

id21 insights

communicating international development research

Palliative care

A basic human right

The global HIV pandemic has raised awareness of the need to provide care for those suffering from incurable diseases. Palliative care aims to maximise the quality of life and relieve the suffering of patients and their families.

Since its origin in the UK's hospice movement during the 1960s, palliative care has become a medical specialty and multi-professional team service for patients and their families. It now exists on every continent, but is only in its infancy in many countries and entirely absent in others.

Palliative care also focuses on providing care and support for carers and families. The breadth of support and intervention addresses the clinical needs of patients such as pain and symptoms as well as the psychosocial, social and spiritual needs of those affected during the course of the disease and into bereavement.

Palliative care was developed in response to the needs of patients with advanced cancer, but is also an essential component of care for non-malignant disease. It has a central role in the management and support of those affected by other conditions such as neurological disease, cardiac failure and dementia.

Managing total pain

Palliative care deals with all kinds of pain: physical, emotional and spiritual. 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. However, integrated palliative and curative approaches offer the potential to hope for the best whilst preparing for the worst.

Research shows that specialist palliative care improves outcomes for patients with advanced disease, improving pain and other symptoms. For palliative care to work, training for nurses and doctors is essential in addition

to a distinct and recognised discipline of palliative medicine. In this way, practitioners can apply basic palliative care skills whilst more complex cases can be referred to specialist teams. In this issue of *id21 insights* **Liz Gwyther** describes the importance of education at all levels, including strengthening postgraduate training opportunities to produce appropriately skilled staff.

It is important that palliative care is delivered by a multi-professional team including doctors, nurses, social workers, occupational and physical therapists, counsellors, psychologists as well as music and art therapists, to address all the needs of patients and their families – social, psychological, and physical.

However, a hallmark of palliative care is often seen as expertise in pain and symptom control. Good quality pain control should be a basic human right but without access to a specialist palliative care team, patients often endure very distressing pain that could be easily managed. The recommended way to control pain is described in the World

In this issue

| | |
|---|---|
| Editorial | 1 |
| Strategic donor support | 2 |
| Palliative care in Latin America | 3 |
| Training health professionals | 3 |
| Uganda's palliative care model | 4 |
| A public health approach | 5 |
| Palliative care and HIV | 5 |
| Poverty shouldn't mean poor care | 6 |

Barbara McPake – Director of the Institute for International Health and Development, Queen Margaret University College provided academic advice on this issue: BMcPake@QMUC.ac.uk

Health Organization's (WHO) pain ladder (see Figure 1). To avoid unnecessary pain, oral analgesics should be given regularly.

Palliative care in poor countries

The growth of palliative care in resource-poor countries has enabled many more people with progressive illnesses to access pain, symptom control and supportive care. However, although all national and international associations generally adhere to the WHO definition of palliative care, how that translates into practice varies.

Meeting all the needs of the patient and family is a huge task in the absence of well resourced welfare systems. Advanced disease may push a family from poverty to destitution. Yet, the growth of palliative care has, as described by **Anne Merriman** and **Suresh Kumar**, pioneered models of care relevant to regional circumstances.

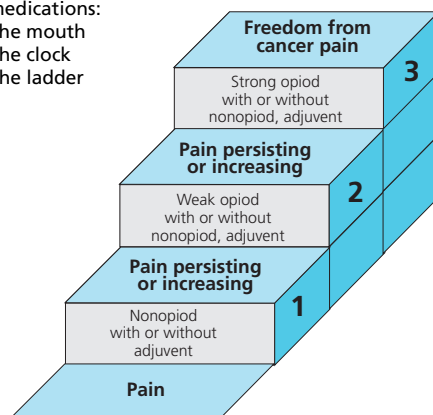
The 'hospice', as an inpatient building, has evolved into the presence of hospices in rural areas with outreach and trained community workers, some of whom even dispense drugs through roadside hospice vehicles. Palliative care has also come into existence through advocacy activities, as highlighted by **Faith Mwangi-Powell**, particularly in securing access to opioids (pain relief drugs). As **Liliana De Lima** describes, some countries have not found it easy to achieve the WHO measures. Clearly, coordination between donors, advocacy workers and trainers is essential.

