

PALLIATIVE CARE STRATEGY

for HIV and other diseases

FAMILY HEALTH INTERNATIONAL

Reprinted February 2009



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ABBREVIATIONS

AIDS	acquired immune deficiency syndrome
ANC	antenatal care
ART	antiretroviral therapy
ARV	antiretroviral
CBO	community-based organization
CHBC	community- and home-based care
CoC	continuum of care
CSO	civil society organization
CT	counseling and testing
DFID	Department for International Development
FBO	faith-based organization
GFATM	Global Fund for AIDS, Tuberculosis, and Malaria
HBC	home-based care
HIV	human immunodeficiency virus
HMIS	health management information system
IA	implementing agency
ICPC	integrated community palliative care
IMCI	integrated management of childhood illnesses
IPD	inpatient department
NGO	nongovernmental organization
OI	opportunistic infection
OPD/C	outpatient department or clinic
OSI	Open Society Institute
OVC	orphans and other vulnerable children
PEPFAR	The US President's Emergency Plan for AIDS Relief
PLHIV	people living with HIV
PMTCT	prevention of mother-to-child transmission
SBC	strategic behavioral communication
SOP	standard operating procedure
TB	tuberculosis
UNAIDS	United Nations Programme on HIV/AIDS
VCHAP	Vietnam-CDC-Harvard Medical School AIDS Partnership
VCT	voluntary counseling and testing
WHO	World Health Organization

EXECUTIVE SUMMARY

The care needs of the over 33 million people living with HIV (PLHIV) worldwide, as well as those affected by HIV, are substantial and require a comprehensive response. An essential component of services delivered to PLHIV and their families, *palliative care* is the combination of measures that relieve suffering and improve quality of life for those facing problems associated with progressive, chronic, life-threatening illnesses such as HIV, cancer, or chronic obstructive pulmonary disease.

This strategy outlines a harmonized approach to palliative care across FHI. The guidance is general, however, as each country and locality will need to adapt the strategy to fit its needs and resources. While palliative care is provided as part of routine care in a number of diseases, this strategy focuses on steps that can be taken to extend palliative care for people living with HIV and their loved ones. As FHI increases its work in new disease areas, such as cancer and heart disease, the principles and approaches laid out in this document will provide an important foundation for tailoring palliative care approaches to each disease.

Palliative care in HIV is vital to address the high burden of pain and other symptoms caused by illness, medicine side effects and toxicity, immune reconstitution inflammatory syndrome, and co-morbidities such as cancer or hepatitis and other problems. Depression and other mental health problems in PLHIV are substantially higher than for the general population, and social and spiritual problems are also common. In addition, even in areas of high ART access such as the United States and Botswana, mortality rates have fallen, but not to the levels expected. For some, the benefits of ART are compromised by limited adherence, socioeconomic barriers, substance use, psychiatric illness, presence of other life-threatening co-morbidities, or resistant disease. Despite the great strides in increasing ART access across the world, there remain many areas where there is no or inconsistent access. Palliative care services are needed in all these contexts, and wherever possible they should be integrated into existing HIV care services.

Palliative care is globally recognized as pivotal in HIV care. While WHO, PEPFAR, DfID, OSI, and other global organizations work at the policy level in palliative care, FHI—with its decades of HIV program and research experience—has the comparative advantage in leading the identification of evidence-based best practices in *operationalizing* palliative care in different care settings. This strategy sets the organization on course of developing, enhancing, and extending palliative care services throughout HIV and other disease programs.

The goal of the FHI palliative care strategy is to improve the quality of life of people and families living with HIV and other diseases that require palliative care. The primary objectives are to

- increase local capacity to deliver palliative care
- support increased access to palliative care throughout the continuum of care
- integrate palliative care into existing care, support, and treatment services
- advocate for sustainable and holistic palliative care locally and globally
- increase access to essential palliative care medicines and commodities
- facilitate development of palliative care policies, programs, and training
- increase the quality of palliative care services

This strategy is complemented by FHI clinical standard operating procedures and other forthcoming implementation tools.

Palliative care is the combination of measures that relieve suffering and improve quality of life for those facing problems associated with progressive, chronic, life-threatening illnesses.

1. AN INTRODUCTION TO PALLIATIVE CARE

Palliative care is the combination of measures that relieve suffering and improve quality of life for those facing problems associated with life-threatening, progressive, chronic illness such as HIV, cancer, or chronic obstructive pulmonary disease. FHI subscribes to the WHO definition of palliative care (see box), which has been adopted and applied in more than 115 countries worldwide.^{1,2}

Palliative care is offered from the point of diagnosis and until death, and continues through bereavement, helping families cope with their loss. Since the needs of people with life-threatening disease change over time, palliative care is based on the principle of client- and family-centered care. Clinical and lay client assessment focuses on determining the needs of the client—whether physical, social, emotional, or spiritual—and developing a plan with the client and his or her family in how to address the problems identified.

Palliative care “improves the *quality of life* of patients and their families facing the problems associated with life-threatening illness through the *prevention and relief of suffering* by means of early identification and impeccable *assessment and treatment of pain and other problems, physical, psychosocial and spiritual*.” —WHO, 2002

Given this holistic approach, services offered may include treatment of pain, treatment of symptoms, counseling and treatment to address psychiatric and psychological problems, support in coping with stigma and discrimination or rejection from the family, referral to social support services not offered wherever the client is receiving primary care, end-of-life care, spiritual care and counseling, and bereavement support for families (see table 1).

Palliative care is provided alongside treatment of the underlying disease, such as HIV or cancer, and other diseases, such as opportunistic infections (OI) or co-morbidities. It is also included in prevention and health-promotion services such as family planning, provision of bed nets, and clean water services. These services can be provided as part of the continuum of care offered by the public health system or through NGO service points such as community- and home-based care (CHBC), daycare, or hospice care.

Palliative care differs from other healthcare specialties in that it uses a developmental approach to disease and recognizes that needs of clients and families change over time. It also recognizes that disease progression, while unique to each person, nevertheless follows a course that includes ups and downs in physical health, emotional and social wellbeing, and spiritual concerns. This makes palliative care unlike other disease specialties that focus on an organ, a particular disease, or a particular age group.

The specialty of palliative care has evolved over the past 40 years.³ It initially focused on cancer and end-of-life care, but it has since evolved into an approach that starts from the time of diagnosis of a life-threatening, progressive, chronic disease and focuses on optimizing quality of life throughout the course of the disease. Some may still view palliative care as end-of-life care or as a discipline focused on the treatment of pain. While these are important aspects of palliative care, they are not the sum total.

While access to palliative care services remains limited in many parts of the world, services are continually being initiated and expanded for people with HIV, cancer, diseases of organs such as the heart and liver, psychiatric diseases, and other problems. There are national palliative care programs or national palliative care associations in more than 90 countries, including many where FHI works (see annex C).⁴

Palliative care is also recognized as a right. According to the 1966 International Covenant on Economic, Social and Cultural Rights (ICESCR), all people with severe illness have the right to palliative care.^{5,6}

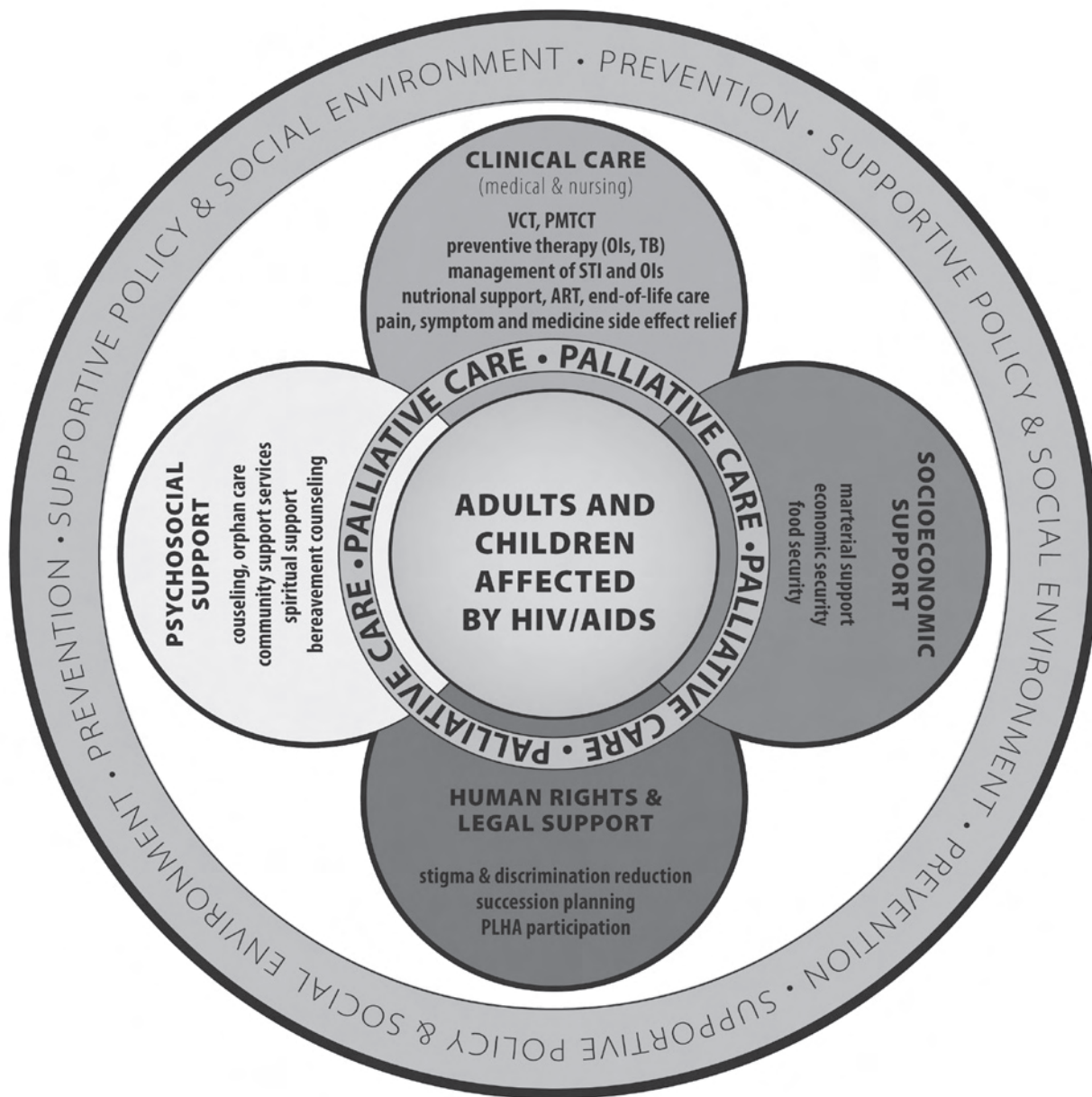
FHI promotes and supports a model of comprehensive care, treatment, and support for HIV. Providing HIV care to PLHIV and their families requires a broad range of services that

Table 1. Palliative care interventions

Palliative Care	Interventions
General	<ul style="list-style-type: none"> • Holistic clinical or lay assessment of physical, emotional, social, and spiritual needs of the patient and his or her family • System of referrals to link clients to services that can help address problems identified
Physical	<ul style="list-style-type: none"> • Assessment, prevention, and treatment of pain • Assessment, prevention, and treatment of other symptoms • Assessment and treatment of medication side effects • Teaching self-care skills for managing symptoms and medicine side effects in the home and recognition of danger signs • Attending to physical needs during end-of-life
Emotional	<ul style="list-style-type: none"> • General counseling and emotional support • Treatment of psychiatric problems such as depression or anxiety • Self-help groups • Care of caregivers (lay and professional providers and family): support groups, counseling • Bereavement support, counseling to help families with grief and future planning
Social	<ul style="list-style-type: none"> • Help with managing stigma and discrimination • Support with legal issues such as preparing a will • Assistance with financial and other material needs such as nutrition, housing, and education
Spiritual	<ul style="list-style-type: none"> • Spiritual counseling • Life-review counseling • Funeral and other life-completion tasks

includes not only medical care, but also supportive services to assure that adequate psychological, social, and daily living support and prevention messages are provided wherever the opportunity arises. This model has enabled FHI to bring critical services to millions of those infected and affected by HIV. Palliative care is a component of this comprehensive approach, and because of its holistic nature is reflected in every area of comprehensive care—clinical, psychosocial, socioeconomic, and legal and human rights. Palliative care compliments and enhances other essential forms of care: ART, OI prevention and treatment, prevention for positives, and health promotion services (see figure 1).

