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HIV and AIDS REPORTER: focus on palliative care and HIV 19 June 2007

produced by the [IDS Health and Development Information](#) team in collaboration with [Eldis](#) and the [DFID Health Resource Centre](#)

This is our monthly email bulletin, bringing together research to inform policy debates on health in developing countries.

The HIV and AIDS Reporter aims to provide readers with a more in-depth look at a particular area of health policy. This month's theme is [palliative care and HIV](#). The bulletin also features summaries of new documents and other additions to the [HIV and AIDS Resource Guide](#).

[HIV and AIDS Reporter archive](#) - an archive is now available on the HIV and AIDS Resource Guide. See previous issues of the HIV and AIDS Reporter at www.eldis.org/go/topics/resource-guides/hiv-and-aids/hiv-and-aids-reporter

All documents listed below are available free on the web. If you are unable to access any of these materials online and would like to receive a copy of a document as an email attachment, please contact i.young@ids.ac.uk.

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Announcements

Feature: Palliative care and HIV

According to the World Health Organization (WHO), three million people die from HIV and AIDS each year. In 2003, there were an estimated 26.6 million people in sub-Saharan Africa living with HIV, 3.2 million new infections and 2.3 million AIDS-related deaths. 1.84 million of these people died in pain. Palliative care improves the quality of life for many people with HIV: relieving pain, controlling anxiety and providing spiritual wellbeing. Through assessment and management of pain, in conjunction with therapeutic strategies where appropriate, palliative care aims to improve the quality of the patient's life and to provide the best possible death. In this way, palliative care adds life to years not necessarily years to life. The traditional view of palliative care as a specialist area introduced at the end of a patient's life has altered. Integrated palliative and curative approaches offer the potential to hope for the best whilst preparing for the worst. Palliative care should begin to be provided from the point of diagnosis.

With the increasing focus on the procurement of antiretroviral drugs, it could be believed that palliative care is becoming less important in the management of HIV. However, many people die of HIV-related conditions, such as Kaposi's sarcoma, or from complications with weak immune systems due to treatment failure. Symptoms are experienced throughout the course of disease and are often poorly managed. At the same time, many people are unable to access or afford antiretrovirals. High quality end-of-life care is essential and should be provided alongside antiretroviral drugs.

Meeting all the needs of the patient and family is a huge task without well resourced care and support systems. Advanced disease may push a family from poverty to destitution. Yet, the growth of palliative care has pioneered models of care relevant to local and national contexts. In Uganda a palliative care service has been successfully implemented in three districts with outreach to other parts of the country. In the Indian state of Kerala 60 community-based palliative care initiatives support a population of over 11 million people. The Kerala programme's success has been achieved by health care professionals and local communities working together. The programme raised more than 80 per cent of its resources through small donations of less than US\$0.07.

Physical pain relief and symptom control are crucial aspects of the holistic palliative care approach and require access to effective opioid drugs. Many countries have fundamental difficulties in obtaining and distributing opioids. This is often due to a combination of factors, such as inadequate funding of health services, lack of health care delivery infrastructure and inadequate facilities for the storage and distribution of medicines. Regulations designed to prevent narcotics misuse by limiting the dosage prescribed to patients are major limiting factors in a number of countries.

To date, many donor countries have not required recipient countries to include end of life care in health plans. Donors need to focus more energy on sustained support for organisations

providing palliative care and improve their own cooperation with existing health systems. Dying with dignity should be a human right. Being poor should not mean that you die in pain and without effective care and support.

Many thanks to Tom Barker, [id21 health](#) for writing this feature and advising on content.

For more information see:

- Palliative care: a basic human right, id21 insights health 8
English: www.id21.org/insights/insights-h08/index.html
French: www.id21.org/insights/insights-h08f/index.html
Spanish: www.id21.org/insights/insights-h08s/index.html
- Palliative care, World Health Organization (WHO)
www.who.int/cancer/palliative/en
- Hospice Africa, Uganda
www.hospiceafrica.or.ug
- Neighbourhood Network in Palliative Care (NNPC), Kerala, India
www.painandpalliativecare.org/nnpc/moreinfo.htm

Recommended readings on palliative care and HIV

1. Pain relieving drugs in 12 African PEPfAR countries: mapping current providers, identifying current challenges and enabling expansion of pain control provision in the management of HIV/AIDS

