



# Supportive and Palliative Care for People Living with HIV/AIDS<sup>1</sup>

BY HELEN SCHIETINGER

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**A**s defined by the World Health Organization (WHO):<sup>2</sup> Palliative medicine is the study and management of patients with active, progressive, far advanced disease for whom the prognosis is limited and the focus of care is the quality of life. [It is] the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social, and spiritual problems, is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are applicable earlier in the course of the illness, in conjunction with treatment. Palliative care:

- Affirms life and regards dying as a normal process,
- Neither hastens, nor postpones, death,

- Provides relief from pain and other distressing symptoms,
- Integrates the psychological and spiritual aspects of patient care,
- Offers a support system to help patients live as actively as possible until death, and
- Offers a support system to help families cope during a patient's illness and with their own bereavement.

In short, palliative care comprehensively addresses the physical, emotional, and spiritual impact a life-threatening illness has on a person, no matter the stage of the illness. It places the sick person and his/her family, however defined, at the center of care and aggressively addresses all of the symptoms and problems experienced by them. Many healthcare providers apply certain elements of the palliative care treatment approach—such as comprehensive care and aggressive symptom management—to the care of all of their patients, not only those who are terminally ill, offering the type of care we would all like to receive when we are sick.

Although the field developed out of the hospice movement of the 1960s—the goal of which is to relieve the suffering of a person with an incurable illness, rather than just prolong his/her life—palliative care embraces the additional goal of improving the person's quality of life.<sup>3</sup>

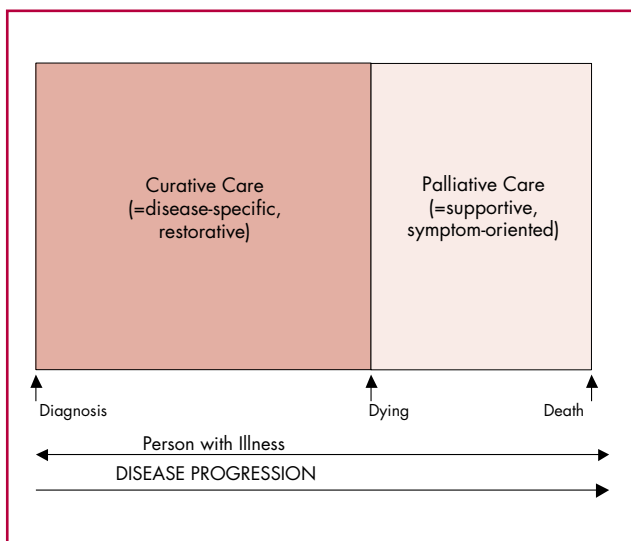
The palliative care approach can be used to care for people with HIV/AIDS throughout the continuum of the disease process, whether their symptoms are caused by opportunistic infections, the underlying HIV virus, or the untoward effects of antiretroviral treatments. In deciding how to incorporate palliative care into a system of HIV/AIDS care, one needs to look beyond the traditional “either/or” dichotomy that often exists between curative and palliative care (see Fig. 1) and embrace the concept of “both/and.”<sup>4</sup> Palliative care enhances HIV care—it is not a substitute for medical care or antiretroviral therapy (ART).

This article endorses the belief that palliative care is an important component of caring for people living with HIV, regardless of

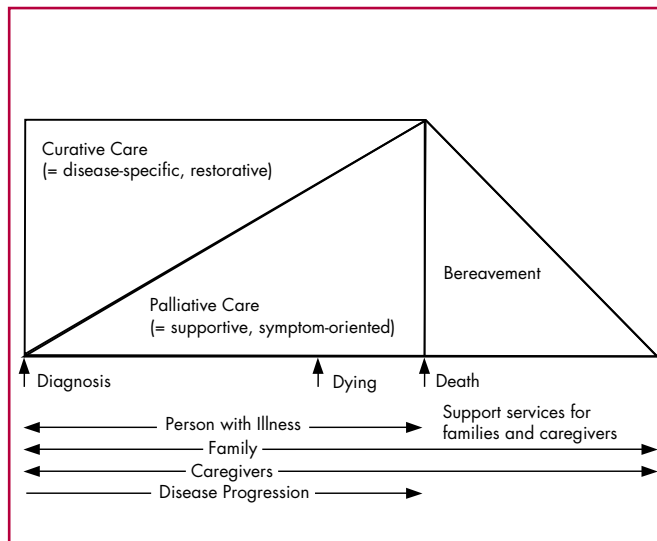


Photo: Vira Illich.

