A Clinical Guide to Supportive and Palliative Care for HIV/AIDS in Sub-Saharan Africa

2006 Edition

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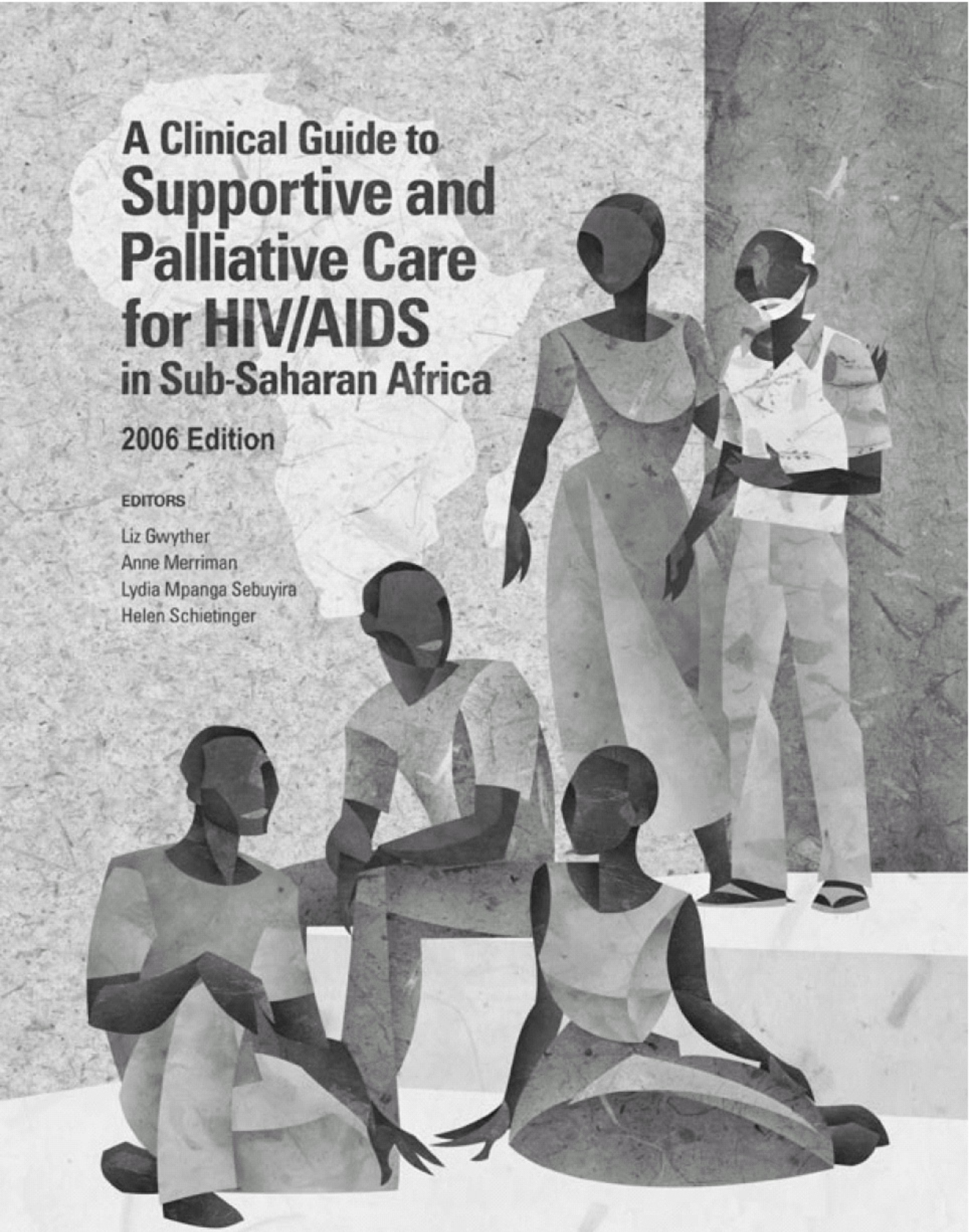

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Clinical Assessment of Children

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At a Glance

Overview

HIV/AIDS in Africa is a multigenerational disease of families in which everyone, whether HIV positive or not, is affected by the disease. Support for the children infected with and affected by HIV must be delivered as a comprehensive package from a platform that can provide continuity of care to the whole family. Palliative care, provided from diagnosis of HIV infection through advanced AIDS, is the approach that best delivers the holistic care needed by children living with HIV/AIDS.

This chapter describes the context for palliative care of children and adolescents in the African setting, natural history and diagnosis, and overall clinical presentation of HIV disease in children. It also covers the diagnosis of HIV infection and the framework for monitoring and ongoing palliative management. Chapter 27 addresses clinical management of the conditions and symptoms of HIV disease, while Chapter 28 covers the integration of palliative care with of antiretroviral therapy (ART). Chapters 29 through 32 focus on the various aspects of psychosocial and spiritual care.

Adapted from Chapter 12: The Care of Children and Adolescents, by Nancy Hutton, MD, in: O'Neill JF, Selwyn PA, Schietinger H, eds. *A Clinical Guide to Supportive and Palliative Care for HIV/AIDS, 2003 Edition*.

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Chapter 26

Clinical Assessment of Children

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Epidemiology of HIV in African Children

Sub-Saharan Africa holds only 10% of the world's population but 60% of all people living with HIV. Of these, 57% are women and girls: 75% of all women with HIV worldwide live in the region. Amongst young women aged 15–24 years, an estimated 6.9% were living with HIV at the end of 2004 (UNAIDS, 2005). The risk of transmission of HIV to a child born to a mother with HIV absent interventions to prevent transmission is about 30–40%. Children who do not acquire HIV from their mothers perinatally still have a 2- to 5-fold risk of mortality as a direct consequence of the mother's HIV disease, when compared to children whose mothers are HIV-negative (ANECCA, 2004).

HIV/AIDS has become a major cause of infant and childhood mortality and morbidity in Africa, accounting for a rise of over 19% in infant mortality and 36% in under-five mortality (ANECCA, 2004). Worldwide, 610,000 children died of AIDS in 2002 and to date over four million children under the age of 15 have been infected with HIV since the epidemic began (UNICEF, 2005; WHO, 2004a).

Ninety-five per cent of children with HIV were infected by vertical transmission from mother to child (MTCT). The other infections are accounted for by sexual abuse, transfusion of blood and related products, and other forms of horizontal transmission (sharing of expressed breast milk, nosocomial spread in nurseries).

In many parts of the continent, people with AIDS are severely stigmatised. Often the mother of a child with HIV will not disclose the diagnosis to her family. Non-disclosure deprives the mother of emotional support from her family and prevents the family from planning for the care of affected family members (see Chapter 29: Psychosocial and Spiritual Care).

Clearly, the prevention of mother-to-child transmission is the most cost-effective means of reducing HIV-related suffering amongst children. However, the infrastructure to make effective interventions available to all does not exist in sub-Saharan Africa. Rapid testing for HIV and perinatal single-dose nevirapine alone can reduce vertical transmission by half. Programmes that also provide ART to mothers with HIV after delivery — referred to as 'MTCT plus' — result in maximal reduction in MTCT and reduce the number of children who are orphaned. As expensive as such programmes may seem, they would reduce both the social cost of the epidemic and the medical cost of treating sick children.

Two Resources on Paediatric HIV Care in Africa

African Network for the Care of Children Affected by AIDS (ANECCA). Tindyebwa D, Kayita J, Mosoke P, et al, eds. 2004. *Handbook on Paediatric AIDS in Africa*. Uganda: African Network for the Care of Children Affected by AIDS. Available at: http://www.fhi.org/en/HIVAIDS/pub/index.htm. Accessed 6/05.

WHO. 2000. *Integrated Management of Childhood Illness: Management of the Child with a Serious Infection or Severe Malnutrition: Guidelines for Care at the First-Referral Level of Care in Developing Countries*. Chapter 8: Children with HIV/AIDS. Available at: http://www.who.int/. Accessed 6/05 (search for IMCI).

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Palliative Care in Resource-limited Settings

Limitations in Paediatric Palliative Management

In Africa HIV/AIDS is a disease often associated with extreme poverty and a lack of access to adequate health care. HCWs are faced with ethical dilemmas in respect of rationing and suboptimal care. The holistic element of palliative care requires that we do the best we can with what we have (see Chapter 33: Effects of Economics on Service Development). On the other hand we should be proactive in our efforts to advance the material cause of our patients and we should be open to opportunities that increase health care resources by non-governmental means (see Chapter 34: Models of Community-based Care and Chapter 37: Partnerships and Collaboration). Faith-based contributions and non-governmental organizations can lay the foundations for meaningful additions to health care resources. Advocacy and activism must follow to achieve the political will necessary to sustain such advances (see Chapter 35: Role of Government).

There are major limitations to palliative care management of children with HIV/AIDS in resource-limited settings.

- *Making a diagnosis of HIV infection is more challenging with limited laboratory resources, especially in very young children.* Healthcare settings with limited laboratory resources must rely on clinical signs and symptoms to diagnose HIV infection (see section in this chapter on clinical presentation and diagnosis). Because most of the clinical conditions are also seen in children who are not HIV-infected, making the diagnosis in this way is more challenging. In addition, even if available, HIV antibody tests in children below the age of 18 months only indicate whether the mother is HIV-positive. This is because even if children younger than 18 months are HIV-negative, they can still have their mother's HIV antibodies. Virological HIV tests, which do indicate the presence of HIV virus in infants, remain expensive. (See section on laboratory diagnosis.) For these reasons, a significant number of children, especially in developing countries, become symptomatic and die during infancy without receiving a definitive diagnosis of HIV/AIDS.
- *Disease manifestation varies with age.* Children are not a uniform population. Younger children with HIV have different opportunistic diseases than older children do. Younger children tend to get the common childhood diseases though they may be severe and more difficult to treat. As they grow older they progressively develop disease conditions caused by reactivation of previous infections, as is often seen in adults.
- *Treatment protocols vary by country.* Each area of sub-Saharan Africa has specific guidelines for first- and second-line treatment of diseases, depending on the antimicrobial resistance patterns and available antimicrobial agents. Because treatment recommendations are not possible, health care workers (HCWs) should consult their national guidelines for treatment of diseases.
- *Living conditions are often not amenable to good hygiene.* For example, unclean water, whether from a tap or natural source, is a common cause of enteric infection. Families that do not have tap water in their homes tend to store water in open containers from which water is dispensed by dipping into it with a pitcher or a cup, perhaps further contaminating the water with organisms from the person's hand. Also, using precious fuel to boil water is a hardship for many families with limited resources.

Palliative Care at the Primary Care Level

Most children with HIV/AIDS will be managed or assessed for referral at the primary health care level. However, this is where health care resources are their lowest. Usually a nurse without advanced training is in charge for a wide range of health activities and for a large number of clients. See Part 6 for more discussion of these issues.

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Most sub-Saharan African countries are implementing the Integrated Management of Childhood Illness (IMCI) (see Box 26.1). HIV/AIDS care has recently been added to this integrated approach but experience is limited on how this is working out. This will certainly raise challenges of diagnosis using clinical criteria and increased demands on the already overloaded and poorly facilitated primary HCWs. Despite these challenges, the basic principles of palliative care still apply even at the community level, including:

- Management of pain and other common symptoms
- The fact that something can always be done
- Communicating with caregivers
- Finding other resources in the community, such as spiritual leaders, who could participate in care
- Appropriate referrals

Box 26.1:

Integrated Management of Childhood Illness

The guidelines for Integrated Management of Childhood Illness (IMCI) focus HCW training and attention on not one but all the leading killers, which can be managed with simple and affordable treatments, and address disease prevention and education of the mother (WHO, 2000). HIV/AIDS is being incorporated into the guidelines for Integrated Management of Childhood Illness in many African countries. HCWs should contact their ministry of health to learn how to obtain information and training on this initiative by the Child and Adolescent Health and Development of the World Health Organisation.

Natural History of HIV in Children with Perinatal Infection

The natural history of HIV disease in children differs from that of adults. Children tend to die more quickly. In the absence of ART, survival is dependent on access to comprehensive and intensive health care. The early death rate is markedly higher in Africa than elsewhere (Spira, 1999). In developed countries, prior to ART fewer than 10% of vertically-infected children were likely to die before they were a year old and median survival from the time of diagnosis was 38 months. In developing countries, 25% of HIV-infected children die before they are a year old and 90% are dead by the time they are three years old. This difference in mortality between 'North' and 'South' points to disparities in resources and access to care.

Early death is due to the common causes of morbidity and mortality among all children in developing countries. In children first diagnosed <6 months of age, a combination of diarrhoea, pneumonia, failure to thrive, and neurological abnormalities should alert one to the possibility of rapidly progressive disease and death. Yet, as is suggested by the far lower annual death rates observed in developed countries, many early deaths are preventable. A small group, perhaps 5–10%, are long-term survivors who may remain asymptomatic and without significant symptoms or signs for many years (Nielsen, 1997; Spira, 1999).

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Clinical Presentation and Diagnosis

Diagnosis Using Clinical Signs and Symptoms

In the absence of laboratory facilities, HCWs must depend upon clinical signs and symptoms in conjunction with a good history to diagnosis children with HIV/AIDS. In general, the clinical features of HIV disease in children are not specific, either in respect of making the diagnosis of HIV infection or in determining prognosis. While the the diseases in the first category in Table 26.1 are diseases that point very strongly to a child having HIV/AIDS, they too usually depend upon laboratory or radiologic tests for diagnosis. The conditions in the second category, common in HIV-infected children and uncommon in uninfected children, are not as specific. When HCWs identify a child with any of these conditions, they should suspect HIV and obtain additional history (such as maternal health) and, if available, laboratory tests.

In the complete absence of laboratory facilities, a simpler list of clinical signs and symptoms can be used to determine whether a child is likely to have HIV/AIDS (see Box 26.2). The WHO Integrated Management of Childhood Illness, adapted by many countries in Africa, uses this approach (WHO, 2000).

Table 26.1: Clinical Signs or Conditions in Children that May Suggest HIV Infection

Specificity for HIV Infection	Signs/Conditions
Signs/ conditions very specific to HIV infection	Pneumocystis pneumonia Oesophageal candidiasis Extrapulmonary cryptococcosis Invasive salmonella infection Lymphoid interstitial pneumonia Herpes zoster (shingles) with multi-dermatomal involvement Kaposi's sarcoma Lymphoma Progressive multifocal leukoencephalopathy
Signs/ conditions common in HIV-infected children and uncommon in uninfected children	Severe bacterial infections, particularly if recurrent Persistent or recurrent oral thrush Bilateral painless parotid enlargement Generalised persistent non-inguinal lymphadenopathy Hepatosplenomegaly (in non-malaria endemic areas) Persistent and/or recurrent fever Neurologic dysfunction Herpes zoster (shingles), single dermatome Persistent generalized dermatitis unresponsive to treatment
Signs/ conditions common in HIV-infected children but also common in ill uninfected chldren	Chronic, recurrent otitis with ear discharge Persistent or recurrent diarrhoea Severe pneumonia Tuberculosis Bronchiectasis Failure to thrive Marasmus

Source: ANECCA, 2004.

