the age of the person for whom we care.

But the ways in which we actually provide palliative care, the way we implement palliative care services will differ according to the individual needs of the people for whom we care, including differences by age and size and development. We will consider issues related to communication with children and adolescents, according to their developmental needs, and with their families. It's important for us to learn skills in assessing children and adolescents regarding the needs they have for palliative care, particularly their needs for symptom management. We also need to be skilled in managing the symptoms that we identify, knowing how to prescribe medications or non-pharmacologic therapies, and how to understand whether our interventions have made a difference in improving children's quality of life.

Case Study

- 12 year old boy with HIV from birth
- In utero drug exposure
- Abandoned in newborn nursery - foster care
- Developmental delay - special education
- Clinically stable until age 8 years

Slide Note

We will begin by thinking about a patient. This is the story of a boy who was 12 years old. He was born with HIV to a mother who actively used drugs throughout her pregnancy, so he was exposed to drugs while he was still in utero. He was abandoned as a newborn in the hospital; his mother simply left him there. He was therefore placed immediately into foster care. As he began to grow it became clear that he had developmental delays, particularly cognitive, learning delays. He required special education services to help with his educational needs.

But through all that, he was clinically stable with his HIV disease until he was about 8 years old.

Disease progression

- Extremely low CD4 count
 - Absolute CD4 = 5
- High viral load
 - HIV RNA >750,000 copies
- Minimal response to antiretroviral therapies
 - Multiple nucleoside RT inhibitors (NRTI)
 - Two protease inhibitors (PI)

Slide Note

When he was 8, he experienced disease progression. His CD4 count became extremely low: his absolute CD4 was 5. His viral load was very very high, as high as could be measured, with an RNA value higher than 750,000 copies. And he had already been treated with multiple different kinds of antiretroviral therapies, including multiple nucleoside RT inhibitors and two protease inhibitors.

Disease progression

- Neurologic deterioration
 - Confusion
 - Gait change
 - Difficulty swallowing
- Opportunistic infections
 - *Pneumocystis pneumonia*
 - *Candida esophagitis*

Slide Note

He began to experience clinical disease progression as well. He had deterioration in his neurologic status. He became confused, and had memory problems. At school, his teachers reported that he used to be able to go the bathroom and find his way back to the classroom, and he was now becoming lost in the hallways at school. His foster mother and his teachers noticed that his gait had changed. He became more clumsy and stumbling. He started having difficulty swallowing, he couldn't eat his food normally. He began to experience opportunistic infections, such as pneumocystis pneumonia, despite the fact that he was taking medication to prevent this, and *Candida esophagitis*, which caused severe substernal chest pain, particularly when he tried to swallow his liquid protease inhibitor. He experienced severe burning and pain when he took his medications.

Quality of life

- Loved by his foster family
- Always smiling
- Attending school
- Disney World five times!
- Foster mother aware of his fragile prognosis
- Does not want him to suffer nor to undergo interventions that would only prolong his dying

Slide Note

Through all that you might imagine that this child would seem sickly and unhappy, but in fact his quality of life was quite good. He was loved by his foster family, he had been with the same foster family for 10 years. He always had a smile on his face - he had the most brilliant sunny, happy face. He always made you feel good every time he came to visit. He was actively attending school. His foster mother very proudly announced that he had been to Disney World 5 times. She was aware of his fragile prognosis. She was fostering several children with HIV diagnoses, and she would talk about how, of the children she was fostering, she could tell that he was the one that would deteriorate, that she would lose him first. She expressed that when his life was ending, she wanted his care to be supportive and dignified. She did not want him to suffer unnecessarily or undergo any interventions that would serve only to prolong his dying.

Acute illness

- Sudden onset, rapid progression over hours to obtunded state
- Intubation and ventilation during acute phase - extubation expected
- Discussion with foster mother about goals of care – she agrees with recommended interventions
- Admitted to intensive care unit

Slide Note

When he was 11 years old, he had a sudden acute illness over a weekend. He developed fever and abdominal pain and was taken to the emergency department where he rapidly progressed over just a few hours to an obtunded state. He became unresponsive, requiring intubation and assisted ventilation. He was presumed to have sepsis, and that once the cause of this acute illness was determined and treated, he would recover and be extubated. The clinic primary care provider contacted his foster mother on the Saturday that he was being admitted to the ICU, and the doctors shared the impression that this was an acute problem that would resolve, just as previous acute problems had. She was very supportive of him being intubated with the hope that it would support him through this acute illness and he would be extubated and improve enough to return home and to school.

In the ICU

- Mental status improved, but much less than baseline
- Breathing independently – ready for trial of extubation
- Acute renal failure - progressive
- No positive cultures – no reversible condition identified

Slide Note

He was given antibiotics and intensive support in the pediatric intensive care unit. Initially his mental status improved somewhat. He was awake, and he seemed responsive, but he was much less interactive, and not really able to communicate. So he was not improving even to his previous baseline mental retardation and recent confusion. While in the ICU, he developed acute renal failure, with very high blood pressure and increasing serum creatinine and BUN. Despite multiple attempts to find an infectious etiology for this illness, no cultures came back positive.

Health care decisions

- Should he be extubated?
- Should he be re-intubated if he deteriorates?
- Should he be dialyzed?
- Should his tube feedings continue?

Slide Note

After about 2 weeks in the ICU, it became quite clear that he was at a juncture where decisions needed to be made. His neurologic condition had stabilized. He was breathing on his own with minimal assistance from the ventilator. It was time to attempt extubation. Yet the risk that he would deteriorate was quite high. The likelihood that he would ever fully recover from this illness was extremely low. The medical staff struggled with several decisions. Should they risk a trial of extubation? If he needed re-intubation, would that add to his suffering? Was that only prolonging his dying? Should hemodialysis be considered as a temporary support measure? Would he become permanently dependent on dialysis? He was receiving nutrition through a nasogastric tube; should this continue?

Decision making

- Adult process
 - Conversation with competent adult patient
 - Review treatment options, risks, benefits
 - Conversation with proxy if patient unable to communicate
- Child process
 - Always have proxy
 - Include child in appropriate way

Slide Note

When making health care decisions, our usual approach for competent adult patients is for the physician or health professional to have a conversation with the patient about their health condition, the treatment options, and risks and benefits of each option. When an adult is not able to make such decisions themselves, (for example, an adult in a coma) then a surrogate or proxy decision maker is identified, and the conversation is held with that person.

With children we always have a proxy, which is the parent or guardian of that child, and to the extent that we can, we include children in those kinds of conversations and decisions in a developmentally appropriate way.

Decision making

- Multiple people sharing “parent” responsibility
- Many health care providers sharing “provider” responsibility
- Ethics committee and court sharing review and oversight responsibility
- Foster mother designated full guardian for decision making

Slide Note

This patient had a much more complex situation than some children who are in life-threatening circumstances. In this situation, because this was a child in long term foster care, there were multiple people who were sharing the parent responsibility in the conversation. There were foster parents who had parented this child, raised him as their own, loved him, and he loved them. They were in the position to understand and advocate what was best for him and yet they had no legal standing to have decision-making responsibility. They were under the umbrella of a foster care agency which also had no legal standing in decision making. They and the agency were appointed to foster this child by the department of social services, who was the guardian for this child. Over his lifetime he had had multiple workers assigned at DSS, and the most recent worker had never met the him and did not know his needs in any personal way that could enable them to advocate or make choices on his behalf.

The other person who had some responsibility was his court-appointed attorney. A child in foster care, when important decisions are made, must have their attorney representing them. And he was appointed a Legal Aid attorney who also had never met him.

He had many health care providers sharing the provider side of the responsibility, including the attending physicians at the pediatric intensive care unit, the consultants, particularly the infectious disease consultants who were helping to evaluate and manage his acute illness. There were also the continuity providers: his HIV outpatient pediatrician and the interdisciplinary team who had knowledge of him and his foster family.

In order to hold this “conversation between parents and providers”, a meeting of the hospital ethics committee was convened. All the responsible people attended. The child’s medical condition was discussed, the possible treatment interventions, and the likely benefits and burdens of these interventions. It was felt that it would be ethically permissible to choose either to continue or to withhold life-sustaining interventions. His social and family situation was also discussed. The recommendation was made that, rather than having a committee of people trying to make decisions for this child, his foster mother, the person who had the most experience parenting him, should be legally designated his full guardian for decision making by the courts.

Foster mother's decisions

- Do not extubate until after his 12th birthday
- Keep him as comfortable as possible
- Continue artificial nutrition and hydration
- Do not reintubate him if he deteriorates again

Slide Note

The court hearing occurred 2 days before his 12th birthday. His foster mother's decision was to not extubate him until he turned 12. She was concerned that if he were to deteriorate that he might not survive to reach his birthday, and that was very important to her. So she asked that he not be extubated until after his birthday. She wanted him to be kept as comfortable as possible, including using pain medication as needed. He was receiving NG tube feedings and IV medications and hydration, and she wanted this to continue. But once he was extubated after his birthday, she did not want him to be re-intubated if and when he deteriorated again.

The family celebrated a birthday party in the pediatric ICU, after which he was extubated.

His Death

He died two days after his birthday, surrounded by family, friends, and staff.

Foster brother came to say good-bye with support of child life specialists.