Authors: R. Harding, .A. Powell, F. Kiyange

Produced by: African Palliative Care Association (APCA) (2007)

This report from the African Palliative Care Association (APCA) identifies a number of problems with the delivery of pain-relief drugs to people with HIV and AIDS receiving palliative care in Africa. The survey was conducted among palliative care organisations and the medicine regulatory bodies in 12 African countries. It found that the key problems were inadequate and unreliable supplies of drugs, restrictive legislation, poor levels of education and training about prescribing such drugs among clinical staff, and practical problems such as high costs and inadequate storage facilities. The key challenges to overcoming these problems were identified as a lack of political will, the need for education and cultural change among medical practitioners and a lack of resources.

The report recommends that where access to pain-relief drugs is currently poor networks should be established between hospices and government providers. Palliative care providers should also work with sites delivering antiretroviral therapy (ART) to ensure that palliative care patients always have access to ART. It also recommends improved training on the use of pain-relief drugs for all new and existing clinical staff, along with educational efforts to address public fears about such drugs. The report recommends that funders and policymakers address the various practical and legal obstacles that are currently restricting the delivery of pain-relief drugs.

Available online at: www.eldis.org/go/topics/resource-guides/hiv-and-aids&id=31958&type=Document

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2. ARV treatment fact sheet 18: symptom control and palliative care

Produced by: International HIV/AIDS Alliance (2005)

This fact sheet from the International HIV/AIDS Alliance (the Alliance) provides information on how to control the painful symptoms of antiretroviral treatment (ART) for people living with HIV. The fact sheet is designed for people working in community-based health settings, and also for people caring for relatives affected by HIV at home. It outlines the common side effects experienced by people receiving ART, and provides a guide to help carers communicate with the person for whom they are caring to identify the source and type of their pain.

The fact sheet emphasises the importance of taking a holistic approach which provides treatment for the physical cause of the pain, but also responds to emotional and social issues that may be causing the patient stress and contributing to their pain. It also provides information on the use of pain-relief drugs. The various types of these drugs are outlined, ranging from commonly used, less powerful ones such as paracetamol, to the more powerful opiates such as morphine. The fact sheet recommends taking a graduated approach to the use of these drugs, starting with the more simple and moving to the more powerful ones until the pain is successfully controlled. It also warns about the potential side effects of morphine and reminds readers that their country will have laws regulating the use of such drugs.

Available online at: www.eldis.org/go/topics/resource-guides/hiv-and-aids&id=31955&type=Document

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3.A community health approach to palliative care for HIV/AIDS and cancer patients in sub-Saharan Africa

Produced by: World Health Organization (WHO) (2004)

This report from the World Health Organisation (WHO) identifies community health programmes as the key element in responding to the palliative care needs of those affected by cancer, HIV and AIDS in Africa. It outlines a project conducted in Botswana, Ethiopia, Tanzania, Uganda and Zimbabwe to strengthen the delivery of palliative care programmes in those countries. The report estimates that up to one per cent of the population in African countries require palliative care annually, with the greatest need in those countries with higher HIV prevalence.

The majority of patients prefer to be cared for at home in the late stages of their illness. The limited resources available to most African health systems is a further incentive to developing a community-based approach. The report identifies a need to advocate for improved policy development on palliative care in the region, based on each person's human right to be free from pain. The most significant issue is access to pain relief drugs and the authors recommend that countries develop a national drug policy based on WHO guidelines and that pharmaceutical companies work to make drugs available at a fair price. The report also recommends a holistic approach to palliative care, which also responds to the emotional, social and financial needs of the individual and their family.

Available online at: www.eldis.org/go/topics/resource-guides/hiv-and-aids&id=31956&type=Document

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4. The forgotten people: care for people dying of AIDS in sub-Saharan Africa

Produced by: id21 health (2004)

What care do sufferers of AIDS receive in sub-Saharan Africa (SSA)? If their lives cannot be saved, are their last days made as comfortable as possible? As more funding is made available for the care of terminally-ill AIDS patients, it is important to look at the level of care currently available. King's College London, together with the US Office of National AIDS Policy, conducted a survey across 14 SSA countries to discover the end-of-life care AIDS patients are currently receiving. In the year 2002 almost 30 million adults and children were affected by the AIDS epidemic in SSA. In that year alone the virus caused 2.4 million deaths together with 3.5 million new infections. As hospitals cannot cope with the sheer numbers of patients, care must take place in the community. Nevertheless, while home-based care seems the only possible solution due to the scale of the epidemic, communities can be overwhelmed by the burden placed on them. In developing countries care of terminally-ill patients must also take into account the need for an income, for food and providing for the orphans created by the disease.