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Box 26.2:

Diagnosis of HIV/AIDS in the Absence of Laboratory Facilities

In the absence of laboratory facilities, classify children as having symptomatic HIV/AIDS if any three or four (depending on the country) of the following conditions are present:

- Recurrent pneumonia
- Oral thrush
- Present or past ear discharge
- Persistent diarrhoea
- Very low weight
- Enlarged lymph nodes
- Parotid enlargement

Source: ANECCA, 2004.

The most common presenting signs of HIV infection in infants include failure to thrive, hepatosplenomegaly, and diffuse adenopathy. In any child, these findings should raise the possibility of HIV infection. Children with HIV/AIDS may also have frequent or chronic diarrhea, frequent minor bacterial infections such as otitis media and sinusitis, and refractory thrush. Extensive warts or molluscum contagiosum, or severe refractory noninfectious skin manifestations such as atopic dermatitis should raise the suspicion of HIV infection. See Chapter 27: Management of Clinical Conditions for more on clinical presentation and management of various symptoms and diseases.

HIV Counselling

Any time a HCW is considering a diagnosis of HIV/AIDS in a child, whether with or without HIV testing, HIV counselling of parents or guardians as well as older children is an important part of the process. HCWs need to determine what they understand about HIV/AIDS, provide them with accurate information, and assist them in coping with the diagnosis. If testing is involved, pre- and post-test counselling should be offered.

Laboratory Diagnosis of HIV Infection

Where tests are available, HIV/AIDS may be confirmed in a child >18 months of age with the following tests:

- Antibody test: an antibody test confirmed with a second (different) antibody test (usually a Western Blot)
- PCR test: an HIV PCR test (also called a viral load test), which is less available and more expensive

In a child <18 months of age, testing for HIV infection is not as simple:

- Antibody test: At this age, an antibody test reflects the mother's HIV status, not the child's (the child still has the mother's antibodies in the blood). However:
  - A negative antibody test is useful in ruling out HIV.
  - A positive antibody test provides the important information that the mother is most likely HIV-positive and may have transmitted the infection to the child. In this case, either immediate PCR testing or antibody testing at 18 months of age can determine whether the child is HIV-infected.
- PCR test: The HIV PCR tests do indicate the child is HIV-infected.

Breast-feeding: If the mother is HIV-positive and continues to breast-feed, she can transmit HIV to her uninfected infant. HIV-exposed children who continue to breast-feed should be retested 3–6 months after complete cessation of breat-feeding before HIV infection can be excluded.

Clinical Classification of Disease Stage

Although there are two international classification systems for staging HIV disease in children, the Revised WHO Clinical Staging of HIV/AIDS for Infants and Children is used more widely in Africa (see Table 26.2). In addition to providing a useful standard for evaluating children, the classification system has been shown to be useful for establishing prognosis and modeling the course of disease. The other international classification is the Centers for Disease Control and Prevention clinical categories for children with HIV (CDC, 1994), available at: http://www.cdc.gov/hiv/pubs/mmwry.htm.

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Table 26.2: Revised WHO Clinical Staging of HIV/AIDS for Infants and Children

Clinical Stage One
Asymptomatic
Persistent generalized lymphadenopathy (PGL)
Clinical Stage Two
Hepatosplenomegaly
Papular pruritic eruptions
Seborrheic dermatitis
Extensive human papilloma virus (HPV) infection
Extensive molluscum contagiosum infection
Fungal nail infections
Recurrent oral ulcerations
Linear gingival erythema (LGE)
Angular cheilitis
Parotid enlargement
Herpes zoster
Recurrent or chronic respiratory tract infections (RTIs) (otitis media, otorrhea, sinusitis)
Clinical Stage Three
Conditions where a presumptive diagnosis can be made on the basis of clinical signs or simple investigations:
Moderate unexplained malnutrition not adequately responding to standard therapy
Unexplained persistent diarrhoea (≥14 days)
Unexplained persistent fever (intermittent or constant, >1 mo)
Oral candidiasis (outside neonatal period)
Oral hairy leukoplakia
Acute necrotizing ulcerative gingivitis/periodontitis
Pulmonary tuberculosis
Severe recurrent presumed bacterial pneumonia
Conditions where confirmatory diagnostic testing is necessary:
Chronic HIV-associated lung disease including bronchiectasis
Lymphoid interstitial pneumonitis (LIP)
Unexplained anaemia (<8 gm/dL), neutropenia (<1000/mm^3), or thrombocytopenia (<50,000/mm^3) for >1 mo
Clinical Stage 4
Conditions where a presumptive diagnosis can be made on the basis of clinical signs or simple investigations:
Unexplained severe wasting or severe malnutrition not adequately responding to standard therapy
Pneumocystis pneumonia
Recurrent severe presumed bacterial infections (e.g., empyema, pyomosyitis bone or joint infection, meningitis, but excluding pneumonia)
Chronic herpes simplex infection (orolabial or cutaneous >1 mo)
Extrapulmonary TB
Kaposi's sarcoma
Oesophageal candidiasis
CNS toxoplasmosis (outside the neonatal period)
HIV encephalopathy
Conditions where confirmatory diagnostic testing is necessary:
CMV infection (CMV retinitis or infection of organs other than liver, spleen, or lymph nodes; onset ≥1 mo of age)
Extrapulmonary cryptococcosis including meningitis
Any disseminated endemic mycosis (e.g., extrapulmonary histoplasmosis, coccidiomycosis, penicilliosis)
Cryptosporidiosis
Isosporiasis
Disseminated non-tuberculous mycobacteria infection
Candida of trachea, bronchi, or lungs
Visceral herpes simplex infection
Acquired HIV-associated rectal fistula
Cerebral or B-cell non-Hodgkin's lymphoma
Progressive multifocal leukoencephalopathy (PML)
HIV-associated cardiomyopathy or HIV-associated nephropathy

Note: Interim African Region version for persons <15 years of age with confirmed laboratory evidence of HIV infection (HIV antibody if ≥ 18 mos of age and virological or P24 antigen testing if <18 mos of age)

Source: WHO, 2005. Reprinted with permission.

Ongoing Clinical Management

Palliative Clinical Management

The best clinical management is delivered from a platform of palliative care. See the next section (Palliative Care Approach) for the multidimensional services this entails. The purely medical aspects of management are presented here. Regular monitoring and prompt attention to symptoms are vital in paediatric HIV/AIDS.

Symptoms are often best controlled by managing the infectious cause of a symptom complex (see Chapter 27: Management of Clinical Conditions). At any particular point in the child's disease course, the HCW will find herself combining elements of symptomatic care with curative interventions. As HIV/AIDS progresses, symptomatic relief will become more prominent, and response to curative intervention less certain.

The burden of the infected child's symptoms increases as the child progresses to 'full-blown AIDS'. The palliative care approach has the overall goal of reducing this burden to a minimum. At best, this goal is achieved by treating the child with ART, thereby reducing the likelihood of intercurrent infections and reversing symptoms arising from the more direct effects of HIV infection on the brain, heart, and lungs and capitalizing on the secondary benefits of improved appetite and levels of energy.

Laboratory Monitoring of HIV/AIDS Progression

Where basic laboratory facilities are available, a total lymphocyte count (TLC — this is part of the full blood count, or FBC) can be used to measure the immune status of a child with HIV/AIDS, especially when HIV-related symptoms are present (ANNECA, 2004). The following TLC values indicate immunosuppression in children:

- <18 months: TLC <3,500/mm^3
- 18 months to 6 yrs: TLC <2,300/mm^3
- >6 yrs: TLC <1,200/mm^3

If available, the CD4 lymphocyte count is used to measure a child's immune status. See Table 26.3 for interpretation of CD4 values according to the staging system developed by the Centers for Disease Control and Prevention in the U.S.

Table 26.3: Immunological Classification Based on Total and % CD4 Count

Immunologic Category	Age of child		
	<12 months	1–5 yrs	6–12 yrs
	CD4/μL (%)	CD4/μL (%)	CD4/μL (%)
1: No evidence of suppression	≥1,500 (≥25)	≥1,000 (≥25)	≥500 (≥25)
2: Evidence of moderate suppression	750–1,499 (15–24)	500–999 (15–24)	200–499 (15–24)
3: Severe suppression	<750 (<15)	<500 (<15)	<200 (<15)

Source: ANECCA, 2004.

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Prophylaxis for Opportunistic Infections

PCP Prophylaxis With Cotrimoxazole

Current WHO guidelines propose PCP prophylaxis for young children with HIV (see Table 26.4) according to the following criteria:

- All children born of HIV-positive mothers, starting no later than 4–6 weeks after birth until 12 months old
- HIV-positive children >1 year of age and <6 years of age *and* CD4 count <500
- HIV-positive children >5 years of age and CD4 count <200

Table 26.4: Cotrimoxazole for PCP Prophylaxis

Weight	If suspension not available	Paediatric suspension***
< 5 kg	1 paediatric tablet* or ¼ adult tablet** bd	2.5 mL bd
5–10 kg	2 paediatric tablets or ½ adult tablet bd	5 mL bd
> 10 kg	1 adult tablet bd	10 mL bd

* *Adult tablets (equivalent to 4 paediatric tablets): 80 mg trimethoprim* ***and*** *400 mg sulphamethoxazole*

** *Paediatric tablets (equivalent to ¼ adult tablet): 20 mg trimethoprim* ***and*** *100 mg sulphamethoxazole*

Paediatric suspension strength: 20 mg trimethaprim* ***and *100 mg sulphamethoxazole per 5 mL*

Adult suspension strength: 80 mg trimethaprim ***and*** *400 mg sulphamethoxazole per 5 mL*

If available, use dapsone for children who are allergic to cotrimoxazole. Give dapsone 2 mg/kg/day. In a study comparing daily (1 or 2 mg/kg) to weekly doses (4 mg/kg) of dapsone in 94 children intolerant to cotrimoxazole, weekly doses caused fewer liver side effects but were associated with more cases of PCP than the 2 kg/mg dose. The 1 mg/kg daily dose were deemed inadequate (McIntosh, 1999).

Primary Prophylaxis for TB

Infants and children whose mothers have TB are at high risk for TB infection and disease. They should receive isoniazid (INH) + pyrazinamide (PZA) and rifampicin (Rif) as prophylaxis for a minimum of three months. It is recommended that all children with HIV living in areas where pulmonary TB is highly prevalent should receive INH prophylaxis at a dose of 5 mg/kg/day, once daily. Pyridoxine should be given with isoniazid.

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The Palliative Care Approach

The Role of Palliative Care Throughout the Course of HIV Disease

Palliative care may be defined as active and total care of patients with an incurable disease. For as long as HIV/AIDS remains incurable, all treatment of infected persons is in essence palliative. In fact, ART is the most effective palliative treatment for HIV disease. Moreover, the palliation of symptoms is appropriate at all stages of HIV disease.

Health care workers in palliative care need a deep and complete knowledge of how HIV infection affects children and the whole family. They need to have insight into how many generations face a variety of difficulties as a result of the disease. The HCW's primary task is to relieve those physical symptoms that limit the child's capacity to achieve emotional, social, and spiritual goals, but successful, high-quality care requires treatment plans for individual patients that address all forms of suffering.

The HIV-infected child's prognosis is uncertain, particularly in the developing world and specifically if the child does not have access to ART. Recovery from a particular infection is dependent on nutritional status, rate of progression of HIV/AIDS, and HIV-related damage to vital organs.

The Importance of Family and Community Support

Social circumstances affect success of management directly. Home care of infants and young children suffers when mothers fall ill. Adherence to medication is at risk where the care of a child is shared by multiple caregivers. Adolescents may find themselves as heads of households, or without parental supervision. (See Chapters 29: Psychosocial and Spiritual Care and 31: Family and Community Support.)

Crowded venues, heavy clinical workloads, and large patient numbers constrain opportunity for proper communication with HIV-affected children and their families. Lack of resources further limits state-funded social support systems in developing countries. The development of low-cost counseling resources such as patient advocates, recruited from affected communities and financed by the non-governmental sector, may be an affordable alternative.

Inasmuch as palliative care is about reducing suffering and morbidity, it is about providing any intervention that can delay progression to AIDS. For an HIV-infected child, access to continuous comprehensive care will slow the rate of progression to AIDS and provide significant relief of suffering. This is why broadly political issues such as access to health care, continuity of care, comprehensive primary health services nutrition, hygiene, and overcrowding are germane to the goals of palliative care.

It is increasingly common to find children living in child-headed households, or in the care of adults who are not their legal guardians. In certain legal jurisdictions (e.g., in Gauteng province in South Africa) consent for HIV testing may be taken from de facto caregivers where there is no legal guardian. Depending on the child's age and level of understanding, the child may give consent (see Chapter 29: Psychosocial and Spiritual Care). Similar situations may be encountered when a parent or grandparent is evidently too ill or demented to act in the child's best interests. Where a parent's illness is advancing, future planning is essential.

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Developmental Aspects of HIV/AIDS

Child development progresses in several channels, all of which are likely to be affected by HIV/AIDS. Growth, motor skills, cognitive ability, and socialization are all potentially affected by HIV infection. In interpreting the child's experience of illness it should be remembered that the impact of disease will depend on the developmental stage at which symptoms present.

Developmental delay, manifesting most commonly as a failure to attain gross motor milestones and develop speech at appropriate ages, is not uniformly present in all children with HIV/AIDS, but is common in those children who are symptomatic in the first two years of life.

Symptomatic HIV infection adversely affects growth and this effect is aggravated by inadequate nutrition and recurrent infections, particularly of the mouth and gastrointestinal tract. Growth effects of HIV infection are reversed by ART. As growth trajectories recover, antiretroviral dosages need constant readjustment (see Chapter 28: Integration of Palliative Care with ART in Children).

As cognitive development progresses, children and adolescents bring changing interpretations to the nature of their disease and its management. It is advisable to interact with children as individuals, not merely according to Table 26.5, which is offered as a broad guideline for age-appropriate interaction (see also Chapter 29: Psychosocial and Spiritual Care and Chapter 30: Loss, Grief, and Bereavement).

Parents tend to want to 'protect' children from the knowledge of a potentially lethal disease, despite extensive evidence that children who are informed are better prepared and less anxious. There is evidence that children allowed pertinent information and knowledge are better able to 'own' their disease, to adhere to medication, and to deal with the discomfort associated with needle sticks and other interventions.