Integration of palliative care

Palliative care is essential to any public health strategy. Indeed, modern palliative care protocols and the plethora of training resources and cheap provision of oral

Figure 1: WHO Pain Ladder

Pain medications:
 ● by the mouth
 ● by the clock
 ● by the ladder



Source: www.who.int/cancer/palliative/painladder/en

- ▶ morphine have made palliative care cheap and easy to carry out: it can be provided by all members of a care team from the point of diagnosis onwards.

The traditional view of palliative care as a specialist area introduced at the end of the patient's life has altered. Increasingly, the aim is to provide palliation from the point of diagnosis (Figure 2).

HIV and palliative care

The WHO has described palliative care as an essential part of quality HIV care. Palliative care improves quality of life for patients with HIV – relieving pain and controlling anxiety and spiritual wellbeing. It can be introduced and withdrawn as necessary and offered alongside antiretroviral (ARV) drugs.

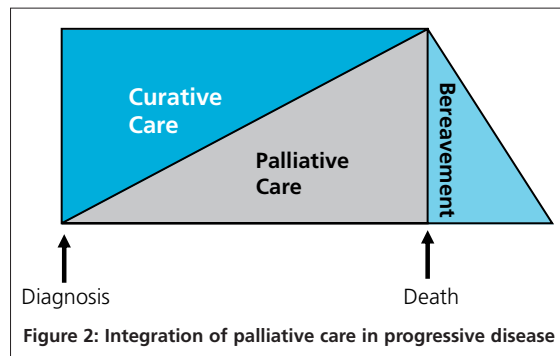
Even in countries with universal access to ARV therapy, people with HIV are still more likely to die earlier than the uninfected. Symptoms are experienced throughout the course of the disease and are historically poorly managed. As **Sarah Cox** states, palliative care can improve the quality of life of HIV patients by managing:

- infections that can occur as a result of medication to strengthen immunity
- symptoms associated with ARVs
- diseases that may occur as life expectancy increases, such as cerebrovascular disease or liver failure
- end-of-life care when a patient presents late with advanced HIV.

Achieving palliative care for all

Palliative care is an essential component of health care. The use of opioids is a cheap, effective and safe means of managing pain

and is a basic right. Although enormous gains have been made, provision is still inadequate and coverage patchy. Impressive advances have been made in developing countries, however. Pioneering services offer valuable lessons on how palliative care can be provided for all those who need it. As **Suresh Kumar** and **Anne Merriman** show from India and Uganda, no country can justify the absence of palliative care in its health system.



National associations, such as the African Palliative Care Association described by **Faith Mwangi-Powell**, and international non-governmental organisations are essential in starting services and maintaining quality. As **Olivia Dix** shows, they should be included in strategic donor activity and advocacy. Both practitioners and academics need to come together in supporting service expansion and in designing educational opportunities.

Policy recommendations drawn from this issue of *id21 insights* include:

- Palliative care should be articulated in every country's Public Health Plan.
- All health care practitioners should have basic training in palliative care.
- Palliative care should be a specialised

training option for doctors and nurses.

- Opioids for pain relief should be on the essential drug list of every country.
- Donors should ensure that palliative care is a component of health care delivery for all who need it.
- All patients and families affected by incurable disease should be continuously assessed with respect to the detection and management of pain: physical, emotional and spiritual.
- Coordinated lobbying for palliative care should make strategic use of national and regional associations.
- While palliative care may vary regionally, the WHO definition and full use of the pain ladder should be the goal of all advocacy and care activities.
- Palliative care should be integrated into existing health care services where possible, with specialist services available for complex cases.
- Palliative care should be available alongside curative care and integrated as early as possible during the course of disease, including provision alongside antiretroviral therapy ■

Richard Harding

Palliative Care and Policy, King's College School of Medicine, Weston Education Centre, Cutcombe Road, London SE5 9RJ, UK
T +44 (0) 20 7848 5589 F +44 (0) 20 7848 5517
richard.harding@kcl.ac.uk

See also

Is there Evidence that Palliative Care Teams Alter End-Of-Life Experiences of Patients and their Caregivers?, Journal of Pain and Symptom Management 25(2), pages 150-168, Irene Higginson et al., 2003
Palliative Care in Sub-Saharan Africa: an Appraisal of Reported Activities, Evidence and Opportunities, The Lancet 365, pages 1971-1977, by Richard Harding and Irene Higginson, 2005
Does Palliative Care Improve Outcomes for People with HIV/AIDS? A Systematic Review of the Evidence, Sexually Transmitted Infections 81, pages 5-14, Richard Harding et al., 2005

Strategic donor support is critical

Given that donor support for palliative care is not sustainable in the long term, donors need to take a strategic approach and work towards embedding palliative care into government health policy and practice. How can they best go about this?

