

## Chapter 2

***Overview of HIV/AIDS and Palliative Care******Overview***

This chapter sets the scene for the Guide by describing the magnitude of the HIV/AIDS epidemic in sub-Saharan Africa (SSA) as it stands at the time of writing (2005) and the symptom burden that is to be addressed by palliative care. The importance of having a definition of palliative care is stressed. The fascinating interaction between the HIV/AIDS epidemic and the expansion of palliative care in SSA is examined, by looking at how the epidemic has affected the development of palliative care and the changing, but still vital, role that palliative care plays in the continuum of care of people living with HIV/AIDS, in the present era of antiretroviral therapy (ART). Various issues that are unique to palliative care in Africa are discussed, and the chapter concludes with a brief look at what the future of Palliative Care in Africa may look like.

Because of the work of visionaries in the fields of HIV/AIDS and palliative care, excellent HIV/AIDS care can be provided by integrating the principles and framework of palliative care into the delivery of care and services to people living with HIV/AIDS throughout the continuum of illness. This integration of services holds the promise of patient and family-centred care that is proactive in addressing the multitude of issues with which patients are challenged. With this Guide we seek to expand the definition of palliative care and to realize palliative care's full potential to improve the quality of care and the quality of life of those living with HIV/AIDS.

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## HIV/AIDS in Sub-Saharan Africa: Some Figures

### *Epidemiology of HIV/AIDS in SSA*

The HIV/AIDS epidemic in sub-Saharan Africa has grown enormously since the first few cases of what was coined ‘Slim Disease’ were reported in the early 1980’s (Serwadda, 1985). By December 2004, figures showed that sub-Saharan Africa has just over 10% of the world’s population but is home to more than 60% of all people living with HIV/AIDS — 25.4 million people (UNAIDS/WHO, 2004). More than three quarters of all women living with HIV are in SSA, and women and girls make up 57% of all people living with HIV/AIDS in SSA — 13.3 million total (UNAIDS/WHO, 2004).

### *Symptoms in HIV/AIDS*

#### Definition of Symptoms

The definition of a symptom as ‘a person’s perception of an abnormal physical, emotional or cognitive state’ (Wilson, 1995) rightly describes a symptom as what the patient feels is wrong with him or her. In palliative care the saying is, ‘Pain is what the patient says hurts’. Defining a symptom

as being physical, emotional, or mental echoes the late Dame Cecily Saunders’ concept of Total Pain, in which pain includes physical, emotional, psychosocial, and spiritual dimensions. (Dame Cecily Saunders, the founder of the modern Hospice/Palliative Care Movement, died in July 2005.)

#### Causes of Symptoms

People living with HIV/AIDS suffer from a multitude of symptoms as the disease progresses, including pain. These may be due to several different causes (see Table 2.1). One relatively recent cause in people receiving ART is the immune reconstitution inflammatory syndrome (IRIS) (Shelnurne, 2002). IRIS is the appearance of pain and symptoms due to opportunistic infections (OIs) or malignancies that result from a flare-up of the immune response as the immune system recovers early in the use of ART. These diseases were latent, incubating, or being treated at the time of starting ART.

**Table 2.1: Causes of Pain and Symptoms in HIV/AIDS**

Cause	Pain: Example	Symptom: Example
Opportunistic infections or malignancies	<ul style="list-style-type: none"> <li>Headache with cryptococcal meningitis</li> <li>Visceral abdominal pain with disseminated MAC</li> </ul>	<ul style="list-style-type: none"> <li>Sweats and fever in MAC</li> <li>Dyspnoea in <i>Pneumocystis carinii</i> pneumonia (PCP)</li> </ul>
Direct effects of the human immunodeficiency virus (HIV)	<ul style="list-style-type: none"> <li>Distal sensory polyneuropathy</li> <li>HIV-related myopathy</li> </ul>	<ul style="list-style-type: none"> <li>Wasting from HIV enteritis</li> </ul>
Medications	<ul style="list-style-type: none"> <li>Dideoxynucleoside-related peripheral neuropathy</li> <li>Zidovudine-related headache</li> </ul>	<ul style="list-style-type: none"> <li>Protease-inhibitor-induced nausea and vomiting</li> </ul>
Immune reconstitution inflammatory syndrome (IRIS)	<ul style="list-style-type: none"> <li>Headache with cryptococcal meningitis</li> <li>Visceral abdominal pain with disseminated MAC</li> </ul>	<ul style="list-style-type: none"> <li>Sweats and fever in MAC</li> <li>Dyspnoea in <i>Pneumocystis carinii</i> pneumonia (PCP)</li> </ul>
Nonspecific manifestations of late stage illness, other non-HIV-related causes	<ul style="list-style-type: none"> <li>Painful pressure sores</li> </ul>	<ul style="list-style-type: none"> <li>Fatigue</li> <li>Malaise</li> <li>Depression</li> </ul>

### Symptom Prevalence

Table 2.2 shows the prevalence of symptoms in samples of people living with HIV/AIDS in Taiwan, Italy, USA, and Uganda. The studies found a wide range of physical symptoms, with no major differences between the studies, even though the subjects were from clinically and culturally very different backgrounds.