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Table 26.5: Interacting With Sick Children at Different Stages of Social Development

Age	Social Development and Needs
Infants (0–12 months)	Non-verbal signals from infants Adults use tone, touch language Need for physical, emotional nurture Very simple explanations Object permanence develops
Toddlers (1–2 years)	Early learning of words Tantrums Adults offer simple explanations Adults must be clear, consistent Adults must prepare child for procedures Adults must be efficient, comforting
Preschoolers (3–6 years)	Sustain simple conversation, ask questions Can play interactively Concerns about bodily integrity Magical thinking Adults must provide concrete information
Children (6–11 years)	Curious about own body, health Questions offer opportunities to inform Children are learning to read Begin to understand causality Can exercise choice, which improves their sense of control
Early adolescents (12–14 years)	Rapid growth, emotional and social change Desire treatment as adults, but are still children Vulnerability/invulnerability issues Need direct, positive adult support Peer relationships are very important
Late adolescents (15–18 years)	Abstract, existential thought Can accept active responsibility for own health care Can make active health care decisions Still need adult structure and support May be shouldering adult responsibilities

Source: Adapted from Hutton, 2003.

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Chapter 27

Management of Clinical Conditions in Children

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At a Glance

Overview

While HIV can affect any organ of the body, skin diseases, malnutrition, diarrhoea, respiratory tract diseases, and fevers are the major causes of symptoms, distress, and mortality in children. This chapter describes the clinical management of the common clinical conditions of HIV disease in children. See also the adult chapters in Part 2 (Clinical Supportive Care) for more on specific clinical conditions.

Chapter 28: Integration of Palliative Care with ART in Children describes the treatment of HIV disease itself with antiretroviral therapy (ART).

Paediatric malignancies are not addressed in this book. Kaposi's sarcoma, non-Hodgkin's lymphoma (NHL), and leiomyosarcomas are the most common malignancies in children with HIV. Prolonged intensive chemotherapy is poorly tolerated by children with HIV/AIDS, but short, dose-intensive regimens are likely to have a better outcome. Kaposi's sarcoma is reported to improve on ART.

Adapted from Chapter 12: The care of Children and Adolescents, by Nancy Hutton, MD, in: O'Neill JF, Selwyn PA, Schietinger H, eds. *A Clinical Guide to Supportive and Palliative Care for HIV/AIDS, 2003 Edition*.

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Chapter 27

Management of Clinical Conditions in Children

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General Principles of Clinical Management

General principles for managing common conditions in children with HIV include:

- Treatment of reversible conditions
- Palliation of symptoms
- Relief of distress for both the parents and children

These three components are all considered essential in the palliative care assessment and management of children with HIV. The relative importance of each component may differ depending on the aetiology of disease and stage of infection. Acute *Pneumocyctis carinii* pneumonia (PCP) and lymphoid interstitial pneumonitis (LIP) may both present with cough and dyspnoea, but PCP requires immediate initiation of specific therapy whereas LIP requires long-standing palliation of symptoms. On the other hand, warts (verruca plana), a skin disease with no specific therapy, requires counselling of caregivers and children so as to mitigate against the distress it causes.

Treatment of specific conditions requires knowledge of the possible aetiology and organism susceptibility to treatment. In resource-limited countries laboratory investigations are not always available and diagnosis may not be confirmed. In such settings, important considerations include the age of the child, presenting clinical signs and symptoms, whether the complaints are acute or chronic, whether the disease is suspected or confirmed, and the stage of the disease. Because it is difficult to exhaust all the causes of disease in children infected with HIV, health care workers (HCWs) evaluating them need to consider both the common and rare cause of symptoms.

Pain

See Chapter 4: Pain Management for a more complete discussion of the assessment and management of pain.

Assessment

It is important to state first and foremost that children suffer from pain. This might seem obvious to many but it is surprising how many HCWs practice as if children never suffer from pain.

Assessment of pain is an essential part of paediatric consultation and requires a careful history as well as close observation (see Box 27.1). As with adults, the gold standard for pain assessment is self-report. Younger children will depend on caregivers for pain assessment. A HCW may assess that a child showing signs of irritability is experiencing pain. The severity of pain may be assessed using numeric scales for older children (older than seven years) and non-numeric scales (e.g., visual analogues, for children 3-7 years). The charts and scales for pain assessment in Chapter 4 can be used with children.

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Box 27.1:

Recognizing Pain in Children

Brief Pain:

- Crying
- Distressed facial expression

Persistent Pain:

- Irritability
- Not wanting to move
- Lack of interest
- Decreased ability to concentrate
- Sleeping problems
- Changes in how the child moves
- Restlessness
- Increased breathing rate or heart rate

Source: WHO, 2004.

Management

Treating Reversible Causes

Managing pain involves identifying and treating any reversible causes of pain (e.g., infections responsive to antibiotic therapy). Specific pain management should complement curative therapies until the underlying problem is resolved and is no longer causing pain.

Painful procedures need to be evaluated for their relevance and avoided if not needed. Children often suffer from pain as a result of multiple procedures, including pricks for blood smears, venipunctures for blood draws, and lumbar punctures. Many children also receive medications by intramuscular injections because there is a common belief in the general public that injections work better than oral medications. It is not uncommon in malaria endemic regions for a malaria blood smear to be done on a child with fever and then for the child to be treated empirically even when the smear is negative.

Non-Pharmacologic Management

Non-pharmacological approaches can be used even in resource-limited settings, especially for procedure-associated pain:

- Distraction (radio, music)
- Relaxation (imagining a pleasant scene)
- Breathing techniques (slow, deep breathing)
- Touch (stroking, massage, rocking, vibration)
- Cold or heat (a damp cloth)

In managing pain it is important to assess and treat the whole child. Problems in various aspects of life (social, psychological, spiritual) may compound pain. Addressing these issues may also help relieve a child's pain:

- Support and counselling
- Information (answering questions and explaining what is happening)

Pharmacologic Management

Many pains, especially in advanced disease, elude clear delineation of aetiology or are due to conditions for which there is no effective therapy. In these circumstances, specific pain management is the pre-eminent therapy.

HCWs need to be comfortable with the use of analgesics and understand the mechanisms of action, dosing options, potential for synergistic effects, side effects, and toxicities. Having a few basic medicines goes a long way toward relieving a child's pain (see Table 27.1).

Table 27.1: Medicines Used in Managing Pain in Children

Name of the Drug	Dosage in Children
Ibuprofen	5–10 mg/kg 6–8 hourly
Paracetamol	10–15 mg/kg 4–6 hourly
Codeine	0.5–1 mg/kg 4 hourly
Amitriptyline	0.2–0.5 mg/kg 12 hourly
Carbamazepine	2.5–5 mg/kg 12 hourly
Phenytoin	2.5–10 mg/kg 12 hourly
Sodium valproate	7.5–20 mg/kg 12 hourly
Morphine	0.15–0.3 mg/kg 4 hourly

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Constitutional Symptoms

See Chapter 5: Constitutional Symptoms for more detail on assessment and management of these problems.

Wasting

Assessment

Wasting may be due to inadequate nutrition or HIV-related wasting syndrome. Inadequate nutrition may also be due to HIV-related complications such as oral/throat sores, poor appetite, diarrhoea, fevers, or actual lack of food. See Chapter 19: Nutrition. The objectives of management depend on the stage of the disease and aetiology of wasting.

Management

For inadequate nutrition:

- Treat the predisposing causes if any.
- Ensure availability of food in the home.
- Provide food in small, high-calorie, energy-dense portions frequently.
- Aim at catch-up growth.

For HIV wasting syndrome:

- Prevent further deterioration by preventing disease and providing adequate macronutrient and micronutrient supplements.
- Assist child to have a sense of well-being and to maintain age-appropriate activities.
- Give vitamin A according to IMCI guidelines.

In children who are terminally ill these objectives may be unachievable. At this stage, HCWs should help the family to provide the child with whatever he or she wants or likes rather than aiming at providing the required calories and protein.

Anorexia

Assessment

Poor appetite may be due to various causes including:

- HIV disease itself, especially when advanced
- Intercurrent disease
- Medications used for HIV disease
- Psychological problems such as depression

Management

Treat the cause of poor appetite if it can be identified.

Alternatively, stimulate the appetite using corticosteroids such as prednisone and dexamethasone or, if available, megestrol acetate.

At the end of life, caregivers need reassurance that decreased food intake will not cause death. The body has decreasing nutritional requirements as death approaches. Forcing a child to eat or drink can be uncomfortable at this time, causing choking, abdominal pain, nausea, vomiting, or diarrhoea.

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Fatigue and Sleep Disturbance

Assessment

As with adults, fatigue and sleep disturbance are challenging symptoms of HIV disease that affect a child's quality of life.

Management

Non-Pharmacologic Symptom Management

For fatigue, promote sleep through adequate symptom control and a peaceful and comfortable environment. Offer quiet activities.

Help the family to encourage the child to play, walk outdoors, and remain awake during the day to promote sleep at night.

Instruct caregivers not to awaken the child unless he or she is taking around-the-clock pain medication.

Move as quickly as possible to long-acting analgesics.

Pharmacologic Symptom Management

Give stimulant medication (methylphenidate 0.1–0.5 mg/kg/dose) to promote arousal during the day.

Fever Treating Reversible Causes

Acute: If the fever is acute and non-localizing, consider malaria and septicaemia. If it is acute and localizing, treat as recommended for the system concerned.

Chronic: Consider tuberculosis, toxoplasmosis, cytomegalovirus disease, disseminated fungal infections, or malignancies.

Non-Pharmacologic Management

Give the child cool baths or wipe with damp cloth.

Give plenty of water and other liquids.

Pharmacologic management

Give paracetamol 15 mg/kg body weight.

Respiratory Problems

See Chapter 6: Respiratory Symptoms for generic management.

Differential Assessment to Treat Reversible Causes

Acute respiratory problems: Common causes of acute cough and or dyspnoea include bacterial pneumonia, *Pneumocystis carinii* pneumonia, malaria, and acute pyogenic pneumonia.

Chronic respiratory problems: If symptoms are chronic, consider tuberculosis, lymphoid interstitial pneumonitis (LIP), and bronchiectasis. Bronchiectasis is often a complication of LIP, asthma/reactive airways disease, and sinusitis. Also, chronic sinusitis is a largely ignored cause of persistent/recurrent cough.

Cough and Dyspnoea

Assessment

Cough and dyspnoea are the most common symptoms associated with HIV-related pulmonary conditions. While identifying and treating the underlying cause, HCWs should also manage these distressing symptoms as well as constitutional symptoms such as fever.

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Management

Non-Pharmacologic Symptom Management

Measures to relieve the child's sensation of shortness of breath include:

- Positioning for comfort (extra pillows to raise the chest)
- Assistance with walking
- Humidified air (create steam by heating a pan of water)
- Fanning the face
- Fresh air

For cough, suggest soothing remedies such as honey and lemon, plain or with eucalyptus leaves or neem tree oil.

To loosen sputum, suggest plenty of water and other liquids.

Pharmacologic Symptom Management

Treat asthma/reactive airways disease with bronchodilators. Add corticosteroids depending on severity and frequency.

Treat the sensation of shortness of breath with:

- Opioids (systemic)

If available, consider:

- Nebulized saline or bronchodilators
- Nebulized opioids
- Oxygen

Pneumonia

Assessment

Both bacterial pneumonia and *Pneumocystis carinii* pneumonia are common in children with HIV (ANECCA, 2004). Clinical diagnosis can be based on history (fever, cough, rapid breathing, fatigue, cyanosis) and breath sounds on auscultation (decreased breath sounds, crackling/crepitations, or bronchial breathing).

Laboratory work can also be useful. Increased white blood cell count with neutrophilia (granulocytosis) suggests bacterial pneumonia.

If available, consider chest x-ray: Not necessary to diagnose and treat acute pneumonia, but may be useful when there is a poor response to treatment or when TB, foreign body, or tumour is suspected.

Pneumocystis carinii pneumonia (PCP) is common in children <1 year of age. Clinical presentation differs from bacterial pneumonia in the following ways:

- Low-grade or absent fever
- Marked respiratory distress (retractions or chest in-drawing, cyanosis, inability to drink)
- Clear chest or diffuse fine crepitations on auscultation
- Poor response to standard antibiotic treatment
- Occasionally, oral thrush, lymphadenopathy, and/or weight loss
- If pulse oximetry available, evidence of severe persistent hypoxia

Recurrent or persistent pneumonia (more than 3 times/yr) should alert the HCW to suspect TB, foreign body, or chronic lung disease.

Management

Treating Reversible Causes

Bacterial Pneumonia: For mild pneumonia, give oral amoxycillin or penicillin or other antibiotic recommended in national guidelines.

For patients on cotrimoxazole prophylaxis, caution should be taken in using it to treat an acute episode of pneumonia as is recommended by some countries like Uganda. Since there is currently no consensus on the matter it would be prudent to consider using other antibiotics according to national guidelines.

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For severe pneumonia, treat in hospital or other inpatient facility in order to give supportive management (see pharmacological symptom management below) and intravenous antibiotics:

- Give antibiotic based on common organisms in the region.
- If common organisms unknown, give chloramphenicol.
- Alternatives include ampicillin/cloxacillin plus gentamicin if there is a high level of resistance to chloramphenicol in the region.
- If available, cephalosporins can be used if there is a high level of resistance to chloramphenicol in the region.

***Pneumocystis carinii* pneumonia (PCP):** If PCP is suspected, continue to treat for bacterial pneumonia, but also treat for PCP:

- Add high-dose cotrimoxazole (CTZ) PO or, if available, IV.
- After treatment, give PCP prophylaxis life-long (see Table 26.4).

Non-Pharmacologic Symptom Management

See section on cough and dyspnoea.
Provide adequate oral hydration.

Pharmacologic Symptom Management

Give vitamin A supplementation if child has not received in last 3 months. If intravenous fluids are used for hydration, use with caution to avoid fluid overload.

For severe pneumonia treated in hospital:

- Correct severe anaemia (Hb<5 g/dL) by transfusion with packed red blood cells

If available, give oxygen

For severe respiratory distress in PCP, give prednisone at 2 mg/kg/day for 7–14 days, and taper if treatment >7 days.

Tuberculosis

Assessment

Tuberculosis is a common OI amongst children with HIV/AIDS. Most frequently the child with HIV acquires TB infection from an adult with HIV in the home. Children with HIV (<5 years or who are severely immunosuppressed) in contact with TB should receive preventive therapy, regardless of whether the sputum smear is negative or positive in the index case (see Chapter 26).

Tuberculosis in a child with HIV is usually suspected in a child with one or more of the following: prolonged fever, chronic cough, contact with an active case, and weight loss. Children are often diagnosed after presenting with less specific symptoms and an abnormal chest radiograph and not responding to treatment with antibiotics. Unusual presentations include extra-pulmonary disease with hepato-splenomegaly, lymphadenopathy, and anaemia in children with more advanced immunosuppression. It is difficult to distinguish unusual presentations of TB from advanced HIV/AIDS itself, lymphoma, deep mycosis, or infection by atypical mycobacteria.

Children with HIV and TB coinfection have a shorter life expectancy than children with HIV alone, but respond to conventional anti-tuberculous therapy both in the acute and the maintenance phase of treatment. In Uganda, based purely on the experience of clinicians, the traditional six months of treatment was increased to nine months for children who are HIV-infected. This is also recommended by the American Academy of Paediatrics (AAP, 2003).