Palliative care is important for everybody with a life-threatening illness. In countries experiencing an HIV/AIDS pandemic, palliative care must not be seen as a luxury at the end of life but as an essential part of the continuum of care for people with HIV/AIDS or any other life-limiting illness. Donors therefore need to be involved in promoting changes in attitude among health professionals, care providers and governments as well as in more traditional grant-giving.

Sustained support for organisations providing palliative care is essential. It is these organisations that provide the services, demonstrate the practicality and effectiveness of palliative care and advocate for more

palliative care in their own countries.

It is not enough, however, to fund islands of excellence. Funded organisations need to demonstrate that they are actively involved in the scaling up of palliative care and in its integration into health policy and the continuum of care. Donors need to ensure that organisational funding goes together with other funding support and advocacy at local, country, regional and international levels.

Donors could help fund:

- the development of education curricula for palliative care
- training courses for health professionals and carers
- local research to provide an evidence base for effective palliative care.

To have the most impact with limited resources, donors with a special interest in palliative care need to work together

At country level donors could work with local partners to advocate for:

- the provision of opioids and other medicines that relieve pain and symptoms, and potentially back changes to the national laws if necessary
- the full integration of palliative care into

HIV/AIDS treatment and care

- palliative care to be part of the training for all health professionals.

International donors could advocate for:

- recognition of the vital importance of palliative care
- more resources from a wider range of donors.

It is likely that palliative care in under-resourced health systems will, for the foreseeable future, require external donors and it is essential that donors cooperate with the existing health system. They should not set up unsustainable parallel systems of care. To have the most impact with limited resources, the small numbers of donors with a special interest in palliative care need to work together.

Palliative care focuses on the individual and their family with a holistic approach to meeting their needs. Yet it is only by thinking and acting strategically that donors can help ensure that palliative care is available to every individual that needs it ■

Olivia Dix

Palliative Care Initiative, Diana Princess of Wales Memorial Fund, County Hall, Westminster Bridge Road, London SE1 7PB, UK
palliativecare@memfund.org.uk

Palliative care in Latin America

Is the WHO strategy working?

Over 20 years ago the World Health Organization (WHO) established pain relief and palliative care as components of its Cancer Control Programme. However, palliative care is still not available to millions of patients worldwide, including in Latin America.

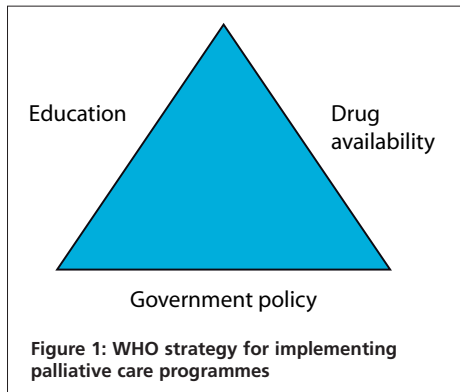
WHO advocates a three-part strategy for including palliative care in national health systems (Figure 1).

Education

Most palliative care providers in Latin America do not receive formal training but gain their knowledge through lectures and self-taught programmes after graduation. Few programmes offer palliative care education including classroom-based and bedside teaching. The basic principles of palliative care need to be learned at undergraduate level, palliative care curricula must be integrated into undergraduate nursing and pharmacy programmes, and into the design of curricula and programmes at graduate level.

Drug availability

Developed countries use most of the morphine consumed globally while only a small percentage is consumed in approximately 100 developing countries. Latin America and the Caribbean consume



less than one percent of the total. Countries such as Uruguay, Argentina, Chile and Costa Rica with mature palliative care programmes report higher consumption than countries where programmes are only beginning or non-existent.

Barriers to the availability of medication include regulations limiting the dosage prescribed per patient, the number of doses given each day, the number of days a patient can receive opioids (pain relief drugs) and how much pharmacies can stock. In addition excessive bureaucracy, inefficient distribution channels, a lack of knowledge amongst health care professionals and a shortage of pharmacists licensed to dispense the medication.

Government policy

Seven Latin American countries offer some form of palliative care through public institutions and only Argentina, Chile, Colombia, Cuba, Peru, Brazil and Paraguay have stated the need for a public health approach to the issue. If palliative care is

left out of national health care policies, countries and institutions are unable to include it in their budgets, health care workers are not paid for their services, and it is not included in insurance programmes.