Slide Note

Two days later he died. He was surrounded by family and friends, and many of the staff who'd worked with him for so many years. There was opportunity to sit, remember, and honor him and to remember fun times and fun stories, to sing and to pray. After he died, his foster father went to school and picked up his foster brother to come in so that he would have an opportunity to say goodbye with supportive clinic staff and child life specialists who could work with him in a developmentally appropriate way.

Impact of HIV/AIDS on Children UNAIDS AIDS Epidemic Update 2003

Children <15 years

- 2.5 million living with HIV/AIDS (6%)
- 700,000 newly infected in 2003 (14%)
- 500,000 AIDS deaths (17%)
- 14 million orphaned by AIDS since beginning of the epidemic

Slide Note

To place this case and this session in a context of the impact of HIV/AIDS on children, we can look at some of the data from the World Health Organization and from UNAIDS. These show that in children who are less than 15 years, at the end of 2003, there were 2 and a half million living with HIV/AIDS. In 2003 alone, 700,000 children were infected, and half a million children died due to AIDS. If we look at that in contrast to the adult epidemic, children less than 15 make up 6% of the cases of HIV and AIDS throughout the world, and yet they make up 14% of the people who were newly infected in 2003, and in fact make up 17% of the deaths that occur. Children are being newly infected and dying at relatively greater rates than adults living with HIV. Significantly, an additional 14 million children have been orphaned by AIDS since the beginning of this epidemic, and the number continues to grow extraordinarily.

Routes of Infection

- Mother to child transmission (MTCT)
- Sexual activity
 - Sexual abuse
 - Heterosexual
 - Men with men
- Injection drug use
- Unscreened blood & blood products
- Contaminated or reused medical equipment

Slide Note

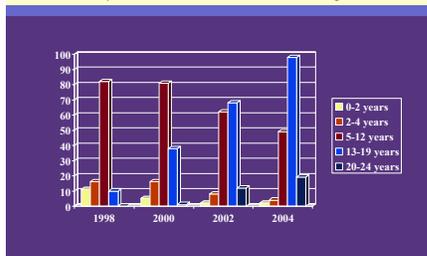
Children can become infected in several ways, but the chief and most common route of infection for young children is mother-to-child transmission. When mother has HIV herself, she can transmit HIV either through pregnancy or most commonly through labor and delivery. If she breast-feeds her baby, she can transmit infection through breast feeding regardless of the age of the child.

We know that intimate sexual contact can infect children and adolescents. There are unfortunately children who have been sexually abused who have acquired HIV through this route. Adolescents and young adults who are sexually active, either heterosexually or young men who have sex with other men, are becoming infected with HIV.

Injection drug use, although not as common in adolescence, is certainly a risk factor. And in areas of the world where there aren't financial resources to appropriately screen blood and blood products, or to appropriately sterilize or discard contaminated or previously used medical equipment like needles, and other sharps, children can be infected through re-use of medical equipment.

Patients Living with HIV/AIDS, by Age Group

Johns Hopkins Pediatric & Adolescent HIV/AIDS Program



Slide Note

In the pediatric and adolescent HIV/AIDS program at Johns Hopkins, the clinical practice is now integrated across the age span from birth to 24 years regardless of how a child or adolescent became infected with HIV. The interdisciplinary team has been expanded to take advantage of the synergy among health providers who are experts in addressing the variety of needs of children and adolescents at different ages. Looking historically at the patient population, you can see that children born with HIV are surviving and getting older. Early on in the AIDS epidemic, we cared for infants and young children. The deaths that occurred were also in this young age group. Now we see predominantly older children and adolescents. The low numbers of young children represent the overwhelming success achieved in preventing mother to child transmission of HIV in the United States through appropriate counseling and testing for pregnant women, and provision of appropriate prenatal care including antiretroviral therapy to treat mother and prevent transmission to her baby. But even more dramatically, one sees the annual increase in the number of surviving adolescents. This is due primarily to children who have acquired HIV perinatally and who have survived into adolescence as a result of good comprehensive care and antiretroviral therapy. Unfortunately, some of these survivors have complex medical disease and drug-resistant HIV, making their prognosis for long-term survival poor.

Holistic Caring

- For the HIV-infected person, the family, and community
- Throughout the disease continuum
- After someone's death

- *Palliative care* provides a framework for caring

Slide Note

People living with HIV need holistic care - for the whole person, in the context of their family and their community. For children and adolescents, this includes the context of their school, their peers, and with the family members who care for them. We need to provide holistic care throughout the disease continuum, from the time of diagnosis through hopefully many years of life through disease progression and at the end of their lives. And we need to continue to care for the family and community in their time of loss and bereavement. Palliative care is the way we can think about and structure our approach to providing this holistic care.

Quality of Life

- Physical well-being
 - Treat HIV with ARVs
 - Prevent & treat infections
 - Control pain & other physical symptoms
 - Provide nutritional support
- Psychological well-being
- Social well-being
- Spiritual well-being

Slide Note

The purpose of palliative care is to improve and provide the best quality of life for our patients with HIV. Quality of life includes physical well being, psychological well being, social well being and spiritual well being.

Physical well being can be advanced through treatment of HIV directly using antiretroviral drugs. This is a core component of HIV palliative care, and it can be argued that antiretrovirals are the best palliative medicine for HIV infection. We know that we can improve symptoms, improve energy, improve mood, help people get back to being able to care for themselves, provide for their own activities of daily living, when they are on good effective antiretrovirals. We also promote physical well being by preventing and treating infections, which cause pain and symptoms and sap the body's energy. And by treating pain and other symptoms directly, particularly if they are caused by conditions that we cannot cure. We promote physical well being by providing good nutritional support, not forgetting the importance of healthy eating and a well balanced diet, appropriate vitamins or supplementation.

We also promote the psychological and social well being of our patients, helping people with HIV and their families to cope with living with a lifelong, life-threatening condition, with ups and downs. Adjusting to and coping with the impact on peer relationships and planning for the future. And not to forget their spiritual well being which we so often do in the medical field. To recognize the importance for so many people of their spirituality. For many, their religious affiliation is a source of support.

Trainer Suggestion

Refer to modules on psychological, psychosocial, and spiritual issues in HIV/AIDS palliative care for more information on this topic.

Slide Note

With our pediatric patients, we see many of the same problems that we see in adults with HIV. Children are susceptible to the opportunistic infections that we see in adults, although the pattern of infections may vary a bit according to their age and what exposures they've had in their lifetimes. Pneumocystis pneumonia and mycobacterium avium infections are seen in children with extremely low CD4 counts. We frequently see recurrent pneumococcal bacteremia, recurrent pneumonia, invasive CMV disease, and invasive candidal disease.

Growth failure is relatively common in children and adolescents who have been born with HIV. They can have either a wasting pattern (poor weight gain or frank weight loss) or a stunting pattern where they do not grow as tall as their peers. This can be particularly stigmatizing for children who experience short stature, such as an adolescent in high school who is the height of a 10 year old. Delayed puberty also occurs, causing a negative impact on self esteem and peer relationships.

Children can also experience neurodevelopmental abnormalities. There can be motor effects, deterioration, changes in their muscle control. This can look like a cerebral palsy presentation. The child can be hypertonic, with stiffness of the trunk and extremities, or hypotonic - very floppy. It can be a child who develops normally and then loses motor skill. There can be cognitive problems as in the case that we began with, where children may have baseline problems that could be due to drug exposures. (Many of the children born with HIV in the 1980's and 90's in the United States were born to women who were substance users.)

There can be constitutional or familial components to mental retardation, and yet for children who are abandoned, we often don't have access to information about their parents' educational abilities. And as children are aging, we see specific learning disabilities more frequently in the HIV-infected population than in the general population of children. Behavioral problems are also more common.

There is a significant proportion of children with attention deficit and hyperactivity, and who are requiring and thankfully responding to stimulant medication to help them with behavior both in school and at home.

And of course we see organ failure: Cardiac failure, cardiomyopathy, chronic lung disease due to infections or due to lymphoid interstitial pneumonitis (LIP), renal failure, and liver failure.

Medical Complications of HIV

- Opportunistic infections
- Growth failure
- Neurodevelopmental abnormalities
 - Motor – cerebral palsy
 - Cognitive – learning problems
 - Behavior – attention deficit & hyperactivity
- Organ failure (heart, lungs, kidney, liver)

Mental Health Complications

- Depression
 - Suicidal thoughts & plans
 - Hopelessness
- Encephalopathy
- Dementia
- Delirium

Slide Note

Mental health complications are becoming more apparent as children survive longer into adolescence with their HIV. There is a significant minority of children with depression, including those who have suicidal thoughts and plans. But there are many children who are just very hopeless about their future, even when they don't have medical reason to be hopeless. For example, there are adolescents who are long term non-progressors with good CD4 counts, on minimal antiretrovirals, but who are orphaned, and who believe that they're going to die before they reach adulthood because their parents died, and because they've gotten the message throughout their lives that they are not going to survive to adulthood. Many are unable to make plans for their future. Will they make it through high school? Will they ever hope to have a family, or go to college, or have a career? There are a number of 15 and 16 year olds whose depression seems very focused on the death of their mothers, which occurred when they were young children. It's as if they were re-experiencing their loss afresh as adolescents who can now understand in a different way because of their developmental maturity, their ability to think abstractly and to understand things in a more complex way. They re-experience this loss in a profound way, and several of these adolescents have required inpatient psychiatric care.