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Management

Acute conditions are curable and should be given specific therapy as recommended by national guidelines.

Antiretroviral, antifungal, and antituberculous drugs interact with one another — refer to Chapter 11 and Appendix 2 for further details.

Treatment for TB should be commenced two months prior to starting ART to avoid the immune reactivation syndrome which results in an exacerbation of the clinical features of tuberculous co-infection (see Chapter 28: Integration of Palliative Care With ART in Children).

Lymphoid Interstitial Pneumonitis

Assessment

Children with HIV most often acquire lymphoid interstitial pneumonitis (LIP) at 2 or 3 years of age.

The diagnosis is generally made on clinical and radiological findings:

- Respiratory distress (hard breathing and cough)
- Failure to thrive
- Finger clubbing
- Parotid gland enlargement
- Prominent generalized lymphadenopathy

If available: Radiological lung infiltrates on X-ray

Acute lower respiratory tract infections occur more frequently with LIP. This finding confounds the analysis of symptoms associated with LIP and contributes to an understanding of the aetiology of both bronchiectasis and cor pulmonale associated with LIP. Children with LIP may die from progressive pulmonary fibrosis, cor pulmonale, or cardiac failure.

The classical chest radiograph in LIP has bilateral, predominantly lower zone reticular or reticulo-nodular opacities. While this pattern is also seen in miliary TB and cytomegalovirus pneumonia, in LIP it is indolent and non-responsive to standard therapy. In children a resolution of this infiltrate has been correlated with a declining CD4 count and advancing immunosuppression, although this association is not absolute.

Management

Non-Pharmacologic Symptom Management

Train caregivers to give daily chest physiotherapy and postural drainage.

See section on cough and dyspnoea for supportive care.

Pharmacologic Symptom Management

Resolution of the pulmonary infiltrate has been observed in response to glucocorticoids as well as ART.

- Glucocorticoids: Pulsed steroid (2 mg/kg for 7 days, tailed to 5 mg/day over a month) offers appropriate palliative therapy for symptomatic LIP (significant hypoxemia, tachypnoea, or dyspnoea on exertion).
- Give bronchodilators for wheezing

If available, consider:

- ART: Triple therapy is the most appropriate and effective treatment, although single and multiple regimens are used.
- Oxygen for hypoxia

Bronchiectasis

Assessment

Pulmonary disease in children with AIDS frequently involves bronchiectasis, especially in the presence of LIP, recurrent or unresolved pneumonia, and CD4 counts <100. Chronic lung disease generally emerges in children who, because of intensive and comprehensive management, survive for longer periods of time.

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The diagnosis of bronchiectasis in children is suggested by:

- History of recurrent, febrile, productive lower respiratory tract infections
- Recurrent signs of lower respiratory tract consolidation
- Finger clubbing

Recurrent infections and increased work of breathing contribute to failure to thrive. Plain chest radiography is not the gold standard for diagnosing bronchiectasis, but recurrent consolidation in the same anatomical distribution sometimes associated with lobar or segmental collapse is suggestive, in the presence of the other features mentioned above.

Management

Non-Pharmacologic Symptom Management

Children benefit from daily vigorous physiotherapy with dependent drainage if damage is focused in a particular anatomical area. Train caregivers in these techniques.

See section on cough and dyspnoea for supportive care.

Pharmacologic Symptom Management

Give bronchodilators for bronchospasm.

Give antibiotics to treat acute bacterial super-infection of lower respiratory tract disease, rotating antibiotic regimen as prophylaxis against progression of bronchietasis-related lung damage. Use care when treating chronic lung disease with antibiotics. Frequent antibiotic use for respiratory signs and symptoms that do not resolve could result in selection for antibiotic resistant pathogens. This is particularly likely when X-rays are unavailable and diagnosis cannot be made with precision.

Bronchiectatic change in HIV/AIDS is generally diffuse and not amenable to surgery. Where it is localised, surgery may be appropriate.

Cor Pulmonale

Assessment

Cor pulmonale is hypertrophy of the right ventricle resulting from disease affecting the function and/or structure of the lung — excepting causes related to primary left ventricular or congenital heart disease. In children with HIV/AIDS, right ventricular hypertrophy is associated with recurrent pulmonary infections and is observed in children with bronchiectasis and/or LIP. Chronic hypoxia caused by interstitial pneumonitis or parenchymal lung disease is likely to play a part in the pathogenesis of cor pulmonale.

Management

Pharmacologic Symptom Management

Drugs for heart failure are appropriate for palliative care:

- Diuretics
- Digoxin

If available, consider:

- Oxygen therapy benefits patients with chronic lung disease greatly.

ART provides unexpected and gratifying benefits in cardiac function. On ART, children with cor pulmonale have fewer episodes of intercurrent lower respiratory tract infections and fewer episodes of infection with associated increase in metabolic rate.

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Draining Ears

Assessment

Otitis media can be acute (lasting less than 14 days) or chronic (may be associated with continued ear drainage and a perforated eardrum). This is one of the most common HIV-related infections in children. Symptoms of acute otitis media involve drainage from the ear and ear pain, exhibited by pulling on the ears, crying, and irritability.

Management

Treating Reversible Causes

Treat acute ear infection with antibiotics.

If available, consider ART, which usually resolves otitis media.

Non-Pharmacologic Symptom Management

Emphasize toilet: ear wicking 8 hourly when there is discharge.

Teach caregivers how to do toilet. Explain to the parents and older children that otitis media often re-occurs.

Diarrhoea

See Chapter 7: Gastrointestinal Problems for more detail on assessment and management.

Assessment

Acute: Acute diarrhoea of childhood is largely considered to be viral and managed by rehydration (assess all children for dehydration and treat promptly). However for children with HIV, a high index of suspicion for other aetiologies such as *Salmonella, Shigella,* and *Giardia lamblia* that are treatable should be kept in mind especially in the following circumstances (Callahan, 1999):

- Diarrhoea with fever
- More than 5 leucocytes/hpf in stool.
- Blood in stool
- Diarrhoea without vomiting

Chronic: Consider *Cryptosporidium, Isospora belli*, lactose intolerance, medications (e.g., ARVs), and idiopathic diarrhoea.

If laboratory facilities are available, collect stool specimens for microscopy and culture and deliver them to the laboratory promptly. Repeat if they remain negative in persistent diarrhoea.

Assess the child with prolonged diarrhoea for malnutrition and investigate the malnourished child more aggressively. Obtain serum electrolytes and a full blood count because anaemia and thrombocytopaenia are relatively frequent complicating factors.

Management

Treating Reversible Causes

Where stools have been tested for microscopy and culture, treat with antimicrobials according to the lab results, using national guidelines.

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For persistent diarrhoea with blood in the stool, presume *Shigella* and treat with an oral antibiotic effective for *Shigella*. If no improvement in 2 days, switch to another oral antibiotic effective for *Shigella*.

If stool tests are not available, treat persistent diarrhoea without blood in the stool presumptively according to national guidelines or as follows:

cotrimoxazole/nalidixic acid and metronidazole for children <8 years

ciprofloxacin and metronidazole for children ≥ 8 years

Be aware of treating for intestinal worms in a patient with acute diarrhoea as a worm bolus can result in an acute intestinal obstruction.

Non-Pharmacologic Symptom Management

The cornerstone of managing chronic diarrhoea is ensuring adequate nutrition during the disease.

Address all episodes of diarrhoea with:

Rehydration: Give parent instructions for mixing oral rehydration fluids (as in Box 27.2 for recipes for homemade oral rehydration fluids or use national guidelines) or a supply of packaged oral rehydration salts (ORS) for suspension in clean water.

Advise caregivers to return to the clinic if the child becomes drowsy or if vomiting prevents fluid retention.

Reduce lactose in diet in case of lactose intolerance.

Give skin care when diarrhoea or incontinence threaten skin integrity.

Advise family members about specific home-based interventions, including:

- Giving more fluids than usual at the onset of diarrhoea. Water, unsweetened juice, and weak tea can be used as maintenance, but should not be used for rehydration.
- Rice water and maize-based oral rehydration salts (see Box 27.2).
- Dilute maize/millet/sorghum pap.
- Encouraging children to drink as much as possible. Often they will not feel thirsty so encourage them to keep a glass nearby and take small sips every five minutes.
- Continuing breast-feeding, but more frequently than before (at least every three hours).
- Encouraging children to continue to eat. If children stop eating when they have diarrhoea this can cause malnutrition or make existing malnutrition worse.
- Preparing food such as porridge more watery than usual so the child gets both nutrition and fluids.
- Giving small amounts of nutritious and easily digestible food frequently.
- In severe dehydration, stopping oral feeds for four to six hours for the carer to concentrate on rehydration (50–100 mL/kg).
- After the diarrhoea has stopped, giving an extra meal each day for 2 weeks helps children to regain any weight lost during the illness.

Box 27.2:

Recipes for Oral Rehydration Fluids for Children

Oral Rehydration Solution

1. 8 tsp sugar
2. ½ level tsp salt
3. 1 litre boiled water
4. Mix well and store covered in a cool place. Make a fresh solution every day.

Rice-Based Oral Rehydration Solution

1. Fistful of dry rice grain (25g)
2. Wash and soak until soft
3. Grind to paste
4. Put 2 cups of water in pan and mix with paste
5. Heat and stir until bubbling
6. Cool and use within 6–8 hrs

Maize-Based Oral Rehydration Solution

1. Add 50g maize to 1 litre water
2. Cook for 5–8 minutes
3. Add 1 tsp salt once cooled

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Pharmacologic Symptom Management

Vitamin A supplementation (200 000 IU every 6 months) is said to prevent or reduce the severity of diarrhoea in vitamin-deficient people and malnourished children, with or without HIV/AIDS.

Zinc supplementation (1 mg/kg/day elemental zinc) reduces the duration of acute and chronic diarrhoea.

Small doses of oral morphine solution may be useful for intractable diarrhoea.

In children with diarrhoea accompanied by signs of shock or intractable vomiting fluid replacement is critical.

If available, admit to hospital for intravenous rehydration.

For shock, give a rapid infusion of normal saline. Infuse an initial aliquot of 20 mL/kg body weight over 30 minutes. The response to adequate resuscitation is a lowering of the heart rate and the return of previously impalpable pulses. Repeat the infusion up to three times.

Introduce feeding and ORS as soon as shock has resolved.

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Skin Problems

See Chapter 9: Skin and Wound Care for more detail on assessment and management of these problems.

Assessment

The common dermatological conditions include bacterial infections, dermatophytosis, scabies, molluscum contagiosum, warts (verruca plana), non-specific dermatitis, drug reactions, and herpetic sores. Scabies in children with HIV/AIDS may have atypical presentation and should be suspected in any child with pruritic lesions. Varicella (chicken pox) may be fatal. Herpes zoster (shingles) causes severe pain and carries a high mortality rate in severely immunocompromised patients. Severely immunosuppressed children may have extensive mucocutaneous disease with persistent vesicle formation.

Management

Non-Pharmacologic Symptom Management

Bathing, moisturizing, and massage all promote skin integrity and prevent skin breakdown.

If child is bedbound, cushion the pressure points and change his or her position frequently to prevent pressure sores.

Pharmacologic Symptom Management

Use antipruritic medications for itching (hydroxyzine, diphenhydramine).

Non-specific dermatitis may improve on ART. However, warts (verucca plana) and molluscum contagiosum, which rarely or poorly improve on therapy including ART, may require intensive counselling for caregivers and children.

Fungal infections, scabies, and herpetic sores need specific therapy.

For chicken pox: Symptomatic treatment with topical calamine lotion is marginally effective. For disseminated chicken pox with complications (e.g., organ system involvement, pneumonia):

aciclovir 20 mg/kg PO 4 or 5 times daily for 21 days

or, if available,

aciclovir 20 mg/kg (up to 800 mg) IV 5 times daily for 7 days

For herpes zoster (shingles): Give analgesia 'by-the-ladder and 'by-the-clock', beginning with a paracetamol and codeine combination 6 hourly (see Chapter 4: Pain Management).

Apply a soothing topical antibacterial cream or calamine lotion.

Post-herpetic neuralgia: amitriptyline 0.25–0.5 mg/kg PO nocté or 12 hourly

Give aciclovir as for chicken pox. With shingles, the best response is obtained by starting aciclovir within 72 hours of the onset of symptoms.

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Neurologic Problems

See Chapter 10: Neuro-psychiatric Problems for more on these clinical issues.

Differential assessment

Neurological impairment is common among children with HIV infection and often takes the form of a progressive encephalopathy. Neurological manifestations are characterized by developmental delays or loss of motor milestones with associated mental abnormalities, stunted growth and development, mental retardation, or even dementia. Children with HIV infection are at risk of secondary infection of the central nervous system resulting in meningitis, seizures, stroke, and delirium. However, most of the neurological findings are as a result of the direct effect of HIV on the brain.

Children with HIV/AIDS often experience developmental delays and delays in the acquisition of skills. Whilst this may arise out of the direct effect of HIV infection of the brain, failure to acquire skills may also arise indirectly as a result of reasons such as malnutrition, lack of stimulation from ill parents, repeated absences from school resulting from the child's illnesses, or the effects of social stigma. Chapter 29: Psychosocial and Spiritual Care addresses ways to provide children with stimulation.

Dementia is rare in younger children with HIV, but appears in adolescents in advanced HIV disease. A study of adolescents with HIV in Uganda identified dementia manifesting as global cognitive impairment but with significant memory deficits and inability to learn new material (Musisi, 2003). See Chapter 10: Neuro-psychiatric Problems for more on dementia.

Delirium and Seizures

Assessment

Common causes of seizures include meningitis (cryptococcal or bacterial) and toxoplasmosis that can be treated with specific therapy (see below). The occurrence of delirium and/or seizures is an ominous sign denoting a medical emergency which needs urgent medical attention, and admission to hospital to find and treat the underlying cause aggressively.

Management

Treating Reversible Causes

If possible, find and treat the underlying cause of the delirium or the seizure.

Pharmacologic Symptom Management

Manage seizures with diazepam 0.5 mg/kg PR or 0.1 mg/kg IV. Repeat this dose every 5–10 minutes as needed up to three times. Other anticonvulsant medications are phenobarbitone and phenytoin, clonazepam, carbamazepine, phenytoin, and sodium valproate.

Control the delirium with a neuroleptic (e.g., haloperidol) or benzodiazipine (e.g., lorazepam)

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Meningitis

Assessment

If a child has meningitis there will be a history of vomiting, fever, inability to drink or breastfeed, severe headache or neck pain, convulsions, or irritability. The child may have a stiff neck, rigid posture, rash, lethargy, or bulging fontanelle. Signs of intracranial pressure include unequal pupils, rigid posture, focal paralysis in any of the limbs or trunk, or irregular breathing.

