

## The Concept of Palliative Care

The concept of palliative care grew out of pain relief and comfort measures for cancer patients. Since AIDS is a fatal disease with many curable manifestations, the distinction between active, curative treatment and palliation is blurred. As a result, current definitions of palliative care define this medical care service as a more holistic one that begins earlier in the course of a chronic, fatal medical condition.

Even without the impact of the AIDS epidemic, the health systems in many African countries are barely coping with the burden of diseases such as malaria, bacterial pneumonia, TB and diarrheal diseases. The numbers of doctors and nurses are grossly inadequate, medications and supplies are in extremely short supply and are often diverted from Ministry of Health hospitals to private clinics.

medical  
AIDS have  
situation, and  
medical  
expected to  
for example, an  
new AIDS cases  
Over 50 percent  
medical wards are  
patients who are  
the countries  
Global AIDS  
health  
totally inadequate  
hospital care for  
thus there is great  
hospital  
discharge AIDS  
with little or no

The World Health Organization defines palliative care as "...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.... 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 care... offers a support system to help family cope during the patient's illness and in their own

Deaths among  
personnel due to  
exacerbated the  
shortages of  
personnel can be  
worsen. In Malawi,  
estimated 70,000  
occur annually.  
of the beds on  
occupied by  
HIV+ in most of  
targeted for the  
Program. Existing  
infrastructures are  
to provide in-  
AIDS patients, and  
pressure on  
personnel to  
patients quickly,  
treatment.

To cope with this crisis, many nations have encouraged "home-based care" (HBC) for persons with an HIV or AIDS diagnosis. Many programs have been developed, and some provide good models that ease suffering and improve quality of life. For example, the Chikankata Hospital program in Zambia provides both hospital care and an intensive program of follow-up in the community. The AIDS Support Organization (TASO) in Uganda has established eight-day care centers that provide medical treatment, counselling, and food supplements for AIDS patients, plus a limited program of home care.

Unfortunately, in many countries, home and community-based care programs are very weak and provide few services. Links to local health centers and hospitals are poor, and HBC volunteers have little or no access to any drugs for palliative care. Diagnosis of tuberculosis and other opportunistic infections is often ignored. Training of HBC volunteers often over-emphasizes "counselling" and does not provide them with practical skills in home nursing. Food supplement programs are either not available or very inadequate, and lack of food for patients and their children is a serious problem.

Palliative care is defined as controlling symptoms, relieving distress, promoting quality of life, and attending to the psychosocial aspects of illness. These are appropriate in all stages of all diseases, not just during a terminal illness. In the case of HIV and AIDS, as the disease progresses, symptom relief, pain management and attention to psychosocial needs will require increased attention. Many infected persons currently lack access to palliative care services and medications. Palliative care can be provided in hospitals and in the home environment.

### **Issues and Challenges**

More than 50 million people die throughout the world each year. The majority – four fifths – of these deaths are in developing countries. HIV has increased the number of deaths, with 3 million people dying in 2000, 2.4 million in sub-Saharan Africa. Even where advanced therapies are available, length of life may be reduced for those with HIV. In addition, advanced HIV illness is associated with severe pain. People living with HIV in developing countries can therefore expect a shorter life span, and their death is likely to be unnecessarily painful and undignified.

Care for the dying is not new, and different cultures have different approaches to helping people at the end of their lives. Palliative care is based on a model developed in response to the needs of cancer patients by the hospice movement in the UK. It aims to make death a pain-free process which includes support, comfort and relief of symptoms, making it possible for people to die with dignity.

For people with HIV, palliative care is an essential part of treatment, not only as death approaches but also through the treatment of potentially fatal symptoms of opportunistic infections. Such treatment, while not curative, nevertheless prolongs life for considerable periods of time and restores quality of life.

The HIV epidemic has led to increased efforts to provide care and support for people in their homes. While this has been a great step towards the care that people need, many home care projects are unable to provide the pain relief and treatment of symptoms that are needed to prolong life and ease dying and death.

Huge investment is needed to ensure that when advanced treatment is no longer effective, or when it is inaccessible for any reason, people can have access to symptomatic treatment and pain relief. The obstacles are political, financial and the lack of understanding and training in the palliative care approach. As with other models of health care, HIV brings its own particular challenges to the concept and implementation of palliative care.

There are existing models of palliative care approaches in developing countries. Some of these were initially developed to respond to the needs of people with cancer and have expanded to include people with HIV, and others which have developed palliative care processes as part of their response to the HIV epidemic. Both face their own particular challenges and there are lessons to be learnt from each – both for each other and for meeting the challenges of increasing the scale of access to such treatment.

In Africa, the Hospice movement has developed and is expanding a few countries, including South Africa, Uganda and Zimbabwe. The principles of the Hospice movement, established initially in the UK, were developed in these projects to treat cancer patients, and are now

working also with people with HIV. This includes home care, treatment to relieve pain and psychological and spiritual support. Some of these, such as Hospice Uganda and Hospice South Africa (HASA) are able to provide training in palliative care to help increase the local capacity in implement palliative care projects. These Hospices, in common with other smaller hospice projects are caring for people with HIV as well as those with cancer. This means understanding the issues peculiar to HIV, including stigma and discrimination and the importance of confidentiality, and the need to set up or link into other initiatives providing voluntary testing and counselling.

Other projects such as TASO, in Uganda, The Mildmay Centre for AIDS Palliative Care in Uganda, the Ministry of Health/NGO Home Care Programme Government NGO in Cambodia, and the Ndola Diocese Home Care programme in Zambia have been established in response to the HIV epidemic. Links between the two models are necessary to ensure that optimum care is made available to those who need it, and that the experiences from different angles are shared. Good referral systems, especially where projects focus on different aspects of palliative care, are also essential.

The response to HIV has been led by NGOs, and often by small community based NGOs with very limited resources. As the health care services have been eroded by the impact of the HIV epidemic, the response has been in many places to establish home care schemes. These are often seriously under-resourced, and while there is no doubt that they help to ease suffering (and if nothing else is available can provide accompaniment and spiritual comfort), it is important that home care schemes are helped and upgraded. Many have a great potential, through partnerships and working with governments, to provide a platform from which proper provision of palliative care can be started. But it is also important that home care, in the sense of providing some minimal level of support, is not confused with provision of palliative care.

As with other aspects of HIV treatment, little research or experience is available on palliative care for children with HIV. The principles of palliative care apply to both children and adults – pain and symptom relief is as essential for children as it is for adults.

Palliative care is not an alternative to other models of health care. It is not in competition with efforts to provide antiretroviral and other advanced therapies, nor is it a poor relative to be implemented where such therapies are currently inaccessible. It is an essential part of a comprehensive health care system, which is missing in many developing countries, and must not be neglected in the efforts to provide greater accessibility to more technical drugs and therapies.