We are also now beginning to see adolescents with more classic HIV dementia. Because adolescent cognitive development approaches that of adults, we can evaluate them as we do adults. Memory problems can be an early sign of dementia. This presentation is in contrast to the progressive brain disease seen in infants and young children. Because their cognitive development is much less mature, we see encephalopathy with alterations in alertness and interaction. Adolescents who may also have delirium may require hospitalization and anti-psychotic medications to control their delirium. When these symptoms arise, it can profoundly disturb the families caring for them and challenge their ability to provide their care at home. It is also very disturbing to health care providers, especially those with long-term relationships with the children.

Clinical Management

- Antiretroviral therapy
 - Control HIV replication
 - Prevent or reverse immunodeficiency
- Opportunistic infection prophylaxis
 - Reduce morbidity and mortality
- Treat reversible complications
- Manage irreversible complications

Slide Note

The approaches to clinical management in children include many of the same approaches we use in adults. We provide antiretroviral therapy with the same goals. Our goals are to control HIV replication and to prevent immune deficiency from happening in the first place, and if it has already occurred, to try to reverse that. The best way to control the symptoms and complications caused by HIV is to control the HIV in the first place. We also provide opportunistic infection prophylaxis, whether through antibiotic medication, or sometimes through intravenous immunoglobulin, and the goal of this is to reduce morbidity and mortality so that children can have the best quality of life.

To identify any complications which are reversible, such as bacterial infections, and then treat them is a very important component to the clinical management of children with HIV. But there are complications that are irreversible, such as renal failure, cardiomyopathy, lung disease, and to some extent brain disease, that we must nonetheless actively manage.

Growth & Development

- Physical growth & physiological maturation
 - Medication dosing
- Motor skills development
 - Independence
- Cognitive development
 - Ability to understand (receptive)
 - Ability to communicate (expressive)
- Social & emotional maturation

Slide Note

Children and adolescents are continuously growing and developing and this influences every aspect of our work with them. We will consider child growth and development in several domains. Physical growth occurs rapidly, especially during infancy and early adolescence. Newborns triple their body weight within one year, an extraordinary change in size. Rapid physiologic maturation occurs at the same time. When first born, renal function and liver function are less mature. This influences which medications we choose and the dosing regimens that we use. Early adolescence is another period of rapid physical growth and physiologic maturation, yet we know relatively little about how and when to shift from pediatric dosing to adult dosing schedules. Medications and dosing regimens used in palliative care must be evaluated in children and adolescents of different ages, sizes, and Tanner stages so that pediatric patients have the same access to symptom relief as adults do.

Children also change in their motor skills over time. Again, in early life this is very rapid development, from being completely dependent to becoming more independent in activities such as feeding oneself, walking, toileting. Obviously, then, the loss of these skills has very profound meaning and sadness for children and families.

Their cognitive development is ongoing, both in receptive language abilities - the ability of children to understand what we're saying to them, (for example, if we're asking them questions to try to assess for symptoms) and in their ability to communicate their needs and their thoughts to us - their expressive language abilities. These language abilities are distinct from each other, and there can be disorders in each. Both are very important in our ability to communicate with children of different ages.

Children gain social skills and mature emotionally over time. The domain of development is affected by frequent illness or hospitalization. Some children regress and others seem to mature more quickly, influencing how they interact with others.

Social & Emotional Challenges

- Social stigma
 - Secrecy, isolation, guilt
- Comorbid conditions in families
 - Substance use, psychiatric conditions
- Socioeconomic need
- Coping
 - Living with life-threatening condition
 - Multiple losses

Slide Note

Children and adolescents endure the same social and emotional challenges that we have become familiar with in working with patients with HIV and AIDS.

The social stigma of HIV is a very potent problem for children and families. It can cause families to become secretive, to not share the diagnosis with other extended family members, or with friends and neighbors, with other people at school. This causes families to become more isolated, and for children to be more isolated, and unable to talk with others about their condition. The problem of guilt, on the part of mothers for having transmitted HIV to their children, can be profound. In fact, within our grandparent generation, there seems to be a great deal of guilt on the part of grandmothers that somehow they are responsible for the fact that their daughters became HIV infected and transmitted infection to their grandchildren.

The prevalence and significance of comorbid conditions in families is quite high. Particularly in the early part of the epidemic in the United States, most of the mothers who became HIV infected were infected through substance use or a combination of substance use and heterosexual exposure.

This means that many children are raised in families where the adults who are responsible for their health and welfare are frequently distracted by their own addictions. Other psychiatric conditions are also more common in HIV affected families. These disorders may interfere with the level of nurturing and physical care necessary for children with special health care needs.

Within our country, people who are most likely to be affected by HIV are those with the least financial resources, live in neighborhoods with poor housing, may be more likely to have not finished school, to be unemployed. There are significant challenges of coping, of living an entire lifetime with a life threatening condition. We are now caring for children who have lived for over 15 years with HIV, have never known a time when they were free from worrying about this condition. And children who've endured multiple losses, who've lost siblings, who've lost parents, who've lost grandparents, aunts and uncles. Who've lost friends who have HIV.

Health Care Planning

- Begins at diagnosis
- Goals of care, values & beliefs
- Effective communication
 - Interdisciplinary health care team
 - Family
 - Child/adolescent
- Disclosure
- Guardianship, permanency planning
- Maintain hope, plan for the future

Slide Note

Health care planning is a core of palliative care and needs to begin at the time of diagnosis. Its purpose is first to clarify the goals of care. What is possible? What is desired? What are we trying to achieve? Then a plan of care is crafted to achieve these goals. It assumes that we understand and respect the values and beliefs held by patients and families. Health care planning therefore requires effective communication among the members of the interdisciplinary health care team, in order to assure a clear assessment of the child’s condition and prognosis, and a comprehensive evaluation of the needs of the child and family. There needs to be effective communication within the family, and with the child or adolescent about their health status, about their disease and treatment - in a way that’s developmentally appropriate. Communication between the family and the child, between the team and the child, between the child and the family, and among all three, must be facilitated. This means that disclosure about HIV is a very important issue in pediatric management. Children can’t participate in any meaningful way in decisions about their health care if they don’t understand what’s going on in their own bodies. They need to understand their HIV in a way that’s meaningful to them, so that they can talk about preferences that they might have, or questions and worries that they might have.

Effective health care planning requires that we know who the guardian of the patient is. As in the case that we discussed earlier, we need to actively anticipate the need for this to be clearly delineated for our children and adolescents with HIV, so that effective decision making can occur. This includes permanency planning for adults with HIV. Mothers with HIV should have plans in place for their children if they should become ill or incapacitated or die before their children.

Always maintain hope for the future. There is always something that we can be doing to try to make things better. We should be always future-focused and future-thinking.

Communication with Child

- At developmentally appropriate level
 - Use appropriate language
 - Focus on child’s concerns
 - Provide necessary information
- Respect child’s individuality and autonomy
- Listen carefully; ask clarifying questions

Slide Note

Communication with the child needs to be at a developmentally appropriate level. We need to use appropriate language – words that children understand. We need to focus on the child’s concerns, understand what they’re thinking about, what they’re worrying about. If a four year old is very worried about the scratch on her leg, even though we might be very worried about her high viral load or low CD4, we need to address the scratch on her leg first. Then she knows that we listen to, respect, and respond to her concerns.

We need to provide necessary information, in a developmentally appropriate way, so that children understand why we’re doing the things that we’re doing, why we’re asking them to take medications, what we expect could happen today, tomorrow, next week. We need to be

respectful of children's individuality and autonomy. Each child, regardless of their age and developmental level, is a distinct, unique, separate, precious human being, and they want to be able to have whatever control is possible over their lives and what happens to their bodies. We need to listen very carefully to what they say and what they ask, and not to make assumptions, but to ask questions if we don't understand what it is they mean.

Interacting with Children and Adolescents at Different Stages of Social Development

Infants (0-12 months)

- Adults should use language, tone, and touch to communicate
- Communicate nonverbally
- Object permanence develops
- Need physical and emotional nurturing
- give simple explanations

Toddlers (1 – 2 years)

- Adults should be efficient and comforting
- Adults should prepare toddlers for procedures just beforehand
- Are learning words
- Adults should give simple explanations
- May have temper tantrums
- Adults should be clear, consistent

Slide Note

Because we need to interact with children in developmentally appropriate ways, the next few slides have some suggestions for health care providers to use in working with children and adolescents at different stages of social development. It's important to remember that a personal or family illness may interfere with the normal progression of a child's socialization process, so developmental level rather than age should be what to keep in mind when interacting with a child.

Trainer Suggestion

You may want to refer to O'Neill et al, editors, *A Clinical Guide to Supportive and Palliative Care for HIV/AIDS* (2003), chapter 12. The information on this and the next 2 slides comes from a table on page 271.

