

# Palliative care: Issues and challenges

Sue Lucas

## 1. Background

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.

## 2. What is Palliative Care

The aim of palliative care is to provide the best possible quality of life both for people approaching the end of life and for their families and carers. It is a holistic approach to care and support, and takes into account emotional, psychological and spiritual needs as well as physical needs. Pain control is central to the concept of palliative care. Freedom from pain allows people to come to terms with their approaching death and enables them to make arrangements for the future of others who depend on them, as well as to live as fully as possible for as long as possible.

WHO defines palliative care as an approach that:

- Affirms life and regards death as a normal process.
- Does not hasten or postpone death.
- Provides relief from pain and other symptoms.
- Offers a support system to help patients live as actively as possible right up to their death.

- Integrates psychological and spiritual care.
- Provides a wider support to help the family cope during the patient's illness and their own bereavement after death.

Support for caregivers is an essential part of palliative care, whether they be family members or professional carers. For professional carers, an integral part of providing palliative care is to work with families and friends to ensure effective communication.

Pain control is central to palliative care, and presents challenges in itself. The analgesia ladder, as developed by WHO, includes three steps:

Step 1: Aspirin or paracetamol.

Step 2: Codeine or dihydrocodeine, with or without non-steroidal or anti-inflammatory drugs such as ibuprofen or indomethacin.

Step 3: Morphine, with or without co-analgesia, and with or without steroid anti-inflammatory drugs. Other strong opioid analgesics include pethidin and fentanyl.

Effective palliative care includes access to these drugs, some of which are controlled through restrictive legislation, and access to authorised staff competent in using them. Training, policy change and change in attitudes towards the use of such drugs is an essential part of developing access to palliative care. Cannabis has also been found to be a helpful in symptom control for people with HIV, and some people living with HIV/AIDS (PLWHA) have argued for it to be made more easily available. It is, however, very strictly controlled in most settings.

### **3. Present models**

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.

#### **4. Public policy issues**

Palliative care, whether for people with HIV or for others with chronic illness, is an essential part of any health care system. WHO has identified three foundation measures to scaling up the provision of such care:

1. *Development of a national policy.* Palliative care is not recognized in many government plans. For example, Uganda is the only country in sub-Saharan Africa that has adopted WHO's foundation measures for establishing a palliative care service. While a handful of other countries in the region have some provision for palliative care, this is provided outside the government health service. Advocacy for provision of palliative care as part of the essential health service system by the government will be a move towards ensuring some budget allocation for provision of care for those with chronic illnesses.
2. *Training for health workers and public education.* Understanding of what palliative is, and training to carry it out, is necessary for policy makers, health professionals and families. For HIV, such training needs to be linked to training on areas specific to HIV such as transmission and control of transmission, issues of stigma and discrimination, and respect for confidentiality.
3. *Pain control.* Pain is as important in HIV infection as it is in cancer. Some studies have shown that pain is reported as a primary symptom by more than half of people with HIV. In many countries, this will require training and awareness raising among health professionals, and advocacy to change laws to make effective pain relief available.

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.