

HIV/AIDS Palliative Care Guidance#1
For the United States Government in-Country Staff
And Implementing Partners



The President's Emergency Plan for AIDS Relief
Office of the U.S. Global AIDS Coordinator

Final

HIV/AIDS Palliative Care Guidance #1
An Overview of Comprehensive HIV/AIDS Care Services in the
President's Emergency Plan for AIDS Relief
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Introduction

Comprehensive palliative care is essential to the health and well-being of people living with HIV/AIDS (PLWHA) and is an integral part of the President's Emergency Plan for AIDS Relief (the Emergency Plan). Palliative care has traditionally been associated with terminal or end-of-life care. However, current thought and practice and Emergency Plan policy take the broader view that palliative care encompasses care provided from the time that HIV is diagnosed and throughout the continuum of HIV infection.

The Emergency Plan envisions a comprehensive, holistic, interdisciplinary approach to HIV care. It recognizes that different types and intensity of comprehensive palliative care interventions are needed, depending upon the stage and progression of disease and the needs of the individual and family.

This document provides initial guidance on the development HIV/AIDS palliative care programs, including definitions and activities be funded under the Emergency Plan. Guidance on many issues will evolve as new information and experience emerge from the field.

This document summarizes key elements related to the development, implementation, and support of palliative care programs necessary to achieve the Emergency Plan goals.

These elements include:

- 1.1 Definition of Palliative Care
- 1.2 Types of Palliative Care
- 1.3 Packages of Care
- 1.4 Palliative Care Delivery Sites
- 1.5 Networks, Linkages and Integration
- 1.6 Food and Nutritional Support
- 1.7 Tuberculosis and HIV/AIDS
- 1.8 Wrap-around Care
- 1.9 Pediatric Care
- 1.10 Gender Issues
- 1.11 Human Capacity Development and Provider Education and Training
- 1.12 Policy Development
- 1.13 Supply Chain Management and the Procurement of Drugs.
- 1.14 Reference Guide

1.1 Definition of Palliative Care

Palliative care, as stated in the *U.S. Five-Year Global HIV/AIDS Strategy*, aims to achieve optimal quality of life for PLWHA and their families and minimize suffering through mobilizing clinical, psychological, spiritual, and social care throughout the entire course of HIV infection. It also provides the routine monitoring that is essential to determining the optimal time to initiate anti-retroviral therapy (ART), and it continues during and after the initiation of treatment. Palliative care includes and goes beyond the medical management of infectious, neurological or oncological complications of HIV/AIDS to comprehensively address symptoms and suffering throughout the continuum of HIV disease. Routine, confidential counseling and testing is an essential component of palliative care to identify those who need or will need palliative care, family members who could also be infected and in need of care and, family members and partners not infected and in need of prevention.

Principles of an effective HIV/AIDS care program include the following.

- Respect for patient autonomy and choice and provision of adequate access to information.
- Respectful and trusting relationships between the HIV-positive person and the caregivers.
- Support of the family, child, and community caregivers in delivering palliative care.
- Integration and respect for cultural values, beliefs and customs.
- Enhanced quality of life throughout the continuum of disease.

1.2 Types of Palliative Care Interventions

Palliative care for HIV-infected individuals becomes increasingly important as the disease progresses. The Emergency Plan can support all areas of comprehensive palliative care offered throughout the course of HIV disease but what individual country programs provide can vary in type, scope, and intensity, based on the progression of the disease, availability of anti-retrovirals (ARVs), and the needs of the individual and family.

The Emergency Plan can support

The Emergency Plan can support the following four categories of essential palliative care, where compatible with national guidelines:

Clinical care is generally provided by nurses, midwives, clinical officers, community and volunteer health workers, traditional healers and physicians. It includes a wide range of treatment and care including: routine, confidential HIV counseling and testing; routine follow-up to determine the optimal time to initiate ART; prevention and treatment of opportunistic infections (OIs) such as tuberculosis (TB); HIV prevention and behavior-change counseling, alleviation of HIV-related symptoms and pain; time-limited support for clinically malnourished PLWHA; and support for adherence to anti-retroviral therapy (ART). Illustrated below are types of interventions that Emergency Plan programs should provide, based on the presence or absence of clinical symptoms:

Asymptomatic clinical care is toward persons who are not experiencing specific signs or symptoms of HIV disease. These interventions include: routine clinical monitoring and assessments, including those that assist in determining the optimal time to initiate ART (including laboratory and clinical evaluations); services to prevent TB, other OIs and

malaria, such as the use of isoniazid prophylaxis, cotrimoxazole; impregnated mosquito bed nets (preferably long-lasting); safe-water systems; nutritional assessment and counseling; HIV prevention counseling, promotion of good personal and household hygiene; and the assessment and management of HIV-related psychosocial problems. Additional guidance will be forthcoming on the elements of basic preventive care for PLWHAs and their families.