Available online at: www.id21.org/health/h5rh2g1.html

5. Mapping levels of palliative care development: a global view

Author(s): M. Wright; J. Wood; T. Lynch; D. Clark

Produced by: International Observatory on End of Life Care (2006)

This pilot study builds on earlier work from the International Observatory on End of Life Care study in Africa, looking at levels of hospice and palliative care development. This report covers 234 countries and categorises provision into four main areas:

- no known hospice-palliative care activity
- capacity building activity (but no service yet)
- countries with localised provision of hospice-palliative care
- and countries where hospice and palliative care activities are approaching integration with the wider health system

The authors find that around half of the 234 countries included in this review have established one or more hospice-palliative care services. Yet only 35 (15 per cent) countries have achieved a measure of integration with wider mainstream service providers. In 78 (33 per cent) countries, no palliative care activity can be identified. Consequently, despite increasing calls for palliative care to be recognised as a human right, there is a long way to go before palliation is within reach of the global community.

Palliative care activists point to a broad range of challenges, which include issues such as absence of policy and legislation, low public awareness of this relatively young discipline, along with palliative care being seen as a less prestigious discipline and the absence of palliative care modules/ placements in medical curriculum.

The report also highlights that it is important not to assume that countries experiencing challenges are located in a particular category or geographic region, for most of these challenges appear in one form or another throughout the world and in all groups of countries. The relationship between a country's wealth (GDP per capita) and palliative care development should therefore be approached with caution, since high and low income countries are

represented in each of the four groups of countries.

Available online at: www.eldis.org/go/topics/resource-guides/hiv-and-aids&id=24398&type=Document

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Other recommended readings

1. Internet use among Ugandan adolescents: implications for HIV intervention

Author(s): M L Ybarra

Published by: Public Library of Science Medicine (2006)

This article from PLoS Med surveys internet use among adolescents in Mbarara, Uganda. Out of 500 students questioned, 45 per cent had used the internet, out of whom 78 per cent had gone online in the previous week. The authors found that, as maternal education increased, so did the odds of adolescent internet use. Almost two in five respondents reported already having used a computer or the internet to search for health information. Over one-third had used the computer or internet to find information about HIV, and 20 per cent had looked for sexual health information.

Among internet users, searching for HIV information on a computer or online was significantly related to using the internet weekly. In contrast, going online at school was inversely related to looking for HIV information via technology. If internet access were free, 66 per cent reported that they would search for information about HIV prevention online. Both the desire to use, and the actual use of, the internet to seek sexual health and HIV information is high among secondary school students in the municipality. The authors therefore conclude that the internet may be a promising strategy to deliver low-cost HIV risk reduction interventions in resource-limited settings with expanding internet access [adapted from author]

Available online at: www.eldis.org/go/topics/resource-guides/hiv-and-aids&id=31667&type=Document

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2. Managing the exchange rate consequences of an MDG-related scale-up in HIV/AIDS financing

Authors: J. Serieux

Published by: UNDP International Poverty Centre (200)

This conference paper from UNDP's International Poverty Centre is the first in a four-part series on macroeconomic policies in low-income countries that restrict the scaling up of financial resources for an expanded response to HIV. The paper argues that, although increased aid inflows do carry potential hazards, proper economic management can counteract potential negative effects. This could include frontloading aid in order to build necessary infrastructure, institutions and human capital. In this way, it is argued, welfare and productivity benefits can be maximised.