For critically ill patients such as this woman at the HIV/AIDS Treatment and Care Department of the Gromashevsky Institute of Epidemiology and Infectious Diseases in Kiev, comfort and compassionate care can help ease the pain of their final days.



**Figure 1a:** Traditional dichotomy of curative and palliative care for incurable illness.



**Figure 1b:** Integrated model of care (curative and palliative together).

the stage of their disease. The first section describes services that comprise palliative care; the second explains the essential elements that must be in place for a palliative care program to succeed; and the third presents various models used to structure palliative care programs specifically for patients with HIV/AIDS.

### Palliative Care Services

Palliative care providers are concerned with a full range of issues faced by persons living with HIV and their families. Components of care include symptom management, especially pain control; psychosocial and spiritual support; and, when needed, end-of-life and bereavement counseling. An important cornerstone of palliative care is listening. Clinicians trained in this approach listen carefully to patients and their families. They help identify and prioritize problems and work with patients and families until these problems are resolved to the best extent possible.

### Symptom management

The central focus of palliative care is symptom management. Palliative care experts have learned that even debilitating pain can usually be controlled and that people with pain from intractable causes can find relief if provided with suitable interventions. To this end, opioids are essential for appropriate pain management and a palliative care program is incomplete without them.<sup>5</sup>

The WHO Analgesic Pain Ladder identifies three levels of pain; each level is treated with medications of increasing potency (see Fig. 2).<sup>6</sup>

#### Step 1: Mild pain

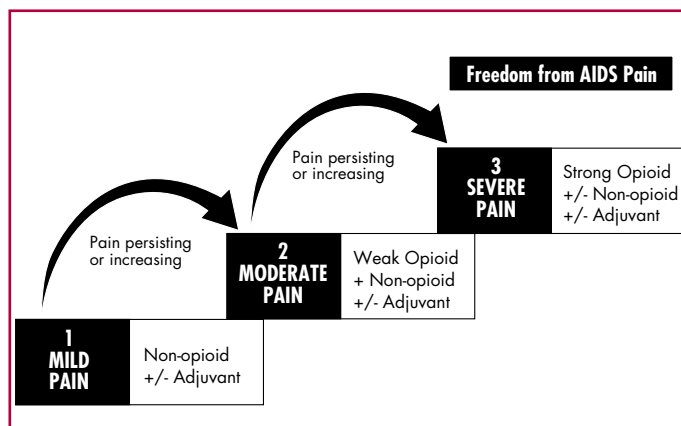
Non-opioid drugs, including aspirin, acetaminophen, and other non-steroidal anti-inflammatory drugs are given, in addition to appropriate adjuvant medications (corticosteroids, anticonvulsants, antidepressants, neuroleptics, local anesthetics, hydroxyzine, psychostimulants, etc.) and physical treatments, such as massage or acupuncture.

#### Step 2: Moderate pain, or mild pain that persists or increases

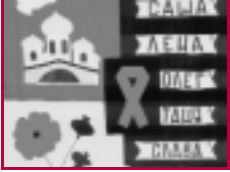
Weak opioid drugs (e.g., codeine) are added to the regimen, and perhaps higher doses of other drugs.

#### Step 3: Severe pain, or moderate pain that persists or increases

Opioid drugs, including morphine, nonopioid pain medication, and adjuvant drugs are used, in higher doses, more frequently.



**Figure 2:** WHO Analgesic Pain Ladder for management of pain in AIDS.



The foundation of pain management is a regimen individualized to each person's needs, given by the simplest route possible, in scheduled doses at levels that prevent recurrence, with added doses for "breakthrough" pain. Level of pain is now considered one of the body's vital signs, along with blood pressure, pulse, respiratory rate, and temperature. To standardize its measurement, a specific tool must be used by all team members. The 0-10 pain intensity scale (see Fig. 3) is a simple, effective assessment tool that does not require any equipment. Patients are asked to rate the level of pain they are experiencing on a scale from 0 to 10, with 0 being no pain and 10 being the worst pain imaginable. A person's scores are compared over time to evaluate the effectiveness of treatment and to achieve and maintain optimal pain control. This and other self-report tools have been found to be remarkably precise in assessing pain and the effectiveness of treatment.