In malarial areas, take a blood smear to check for cerebral malaria, either as a differential diagnosis or co-existing condition.

If possible, obtain a lumbar puncture unless there are signs of raised intracranial pressure. In children with HIV, differential diagnoses include bacterial, tuberculous, and fungal infections (WHO, 2004).

Bacterial meningitis: *Streptococcus pneumonia* and *Haemophilus influenza* type b (Hib) are frequent causes of acute meningitis in children with HIV/AIDS.

Tuberculous meningitis: Tuberculous meningitis is a significantly more common cause of meningeal infections presenting with sub-acute and chronic symptoms.

Cryptococcal meningitis: *Cryptococcus neoformans* is an infrequent cause of meningitis in young children with HIV/AIDS but is common in older children and adolescents.

Management

Treating Reversible Causes

Bacterial meningitis: First-line therapy is chloramphenicol 50–100 mg/kg/day IV in 24 divided doses or a third-generation cephalosporin (e.g ceftriaxone 100 mg/kg IV or IM once a day).

Tuberculous meningitis: Isoniazid, pyrazinamide, and ethionamide penetrate the blood-brain barrier well, rifampicin less well. Ethambutol and streptomycin only penetrate in adequate concentrations in the early stages of treatment, when the meninges are inflamed. Experience suggests that 12 months of treatment with rifampicin and isoniazid together with pyrazinamide and a fourth drug (ethambutol, ethionamide, or streptomycin) for at least the first two months provides good results. Corticosteroids are recommended as adjunctive therapy in more serious cases.

Cryptococcal meningitis: Give amphotericin B 0.7–1 mg/kg/day IV for 2 weeks, followed by fluconazole 3–6 mg/kg/day for 8 weeks or until CSF is sterile. If amphotericin B is not available, fluconazole can be used initially, but has a higher rate of relapse. Fluconazole requires an induction dose especially in children (10–12 mg/kg PO or IV in 2 divided doses). Maintain prophylaxis with fluconazole unless the child is on ART and with sustained immune recovery (3–6 mg/kg/day PO or IV).

Non-Pharmacologic Symptom Management

See sections on pain, constitutional symptoms, and delerium and seizures.

If child is unconscious, educate caregiver how to maintain clear airway, nurse the child on the side to avoid aspiration of fluids, turn every 2 hours, change bedding when wet, and pay attention to pressure points (WHO, 2004)

Pharmacological Symptom Management

Address symptoms aggressively. See sections on pain, constitutional symptoms, and delirium and seizures.

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Focal Neurologic Deficits

Assessment

Toxoplasmosis, lymphomas, and tuberculomas can cause space-occupying lesions that result in focal neurological deficits such as paralysis that look like stroke, as well as focal seizures (see section on delirium and seizures).

Management

If available, provide physiotherapy to palliate the paralysis.

Treat toxoplasmosis presumptively with specific therapy (see Chapter 10: Neuro-psychiatric Problems).

Lymphomas may require radiotherapy, *if available*.

Encephalopathy

Assessment

Encephalopathy commonly manifests in children as developmental delays. Diagnosis is mainly clinical and depends on the presence of at least 2 of the following for at least 2 months (ANECCA, 2004):

- Failure to attain or loss of developmental milestones or loss of intellectual ability
- Impaired brain growth or acquired microcephaly
- Acquired symmetrical motor deficit manifested by 2 or more of the following: paresis, pathologic reflexes, ataxia, or gait distrubances
- Normal CSF (or non-specific findings) and, if CT scan available, evidence of diffuse brain atrophy

Developmental delays: Mental retardation is the developmental failure of a growing child to achieve his or her potential Intellectual Quotient (IQ). Such children are slow in learning, repeating classes and presenting as chronologically older than their classmates, though they may look smaller than expected for their chronological age. Other marks of retarded development including stunted growth and delayed pubescence. Children with developmental delays may develop other HIV-related neuropsychiatric problems.

Both progressive multifocal leukoencephalopathy (PML) and HIV encephalopathy are indicative of advanced HIV disease.

Note: HIV encephalopathy can only be reversed by ART. If ART is available, it is critical for children to be assessed for neurological function early so that ART can be initiated before severe, irreversible brain damage develops.

Management

Non-Pharmacologic Symptom Management

Address movement disorders, attention deficit disorder, and psychiatric/behavioural disorders. If available, provide occupational, speech, and physiotherapy.

Address developmental delays. If available, institute special education classes for affected children after thorough neuropsychological assessment.

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Pharmacologic Symptom Management

Treat pain according to WHO 3-Step Analgesic Pain Ladder (see Chapter 4: Pain Management).

HIV encephalopthy, irrespective of CD4 counts or percentage, is a specific criterion for initiation of ART. If ART is available, it is unacceptable to wait for the child to develop severe brain damage due to HIV before starting ART.

Psychological Problems

See Chapter 14: Communicating with Patients and Their Families and Chapter 29: Psychosocial and Spiritual Care for more on assessment and management of these problems.

Assessment

Psychosocial problems, including low self esteem, inadequate family support, poor social skills, stigmatisation, and unresolved grief, are very common among children living with HIV/AIDS. Problems can result from trauma to the child, depletion of household resources, having to drop out of school, becoming orphaned, and other events that may occur any time along the HIV/AIDS journey. They may be a consequence of either the child or a significant member(s) of the family becoming infected with HIV.

Psychosocial problems are a major cause of distress and compound the pains children living with HIV/AIDS may have. Unfortunately, these problems are often ignored by curative models of HIV care.

Management

Non-pharmacologicl symptom management

If a child is anxious or depressed, the value of another human presence should not be underestimated. Encourage the child to use both verbal and non-verbal avenues for expression.

Manage psychosocial issues using a multidisciplinary approach in partnership with caregivers and various resources from the community. Poverty, which propagates HIV transmission and is in turn a consequence of the disease, also needs to be considered in all attempts to mitigate the effects of HIV/AIDS on the child.

Pharmacologic Symptom Management

Anxiolytics and antidepressants have important roles in relieving anxiety and depression. If the child is on ART, it must be noted that drug interactions are common between these drugs and protease inhibitors and NNRTIs (See Chapter 11: Pharmacology and Appendix 2).

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Chapter 28

Integration of Palliative Care With ART in Children

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At a Glance

Overview

Although most children in sub-Saharan Africa do not currently have access to antiretroviral therapy (ART), the numbers are increasing. Palliative care should be integrated into paediatric medical care at all stages of HIV disease and for all levels of care including those in which ART is available. Palliative care can enhance symptom management, adherence, and quality of life for children undergoing ART. Moreover, ART is the most potent form of palliative care for HIV disease.

The goals of ART for children are to (ANECCA, 2004):

- Prolong life
- Promote optimal growth and development
- Preserve, enhance or reconstitute the immune system and therefore reduce opportunistic infections
- Suppress HIV replication and therefore prevent disease progression
- Reduce HIV-related illness and improve quality of life

The purpose of including this chapter in a book about palliative care is to provide palliative and primary care health workers with a basic understanding of their young patients who may be on ART. For more information, see also the adult chapter on ART, Chapter 12: Integration of Palliative Care with Antiretroviral Therapy. ART is best administered and monitored by prescribers who have been trained and have experience in HIV management.

See Chapter 26: Clinical Assessment of Children for diagnosis and staging of HIV disease and for prophylaxis for opportunistic infections.

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Chapter 28

Integration of Palliative Care With ART in Children

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Criteria for Commencing ART

Prerequisite criteria for commencing ART are important both because of the adverse effects of the drugs themselves and because supplies are limited. The drugs pose significant health risks to the child if not taken correctly, so they must be prescribed only in appropriate cases. In areas where antiretroviral drugs (ARVs) are scarce, it is important that they be given to those who will benefit the most. To assure children are appropriate candidates for ART, they need to meet both medical and social criteria before starting therapy. The following criteria are provided only as a guide (ANECCA, 2004). Refer to national guidelines for specific criteria for commencing ART as well as for information about specific drugs that will be used.

Medical Criteria:

- Confirmed HIV diagnosis by laboratory test (see section on laboratory diagnosis of HIV in Chapter 26)
- WHO recommends ART in all children with Stage 3 or 4 disease (for staging, see Table 26.2 in Chapter 26)
- WHO recommends ART in children with Stage 2 disease if:
  <18 mos of age: CD4 <20%
  >18 mos of age: CD4 <15%
- Where CD4 testing is not available, WHO recommends ART in children with Stage 2 disease if:
  <18 mos of age: TLC <3,400/mm^3 or mother has severe symptomatic disease or has died
  >18 mos of age and <6 yrs of age: TLC <2,300/mm^3
  >6 yrs of age: 1,200/mm^3

Social Criteria:

- A clearly identified caregiver who understands the prognosis of HIV infection, side effects of medicines, how to administer and store medicines, implications of non-adherence, and that therapy is life-long. Indicators of reliability may be used, such as history of regular clinic attendance or record of previous adherence to nutritional supplements/other chronic care regimens such as TB drugs.
- Ability to attend the ART centre on a regular basis (transport may need to be arranged for patients in rural areas or for those remote from the treatment site).
- Access to supportive processes, such as counselling services and family support groups.
- Access to nutritional supplements and cotrimoxazole prophylaxis.
- Facilities at home for safe and appropriate storage of medications.

The clinical team at the referral site should make the decision to refer for treatment. The referral team should include medical, nursing, and counseling staff, and the child's mother or other caregiver.

The ART treatment site should have trained personnel and a regular supply of drugs to prevent and to treat opportunistic infections, ARV drugs, laboratory reagents, and the capacity for ongoing monitoring. Treatment of parents and siblings with HIV infection should be considered to preserve the family unit; the health of the caregiver is particularly important for the survival of the child (ANECCA, 2004).

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Process for Commencing and Monitoring ART

Children receiving ART require close monitoring. Caregivers must be able to make frequent trips to clinic. Members of primary care and palliative care health teams need to support the family in assuring that appointments are kept, the child takes medications properly, and symptoms and side effects are managed. Box 28.1 provides tips for assisting caregivers in administering medications.

Because availability of drugs varies throughout Africa, health care workers are advised to refer to the guidelines for ART therapy in their own regions and countries. See Chapter 11 for adverse effects of specific drugs. The process for commencing and monitoring ART is listed below.

Assessment Visit Prior to Starting ART

- Conduct complete history and clinical evaluation including weight, length/height, and head circumference.
- Update growth chart.
- Conduct a developmental assessment for a baseline and repeat yearly.
- Ensure that TB is adequately excluded (see Box 28.1):
  - History of TB contact
  - Chest radiograph
  - Gastric aspirates or induced sputum if abnormal chest X ray
  - Mantoux test
  - *If available and clinically indicated,* abdominal ultrasound for lymphadenopathy.
- Obtain blood tests (see Laboratory Monitoring below):
  - Full blood count (FBC) and differential count, including total lymphocyte count (TLC)
  - Alanine aminotransferase (ALT)
  - *If available:* CD4 count and viral load
  - Baseline tests as needed to monitor specific ARVs (e.g., fasting cholesterol and fasting glucose if on protease inhibitors — refer to national guidelines).
- Identify and name the caregiver responsible for medication and make sure that this person can be present during all discussion regarding ART.
- Explain the importance of adherence to the caregiver. Give tips for administering medicines (see Box 28.1).
- Explain the side effects of ARV drugs with emphasis on problems associated with the chosen drug regimen.
- Explain exact drug schedule to the caregiver and, if appropriate, to the child.

Visit to Initiate Treatment:

- Complete history and clinical evaluation including weight, length/height, and head circumference.
- Update growth chart.
- Calculate body surface area for dosing.
- Check baseline blood results (taken at first screening visit).
- Explain the importance of adherence and review medicine tips.
- Explain possible side effects of ARVs with emphasis on the problems associated with the chosen drug regimen.
- Explain drug schedule for the child to the caregiver and child, as appropriate, using the diary card.
- Commence ART.
- Prescribe medication for 2 weeks, calculating total volume of medicine and number of units required. Request that all empty containers and unused drugs be brought back for all follow up visits.
- Issue pillboxes, syringes, and diary cards.
- Arrange adherence contact or phone call in 1 week (if possible).
- Arrange followup visit after 2 weeks.

Monitoring Visits (2 weeks, then monthly for 3 months, then 3-monthly):

- Complete history and clinical evaluation including weight, length/height, and head circumference.
- Update growth chart.
- Calculate surface area for dosing.
- Conduct adherence assessment (3-day recall).

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- Reconcile returned empty containers with volume of medication prescribed for prior interval.
- Issue pillboxes, syringes, and diary cards where needed.
- Look for signs of toxicity (e.g., right upper quadrant tenderness, pallor, rash) and ask about adverse effects.
- Check results of laboratory tests from previous visit and obtain blood tests as appropriate (see laboratory monitoring below).
- Address ongoing medical problems, including skin and dental problems and organ-specific complications of HIV infection.
- Treat intercurrent infections if present.
- Check the doses, adjust the dosing schedule, and review the drug schedule with the child's caregiver, using the diary card.
- Issue medication for 4 weeks, calculating total volume of medicine and number of units required.

At subsequent 3-monthly monitoring visits:

- Repeat measures from monitoring visits above.
- When 3-monthly visits are initiated, make sure the caregiver understands what it means to collect repeat medicines at monthly intervals until the next visit.
- At each visit, enquire about surplus units of medication at home and include these in the calculation of volumes to be issued.

Box 28.1:

Tips for Medicine Use

When using liquid medicine, switch to tablets as soon as possible.

When prescribing medicines requiring refrigeration to children in homes without refrigeration, teach caregivers to put the bottle inside a pottery bowl or jug that is placed in a container of water. The moisture evaporating from the clay pot will cool the medicine. See Figure 28.1.

Teach caregivers to:

Train children to swallow pills.

Give food or drink after medicines to settle stomach and wash away bad taste except when medicines should be given on an empty stomach.

Identify measuring devices for liquid medicine.

Establish a consistent time, place, and sequence of events so child knows what to expect.

Link medicine time with ADLs to establish as part of daily routine.

Watch for side effects.

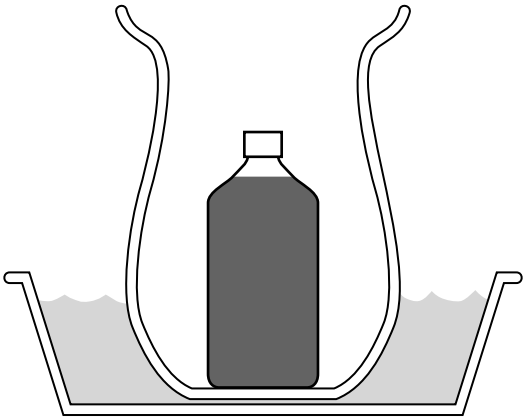
Praise child for taking medicine.

Store medicines in a secure place, where other children will not have access to them.