- Gastrointestinal symptoms were fairly common (1.5 – 51%), as was pain (24 – 48.9%) in the different patient samples.
- Constitutional symptoms such as fatigue and fever or sweats were the most common symptoms in two studies, reported by over half the subjects in each (Fantoni, 1997; Mathews, 2000).
- In contrast, in Tsai's study of Taiwanese people living with HIV/AIDS a significant number reported anxiety (21.6%) and fear (14.2%) as major symptoms (Tsai, 2002).

**Table 2.2: Prevalence of Current Symptoms in Different Patient Populations with HIV/AIDS**

	Patient Populations			
	Tsai (Taiwan) n = 134 % (rank)	Fantoni (Italy) n = 1128 % (rank)	Mathews* (USA) n > 4000 % (rank)	Ssemafumu** (Uganda) n = 206 % (rank)
Nausea	40.3 (1)	22.0 (5)	49.8 (3)	-
Vomiting	16.4 (4)		-	-
Diarrhoea	14.9 (5)	11.0 (9)	51.0 (2)	5.3 (7)
Anorexia	10.4 (7)	34.0 (2)	-	1.5 (8)
Pain	24.6 (2)	29.0 (4)	-	100 (1)
Dysaesthesias	-	-	48.9 (4)	-
Severe headache	-	-	39.3 (5)	21.8 (3)
Oral pain	-	-	-	17.0 (6)
Visual loss	-	12.0 (8)	-	-
Anxiety	21.6 (3)	-	-	-
Fear	14.2 (6)	-	-	-
Insomnia	-	-	-	1.0 (9)
Fatigue	-	55.0 (1)	-	-
Fever/ sweats	-	-	51.3 (1)	18.9 (4)
Cough	-	32.0 (3)	-	24.3 (2)
Dyspnoea/respiratory symptoms	-	19.0 (6)	-	-
Pruritis /dry skin	-	17.0 (7)	-	18.4 (5)

\* Mathews et al did not include psychological symptoms in their survey.

\*\* Ssemafumu's study inclusion criteria: the subjects needed to have reported pain in the period in question, so all the subjects had pain. This was actually 21% of the total population from which the patients were taken.

Sources: Tsai, 2002; Fantoni, 1997; Mathews, 2000; Ssemafumu, 2001.

In another study, in Swaziland, Southern Africa, patients living with HIV/AIDS reported an average of 17.58 symptoms each, with psychological symptoms such as stress, anxiety, and fear occurring much more frequently than physiological symptoms like diarrhoea (Makoae, 2005).

In a recent cross-sectional audit of 38 patients enrolled on a palliative care service in Kampala, Uganda, 18 (47%) had serological (15) or clinical (3) diagnosis of HIV/AIDS and the rest had cancer with unknown HIV status. The study identified an average of 9.5 significant symptoms per patient. Pain was the most common symptom (50%), followed by dry mouth (40%) and mobility problems (39%). Psychological and emotional symptoms were also very common (34%), and surprisingly, hunger (24%) was reported as well as anorexia (31%) (Clipsham, 2005).

In looking at this range of studies, we learn that people living with HIV/AIDS in sub-Saharan Africa, in common with people in other regions of the world, have many bothersome symptoms at any given time. They need to be asked about their symptoms, which are physical, psychological and emotional.

### Assessment and Management

The clinical chapters in Parts II and V of this Guide address how to assess and manage the full range of pain and symptoms associated with HIV/AIDS. Relieving patients' pain and other symptoms is crucial in relieving their distress and improving their quality of life.

## What Is Palliative Care?

It is more important than ever to define what we mean by palliative care, in Sub-Saharan Africa, and in the context of HIV/AIDS. The African Palliative Care Association (APCA) and its member National Palliative Care Associations use the World Health Organization definition of palliative care, which is the most widely accepted definition (see Box 2.1). According to this definition, palliative care aims to improve the quality of life of patients and their families and is holistic, in that it addresses their physical, psychosocial, emotional, and spiritual needs.

Palliative Care has two essential components (Merriman, 2005):

**Pain and symptom control:** Modern evidence-based methods are used, including the administration of oral morphine for severe opiate-sensitive pain.