Symptomatic clinical care is directed toward individuals who are experiencing progressive immunological impairment and related HIV symptoms. These interventions include: treatment of symptomatic illness; pain control (with opioids and non-opioids); prevention of TB, other OIs, and malaria using medications such as isoniazid prophylaxis, cotrimoxazole, and/or the use of (preferably long-lasting) impregnated mosquito bed nets; safe-water systems; nutritional assessment and counseling; promotion of good hygiene; the assessment and management of HIV-related psychosocial problems; basic nursing care (including but not limited to assessment and monitoring of symptoms and adherence to medications; assistance with bathing, mobility, mouth care and skin and wound care); preparation and support prior to and throughout ART; and time-limited nutrition rehabilitation and supplementation for clinically malnourished PLWHA.

Future guidance will provide details on food and nutrition programs the Emergency Plan can support. United States Government (USG) teams in Emergency Plan countries that are also part of the President's Malaria Initiative should coordinate closely and use both funding streams creatively to serve HIV-affected individuals in the distribution of (long-lasting) insecticide-impregnated bednets.

End-of-Life and bereavement care is directed toward the individual and family members in need of intensive management of symptoms and pain [using non-opioids and/or opioids and directed by the World Health Organization (WHO) analgesic ladder¹]. They include culturally appropriate end-of-life care and bereavement interventions, as well as appropriate succession planning and referrals for orphans and vulnerable children.

Psychological care addresses the non-physical suffering of individuals and family members, and can include: mental health counseling; family care and support groups; support for disclosure of HIV status; bereavement care; development and implementation of culture- and age-specific initiatives for psychological care; and treatment of HIV-related psychiatric illnesses, such as depression and related anxieties.

Spiritual care addresses the major life events that cause people to question themselves, their purpose and their meaning in life. The interventions should be sensitive to the culture, religion(s) and rituals of the individual and community, and can include (but are not limited to): life review and assessment; counseling related to hopes and fears, meaning and purpose, guilt and forgiveness; and life-completion tasks.

Social care assists individuals and family members in maintaining linkages to and use of care, preventing HIV infection, and ensuring adherence to treatment. These can include: community-based support groups; community mobilization and leadership development of PLWHA; efforts to reduce stigma; legal services to assist with succession planning, inheritance rights, and legal documentation (such as a living will or power of attorney); assistance to secure government grants, housing, or health care; linkages to food support and income-generating programs; efforts to increase community awareness of HIV care, treatment, and prevention; and other activities to strengthen affected households and communities.

¹ In countries where national legislation or government regulation or policy prohibits or severely restricts the use of opioids for palliative care, including end-of-life care, USG teams should advocate for changes in statute, regulations or policy to broaden access to pain medication in ways that will increase the ability of providers to alleviate suffering while continuing to maintain appropriate safeguards against abuse of medications.

Prevention for HIV-infected persons has been shown to be both effective and efficient at preventing new infections. Emergency Plan programs should incorporate prevention for positives into palliative care and treatment. Models to provide these interventions can include: interventions for sero-discordant couples, including confidential testing and ongoing counseling; community and clinic-based support groups; case-management and provider-delivered prevention messages focused on disclosure; partner testing; correct and consistent condom use for populations engaged in high-risk behavior and mutual fidelity.²

1.3 Packages of Care

Participating USG agencies have discussed extensively the concept of providing a minimum set of evidenced-based care interventions, or a “package of care” for HIV-infected persons in recent months. The Emergency Plan palliative care programs should provide this set of interventions regardless of stage of HIV disease or clinical condition. Additional guidance on Preventive Care Packages for Adults and Children will be forthcoming.

The Emergency Plan recognizes that a “package of care” cannot be standardized for all countries. Each USG team should adapt the basic package and support care packages in a way that is appropriate for the country in which it works.