Interacting with Children and Adolescents at Different Stages of Social Development

Preschoolers (3 – 4 years)

- Adults should provide concrete information about what is happening and why
- Can play with others
- Show magical thinking
- Have simple conversations, can ask questions
- Have concerns about body integrity

Children (5 – 11 years)

- Spontaneous questions are opportunities for adults to tell children the truth
- Are curious about own body and health
- Learn to read
- Offering children choices improves their sense of control
- Begin to understand cause and effect

Interacting with Children and Adolescents at Different Stages of Social Development

Early Adolescents (12-14 years)

- Puberty - a period of rapid physical, physiologic, emotional, social change
- Want to be treated like adults
- Peer relationships are very important
- Struggle with vulnerability
- Need positive adult support

Late Adolescents (15-18 years)

- Can accept responsibility for health care
- Are abstract, existential thinkers
- Active in health care decisions
- Need adult structure and support
- May be shouldering adult responsibilities

Communication with Parent/Guardian

- Honesty
- Clarity
- Unknowns
- Listen carefully, ask clarifying questions
- Respect individuality and autonomy
- Provide comfort

Slide Note

The guidelines for communication with parents and guardians are really the same as the guidelines for any good communication between providers and patients and families. When we communicate with parents and guardians, we need to be honest and clear. We don't do anybody any favors by sugar-coating our words or beating around the bush when adults responsible for children need to know how serious a child's illness is, how poor a prognosis may be, or how important perfect adherence to medication is.

We need to know when we don't know the answer - to recognize what the unknowns are and share those with parents.

Active listening is such a critical component to palliative care. We need to ask clarifying questions to make sure that we really do understand what we think we're hearing.

We need to respect the individuality and autonomy of the adults as we do for the children, and we always need to provide comfort to them, because their hearts are so heavy and sore when their children are sick and dying.

Trainer Suggestion

See modules on Communication with Patients and Families, and on Cultural Issues in HIV/AIDS Palliative Care for more information on this topic.

Decision-making

- Child's role
- Parent/guardian's role
- Health professional's role
- Conflict vs. partnering

Slide Note

When it's time to make decisions, such as changing to a more complex medication regimen or discontinuing antiretroviral therapy or choosing home hospice care, we have to think about and honor the role the child has in those decisions, and to consider their rights and responsibilities to speak for themselves. We need to recognize the role for the guardian or the parent, and our need to know who that parent or guardian is. We need to recognize our own roles as health professionals in the decision making process, and our responsibility to make professional recommendations when parents and children need this.

And above all, we need to partner with children and families as we approach health care decision making. This should not be a conflictual or antagonistic kind of relationship. We need to find the common ground or common goals of helping our children live the best lives that are possible, and partner with children and families to achieve those goals. Conflict can arise when providers and families have different values and beliefs about health care interventions. For instance, health care providers may offer to withdraw assisted ventilation in a dying child in order to minimize suffering due to futile intervention. The child's family may hear that offer as the health care team "giving up" on their child or valuing their child's life less than that of another child. They may mistrust the health care system based on a past personal or community history of discrimination and lack of access to the best medical care. Or they may agree that their child is dying, but believe that every moment of life is precious regardless of the hardship. It is our duty to understand and respect the family's values and beliefs. Once families know that, then decision-making becomes more collaborative and trustful, ensuring the best outcome given the circumstances.

Disclosure to children

- Anticipate opportunities for disclosure of HIV diagnosis
 - By age
 - At time of diagnosis
 - When initiating or changing medication
- Plan what to say, who will say it
- Be simple and straightforward
- Adults worry about stigma and loss of hope
- Provide comfort

Slide Note

We need to disclose HIV to children at an age that's appropriate and in appropriate ways. This means anticipating opportunities for disclosure. There are ages at which children are naturally curious about their bodies and about what's going on. By the age of 6 to 8 years, when children are in first grade or so, they often will ask questions about their bodies. When they ask questions such as, "Why do I take medicine?" or "Why do I go to the doctor?" or "What is this blood test for?" they need simple but honest answers. It's critical that we don't lie to children ever. For adults who feel they cannot answer the question, it's better to say, "I don't know," or "I can't talk about this now," or "Let's talk about that when we go to the clinic and ask the doctor there."

At the time a diagnosis is made is another important opportunity. If a child is old enough to hear the name of the diagnosis, generally aged 8 and above, it's an appropriate time to be sharing with the child as we would be sharing with the family members, about the diagnosis. For some children, when initiating or changing complex medications is an opportunity to talk. Children, who are accustomed to

coming to the clinic frequently and have felt well all of their lives, are going to know that something has changed if they go from taking one pill to taking 6 pills or 8 pills at a time. We need to provide some explanation, which is an opportunity for disclosing. It's an opportunity to say, "You're older now, and you understand more complicated things, and we'd like to take this chance to talk in more detail now because we think you can understand this kind of information now."

It's important to plan ahead what to say, how to respond to questions, who is going to talk about it, will we do the discussion at the clinic or at home? And to recognize that it's a process, that pieces of information can be shared sequentially, particularly if we start the process when children are younger. Always it's important to be simple and straightforward, and also it's important to recognize that it's the adults who worry most about stigma and loss of hope. Many parents or grandparents will say, "I don't want my child to know because I'm afraid that they'll give up hope." In fact, children often take the information in stride. When they're at the elementary age, they are very concrete in how they hear and process information. They are likely to hear the information and think of practical ways in which it applies to them. Usually they are not aware of the stigmatizing or life-threatening nature of HIV and therefore do not have the intense emotional response that adults experience. Children who have already experienced the death of loved ones may ask if they also will die. Comforting answers, such as "we are working together to keep you healthy" are appropriate in these situations.

Symptom Management

- Excellent medical management to control symptoms
 - Pain (head, chest, abdomen, limb)
 - Dyspnea
 - Nausea and vomiting
 - Diarrhea
 - Bleeding

Slide Note

Another core component of palliative care is providing excellent medical management to control symptoms. Children experience the same symptoms as adults. They have many pains. They can have headache, pain in their chest from esophagitis, from pneumonia. Pain in their abdomen from diarrhea, liver disease, mycobacterium avium in their gut, tumors, they can have limb pain from neuropathy, from bone pain, joint pain. They can have dyspnea, shortness of breath due to pneumonia, due to cardiomyopathy, due to chronic lung disease. They can have nausea and vomiting with an acute illness, because of g.i. disease, or because of side effects of their medication. Children experience diarrhea, either from their medications or from the infections to which they're susceptible. They can have bleeding either due to liver disorders or to low platelet counts.

In this era of highly active antiretroviral therapy, symptoms and side effects adversely affect adherence to medication. We can improve adherence by anticipating and aggressively managing medication side effects. Integrating palliative care from the time of diagnosis thus improves a child's quality of life in the short term and survival in the long term.

Symptom Management

- Assess accurately
 - Developmental approach
- Manage effectively
- Barriers to effective management
 - Fears (morphine, addiction, death)
 - Lack of professional knowledge & skill
 - Effective medicines unavailable

Slide Note

For children as for adults, it's important to assess for symptoms accurately. This means we have to have a developmental approach to the *assessment* of symptoms. And we need to *manage* their symptoms effectively. This requires us to know what treatments bring relief.

There are barriers to effective management. There are fears, on the part of parents and on the part of health care professionals, of morphine for instance: "If you're giving morphine to my child, it must mean my child is going to die." Some fear addiction; this is particularly important in families that have already suffered with substance abuse and addiction behaviors in adults. Worries that their children could become addicted can cause adults to withhold opioids from children who need them to manage their pain and their dyspnea. Some fear that death will occur from the use of opioids for treating symptoms.

Other barriers include the lack of professional knowledge and skill on the part of pediatricians who don't have palliative care skills and experience, and of adult palliative care professionals who don't have pediatric skills.

Sometimes the effective medications are unavailable, or we don't have proof that they are safe and effective for children, or we don't really know the best doses for young children, or the formulations in which medications are dispensed are not ones that children can use.

Symptom Management

- Screen
 - Ask about symptoms at each encounter
- Assess
 - Severity, pattern, previous treatments
- Treat
 - Medicines and non-medicine techniques
- Re-assess
 - Has the treatment worked?
- Titrate as needed
- Re-assess at regular intervals

Slide Note

The cycle for symptom management is the same as in adults. We need to screen first, and it is so important to remember to ask about symptoms in each of our encounters with children whether in the outpatient arena or inpatient arena. It's remarkable how many things children won't tell us about if we don't ask, how many things parents won't tell us about if we don't ask. We have to ask.

When we find out that a symptom exists, we need to assess that symptom – how severe is it, what's the pattern of the symptom, what previous treatments have the patient and family already tried, and how did they work? We need to treat the symptom, using medicines when that's appropriate, and using non-pharmacologic techniques whenever that can be helpful. And then we need to assess, did our intervention work? Has the treatment been effective? If it has, we need to continue it. If it hasn't we need to change it until it becomes effective. We need to titrate doses whenever needed in order to achieve our goal of controlling symptoms. And then we need to reassess at regular intervals to be sure that our symptom management strategies are still working, that new symptoms haven't occurred, or that symptoms have resolved and the treatment can be discontinued.

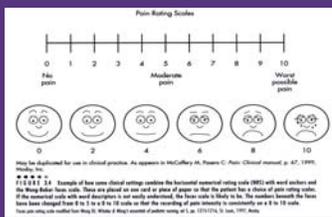
Assess Symptoms

- Pain assessment most developed
- Tools require child response
 - Faces scale
 - Visual analog scales
- Direct observation: facial grimace, tense, quiet, fearful
- Therapeutic trial of analgesia

Slide Note

In assessing symptoms, pain is the symptom that we have the most experience assessing in children. We have tools that have been developed for children, but they require the child to be able to answer a question such as, “how much pain do you have?” by using the Faces Scale or a visual analog scale. For children who are nonverbal or not able to use those scales, we are left with direct observation. Behavioral observation scales exist for infants. Children with facial grimacing, children who are very tense, have tension in their bodies, who are very quiet, who seem very fearful, are children who can be in pain. Sometimes a therapeutic trial of analgesia is the best and only approach that we have to determine if pain is what’s causing the child’s distress.