**Supportive care:** The psychological, social, spiritual, and cultural needs of the patient and family, including bereavement care, are attended to.

An organization addressing only one of these two components is not providing palliative care by the modern definition. However, the needs are so wide that usually no one organization or person can meet them all. In order to provide comprehensive palliative care, organisations must collaborate with each other. For example, an organization providing supportive care must network closely with another organization providing full pain and symptom control. On the other hand, pain and symptom control is being grafted onto many of the excellent supportive services available in sub-Saharan Africa. See Chapter 34: Models of Community-Based Care.

Palliative care for HIV/AIDS must be able to adapt to the fluctuating yet ultimately downward course of HIV disease. In situations where ART is available, the central role of medication adherence is not to be underestimated in stabilizing the course of disease, but other factors can be equally important in optimizing clinical outcomes. These factors include a wide range of

hard-to-control socio-economic as well as personal characteristics: an understanding of the disease process, empowerment in relation to personal health, a safe place to live, freedom from pain and distressing symptoms, adequate nutrition, poverty alleviation, treatment for substance abuse, depression, and other mental illness, hope and spiritual support, and adequate help of friends, family, and other caregivers, especially when functional status is diminished and disease progression is ongoing. These challenges can be met successfully by using a palliative care framework to approach the patient, providers, caregivers, family, loved ones, and the health care system.

**Box 2.1:**

**WHO Definition of Palliative Care**

*Palliative Care* is an approach which improves the quality of life of patients and their families facing life-threatening illness, through the prevention, assessment, and treatment of pain and other physical, psychosocial, and spiritual problems.

Palliative Care:

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends neither to hasten nor postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patient's illness and in their own bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
- Will enhance quality of life, and may also positively influence the course of illness;
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as antiretroviral therapy, chemotherapy, or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