1.4 Palliative Care Delivery Sites

Comprehensive care includes a wide range of interventions to improve the quality of life for the individual and family. These interventions are not specific to any one setting or location. Delivery sites for care generally are home-, community-, and/or facility-based. As discussed below, it is essential that Emergency Plan programs link these interventions and sites to ensure coordinated access to a comprehensive array of primary, secondary and tertiary care and hospice care.

Home-Based Care

Home-based programs deliver various types of HIV/AIDS care in the patient’s home. Given the relative availability and affordability of home-based care programs for most resource-poor settings, these programs play a significant role in providing access to comprehensive palliative and supportive care for a large proportion of individuals and families affected by HIV disease. However, many home-based programs either do not include or are missing key palliative care interventions. The introduction of comprehensive care into home-based programs requires the training and education of medical providers (e.g. nurses, clinical officers, and physicians, including pediatricians and pediatric nurses) and community-care providers in the following areas:

- Clinical diagnosis and care, including pain, symptom and OI-assessment and -management.
- The delivery of medications (including pain medications) and other clinical interventions within the community and home.
- Basic nursing care, including client and household hygiene and promotion of disease prevention in the home.

² Office of the Global AIDS Coordinator ABC Guidance

- The use of established patient management protocols and standards.
- Procedures for referring patients for diagnostic, care, and treatment.
- Communication skills, including patient education in local languages on HIV/AIDS and HIV prevention messages, counseling on disclosure of HIV status, and grief, anxiety, and bereavement care.
- The establishment of interdisciplinary teams to address physical, psychosocial support, and spiritual needs of clients.
- Other standards and procedures for providing quality care.

Community-based Care

Community-based care is provided in a variety of community settings including free-standing outpatient clinics, day care centers, school or university-based clinics, community health centers, workplace clinics or stand-alone hospices. These delivery sites often provide a wide range of interventions, including primary care, management of acute and chronic medical conditions and supportive care. Emergency Plan programs should also link them with inpatient facilities, such as provincial or district hospitals.

Facility-Based Care

Hospital-based outpatient clinics and inpatient facilities provide direct and more advanced clinical care in the facility and are essential sites for the delivery of HIV palliative care. Both types of delivery sites provide access to health and basic social-service providers trained in the diagnosis and management of acute and chronic medical conditions and supportive care needs and are often linked to home- and community-based care providers for patient follow-up.

Hospice Care

Hospice is an approach to delivering end-of-life care, often provided in the home by trained nurses and or community care-givers, in community-based and hospital-based facilities, or in a free-standing hospice. Hospice care includes intensive end-of-life care, such as severe pain control with opioids and other medications³, as well as support in the last months of life for individuals with a terminal illness. Hospice also provides intensive family and bereavement support.

1.5 Networks, Linkages and Integration

As stated in the *U.S. Five-Year Global HIV/AIDS Strategy*, the Emergency Plan works to integrate the delivery of prevention, treatment, and care across facilities, clinics, communities, and homes, to build and sustain comprehensive HIV/AIDS care systems. USG teams should develop network systems, foster linkages, and establish and strengthen referral to care at various levels. Network systems represent formal relationships among providers to create a comprehensive system of care, and include the following:

³ In countries where national legislation or government regulation or policy prohibits or severely restricts the use of opioids for palliative care, including end-of-life care, USG teams should advocate for changes in statute, regulations or policy to broader access to pain medication in ways that will increase the ability of providers to alleviate suffering while continuing to maintain appropriate safeguards against abuse of medications.

- **Linkages between delivery sites** to support referrals among and within HIV prevention, orphan and vulnerable children programs, palliative care, and treatment sites.
- **Integration of care** to allow for incorporation of new interventions into existing delivery sites, for example, locating palliative care in existing ART-delivery sites.

Networking should include close coordination and collaboration with other groups and organizations that provide complementary care. These may include hospitals, clinics, hospices, schools, universities, home- and community-care programs, government and international partner programs in other sectors, community groups, legal services, food and nutritional support providers, transportation between and among referral sites and home, PLWHA support groups, orphans and vulnerable children programs and advocacy organizations. USG teams in Emergency Plan countries should also coordinate closely with the President’s Malaria Initiative and programs funded by the Global Fund to Fight AIDS, Malaria and Tuberculosis.