Wong-Baker Faces Scale



Slide Note

This is the Wong-Baker Faces Scale. The scale is printed on a pocket card carried by the clinician and used to ask children about their pain. On a scale from 0 to 10, zero means no pain at all and ten is the worst pain that you can imagine. You can see there’s a smiling face at zero that a child may recognize as being consistent with no pain. There is a sad and crying face at ten signifying severe pain. It’s important to tell children that just because that face has tears doesn’t mean that they have to be crying to say it’s a 10; if it’s the worst pain, then that’s a 10 even if they’re not crying.

Assess Symptoms

- *Vomiting, Diarrhea*: direct observation in infants and young children
- *Nausea*: need to ask, difficult to describe, decreased oral intake, fussy
- *Constipation*: often ignored, children don’t keep track

Slide Note

Assessing other symptoms: vomiting and diarrhea we can assess direct observation because we can tell when it’s happening. That comes out, the diarrhea comes out, and we have to clean it up so we know when it’s happening. Nausea, on the other hand, we have to ask about, and it’s very difficult to describe. We may only notice it because children are not taking much orally. They may be fussy. A child may say they have abdominal pain, but in talking further, it becomes clear that what they are describing is nausea. One might ask, “do you feel like you might be sick?” or “do you feel sick to your stomach?” It’s a difficult symptom to articulate or measure in children. Constipation is an important symptom in palliative care and yet we usually don’t keep track of when they have a bowel movement, often ignored. If they’re old enough to use a toilet independent parents may not know whether they’re constipated or not, making it a difficult symptom to assess. One can ask, “did you have a bowel movement today? yesterday?” or “is it hard to have a bowel movement does it hurt?”

Assess Symptoms

- *Fatigue*: need to ask, difficult to describe, may observe quiet, sleep, minimal activity, decreased play
- *Anxiety*: anticipatory fears
- *Depression*: sad, withdrawn, not interacting, changes in sleeping and eating

Slide Note

Fatigue may also be difficult to describe. Children may seem quiet, they may sleep more, activity level may be less, they may play less.

Anxiety is an important symptom. This may come out as anticipatory fears, fears before procedures such as blood drawing or other things that can cause pain.

Depression – children can be sad, they can be withdrawn, not interacting. They may sleep more, sleep less, they may eat less.

Assess Symptoms

- Direct observation can detect that something is wrong. It is nonspecific in determining which symptom is a problem.
- Need child's feedback for specificity. This is limited by child's developmental level. Adult proxies may not provide accurate assessment.
- Need to detect changes in severity over time, not only presence or absence of a symptom.

Slide Note

In summary, we can see that in assessing symptoms in children, direct observation is very important and can tell us that something's wrong. But in fact it's very nonspecific in determining *which symptom* is the problem. The child that's being very quiet or seems listless could be nauseous, could be fatigued, could be in pain, could be constipated. We don't know. We need the child's feedback to be more specific about which symptom we're dealing with, and this is limited by a child's developmental level. So we're left with trying to ask the adult proxies – the child's parent preferably – and yet sometimes they can't give an accurate assessment. But it may be the best we can get – a child's mother or father, or a nurse who has worked with the child over time, is often the best person to assess behavioral changes in the child.

Of course we want to detect changes in severity over time, not just whether the symptom is present or absent. And yet for some children the latter is all we're able to determine. They can't really tell us whether it has gotten better or worse over time. They may only be able to say it hurts now or it doesn't hurt now.

This limitation in our ability to objectively assess the presence and severity of symptoms in children means that adult caregivers, whether family members or pediatric health care professionals, must know how the child behaves when feeling well and then must spend enough time with the sick child to identify and interpret patterns and changes in behavior. More research is needed to develop accurate and reliable tools for symptom assessment in young and nonverbal children.

Manage Symptoms

- Emotional support
- Physical methods
 - Touch (stroking, massage, rocking, vibration)
 - Ice or heat
- Cognitive methods
 - Preparation for procedures
 - Distraction (music), imagery, hypnosis
 - Play
- Traditional practices that are helpful

Slide Note

In managing symptoms, we can provide a number of different kinds of non-medicine support. For example, emotional support is very important and can help to ameliorate the severity of some symptoms, particularly pain and shortness of breath, anxiety, and sleep problems. Physical touch is very important to children. Stroking, massage, rocking, vibration, are all important modalities. And in fact these are ones that we can be teaching or helping parents to be able to do. It gives them something to do to help comfort their children. The use of cold or of warmth may also help. Cognitive methods include preparation for procedures. The child life specialists in children’s hospitals and in our team are very important professionals in helping children to prepare, to understand procedures before they’re going to happen, and ways in which they can cope with procedures. Even painless procedures may seem frightening to children. Distraction, use of music, singing songs, imagery, hypnosis, are all useful in working with children and adolescents. And of course the use of play is a core modality in childhood. Traditional practices may be helpful for families from cultural groups that have traditional medicine or other alternative therapies that they know to be effective.

Manage Symptoms

- Essential drugs
 - Opioid availability
- Pediatric dosing
 - Safety and efficacy
 - Formulations
 - Pharmacokinetics
- Route of administration
- Drug interactions

Slide Note

We need to have essential drugs available. Opioid availability is essential. Children experiencing pain and dyspnea can suffer unnecessarily when opioids are not available, for example in certain countries, or in a country where there are laws that say that prescribing opioids or having opioids in any place except a hospital is illegal. We need to know the pediatric dosing for medications that are safe and effective. We need formulations, for example liquid formulations and concentrated formulations, that children can swallow and for which we can individualize doses as children change in size and body weight. We need to know their pharmacokinetics, how high a dose to use, how frequently can we use it, how that changes in the face of renal and liver disease, or by route of administration. Children don’t like needles, so we need to avoid things that are injected if at all possible. Can we give medicines orally? Children dislike rectal administration. Transdermal would seem perfect, but very few medications are available in child doses for transdermal administration. There are drug interactions between some palliative medicines and certain antiretrovirals. The protease inhibitor and NNRTI classes of antiretrovirals cause varying degrees of stimulation and inhibition of the cytochrome P450 enzyme system. Some palliative medications, such as midazolam, are contraindicated in patients taking protease inhibitors, such as ritonavir. We currently extrapolate this information from adult studies and apply it to children because there are no pediatric specific data to evaluate this interaction.

World Health Organization 3-Step Analgesic Ladder

- | |
|--|
| Step 3: Opioid for moderate to severe pain
+/- Non-opioid
+/- Adjuvant |
| Step 2: Opioid for mild to moderate pain
+/- Non-opioid
+/- Adjuvant |
| Step 1: Non-opioid for mild pain
+/- Adjuvant |

Slide Note

This slide illustrates the World Health Organization 3 step analgesic ladder. At a minimum, we need to know how to prescribe non-opioids like acetaminophen or ibuprofen for mild pain. We need to know how to prescribe opioids for mild to moderate pain, when acetaminophen or ibuprofen are not controlling the pain. And we need to know how to titrate opioid dosing in children to achieve pain relief.

Trainer Suggestion

You may wish to refer to the module on pain and symptom management for more information.

Non-opioid Analgesics

- Acetaminophen
 - 10-15 mg/kg/dose by mouth every 4-6 hours
 - Not anti-inflammatory
 - No gastrointestinal or hematological side effects
- Ibuprofen
 - 5-10 mg/kg/dose by mouth every 6-8 hours
 - Anti-inflammatory
 - Gastrointestinal and hematological side effects
- "Ceiling effect"
 - No further analgesic effect if higher dose
 - Increased toxicity

Slide Note

The non-opioid analgesics are acetaminophen at a dose of 10 to 15 milligrams per kilogram per dose, given by mouth every 4 to 6 hours. It's a pain reliever and a fever reliever, but it's not anti-inflammatory. It does not have gastrointestinal or hematologic side effects, so it's a good choice when those side effects must be avoided.

Ibuprofen is also a very effective fever and pain treatment, at a dose of 5 to 10 milligrams per kilogram per dose, given by mouth every 6 to 8 hours. It does have anti-inflammatory effects, but it also causes gastrointestinal irritation and can have anti-platelet effects. For children with platelet problems due to HIV, ibuprofen and other non-steroidal anti-inflammatory agents are not optimal choices. Unfortunately with non-opioid analgesics, there is a ceiling effect, so that even if we give higher doses, we don't get any further analgesic benefit, and in fact we get increased toxicity. So there's a limited therapeutic window in using these agents.