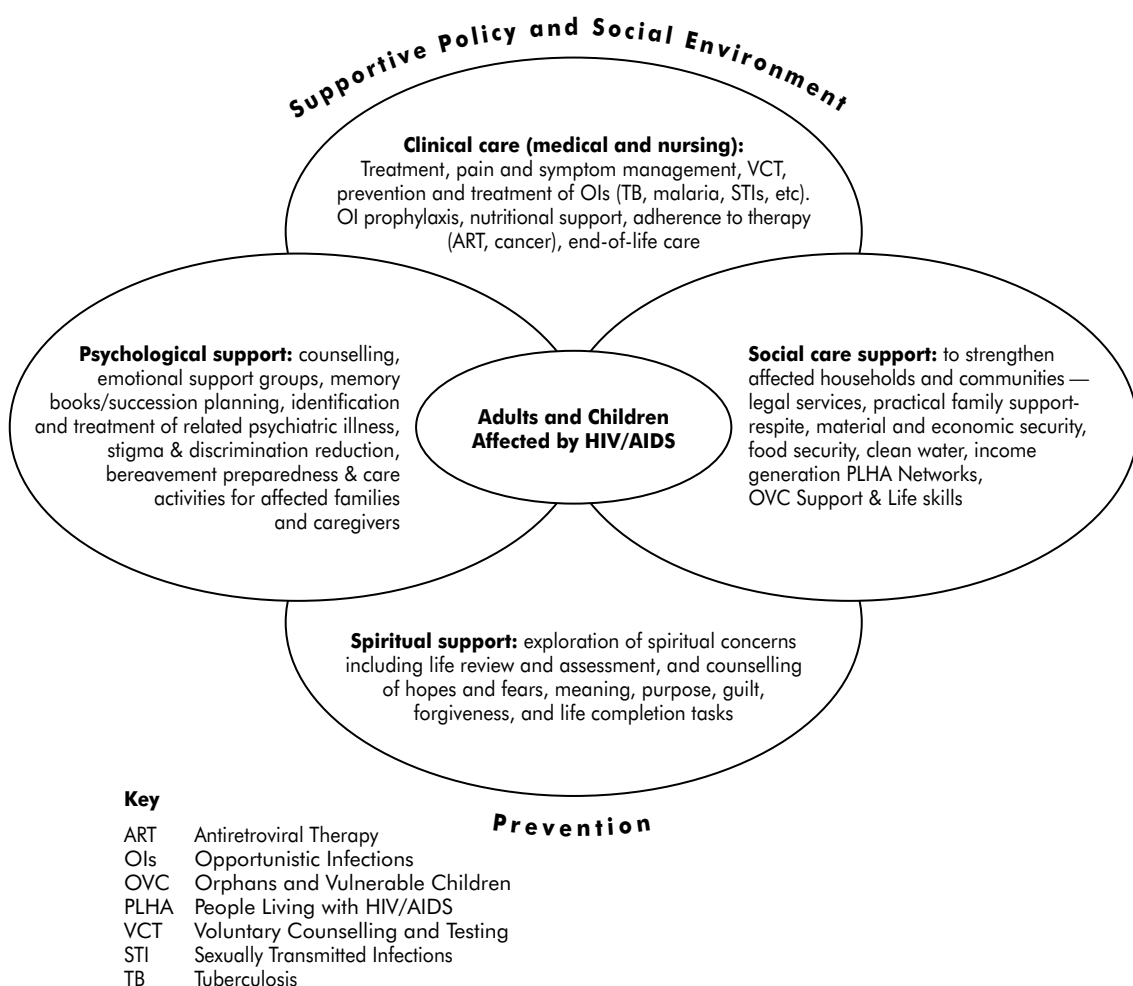
*Source: Sepulveda, 2002.*

**The Continuum of Care**

The needs of persons living with HIV/AIDS fall into four spheres (see Figure 2.1), all of which must be addressed by palliative care, within the context of prevention and a supportive policy and social environment. However, these needs change over time, so that the proportion of the total care given as disease-modifying/curative treatment (e.g., treatment for an OI, ART) and the proportion given as palliative treatment (e.g., pain and symptom control) will also vary. This is illustrated in Figures 2.2a and 2.2b. Figure 2.2a

pictures what was considered palliative care in the past — that it should come as a last resort, once a patient was thought to be dying. This was an *‘either/or’ scenario*: either you have curative treatment, or palliative care. The more modern, comprehensive kind of palliative care is shown in Fig 2.2b, where palliation comes earlier in the course of the disease, working hand-in-hand with disease-modifying treatment. This is the *‘both-and’ scenario* supported by this Guide: palliative care is integrated into the continuum of care together with curative or disease-modifying treatment (Selwyn, 2003).

**Figure 2.1: Comprehensive Palliative and Supportive Care for Adults and Children Living With and Affected by HIV/AIDS**



Source: Adapted by Manjīt Kaur from (FHI, 2001).

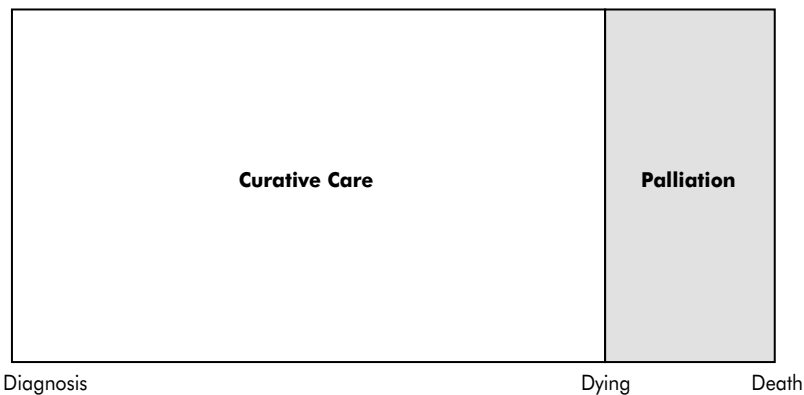
The need for palliative services changes in type and intensity based on the disease progression (which is itself unpredictable — declining health may alternate with periods of physical and emotional stability, resulting in chronic uncertainty, depicted by the wavy line in Figure 2.2b), the availability of treatment such as ART and chemotherapy, and the needs of the patient and family.

The provision of comprehensive palliative care requires the input of many people, ranging from family members to health professionals, and from community members, including traditional healers, to non-governmental organizations (NGOs) or community-based organizations (CBOs), so as to create a continuum of services through all stages of illness: diagnosis to

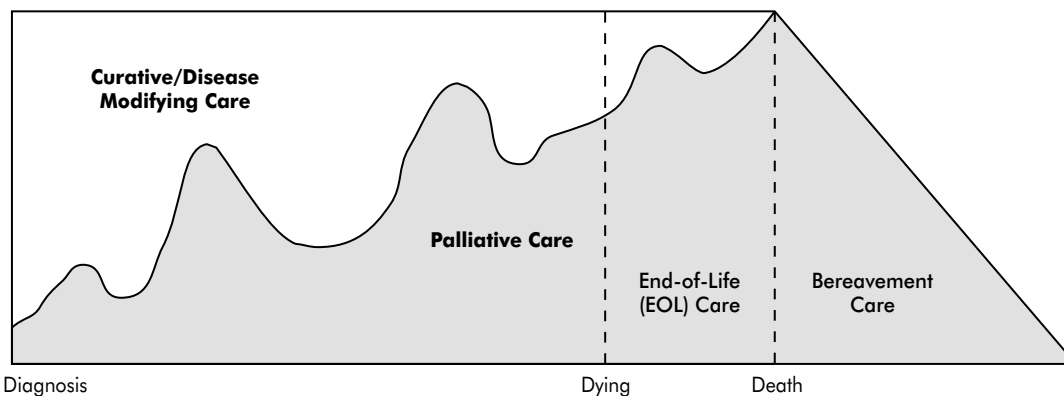
progression through end of life and bereavement. As the illness progresses, the types of services needed also changes. It is this provision of comprehensive care across a continuum from home care and community support to institutional services (primary, secondary, and tertiary), social services, and back that will ensure the needs of patients and their families are met.