What about access?

The WHO approach ignores access. However, making medication and services available is not enough – patients need to be able to reach the services. What can be done to make this happen?

- Educate health care professionals in providing palliative care.
- Establish advocacy programmes to generate more demand for services at the grass-root level.
- Pressure governments to eliminate barriers in laws and regulations.
- Allocate funds to provide palliative care – ideally a mix of international and local support.
- Include palliative care in national health care policies and establish a network of support within government ■

Liliana De Lima

International Association for Hospice and Palliative Care, 5535 Memorial Dr. Suite F – PMB 509, Houston TX 77007, USA

ldelima@iahpc.com

See also

Cancer Pain Relief with a Guide to Opioid Availability (2nd edition), World Health Organization: Geneva, 1996

Framework for a Regional Project on Cancer Palliative Care in Latin America and the Caribbean, Pan American Health Organization: Washington DC, 1997
'Legislation Analysis according to WHO and INCB Criteria on Opioid Availability: a Comparative Study of Five Countries and the State of Texas', *Health Policy* 56, pages 99-110, by Liliana De Lima et al, 2001

Training health professionals in palliative care

Lessons from South Africa

Palliative care should be an integral part of every health care professional's role; education in palliative care forms the foundation of quality care for patients and their families.

A key aspect of palliative care training involves raising the awareness of health care professionals, service providers and users. Palliative care should not just be seen as the compassionate care of dying patients but as an active discipline including assessing and treating pain and other problems. Health care workers need specific training to be able to offer quality palliative care to their patients.

In South Africa palliative care training was traditionally carried out by hospices and offered to volunteer carers. Since 1989 hospice training centres have trained nurses in palliative care.

Palliative care training falls under the Health and Welfare Sector Education and Training Authority (HWSETA). Hospice Centres for Palliative Learning have applied for HWSETA accreditation to include curricula and training courses developed by the Hospice Palliative Care Association (HPCA), an interdisciplinary

introduction to palliative care, and palliative care for children. A training programme for psychosocial and spiritual palliative care will be piloted from May 2006.

The Cape Peninsula Technical (CPUT) and Pretoria Technical Universities both offer degree courses in palliative nursing; CPUT also offers a Masters degree. The University of Cape Town offers postgraduate courses for doctors working with patients with terminal illnesses.

Health care workers need specific training to be able to offer quality palliative care to their patients

Collaboration with medical schools has led to the integration of palliative care into the undergraduate curricula of all medical schools. The South African Nursing Council is working towards including palliative nursing in the initial training of all nurses.

The challenges ahead

- Perception: palliative care must be seen by health care professionals as far more than compassionate companionship and acknowledged for its professionalism.
- Attitude: health care professionals are trained to cure. If this isn't possible doctors and nurses must be encouraged with training not to opt out of patient care.
- Human resources: qualified health care professionals are in short supply in the face

of South Africa's worst health care crisis.

A clear cut career path in palliative care is needed.

- Funding is needed to pay health care professionals working in palliative care and to develop palliative care training sites: there are currently no full-time professional palliative care trainers in medical or nursing schools.

Current training initiatives are effective and have led to better patient and family care. By educating community leaders the growing pool of palliative care professionals may soon reach the critical mass needed to initiate changes in attitude towards palliative care.

The Department of Health in South Africa has established a working group to ensure the integration of palliative care into the health care sector. An education and training team is working to identify a strategy to provide training for health care professionals in the work place.

Palliative care is growing as a professional discipline and the initiatives on many fronts in education and advocacy provide hope for health care professionals, patients and families.

Liz Gwyther

School of Public Health, University of Cape Town, Observatory 7925, South Africa
 lgwyther@cormack.uct.ac.za

See also

Hospice Palliative Care Association of South Africa
www.hospicepalliativecaresa.co.za

Uganda's palliative care model for Africa

In Uganda a palliative care service has been successfully implemented in three districts with outreach to other parts of the country. The key to its success is that service is centered on the patient and focused on the quality of care rather than quantity.

Hospice Africa Uganda's (HAU) palliative care service started in Kampala in 1993 with funds for a team of three over three months. The Government also allowed the importation of low cost powdered oral morphine. The powder continues to be imported, made into liquid form locally and distributed to all mission hospitals and Government services on request.