Opioid Analgesics

- Codeine
 - Oral: 0.5-1.0 mg/kg/dose every 3-4 hours
- Morphine
 - Oral: 0.15-0.3 mg/kg/dose every 2-4 hours
 - IV: 0.05-0.1 mg/kg/dose every 2-4 hours
- Infants <6 months – start at ¼ dose
- No “ceiling effect”
 - Titrate to effect
 - No maximum dose
 - The correct dose is the dose that works

Slide Note

On the other hand, opioid analgesics are very effective and safe in children when used in appropriate doses. Although codeine is not the most effective opioid, it is a more available opioid, especially in combination with acetaminophen, in community pharmacies. Therefore it's an important medication to know how to use in children. Children can receive codeine orally at a dose of 0.5 to 1 milligram per kilogram per dose, and it can be given every 3 to 4 hours. Morphine is safe and effective for children. Doses start at 0.15 to 0.3 milligrams per kilogram per dose, every 2-4 hours. The IV dose is one third that: 0.05 to 0.1 milligrams per kilogram per dose every 2 to 4 hours. Young infants, under 6 months, do not metabolize opioids as quickly as older children, and therefore we start at a much lower dose. It's recommended to start at a quarter of the child dose, recognizing that one needs to titrate up to effectiveness even in young infants.

In contrast to NSAIDs, opioids have no “ceiling effect”.

This means that the higher the dose of opioid, the greater the analgesic effect. There is no maximum dose. We titrate to effect, so that the dose that works is the right dose. We need to give enough medicine to control a child's pain.

As pain resolves, the dose required for symptom relief decreases until it can be safely discontinued. If ‘around the clock’ opioids have been used for several days or longer, it is important to taper the dose prior to discontinuation. It is helpful to reassure family members and pediatric health care providers that tolerance to opioids (the need for higher doses to achieve the same effect) and dependence on opioids (the fact that withdrawal symptoms can occur with abrupt discontinuation of drug) are well described medical phenomena that we know how to manage in children. This is NOT addiction. Clinical examples that may help to put these concepts into perspective include the need to taper steroid therapy for asthma if given for longer than five days, or the need to initiate ritonavir or nevirapine at low doses that are increased over time as the body's metabolism adjusts to the presence of the new medication.

Manage opioid side effects

• Constipation	Prevention is key
• Nausea and/or vomiting	Antiemetic
• Itching	Antihistamine
• Respiratory depression	Stimulate child
	Hold/reduce next dose
• Confusion/hallucinations	Change opioid
	Neuroleptic
• Myoclonus	Benzodiazepine
• Somnolence	Usually temporary
	Stimulant

Slide Note

It's important to anticipate and manage opioid side effects in children. In this slide, we can see some of the side effects on the left, and suggested interventions on the right. For constipation, it's important to prevent it using bulk and laxative agents as needed. We can provide antiemetics to children for nausea or vomiting, antihistamines for itching. If there's respiratory depression, we can stimulate the child. We don't expect respiratory depression to occur if we start with appropriate doses and titrate as needed for pain. But if a child should breathe too shallowly or too infrequently, we can shake or awaken the child, we can wait longer to give the next dose, or we can reduce the amount of the next dose. With continued assessment, we can determine the most effective dose and frequency.

If confusion or hallucinations occur, we can consider changing to another opioid or using a neuroleptic as we do for adults. If there's myoclonus, we can give a benzodiazepine. And if the child is too sleepy, stimulant medication may help relieve this symptom.

Adjuvant Therapy for Pain

Neuropathic pain
• Antidepressants
– Amitriptyline
• Anticonvulsants
– Gabapentin
– Phenytoin
Increased intracranial pressure
• Corticosteroids
– Dexamethasone

Slide Note

We can use adjuvant therapy for other kinds of pains. For neuropathic pain, which is common in HIV, giving antidepressants, such as amitriptyline, can be helpful. Anticonvulsants, such as gabapentin, or phenytoin, in addition to opioids or anti-inflammatories, can be helpful for neuropathic pain. And for children who have increased intracranial pressure due to infections, meningitis, abscesses, or tumors, giving corticosteroids such as dexamethasone can help headache due to increased intracranial pressure.

Procedural Pain

- Painless
 - X-ray
- Mildly painful
 - Venipuncture
- Moderately painful
 - Lumbar puncture
- Moderately to severely painful
 - Bone marrow aspiration

Slide Note

Children are concerned about procedural pain. There are some procedures that are painless, like having x-rays done, but for which children can be very fearful about the equipment. And in that case, psychological preparation and distraction is important.

There are procedures that are mildly painful, like venipuncture, that some children are terribly frightened of. Using topical anesthesia, like EMLA or Elamax cream, in preparation, can be very helpful. This can also be helpful in lumbar puncture.

And then there are procedures that are much more painful, like bone marrow aspiration or pleural tap, that require much more aggressive analgesia management. Collaboration with a pediatric pain specialist is recommended.

A combination of pharmacologic and non-pharmacologic approaches generally works best. For instance, an 8 year old may tolerate a lumbar puncture well if prepared beforehand about what to expect, a comforting adult is present to provide distraction such as video, and pain prevention using topical analgesia followed by subcutaneous lidocaine.

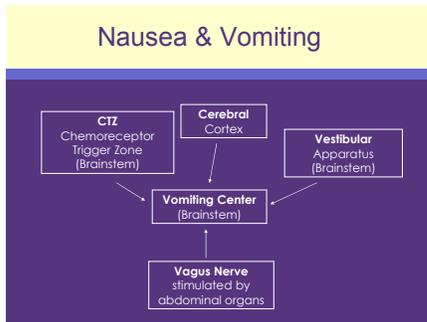
Anorexia

- Evaluate for underlying cause
 - Nausea
 - Pain
 - Depression
- Dexamethasone
- Megestrol acetate

Slide Note

Anorexia in children causes a lot of distress for parents and caregivers. The preparation and sharing of food holds great importance in our society. It is the mark of a good parent. We know children are well if they eat well, and if they don't eat, we worry about them very much.

Evaluate children for underlying causes of anorexia, such as nausea or pain or depression, or dysphagia. Perhaps they're hungry but when they start eating it hurts, so they stop. If there's not a treatable underlying cause for their anorexia, then we can sometimes stimulate their appetite using megestrol acetate or other steroids such as dexamethasone.



Slide Note

Nausea and vomiting are triggered in multiple ways so the choice of medications depends on our understanding of the cause of the symptom. Nausea and vomiting is most often associated with abdominal problems. Examples include infections, such as gastroenteritis, or drug side effects, such as gastric irritation due to protease inhibitors. These local signals are transmitted from the affected abdominal organs via the vagus nerve to the brainstem, where the vomiting center controls vomiting.

However some drugs and metabolic problems stimulate the chemoreceptor trigger zone (CTZ) directly via the bloodstream which in turn signals the vomiting center in the brainstem.

Anticipatory nausea and vomiting, seen in some children taking protease inhibitors, is mediated in the cerebral cortex. The sight or smell of the medicine is associated with past vomiting and the symptom occurs even before the dose is taken.

Nausea & Vomiting

- Metoclopramide
 - Prokinetic (cholinergic) promotes gastric and small bowel activity
 - CTZ
- Diphenhydramine, Hydroxyzine, Promethazine
 - Antihistamines
 - Vomiting center
- Haloperidol
 - Neuroleptic
 - CTZ
- Dexamethasone

Slide Note

We can treat nausea and vomiting in children with agents that target these different zones and vomiting centers.

Metoclopramide has prokinetic characteristics, promoting gastric emptying and small bowel activity to move things along so that they're not regurgitated, and it also works at the chemoreceptor trigger zone to help reduce messages to the vomiting center to vomit.

Antihistamines such as diphenhydramine, hydroxyzine, and promethazine, work directly at the vomiting center.

Haloperidol, which is a neuroleptic, works at the chemoreceptor trigger zone. And dexamethasone can be added for refractory nausea and vomiting.

Constipation

• Senna	stimulant
• Bisacodyl	stimulant
• Lactulose	osmotic
• Docusate sodium	surfactant
• Mineral oil	lubricant
• Glycerin suppositories	rectal
• Enemas	rectal

Slide Note

Medications to prevent and treat constipation fall into two main categories: drugs that increase the moisture content of stool, increasing bulk and ease of evacuation, and drugs that stimulate intestinal peristalsis. Senna and bisacodyl are taken orally and stimulate peristalsis. Lactulose and docusate are oral osmotic agents that draw water into the bowel lumen, softening the stool. Enemas and glycerin suppositories stimulate rectal evacuation directly.

Diarrhea

- Identify and treat infectious causes
- Maintain hydration
- Continue eating
- Give a constipating drug:
 - Loperamide
 - Codeine
 - Morphine

Slide Note

Management of diarrhea involves trying to identify any infectious causes that we can treat directly to resolve the diarrhea. It's important throughout to maintain hydration and to continue eating in order not to become malnourished. If the diarrhea is chronic, particularly if it's due to a side effect of antiretroviral medication, giving a constipating drug can be helpful, such as loperimide or codeine or morphine.

Respiratory Symptoms

Breathlessness – reversible

- Infections
 - Antibiotics
- Bronchospasm
 - Inhaled bronchodilator
 - Prednisone
- Congestive heart failure
 - Diuretic
 - Digoxin
 - Fluid restriction

Slide Note

Respiratory symptoms are very distressing. In children who are breathless, we need to look for reversible causes of breathlessness. So infections, such as pneumonias that can be treated with antibiotics, should be treated to reverse this symptom. Children who have bronchospasm, asthma, or reactive airways disease, can receive inhaled bronchodilators and prednisone to reduce bronchospasm and inflammation. Children with congestive heart failure can be managed with diuretics and digoxin, and if necessary fluid restriction.