FIGURE 1. COMPREHENSIVE HIV/AIDS CARE AND SUPPORT



2. EXTENT OF PALLIATIVE CARE NEED

Although palliative care is an essential form of care, it is frequently unavailable to those who need it. Every year, millions endure pain or psychosocial and spiritual suffering. Millions more struggle to care for sick loved ones or grieve their loss. And while a vast number of children need palliative care, the availability of pediatric palliative care programs is even more limited than for adults.⁷

An estimated 33.2 million people are living with HIV and another 24 million with cancer, three-quarters of them in resource-limited countries.^{8,9} By 2025, more people will die from chronic illness rather than acute illness.¹⁰ Over the next 50 years cancer rates in Africa are expected to grow by 400 percent.^{11,12} Study after study shows that people with such life-threatening illness experience high rates of pain and psychosocial and spiritual distress throughout the trajectory of the illness.¹³

Palliative care needs are often under-assessed and under-addressed. Up to 80 percent of pain in PLHIV is under-treated.¹⁴ And about two-thirds of palliative care needs are missed on clinical visits.¹⁵ Some populations, such as women and drug users, are documented to have more palliative care needs than others.¹⁶ Both populations are more likely to have problems under-assessed, and have higher levels of physical and psychosocial suffering and lower quality of life.^{17,18,19}

PALLIATIVE CARE NEEDS OF PLHIV

Between 30 and 98 percent of people with HIV experience pain, which generally increases in frequency and severity toward the end of life.^{20,21} Among those with AIDS, the range is 63 to 98 percent. Studies documenting pain among PLHIV on ART have found from 30 to 60 percent presenting with moderate to severe pain.^{22,23,24} Physical symptoms, including pain, are also experienced early in diagnosis and during ambulatory periods of disease.²⁵

Prevalence of other symptoms is also high among people with HIV. Distressing symptoms can range from fatigue to nausea and insomnia. In people who are symptomatic or have AIDS, the following symptoms are particularly prevalent:

- anorexia (63 percent)
- fatigue (60–71 percent)
- fever (48 percent)
- insomnia (51–55 percent)
- skin problems (34–72 percent)
- cough (37–58 percent)^{26,27,28}

However, symptoms and medication-related side effects are also common among PLHIV on ART. The presence of symptoms and side effects has also been documented as a barrier to ART adherence in a growing number of studies.^{29,30,31}

Psychological distress is also prevalent. PLHIV in the United States are three times more likely to have psychiatric illness than those who are HIV-negative. Studies show that from 38 to 75 percent of PLHIV will experience one psychiatric disorder.³² Rates of depression range from 22 to 63 percent (15 percent is the rate of depression in the general US popula-

tion).^{33, 34, 35} Among newly diagnosed, asymptomatic women in Tanzania, 57 percent were found to have symptoms of depression.³⁶ In a recent study from Vietnam, 82 percent of PLHIV reported being unhappy or very unhappy most of the time.³⁷

Spiritual concerns have been documented as a significant source of suffering. A 2003 spiritual wellbeing and palliative care study found strong correlation between low scores in spiritual wellbeing (lack of peace, feeling that one's life is meaningless or purposeless) with hopelessness, desire for a hastened death, or suicidal thoughts.³⁸

Children need palliative care services tailored to them, but awareness among pediatric palliative care providers is often limited. Pain among children with HIV is an indicator of rapid disease progression and mortality, but is often under-assessed.³⁹ A study in Africa found that half of children with terminal AIDS did not receive analgesics, and 56 percent did not have a comfort care plan.⁴⁰

PALLIATIVE CARE NEEDS OF PLHIV ON ART

Palliative care is essential for PLHIV on ART. HIV for many on ART will continue to lead to different forms of suffering. This has been documented in a number of studies, including one recently conducted in Tanzania, where 53 percent of patients on ART presented with a palliative care need.⁴¹ Studies are indicating that while ART increases immune function, reduces morbidity, and improves prognosis among PLHIV, it does not always lead to major improvements in psychosocial wellbeing, and in some cases leads to reduced quality of life.^{42, 43, 44} PLHIV on ART may have a number of psychological, social, and spiritual problems while on ART. In addition, depression and lack of social support are associated with significantly reduced adherence to ART.⁴⁵

A number of factors make palliative care vital for PLHIV on ART. One is that those on ART, particularly those who start therapy late, may have physical problems or experience multiple, distressing side effects such as immune reconstitution inflammatory syndrome, chronic pain due to previous illness, persistent or new illness, and other chronic illness such as heart disease, hepatitis, or cancer.^{46, 47, 48}

Despite efforts to ensure all PLHIV who need ART have access to it, the reality in both rich and poor countries is that there are disparities in access. These differences persist in countries with strong healthcare systems such as the United States, and in countries where ART is being provided by less-developed systems.⁴⁹ In Botswana, where ART access is universal, the annual mortality rate of PLHIV has decreased but is still relatively high.⁵⁰ Elsewhere access to ART is much lower. In Africa, as of December 2006, only 28 percent of those in need of treatment were receiving it.⁵¹ Similarly, in Asia, 26 percent of those in need of ART receive it.⁵² Palliative care services need to be made available in these different contexts.

3. KEY PALLIATIVE CARE CONCEPTS

Six interlinked concepts are very important to palliative care service delivery:

- 1) Palliative care should be provided through a continuum of care.
- 2) Palliative care should be integrated into existing service hubs.
- 3) Palliative care teams should be developed to deliver coordinated services.

- 4) Palliative care should be part of a comprehensive package of care that includes ART, OI prevention, and treatment and prevention for positives.
- 5) Palliative care should be family-centered.
- 6) Palliative care services should be tailored to the specific needs of different populations.

CONTINUUM OF CARE

Because life-threatening diseases are often chronic, the needs of patients and their families will change over time. Thus, a range of palliative care services must be available at each point of disease. A continuum of care is needed in order to best meet changing needs over time. The continuum of care (see figure 2) is a set of comprehensive and linked care, treatment, and support services provided at all levels, from health facility to community to home. Services are generally provided by a combination of providers, including government, NGOs, community- and faith-based organizations, PLHIV, and family members.

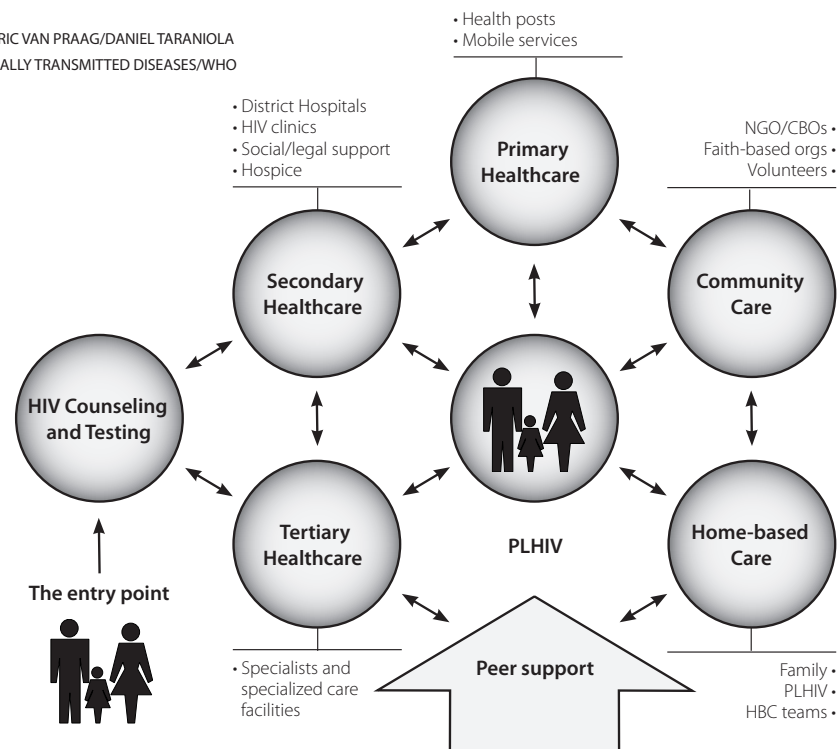
HUBS OF CARE

Given the importance of coordinated care for PLHIV, palliative care should be provided in tandem with other essential care at the same site wherever possible. HIV care is often provided through HIV outpatient clinics or ART clinics. Providers at these sites can be trained in palliative care and supported with clinical assessment tools and medicines as needed to provide basic palliative care on-site.

FIGURE 2. THE CONTINUUM OF CARE

refers to a set of comprehensive and linked care, treatment, and support services provided at all levels, from health facility to community to home. Services are provided by government, NGOs, community- and faith-based organizations, PLHIV, and family members. Palliative care is offered throughout the entire continuum.

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HIV/AIDS AND SEXUALLY TRANSMITTED DISEASES/WHO



At the primary care level, where healthcare workers are increasingly providing routine HIV care to PLHIV, healthcare workers also need to be trained in palliative care assessment and care in line with whatever the overall HIV care and treatment role of the primary care facility is in that country.

At the CHBC level, teams can be trained in palliative care and equipped with basic assessment tools and guidelines to provide medicines to treat pain, symptoms, and side effects; build health literacy/knowledge; facilitate self-care skills of clients; provide counseling and referrals; give end-of-life care; and support ART adherence, access to and enrollment in PMTCT services, care for OVC, and other vital support.

FORMING PALLIATIVE CARE TEAMS

To best address the wide variety of holistic palliative care needs, teamwork is essential. Palliative care teams should integrate into existing public and private care services such as in hubs of HIV care previously discussed. The team develops a system to provide palliative care that fits their circumstances and ensures the best use of each member's time and skills. Some of the services can be provided by trained lay health workers, with supervision and support from the health professionals. Teams can be composed of members from a single facility or of both clinic and community members. Depending on the available resources and setting, teams may be very small (for example, nurse, community caregivers, and pastor), while others can be more comprehensive (for example, doctor, nurse, pharmacist, social worker, PLHIV support group member, nutritionist, physiotherapist, community home-based caregiver, pastor, occupational therapist, traditional healer, lay counselor).

When palliative care is provided at all service levels by interdisciplinary teams, not only does quality of life improve for the patient and family but the burden on health services is lessened. Families receiving support in the community through trained volunteer palliative care providers are less likely to feel they need to hospitalize their dying patient. Providing palliative care through teamwork at all levels brings a more efficient and effective use of resources.