These services should create a ‘continuum of care’ that is adapted to fit in as much as possible with the lives of the people needing care. This means that services should be delivered at times and places that are convenient for patients and their carers and in a manner that is culturally and socially sensitive. The referral processes between agencies providing services should be as tight and efficient as possible.

**Figure 2.2a: Traditional Dichotomy of Curative and Palliative Care for Incurable Disease**



**Figure 2.2b: Integrated Model Including Both Curative and Palliative Care for Chronic Progressive Disease**



Source: Adapted from WHO, 1990.

***The Importance of a Definition of Palliative Care***

***Without an agreed definition of what palliative care is and includes, there is a real danger of diluting the palliative care that is provided.***

It is agreed that palliative care consists of a whole spectrum or continuum of care that includes pain and symptom control and supportive care and that providing only a part of that is not palliative care. It is also a fact that no one person or organization may be in a position to provide the whole spectrum from prevention to diagnosis, through to death and bereavement care. So how does an organization decide where to fit in this continuum? Also, what proportion of comprehensive services must an organisation provide in order to be called a palliative care provider?

This is a complex question that involves three fundamental issues:

**Palliative care standards:** Provision of quality palliative care depends on a sound definition of what palliative care is. Standards are set by national and regional palliative care associations, and should take into account the level of resources available and the minimum requirements for palliative care to be provided at that level. It is possible to provide good quality care, even with limited resources. See Chapter 39: Monitoring and Evaluation.

**The focus of the service provider:** The service provider needs to decide what to focus on, depending on its capacity, both human and financial. For example, a specialized palliative care provider, whilst offering high quality pain and symptom control and paying attention to the spiritual, social, and psychological needs of its patients and families, may not have the human or financial capacity to provide a school fees service for orphans and vulnerable children. The organisation would need to identify and work closely with another agency that is able to take on the complex issues of children in school, thus freeing it to focus on its own area of expertise.

**Funding available for palliative care:**

Without funding, no services can be provided in a sustainable manner. However, when funding for palliative care is available but limited, what decisionmakers consider to be palliative care may have a significant effect on the money available for each component. Also, when donors are not clear on the definition of palliative care, they may give funding to organizations that are not actually providing palliative care as described by the WHO definition, leaving out those organizations that are. Such organizations have in some cases been funded to train others in palliative care, when they themselves may not be doing palliative care at all! See Chapter 33: Effect of Economics on Service Development and Chapter 35: Role of Government.

**How Has the HIV/AIDS Epidemic in SSA Affected the Growth of Palliative Care?**

***It Has Increased the Numbers of People Needing Palliative Care***

Palliative care was initially introduced into Africa for cancer patients, in the 1980s in South Africa and Zimbabwe, and in the early 1990s in Kenya and Uganda. The HIV/AIDS epidemic increased the number of people in SSA needing palliative care to overwhelming numbers. In Uganda, for example, the numbers dying from HIV/AIDS are far higher than those dying from cancer (see Box 2.2).

**Box 2.2:**

**Scale of the Problem in Uganda: Demand for Palliative Care**

Disease	Number of Deaths/Year
HIV/AIDS	84,500
Cancer	10,500
Total	95,000

Number of people with HIV/AIDS who need Palliative Care >400,000.

Source: UNDP 2002; UNDP 2004.

***It Has Increased Awareness of the Need for Palliative Care***

**Public:** HIV/AIDS has raised an outcry from the grassroots. An overwhelming community response to the epidemic has led people to search for ways of mitigating the devastating effects of HIV/AIDS on their families and communities. Palliative care advocates have worked hard to raise public awareness of palliative care. In some countries, not only do patients refer themselves to palliative care services, but trained community workers identify those in need of care and refer them appropriately.