Respiratory Symptoms

- Breathlessness – irreversible end stage lung or heart disease
 - Codeine, morphine for comfort
 - Lorazepam for anxiety
- Secretions
 - Hyoscyamine
 - Glycopyrulate
- Cough – severe, chronic
 - Codeine, morphine

Slide Note

But sometimes breathlessness will be irreversible, due to end stage lung or heart disease. In those situations, we need to provide comfort using opioids such as codeine or morphine. Even small doses of opioids may provide relief from the sensation of breathlessness or dyspnea. If children become very anxious at this time, be prepared to provide lorazepam for their anxiety as well. If the respiratory symptoms are due to increased secretions - oral secretions, pharyngeal secretions – giving hyoscyamine or glycopyrulate can help to dry secretions. Robinol can also help to dry secretions so that they don't cause symptoms. And cough that's severe or chronic can be suppressed using opioids such as codeine or morphine.

Trainer Suggestion

You may wish to refer to the pain and symptom module for more information on managing dyspnea.

Fevers

- Acetaminophen
- Ibuprofen

Slide Note

Fevers can be recurrent or chronic and very uncomfortable. Treating fever with acetaminophen or ibuprofen, even when we can't find or treat the underlying cause, can provide comfort. Sometimes administering antipyretic around the clock is more effective than giving it prn.

Restlessness & Agitation

- Evaluate for underlying causes
 - Metabolic, infectious, drug toxicity
 - Treat pain directly
- If agitation persists
- Lorazepam: initial dose 0.02 – 0.04 mg/kg/dose up to 4mg by mouth or IV every 4-6 hours
- Severe, unresponsive agitation or psychosis
- Haloperidol: 0.01 – 0.1 mg/kg/dose by mouth or IV every 8 hours

Slide Note

Some children will become restless and agitated. We always need to evaluate for underlying causes, as in adults. Look for metabolic causes, look for infectious causes. Look for and suspect drug toxicity.

It's not appropriate to sedate someone for agitation when they're agitated because they're in pain and can't tell us. We need to assess for pain, and if pain could exist, we need to treat that directly. If the agitation persists after we've evaluated and treated potential causes, then we can consider using lorazepam in an initial dose of 0.02 to 0.04 milligrams per kilogram per dose, up to a maximum of 4 milligrams per mouth or IV every 4 to 6 hours. Severe, unresponsive agitation or frank psychosis can be treated using haloperidol, 0.01 to 0.1 milligrams per kilogram per dose, either by mouth or by IV every 8 hours, as a starting dose. An advantage of haloperidol over other neuroleptics is that it can be given intravenously in a child who is too unresponsive to take medication by mouth.

Sleep Disturbance

- Sleep inducing drug at bedtime
- Lorazepam
 - Diphenhydramine
 - Chloral hydrate
 - Melatonin
- Stimulant drug in morning
- Methylphenidate
 - Dextroamphetamine

Slide Note

Sleep disturbance is exhausting for the patient and for the parents. Consider giving a sedating drug at bedtime, such as lorazepam or diphenhydramine or chloral hydrate. Melatonin may also be effective in regulating sleep onset. We can also try a stimulant drug in the morning, to try to have children stay awake during the day so that they don't nap and they are able to sleep better at night. We've had success using methylphenidate or dextroamphetamine in the morning for this purpose.

Advanced Disease

- How do we know a child is approaching the end of life?
 - Pattern of complications more frequent and severe
 - Recovery is never back to baseline
 - Not responding to HAART
 - Help one problem and two more get worse
- Death can be sudden and unexpected

Slide Note

What about when children have advanced disease? How do we know when a child is approaching the end of life, despite all of our efforts to treat and aggressively manage their HIV disease? We recognize that children are deteriorating when the pattern of their complications becomes more frequent and severe, or if they improve after a complication, but their recovery is not back to baseline. When children stop responding to their antiretroviral therapy, no matter what combinations we give, or what we try, they're just not able to increase their CD4, or maintain their clinical status. And finally, when we work very hard to treat one problem, and at the same time 2 more get worse, and we feel like the problems are spinning out of control, then a child is approaching the end of life. Although death from HIV can often be anticipated if we heed these clinical patterns, we also recognize that for children with HIV, death can be sudden and unexpected. We've had adolescents with good CD4 counts, on minimal therapy, who had sudden episodes of sepsis or cardiac arrest for which we and the families were completely unprepared. So even in good clinical situations, we have to recognize that we do not control the outcome of this disease. On some level, we must always be prepared for the unexpected. This is another reason to integrate palliative care with HIV treatment right from the beginning.

Advanced Disease

- Decisionmaking
 - What is medically possible?
 - What is uncertain?
- Review values and goals
 - Views change with time and experience
 - Patients may become unable to communicate
- Listen carefully; respect child and family wishes
- "Hope for the best; plan for the worst"

Slide Note

It's important, as disease advances, to remember decision making, and to review: What is possible and what is uncertain. We must be honest with ourselves and honest with our children and families about what we know and what we don't know, what we can do and what we can't do. It's important to review again values and goals for children and families. Views of what's important change with time, and change with experience of illness, with hospitalization, with deterioration, with deaths of other people who are close to them. We need to do this before patients become unable to communicate with us. We've had a number of adolescent patients who've had strokes and who've been unable to then talk with us and unable to share with us their preferences, their wishes for future care. We need to listen carefully and be respectful of the child's and family's wishes. And we always hope for the best but we plan for the worst. We always hope for miracles but we recognize that we need to be prepared in case the miracle we're hoping for doesn't occur.

Advanced Disease

- Discontinue antiretroviral therapy
 - If all regimens have failed
 - If medicines are causing more problems than they are helping
 - If it is impossible to administer the medicines
- Continue active management consistent with palliative care goals
- There is NEVER "nothing more we can do"

Slide Note

When children have far advanced disease, it's appropriate to consider whether to discontinue antiretroviral therapy. If all the antiretroviral regimens have failed, then why are we continuing them? If the medicines are causing more problems than they're helping, why are we giving them? If they're causing more side effects without giving benefit, what's the point? It may become impossible to administer the medications. The medications we give for HIV are available only as oral preparations, often only as pills. If children are so sick that they can't tolerate oral medication, if they can't swallow, if they can't tolerate nasogastric or gastrostomy tube feedings or medications, then we can't give the medicines any more.

Even in these situations, we must continue active management that is consistent with the palliative care goals. There is never ever nothing more that we can do.

Social & Emotional Care near End of Life

- Developmentally appropriate activities
 - Physical touch
 - Play
- Honesty
- Legacy and memory making
 - Photographs & videos
 - Hand molds, hand prints
 - Child's wishes after his/her death

Slide Note

We need to provide social and emotional care at the end of life that's developmentally appropriate. Again, remember the importance to children of physical touch, the importance of play, and the importance of being honest and open about what's going on. But also remember that honesty does not extend to burdening children with our worries. We should not insist that they talk about death, or plan for death if that's not what they understand or not what is important to them right then. Recognize the importance to them of having loved ones near, and of doing favorite things. The importance to families of being near their children and of knowing that the end of life is approaching, so that they can be spending time and doing valued activities.

Remember the importance of legacy and memory making activities, of taking photographs, of making videos of children, making hand molds or hand prints for people to keep after their children die. Of finding out from children and adolescents if they have wishes for after their death. We've had adolescents who had very specific instructions for favorite toys and belongings to be given to other people. Others have thought about or planned their funeral.

Physical Comfort at the End of Life

- Moisten lips, mouth, eyes
- Keep child clean & dry
- Only give essential medications
- Control symptoms with medical treatment as needed
- Eating less is OK
- Skin care/turning at least every 2 hours
- Make sure pain is controlled

World Health Organization, IMAI

Slide Note

It's important to remember physical comfort at the end of life. We can instruct and remind parents that they can actively promote their child's comfort in several ways. To moisten the child's lips and mouth and eyes, to keep a child clean and dry. To give only those medications that are essential for controlling symptoms, that are helping them to feel better, to improve their quality of life. And not treatments that simply add burden by giving lots of pills and liquids. To remember that eating less is okay – it's part of the dying process. And comforting parents to know that this is a normal part of the end of life rather than a failing on their part to have their child be hungry or eat. Providing good skin care, turning the child at least every few hours, and making sure that pain is well controlled.

End of Life

- Breathing pattern changes
 - Apnea, agonal, rattle
- Sleeping more
- Appetite less
- Urination less
- Pain may lessen with loss of consciousness
- Extremities cool to touch

Slide Note

We need to help our families learn about what happens during the last days and hours of life. If they know what changes might occur, what they can expect, they don't have to be frightened about the unknown. They need to know that the breathing patterns may change. That the child may be apneic, may hold their breath – not breathe for several seconds at a time. They may observe agonal breathing: the cyclic variation of deep breathing to shallow breathing to apnea and back again. That a rattling sound in the throat may occur in children. It is important to reassure families that this isn't suffocating or drowning in their secretions, but rather a small amount of fluid that is pooling in the throat. Despite the unpleasant noise, it does not cause the child any distress. Children may sleep more, and that's okay. Their appetite will be less, and that's okay. They will urinate less, because they're taking in less fluid, and their body is gradually slowing down. As children lose consciousness, their pain may decrease. Pain medicines should be reviewed frequently at this time to maintain comfort without administering unnecessary medication.

As circulation decreases, the extremities become cool to the touch. Families should be encouraged to remain physically present with the child, talking to the child in comforting tones, and touching or holding the child until death occurs.