INTEGRATION OF PALLIATIVE CARE WITH HIV CARE AND TREATMENT

Palliative care complements ART treatment, OI prevention and treatment for positives, adherence and retention, psychosocial, and nutrition services; together they enhance the quality of life of people with life-threatening illness. Given the need to offer palliative care as part of comprehensive care services, it is important that it be incorporated into the planning of HIV care services. It is also important that staff be trained, relevant palliative care medicines be available, and patient charts incorporate pain, symptom, psychosocial assessment, and follow-up.

FAMILY-CENTERED CARE

Family-centered care is the organization and coordination of care services and systems so that families affected by HIV can access care, including palliative care, that best meets their changing needs. When family-centered care is available, it can save the lives of parents and their children. Bringing the right intervention at the right time is critical, especially for infants and children. If the caregiver or parent is not given appropriate and timely treatment or care, all family members suffer.

Family-centered care links services to all members of the affected household, with the result that they receive services closer to the time they need them. The family-centered approach may make it easier for parents to disclose their HIV status to their children or to disclose the status of an HIV-infected child. This is because the approach sensitizes the whole family to HIV, selfcare skills, and the importance of ART adherence, helping them become more comfortable living with HIV.

TAILORING CARE TO NEEDS

Palliative care services must be tailored to needs. In places where PLHIV are predominantly drug users, addiction and addiction treatment will need to be factored into the care services. Special training and sensitization will help healthcare workers better understand issues such as hypersensitivity to pain, pain management for injecting drug users on opioid substitution therapy, fear related to further addiction, and medicine diversion.

Populations living in closed settings, such as those in prisons, rehabilitation centers, and refugee camps, need special consideration. Ensuring availability of good palliative and end-of-life care, identification of family, notification of death to loved ones, and caring for family members—including children—left behind all pose special challenges.

Others, including sex workers, men who have sex with men, and migrants, may have specific support needs that should be incorporated into palliative care programs.

4. BENEFITS OF PALLIATIVE CARE

The benefits of palliative care to patients, their families, and society are numerous. Several studies have documented the impact of palliative care on physical, emotional, social, and spiritual wellbeing, as well as the macroeconomic advantages.

IMPROVES QUALITY OF LIFE

Addressing physical, emotional, social, and spiritual needs, and supporting people to achieve a sense of peace and life meaning, can prevent end-of-life suffering and despair. Studies show an intrinsic link between the overall physical health of PLHIV and their emotional, social, and spiritual wellbeing.^{53, 54, 55} Palliative care has demonstrated improvements in quality of life through a variety of services offered in diverse settings across high, middle, and low-income countries.^{56, 57} In Uganda, a recent study on the impact of a linked outpatient clinic and CHBC program for PLHIV found that it improved social aspects of quality of life.⁵⁸

PROMOTES BETTER HEALTH OUTCOMES, ADHERENCE, AND RETENTION

Palliative care services greatly improve outcomes for PLHIV on ART. Recent studies in Malawi,⁵⁹ and one conducted in several HIV care programs in Africa and the Caribbean,⁶⁰ found much lower loss to follow-up rates among PLHIV enrolled in programs that provided CHBC care and ART than those that only provide clinic-based services. The Malawi study also documented significantly lower death rates among PLHIV enrolled in the comprehensive program. Since symptoms, side effects, depression, and anxiety all have been shown to contribute to lower adherence, palliative care interventions are very important to improving levels of adherence.⁶¹

IS COST EFFECTIVE

Hospital, community, and home-based palliative care are generally cost effective. Several studies have shown that by using a public health approach to palliative care—reaching as many people as possible with proven, cost-effective palliative-care interventions—decreases costs to individual households and hospitals. The evidence also shows related improvements in disability-adjusted life years (DALY), increased rational use of healthcare services, reductions in hospitalization, and improved quality of care.^{62, 63, 64}

Costs of care are reduced by providing palliative care that is integrated into existing HIV care services (e.g., outpatient clinics, inpatient departments, home-based care, hospices), encouraging rational use of hospital-based care, and training PLHIV and families in self-care. Helping PLHIV manage treatment side effects and adherence to ART also prevents costs related to low adherence and loss to follow-up. However, cost effectiveness is also influenced by the parameters of the services offered: highly specialized hospices that serve few clients, or CHBC teams that travel long distances to visit clients, are less cost effective than integrated services and community- and home-based care that is close to the families.

5. STATE OF THE ART IN PALLIATIVE CARE

The state of the art in palliative care includes eight main elements.

INTEGRATION INTO HIV CARE SERVICES

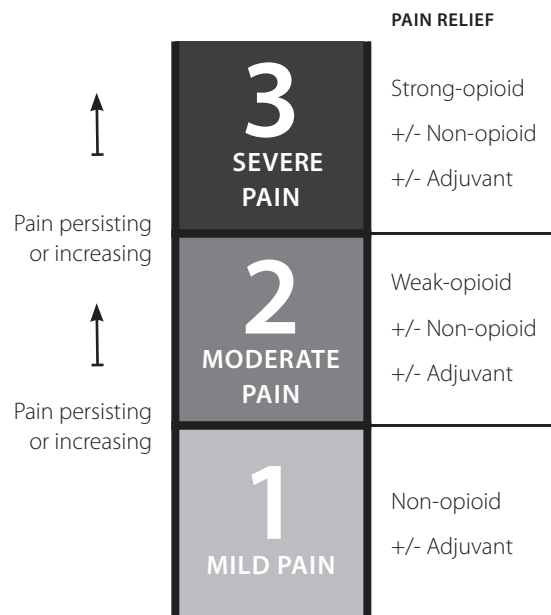
Because palliative care covers the continuum from diagnosis through death and bereavement, palliative care services are best delivered if they are integrated into key service delivery hubs. WHO has called on HIV service providers to adopt a public health approach to palliative care by making it available where most PLHIV seek their HIV care. An example of a successfully integrated HIV palliative care program is the Lighthouse Centre in Malawi, which describes its services as a “circle of care.” Palliative care is provided through the district hospital outpatient clinic, inpatient department, and through CHBC teams. The nurses providing CHBC are responsible for administering morphine in the home; and providing care for other symptoms, ART adherence follow-up, side-effect care, and psychosocial support.⁶⁵

PREVENTION, DIAGNOSIS, AND TREATMENT OF SYMPTOMS

Physical symptoms related to HIV, OIs, and medication side effects are very common in PLHIV and can result in tremendous suffering. State-of-the-art practice in palliative medicine includes training and equipping providers to assess, prevent, and treat distress-causing symptoms and side effects such as pain, fatigue, nausea, and diarrhea. In successful integrated palliative care approaches, care providers in community and home-based care teams, outpatient clinics, and hospital inpatient departments follow national or WHO palliative care symptom guidance and are skilled in using pain scales and the WHO pain treatment ladder to assess and treat pain (see figure 3).

While the prevention and treatment support of OIs is not palliative care, when an OI causes suffering, both treatment and palliative care need to be provided in tandem to ensure that symptoms are rapidly addressed and OIs are prevented and rapidly treated, thus mitigating the source of suffering.

FIGURE 3.
THE WHO THREE-STEP ANALGESIC LADDER



WORLD HEALTH ORGANIZATION. *CANCER PAIN RELIEF AND PALLIATIVE CARE*.
GENEVA: WHO, 1990.

EMOTIONAL SUPPORT

Those with life-threatening illness experience a range of emotional and mental health problems. Fear, guilt, anxiety, and depression are all common and can cause significant suffering to the ill person and loved ones. Mental health services should be integrated into palliative care for the patient and family members. Emotional support may be provided by trained caregivers, family members, neighbors, friends, or fellow patients. Support groups are a critical resource for strengthening the patient and family members' capacity to manage problems that cause distress and suffering. HIV care providers working in CHBC and out/in-patient care services can be trained in communication and counseling, basic mental health assessment, and

making referrals. In some countries, the training and placement of lay counselors has resulted in major improvements in the identification and care of mental health problems.

SOCIAL SUPPORT

Patients and their families need social support systems and services. Isolation, rejection, and separation from society cause significant suffering. Palliative care programs anticipate the impact of social suffering by taking measures to reduce stigma and discrimination from family members, the community, and healthcare workers. They inform and support clients about their rights and model treating people with dignity and respect. They can also provide or build linkages to

- legal services that can assist with succession planning, inheritance rights, and legal documentation
- assistance to secure government services such as grants, housing, or healthcare
- links to food-support and income-generating programs
- community-based efforts to increase awareness of HIV care, treatment, and prevention
- other services to strengthen affected households and communities

SPIRITUAL CARE

Life-threatening illness often brings up painful questions and issues related to facing death, including the loss of faith or a strengthened relationship with one's belief system and support. Sharing the anxieties and joys of the spiritual experience for patients and families is

FIGURE 4. PALLIATIVE CARE SUMMARY

Suffering	Care
PAIN	TREATMENT OF PAIN
+ other physical symptoms	+ other physical symptoms
+ psychological problems	+ psychological problems
+ social difficulties	+ social difficulties
+ spiritual concerns	+ spiritual concerns
= TOTAL SUFFERING	= INTERDISCIPLINARY PALLIATIVE CARE

ADAPTED FROM THE IAHPC MANUAL OF PALLIATIVE CARE 2ND EDITION, INTERNATIONAL ASSOCIATION FOR HOSPICE AND PALLIATIVE CARE, 2004.

a form of support that can be provided by volunteers, professionals, friends, family members, members of a religious organization, or anyone else clients trust.

FUTURE PLANNING AND END-OF-LIFE CARE

Palliative care providers assist individuals and families in future planning, including wills and other legal arrangements, deciding how to say goodbye to friends and family, appointing a guardian for children, and determining end-of-life care arrangements. Palliative care providers also help clients and families understand what to expect as death approaches and help patients through the last weeks of life. They answer questions and provide reassurance, physical comfort, and emotional support, and they ensure that plans made by the patient and family are kept updated.

BEREAVEMENT SUPPORT

While the patient and family go through various stages of the illness and dying process, bereavement support is required. Bereavement varies from one individual to another, so support needs to be both individualized and culturally sensitive. Support may be needed for anticipatory grief—the knowledge that loss is imminent. Bereavement support to children is as important as support to a surviving spouse or adult family member.

CARE FOR ORPHANS AND OTHER VULNERABLE CHILDREN

Children’s role in the family—whether as patient, caregiver, or close family member of a patient—necessitates palliative care services tailored to their stage of development. External programs addressing children’s needs, such as schools, are important links for palliative care. It is vital that there be close cooperation between palliative care and OVC programs, and that they form a linked network of supportive services for families. It is also critical that children’s palliative care needs be addressed through an integrated approach to children’s services within the palliative care service. Annex B provides an illustrative methodology for assessing and addressing children’s palliative care needs.

6. FHI'S PALLIATIVE CARE GOALS AND OBJECTIVES

FHI's palliative care services goal is to improve the quality of life of people living with HIV and other chronic illness and their families through

- preventing and minimizing physical, emotional, social, and spiritual suffering
- improving access to care, treatment, and support throughout the course of the disease
- planning for bereavement and succession
- supporting surviving children and family members

The objectives are to

- increase local capacity to deliver palliative care
- support increased access to palliative care throughout the continuum of care
- integrate palliative care into existing care and support services
- advocate for sustainable and holistic palliative care locally and globally
- increase access to essential palliative care medicines and commodities
- facilitate development of palliative care policies, programs, and training
- help increase the quality of palliative care services

7. FHI'S TECHNICAL AND PROGRAMMATIC APPROACHES

GUIDING PRINCIPLES

FHI recognizes the need for comprehensive care for persons living with and affected by HIV and other chronic diseases. FHI also believes that palliative care is an essential component of comprehensive care.