Mobile Hospice Mbarara and Little Hospice Hoima started to train undergraduate doctors and nurses in palliative care in 1998 with few resources. Today, service, education and training are now carried out from three sites, offering an excellent model for other countries to adapt to their own needs.

Relief of pain and symptoms is vital; counselling is difficult when a patient is in pain and their family is upset

National government support

After five years of advocacy led by HAU the Ugandan Government is now committed to palliative care. It was introduced in 2000 as an essential part of the National Health Strategic Plan. Government commitment was further demonstrated in 2004 by the expansion of the law allowing midwives to prescribe pethidine while registered nurses and clinical officers with nine months special training in palliative care can prescribe morphine.

Quality versus quantity

Building a dedicated palliative care team can be time consuming.

Focusing on quality rather than quantity of staff works best with limited resources. Team members are chosen for their dedication to the relief of suffering. Relief of pain and symptoms is vital; counselling is difficult when a patient is in pain and their family is upset.

Controlled expansion

Rapid expansion can lead to a decline in the quality of care. AIDS organisations and donors measure success by the number of patients seen. Yet each patient needs time, attention and commitment. When attaching palliative care onto support organisations, palliative care should remain a separate service to ensure that quality of care is maintained.

Planning and reporting

Clear objectives from the outset are essential. Planning should be led by service providers rather than donors who may not be clear about local priorities or who may push for broader inappropriate care. Regular assessment and reporting on service delivery should be shared with donors to ensure better targeting of funds.



Home is home is where I want to be... Martha (left), a palliative care nurse from Hospice Africa Uganda in the west of the country, cares for her patient at home. The care (daughter, right) holds written instructions for the medications. Caring for patients in their home reduces anxiety and enhances the emotional wellbeing of the patient and their family.

Photo by Karen Frame

What is palliative care?

The World Health Organisation (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.'

Source: www.who.int/hiv/topics/palliative/care/en

With dedication and medications, 95 percent of pain can be controlled 95 percent of the time

Local need

Training must meet local needs. Although outside educators can provide broad training, the practicalities need adapting to local circumstances. Hundreds of medications are available for the control of pain and symptoms in developed countries whereas only 21 are affordable and available to use in Africa. Yet with dedication and these medications, 95 percent of pain can be controlled 95 percent of the time.

Experience from Uganda suggests that governments should:

- be committed to working with the International Narcotics Control Board to make oral morphine, the main affordable analgesic in Africa, available
- extend the prescribing powers of health care providers, as has happened in Uganda, to ensure that drugs are dispensed effectively
- focus on high quality palliative care services that meet local needs ■

Anne Merriman

Hospice Africa (Uganda), PO Box 7757, Kampala, Uganda

anne@hospiceafrica.or.ug

www.hospiceafrica.or.ug

Forthcoming issues

- Food security
- Urban governance
- Tourism
- Education & language
- Substance abuse
- Budget support

Advocating a public health approach

National programmes for palliative care offer the most effective means of improving the quality of life for the greatest number of patients and families, even where resources are severely constrained. Palliative care, however, is low on the list of under-resourced governments' health care priorities. What part can advocacy play in raising its profile and promoting its value?

According to the World Health Organization, a public health approach to palliative care has three foundations:

- Governmental policy: adoption of a national palliative care strategy.
- Education: training of health care professionals and creating awareness among the general public.
- Drug availability: assuring the availability of drugs for pain control and symptom management.

These measures, combined with committed leadership to achieve an effective national programme, are vital components for the sustainable delivery of palliative care. However, while these measures are critical, in many parts of Africa they are simply not in place. Consequently, advocacy has a crucial role to play in ensuring these measures are adopted and implemented.

While there are many competing priorities for inadequate resources in Africa, a public health approach to palliative care is feasible. The African Palliative Care Association, which was established to support affordable and culturally appropriate palliative care across the continent, views sustained advocacy as a critical means by which this goal can be achieved by securing the political and financial commitment of government.

The Uganda success story

Whilst successful examples of how advocacy has been used to achieve a public health approach in palliative care are

limited, they do exist. One notable example is provided by Hospice Africa, Uganda (HAU), for many years the main advocate for palliative care in Africa. Through targeted advocacy, HAU persuaded the Ugandan Government to include palliative care as an essential part of its National Health Sector Strategic Plan 2000 to 2005.