Care at Home

- Most children prefer to be at home with family
 - What if they are orphaned?
- Family caregivers need training and support
 - Physical care and comfort
 - What to expect as death approaches
 - Bereavement care

Slide Note

It's important to prepare and support families to allow children to die at home if possible. Most children prefer to be at home with their families, especially when they feel sick. They do not want to be alone or separated from those they love. But how do we fulfill this wish for children and adolescents who are orphaned by the AIDS epidemic or who have no home? We need to advocate for inpatient hospice services for children and adolescents, whether hospital-based or community-based. And we must remember to advocate for stable guardianship and living situations for all children and adolescents with HIV/AIDS throughout the course of disease.

Families need training and support – in how to provide physical comfort and care, providing concrete examples as we've already discussed, so that they know they can actively promote comfort.

Families need to know what to expect when their child is dying. How to know when death is near. When to call other family members, siblings to visit, to say goodbye.

Palliative care includes bereavement care – the loss of a child is the most profound loss that parents can experience. It is an excruciating and lifelong loss. Siblings also need bereavement support that is developmentally appropriate. It should fit their understanding of illness and death. Parents and other adults need to learn that children will react to death in different ways related to their cognitive level of understanding.

Hospice care

- Home or facility
- Interdisciplinary team
 - Nurse
 - Physician
 - Social worker
 - Spiritual care
 - Bereavement care
 - Volunteers

Slide Note

Hospice care for children is usually provided in the home. Theoretically inpatient hospice should exist for children when needed for respite or for symptom control, but in reality this is often unavailable. We need to integrate hospice care into our inpatient care for children dying with HIV.

Hospice care for children is provided by an interdisciplinary team. Many pediatric HIV centers are staffed with interdisciplinary HIV care teams. They have continuity and long-term relationships with children and families and are in an excellent position to provide palliative care and link closely with hospice professionals to provide comprehensive hospice services.

Care of the Family

- Saying goodbye
 - Sibling visits
 - Extended family
- Bereavement support
 - Maintain contact
 - Families want to know their child is not forgotten

Slide Note

Families will not have the opportunity to say goodbye if we do not inform them that a child is nearing the end of life. It is important to provide siblings opportunities to visit their sick brother or sister, even in the potentially frightening environment of the intensive care unit, in order to know that they have been cared for and to say goodbye. Child life specialists are skilled in preparing and facilitating sibling visits.

Bereavement support is provided when we maintain contact with families after the death of their child. Telephone calls, cards, visits are all deeply appreciated. Families appreciate knowing that their child is not forgotten.

Caring for the Caregiver

- Compassion fatigue & burnout
 - Multiple losses
 - Young death “unnatural”
- Intentional plan for prevention
 - Rest
 - Exercise
 - Our families
 - Personal reflection

Slide Note

Caring for children and adolescent with HIV/AIDS is emotionally and professionally rewarding and yet consuming. Professionals are at risk for compassion fatigue and burnout. HIV caregivers experience multiple losses. Pediatric caregivers may experience more complicated emotions due to the “unnaturalness” of child death and of our identification with the parents’ profound loss.

To prevent burnout from occurring, adequate rest, both sleep and time away from our work, are necessary to restore our energies. Getting exercise. Spending time and attention on our families, nurturing our important relationships. We need to take time to reflect on ourselves, our work, what brings meaning to our lives, what we can control, and importantly, what we cannot control.

In summary

- Children are infected and affected by HIV/AIDS throughout the world
- HIV management involves treatments used in adults, but must be tailored to the child
- As children survive longer with HIV, their medical and social needs change
- HIV/AIDS affects the whole child in the context of his or her family and community

Slide Note

In summary, children are infected and affected by HIV/AIDS throughout the world. Their needs must be recognized and addressed in all countries and in all HIV programs. HIV management uses most of the same medicines, tests, and interventions used in adult patients. But they need to be tailored for the child – to their size, or their understanding, or to their home and family living situation.

We are now seeing children born with HIV survive through adolescence and into early adulthood. Their medical needs become more complex as they live longer with this disease and are exposed to more medications with new and emerging side effects and toxicities. Their social needs change as their peers become more important, intimate relationships begin, and adult caregivers become sick and die.

HIV affects every aspect of the child’s life, including the family and community in which they live.

In summary

- ARV dramatically alters the course of HIV when taken perfectly, but some children are unable to achieve this goal
- There is still no cure for HIV
- Palliative care promotes quality of life. It is an integral part of HIV care, beginning at diagnosis and continuing throughout a child's life

Slide Note

We know that antiretroviral therapy dramatically alters the course of HIV in children and adolescents as it does in adults – as long as it is taken perfectly – but some children are unable to achieve this goal

There is still no cure for HIV – we must not forget the ultimate prognosis and outcome as we plan care and weigh options.

Palliative care provides the framework for holistic comprehensive HIV care that begins at the time of diagnosis and continues throughout a child's life, however long it will be.

Contributors

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This project is funded by the Health Resources and Services Administration (HRSA) and the Robert Wood Johnson Foundation (RWJF).

Pediatric HIV/AIDS Palliative Care

Pre-Training Survey

Thank you for completing this survey. Your input will help us improve our training program and will provide information about its effectiveness to guide future planning. Please answer these questions as best you can – if you're not sure of an answer, just give it your best try.

Date: ___/___/___ ID: Birth month: ___ Day: ___ Last 4 digits of SSN: _____

- 1. Please rank your current level of skill in the area of pediatric HIV/AIDS Palliative Care by checking one of the following numbers from 1 to 5:**

Need more skill for basic competency			Moderately skilled			Highly skilled
1	2	3	4	5		
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- 2. What is your level of personal comfort with providing pediatric HIV/AIDS Palliative Care?**

Very uncomfortable			Somewhat comfortable			Very comfortable
1	2	3	4	5		
<input type="checkbox"/>						

Post-Training Survey

Thank you again for your input to help us improve our training program and guide future planning. As before, please answer these questions as best you can – if you’re not sure of an answer, just give it your best try.

Date: ___/___/___ ID: Birth month:___ Day:___ Last 4 digits of SSN:_____

1. Please respond to the following questions regarding this training using the scale below:

	Not at all		Somewhat		Very much
Did the training hold your interest?	<input type="checkbox"/>				
Did you learn things in the training that will be useful for your work?	<input type="checkbox"/>				
How understandable was the material presented to you?	<input type="checkbox"/>				
Were the educational materials, such as slides or handouts, useful?	<input type="checkbox"/>				
How responsive was the trainer to the audience’s questions?	<input type="checkbox"/>				
Did you feel the trainer’s presentation was culturally sensitive?	<input type="checkbox"/>				

2. What were the strengths of this presentation?

3. How could we improve this presentation?

4. Would you recommend this training to someone else? Yes No

5. Please rank your current level of skill in the area of pediatric HIV/AIDS palliative care by checking one of the following numbers from 1 to 5:

Need more skill for basic competency		Adequate skill		Highly skilled
1	2	3	4	5
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6. What is your level of personal comfort with providing pediatric HIV/AIDS palliative care?

Extremely uncomfortable			Somewhat comfortable		Extremely comfortable
1	2	3	4	5	
<input type="checkbox"/>					

7. What do you anticipate doing differently in your work as a result of this training?

8. How much did this training help prepare you to do the following:

	Not at all		Somewhat		Very much
Provide primary end-of-life care for patients with HIV?	<input type="checkbox"/>				
Provide education and training to other clinicians on end-of-life care issues?	<input type="checkbox"/>				
Advocate for better palliative care in your workplace?	<input type="checkbox"/>				
Other _____	<input type="checkbox"/>				

9. Would you be willing to be contacted in one month for a brief follow-up? Yes No
If yes, what is your email address? _____

10. Please write any additional comments, thoughts, or suggestions here. We appreciate your taking the time to complete these surveys. Thank you very much!

Pediatric HIV/AIDS Palliative Care

Follow-Up Survey

[This is a sample of a letter to send out to your training participants 4-6 weeks after the training.]

Hello!

About a month ago, you attended a presentation on Pediatric HIV/AIDS Palliative Care, given by [presenter].

Thank you for participating in our evaluation. Your survey responses have been very helpful for planning the next steps in our training program. Thanks also for agreeing to answer some follow up questions for our evaluation. If you have a few minutes to answer the following questions, it would be very helpful.

Now that a month has gone by...

1. What changes, if any, do you feel you have made in your work as a result of this training session?
2. Please rank your current level of skill in pediatric HIV/AIDS palliative care:
(1=Need more skill for basic competency; 3=Adequate skill; 5=Highly skilled)
3. What is your overall rating of the quality of the session you attended?
(1=Poor; 3=Average; 5=Excellent)
4. Please write any additional comments, thoughts, or suggestions here.

Please contact me [your contact information here] if you have any questions about our project or if you'd like us to keep you informed of any upcoming training sessions. Thanks again!

Suggested Handout

1. Hutton, N and Oleske, JM, (2003) The care of children and Adolescents, in O'Neill J et al, A Clinical Guide to Supportive and Palliative Care for HIV/AIDSvU.S. Department of Health and Human Services Health Resources and Services Administration, HIV/AIDS Bureau. At [http:// http://hab.hrsa.gov/tools/palliative/](http://hab.hrsa.gov/tools/palliative/)

Resources

Pediatric HIV/AIDS Palliative Care Resources

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