Networks

A health network consists of a system of clinical and non-clinical programs for the care of PLWHA and families. Governments (particularly Ministries of Health), community-based and faith-based organizations (CBOs and FBOs), non-governmental organizations (NGOs), private companies, or consortiums composed of some or all of the above entities. A network is a system of care that includes primary, secondary, tertiary, and home-based care—for example, a regional treatment center that is associated with a district clinic, a health post, and a home-based treatment program. In such a system, patients are able to access each service within the network based on need. Components may be both facility- and non facility-based.

In optimal circumstances, comprehensive care is provided across various delivery sites and through an integrated model of community care which emphasizes a continuum of care between the community care provider and all sectors of the formal health care system.

Building Networks through Program Linkages and Integration

Linkages and integration provide for the coordination and collaboration of multiple provider groups through referrals and co-location.

For example, a linkage model could consist of an HIV/AIDS clinic linked with a palliative care provider, an orphan and vulnerable children (OVC) program, a TB clinic, a voluntary family planning program, and a food assistance program, with the client being referred among programs for access to comprehensive care. An integrated model could include the establishment of ART within an existing home- and community-based care program.

Networks may be built through the integration of palliative care into all existing HIV prevention, treatment, and care programs, or through linkage of home-based, outpatient, hospital, and hospice providers. Examples of network development in specific program areas the Emergency Plan can support appear below.

- **Prevention** – Care programs should include prevention for all PLWHA, their families and partners should integrate or link with prevention programs, including those with a particular focus on behavioral interventions. As appropriate, care programs should include counseling on risk of transmission and measures to avoid infection, including ABC (see Emergency Plan ABC guidance document), prevention for maternal-to-child transmission, prevention between sero-discordant partners, among intravenous drug

users and through medical procedures to ensure safe injections and blood transfusions. All care programs should incorporate provision or referral for routine, confidential counseling and testing. HIV-infected individuals should receive prevention counseling at every treatment visit, and through all palliative care interventions.

- ***Treatment*** - Care programs should integrate or link with treatment programs. Programs prepare and support HIV-infected individuals and families prior to and throughout ART. Services may include symptom management (including pain control, adherence counseling, and prevention and treatment of TB and other OIs), psychological and spiritual care, nutrition counseling, and support for the family and caregivers of those who are on ART.
- ***Orphans and Vulnerable Children (OVC)*** - A comprehensive care program addresses the needs of HIV-positive children, children whose parent/s or principal caregivers have HIV/AIDS, and children whose parents have died. Programs include early identification of these children and appropriate interventions to support them and their families. Program providers at all levels need to have the communication skills necessary for working with HIV-positive family members and the clinical skills needed to identify HIV infection in OVC. Providers should also have the capacity to provide case management for children and families, as well as referrals to other OVC care.

Care providers should coordinate and collaborate with other government and donor programs including the President's Malaria Initiative and the Global Fund to Fight AIDS, Tuberculosis, and Malaria, to maximize efficiency and effectiveness of service delivery and minimize duplication of effort.

1.6 Food and Nutritional Support

Food and nutritional support can be an important component of palliative care. It must also be noted, however that the Emergency Plan works in many communities that food insecurity broadly affects. Larger issues of food security are extremely complex, and other organizations and international partners have a strong comparative advantage in the area of food assistance. Thus a key precept of interventions supported by the Emergency Plan is to remain focused on HIV/AIDS, and to provide support for food only in limited circumstances and leverage other resources whenever possible. Further guidance on the limited circumstance in which the Emergency Plan can support food and nutrition interventions is in preparation and the Office of the Global AIDS Coordinator will disseminate it shortly.

1.7 Tuberculosis and HIV/AIDS

TB is the most common OI in HIV-infected persons in sub-Saharan Africa, and in some facilities up to 70 percent of TB patients are HIV-infected. It is also a leading cause of death in individuals with AIDS in developing countries, and accounts for 15 percent of deaths in PLWHA in Africa. Therefore, interventions that target TB in HIV-infected persons have a significant public health and individual clinical impact.