Laboratory Monitoring

- Full blood count (FBC) and differential count, including total lymphocyte count (TLC): at baseline, then according to drugs being used.
- If available, CD4 count and CD4 %: at baseline and 6-monthly.
- FBC and ALT: at baseline and after 1 month of treatment. If normal, repeat 6-monthly. If on protease inhibitor, test fasting lipid profiles (cholesterol and triglycerides) at baseline and then annually.
- If available, viral load tests: at baseline and 6-monthly. If viral load tests not available, monitor clinically and with CD4 count and % or total lymphocyte counts.

Figure 28.1: Keeping Medicines Cool at Home Without Refrigeration



Water evaporating off a pottery jug keeps the medicine cool inside.

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Box 28.2:

Treat Active TB Before Commencing ART

For children with active TB, commence treatment two months prior to starting ART, to avoid the immune reactivation syndrome which results in an exacerbation of the clinical features of tuberculous co-infection

Paradoxical reactions to ART are defined as transient worsening of signs and symptoms or the appearance of new signs, symptoms, or radiographic features of TB that occur after the initiation of treatment. They are not a sign of treatment failure, but are thought to be a manifestation of an immune reaction to tubercle bacilli, previously inert because of immune suppression. Such paradoxical reactions are reported in up to 36% of patients starting treatment.

Immune reconstitution symptoms occur within days to weeks after starting ART. Initiation of ART within the first two months of starting antituberculous therapy is associated with an increased risk of a paradoxical reaction.

Common presenting signs include fever, enhanced adenopathy, serositis, cutaneous lesions, and new or expanding central nervous system lesions. Most patients with paradoxical reactions have advanced HIV infection with CD4 counts <50 cells/mm^3 and very high viral loads. Treatment includes non-steroidal anti-inflammatory agents and reassurance. High dose corticosteroids (prednisone 2 mg/kg for 7 to 10 days) are indicated in the case of lymphadenopathy with life-threatening airway compression.

Deciding When to Stop ART

If a child on ART appears to be failing therapy, at some point the child may lose all potential for recovery from the present infection or complication. At this time, further survival may only mean further suffering and proper care will entail the curtailment of curative interventions and just the continuation of comfort care (see Chapter 32: End-of-Life Care of Children). It is very difficult to know when a particular child has reached this 'point of no return', the more so if the care of the child has been discontinuous. It is particularly difficult to know how to achieve the proper balance of care when a previously unknown child is admitted in extremis. Because ART is potentially the most effective palliative care in HIV disease, and can reverse the course of very advanced HIV disease, it should be considered if it is available. If prior care was inadequate, the child will have progressed to the terminal state prematurely and palliative care, in that it has not optimized health and limited symptoms as far as possible, may be said to have failed.

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Chapter 30

Loss, Grief, and Bereavement in Children

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At a Glance

Overview

AIDS has made children even more vulnerable and exposed them to multiple losses, often from a very early age. In many cases the adults who would have supported and cared for them at a time of loss are either dead or ill. The child's guardian may be an elderly relative or a teenage sibling, without the emotional resources, time, or energy themselves to deal with their own grief and to help a child, or children, grieve.

Losses are not only related to the death of a parent or family member, but include loss of education; loss of a home; loss of childhood when children have to care for their siblings; loss of self-esteem through stigmatisation; and loss of dreams for their future. An ill child also goes through a period of anticipatory grief at the prospect of losing his or her own life. The child's grief is often disenfranchised, and adults are ill-equipped to identify the child's emotions and help the child to deal with loss and grief. All these factors put the child at risk for complicated grief, which requires professional interventions.

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Chapter 30

Loss, Grief, and Bereavement in Children

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Unique Aspects of Children's Grief

AIDS-related deaths are often hidden or kept secret because of the stigma and lack of social support for the infected or affected. For this reason, children's grief, like adults' grief, often is 'disenfranchised'. It is frequently compounded by the fact that they may be considered too young to understand what has happened. A child's age, intellectual and emotional developmental stages, as well as circumstances of the loss, will affect her or his experience of grief. It has been noted that children often initially experience shock and disbelief, then experience physiologic responses similar to adults: fatigue, changes in sleep patterns, appetite changes, headaches, and/or tightness in the throat. They also tend to experience a wide variety of emotions and cognitive responses.

One unique aspect of children's grief is regressive behaviour — such as wanting to nurse, sleep with a parent, use baby talk, or suck their thumb even though they may not have exhibited such behaviour for a while. This has been attributed to a desire to return to an earlier time when the child felt protected and secure. Children also may approach grief 'in bits and pieces' — crying or calling out for the loved one, then returning to play moments later. This coping mechanism works well for the child but can be difficult for the family to understand. A child also may act in ways that attempt to get attention. Even if a child is unable to comprehend the loss, he or she can respond to the changes in the family's emotional status.

Developmentally, children must come to understand that death is final, irreversible, inevitable, unpredictable, and universal. Children dealing with AIDS-related deaths may be coping with the deaths of other family members or have HIV themselves. They are at risk for complicated grief because of the disenfranchised nature of their grief experience. As for adults, complicated grief can include somatic discomfort and emotional distress.

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Grief at Different Developmental Stages

Grief is experienced and expressed differently according to a child's developmental stage, requiring age-appropriate support from adults (see Table 30.1). It is helpful to understand the child's concepts of death at different developmental stages. In summary:

The baby and very young children have no concept of death, but may instinctively experience the loss of a loving and consistent caregiver or parent.

Ages 3-5: Children may have some concept of death but often think that death is a reversible and temporary occurrence. 'Magical thinking' may mean they feel responsible for the death due to bad behaviour or thoughts. This may lead to excessive guilt and shame.

Ages 5-7: Children at this age may have an incomplete, partial understanding that death is irreversible. They may still feel responsible for the death, with concomitant guilt and shame.

Ages 8-9 and upwards: Children at this point see death as universal and inevitable, and can understand that all living things die. Older children experience grief in a manner similar to adults.

In children, the experience of grief following loss may be associated with a number of factors including:

The child's age and/or developmental stage.

Hindered normal development from frequent illnesses, poor nutrition, and lack of developmental stimulation if the child is also infected with HIV. These children may in fact grieve in a manner usually associated with younger children.

The closeness of the relationship with the person the child has lost. The closer the relationship, the deeper will be the experience of loss and grief.

The socio-economic situation in which the child lives. If children are provided with a safe home, food, and basic comforts, the loss may be easier to endure.

Inadequate preparation for the loss. Children who are old enough to understand need to be told the truth about the situation that will lead to loss. Simple explanations that are age-related, and ongoing support, help them to prepare for the time of loss or death.

The child's own health status. Children coping with the loss of their own health and life will have few emotional resources to deal with other losses.

Insecurity about the future. Loss is magnified when there is no certainty about the future. Children need to feel secure and know that they will have a home and support from a suitable, caring adult.

The presence of hope in their lives despite the loss. The hope can include knowing they will be cared for, continue with their education, or stay in the same neighbourhood with their friends.

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Table 30.1 Age-Appropriate Responses to Loss

Age-Related Response	What Can Help
Babies 0 to 3 Years Old	
• Inability to talk about grief, expressing it physically • Crying, regressive behaviour • Delayed progress in speech, walking • Fearfulness, clinginess • Problems eating, sleeping, or with toilet habits • Development of comfort habits, such as thumb sucking	• Patience – can take a year or longer before progress is made in independence and confidence • LOTS of cuddles, love, attention, and patience • Familiar routines • Prayer in family's spiritual tradition
Preschoolers 3 to 5 Years Old	
• More difficult to calm • Naughty behaviour, due to emotional stress and hurt • Physical expressions of grief • Outbursts • Refusal to be comforted • Fluctuation between happy and sad within minutes • Repetition of questions • More understanding than is verbalised • Regressive behaviour • Feelings that God is very real • A developed sense of right and wrong	• Patience — recovery can take up to two years • Hugs, attention, cuddles • Making them feel important by, for example, helping in the home • Encouraging them to talk about event through stories, puppets, art • Helping them understand it is not their fault. They can't wish something into being. • Memory work (all ages) • Maintainence of routines • Prayer in family's spiritual tradition
Children Aged 6 to 12 Years Old	
• Ability to think logically, talking and remembering • Ability to understand what causes death • Tendency to recover faster than younger children • Grief similar to adults and older children • Loss of concentration and poor school work • Aggression • Aches and pains • Nightmares, anxiety attacks • Feelings of helplessness and vulnerability to further loss	• Non-judgmental listening • Encouraging expression of feelings through means such as art • Allowing the name of deceased to be mentioned • Supporting a loving relationship with the caregiver • Structure and stability • Allowing the child to be a child, to have fun without guilt • Providing opportunities to help others, regain sense of control, value, and belonging • Prayer in family's spiritual tradition
Adolescents	
• Feelings of weakness and helplessness • Understanding that death is irreversible and final • Ambivalence about their bodies • Life crisis of transition to adulthood • Denial of feelings, seeing the need for consolation as immature • Anger and rebellion • Lack of trust, feelings of being let down • RISKS: Running away, seeking out undesirable peers, promiscuity, substance abuse, eating disorders, suicidality, depression, morbid thoughts	• Peer support • Recreation • Have a trusted adult to talk to • Respite, such as walks or camp with carer • Creating interest in the future • All interventions for children 6 to 12 years old • Prayer in family's spiritual tradition

Sources: Papadatou, 1991; Ramsden, 2002.

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Expressions of Grief

Children Express Their Grief in a Variety of Ways

Initial shock and disbelief, and spending a great deal of time searching for the person they have lost. Even very young babies appear to know when a loving and caring person has gone.

Separation anxiety and 'clinginess' caused by fear of losing another significant adult. The child may insist on sharing a bed with the adult to ensure that this person does not also disappear.

Regressive behaviour, such as bed-wetting, baby talk, and thumb sucking. This may be an attempt to return to an earlier, safer, happier time of their lives.

Short bursts of anger and temper tantrums, excessive crying, attention-seeking, and destructive behaviour, followed by times of quiet play and normal behaviour.

Depression, which is often under-diagnosed, especially in resource-limited settings where children may have little access to professional evaluation and treatment.

Physical signs such as loss of appetite, insomnia, weight-loss, palpitations, headaches, sore neck, and other areas of the body showing signs of stress, heartburn, and increased susceptibility to infections.

Addressing Grief and Bereavement in Children

Encouraging Adult Caregivers to Help Children Grieve

Most children respond well to the presence of a consistent and caring adult; open lines of communication; respect for and opportunities to express their feelings; and a safe and comforting environment. Unfortunately, these are often lacking. Most adults do not know how to communicate with a grieving child and many children are unable to communicate their feelings in words. However, health care workers can model appropriate behavior toward children and encourage other caregivers in children's lives to help them grieve (see Table 30.2).

Using Memory Work

Memory work is becoming increasingly used in Africa (see Chapter 29: Psychosocial and Spiritual Care). The use of memory books and memory boxes may help children maintain their sense of identity, of where they come from and belong. It also assists the parents to prepare for their own death, whilst having the comfort of knowing that they have left something precious for their children. This special legacy left to the child is especially comforting to a parent who has little in the way of financial resources to leave the child.

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Helping Children Communicate Their Grief

Communication needs to be appropriate to the child's age and development. Children may communicate their emotions through art, story-telling, and play rather than in plain speech. Some of the useful ways adults can help children communicate their feelings of loss and grief are to:

- Listen to them so they can share their understanding of the loss or death.
- Encourage them to use symbolic language to explain their feelings and concerns.
- Encourage them to express and examine their feelings. Music, dance, and art may be effective with all age groups and in all cultures in expressing emotions.
- Help them to deal with guilt and feelings that they are responsible for the loss.
- Encourage them to express their feelings, examine the truth behind the feelings, and put them into perspective to assist them to gain control over these feelings.
- Build their self-esteem through encouragement and compliments.
- Assist them to develop new skills.
- Provide ongoing support to help them cope with the loss.
- Reassure them that they are not different or unusual because of their loss. In Africa, so many children have experienced loss that the fact that they are not alone and different helps them cope with death and loss. Many of their peers have experienced similar emotions and can be very empathetic.

Family Conferences

Planning for the child's future should ideally begin before the parent dies. A meeting of all the relevant family members and, in some cases, good friends and leaders of the family's church or other faith-based organisation, is called to discuss the future care of the child with the child's best interests as the focus (see Chapter 14: Communicating with Patients and Their Families). During these conferences plans can be made to keep the child in contact with family members. The importance of a will is often not understood, and children may be left without any of their parent's possessions, which are taken by adult family members once the parent dies.

Table 30.2 How to Help a Child Grieve

Do	Don't
• Give assurance of love and support. • Use opportunities to teach about death (e.g., a dead bird). • Encourage children to participate in family sorrow (e.g., let them attend the funeral). • Notify the child's school, day care about death/illness. • Refer to spiritual leaders, supportive people, other professionals. • Consider support groups for children, where available.	• Avoid the subject at home, school, or church. • Discourage emotional response. • Tell children something they will need to unlearn (e.g., Mom is gone on a long holiday). • Alter the child's role (e.g., little boy becomes man of the house). • Speak beyond the child's level of comprehension.

Adapted from Papadatou, 1991.

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Supporting Children Orphaned by AIDS

So many children have lost parents to AIDS, other chronic diseases, trauma, and infections in Africa that children may be split from their siblings and sent to relatives far away from their homes and other members of the family. Older children may be left homeless and begin to live on the streets, become involved in gangs and crime, and/or become addicted to substances such as sniffing glue or petrol, which are cheap and easy to obtain.

This may lead to uncertainty about their identity and lack of knowledge about their parents and background. A child needs a sense of identity and belonging for emotional well-being.

For the HIV-positive parent to plan for his or her child's future — a future without the parent — can be very emotionally painful, and this must be handled with compassion and sensitivity. Many parents find that it is emotionally satisfying to know that their children will be cared for after their death.

Complicated Grief

Grief is defined as complicated when the child is not able to adapt to the loss and when grieving does not lessen with time. Signs of complicated grief may include continued changing behaviour, outbursts of anger and tantrums, depression, sleep disturbances, anorexia, and bodily complaints. Complicated grief is best attended to by professionals such as social workers where available.

Factors predisposing to complicated grief include the lack of a caring adult or family support, lack of ability to express emotions, living with adults who are grieving themselves and do not have the emotional resources to support the child, and increased vulnerability due to poverty and lack of a safe and secure environment. The death of a parent or sibling may bring with it a change of role, as children may be heading households or caring for ill family members and thus have no time to grieve properly.

Adults caring for children may not be able to identify complicated grief and are often uninformed about services that may be available. Teachers may be taught to identify grief-related behaviour, and in South Africa schools are becoming increasingly involved in support of grieving children. Programmes to assist teachers and faith leaders to identify complicated grief, and refer where there is assistance available, have been initiated in some countries. There may be support groups in schools and churches, but often the person facilitating these groups is not qualified to identify complicated grieving. There is a great need for training bereavement counselors in communities, and for education on signs of complicated grief and the resources available to help.