**Policy makers:** WHO started a 5-Country African Palliative Care Project in 2001 in response to the overwhelming needs arising from the HIV/AIDS epidemic. Palliative care services were introduced into Ethiopia and Botswana, countries with very rudimentary palliative care services. The growth of services was encouraged in Tanzania, Zimbabwe, and Uganda, which had existing services (Sepulveda, 2003). In addition, some African countries, starting with Uganda and South Africa, have incorporated palliative care into their health policy to address HIV/AIDS.

**Donors:** Large amounts of money have been put aside by the affluent nations of the world to assist in fighting HIV/AIDS in Africa. Two examples are the Global Fund for AIDS, TB, and Malaria (GFATM), and America’s President’s Emergency Plan For AIDS Relief (PEPFAR) established in 2003. Fifteen percent of the US\$15 billion in PEPFAR Funds have been promised for palliative care in the recipient nations (Botswana, Côte d’Ivoire, Ethiopia, Kenya, Mozambique, Namibia, Nigeria, Rwanda, South Africa, Tanzania, Uganda, and Zambia in Africa; Guyana and Haiti in the Caribbean; and Vietnam). The magnitude of the funding for palliative care has enabled a planned scaling up of palliative care services in the recipient SSA countries, raising services to a level not seen before, and increasing access to palliative care in rural areas.

***It Has Broadened the Scope of Palliative Care***

Palliative care is by nature needs-driven. The wide-reaching effects of HIV/AIDS on the patient, family, and community have led long-time palliative care providers to look long and hard at adapting palliative care services to meet the new needs. Fifteen years ago palliative care 'veterans' in the West questioned some of the then new, more interventional palliative medicine approaches, yet accepted them. In the same

way, the present HIV/AIDS-related needs in SSA are leading to a broadening of the scope of services provided in palliative care. For example, prevention messages are very much linked to care when the palliative care team visits the family at home; voluntary counseling and testing for HIV/AIDS offered to the spouse of the patient is also part of the patient and family care.

**The Role of Palliative Care in the Era of ART**

The development of ART in the late 1990s brought about a revolution in the thinking about HIV/AIDS illness. It was no longer a disease that inevitably brought about a steady decline in well-being leading to death. With ART, used properly with adherence and close monitoring of the patient, HIV/AIDS has become a manageable chronic disease akin to hypertension and diabetes. In the West, so many recipients of ART have experienced a return to function that many inpatient palliative care units and AIDS hostels have had to close down. This led to an erroneous conclusion: 'Palliative care is no longer necessary in the era of ART'.

In this guide we argue that:

1. ART itself is a vital and effective form of palliative care
2. Palliative care is still very necessary, even in the era of ART.

***ART Is a Vital Form of Palliative Care***

The aim of ART is to reduce viral load and raise the CD4 count, thus improving immunity. This improves and/or prevents symptoms related to OIs and HIV-related malignancies, and therefore prolongs as well as improves quality of life. Here are some examples:

- ART reduced the incidence of AIDS-defining illnesses in one European study from 30.7/100 patient years in 1994 to 2.5/100 patient years in 1998 (Mocroft, 2000).
- ART reduces the incidence of non-Hodgkin's lymphoma (Balestre, 2003).
- Combining ART with chemotherapy brings about much improvement in HIV-related Kaposi's sarcoma.
- ART markedly improves HIV-related skin rashes such as nodular prurigo and molluscum contagiosum.
- ART is the only known effective treatment in HIV-related brain syndromes such as progressive myeloleukoencephalopathy (PML), HIV brain atrophy, and HIV dementia (last three findings based on personal communication from Dr Emmanuel Luyirika, Director of Clinical Services, The Mildmay Centre, Uganda).

### *Palliative Care Provides Many Benefits in the Era of ART*

#### **Pain and Symptom Control in Specific Circumstances:**

- Side effects of antiretroviral drugs (ARV) (e.g., painful peripheral neuropathy caused by DDI and D4T, Stevens-Johnson Syndrome secondary to nevirapine)
- OIs and their persisting effects (e.g. post-herpetic neuralgia, which is pain after the herpes zoster rash has healed)
- HIV-related malignancies (e.g., Kaposi's sarcoma, Non-Hodgkin's lymphoma)
- Immune reconstitution inflammatory syndrome (IRIS)
- AIDS-related disabilities that occurred before ART was started

**Severe or under-treated pain and other symptoms during ART can lead to non-adherence to therapy, and development of viral resistance, a very serious issue.**

#### **Adherence Follow-up:**

- The palliative care team can use every contact with the patient as an opportunity to check adherence to ART.
- Palliative care addresses social issues that are vital to adherence, like the identification of a treatment 'buddy' or partner from the family or community.

#### **Supportive Services:**

- Even whilst on ART, the person living with HIV/AIDS may still need counseling services, legal services, and succession planning — especially for orphans and vulnerable children and surviving partner/spouse. If unemployed, the person will need assistance to start and maintain income-generating activities.