- **Palliative care improves quality of life:** Quality is defined by the individual, not the service provider. Serious effort should be made to improve quality of life, regardless of the stage of illness or individual circumstances.
- **Palliative care respects individuals:** We must respect people's right to make choices, express their unique cultural and personal values, receive confidential services, and be treated with dignity.
- **Palliative care is holistic:** Services should be viewed holistically, with physical, emotional, spiritual, and social aspects equally weighted. Services should be provided by *interdisciplinary teams* to better address the diverse needs. The unit of care is the family—as defined by the client or patient—and includes adults, children, and family caregivers.
- **Palliative care is sustainable:** While the process of sustainability takes time, services in the long run should be sustainable, accessible, and integrated into local communities.
- **Palliative care is integrated with other services:** Palliative care services should be provided through existing health, psychosocial, and spiritual support services.

TECHNICAL APPROACH

Palliative care services need to be adapted to the communities and environments where they are provided. Whether facility- or community-based, services must meet the holistic needs of patients and families throughout the continuum of care: from home to facility and back, and from diagnosis through the course of disease to death and bereavement.

PALLIATIVE CARE SERVICE DELIVERY OVERVIEW

To ensure palliative care services are available across the continuum of care, it is important they are offered through

- outpatient care (e.g., HIV outpatient clinic)
- inpatient care (e.g., hospital-based, hospice)
- community and home-based care (e.g., home-based care teams)
- closed settings (e.g., rehabilitation centers, prisons)

Palliative care services consist of the following components no matter where they are offered:

- coordinating body
- interdisciplinary team providing palliative care (including physicians, nurses, social workers, PLHIV)
- training and mentoring of providers in palliative care
- regular palliative care needs assessment for all clients and families (see example in annex 1), including physical, psychosocial, and spiritual needs included in patient intake and follow-up forms
- palliative care medicines
- emotional support, including adherence and bereavement counseling
- spiritual support, either directly or through referral
- care for families, including care for caregivers and skills transfer
- referral system to ensure clients can access services not offered by the palliative care program (e.g., legal services, schooling assistance to children)
- quality assessment and quality improvement (QA/QI)

PALLIATIVE CARE SERVICE COMPONENTS

Coordinating Body

To maximize available palliative care support to patients and families in a given program area, linking with an existing network of services or helping to develop of a continuum of care of services is crucial. In many countries, at the district or provincial level, a coordination system (e.g., a committee, or appointment of a coordinator or focal person) is established to guide provision of services and mobilize community support and coordination. This committee can facilitate the development of referral relationships and formal cross-program linkages related to palliative care.⁶⁶ In some settings, an existing body that coordinates health services may be able to fulfill this role.

At the service delivery level (e.g., district level) a palliative care program management team and program coordinator are responsible for developing and maintaining the referral network, training, procuring supplies, reporting to funders and authorities, monitoring activities, coordinating community support activities, recruiting and managing human and financial resources, mobilizing resources, and providing any other programmatic oversight. They are also responsible for the quality of care provided and ensuring that services follow national standards or standard operating procedures. Again, there may be a program management team in place that can fulfill this role. However, it is important to assure that the management team and program coordinator are well versed in and supportive of palliative care services.

Interdisciplinary Teams

Palliative care requires a team of professionals representing different disciplines as well as lay caregivers and supporters with other expertise. It may not always be possible to have all the members listed below, but it is important to make strong links between people who can provide input from that discipline's perspective. For example, if the pharmacist is not able to be a regular team member, the nurse may be able to identify issues that require input from a pharmacist and consult with him or her as needed. The team composition will also depend on the nature of the service and service delivery level. For example, outpatient or inpatient care and CHBC teams will likely have different compositions. Ideally, the interdisciplinary team would cross levels of service, representing the continuum of care. This team includes members from inpatient, outpatient, and community palliative care services. In South Africa, the Integrated Community Palliative Care program brings health professionals from the nearby clinic, home-based caregivers, lay counselors, spiritual counselors, social workers, traditional healers, and allied health professionals into the interdisciplinary team.

Illustrative Interdisciplinary Team

- medical doctor or clinical officer
- social worker
- nurse
- pharmacist
- PLHIV peers/expert patients
- home-based caregiver coordinator
- social worker/case manager
- counselor
- spiritual counselor
- nutritionist
- substance use specialists
- traditional healer
- physiotherapist
- vocational counselor or occupational therapist

Patients and family caregivers are also part of the team. Patients are educated about every aspect of care, diagnosis, and treatment so as to be able to make decisions, prioritize resources, and lead as much as possible the course of their care. When patients are incapacitated, care-

givers must have enough information to make good decisions for them in line with family values, culture, and traditions. In situations where children are the caregivers, the palliative care team needs to bring as much care and support as possible, providing age-appropriate information about care, prevention of infection, and emotional and spiritual support. When patients no longer require palliative care and are able to move into self-care and chronic disease management, the team helps the patient and family with this transition.

Preparing and Supporting Interdisciplinary Palliative Care Teams

Teamwork requires team building and clear roles and responsibilities. The team should meet regularly, gain the requisite skills and training, and agree on a consistent approach to care. Where those in some settings may not have as much access to formal training in palliative care, such training should be encouraged. The continuum of care relies on the depth of knowledge within the team and across levels of care. From hospital to home, and within communities and families, palliative care training and information are the basis for quality care. All members of the team, whether formally trained or not, need to have a basic understanding of the principles and practices of palliative care. Integrated case reviews, including out/inpatient services and CHBC are essential to quality support for clients as they move through different services. In Ho Chi Minh City, Vietnam, the CHBC team and outpatient clinic staff meet every morning to review client needs and discuss where follow-up is needed by CHBC, outpatient clinics, or both.

Training

Many organizations are capable of providing palliative care training, but it is important that national guidelines and curriculums be developed in consultation with palliative care professionals. As much as possible, the training should include hands-on experience and mentoring. The following synopsis lists topic areas that should be included in palliative care training at all levels. Education in palliative care includes at least a minimum of learning in three important areas (WHO 1990):

1. Attitudes, Beliefs, and Values

- philosophy of palliative care
- ethics and human rights
- interdisciplinary teamwork
- the family as the unit of care
- patient care self-management
- personal attitudes toward HIV/AIDS, pain, dying, death, and bereavement
- illness as a complex state with physical, psychological, social, and spiritual dimensions

2. Knowledge Base

- principles of effective communication
- documentation of needs assessments, care plans, progress, and outcomes
- common symptoms and changes associated with disease
- assessment and management of pain
- assessment and management of symptoms

- HIV/AIDS and ART
- other chronic diseases (e.g., diabetes, cardiovascular disease)
- human sexuality and family planning
- nutrition
- substance use prevention, harm reduction, and treatment
- care of caregivers
- appropriate care of children and adolescents
- spiritual support
- future planning
- social support
- universal precautions
- referral system and community resources
- counseling/emotional support
- death and dying
- grief and bereavement
- QA/QI

3. *Skills*

- goal setting in physical, psychological, social, and spiritual dimensions
- development of a family care plan
- communication and counseling
- promotion of patient self-care and wellness
- assessing and treating pain and symptom management
- adherence support and client empowerment in adherence and self-care
- making and monitoring referrals
- problem solving and patient advocacy
- monitoring and evaluation
- teaching caring skills to others

Team Member Support

Training is often essential but rarely sufficient: it should be ongoing and reinforced through supportive supervision,* mentorship, and team meetings. When much of the care is provided by trained community caregivers, weekly supervision should be provided by a nurse or other health professional. Standard checklists—based on commonly agreed upon standard operating procedures—should be used to assess the quality of care provided by palliative care workers. Areas of weakness should be addressed using a supportive supervision approach.

* Supportive supervision means skills building with the aim of empowerment.

Routine meetings are also a very important form of support. The interdisciplinary team should meet at least weekly to discuss the following:

- assessments and initial care plans—presentation of new cases
- workload
- team debriefings of new issues, difficult cases, deaths
- education
- information sharing
- ongoing care plan development
- ongoing reassessment of patients
- team planning (visits, supplies, transport, schedules)
- problem solving (drug reactions, symptom and pain management, family conflict issues)

Mentorship is another important way to develop a care team and palliative care services. The voluntary and mutually beneficial relationship can occur at both individual and organizational levels and involve guidance, support, leadership, supervision, advocacy, and training. Nascent palliative care providers and organizations should be encouraged to establish mentoring relationships through national associations or international palliative care organizations that can offer mentoring support. FHI technical advisors can also serve as mentors.

ESSENTIAL PALLIATIVE CARE SERVICES

At a minimum, all services that provide palliative care must address the following:

1. Staffing, training, and capacity building
 - develop interdisciplinary team structure
 - assess staffing requirements and workload
 - key providers trained and mentored in palliative care
 - care for caregivers
2. Service delivery
 - routine assessment and follow-up of pain, other physical problems
 - use of a pain scale to determine severity of pain
 - access to essential palliative care medicines
 - psychosocial and spiritual needs assessment and support
 - strong referral system
 - continuity of care—clients are not neglected
 - family-centered service—ensure children receive needed care
3. Routine supportive supervision, monitoring, and QA/QI

ESSENTIAL PALLIATIVE CARE SERVICES BY DELIVERY LEVEL

How palliative care services are integrated depends on which service they are being incorporated into and at what level of the healthcare system. The following is an example how pallia-

tive care services can be incorporated into 1) district/provincial outpatient care, 2) district/provincial inpatient care, 3) primary care, and 4) community- and home-based care.

- **Outpatient Facility:** Outpatient clinics are often the center of ambulatory care for PLHIV. Staff may not have been trained or the centers equipped to provide palliative care. The outpatient clinic is an important site for providing palliative care. In order to integrate palliative care, the following can be done:

- » Develop an interdisciplinary team. Assess and fill gaps in current teams related to palliative care. Nurses play a very important role in palliative care, often working as coordinators of care services in a clinic. Social workers, counselors, and lay workers are very important palliative care providers.
- » Train service providers in adult and pediatric palliative care.
- » Incorporate palliative care medicines in the service/essential drug list.
- » Include standardized pain and other symptoms assessment (e.g., memorial symptom assessment scale) tools as part of routine patient intake and follow-up forms.
- » Ensure identified symptoms are managed for optimal reduction of patient suffering.
- » Include a psychosocial assessment (including screening for alcohol and drug use) as part of patient intake and follow-up forms.
- » Use client-held record forms where the palliative and other care plans are documented and updated as needs change; keep a copy in patient file.
- » Ensure providers regularly assess pain and other symptoms in all patients, whether on ART or not. Develop service provider skills in appropriately classifying pain (e.g., nociceptive and neuropathic).
- » Establish a referral network and systems with services that provide psychosocial support, spiritual care, legal services, and assistance to children.
- » Develop supportive counseling services for clients, families, and caregivers, including bereavement counseling.
- » Where possible, provide assistive devices to support home care (e.g., wheelchair or bedpans).