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Chapter 31

Family and Community Support

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At a Glance

Overview

Hospice and palliative care programs are challenged to provide and promote circles of support for children, families, and communities that include support at individual, governmental, and global levels. Palliative care programs need to be fully integrated and incorporate advocacy and lobbying for all-around quality services for children and their families. Understanding the total picture ultimately influences governments and affects how service organisations render their services at the family and community levels.

Children are more likely to cope with excessive trauma and loss if they are able to live in familiar surroundings that are stable and nurturing. There is general consensus that orphans should be cared for in family units and extended family networks, and that siblings should not be separated. Institutionalised care on this scale is also not cost-effective. The extended family could possibly take care of these children provided they are adequately supported on all levels.

Empowering families and communities to provide effective care of children is a catalyst for facilitating healing and restoring wholeness to wounded and broken children and, by implication, the rest of society. This singularly important task needs to be tackled collaboratively by governments and organisations so that child-friendly policies and programs, linked to promoting community conversations about the best ways to care for orphans and vulnerable children, become commonplace. There is probably no single intervention more deserving of resources because, as Nelson Mandela frequently says, 'our children are our future'.

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Chapter 31

Family and Community Support

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Global Picture

The HIV/AIDS epidemic has had a staggering impact on the well-being of children, especially those in sub-Saharan Africa (see Box 31.1). In response, in 2001 the United Nations General Assembly Special Session on HIV/AIDS adopted the Declaration of Commitment on HIV/AIDS. The Declaration reflects global consensus on a comprehensive framework for achieving the Millennium Development Goal of halting and beginning to reverse the pandemic by 2015.

The goals of the Declaration are rooted in human rights principles, specifically the United Nations Convention on the Rights of the Child (UN, 1989). The African Charter on the Rights and Welfare of the Child complements the UN Convention by also emphasising the child's responsibilities (OAU, 1990). Broadly speaking, there are four basic rights — the right to protection, development, participation, and survival — which must be applied to all children, including those infected and affected by HIV/AIDS.

The Declaration's signatories committed themselves to:

- Develop, and make significant progress in implementing, comprehensive care strategies to strengthen family and community-based care, including that provided by health care systems and the informal sector; to provide and monitor treatment of people, including children, living with HIV/AIDS; and to support individuals, households, families, and communities affected by HIV/AIDS.
- Ensure that national strategies are developed to provide psychosocial care for individuals, families, and communities affected by HIV/AIDS.
- Develop and implement national policies and strategies to build and strengthen the capacities of government, families, and communities to provide a supportive environment for orphans and girls and boys infected and affected by HIV/AIDS, including appropriate counselling and psychosocial support; ensure their enrolment in school and access to shelter, good nutrition, and health and social services on an equal basis with other children; and to protect orphans and other vulnerable children from all forms of abuse, violence, exploitation, discrimination, trafficking, and loss of inheritance.
- Ensure non-discrimination and full and equal enjoyment of all human rights through the promotion of an active and visible policy of destigmatisation of children orphaned and made vulnerable by HIV/AIDS (UNAIDS, 2003).

Box 31.1

The Impact of HIV/AIDS on Families and Children in Sub-Saharan Africa

In the hardest-hit countries of sub-Saharan Africa, HIV/AIDS has profoundly affected children and their families, causing:

- Increased vulnerability
- Economic hardship
- Lack of love, attention, and affection
- Lack of education
- Loss of inheritance
- Psychological distress
- Increased risk of abuse, neglect, and infection
- Malnutrition and illness
- Stigma and discrimination

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Key Interventions for Supporting Families and Communities

Key interventions, developed by the UN and UNICEF, should be integrated at all levels, including prevention. Individual community-based organisations (CBOs), nongovernmental organisations (NGOs), and government structures must define the exact nature of the action they need to take to implement these strategies (UNAIDS, 2003; UNICEF, UNAIDS, USAID, 2003).

1. Strengthen the Capacity of Families to Protect and Care for Orphans and Vulnerable Children.

- Improve household economic capacity.
- Provide psychosocial counselling and support.
- Strengthen and support childcare capacities.
- Support succession planning.
- Prolong the lives of parents.
- Strengthen young people's life skills.

2. Strengthen and Support Community-Based Responses.

- Engage local leaders in responding to the needs of vulnerable community members.
- Organise and support activities that enable community members to talk more freely about HIV/AIDS.
- Organise cooperative support activities.
- Promote and support community care for children without any family support.

3. Ensure Access to Essential Services.

- Increase school enrolment and attendance.
- Register births of all children.
- Provide basic health and nutrition services.
- Improve access to safe water and sanitation.
- Advocate for judicial systems to protect vulnerable children.
- Ensure placement services for children without family care.
- Strengthen district/local planning and action.

4. Ensure That Governments Protect the Most Vulnerable Children.

- Adopt national policies, strategies, and action plans.
- Develop and enforce a supportive legislative framework.
- Allocate adequate resources and ensure their use at the community level.
- Establish mechanisms to ensure coordination of efforts.

5. Build the Capacity of Children to Become Self-Supporting and to Participate at All Levels

- Equip children with life skills.
- Make children aware of their rights.

6. Create a Supportive/Enabling Environment for Affected Children and Families

- Conduct a participatory situation analysis.
- Mobilize influential leaders to reduce stigma, silence, and discrimination
- Strengthen and support social mobilisation efforts at community level.

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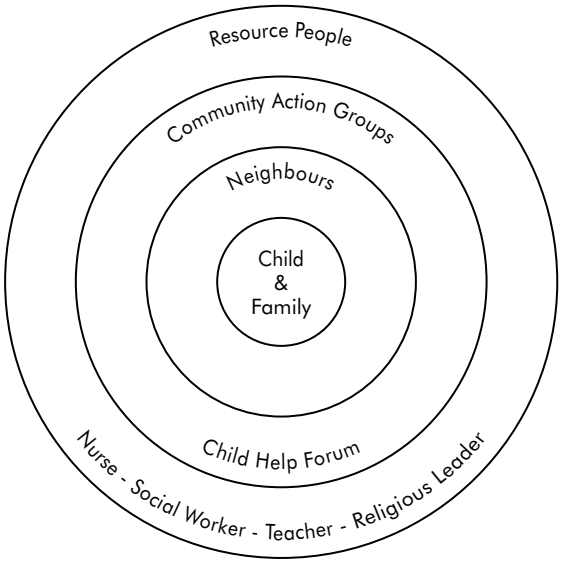
Guidelines for Strengthening Community Support

Children come from a family that forms part of a neighbourhood, neighbours; are a segment of a broader community, which is part of wider society that includes governments, NGOs, CBOs, faith-based organisations (FBOs) and resource groups (Ramsden, 2002). Hospice and palliative care programmes are challenged to promote circles of support using all of these elements (see Figure 31.1)

The following lessons have been learned from numerous small-scale programmes serving orphans and vulnerable children.

- Focus on the most vulnerable children and communities, not only those orphaned by AIDS.
- Define community-specific problems and vulnerabilities at the outset and pursue locally determined intervention strategies.
- Involve children and young people as active participants.
- Give particular attention to the roles of boys/girls, men/women, and address gender discrimination.
- Strengthen partnerships and build coalitions.
- Link HIV/AIDS prevention, care, and support activities to support for orphans and vulnerable children.
- Provide external support to strengthen community initiative and motivation.

Figure 31.1: Community Circles of Support



Neighbours and Friends:

Assist a child with homework if parent is too ill
Look after young children of sick parents
Do shopping for family

Community:

Form child support group/ forum
CBO's provide home-based care
Crèches and Early Childhood Development sites

Government/Resources:

Government grants
Welfare organizations and Children's Homes

The child and the child's immediate family are at the centre of the concentric rings. Each child is depicted as being at the centre of his or her own family. Surrounding the child and family are the neighbours who are in turn surrounded by their community. Finally, all communities form part of a larger social system that incorporates government and civil structures. The people involved in each concentric 'ring' can provide some form of assistance to the child and the child's family that culminate in 'Circles of Care'.

Source: Children's Rights Centre, 2003.

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Psychosocial Support

Psychosocial support is the ongoing process of meeting the physical, emotional, social, mental, and spiritual needs of children (see Table 31.1), all of which are essential elements of meaningful and positive human development (REPSSI, 2003). See Chapter 29: Psychosocial and Spiritual Care for more in-depth discussion of how to work with and counsel children and their families.

Table 31.1: A Simple Model of Psychosocial Support

Emotional	Physical	Social	Spiritual	Educational
Memory work Bereavement Counselling	Food and clothing parcels Assistance with grant applications	Visiting children in their homes	Rituals that help the healing process The power of faith	Helping children remain in school (school fees)

Source: Brakarsch, 2003.

Emotional Support

Grotberg describes resilience as 'the human capacity to face, overcome and be strengthened by or even transformed by the adversities of life' (CAFO, 2002). All interventions ought to focus on developing resilience because resilient children are better able to cope with life's adversities.

Factors that help children cope:

- Understanding an adverse event
- Belief in themselves
- Knowing that they have some control over what happens
- Giving deeper meaning to an adverse event

These capabilities are usually developed in children by age 15 and are facilitated by external and internal resources as depicted in Table 31.2.

Resilience is developed by:

- Providing a safe, nurturing environment in which the child's needs are met
- Spending time with the child, listening, and showing interest in what she or he does, thinks, and feels
- Teaching children how to communicate
- Allowing for mistakes
- Involving the child in day-to-day activities
- Teaching the child family routines
- Praying with and for children
- Acknowledging children for what they are, not only what they do
- Trust

Table 31.2: External and Internal Resources that Develop Resilience in Children

External Resources	Internal Resources
• Close, secure relationship with caregiver • Close relationship with remaining relatives • Education • Financial stability • Close links with cultural community	• Wide range of emotions • Sense of belonging • Interest in others • Value and belief system • Creativity, innovation and curiosity • Self-confidence

Source: Mallman, 2002.

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Physical Support

Medical Care and Palliative Care

Children who are infected with HIV need regular and ongoing primary care (see Chapter 27). They also should be provided palliative care, including home-based care if needed. Where available, antiretroviral therapy (ART) should be made available to children in conjunction with holistic care programmes (see Chapter 28).

Children under six years of age are generally entitled to free primary health care at clinics and state hospitals.

Material and Food Assistance

The distribution of food, clothing, and toys to families in need forms part of the holistic care a palliative care organisation attempts to provide. In particular, nutrition and HIV/AIDS operate in tandem at the individual and social levels (see Chapter 19: Nutrition). Undernourished people are susceptible to infection. Nutrition is also linked to treatment adherence, and will have even greater significance once ART is made accessible. Children can be taught how to grow their own vegetables in communal vegetable gardens. In addition to being a source of nutrition, this provides them with an opportunity to develop a sense of achievement and self-worth. Income generation projects represent one strategy to promote food security and are well within the scope of smaller NGOs.

Programs should establish a resource list that includes large NGOs, FBOs, and private businesses that are sources of bulk food or are able to warehouse and distribute it to organisations that visit families in their area of operation. Service organisations such as Rotary and Round Table can be engaged to support such activities.

Accessing Welfare Grants

Few countries in Africa have a social security system that provides a grant for the child or for the person caring for or fostering the child. Organisations dealing with children and families should stay informed about any available welfare support available to vulnerable children. For example, in South Africa, where welfare grants are offered by the government, frequent policy changes necessitate regular contact with relevant authorities in order to keep abreast of the current value and application procedure. A birth certificate is a prerequisite for the submission of a grant application — and many children do not have one.

Partnerships between NGOs and relevant government departments can speed up the process of accessing documents and making applications for assistance (see Chapter 24: Financial and Legal Issues). NGOs and service organisations can facilitate access to documentation by bringing social workers with the necessary knowledge and expertise to process documentation for large groups of children at one time.

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Social Support

Child-headed Households

Usually relatives in the extended family take over the care of children after their parents die. In many cases, it is assumed that the grandmother will care for the child, but evaluation of the grandmother's situation may show she is too old, has many other grandchildren in care, lives in poverty, or is in poor health. One of the tragic outcomes of the HIV/AIDS pandemic is the fact that as families are no longer able to absorb the burden of so many deaths, child-headed households have become relatively commonplace. Children in these circumstances require additional support in all spheres of their lives. NGOs and FBOs are in a good position to offer them support.

Optimal Placement of Orphans and Vulnerable Children

In countries where welfare placement agencies exist, it is imperative that home and palliative care programmes develop sound partnerships with them. In South Africa, until a vulnerable child or orphan is officially placed, she or he has no security in terms of legal status. One way of speeding up an often long-winded process is to alleviate the workload of state social workers by doing as much of the background investigation and paperwork as possible.

In South Africa, it has been observed that starting children on antiretroviral therapy sometimes has the effect of stimulating the welfare staff in children's homes to trace blood relatives. Such children are being returned to their families.

It is essential also to identify orphans and potential foster parents or caregivers as early as possible. This allows the dying parent to participate in the process. Knowing who will care for their children often helps parents to die in peace.

Figure 31.2 depicts an example of an optimal placement process. Although the flow chart focuses on foster placements, this process can also be used to identify other types of potential caregivers whilst the parent is still is alive but too ill to care for the child.

Guardianship

It is increasingly common to find children living in child-headed households, or in the care of adults who are not their legal guardians. Neither chronological age nor physical development are fail-safe indicators of psycho-social maturity or the capacity to manage a household, to adhere to a taxing therapeutic regimen, or to give appropriate and informed consent for an intervention. In cases where a child-headed household is identified and no other source of care is available, efforts to support the household should focus on developing and strengthening a local safety net through home-based care. It is usually not in the interest of the child or the household to assume independent capacity to cope. There are, however, some remarkably resilient children who are coping more than adequately.