Prevention and treatment of TB are thus an integral part of comprehensive palliative care, and the Emergency Plan clearly defines care as including treatment and prevention of OIs, including TB. Emergency Plan goals relating to TB are the following: 1) to diagnose, care and treat all PLWHA with active TB disease; 2) to provide HIV counseling and testing for all patients who are seeking care in TB programs; and 3) consistent with local guidelines to provide preventive

TB care for HIV-positive persons who are not diagnosed with active TB, and to ensure that all eligible co-infected PLWHAs receive ART.

Resources must be allocated to achieve these goals, and Emergency Plan programs should test all persons with TB for HIV. Successful prevention and treatment of TB in HIV-infected individuals can mitigate TB-associated morbidity in patients and significantly reduce TB-associated risk of death. Treatment of TB also reduces TB transmission in the community and in care settings. Programs should seek all opportunities to improve coordination of TB and HIV/AIDS interventions.

1.8 Wrap-around Interventions

Wrap-around programs are programs not funded by the Emergency Plan, but can improve the quality of life for people infected and affected by HIV/AIDS and complement the programs of the Emergency Plan. These programs include those funded by the USG (e.g. USAID Development Assistance, etc.), other international partners including the Global Fund, the United Nations (World Food Program, UNICEF, etc) and other partners. They include, but are not limited to initiatives that:

- Strengthen household livelihoods;
- Build local governance and democracy;
- Improve access to education and skills development;
- Promote gender equity;
- Strengthen economic capacity and generate income;
- Stabilize communities in crisis;
- Enhance food supply including community/home gardens;
- Improve sanitation in communities;
- Provide clean water in communities; and
- Strengthen non-HIV health, including voluntary family planning, child health and nutrition.

1.9 Pediatrics and Palliative Care

Palliative care for children mirrors that of adults, inasmuch as it includes clinical, psychological, spiritual, and social care implemented by a multi-disciplinary team. There are, however, important differences between adults and children that affect providers' decisions related to palliative care. Children are growing, and have different metabolisms and different manifestations of HIV disease. Palliative care for children begins when an infant is exposed to HIV (in utero, in labor, and/or through breastfeeding). It continues through diagnosis, care, and treatment, and extends to end-of-life care. Further discussion of this topic is included in Appendix I.

It is important to recognize that the “family” is the unit of care when it comes to addressing the needs of children. Working with families can be an entry point for identifying HIV-infected children. Programs should be established to provide access to a coordinated system of both adult and pediatric care. The goal is to identify all HIV-infected family members and to provide (directly or through referral) access to a wide range of comprehensive care. These include HIV prevention, treatment and other support such as family mental health and bereavement counseling and voluntary family planning.

1.10 Gender Issues

Gender is a critical issue in palliative care. HIV/AIDS has increased the palliative care burden on women and girls in developing countries, as they are often responsible for those living with HIV in their families and communities. Women and girls are usually not remunerated for the care they provide, which has social, economic, and health implications for themselves and their families. Efforts are needed to involve men in community care giving for PLWHA. Palliative care programs supported by the Emergency Plan should pay special attention to this issue, and work to facilitate dialogue and policies that improve support for women and girls who are caregivers, and to foster the involvement of men.

The equitable distribution of medications to ensure inclusion of women and girls must receive high priority. Programs should also work with men on the issues of gender power imbalance and domestic violence as they relate to care, as well as their roles in home-based care. More attention must also be given to creating legal protections and creating linkages to legal services for women and girls. Palliative care programs need to act as instruments of change, highlighting the need for effective efforts to ensure gender-sensitive access to treatment and care issues.

1.11 Human Capacity Development and Provider Education and Training

In many developing countries, inadequate human resources and palliative care training policies and weak or non-existent institutions contribute to the insufficient supply of health care professionals and other caregivers. Limited support for caregivers also deteriorates the human capacity which is essential to delivery quality care, and it is important for programs and policies to consider the extraordinary physical, psychological, practical (food and housing), and spiritual demands caregivers face. Support for all caregivers is important to maintaining a viable and effective health-care team. This support should address economic and subsistence needs of caregivers, education and skills development, caregiver recognition and access to HIV care for caregivers who are living with HIV/AIDS.

Several categories of health care providers are necessary for an effective palliative care program. Each has a unique role and training needs.