The author concludes that the macroeconomic disturbances usually associated with increased aid absorption are necessary for the appropriate adjustment of the economy and should not be countered in the short run. Mitigation is only called for if these systems persist or escalate. Appropriate policies include maintaining domestic savings rates and ensuring the productive

use of aid. Less aid is not a long-term policy alternative to full and effective micro-absorption of funds. However, it is recommended that recipient countries build up modest reserve cover in the early stages of scale up of aid flows in order to insure against possible volatility

Available online at: www.eldis.org/go/topics/resource-guides/hiv-and-aids&id=31665&type=Document

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3. The Observatoire: how civil society engagement turned around the national response to HIV in Senegal

Published by: International HIV/AIDS Alliance (2007)

In 2002, Senegal received significant new funds to scale up its response to HIV. However, there were concerns about the lack of a national strategy and the marginalisation of civil society. This policy briefing from the International HIV/AIDS Alliance looks at lessons learnt from the the Observatoire de la Reponse au VIH/SIDA au Senegal (the Watchdog of the Response to HIV/AIDS in Senegal), set up in response to those concerns. Although the Observatoire faced many challenges during its development, the paper finds that it made a significant contribution to the strengthening of the national response to HIV in Senegal.

The authors argue that strong civil society engagement can help turn around a declining national response to HIV, especially by enhancing the scale-up of programmes and the management of new funds. However, they note that civil society groups can influence a government more effectively if they share a common vision and work together. Concrete solutions are needed, based on sound analysis. It is also important that civil society groups remain independent and critical of their own actions.

Available online at: www.eldis.org/go/topics/resource-guides/hiv-and-aids&id=31664&type=Document

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4. Behind the pandemic: uncovering the links between social inequity and HIV/AIDS

Authors: L. De Pauw

Published by: Interagency Coalition on AIDS and Development (2007)

This education kit, produced by Interagency Coalition on AIDS and Development, is designed to help Canadians better understand the complexities of HIV and its impact on sustainable development. It is based on UNAIDS' Expanded Response Model. Module one looks at the basics and background information; module two at the global pandemic simulation; module three at moving into action to stop the pandemic. Each module includes handouts, overheads, and learning tools, with key concepts highlighted in the glossary. The resource is intended for use in the school system and in non-formal settings, such as volunteer and staff trainings within relevant organisations. Group sizes of between fifteen and fifty participants are recommended.

The author aims to give participants an emotional and intellectual understanding of the scope of the global HIV pandemic and its impact on global development and humanity. The concepts of risk, vulnerability and impact are used to deepen participants' understanding of HIV and the social dynamics behind it, and to apply what they have learned to the global response. In particular, the tool examines the connection between social inequities and HIV as root cause and consequence. It recommends integrating prevention efforts with care and support for an expanded response.

Available online at: www.eldis.org/go/topics/resource-guides/hiv-and-aids&id=31663&type=Document

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See the HIV and AIDS Resource Guide for a complete list of new additions at: <http://www.eldis.org/go/topics/resource-guides/hiv-and-aids>

Announcements

Online discussion: Taking Action - the UK strategy on AIDS

From 11th June to 27th July, the UK Consortium on AIDS & International Development will be holding a series of open online discussions on the [AIDSPortal](#) to input into the consultation to update "Taking Action" - the UK strategy on AIDS. Running parallel to the main consultation process, these discussions will offer the opportunity to focus in more detail on specific issues drawn from the consultation questions. See more on the discussion at:

<http://www.eldis.org/go/topics/resource-guides/hiv-and-aids/go/topics/resource-guides/hiv-and-aids/aidsportal-discussion/>

Also see more on the DFID consultation process www.dfid.gov.uk/consultations/aids-strategy.asp

See the complete list of new additions, announcements, job adverts at: www.eldis.org/hiv aids

The HIV and AIDS Reporter is produced by the IDS Health and Development Information team in collaboration with the DFID Health Resource Centre (HRC) and Eldis.

The IDS Health and Development Information team promotes health and equity in developing countries through the provision of high quality, accessible information to policymakers and practitioners. IDS Health and Development Information currently has three flagship products:

- Health Resource Guide - <http://www.eldis.org/health/index.htm>
- Health Systems Resource Guide - <http://www.eldis.org/healthsystems/index.htm>
- HIV and AIDS Resource Guide - <http://www.eldis.org/go/topics/resource-guides/hiv-and-aids>

The HRC provides access to technical assistance and information for the Department for International Development (DFID UK), and its partners, in support of pro-poor health policies as well as health systems, service delivery and public health topics and programmes.

Eldis currently includes descriptions and links to over 4,500 organisations and over 16,000 full-text online documents covering development and environmental issues. It can be searched or browsed free over the Internet.

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