Because opioids are the most effective drugs for reducing or alleviating pain, they are the mainstay of pain management, but many untrained clinicians do not use high enough doses of opioids to relieve their patients' pain because they are afraid of causing addiction. However, treating pain does not cause addiction, it alleviates suffering and improves quality of life.<sup>7</sup>

People with HIV suffer from a variety of physical problems even in the early stages of HIV infection, so symptom management is essential throughout the continuum of the illness. Alleviating symptoms enables patients to function, freeing them from the restrictions of the disease as much as possible. Some of the most persistent and difficult symptoms of HIV include fatigue, dyspnea, general pain, weight loss, anorexia, anxiety, depression, insomnia, coughs, nausea and vomiting, diarrhea, and constipation.<sup>8</sup> Identifying and treating infec-

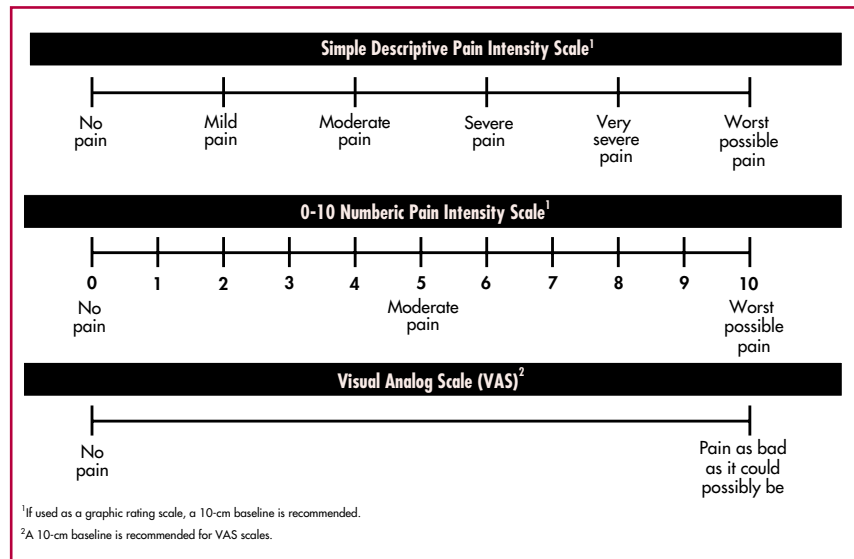


Figure 3: 0-10 Numeric Pain Intensity Scale.

Effective palliative care requires an interdisciplinary team that includes not only medical personnel, but also people such as social workers, psychotherapists, and pastoral counselors who are trained to provide counseling and to address mental health issues.

tions such as oral candidiasis is one step in symptom control; however, it may not be the only one. A clinician needs to continue to work with a patient if symptoms persist after infections have been treated or ruled out—trying first one remedy then another until relief is found. Accepting that a patient may still be suffering even after recommended treatments have been tried and being willing to continue to work with a patient to find a solution characterizes a true palliative care clinician.

### Psychosocial support

In addition to coping with a life-threatening disease and possibly debilitating symptoms, people living with HIV must often manage changing family dynamics, stigma in the community, the illnesses of other family members, loss of their own physical functions, loss of income, depression, and hopelessness. Even in communities that have actively campaigned to prevent HIV/AIDS discrimination, people with HIV and their families experience stigma.<sup>9</sup> In this context, psychosocial support can significantly improve their quality of life.<sup>10</sup>

Effective palliative care requires an interdisciplinary team that includes not only medical personnel, but also people such as

Source: Acute Pain Management. Clinical Practice Guideline. AHCPR Pub 92-0032. Rockville, MD: Agency for Health Care Policy and Research, February 1992. Also available at <http://ftp.hrsa.gov/hab/F4.2.pdf>.

social workers, psychotherapists, and pastoral counselors who are trained to provide counseling and to address mental health issues. These professionals enhance the clinical care patients receive by helping them deal with the emotional effects of their illness, as well as the social environment in which they function.

