

FACT SHEET

Palliative care and HIV

This fact sheet sets out to explain what palliative care is, the relationship between HIV, AIDS and palliative care, and information on access to pain drugs as a barrier to effective palliative care provision.

WHAT IS PALLIATIVE CARE?

Palliative care is a holistic and comprehensive approach to care and support that includes physical, psychosocial, spiritual, economic and legal support from the point of diagnosis until the end of life with the aim of improving quality of life. Whilst end of life care is a vital element of palliative care, it is only one component. Palliative care is an approach that helps people living with a life-limiting illness to live as actively as possible, from the point of diagnosis to end of life, as well as offering a support system to help families cope during the patient's illness and after death through bereavement support.

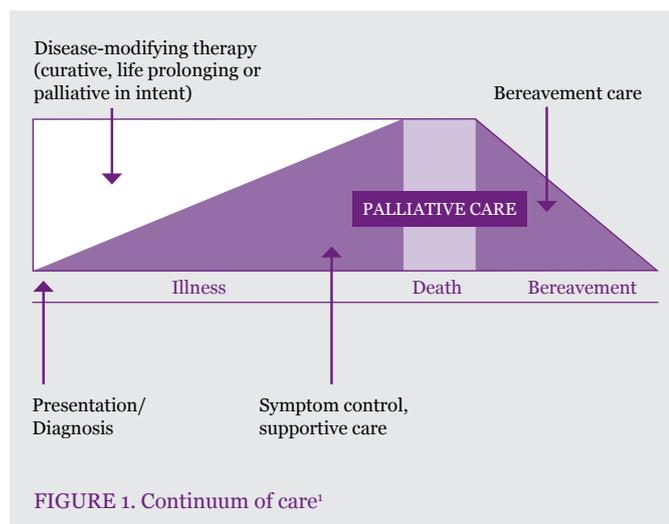


FIGURE 1. Continuum of care¹

The World Health Organization (WHO) defines palliative care as “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.”² However, in resource-poor settings, the scope of palliative care is expanded to include the provision of social and legal support that will also assist with poverty alleviation, food security and, where appropriate, planning for the future care of potential orphans.³

Palliative care services are provided by a multi-disciplinary team where possible including doctors, nurses, social workers, community caregivers and family members. The result is that services are provided in a variety of settings including hospitals, hospices, community-based health centres, and within the home.

PALLIATIVE CARE IN AN HIV CONTEXT

Everyone living with HIV would benefit from receiving palliative care, from the time of diagnosis of HIV infection and in conjunction with taking anti-retroviral drugs (ARVs). People living with HIV may experience both physical and psychosocial pain and suffering - requiring a comprehensive approach to care and support. Taking a palliative approach to HIV care has been shown to support better patient outcomes and to improve adherence to ARVs.⁴ Palliative care is not a substitute for HIV treatment, it is part of the package of services that patients on ARVs (as well as those unable to access treatment) may need, and have a right to access throughout their lifetime. Treatment adherence to ARVs is vital and palliative care can assist with this. Early palliative care can be provided by clinicians and staff in the HIV clinic. HIV clinic staff should be trained in palliative care so that they can manage pain and other distressing symptoms, psychosocial and spiritual problems and can identify when to refer the patient to a palliative care service.

People living with HIV face significant side effects, co-morbidities, opportunistic infections, psychosocial issues, health complexities associated with aging and moderate to severe pain. A study in the *European Journal of Pain* (2012)⁵ looked at South African outpatient HIV clinics and found that 60% of clients were experiencing moderate to severe pain at the time of the interview. In rural areas, only 29% of clients were receiving treatment to manage that pain.

It is a misconception that people living with HIV are ‘asymptomatic’ in the early stages of the illness. Initial testing and awareness of one’s status, disclosing to friends and family, asking questions of why this has happened, are all aspects of experience that require adequate care and support. A palliative approach to care needs takes into account the totality of pain (physical, psychosocial and spiritual), seeking to relieve it in its many forms, throughout the course of illness. It is also a misconception that people with access to ARVs do not have continuing care and treatment needs. People living with HIV suffer from pain, dyspnoea, wasting, psychosocial distress, and other debilitating symptoms.⁶ Research estimates that in the early stages of infection, around 30% of people with a CD4 count of more than 500 experience clinically significant pain, with up to 75% of people with AIDS suffering from pain.⁷

“Palliative care is an essential component of a comprehensive package of HIV/AIDS because of the variety of symptoms they can experience – such as pain, diarrhoea, cough, shortness of breath, nausea, fatigue, fever and confusion. At the community level, lack of palliative care places an unnecessary burden on hospital or clinic resources.”

WHO DEFINITION OF HIV PALLIATIVE CARE

Integrating palliative care into HIV services: A practical toolkit for implementers

This toolkit, written by FHI 360 with support from The Diana, Princess of Wales Memorial Fund, seeks to provide HIV care and treatment programme managers and clinicians with practical steps on how to integrate palliative care into adult and paediatric HIV services. The toolkit:

- reviews the many benefits of integration for the patient and health system
- presents key issues to consider when planning for integration
- offers clear, succinct ways to initiate and sustain integration
- provides clinical and organisation tools to guide integration

The toolkit is available at: www.fhi360.org/en/Publications/index.htm

ACCESS TO OPIOIDS

A critical component of palliative care is the ability to manage physical pain. Oral morphine, which can be a very inexpensive drug, is included as an analgesic in the WHO List of Essential Medicines and the IAHPC List of Essential Medicines for Palliative Care. Yet morphine availability and accessibility varies considerably between and within countries. It is estimated that one million end-stage HIV and AIDS patients live in countries with low or no access to controlled medications and have no or insufficient access to treatment for moderate to severe pain.⁸

A report by Human Rights Watch⁹ suggested that the following actions must be taken to improve access to opioids:

- Governments must eliminate legal barriers and ensure regulations do not stand in the way of affordable access to medicines
- Supply and distribution systems must be strengthened to adequately assess the need for opioids
- Training must be provided for healthcare workers to dispel myths associated with use of opioids and reduce the fear attached to prescribing
- Training must be provided for health system leadership to understand the multiple benefits and limited costs of pain management

Further information

- Worldwide Palliative Care Alliance: www.thewpca.org
- Open Society Foundation: www.opensocietyfoundations.org/topics/palliative-care
- Human Rights Watch: <http://www.hrw.org/topic/health/health-care-access>
- Global Access to Pain Relief Initiative: www.gapri.org
- E-Hospice: www.ehospice.com

Integrating HIV and palliative care in Tanzania, a community-based response

Palliative care can be integrated into existing home-based care programmes, as has been piloted with Tearfund's church partners in the Lake Zone region of Tanzania. Building on existing programme infrastructure and strengthening community and health system linkages, palliative care has proven to be feasible and a notable improvement on home-based care services. Providing a holistic and comprehensive approach to care, alongside access to pain relieving medications, such as opioids, has provided the church the opportunity to improve the quality of life for people living with life-limiting illnesses in their community.



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