

The State of Palliative Care and HIV/AIDS in Latin America

Palliative care, as defined by the World Health Organization, is “an approach that 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.” Palliative care is a vital and necessary component in the care of children and adults living with HIV/AIDS. It should be delivered concurrently with curative treatment beginning at the time of diagnosis as it helps to alleviate pain and other physical symptoms, as well as address the psychological and social effects that result from living with a life-limiting illness.

HIV/AIDS in Latin America and the Role of Palliative Care

There are currently 1.6 million people reported to be living with HIV/AIDS in Latin America. In 2007, an estimated 100,000 people became infected with HIV and 58,000 died of AIDS.¹ Young adults, ages 15–24, comprise the majority of HIV infections within Latin America, while globally 2.1 million children under the age of 15 are living with HIV.^{2,3} Research has shown that 60–80 percent of patients with HIV/AIDS experience moderate to severe pain during the course of the illness with pain most prevalent in the advanced stages of the illness.^{4,5} Children and adults with HIV/AIDS often suffer from opportunistic infections and a range of symptoms such as fatigue, anorexia, dyspnea, fever, numbness, anxiety, and depression. These symptoms create pain and discomfort, placing an additional burden of physical and psychological distress on the patient and their family members.

Palliative care must be an essential part of HIV/AIDS care. It serves as a model of care that is patient-centered and focused on relieving pain and other distressing symptoms that are a result of the disease and its treatment. Bereavement care for family members is also an essential component of palliative care.

Of the total number of people who need palliative care services in Latin America, experts estimate that only 5–10 percent receive it, with the majority of services available in large cities, leaving the rural population largely underserved.⁶ UNAIDS reports that globally, palliative care “is one of the most neglected aspects of health care.”

HAART and Palliative Care

HAART (highly active antiretroviral therapy) is an integral component of palliative care for children and adults living with HIV/AIDS. Although it does not provide a cure, it can greatly

improve a patient's health and quality of life. If delivered early in the course of the illness, HAART can have a positive impact on the trajectory of the disease. HAART can be highly effective in extending the life of a person living with AIDS, with the disease resembling more of a progressive or chronic illness in which palliative care expertise and services are needed to manage pain and symptoms over a longer period of time. Because patients often experience multiple symptoms as side effects during HAART, concurrent palliative care is essential in managing these symptoms. Research data shows that when palliative care is used to treat the pain and symptoms associated with HAART, a patient is more likely to adhere to the prescribed drug regimen and less likely to discontinue treatment.^{7,8} In low-resource countries where patients often present very late in the course of the illness, HAART may not be possible. Palliative care offers the most humane and appropriate response to care for dying patients and their families. It is estimated that 75 percent of the adult population in Latin America has access to HAART, but the level of access for children is less than 35 percent.⁹

Where Palliative Care is Provided

Palliative care is provided at a national, regional, and local level and in a variety of settings: hospitals, clinics, hospices, assisted living facilities, and at home. Comprehensive palliative care should be integrated across a continuum of health care services and is delivered by doctors, nurses, community-based home care workers, social workers, psychologists, spiritual leaders, and trained volunteers. Palliative care focuses on the needs of the patient and the family and is coordinated by a team of health care professionals involved in the various aspects of care. Community-based home care models of palliative care for children and adults with HIV/AIDS provide excellent examples of the role of a palliative care team working through trained community health workers in resource poor settings. These models enable care to take place at the home and support the patient and the family during

advanced illness, providing bereavement services to the family following death.

Palliative Care in Latin America

In Latin America, palliative care is at varying levels of development. Currently, Costa Rica, Cuba, and Chile are the only countries that have national health programs that include palliative care. A study conducted by the Latin American Association for Palliative Care found that while 86 percent of respondents reported to have a national HIV/AIDS program in their country, palliative care was included in less than a quarter of them.¹⁰ Of the 35 countries in Latin America and the Caribbean there are only eight countries—Argentina, Brazil, Colombia, Costa Rica, El Salvador, Paraguay, Peru, and Uruguay—that have a national palliative care association.¹¹ Access to essential palliative care drugs is also very limited; for example, morphine, an inexpensive and highly effective opioid used as the mainstay of therapy to treat pain in patients with cancer or AIDS, is widely underused in Latin America with an average consumption rate of 0.8723 mg in 2006, well below the global mean of 5.98 mg, and less than one percent of the global consumption.^{6,12}

Barriers to Palliative Care

Lack of a national health policy, lack of drug policies to assure the availability of essential medicines, and lack of education of health care professionals and the public are the three main barriers to the provision and delivery of palliative care. Health care professionals are often lacking the necessary training to assess pain and administer opioids properly for patients with HIV/AIDS, or fail to prescribe these drugs because they are fearful of addiction or misuse. As a result, opioids are under-prescribed and under-supplied in pharmacies and hospitals, making them unavailable or inaccessible to the patients who need them.

Palliative care must be integrated into national health care systems to work successfully and not be delivered as a separate service of care. National

health care plans and policies often do not include palliative care or the necessary and balanced regulatory drug policies that allow for the proper delivery of pain and symptom management. As a result, palliative care is not integrated into delivery systems.

Palliative care is often not included in the curriculum at medical universities or nursing colleges, leaving doctors, nurses, psychologists, social workers, and other health care professionals ill-equipped to deliver the type of care needed for patients and their families. Data from surveys show that many countries in Latin America do not recognize palliative care as a medical specialty or discipline.⁶

Providing Comprehensive and Integrated Palliative Care for People with HIV/AIDS

Countries that want to integrate palliative care as a part of their national health care system need to develop national policies for palliative care, and include palliative care in national AIDS plans. National drug policies must ensure opioid availability and accessibility for patients. Legal frameworks need to be put in place that outline and promote palliative care development and financing, implement and integrate palliative care services across public and private health care systems, and include palliative care in professional education.

Policymakers need to ensure that essential medicines, such as morphine, are not restricted by drug policies that inhibit the affordability, accessibility, and availability for patients and are distributed in both urban and rural areas. Laws should also ensure that prescribing policies are efficient so as not to delay the delivery of medication to patients in pain. Health care professionals should be able to prescribe in doses that are recommended and considered necessary by international health bodies, such as the World Health Organization. Palliative care education must be included in the training of health care professionals and part of all national health care strategies, including national cancer and HIV/AIDS plans.

Health care professionals need to recognize the importance of palliative care as an essential component to HIV/AIDS care or any treatment of a life-limiting illness, and that it begins for the patient at the time of diagnosis. The health care professionals who treat patients with HIV/AIDS need to be trained in palliative care to deliver the best and most comprehensive level of care for their patients. In order for a palliative care curriculum to become an integrated part of training in undergraduate and graduate education, health care professionals must become advocates and leaders who can call attention to this critical gap in service delivery.

The following have been identified as key steps to getting palliative care on a national agenda:

- Engage opinion leaders within a country.
- Conduct a needs assessment to determine the situation within the target population.
- Develop an action plan and hold a workshop with key stakeholders.
- Establish a national steering committee to implement the action plan.
- Ensure that policy and drug availability issues are addressed, leaders identified, and centers of excellence developed.¹³

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RESOURCES

International Association for Hospice and Palliative Care:
www.hospicecare.com

International Observatory on End of Life Care:
www.eolc-observatory.net

World Health Organization Cancer Control Program:
www.who.int/cancer

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