#### **Care for People for Whom ART Has 'Failed':**

- Second and third-line ARV regimens are often expensive and more difficult to adhere to. When a patient has run through the available treatment options and these have failed to control the disease, palliative care is the main treatment option. Palliative care services in SSA have a significant number of AIDS patients requiring terminal care while still taking their ARVs (see Chapters 12 and 13 for discussion on when to stop ART).

#### **Care for Those Who Have no Access to ART:**

- A massive effort has been made to achieve the WHO emergency initiative to get ART to 3 million patients in developing countries by the end of 2005 ('3 by 5'), of which 2.5 million are in SSA. By June 2005, 1 million people requiring ART in developing countries had been recruited, 500,000 of those from SSA (WHO, 2005). That was still way behind the WHO targets (Lancet, 2005) and certainly was not catching up with the escalating need for ART. Only 12% of the 4.1 million people living with HIV/AIDS who need ART in SSA had access to it at that time (WHO, 2005). The large majority of people living with HIV/AIDS in SSA, especially in the rural areas far from centres where ART is being rolled out, will not have access to these drugs, and therefore will rely solely on prophylaxis and treatment of OIs and other forms of palliative care.

### *The Answer to the Question Is Undisputable*

Antiretroviral treatment is an effective form of palliative care, in that it improves immunity, function, and quality of life. The fight against HIV/AIDS must involve improving access to ART. Patients must be carefully selected for likely adherence and be closely monitored to assess the effectiveness of the ART, manage the side effects, and minimize drug interactions. However, ART is only part of the total care that patients need. Palliative care remains a very important part of the continuum of care for persons living with HIV/AIDS, even in the era of ART.

## Issues in African Palliative Care

Several issues pertinent to palliative care in Africa are outlined briefly below.

### *Access to Palliative Care*

There are still too few palliative care services in SSA, and the coverage is patchy. Thus the majority of people living and dying with HIV/AIDS do not get access to palliative care. This is due to several reasons:

- Many live too far from a health and/or palliative care facility.
- There are too few HCWs trained in palliative care; those who do receive some post-registration training may not be officially recognized, remunerated as trained, or freed from other duties to practice palliative care.
- There are too few prescribers of palliative care drugs (i.e., doctors).
- Many persons living with HIV/AIDS may live in difficult-to-reach communities, such as in conflict areas, internally displaced people's camps, prison, or remote areas (see Chapter 23: Special Populations).

A wide range of cadres need to be educated in palliative care.

**Health care workers:** Many more HCWs need training in palliative care starting with their pre-registration training.

**Many more prescribers:** Sensitize the doctors, and if possible, change the law. Uganda passed a law in 2004 allowing specialist palliative care nurses and palliative care clinical officers to prescribe morphine.

**Traditional healers and community volunteer workers:** Helpers living in the community have more access to the people and are more acceptable to them. They can offer treatment and basic nursing care in the community, and identify and refer those who need palliative care.

**Peer support workers:** People living with HIV/AIDS are often the best peer supporters and peer educators. They can form networks that are vital in care.

### *Acceptability of Palliative Care*

Palliative care needs to be delivered in the place and mode most acceptable to the patients and their families. African needs assessments have determined that the majority of patients and their carers would like to be cared for at home (Kikule, 2003; Sepulveda, 2003). See also Chapter 34: Models of Community-Based Care.

- Family-based care has been proven to be widely acceptable and effective in uptake of voluntary counseling and testing (VCT) and ART.
- The community capacity to care still needs scaling up by provision of resources, training, and clinical supervision, which are often lacking (Harding, 2005).
- Cultural and religious issues play a large part in the African approach to life, sickness, death, and dying, and they must be sensitively addressed in our provision of palliative care (see Chapter 16: Spiritual and Cultural Care).

### *Drug Availability*

Availability of drugs needed for palliative care is patchy; in particular, oral morphine is not legally available in many SSA countries (see Chapter 36: Drug Policy). This is compounded by:

**Lack of training:** Health professionals often lack understanding about their appropriate use.

**Fear of addiction:** In many cases, even where opiates are available for treating severe pain, many health professionals are afraid to prescribe them due to the myth of promoting addiction in the patient.

**Inadequate supply of stocks:** Drug supplies are intermittent due to lack of appropriate and timely upkeep of stocks. Even when morphine is available, other vital drugs like laxatives and adjuvant analgesics may not be available.

**Advocacy** with the policy makers and training of those involved in procurement and storage of palliative care drugs must go hand in hand.