- **Inpatient Facility:** Inpatient departments often care for PLHIV who are seriously ill or at the end of life. Few inpatient providers have been trained in palliative care—a shame given the number of PLHIV who are cared for in these departments. The following can be done to integrate palliative care:

- » Train service providers in palliative care.
- » Identify volunteers (often PLHIV or community members) who work in the inpatient facility and can provide ongoing support.
- » Incorporate palliative care medicines on the service drug list.
- » Include standardized pain and other symptoms assessment (e.g., memorial symptom assessment scale) tools as part of routine patient intake and follow-up forms.

- » Ensure identified symptoms are managed for optimal reduction of patient suffering.
 - » Develop skills in end-of-life care.
 - » Include a psychosocial assessment (including screening of alcohol and drug use) in patient intake and follow-up forms.
 - » Use client-held record forms where the palliative and other care plans are documented and updated as needs change; keep a copy in the medical file.
 - » Ensure providers regularly assess pain and other symptoms in patients both on and not on ART. Developing service provider skills in appropriately classifying pain (e.g., nociceptive and neuropathic) in people on and not on ART.
 - » Establish a referral network and systems with services that provide psychosocial support, spiritual care, legal services, and assistance to children.
 - » Provide clear, effective discharge plans and necessary instructions, medicines, and information for patient and caregivers.
 - » Develop supportive counseling services for clients, families, and caregivers, including bereavement counseling.
 - » Make provisions for last rites, funerals, and burial.
- **Primary Care:** HIV care services at the primary care level (e.g., health center or health post) are the closest point to the community and often the first place PL-HIV seek care. Increasingly, primary care sites are involved with the treatment of OIs and provision of ART. Often home-based care services are linked to or based in primary care facilities and this relationship between the home, community, and primary healthcare center are vital in effectively identifying and addressing palliative care needs. To integrate palliative care, the following can be done:
 - » Develop an interdisciplinary team. Assess and fill gaps in current teams related to palliative care. Nurses and allied healthcare workers play a pivotal role in coordinating care at the primary level. Counselors and lay workers are very important palliative care providers.
 - » Train service providers in adult and pediatric palliative care as appropriate for the primary care level.
 - » Incorporate relevant primary care palliative care medicines in the service/essential drug list.
 - » Include standardized pain and other symptoms assessment (e.g., brief form of memorial symptom assessment scale) tools as part of routine patient intake and follow-up forms.
 - » Ensure identified symptoms are managed for optimal reduction of patient suffering.
 - » Establish system of referral to secondary healthcare facility to manage complex, advanced needs of patients.
 - » Include a brief psychosocial assessment (including screening of alcohol and drug use) as part of patient intake and follow-up forms.

- » Use client-held record forms where the palliative and other care plans are documented and updated as needs change; keep a copy in medical file.
- » Ensure providers regularly assess pain and other symptoms in patients both on and not on ART. Develop service provider skills in appropriately classifying pain (e.g., nociceptive and neuropathic) in people on and not on ART.
- » Establish a referral network and systems with services that provide psychosocial support, spiritual care, legal services, and assistance to children.
- » Develop supportive counseling services for clients, families, and caregivers, including bereavement counseling.
- » Work closely with CHBC services to ensure close linkages for referral and, if feasible, supervision and mentoring of CHBC service providers.
- » Help stock and restock medicines and supplies in home-care kits.
- ♦ **Community- and Home-Based Care:** CHBC services provide vital support to PLHIV and families. However, as with the above services, elements of palliative care may be missing. The following can be done to integrate palliative care:
 - » Form an interdisciplinary team. This can include PLHIV, healthcare workers, social workers, lay counselors, and others.
 - » Train teams in palliative care.
 - » Reinforce palliative care provision through reorienting the thinking of CHBC teams and providing routine supportive supervision and mentoring.
 - » Equip CHBC teams with appropriate palliative care medicines.
 - » Where possible, provide assistive devices to support home care (e.g., wheelchairs or bedpans)
 - » Include pain assessment and a pain scale, and record other symptoms during patient intake and on follow-up forms.
 - » Include psychosocial assessment (including screening of alcohol and drug use) in patient intake and follow-up forms.
 - » Use client-held record forms where palliative and treatment plans are documented and updated as needs change.
 - » Ensure providers regularly assess pain and other symptoms in patients both on and not on ART. Developing service provider skills in appropriately classifying pain (e.g., nociceptive and neuropathic) in people on and not on ART.
 - » Introduce danger sign algorithms so CHBC teams are better able to refer clients responsively and effectively.
 - » Create formal service partnerships with primary care sites, HIV out- and inpatient care to promote client access to care.
 - » Establish referral networks and systems with services that provide psychosocial support, spiritual care, legal services, and assistance to children.
 - » Develop supportive counseling services for client, families, and caregivers, including bereavement counseling.
 - » Make provisions for last rites, funerals, and burial.

CARING FOR CAREGIVERS

The term “caring for caregivers” acknowledges that caring can produce stresses and strains on caregivers. Caring for caregivers involves ensuring the mental and physical wellbeing of those who provide care at all levels and helping them to lead healthy lifestyles. Because of the intensive work, palliative care supervision entails looking after the emotional, social, spiritual, and physical wellbeing of all team members—volunteers, professionals, and family members. Stress and accompanying burnout need to be watched for and managed.

Caring-for-caregivers interventions address

- realistic expectations
- clear roles and responsibilities
- regular supervision and emotional support
- manageable workloads
- skills and information to assure competency
- time off
- incentives and recognition
- support for personal and interpersonal problems
- support for dealing with fears and feelings of powerlessness
- personal health and wellness
- promotion of self-care by the client and family

REFERRALS

A strong referral system is essential to the success of a palliative care program. Referral forms, focal persons, a feedback system, resource directory, and a referral network all are necessary to ensure that palliative care is provided through a continuum care. There must be formal links with essential supportive services. Designated staff should be members of or develop a referral network committee to promote stronger referral relationships.

Palliative care providers should promote development of links with essential services within a health facility, health facilities at other health system levels, and with psychosocial, nutritional, welfare, legal, and spiritual support services. If needed, the provider may accompany the patient to the service or identify a volunteer to assist the patient in obtaining the needed service. Core palliative care services (out/inpatient care, primary care, and CHBC) need to be linked into one system of care to ensure clients can easily access needed care.

Special consideration to maintain client confidentiality and autonomy needs to be given when making referrals. While services such as home-based care and social services are important and helpful to PLHIV and families, they must be provided only with the explicit approval of the patient and family.

At a minimum, referral relationships should also be made with

- inter-healthcare facility services (TB-ID, maternal and child health, antenatal care, sexually transmitted infections, pediatrics, lab, mental health, radiology, reproductive health, and other relevant services)

- tertiary general and specialty hospitals (e.g., infectious diseases, maternal and child health, TB, cancer, mental health)
- support groups
- hospice
- faith-based institutions and organizations
- social welfare
- harm reduction, opioid substitution therapy, and drug and alcohol rehabilitation programs
- child care and protection agencies
- legal support services
- development organizations (food security, income generation, etc.)

PROGRAMMATIC LEVELS OF SERVICE DELIVERY

FHI works at different levels to ensure direct access to quality palliative care services at the local level while developing an enabling environment for palliative care at the policy and regulatory level. Through this approach, FHI contributes to the development of long-term, institutionalized national palliative care systems and services.

Local Level

FHI partners with local implementing organizations to provide quality palliative care to people with HIV and other chronic illness. FHI builds capacity of implementing agencies in palliative care and provides them with supportive supervision to enhance their quality of service. Select local services are utilized as learning sites for other implementing, partners, and policymakers.

National Policy, Program, and Regulatory Level

In many countries, FHI has provided technical support to ministries and other state bodies to develop and implement HIV care services. Building on these relationships, FHI assists governments in assessing and quantifying palliative care gaps and needs, developing national palliative care guidelines, reforming narcotic control laws to accommodate access to opioids for pain relief, and piloting innovative palliative care services from which policy and regulatory bodies can learn and adapt current laws and programs. In Vietnam, PEPFAR and Open Society Institute funds have been combined to advocate for regulatory reform for use of opioids in palliative care.

In Côte d'Ivoire, Nepal, Tanzania, South Africa, Vietnam, and other countries, FHI has provided instrumental support to national governments in creating national palliative care and community- and home-based care policies and programs.

Regional and Global Levels

At the regional and global levels, FHI brings technical and programmatic leadership in palliative care to improve access and quality of services. For example, in Asia, FHI is collaborating with WHO and the Asia Pacific Palliative Care Association to support palliative care initiatives regionally. And in Africa, FHI is working with members of the African Palliative Care Association and PEPFAR to support palliative care.

8. LINKS AND PARTNERSHIPS

Since palliative care is holistic and addresses the whole spectrum of human needs, linkages and referral relationships with a spectrum of different service providers are essential. In general, services that offer palliative care or palliative care programs will need to develop relationships with providers of legal support, and economic assistance; child welfare programs; domestic violence protection programs; and services aiding people with substance use issues. Some of these essential services include the following:

CHILDREN'S SERVICES: OVC AND PALLIATIVE CARE PROGRAMS WORKING TOGETHER

Children require special attention because of their unique development needs. OVC and palliative care programs must work together to ensure that emotional, social, health, and educational services are made available to children. Children require a safe and nurturing environment for their wellbeing and survival. Palliative care services assure that the needs of children are appropriately met, whether in the home of a patient, young patients, bereaved, in vulnerable circumstances, or orphaned.

ECONOMIC SUPPORT

A primary need among families affected by chronic illness is access to stable livelihoods. While palliative care programs may not be designed to assist clients directly in employment and other forms of sustained economic security, they need to be well linked with services that do. There are excellent, specialized services worldwide that assist the poor in accessing capital, developing marketable skills, and securing employment. A functional palliative care program requires formal relationships with such organizations.

LEGAL ASSISTANCE

Legal issues may arise for people with life-threatening illness and their families. These can include development of wills and other legal measures to protect property, future planning and guardian appointment, end-of-life care, choosing when and how to die, protection from violent family members, and access to controlled medicines. Palliative care programs rarely contain all the legal expertise a client may need, so links with the services that do are very important. A partnership with a legal aid organization can make a big difference to some clients.

PREVENTION PROGRAMS

Many families impacted by HIV and other chronic disease are still not aware of how to prevent infection or illness. Health education is part of palliative care but it must also link with other providers of prevention programs and services such as malaria and TB prevention and awareness, safe water, and hygiene initiatives.

CHRONIC DISEASE MANAGEMENT

Health systems are moving to include PLHIV in chronic disease management. This is an important approach for patients who have been successful in managing their disease pro-

gression. However, chronic disease patients may still need palliative care and the linkages between the two—palliative care and chronic disease management—are mutually supportive and need to be well integrated with each other so PLHIV are able to access the care they need with ease.

NUTRITION

HIV and other chronic diseases place an extra burden on the body and proper nutrition must be assured. Food security is a problem in many of the areas where FHI works. Often palliative care providers work through partnerships with agencies and authorities in the community who are able to provide food, nutrition counseling, grants for the purchase of food or food supplements. Some HIV clinics offer therapeutic and supplemental feeding support, in these sites, palliative care and nutritional interventions can be well linked. Starting good nutrition as early as possible means the client will stay healthy longer and have better quality of life. Safe food practice (proper storage and preparation) and a recommended diet are part of the palliative care focus either directly; or through referral to a dietician in the health system, or other available nutritional support and food security programs.