Medical Providers

The role of medical providers (physicians, clinical officers, and cadres of nurses) includes assessment, prevention, diagnosis, treatment, and management of pain and suffering experienced by PLWHA and their families. To fulfill their role, providers need training in the use of standard protocols for assessing pain, symptoms, and TB and other OIs. They must be able either to directly diagnose and treat the patient, or to refer the individual for appropriate care. Given the severe shortage of physicians, nurses must be trained in aspects of diagnosis and management as appropriate under local professional standards of practice and licensure. Access to continued training for all clinicians is essential.

Traditional Healers

The Emergency Plan acknowledges the important role of traditional healers in delivering health care to many individuals and families. They are often the link between the community and the health care system and are important partners in improving access to care. When appropriate, they should be included in the palliative care team. It is also important to recognize the critical cultural, supportive, psychological, and spiritual role of the traditional healer when patients and

their families are searching for meaning in illness and death. To support the participation of traditional healers in the palliative care team, training should be made available to them.

Community Health Workers

The use of trained community health care workers such as volunteers, medical assistants, counselors, and family members could provide opportunities to expand the delivery of palliative care in the community setting. Trained community health workers can provide basic nursing care, support for treatment adherence and HIV prevention, monitoring and assessment of medication impact (including symptom improvement and adverse drug reactions), referrals, pain and symptom assessment and management, psychosocial and nutrition counseling, and determination of need for, and provision of, social support (such as referrals to community-based support groups and income-generating activities).

People Living with HIV/AIDS

The success of palliative care programs depends on the involvement and leadership of PLWHA. As a result of their personal experiences, PLWHA can contribute to better understanding of the true needs of other PLWHA and best practices in HIV care programs. PLWHA are often the best counselors and educators for others who are HIV-positive and their families, particularly in regards to treatment literacy and symptom and pain management. All care and treatment programs must make a concerted effort to recruit PLWHA and support leadership roles for them.

Program staff who are PLWHA must receive the same level of palliative care as the program recipients to ensure full PLWHA participation in program leadership.

Interdisciplinary Teams

Given the many ways in which HIV disease affects individuals, communities, and families, it is important to establish interdisciplinary teams able to address the physical, psychological, supportive, and spiritual needs of the individual, family, and orphans. This collaboration allows for a more integrated and holistic approach to complex and interrelated problems and needs of adults and children infected or affected by HIV/AIDS. These teams should consist of professional health care workers such as palliative care nurses, community volunteers, clergy or religious leaders, family members, mental health counselors, traditional healers when appropriate, and other health care and support service providers and community workers.

The actions listed below promote human-resource capacity development. Each offers a unique opportunity to increase the capacity of the overall health care system:

- Support pre-service and in-service training and education in palliative care for professionals and community health workers (several countries have already developed comprehensive curricula).
- Ensure that the full range of providers, including physicians, nurses, traditional healers, community and volunteer health workers, PLWHA, pharmacists, social workers, and spiritual counselors are available and trained appropriately. It is important to utilize the various types of nursing professionals and their varied competencies and skill levels.

- Ensure care resources and tools for health workers (e.g., availability to first level health workers of the WHO IMAI modules: Acute Care, Chronic HIV Care, General Principles of Chronic Care, and Palliative Care⁴ on symptom management and end-of-life care).
- Train program staff in fiscal accounting and management practices, including identification of diverse funding streams.
- Develop accreditation standards and support achievement of competencies in palliative care.
- Provide resources and technical assistance to develop quality standards, including the monitoring and evaluating of such standards from in-country or regional palliative care experts.
- Provide mentorship, twinning, and support for South-to-South exchanges among palliative care organizations.
- Develop and strengthen initiatives to care for caregivers (including professionals, community health workers, and family caregivers).
- Support the formation of interdisciplinary teams.
- Provide training and other support for family members and community caregivers to provide basic health care.
- Support regional training centers in palliative care.

Each of these options provides opportunities to expand human-resource capacity for delivering palliative care. It is important that these and other activities be considered elements in establishing sustainable care programs.