### Important Drug Interactions

There are important interactions between ARVs and drugs used in palliative care. They may either lead to increased toxicity, reduced effectiveness of either drug, or resistance of the virus to the ART. These are discussed in detail in Appendix 3. Some examples are shown in Table 2.3. ALWAYS CHECK THE DRUG INTERACTION LIST BEFORE ADDING A DRUG FOR A PATIENT ON ART. (See also Chapter 12 and Appendix 1 for sources of information on further drug interactions.)

### Quality of Palliative Care Services in SSA

- Quality of the services must be based on agreed palliative care standards. However, in order for quality to be improved, there must be monitoring and evaluation, and regular audit of the services. The skills, funding and resources for these activities, as well as the perceived time by the service providers to do them, are lacking in many SSA palliative care services (Harding, 2005). See Chapter 39: Monitoring and Evaluation.

- Referral networks must be put in place and strengthened, in order that the continuum of care can be effective and efficient.
- The multidisciplinary team, the ideal way to meet the diverse needs of the patient and family in palliative care may not exist in full in the majority of African situations. More often, a lone practitioner, most likely a nurse, will have to have multiple skills, and have the capacity to refer to colleagues of the appropriate discipline where possible.

### Research in African Palliative Care Initiatives

Very little research or recorded experience from African palliative care initiatives exists. Research priorities need to be identified and resources and research skills training made available so that the wealth of African palliative care knowledge and expertise can be shared and used to advise future care.

**Table 2.3: Examples of Drug Interactions Between ARVs and Other Drugs**

ARV	Other Drug	Effect	Action
Kaletra (lopinavir/ritonavir)	Phenytoin (anti-epileptic, adjuvant analgesic for neuropathic pain — Chapter 4; Pain Mgt)	Phenytoin levels decrease by 33%, <ul style="list-style-type: none"> <li>• Increased tendency to seizures</li> <li>• Reduced analgesia for neuropathic pain</li> </ul>	Do not use phenytoin when patient is on Kaletra
Nevirapine (NVP)	Rifampicine (Anti-TB)	Reduced levels of nevirapine <ul style="list-style-type: none"> <li>• Reduced effectiveness of NVP</li> <li>• May lead to resistance to NVP</li> </ul>	Either substitute Efavirenz for NVP, or treat TB first, then start ART with NVP.
NVP, Ritonavir, non-nucleoside reverse transcriptase inhibitors NNRTI (e.g., DDI, D4T)	Oral Contraceptive Pill	Reduced oestrogen level <ul style="list-style-type: none"> <li>• Can get pregnant</li> </ul>	Use Depo-Provera and/or condom instead

## The Future of African Palliative Care

At the time of writing in August 2005, African palliative care for HIV/AIDS and cancer appears to be on the crest of a wave of rising needs, rising awareness of palliative care at all levels, supportive political will, and large amounts of money promised and being given to the new and established palliative care initiatives. As we ride the crest of the wave, we are aware of the vast shore, buffeted by the horrors of the HIV/AIDS epidemic, which needs to be washed with the refreshing waters of quality holistic palliative care. We are also very much aware that there are just a few of us, paddling very hard to reach that shore, and we need to bring many more on board, very quickly, before the momentum of the wave is lost and we are drawn back out to sea again, or dashed on the rocks of failed good intentions. There are major threats to this venture.

- Funding needs to be increased and sustained. Major drawbacks, like the temporary freezing of Global Fund support to five projects in Uganda in August 2005 due to possible mismanagement of funds, could reduce the momentum considerably unless alternative funding is sought.
- Unless advocacy continues at an increased intensity, political good will at national and local levels may dwindle.
- Unless we train homegrown African palliative care specialists, and increase the palliative care knowledge and skills base at all levels in the continuum of care, we may fail to sustain the growth of the wave, and cease to be relevant to Africa whilst the epidemic grows.
- We must remember that every country and community is unique in its palliative care 'climate' and tailor our palliative care delivery to fit. Otherwise we may waste our efforts in trying to duplicate success on other shores.

The future of African palliative care lies in strengthening the three WHO foundation measures for establishing a sustainable palliative care service, which are:

1. **Political Will**, through advocacy
2. **Drug Availability**, through advocacy
3. **Education** at all levels, from the family and community level, to the level of palliative care specialists in the training schools for health care workers

All this must be underpinned by **sustainable funding**, and sufficient people with 'fire in the belly' (Merriman, 2005) to **champion** the cause. The best way to support these efforts, and have a strong voice, is to work through **palliative care associations**, national and regional (see Chapter 41). To return to the picture of rowing ashore, we must all pull together, in the same direction, at the same time and to the same rhythm, in order to arrive safely home to harbour.

*Together, We Win!*

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