9. ILLUSTRATIVE ACTIVITIES

SOUTH AFRICA: INTEGRATED COMMUNITY PALLIATIVE CARE

The impact of HIV/AIDS in South Africa has led to many innovative responses to the need for care and support for adults and children, such as the development of community-based models of palliative care. In accordance with a main goal of the National HIV/AIDS/STD Strategic Plan (2000–2005),* and in line with the broader aims of the Strategic Priorities for the National Health System (2004–2009),** the National Department of Health (NDoH) recognizes that increased access to a comprehensive range of care services is essential, particularly in underserved areas. The NDoH thus prioritized the mainstreaming of community palliative care as part of the primary health response within the continuum of care. The aim is to have a palliative care site in each province by 2009.

The NDoH asked FHI to develop a pilot model in four districts within the two provinces chosen for the project. This is an approach that includes the family, makes use of available community resources, and aims to be implementable in limited-resource settings.

An assessment of current palliative care services and existing health structures conducted in the four districts informed the project design and assisted with the development of formal partnerships in the districts. It also led to the integrated community palliative care (ICPC) model. ICPC links the existing health system with community care support mechanisms—home-based care, hospice, and support groups, where available—to provide different levels of palliative care activities and build sustainability into the model.

The guiding principles of the ICPC model are four-fold: it is family-centered, sustainable, applies a comprehensive, holistic approach, and features an integrated system and team

* To provide adequate treatment, care, and support services in communities.

** To contribute toward human dignity by improving quality of care.

approach. ICPC integrates support throughout the entire holistic health system, including primary healthcare facilities and their multidisciplinary teams, ART sites and their interdisciplinary care teams, community and home-based care groups, support groups, and communities and families themselves. The integrated service delivery of ICPC makes it possible to provide a full continuum of palliative care from diagnosis to support end-of-life care and bereavement.

Each component of the ICPC model is critical to its success, but of paramount importance is the integration of complementary, comprehensive palliative care and wellness services into the existing health structure and community-based providers. Provision of integrated services is the only way that all the continuum of care needs can be met. No one health provider can address all the physical, emotional, social, and spiritual needs of holistic palliative care and wellness support that a pediatric and/or adult client has. A team approach is warranted to meet these complex, chronic care needs.

Palliative care training of NDoH health professionals, CHBC caregivers, and other members of the multidisciplinary team in each site has been conducted. Additionally, palliative care training with traditional healers and pastors has also assisted in bringing a holistic approach to the ICPC program. Patients and their families have already experienced an improvement in their quality of care, and beneficial links between facility and community-based services have strengthened the continuum of care.

ETHIOPIA: COMMUNITY SUPPORT FOR CHBC

FHI/Ethiopia has been exerting commendable efforts in implementing comprehensive community and home-based care through community mobilization in 14 communities since October 2004. The program has made a significant difference in quality of life at the individual, family, and community level.

The CHBC program is the result of a unique partnership between community organizations, NGOs, and governmental organizations. From the very beginning, the implementing NGO and concerned governmental organizations (HIV/AIDS prevention and control offices and health bureaus [HAPCOs]) worked together in identifying and mobilizing *idirs* or traditional burial societies. Regional HAPCOs provide funds to fulfill the needed supplies (medical and nonmedical items and food). Local administrations provide shelter, in most cases free of rent, and construction materials for renovation, rent-free offices for CHBC, and land for patients whose health status has improved to cultivate for income.

The program has resulted in the reduction of self-stigmatization; PLHIV communicate more openly with their families, neighbors, and visitors. Participants report being satisfied with the service and are active in identifying new clients as well as organizing self-help groups. At the family level, there is less stigmatization of family members with signs and symptoms of HIV, and families are willing to accept CHBC caregivers into their households. There is improved acceptance of the skills transferred from the caregivers to family members or neighbors in caring for the patient.

The introduction of the CHBC program in communities has resulted in visible changes in the activities of *idirs*. *Idirs* have revised their bylaws to provide services before death, whereas before they only helped after the death of a community member. They are actively involved in identifying patients to be enrolled in the service, are engaged in mobilizing

resources (food, clothes, money) for patients in need and OVC, and they contribute to addressing the pressing needs of PLHIV including shelter. Most *idirs* are becoming more visionary, showing strategic thinking toward sustainable ways to address community problems such as OVC.

The existence of dedicated CHBC caregivers in the program has tremendously improved community attitudes. There is an appreciation for what the caregivers are doing, as opposed to the resistance at the start of the program. Most caregivers are proud of what they are contributing and have developed a feeling of responsibility for their patients. In general, there is positive change toward voluntarism, and the caregivers are seeing that participation in service provision has a positive impact on their own lives, because they acquire knowledge and skills through their engagement. The involvement of caregivers has positively increased neighborhood support for visiting and supporting patients; many have started to supply food and are helping with household chores.

VIETNAM: DEVELOPMENT OF NATIONAL PALLIATIVE CARE PROGRAM

In 2005 a team of PEPFAR partners* responded to a request from the Ministry of Health Therapy Department to develop national palliative care guidelines—standards that would form the basis for a national palliative care program for the estimated 300,000 PLHIV and approximately 200,000 people diagnosed with cancer each year.

The 2005 Ministry of Health Palliative Care Needs Assessment found that

- 75 percent of PLHIV and people with cancer reported pain
- 5 percent of healthcare workers reported availability of oral morphine in their healthcare setting
- 76 percent of healthcare workers were unable to identify correct pain management strategies
- 85 percent of policymakers recognized that measures to address pain and other symptoms were inadequate in Vietnam

The first step was to assess palliative care needs among people with HIV/AIDS and cancer. The assessment included 451 people with HIV/AIDS and cancer, their caregivers, healthcare policymakers, and healthcare providers in five high-HIV and cancer provinces. Results from the assessment were compelling (see box) and provided a foundation for the development of national palliative care guidelines in 2006.

PEPFAR partners provided significant support to a technical working group led by the Ministry of Health Therapy Department in creating the

guidelines. Drafts were presented to a body of experts who provided feedback and comments, and the final version was approved by the Ministry of Health Scientific Committee in September 2006. They are comprehensive and include all elements of palliative care as outlined in this paper: palliative care principles, management of pain and other symptoms, psychosocial needs and support, spiritual support, end-of-life care, and care for caregivers.

* FHI/Vietnam, Vietnam-CDC-Harvard Medical School AIDS Partnership (VCHAP), and the Health Policy Initiative.

In February 2008, the Ministry of Health approved revisions to previously restrictive opioid prescription guidelines for treatment of pain and other medical purposes. These changes include eliminating upper limits to the amount of opioids which can be prescribed, so that prescriptions can be made on clinical diagnosis rather than perceived need to limit access to opioids. The duration of the prescription has extended from 7 to 30 days. They also authorize all district hospital pharmacies to directly procure opioids. Previously only very few pharmacies were authorized to procure and dispense opioids.

To ensure integration of palliative care training within the healthcare system, FHI and other PEPFAR partners have assisted the Ministry of Health in developing a national certification training program for physicians and nurses for hospital, hospice, and home-based care.

By using a step-by-step process to assess palliative care service needs, using results to develop guidelines, and then preparing a national training plan to ensure improved care capacity of providers, fledgling palliative care services in Vietnam are provided with much needed guidance and support.

CAMBODIA: CARING FOR THE WHOLE FAMILY

In 1998, the Cambodian Ministry of Health introduced a national community and home-based care program for PLHIV and families. This program became the foundation for the development of the national continuum of care, including hospital-based HIV care and treatment.

FHI/Cambodia was among the first NGOs to work with local government and PLHIV groups to provide CHBC in Battambang province. There, FHI supports a network of six NGOs who provide family-centered care for HIV-affected families. Each NGO provides community and home-based care to PLHIV, their families, and the bereaved, including children left behind. All families enrolled in the program are supported through home-based care teams who assess the needs of PLHIV, children, and other family members.

The home-based care teams act as case managers, providing care and counseling, linking families to needed services and advocating for increased support. Team members are also involved in organizing community support services for HIV-affected families including therapeutic play groups, youth groups, parenting meetings, and community sensitization to reduce discrimination and increase acceptance.

The services these NGOs support are implemented in partnership with local health center staff and PLHIV, and are linked to hospital-based family-centered care services. FHI assistance to hospital services for families has led to integrated care and treatment for parents/caregivers and children with HIV in the same outpatient clinic in hospitals.

Palliative care services still have a way to go in Cambodia. Essential palliative care medicines, including morphine, are difficult to access, and national guidance is not clear on the parameters and responsibilities of healthcare workers in providing palliative care. However, this link from hospital to community and home has significantly increased access to services, and the family focus has diminished potential barriers.

NEPAL: NATIONAL CHBC TRAINING CERTIFICATION

Despite prolonged insurgency, political instability, and geographical constraints, the Ministry of Health's National Center for AIDS and STDs Control (NCASC), with support from

FHI, USAID, and others, has developed comprehensive HIV care, treatment, and support, including CHBC services in several locations.

While the national HIV/AIDS strategy called for expansion of CHBC services, no guidelines, training protocols, or other standards were in place to guide the rollout. In 2005, NCASC invited FHI/Nepal to support it in developing a national training curriculum to certify CHBC providers. A team representing NCASC, FHI, USAID, the Nepal Network of People Living with HIV (NAP+N), and the National Nurses Association convened to assess CHBC needs and develop a training package to best meet the care needs of PLHIV and families in the community. The CHBC training incorporates palliative care principles, including the identification and treatment of pain and other symptoms, nutrition and hygiene support, adherence counseling, psychosocial support and counseling, spiritual support, end-of-life care, future planning and support for children, and community mobilization and discrimination reduction.

With the training package finalized in 2006, NSASC, FHI, Global Fund, and NAP+N provided training of trainers in the curriculum for more than 50 CHBC program managers and trainers. The training has now been offered to more than 500 individuals across the country, including those managing the largest HIV care services in the country: Global Fund, FHI, NAP+N and Sakriya (a local NGO).

CHBC is now being offered in Nepal as part of a continuum of care. PLHIV group members have been the keystone to linking other PLHIV to care, working as caregivers and ART adherence counselors and providing these services through CHBC, outreach centers, in peripheral clinics and the hospital ART clinics. Geographical and economic constraints make frequent patient visits to the hospital ART clinic difficult. CHBC provided by NGOs and PLHIV groups are helping to overcome some of these barriers by bringing follow-up and counseling services to the communities. Involvement of PLHIV in the process has led to reduction in stigma and discrimination in the communities affected and improved access to CHBC and hospital-based care.

10. INTERVENTION-LINKED RESEARCH

Priority research areas include the following:

- impact of palliative care-related policy change on provider practice and palliative care outcomes for PLHIV and families
- tracking trends in consumption of opioids and other essential palliative care medicines
- palliative care needs of children; optimal models of care for children
- impact of introduction of pain assessment in HIV outpatient clinics
- identifying quality of life and adherence outcomes of palliative care models
- evaluation of specific palliative care approaches, e.g., CHBC
- comparing cost effectiveness of different palliative care models
- identifying emotional, social, and spiritual support needs of PLHIV and effective approaches in addressing those needs

11. MONITORING AND EVALUATION

Illustrative output indicators include the following:

- number of PLHIV receiving palliative care

- number of PLHIV assessed and appropriately treated for pain
- number of PLHIV receiving social support services
- number of PLHIV have their initial care plan updated at least every six months
- number of palliative care programs
- number of HIV healthcare workers trained in palliative care (pain, symptoms, psychosocial support)
- number of HBC providers trained in home-based palliative care
- number of HBC teams equipped with medicines to treat pain and symptoms
- number of HBC teams formally linked to a hospital HIV care, treatment, and support service (e.g., outpatient clinic)

Illustrative outcome indicators should include quality of life and quality of care.

