



DFID MSP BEST PRACTICES: WITS PALLIATIVE CARE – BUILDING THE FOUNDATIONS FOR A NATIONAL PALLIATIVE CARE SERVICE

The MSP has identified Wits Palliative Care as a ‘best practice’ case study. The following provides a brief background, describes the project’s aims, objectives and approach, and highlights achievements, challenges and lessons learned.

Project background

South Africa has an estimated 5.5 million people living with HIV and AIDS is the leading cause of death. Despite progress in increasing availability of antiretroviral therapy, the number of people experiencing advanced HIV illness and dying from AIDS remains high.

People with HIV suffer pain and other symptoms early on in the illness as well as at the end of life. The World Health Organisation estimates that at least half of all people with HIV experience severe pain in the course of their disease (WHO 2002). Palliative care, which provides relief from pain and symptoms and prolongs and improves the quality of life, is an essential part of treatment, care and support for people with HIV but is one of the most neglected aspects of HIV care (UNAIDS, 2004).

Palliative care is based on a model developed by the hospice movement to meet the needs of cancer patients. It aims to provide support, comfort and relief of symptoms, to allow people to die with dignity and without pain. WHO defines palliative care as an approach that:

- Provides effective relief from pain and other symptoms.
- Affirms life and regards death as a normal process.
- Does not hasten or postpone death.
- Offers support to help people live as actively as possible right up to their death.
- Integrates psychological and spiritual care.
- Provides support to family carers and helps families to cope with a patient’s illness and with bereavement.
- Provides support to professional carers.

In South Africa, 95% of people with HIV do not have access to pain and symptom relief. Although national health policy recognises the importance of palliative care, there is no implementation plan or budget and there is an urgent need to develop a national framework for the delivery of palliative care in the public sector and to strengthen the capacity of the public sector to provide palliative care services.

The Wits Palliative Care Programme developed from the 3-year N’doro project, funded by Irish Aid from 2003 to 2006. The N’doro project focused initially on piloting a model of public sector provision of palliative care, broadening over time to address wider professional, social and organisational issues that affect public sector capacity and access to palliative care. The pilot showed that the service ‘model’ was feasible, effective, acceptable and affordable, and the model was adopted by Gauteng Department of Health. Subsequent funding from DFID, through the MSP, and other donors, has enabled the Wits Centre for Palliative Care to become a ‘centre of excellence’.

Project design

Aims and objectives

The overall aim of the Wits Palliative Care Programme is to contribute to universal and equitable access to palliative care in South Africa. The specific objectives of MSP-funded activities are consistent with the mandate of the Centre, which is to:

- Serve as a national and regional resource for teaching and training in palliative care in the public sector.
- Conduct health policy and systems research relating to provision of palliative care in the public sector.
- Deliver palliative care services in urban areas and provide technical assistance for rural service delivery.
- Contribute to palliative care policies and lead in advocacy campaigns to support access to palliative care in the public sector
- Develop evidence-based best practice and benchmark standards of palliative care.
- Advocate for policies that reflect best practice and for access to palliative care in the public sector.

Guiding principles

The principles upon which the Centre was founded emphasise:

- Integrating palliative care within the continuum of care and enhancing quality of care for people with HIV.
- Responding to needs, based on consultation with a wide range of stakeholders including patients and other service users, caregivers, communities, public sector, NGO and hospice service providers, government officials and universities.
- Assessing resources available within the Department of Health to ensure that the approach developed is cost-effective, appropriate and acceptable in the South African context.
- Identifying existing networks and service providers to avoid duplication.

Approach and activities

Wits Palliative Care takes an integrated approach involving four complementary areas of activity: education and training; research; service delivery; and advocacy.

Education and training

- The Centre highlights the importance of teaching a holistic approach to palliative care to all health practitioners and focuses on education and training for service delivery. Education and training are guided by the WHO model for an effective national palliative care programme and apply principles drawn from adult, community and participation education.
- The Centre educates a wide range of professionals and lay people who address the clinical, spiritual and psychosocial aspects of palliative care for patients and their families. Pre-service and in-service training in palliative care is provided for health practitioners. Palliative care is now a compulsory taught and assessed course within the Wits undergraduate medical curriculum. The Centre aims to include palliative care in the

nursing curriculum at Wits and the Chris Hani Nursing College. The Centre also offers short courses for primary health care nurses, hospital nurses and general practitioners as well as postgraduate courses and tailored training. One example of the latter is training for prison nurses, doctors, parole board members and peer carers at the request of the Department for Correctional Services.

- The Centre has produced training materials including a manual for medical students for both undergraduate and postgraduate levels, curricula for nurses and pastors, and multi-media material for Mindset (a National Department of Health and private sector collaboration using satellite television and computers to enhance training of health care workers). It has also used and contributed to multi-media and interactive learning including the e-learning project, which includes a 3-hour electronic course on a CD-Rom introducing palliative care for adults with HIV and cancer.