Palliative care is part of Uganda's minimum health care package, with explicit goals and guidelines for implementation and verification. Moreover, Uganda has an essential drugs programme, and the revision of restrictive drug laws now allows trained palliative care nurses to prescribe and administer oral morphine at home.

Two factors were central to this success: first, effective networking with, and persuasive lobbying of, key government

officials and influential supporters. HAU provided specific information and advice on what policies needed to be introduced or revised, as well as assisting with the drafting of policies. Government concerns about the cost effectiveness of these policies were relieved using existing examples of effective and affordable service provision by HAU. Second, HAU conducted formal and informal educational sessions with senior Ugandan doctors to address the common myths of morphine use, such as addiction and intolerance.

Hospice Africa in Uganda provided specific information and advice on what policies needed to be introduced or revised

Drawn from the Ugandan experience, recommendations for advocacy include the need to:

- target advocacy work at key governmental officials, ideally those who can act as product champions
- ensure the advocacy agenda is specific and explicit
- address any cost effectiveness implications
- use existing practical examples to illustrate and strengthen the case
- address the concerns of other key stakeholders (such as senior doctors) who can impede the implementation of policy changes ■

Faith Mwangi-Powell

African Palliative Care Association, P.O. Box 72518, Kampala, Uganda
mpowell@apca.co.ug
www.apca.co.ug

See also

Summary Booklet of Best Practices, UNAIDS Issue 2, UNAIDS: Geneva, 2000
Advocacy Manual, The Diana, Princess of Wales Memorial Fund: London, by Faith Mwangi-Powell, 2002

WHO definition of HIV palliative care

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

Source: www.who.int/hiv/topics/palliative/care/en

Palliative care and HIV management

Will palliative care become obsolete in the management of HIV? Evidence from the United Kingdom suggests not.

Even with widespread availability of antiretroviral drugs, a small number of infected people will still die of HIV-related conditions such as Non-Hodgkin's Lymphoma or from complications with weak immune systems due to treatment failure. High quality end-of-life care will always be required for these patients.

Those who receive and respond to antiretroviral (ARV) therapy have a high incidence of physical symptoms. Symptoms arise from HIV viral damage and associated diseases but also as side effects of ARVs. Symptoms must be addressed so that affected individuals can enjoy their improved life expectancy. If drug-related symptoms are not relieved then adherence to ARV therapy may be poor. Painful damage to the peripheral

nervous system is common and debilitating. Nausea and diarrhoea frequently occur during ARV therapy and can result in treatment being stopped.

Individuals may respond well to ARV therapy but feel their quality of life is poor. Access to palliative care allows for holistic assessment and the possibility for some issues to be addressed. Working closely with the treatment team is essential to ensure complications are accurately diagnosed and that prescribed drugs do not interact badly with one another or harm the patient.

HIV services that focus on immunological control will inevitably not prioritise symptom control and holistic care. Providing palliative care alongside active treatment continues to be a priority for individuals with HIV, even where there is good access to effective antiretroviral therapy.

Sarah Cox

Chelsea and Westminster Hospital, 369 Fulham Road, London SW18 5AR, UK
T +44 (0) 20 82375054 F +44 (0) 20 87468863
sarah.cox@chelwest.nhs.uk

Subscribe to id21 insights

To subscribe to id21 insights health for free please send your full postal address to:

**id21
Institute of Development Studies
University of Sussex
Brighton BN1 9RE, UK**

email id21@ids.ac.uk

You may also wish to subscribe to id21 insights education and id21 insights

id21 email newsletters

Free email updates on the latest research findings from id21
www.id21.org/id21-email/email.html

Poverty shouldn't mean poor quality palliative care

The increasing commercialisation of health care, decreasing public spending on health and the introduction of expensive high technology interventions are making basic health care less accessible to poor people living with incurable and chronic diseases. An experiment in Kerala, India has been trying to address this problem through interventions by community volunteers.

Many people living with incurable and chronic diseases experience psychological and social problems. Because of this, eight palliative care initiatives were set-up in the Malappuram district of Kerala in 2000 to look at the existing institution-based model of care. The Neighbourhood Network in Palliative Care (NNPC) works to empower local people to plan and deliver services in their communities with the help of health care professionals.

Local people were brought together by four non-governmental organisations in Kerala to discuss the problems faced by patients with chronic or incurable conditions. Those willing to spend a minimum of two hours per week helping patients were given structured training, registered as community volunteers in palliative care and encouraged to plan locally relevant services. The basic 15 hours of training focused on the organisation of services, psychosocial support and basics of disease process.