Peer support is a vital component of psychosocial HIV care. Whether in the form of one-on-one counseling or group discussions, assistance provided by self-identified people who are also living with HIV enables patients to break down their own fears and stereotypes about the disease and to see that people continue to live productive lives after being diagnosed with the infection. Meeting someone living with HIV face-to-face can be the most important positive experience for a newly diagnosed person and, in some cases, has been a life-saver.

Palliative care cannot be provided in a vacuum; when a person's basic survival needs—physical safety, housing, food, and clothing—are not being met, all else becomes irrelevant. It is often the palliative care team's social worker who ensures that the essential needs of a patient are in place, networking with community agencies that address the unique issues facing vulnerable people. Programs providing palliative care must be able to work with governmental, non-governmental (NGO), and faith-based organizations, as well as with individual community and family members, to ensure that patients are safe, fed, clothed, and housed. In regions with entire communities of displaced or economically marginalized people, the unmet survival needs of patients may ultimately undermine a program's ability to provide other components of palliative care.<sup>11</sup>

Many people become infected with HIV because of underlying problems with drug addiction, alcoholism, and/or mental illness. Palliative care providers need to be trained to work with persons suffering from behavioral health problems and palliative care programs must be ready to address these issues, as well as to actively collaborate with appropriate programs in the community that help patients deal with these afflictions.

Finally, issues related to children are an important aspect of providing psychosocial care to families. Permanency planning—helping parents decide who will care for children after they die—and legacy building—helping parents create memories and tangible mementos for children—are two ways programs can support parents.

### **Spiritual support**

Attending to spiritual needs is another key component of palliative care. Some programs have pastoral counselors on staff, while others collaborate with faith-based community organizations to assure spiritual support for their patients. This type of assistance can help HIV-positive persons and their families prepare for death when it becomes inevitable, assist with funeral and burial plans, and provide ongoing comfort to the bereaved family. Psychosocial and spiritual support are often inextricably united, especially in communities with a strong faith tradition.

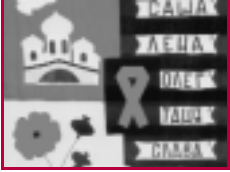
HIV infection is a life threatening illness that compels a person to face the reality of death from the moment he/she receives a positive test result. The natural inclination of many individuals is to turn to the faith tradition in which they were raised. However, countless religious communities have passed negative judgment on or rejected people with HIV. Even in communities of faith that are accepting of HIV-positive people, those who find they are infected often do not reach out for support because they are afraid of being rejected. To better serve those with HIV, it is all the more important that palliative care programs include nonjudgmental and accepting spiritual support that encompasses the faiths of all its patients and that meets the needs of patients who do not belong to a faith-based tradition, for whatever reason.

The cultural uniqueness of each community often determines how spiritual support is structured and provided, but in diverse communities or in communities that include displaced persons, those providing palliative care must be respectful of the needs and values of those who come from outside the predominant cultural tradition. Training in cultural sensitivity can be useful in helping staff learn to appreciate the diversity of their patients.

### **Support related to end-of-life care**

Advance-care planning is the term used for addressing how decisions will be made as a person reaches the later stages of disease. It is part of the palliative care process and an important topic of discussion to raise with patients and families. A team member, often a social worker, must assume the task of bringing

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up questions about what will happen when the patient can no longer make decisions and when the patient dies. Difficult subjects that are best decided upon and written down early include who should become the person's decision-maker for healthcare and financial issues; planning the funeral and burial; designating who will receive a person's belongings, property, and other assets; and planning for the future needs of children. Generally, the patient and the family are relieved when these issues are introduced and decisions are made.