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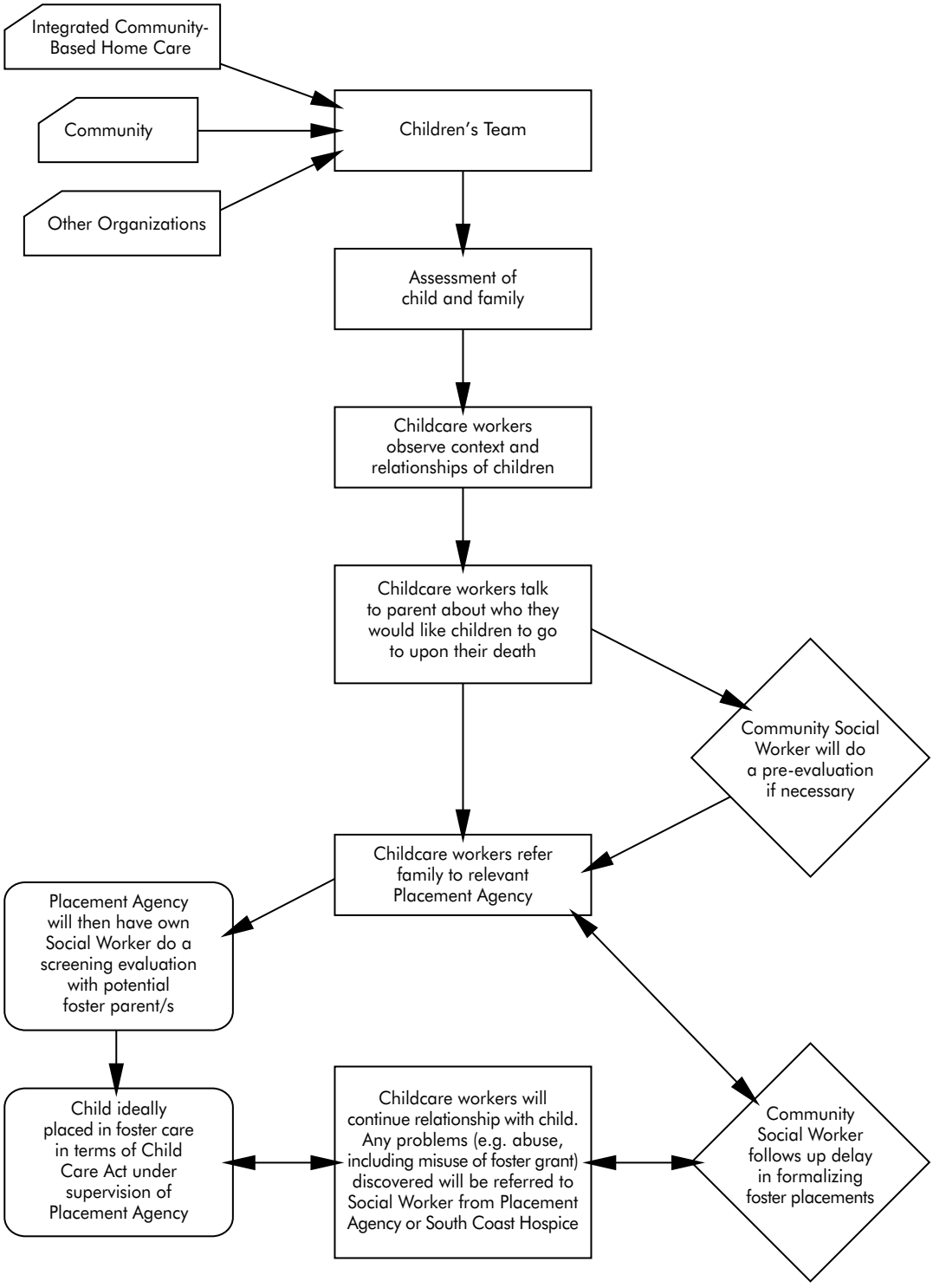
Figure 31.2: Flow Chart for Placement of Vulnerable Children



Source: Juliet Carter, 2004. Courtesy of South Coast Hospice, KwaZulu Natal, South Africa.

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Spiritual Support

Hospice philosophy affirms both life and quality of life. No one has the right to take away hope from a child or an adult. Hope is sometimes all a child has left to cling to in the face of overwhelming loss and suffering. The child needs to make sense of and find meaning in her or his suffering. This is directly related to developing resilience in the child.

Educational Support

Education

Children have the right to education. Communities at all levels can assist children with their schooling by recycling secondhand uniforms, stationery, and books. Groups can organise bursaries, feeding schemes, and help for children with homework.

Advocacy

It is important to know the law to be able to advocate for children. For instance, the South African Schools Act (84 of 1996) Section 39(4) and Namibian law clearly spell out the rights of a child to a free basic education. The South Africa Department of Labour offers free vocational training courses for unemployed persons over age 16.

Advocacy also plays a central role in the other areas of support, such as lobbying for access to ART, food security, and adequate shelter. Reducing the stigma attached to HIV/AIDS is also a key component of advocacy.

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Chapter 32

End-of-Life Care of Children

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At a Glance

Overview

The overwhelming number of children orphaned as a result of HIV/AIDS in sub-Saharan Africa has tended to overshadow the increasing number of children who themselves have AIDS.

Care of children in the end stages of AIDS often takes place in the home, as hospitals and other formal health care institutions increasingly are caring only for children with acute conditions. They often do not have the capacity to care for these children anyway.

There are few children's hospice or palliative care programmes and little training on the care of a child dying of AIDS available in Africa, although programmes have been operating in Uganda since 1999 and in South Africa since 1998. Support in the communities rests increasingly on the shoulders of community caregivers, who work with great compassion but often with little knowledge and skill in the field of paediatric palliative care, and often without professional supervision (see Chapter 38: Training, Mentorship, and Supervision).

Important issues during the final stage of the child's life include promoting the best possible quality of life for the child, supporting the family, and ensuring that the child receives skilled and compassionate care that effectively relieves pain and other symptoms (see Chapter 13: End-of-Life Care). All care interventions should aim to support the child physically, emotionally, spiritually, and socially. Palliative care for the child should always be appropriate to the needs of each child and be culturally acceptable.

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Chapter 32

End-of-Life Care of Children

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Promoting quality of life and dignity in dying for the child with AIDS involves:

- A caring adult to provide love and security
- The presence of family and/or friends for support
- Simple comfort measures to relieve pain and other distressing symptoms
- Access to medication for the relief of suffering and open communication will do much

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Involving the Family and Community

There can be few more painful experiences than watching the dying and death of your child. Families need to be supported with compassion, practical help, counselling, education, and a caring presence throughout the child's illness and into the bereavement period. In Africa, trained and untrained community caregivers are often their only form of support.

It is important to assess the family's support structures before the death and to prepare these people to help the family at the time of death and in the bereavement period (see Chapter 29: Psychosocial and Spiritual Care; Chapter 30: Loss, Grief, and Bereavement in Children; and Chapter 31: Family and Community Support).

The family has often suffered multiple losses and does not have the emotional energy required to support the dying child. Support may come from the community, faith-based organisations, non-governmental organisations, and friends. Where the child is likely to die at home, families need to be prepared for the dying process, and be given the name and contact details of who to contact once death has occurred.

The belief that 'every child is my child' and that it takes a village to help a child grow is still found in many rural areas. Whatever the home circumstances it remains essential to have the family, and child, take part in important decision making as they have knowledge and insights that the care team do not. Respect for cultural differences must be part of all care planning. Many children are seen by traditional healers as well as medical doctors, and their treatments should also be respected.

Effective end-of-life care can be provided through community-based home care — despite the fact that the home environment may be less than ideal for children living in extreme poverty — if there is a caring adult, basic comfort, access to medication to relieve suffering, and a support system for the child and family. When these conditions are not available, residential care is preferable if possible, in a hospital, children's home, a hospice, or a shelter.

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Recognising the Child Is Approaching the End of Life

Health care workers (HCW) often have difficulty admitting that a child is nearing the end of life and that no further curative treatment is indicated. At this stage, good palliative care can help the HCW and the family realize that they are providing the best possible care for the child (see Chapter 14: Communicating with Patients and their Families).

Identifying when the end of life is approaching may be difficult in a child with AIDS who is not on antiretroviral therapy (ART) as the weakness and disability may be due to poor nutrition and untreated opportunistic infections, including tuberculosis. In these cases, the child's health may be dramatically improved with good nutrition, vitamin supplementation, and effective treatment of infections. Active treatment of infections and improvement of nutritional status can take the child from 'dying' to relative health in a very short period of time. Children recover more quickly than adults, and the 'Lazarus effect' is frequently seen after the implementation of simple interventions.

When the child is truly nearing the end of life, however, an increase in clinical symptoms indicates disease progression (see Chapter 13: End-of-Life Care). If laboratory facilities are available, an increase in the viral load and a decline in the CD4 count can also be used to indicate that the condition is worsening.

When the family has accepted that the child is approaching the end of life, pain and symptom management and good holistic care become the focus of care (see Table 32.1). However, children should be encouraged to continue with their usual activities as far as possible, including education and play. Good control of pain and other distressing symptoms may be difficult in the homecare setting in countries that lack ready access to morphine and other palliative care drugs.

Treatment by traditional healers can be very effective in controlling some symptoms, and the use of complementary therapies such as massage and reflexology, have been shown to be effective (and low-cost) in relieving some painful conditions or emotional distress (see Chapter 15: Traditional Medicine and Chapter 18: Complementary Care). However, it is not advised to abandon prescribed medicines or to rely exclusively on traditional healers' remedies, which should not be viewed as replacements for 'Western' medication.

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Table 32.1: Management of Common Symptoms at the End-of-Life

Symptom	Causes	Management
For detailed symptom management in children, see chapter 27: Management of Clinical Conditions.		
Pain	Neuropathy, infections, malignancies, wounds	Provide distraction. See Chapter 29 for play therapy and other psychosocial means of distraction. Give back rubs and massage, reposition. Give pain medication according to WHO Pain Ladder. See Chapter 4: Pain Management.
Nausea and vomiting	Drugs, gastrointestinal infections, fever	Small frequent feeds, fluids between meals. Offer cold foods. Feed before giving medications. Avoid sweet, fatty, salty, or spicy foods. See Chapter 7: Gastrointestinal Symptoms.
Sore mouth	Herpes simplex, aphthous ulcers, thrush, gingivitis	Keep mouth clean: use soft cloth or gauze and clean water mixed with a little salt. Give clear water after each feed. Avoid acidic drinks (e.g., orange juice) and hot food. Give sour milk or porridge, soft and mashed. Cold food may help (yoghurt, ice cream, ice cubes if available). See Chapter 8: Mouth Care
Chronic diarrhoea	Infections, malabsorption, malignancies, drugs	Rehydration. Diet modification (e.g., give yoghurt rather than milk). Oral morphine can alleviate intractable diarrhoea. If available, micronutrient supplements. See Chapter 7: Gastrointestinal Symptoms.
Persistent cough	Infections, LIP, bronchiectasis	Low-dose morphine. If available, chest physiotherapy and nebulized air. See Chapter 6: Respiratory Symptoms.
Severe dermatitis	Infections and infestations, hypersensitivity reactions, malignancies	Keep nails short to minimise trauma and secondary infection from scratching. Apply emollients, antihistamines, antiseptics, topical steroids. See Chapter 9: Skin and Wound Care.
Convulsions	Infections and infestations, encephalopathy, malignancies, metabolic disorders	Give anticonvulsants, dextrose, steroids. If available, give mannitol. See Chapter 10: Neuro-psychiatric Problems.
Wounds	Infections, pressure, malnutrition	Dress wounds. Apply honey on clean wounds. Apply metronidazole powder to control odour. See Chapter 9: Skin and Wound Care.

Source: Adapted from ANECCA Handbook, 2004.

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Telling the Truth to the Child

Many times parents or guardians have a very difficult time disclosing to a child that she or he has an incurable condition and is dying. The parents' own fear of death may lead them to avoid telling the child the truth, but children often know intuitively that they are dying and need to speak of this to enable them to deal with their emotions (see Chapter 29: Psychosocial and Spiritual Care for issues of disclosure).

Many questions beg answers and their needs can only be served by the truth, told in a compassionate and age-appropriate manner. Children should be told the truth about their diagnosis and treatment, from the time of diagnosis, in a way that is appropriate to their age, understanding, and developmental stage. In some cases the parents' wish to 'protect' the child from the knowledge of the condition and approaching death may lead to a breakdown in communication, with the child not speaking of what she or he knows or suspects to 'protect' the parents, and the parents not telling the child the truth about his or her condition to 'protect' the child. This is called 'mutual pretence', a situation in which all parties know that the child is dying but act as though the child will live. Truth allows the child to become a full partner in the care, builds self-esteem, and establishes some form of control in a situation that often feels out of control.

The child who asks, 'Am I going to die?' has picked the best person to ask — a person she or he trusts and believes. An honest 'yes' and a time allowing the child to express fears and concerns open the door for further discussions. The parent or guardian should be responsible for disclosing this news to the child unless the HCW is asked to assist by, and in the presence of, the parent or guardian. In general, the child will trust the word of the parent or guardian.

To facilitate this disclosure, HCWs must know the wishes of the parent or guardian, what the child has been told by the parent/guardian, and what questions, if any, the child asks. This way if a child asks, 'Do I have AIDS?' the HCW will know whether to explore the question and refer the child back to the parent or guardian, if the child has not been told his or her status, or to respond with honesty and hope in an age-appropriate manner. Where a team are caring for a child, permission may be sought from the child after disclosure for shared confidentiality.

Box 32.1:

How Children Disclose Their Knowledge of Illness and Their Own Death

Children often sense that they are dying and communicate their knowledge of death in different ways. Caregivers need to be alert to verbal and non-verbal communication. They may tell stories related to someone or something dying; or ask for special prayers to be said for them or their loved ones.

Children may communicate their knowledge through art, and the colours they use often indicate their feelings. They typically choose increasingly dark and drab colours as they approach death. Children can be asked to tell a story about a picture with a child in it, into which they will usually intertwine their own story and inform the listener of their understanding of their illness and impending death.

Communication through play, often with dolls and/or puppets, allows children to enact their feelings (see Chapter 29: Psychosocial and Spiritual Care). They may use symbolic language and story-telling. Older children may even make plans for their own funeral and for the distribution of their belongings to family and friends after their death.

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Ethical Decisions in End-of-Life Care for Children

Withholding or Withdrawing Therapies

In Africa's many poor economies, issues around the best use of limited resources affect decisions to provide treatment or not. Health departments spend an increasingly large percentage of their budgets on treating conditions associated with HIV/AIDS, often leading to cuts in their budgets for non-AIDS conditions such as cancers.

In the acute care setting, when it is perceived that 'nothing more can be done', all treatment is usually withdrawn — instead of initiating good, active palliative care. We need to capacitate colleagues in acute care through the development of palliative care to integrate palliative care early in the trajectory of the illness. In countries where patients must pay for medications themselves, and resources are insufficient, HCWs or families often must choose to evaluate the benefit of treatment in relation to life expectancy. They may feel it necessary to provide for the needs of the living rather than those who are going to die, a difficult but not callously made decision.

Decision Making

The family and, where possible, the child, should always be included and kept well informed in decisions around treatment. A child can make decisions related to his or her developmental stage and level of understanding.

- Even very small children can be involved in simple decision making, such as choosing between two pain medications or deciding what to eat and when.
- Financial implications often affect a decision taken by a family. For example, a child may be transported home when dying, despite discomfort and long distances, as it is more affordable for the family to transport the child whilst living than to transport the child's body home for the funeral.
- In areas where so many children have been orphaned, it may prove difficult to find the child's parent or legal guardian to make a decision. This may place an increased burden on the HCW, who must then make difficult decisions without the input of the child's family.

Disclosure and Sharing Information

Children have the right to expect their AIDS diagnosis to be kept confidential, especially as they are too vulnerable to defend that right themselves. In many cases, however, the diagnosis is impossible to keep confidential from donors or visitors from organizations that care for children with AIDS or orphaned because of AIDS. Confidentiality is vital to respect, however, within the community.

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