12. FURTHER READING AND RESOURCES

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J.F. O'Neill, P.A. Selwyn, and H. Schietinger, eds. 2004. *A Clinical Guide to Supportive and Palliative Care for HIV/AIDS*. (Washington, DC: US Department of Health and Human Services, Health Resources and Services Administration, HIV/AIDS Bureau). www.hrsa.gov

L. Gwyther, A. Merriman, L.M. Sebuyira, and H. Schietinger, eds. *A Clinical Guide to Supportive and Palliative Care in Sub-Saharan Africa*. (Washington, DC: US Department of Health and Human Services, Health Resources and Services Administration, HIV/AIDS Bureau). <http://www.fhssa.org/i4a/pages/Index.cfm?pageID=3359>

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World Palliative Care Alliance and Help the Hospice. 2007. *Palliative Care Toolkit: Simple Tools for Resource Poor Settings*. www.helpthehospice.org

U.S. Government PEPFAR Guidance Documents (www.pepfar.gov/guidance/).

- Palliative Care Guidelines
- Prevention Care Package for Adults
- Prevention Care Package for Children
- Food and Nutrition Guidance

USEFUL EMAIL LISTS AND WEBSITES

Website/Email List	Information
WHPCO Email List–World Hospice and Palliative Care Online	To subscribe, email Ann Mason: anne@hospiceinformation.info
International Association for Hospice and Palliative Care (IAHPC) Email List and Website	To subscribe, email webmaster2@hospicecare.com www.hospicecare.com
Help the Hospices	www.helpthehospices.org.uk
African Palliative Care Association	www.apca.org

ANNEX A. ASSESSING AND ADDRESSING PALLIATIVE CARE NEEDS OF ADULTS⁶⁷

Initial PLHIV Palliative Care Assessment
<p>History</p> <ul style="list-style-type: none"> • Present illnesses and treatments administered • Past medical history, including all co-morbidities (e.g. TB) and past HIV-related complications, other major illnesses, hospitalizations, surgeries and date of HIV diagnosis • Medication history • Drug allergies • Substance use and dependence history, including treatment • Family history • Social history • Social resources • Spiritual support • Financial issues • Nutrition • Current symptoms (i.e., pain, weight loss, anorexia, fatigue, lack of energy or weakness, fevers, night sweats, insomnia, sadness, anxiety, dyspnea, cough, nausea/vomiting, diarrhea, other) • Chronology of symptoms; exacerbating and relieving factors • Current medications or other treatment for symptoms • Cause, type and grade of pain • Symptom cause, type and characteristics • Impact of <ul style="list-style-type: none"> – symptoms on functional capabilities – symptoms on each other – specific therapies on each symptom – symptoms on patient’s quality of life • Mental health history and treatment (e.g., depression, anxiety disorder, delirium, psychosis), and any current mental health problems
<p>Physical examination</p> <ul style="list-style-type: none"> • Full clinical examination • Systems review including: <ul style="list-style-type: none"> – constitutional (e.g., fatigue, anorexia, fevers, weight loss) – neurological – mental status – dermatological
<p>Other examinations and investigations as required</p>
<p>Assessment including differential diagnosis</p>
<p>Development of care plan</p>

ANNEX B. ASSESSING AND ADDRESSING PALLIATIVE CARE NEEDS OF CHILDREN⁶⁸

The NEW ENGLAND JOURNAL of MEDICINE

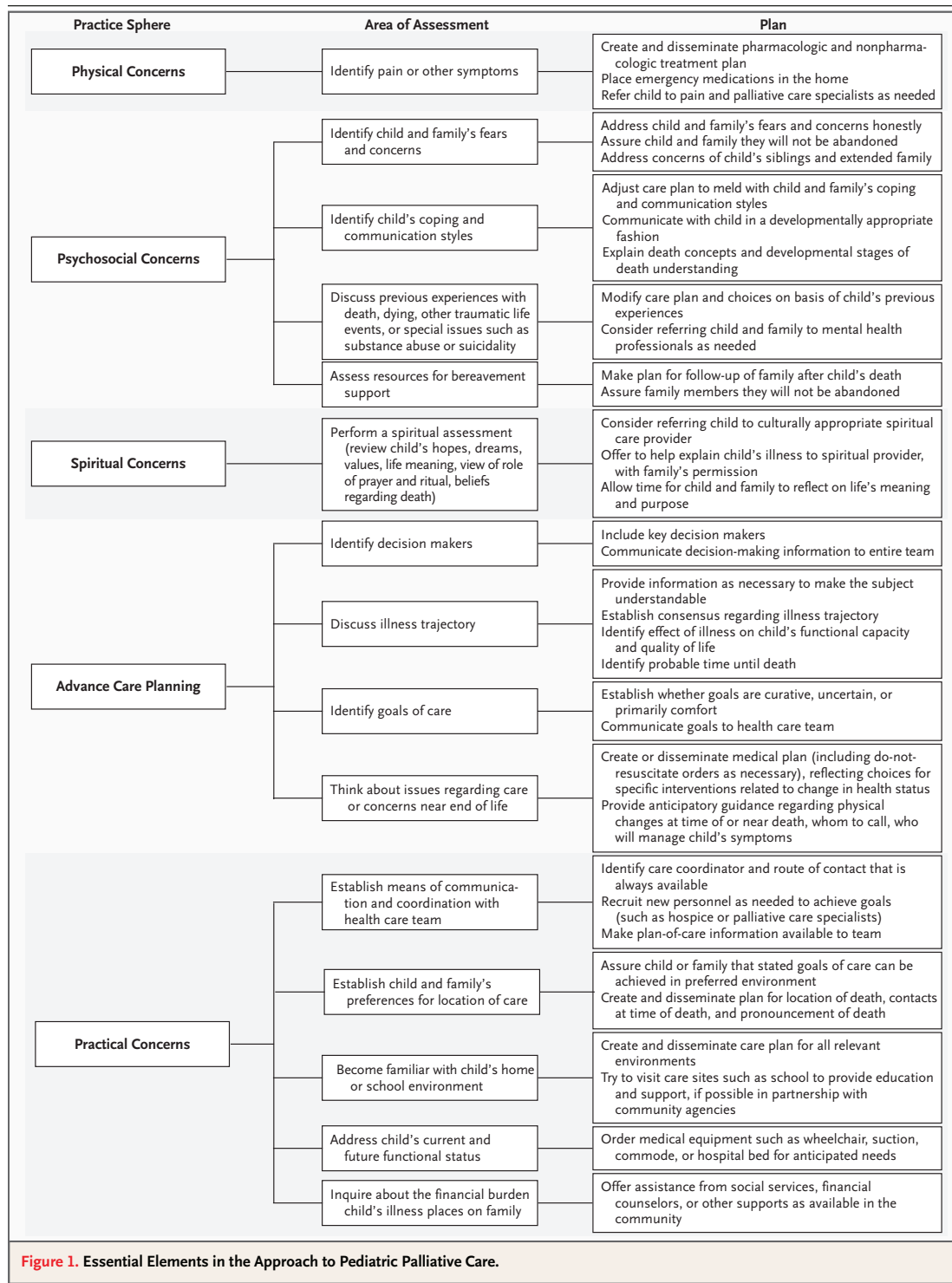


Figure 1. Essential Elements in the Approach to Pediatric Palliative Care.

ANNEX C. NATIONAL, REGIONAL, AND GLOBAL PALLIATIVE CARE ASSOCIATIONS

The role of these associations is to promote and support the development of palliative care within their geographical region. Most produce online directories of palliative care services including details of national palliative care associations, as well as individual hospices and palliative care services in each country. They may also provide information on research, resources, publications, education and training, standards, etc. Some key regional information/resource centers are also included below.

REGIONAL AND GLOBAL ASSOCIATIONS

AFRICA

African Palliative Care Association (APCA)

E: info@apca.co.ug

W: www.apca.co.ug

Hospice Africa (Uganda)—Resource and Training Centre

E: info@hospice.or.ug

W: www.hospiceafrica.or.ug

A key publication available is *The Little Blue Book*, a palliative care manual for cancer or PLHIV in Uganda and Africa.

ASIA PACIFIC

Asia Pacific Hospice Palliative Care Network

Includes: Australia, Hong Kong, India, Indonesia, Japan, Korea, Malaysia, Myanmar, New Zealand, Philippines, Singapore, Taiwan, Thailand, and Vietnam. Education, training, and resources require membership to access.

E: aphn@nccs.com.sg

W: www.aphn.org

The Pain and Palliative Care Society, Kozhikode

A WHO demonstration project in palliative care providing training and low-cost publications aimed at people from developing countries.

E: pain@vsnl.com

W: www.painandpalliativecare.org

AUSTRALASIA

Palliative Care Australia

E: pcainc@pallcare.org.au

W: www.pallcare.org.au

Hospice New Zealand

E: coms@hospice.org.nz

W: www.hospice.org.nz

EUROPE

European Association for Palliative Care (EAPC)

Website also includes the EAPC Task Force on the Development of Palliative Care in Europe.

E: e.a.p.c@istitutotumori.mi.it

W: www.eapcnet.org

EASTERN and CENTRAL EUROPE

Eastern and Central Europe Palliative Task Force (ECEPT)

E: ecept@oncology.am.poznan.pl

E: mmstanczyk@am.poznan.pl

W: www.oncology.am.poznan.pl/ecept

Casa Sperantei, Regional Resource and Training Centre for Palliative Medicine

Courses available in Romanian and English.

E: cshospice@hospice.bv.astral.ro or

crhospice@hospice.bv.astral.ro

W: www.hospice.ro

NORTH AMERICA

National Hospice Palliative Care Organization.

E: nhpco_info@nhpco.org

W: www.nhpco.org

NHPCO Office of International Development

W: www.nhpco.org/global

Canadian Hospice Palliative Care Association (CHPCA)

E: info@chpca.net

W: www.chpca.net (English version)

W: www.acsp.net/debut.htm (French version)

LATIN AMERICA

Asociación Latinoamericana de Cuidados Paliativos (ALCP)

E: info@cuidadospaliativos.org

W: www.cuidadospaliativos.org

Pallium Latinoamerica

Education, training, and resources (including a free download of the manual *Fundamentos de cuidados paliativos*.)

E: info@pallium.org

W: www.pallium.org

WORLDWIDE

Worldwide Palliative Care Alliance

A network of national palliative care associations across the world which works to support efforts to develop hospice and palliative care services globally.

E: international@helpthehospices.org.uk

W: www.wwpca.net

NATIONAL ASSOCIATIONS AND SERVICES

Each country below has several palliative care services—only the national association or primary service is listed.

BOTSWANA

Holy Cross Hospice

Private Bag 00287

Gaborone

T/F: + 267 30 29 80

E: holycross@mega.bw

30 beds planned for adults and children with all serious illnesses. Nursing care provided at no charge. A palliative care home team and education and training service are also available.