At the time when a person is nearing death, a different set of needs and priorities becomes evident. Keeping the person clean, dry, and comfortable can be incredibly demanding and some palliative care or home hospice programs have trained volunteers to assist the family with what becomes around-the-clock care. The need for psychosocial and spiritual support intensifies. In many cultures, the community reaches out to the family at this stage with gestures such as bringing food or making short visits to pray with the patient. The patient's healthcare providers, however, sometimes withdraw because they feel helpless, leaving the patient and family feeling betrayed and deserted at their time of greatest need. But skilled clinicians can provide much assistance and support at this time, as symptoms become more intense and the physical needs of the dying person become more demanding. Pain control is a vital concern and should be carefully managed for the sake of both the patient and the family. The amount of morphine required to alleviate pain may increase dramatically if the person has already been taking morphine regularly and has developed a tolerance. Experience in caring for the dying enables providers to become comfortable in adjusting doses upward as need increases and in reassuring the family that it is safe to do so.

Palliative care programs usually provide family members with bereavement support for a year after a person dies. Patients are comforted knowing that loved ones will receive assistance after they are gone. The emotional work of grieving and letting go is eased through services such as support groups, outings for bereaved families, and visits to the family by pastoral or peer counselors. Providers can express their sympathy and acknowledge the family's loss through simple acts such as attending the funeral or sending the family a card on the anniversary of the death.

### Essential Elements of a Palliative Care Program

Certain elements must be in place in order to provide effective palliative care, whether as a separate program or integrated into an HIV or primary care program. WHO recommends that three foundation measures be established for an effective national program: policies, education, and appropriate drugs (see Fig. 4).<sup>12</sup>

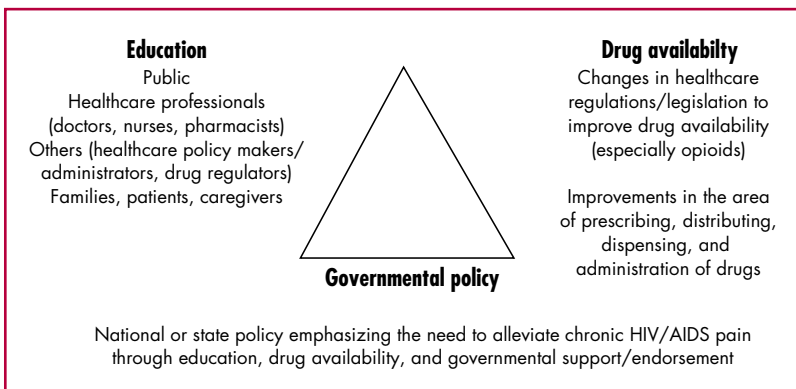
First and foremost, government policies must be in place to support a palliative care approach. Second, education must be available for those delivering the care, other health workers, and the public. Third, appropriate drugs for pain and symptom control must be available. Opiates are essential. These same three measures are also important at the institutional level when establishing a local palliative care program.

Other elements essential for success are an interdisciplinary team, mechanisms for coordinating ongoing collaboration among team members, and evaluation measures built in from the onset.

### Policies

Governmental policies provide vital support when establishing palliative care programs, whether they are being integrated it into the national healthcare system, incorporated into an HIV care program, or established as a discrete local hospice program. Having appropriate policies in place alleviates barriers to care, such as lack of access to drugs, and facilitates advocacy for resources and funding. Using the public health approach recommended by WHO also assures that palliative care is a key component of national healthcare plans, that adequate coverage is established through home care and community support services, and that the approaches used are acceptable, maintainable, and affordable at the community level.<sup>13</sup>

Source: Foley KM et al., "Palliative care in resource-poor settings," in F O'Neill et al., eds., *A Clinical Guide to Supportive & Palliative Care for HIV/AIDS* (HHS, Rockville MD, 2003); <http://hiva.gov/hab/F192.pdf>.



**Figure 4:** Pyramid of education, drug availability, and government policy. These are foundation measures necessary for an effective national program.

National policies can grow out of an assessment of the magnitude of the need for palliative care. Demographic information such as the total number of deaths in the previous year and the incidence of cancer or HIV can provide the basis for estimating the number of people in need of this service. In addition, specific indicators can be built into programs at the planning stage to ensure ongoing monitoring and evaluation. For example, while pain assessment indicators are used to provide the palliative care team with immediate feedback regarding their care for individual patients, these same data can be collected over time to track how well the program relieves patient pain, providing evidence that can be used to justify the program's continuation and growth. With multiple competing healthcare objectives, ministries of health need to understand that palliative care programs do provide necessary services and are cost-effective. Regular documentation of carefully selected indicators can make powerful statistics available in the years after a program's inception, as well as facilitate further planning and decision making.