Groups of trained volunteers are tied to palliative care professionals and health facilities in their communities. Action plans define individuals' and institutions' roles and responsibilities. This process has resulted in:

- a focus on home care with outpatient clinics and inpatient units in support
- attention to social and emotional wellbeing as much as physical health
- using local resources
- the building up of skills and confidence in the local community
- a network with more than 4,000 volunteers, 36 doctors and 60 nurses looking after 5,000 patients at any point in time. All the doctors and nurses in the network are employed by the community initiatives.

Within less than five years, the NNPC initiatives have:

- established more than 60 community based palliative care initiatives in northern and mid-Kerala covering a population of more than 11 million



id21 insights health is published twice a year and is online at www.id21.org/insights. The id21 site also offers free access to hundreds of short easy-to-read highlights on current international development topics such as health, natural resources, education and social policy issues. To subscribe to our email newsletter email us at id21@ids.ac.uk with the words 'subscribe id21health news'. For further information or to subscribe to id21 insights health see www.id21.org or contact us at the address below.

id21
Institute of Development
Studies
University of Sussex
Brighton BN1 9RE, UK
T +44 (0)1273 678787
F +44 (0)1273 877335
Email id21@ids.ac.uk



Institute of
Development Studies

id21 is hosted by IDS and supported by the UK Department for International Development. Views expressed in id21 insights do not necessarily reflect those of DFID, IDS or any other contributing institution. Unless rights are reserved in specific cases any article may be copied or quoted without restriction, providing the source (id21 insights) and author are properly acknowledged and informed.

© Institute of Development Studies 2006;
ISSN 1478-6982 IDS is a Charitable Company
no. 877338 limited by guarantee and registered
in England

Editor: **Tom Barker**
Senior Editor: **Louise Daniel**
Editorial and
technical support: **id21 team**
Design: **Robert Wheeler**
Printed by: **Colorscope Printers Ltd**

Printed on paper produced from
sustainable forests

Keywords: palliative care, human right, pain relief, symptom control, HIV, end of life, death, dying, incurable disease, training and education, donor support, advocacy, poverty

Useful web links

African Palliative Care Association
www.apca.co.ug

Elton John AIDS Foundation
www.ejaf.org

Foundation for Hospices in Sub-Saharan Africa
www.fhssa.org

Help the Hospices
www.helpthehospices.org.uk

Hospice Information Service
www.hospiceinformation.info

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

International Observatory on End of Life Care, Lancaster University, UK
www.eolc-observatory.net

Open Society Institute: Public Health Programme, Palliative Care Initiative
www.soros.org/initiatives/health/focus/ipci

Palliative Care Initiative, The Diana, Princess of Wales Memorial Fund
www.theworkcontinues.org/causes/palliative.asp

Palliative care. The solid facts
www.euro.who.int/document/E82931.pdf

Project on Death in America
www.soros.org/initiatives/pdia

World Health Organization: national cancer control programmes – policies and managerial guidelines
www.who.int/cancer/publications/en/#guidelines

- an estimated coverage of more than 70 percent in palliative care and long-term care in the region compared to a national average of around 1 percent
- raised more than 80 percent of the resources for the projects locally through small donations of less than 10 pence.

Within less than five years, 80 percent of the projects' resources were raised locally through small donations of less than 10 pence

The NNPC is probably the first large-scale palliative and long-term care programme of its kind in developing countries. Its success has been achieved by health care professionals and local communities working together and has shown that sustainable good quality palliative and long-term care is possible with few resources.

Lessons from the NNPC include:

- People living with chronic debilitating illness need regular care for the rest of their lives. Home care and care in the community are the best ways of providing continuous support.
- Trained volunteers can play a major role in patient care if supported by health care professionals. The doctors and nurses in the group look after the medical and nursing care and link up with health institutions.
- Obtaining resources is not a major problem when a community owns the programme ■

Suresh Kumar
Institute for Palliative Medicine, Medical College, Calicut 673008, Kerala, India
skumar90@hotmail.com

See also
Neighbourhood Network in Palliative Care (NNPC)
www.painandpalliativecare.org/nnpc/moreinfo.htm
Indian Journal of Palliative Care, Volume 11, Issue 1, 2005
www.jpalliativecare.com