1.12 Policy Development

Public policies that advance development and implementation of palliative care are critical to the success of the Emergency Plan. Policies can be generated from various levels of government and public and private institutions, such as medical and nursing schools, public and private health care facilities, and CBOs and FBOs. Policies often prevent scale-up of care because of legal or regulatory restrictions on who can deliver care. Many types of providers can provide excellent quality care by including, but not limited to, trained doctors, various cadres of nurses, paramedicals, medical assistants, clinical officers, traditional birth attendants, community volunteers and health workers, etc.. Key actions for policy development include the following, among others:

- Recognize other cadres of health workers and expand roles of nurses, community health workers and other health care providers to provide palliative care and medications.
- Train, supervise and develop capacity of health care providers.
- Offer equitable access to a wide range of medications to prevent and control pain and symptoms, and to prevent and treat TB and other OIs.
- Establish integrated programs and networks of service providers, including community health associations and organizations.
- Establish evidence-based care standards and care packages.

⁴ WHO (2004). Palliative care: symptom management and end-of-life care
<http://www.who.int/3by5/publications/documents/en/genericpalliativecare082004.pdf>

The advancement of these policies is often accomplished through a well-organized effort to bring together leaders and practitioners in the field of palliative care with senior administrators and decision-makers in government and institutions. This type of collaboration promotes development of policies that reflect both the existing capacity within the government and health care system and the socio-cultural conditions of persons living in the community, and that respond to the specific health and supportive needs of PLWHA.

The following are among the actions that can be taken to develop appropriate policies:

- Support the establishment of national standards, regulations, guidelines and oversight.
- Work with governments to expand prescribing privileges and training for clinical officers, midwives and nurses to safely prescribe OI treatment and pain/symptom control medications.
- Develop the capacity of national palliative care organizations and associations to conduct policy advocacy for palliative care.
- Support training, skill development and supervision for volunteers or community health workers to provide home and community- based palliative care.
- Work with key government officials to help them understand and integrate comprehensive palliative care (not limited to home-based or hospice care) into national health strategic plans and national HIV/AIDS strategies.
- Establish policies to ensure access to HIV care and treatment for HIV-infected health care providers – professionals, community health workers, and caregivers.
- Work with key government officials to promote policies and programs to expand and enhance access to appropriate pain- and symptom-control medications, including the availability and prescribing of opioids, the integration of pain and symptom control and other palliative care into existing home-based care policies, and the adoption of professional curricula in academic training programs.

1.13 Supply-Chain Management

The *U.S. Five-Year Global HIV/AIDS Strategy* defines supply-chain management as a systematic process to “create, enhance, and promote an uninterrupted supply of high-quality, low-cost products that flow through an accountable system.” The goal of supply management is to eliminate drug diversion, counterfeiting, waste, and gaps in distribution systems to ensure an efficient and sustainable delivery of essential drugs, supplies, and equipment. The Strategy identifies these four key areas for developing supply chain management:

1. Rapid scale-up of logistic systems to manage supplies and products.
2. Build-up of sustainable procurement and distribution mechanisms.
3. Establishment of quality-control standards for drugs, test kits, and other supplies.
4. Protection of intellectual property laws at national and international levels.

Each of these strategies has implications for the delivery of palliative care and program management.

Palliative care providers at all levels of the health system need access to specific drugs and supplies. In addition to medications for pain and symptom relief and OI management, providers need access to items necessary for managing clinical conditions (e.g., drug-dispensing equipment,

gloves, wound-care and mouth-care supplies, HIV test kits, sterile needles). Product selection procedures, distribution systems and networks, and information-management systems are needed to provide these products. Centralized procurement mechanisms, demand forecasting procedures, and coordination between supply-chain managers and program-service managers are needed to ensure patient enrollment and continual product availability. An accountable system is necessary to protect against the misuse or diversion of opioids used for pain control. The development of a supply management system with accountability is needed to increase service capacity to deliver effective care.

1.14 Reference Guide

The USG has published a *Clinical Guide to Supportive and Palliative Care for HIV/AIDS*⁵ and, in collaboration with African care experts, is developing a similar clinical guide for sub-Saharan Africa. The WHO Secretariat has developed guidelines for symptom management and end of life care.⁶ USG, the WHO, Ministries of Health, and other academic bodies around the world have developed guidelines addressing OIs, acute care, and other aspects of palliative care. Additionally, the USG is delineating a menu of evidence-based care interventions for PLWHA, HIV-infected children and pregnant/post-partum women and newborns. Below are additional palliative care resources:

- U.S. Department of Health and Human Services (HHS), Centers for Disease Control and Prevention, Global AIDS Program. Strategies: Palliative Care. http://www.cdc.gov/nchstp/od/gap/strategies/4_3_palliative_care.htm
- The World Health Organization: <http://www.who.int/cancer/palliative/definition/en/>
- The African Palliative Care Association: APCA, PO Box 7757, Kampala, Uganda Email: apca@hospiceafrica.or.ug http://www.theworkcontinues.org/docs/news/apca_newsletter.pdf
- The U.S. National Hospice and Palliative Care Organization <http://www.nhpco.org/>
- The Diana Fund: <http://www.theworkcontinues.org/causes/palliative.asp>
- Center for Advanced Palliative Care <http://www.capc.org/>

⁵ The Health Resources and Service Administration (HRSA) HIV/AIDS Bureau (2003). A Clinical Guide on Supportive and Palliative Care for People with HIV/AIDS <http://hab.hrsa.gov/tools/palliative/>

⁶WHO (2004). Palliative care: symptom management and end-of-life care <http://www.who.int/3by5/publications/documents/en/genericpalliativecare082004.pdf>

Appendix I

Pediatric Palliative Care

Issues related to the delivery of HIV palliative care for pediatric clients include the following:

- The clinical course of HIV is more rapid in children, and mortality for infected babies is as high as 40 percent in the first year of life.
- Maternal antibodies make serologic diagnosis of HIV difficult in the first 18 months. Unless virologic diagnostic tools are available, this means that interventions such as cotrimoxazole prophylaxis and safe infant feeding must be initiated before diagnosis is confirmed.
- The appropriate interventions and methods of administration change with the age of the child. The infant and adolescent have very specific and age-dependent needs. Drug dosages also change with age, and child-friendly formulations are required.
- Children are dependent on adults for their care. These adults need to be identified, recruited, and educated as to how to care for the child. Family-centered care need to be supported, and caregivers encouraged to seek care and treatment interventions for the child, including ART when appropriate. Such caregivers are critical for adherence support for ART and other interventions.
- Certain symptoms are more common in children, including skin disorders, sore mouth, and convulsions. Some, such as pain, are more difficult to diagnose in children.
- Nutrition and growth are critical indicators of well-being, and of response to care and treatment. Failure to thrive is a key indicator of clinical deterioration. Safe infant feeding is a critical issue both for prevention and for care.
- If a child is infected, it means that one or both of his/her parents are or will likely become sick as a result of HIV/AIDS. Other siblings could also be infected. The family must therefore be assessed and supported as a unit.
- Disclosure of HIV status for children living with HIV/AIDS needs to be tailored to the child's understanding, and approached gradually and with parental consent, and preferably communicated by the parents.
- Communicating with children requires creativity and sensitivity, and often the use of stories, make-believe, drawing, dance and drama.
- Bereavement counseling and succession planning should be an intrinsic part of psychosocial support for children living with HIV/AIDS, and their families.

The Office of the U.S. Global AIDS Coordinator is finalizing the specific care package for children living with HIV/AIDS. Emergency Plan programs also need to consider the needs of the non-infected or asymptomatic child living with HIV/AIDS. These include immunizations, monitoring of growth and development, safe infant feeding, hand-washing and personal and household hygiene, and malaria prevention in endemic areas.

Pain management for children also follows the principles of the WHO analgesic ladder. Non-opioids, such as paracetamol and ibuprofen, can be used, but aspirin should be avoided because of the risk of Reye's Syndrome. Because young children might not be able to complain of pain or describe its intensity, it is important to observe for signs such as listlessness, irritability, poor appetite, changes in sleep patterns, and loss of interest in play.

Emergency Plan programs must ensure several important linkages to providers. OVC programs should help identify the small proportion of orphans that are HIV-positive for referral to health care. Adult home-based care programs should help identify children who are single or double

orphans or whose parents are very sick, and enroll them in OVC programs. PMTCT programs need to ensure follow-up of infants and children at the community level and refer children for diagnosis and treatment and commence co-trimoxazole and infant feeding interventions. HIV/TB programs must inquire about children in the home who may have been exposed to TB (regardless of HIV status), and provide treatment or INH prophylaxis as appropriate. Emergency Plan programs must support specific provider training and other human-capacity development strategies for the expansion of pediatric palliative care. Finally, Emergency Plan programs should integrate wrap-around programs, including child health and nutrition programs that are operating at the community level, particularly in high-prevalence countries.