### **Training and Education**

From training care providers to integrating palliative care into the curriculum of a medical or nursing school, education is critical to the successful implementation of palliative care. A number of countries have instituted post-graduate certificates or degrees in this type of care. For example, the Hospice Association of South Africa offers a program for medical students at the University of Cape Town that awards a diploma in palliative medicine and also offers a training program in palliative care for professional nurses.

Ultimately, palliative care is only as good as the skills of its providers. The best training includes hands-on clinical experience under the supervision of a skilled professional who serves as a mentor and guides colleagues in every aspect of this approach—from symptom management, especially pain control, to the art of listening. Team members benefit from observing how a skilled provider introduces and addresses difficult issues, such as planning who will care for the children or achieving adequate relief for intractable pain. Interdisciplinary training also provides an opportunity for team-building and helps each team member understand and respect the importance of the types of care provided by others on the team.

Healthcare professionals who are not members of the team should also learn about palliative care. Education reduces com-

mon misconceptions about this approach—especially regarding the use of narcotics to relieve pain—and can increase appropriate referrals to palliative care services.

Since the advent of ART, HIV care specialists are less often trained in palliative care, even though the expertise in pain management and symptom control that the field provides would greatly benefit their patients. While these specialists tend to focus on achieving success through antiretroviral treatment, they also must know what to do—for example how to manage pain and provide comfort—when ART fails.

### **Drug availability**

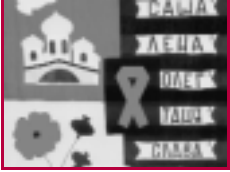
The list of drugs needed in an HIV palliative care formulary is quite basic and short; it can be found on any country's essential drug list. However, availability of appropriate drugs for pain control and symptom management may be hampered by government policies regulating controlled substances—such as opioids—or ineffective systems for distributing and dispensing the drugs. Even if the resources are available to purchase pharmaceuticals, it still may not be legal to bring them into a country. Palliative care experts may have to advocate for legislative or regulatory changes at a national level to make appropriate drugs, especially opioids, available for palliative care programming. In Uganda, as chairman of the National Drug Authority, Jack G.M. Jagwe was instrumental in establishing appropriate government policies that make morphine available for pain control.<sup>14</sup>

Procedural barriers may also need to be overcome for drugs to reach patients. For example, in Uganda, there are few physicians and they are the only legal prescribers of morphine, which limits patient access to opioids. To alleviate this problem, the Ugandan Ministry of Health is working to legislate a statute change that will enable palliative care nurse specialists to prescribe morphine and other pain medications.

Drug availability is not only dependent on appropriate policy and efficient procedures, but also on the wise utilization of resources. Again, Uganda, with a limited budget for drug procurement, provides an example. Morphine is purchased in powder form and then made available in liquid form for oral administration, which is much less expensive than purchasing tablets or preparations for intravenous administration.

### **A patient-centered, interdisciplinary, collaborative team approach**

Certain key elements of the palliative care philosophy must be



built into all programs. The patient and family are integral parts of the palliative care team and are always the ultimate decision-makers in issues related to care. In order to meet a patient's wide range of medical, psychosocial, and spiritual needs, the interdisciplinary team needs to include staff from a range of fields, for example, physicians, midlevel providers—nurse specialists, physicians assistants, clinical officers—nurses, social workers, chaplains, psychologists, and counselors. There may also be a case manager who coordinates care and stays in touch with other members of the team.

Whether the team members are all part of the same program or work at different organizations in the community, there must be a formal system for regular communication and collaboration, such as a weekly meeting or a patient chart shared by all. Ideally, all team members will have gone through a special training program together, which strengthens the cohesion of the team. Volunteers, often integral to both HIV and palliative care programs, are usually recruited, trained, and supervised by a volunteer coordinator; they provide services such as peer support, physical assistance, accompaniment to appointments, social visiting, and spiritual support.