Board of Trust Chairman: Rev Nick Darby

E: holycross@it.bw

Acting Director: Una Ngwenya

E: holycross@mega.bw

Languages spoken: English, Setswana, Kalanga, Ndebele, and Shona.

DEMOCRATIC REPUBLIC OF CONGO

Fondation Tout-Age

AV Mukwala N 14

Commune of Mont-Ngafula

Kinshasa

Developing a home-based palliative care service.

Contact: Mr Antoine Kamunga Mulowayi

REPUBLIC OF CONGO

Association Congolaise Accompagner

BP 878, Cathédrale

Brazzaville

T: + 242 551 0828 F: + 242 82 50 27

E: accompagnerbzv96@hotmail.com

Home care support for patients with advanced cancer and other terminal illnesses.

President: Sister Elaine Julienne Boukaka

EGYPT

Cairo Evangelical Medical Centre

2 Elmeligi St from Elgomholia St
Cairo

T: + 202 258 1958 F: + 202 588 2801

E: nmelnikhaily@hotmail.com

Contact: Dr Naguib Elnikhaily

Hospital-based palliative care team, 14 care beds, bereavement service, and education and training service.

Languages spoken: Arabic and English

GHANA

Palliative Care, Ghana

PO Box KD 44

Konda, Accra

T: 233 21 221 874/ 24 426 3678

A palliative home care team for adults and children with care provided at no charge.

An education and training service is also available.

E: palliativegh@yahoo.com

Medical Consultant: Dr Stephen Addo

E: ayisi71@yahoo.com

Specialist Surgeon: Matthew Kyei

E: matkyei@yahoo.com

Languages spoken: English, Ewe, Twi, Fante, and Ga.

KENYA

Kenya Hospices and Palliative Care Association (KEHPCA)

PO Box 20854, Nairobi, 00202

T: + 254 20 2729302 F: + 254 2 2712041

National Coordinator: Dr Zipporah M Ali

E: info@kehpc.com

E: zippy@kehpc.org

W: www.kehpc.org

Nairobi Hospice

Hospital Road, Kenyatta National Hospital Complex, Next to Casualty

PO Box 74818-00200

Nairobi

T: + 254 (0)20 271 2361 / 9383

F: + 254 (0)20 272 2212

E: nhos@wananchi.com

W: www.thenairobihospice.org

E: info@thenairobihospice.org

E: nhos@wananchi.com

Palliative home care team, day care, bereavement service, and education and training. Cares for patients with all serious illnesses.

Chief Executive Officer: Mrs Brigid Sirengo

Languages spoken: English and Kiswahili

(Affiliated with Hospice Care Kenya)

MALAWI

Palliative Care Association of Malawi

PO Box 32625, Blantyre 3

T: + 265 875 707

E: pacam@sdpn.org.mw

Program Officer: Jessica Mack

Supports, develops, and promotes provision of affordable and culturally appropriate palliative services in Malawi.

Languages spoken: Chichewa and English

The Lighthouse

Lilongwe Central Hospital

Box 106, Lilongwe

T: + 265 (0)1 758 705 F: + 265 (0)1 758 705

E: pc_coord@lighthouse.org.mw

Palliative Care Coordinator: Mr Lameck Thambo

Palliative home care team and day care center for patients with all serious illness.

Languages spoken: English and Chichewa

MOZAMBIQUE

Douleurs Sans Frontières

Av. Valentin Siti, #276

Maputo C.P. 4331

T: + 258 82 325 988

E: dsfmz@tvcabo.co.mz

W: www.douleurs-sans-frontieres.org

Contact: Paolo Magnetti, National Coordinator

Palliative care service, home care, and education and training. Cares for patients with advanced cancer and other serious illnesses.

Languages spoken: French, English and Portuguese

NAMIBIA

Ongwediva AIDS Care and Training Centre

Oshakati State Hospital

PO Box 2980

Oshakati

T: + 264 81 283 7146 F: + 264 65 231 764

E: jmulambya@yahoo.co.uk

Medical Officer: Dr Mulambya Jairos

Developing an interest in hospital-based palliative care; 8 beds, home

care, and education and training.

Cares for patients with advanced cancer, HIV/AIDS, and other serious illnesses. *Languages spoken:* English and Oshiwambo

NIGERIA

Hospice and Palliative Care Association of Nigeria (HPCAN)

National Secretary HPCAN, C/O

Federal Medical Centre, Bisi-Onabanjo Way, Idi- Aba, P.M.B 3031, Sapon PO, Abeokuta, Ogun-State

President: Dr T. Ayo Olasinde

Secretary: Dr Folaju O Oyebola

Assistant Secretary: Rev Sister Osheiza A Otonoku; E: osheiza@hotmail.com

E: HPCAN@yahoogroups.com; Hpcan@yahoo.com

Serves as the national umbrella for all palliative care interest groups in the country. HPCAN's focus includes the provision of education, research, and standard of palliative care services across Nigeria.

Centre for Palliative Care, Nigeria

Department of Anaesthesia, College of Medicine, University of Ibadan, University College Hospital

PO Box 1089

Agodi, Ibadan, Oyo State

T: + 234 2241 1844 F: + 234 2241 3545

E: pallcarenigeria@yahoo.com

Program director: Professor Olaitan

Soyannwo

E: folait2001@yahoo.com

Assistant Director: Dr Adeniyi

Adeniperun

E: adenipek2000@yahoo.com

Hospital-based palliative care team and home care for adults and children with all life limiting illnesses. Education and training service also available. A charge is made to patients for medication only.

Languages spoken: English

Would like to explore twinning possibilities.

RWANDA

Palliative Care Association of Rwanda (PCAR)

PO Box 6535, Kigali

T: + 250 0846 4686

E: pcar_rwanda@yahoo.com

President/Principal contact: Schadrack Habimana

PCAR is the National Palliative Care Association for Rwanda.

Swaa Rwanda Ihumure

BP 5196 Kigali Rwanda, Kigali, +250

T: +250 0859 6647

Contact: Grace Mukankuranga

E: mukagraced@yahoo.co.uk

Day care center, home care, and an education and training service. Full medical and nursing care is provided at no charge to adults and children dealing with HIV/AIDS.

Languages spoken: English, French, and Kinyarwanda

SOUTH AFRICA

There are many palliative care services in South Africa. Contact HPCA (below) for a list of local services.

The Hospice Palliative Care Association of South Africa (HPCA)

T: + 27 21 531 2094 F: + 27 21 531 1706

E: hpca@iafrica.com

W: www.hospicepalliativecaresa.co.za

The Hospice Palliative Care Association of South Africa (HPCA) is an association of 75 independent member hospices committed to providing palliative care

for people with incurable and life limiting conditions and their families. HPCA members are found in all 9 provinces of South Africa in rural, urban, peri-urban, and metropolitan areas.

A directory of services is available at www.hospicepalliativecaresa.co.za

Contact: Jenny Mills

SUDAN

National Cancer Organisation

(Radiation and Isotopes Centre Khartoum RICK)

Sudanese Hospice and Palliative Care Unit

10 Alqaser Street
Khartoum, 846

T: + 249 183 776 905 F: + 249 183 774 780

Medical Director: Dr Kamal Hamad

E: kamaledein4@hotmail.com

A hospital-based palliative care team with five beds. This unit provides full medical and nursing care for adults and children with cancer. A charge is made to patients for medication only.

Languages spoken: Arabic

SWAZILAND

Swaziland Hospice

PO Box 23
Matsapha

T: + 268 518 4485 F: + 268 518 6405

E: hospice@net.co.zsz

Palliative home care, education and training. Cares for patients with all terminal illnesses covering the four regions of the country.

Director: Ms Thulile D Msane

Information, Education and

Communication Officer: Mrs Zodwa Gamedze

TANZANIA

Tanzania Palliative Care Association (TPCA)

C/O Ocean Road Cancer Institute,
Palliative Care Section, PO Box 3592,
Dar es Salaam

Chair: Dr Msemo Diwani

T: + 255 773 296 627

E: msemodiwani@hotmail.com

Mobile: + 255 745666143.

Vice-Chairman: Christopher Mnzava

E: mnzavachris@yahoo.co.uk.

TPCA was formed in 2006/07 and expects to provide significant assistance towards advocacy and palliative care education/curriculum.

UGANDA

Palliative Care Association of Uganda

C/O Hospice Uganda

PO Box 7757

Kampala

T/F: + 256 41 267488

E: pcau@hospiceafrica.or.ug

President: Dr Lydia Mpanga

Secretary: Dr Henry Dungu,

Education Director: Dr Rose Musake,

Hospice Africa Uganda

PO Box 7757

Kampala

T/F: + 256 41 266 867

E: info@hospiceafrica.or.ug;

anne@hospiceafrica.or.ug

W: www.hospiceafrica.or.ug

A model hospice to encourage initiation of Hospice in other African countries. Provides palliative home care, day care (weekly basis), bereavement support, and education and training. Information and resource center. For patients with advanced cancer and AIDS.

Director for Policy and International

Programmes: Dr Anne Merriman MBE

Chief Executive Director: Nina Shalita

Director of Training and Education: Dr

Lydia Mpanga-Sebuyira

Resource Centre Manager: Emmanuel Luyombya

ZAMBIA

Palliative Care Association of Zambia (PCAZ)

PO Box 31566, Lusaka

T: + 260 1 221701 ext 410 F: + 260 1 222564

National Coordinator: Mary Margaret Mpomba

E: pcaz.zambia@gmail.com

The national palliative care association of Zambia. PCAZ supports and promotes the development of palliative care in Zambia.

Catholic Relief Services (CRS)

Plott 106 Great East Road, Lusaka

T: + 260 21 1 224131 ext 124

Senior Technical Manager: Colette Cunningham

E: ccunningham@crszam.org.zm

CRS Zambia supports all Zambian hospices through US Government PEPFAR funds and with technical support.

ZIMBABWE

Hospice Association of Zimbabwe (HOS-PAZ)

PO Box A1822 Avondale

Harare, Zimbabwe

T: + 263 4 705771/705772 F: + 263 4 253540

E: info@hospaz.co.zw

National organization that plans to bring training, advocacy and standards in palliative care to the country and region, supporting palliative care providers, hospice, and home-based care groups.

Bulawayo Island Hospice Service

PO Box 3380, Bulawayo

T: + 263 9 77972 F: + 263 9 62212

E: hospicebyo@gatorzw.co.uk

Contact: Miss D M Clark, Nurse Co-ordinator

Palliative home care team and bereavement service. Cares for patients with cancer at no charge.

Languages spoken: English, NDEBELE, Shona

NOTES

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Palliative care—the combination of measures that relieve suffering and improve quality of life for those facing life-threatening illness—begins from the point of diagnosis and continues through death and bereavement. Palliative care is one of the most important forms of care for individuals with active, progressive, or far-advanced illness. Yet millions continue to endure pain or distressing psychosocial and spiritual suffering. Millions more struggle to care for sick loved ones or grieve their loss. And a vast number of children need palliative care, but their access to programs is even more limited than for adults.

Family Health International has long recognized the importance of palliative care in its public health programs. This document defines the need, explains the technical approach, and suggests illustrative activities for FHI country offices and implementing partners working toward the goal of providing palliative care for all chronically ill individuals and their families. The strategy supports adapting palliative care services to the communities and environments where they are provided. Whether facility- or community-based, service delivery must meet the holistic needs of patients and families throughout a continuum of care: from home to facility and back, and from diagnosis through the course of disease to death and bereavement.

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