### Models of Palliative Care

Ultimately, palliative care is simply a set of principles and skills that can be delivered through many different models. Some palliative care services are discrete programs within a community while others are regional or national in scope and integrated into the primary care infrastructure. The palliative approach can be incorporated into programs targeting a specific population—such as people with HIV—or into healthcare programs serving the general population. Palliative care programs are developed to complement services that already exist and to function within entire healthcare systems. A key to a program's success is careful planning based on an in-depth assessment of the needs of a community or country.

### Types of programs

The inpatient palliative care unit—located in an acute hospital, a long-term care facility, or a separate building, sometimes called a hospice—is one model of care. In one inpatient model, the entire unit's interdisciplinary staff specializes in and provides comprehensive palliative care services, sometimes with the assistance of the family. Another inpatient model involves a palliative care advisory or consulting team. Here, patients are cared for in general hospital beds by their primary care physicians, oncologists,

or HIV physicians, and the team provides consultation in pain and symptom management, as well as other palliative care needs. Perhaps the most prevalent model, however, is an outpatient, community-based program, in which mobile palliative care teams provide services to patients in their homes or as they move from setting to setting.

### Integration into primary healthcare

Palliative care is being integrated into primary healthcare in countries as diverse as England, Spain, and Uganda. Widespread training and the establishment of essential policies and protocols as described above enable this integrated approach to work, as long as there are adequate resources, including staff, to provide the needed services. In Spain, the Catalonian Palliative Care Planning and Implementation Pilot Program, a WHO project from 1990-95, has developed a region-wide palliative care network that serves cancer and other terminally or chronically ill patients.<sup>15</sup> The staffing and service capacity in terms of beds and number of homecare teams was determined after completion of a careful needs assessment. The network consists of palliative care teams who provide treatment and services in the home, in acute hospitals, and in long-term facilities. The variety of available care locations gives the patient and his/her family the flexibility to choose the setting best suited to their needs and the ability to move among these settings as their situation changes. Creating a palliative care program across service settings also resolves problems of communication between agencies organized under different authorities.

### Palliative care services in Eastern Europe

The palliative care movement was slow to develop in Eastern Europe and Eurasia, but in the early 1990s hospice and palliative care programs began to emerge. By 2002, 23 countries in this area had at least one hospice or palliative care service<sup>16</sup> with a total number of 467 programs in the region. The vast majority of these are in Poland and Russia, but the concept has become a priority in many countries. Five palliative care service programs have been identified as “beacons of excellence.” Located in Brasov, Romania; Budapest, Hungary; Poznan and Warsaw, Poland; and St Petersburg, Russia, they can serve as models for policymakers and health professionals in other parts of the region.<sup>17</sup>

### The role of networks

The establishment of a regional or national hospice/palliative care association can serve as an important catalyst and communication tool. In Spain, for example, since 1992, the Spanish Pal-

liative Care Association (SECPAL; [www.secpal.com](http://www.secpal.com)) has facilitated much interdisciplinary collaboration across the country.<sup>18</sup> It serves as a resource directory, provides training and education, and assists others at national and regional levels to develop appropriate rules for prescribing drugs, as well as sets standards and guidelines for developing palliative care and educational programs. In addition, SECPAL educates healthcare professionals throughout the country about palliative care. The Hospice Palliative Care Association of South Africa (HPCASC) and the Latvian Palliative Care Association serve the same functions in their respective countries, and the International Association for Hospice and Palliative Care (IAHPC; [www.hospicecare.com](http://www.hospicecare.com)) provides contact information for national and regional palliative care associations around the world, including many Eastern European countries. All of these organizations are good resources for communities to turn to when establishing a system of palliative care.

## The Role of Palliative Care in Today's World

As a new and growing healthcare discipline, palliative care has become a crucial part of any healthcare system, particularly one providing services to people living with HIV. Expertise in palliative care enhances the ability of healthcare providers to relieve the symptoms of their patients, to communicate with patients and their families, and to collaborate with other service providers. The number of people requiring care for chronic and life-threatening illnesses, as well as old age, is increasing—and with it, the number requiring palliative care increases as well. ■

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