Research

- Wits Palliative Care is conducting basic sciences, clinical, health systems and policy research (see below), intended to support the development and implementation of a national framework for public sector provision of palliative care. The emphasis is on research for action and wide dissemination of research findings, through peer-reviewed journals, presentations at local and international conferences, and the media.

Research themes and topics include:

- Palliative care in the public sector in a high prevalence setting.
- Integrating palliative care into the formal health system and service development models for the public sector.
- Effective and affordable palliative drug therapies for the public sector.
- Effective pain management for HIV and AIDS and in community palliative care services.
- Gender, volunteerism and networking.
- Pastoral training in palliative care.
- TB in palliative care.
- Health economics of palliative care.
- Measuring outcomes and evaluation to improve services.

- Wits Palliative Care takes a multi-disciplinary approach that includes general medicine, oncology, nursing, psychiatry, neurology, psychology, rehabilitation, ethics and medical sociology. Research both cuts across the University Faculty of Health Sciences and involves collaboration with other faculties such as anthropology. The Centre is also conducting collaborative research with local, national and international partners including Wits Hospice, Chris Hani Baragwanath Hospital, Soweto Caregiver's Network, Gauteng Department of Health and health districts in Limpopo and Northern Cape, Hospice and Palliative Care Association of South Africa, African Palliative Care Association, Southern African Migration Project, University of Cape Town, Kings College London and University of Manchester in the UK.

“.... Hospice has been called a bit of heaven for the few ... Our approach is different; our approach is a bit of pain relief and dignity for the many...it is a fundamental right to die pain free... with some dignity”



Wits Palliative Care staff provide care and support at the Palliative Care Centre

Service delivery

- Wits Palliative Care has continued to use the nurse-led N'doro model of service delivery, delivering services through the Wits University Hospitals and home visits in Soweto and Diepsloot. This approach ensures the most rational use of public sector resources, reducing the need for repeat hospital visits by patients and use of specialists to provide general and intermediate palliative care. The approach (see below) has been developed into a framework of principles that now informs public sector palliative care provision in South Africa.

The Wits Palliative Care approach is as follows:

- General palliative care – provided by all health care providers able to institute basic pain and symptom relief. General palliative care is protocol driven and mainly provided by primary health care workers.
 - Intermediate palliative care – provided by health care providers who have a more detailed knowledge and understanding of palliative care and for patients with more frequent need for palliative care.
 - Specialist palliative care – provided by a specialist multidisciplinary team working closely with other specialists and generalists.
- The Centre has around 45 staff working in the hospital and in the community and a training and education team. Chris Hani Baragwanath Hospital health and outreach workers currently carry out approximately 5,400 consultations with patients each year and the Johannesburg team conducts approximately 1,500 consultations each year.

Despite an increased number of referrals, a well-established and highly trained team, together with an improved management system, has increased the rate of patient contacts. The team also conducts bereavement visits and runs an outpatient clinic for patients whose health has improved as a result of starting on antiretroviral therapy.

- The Centre works closely with the Soweto Caregivers Network, which has 72 NGO members, to improve the quality of services these NGOs deliver.

Advocacy

- The Centre works with a range of partners to advocate on issues relating to palliative care. This is important because palliative care is still a relatively new multidisciplinary science and myths and misconceptions about palliative care, euthanasia and safety of morphine remain. Advocacy activities focus on encouraging government to fulfil its mandate to provide palliative care in the public sector, and the Centre is working with the Palliative Care Society of South Africa and the Hospice and Palliative Care Society of South Africa to lobby for a parliamentary hearing on palliative care. Wits Palliative Care also sits on government advisory committees for palliative care and is also part of the expert working group on disability grants.

Achievements

In less than three years, Wits Palliative Care has:

- Developed and tested a framework of principles for delivery of palliative care in the public sector, which can be adapted for use in different settings. Mpumalanga Province, for example, is adapting the framework to deliver palliative care services in rural areas, with technical support from Wits. Services in rural areas. The National Department of Health has also requested inputs from Wits Palliative Care to the review of national guidelines for palliative care.
- Secured commitment to palliative care service delivery from Gauteng Department of Health, which has adopted the framework and created 18 permanent service delivery posts as well as providing facilities, drugs and management support.
- Improved delivery of palliative care in the public sector as well as contributing to more equitable access to palliative care services through technical support for application of the framework in other provinces.
- Achieved recognition of the importance of palliative care from the University, which now provides support for palliative care teaching and research in the Faculty of Health Sciences and includes palliative care in medical education. The Faculty has the only clinically attached and assessed palliative care medical programme in Southern Africa and more than 560 doctors are practising having achieved this standard.
- Improved public sector delivery of palliative care services and helped to increase access to these services in other parts of South Africa such as Mpumalanga.
- Demonstrated a positive impact of the nurse-led approach on pain and symptoms, based on clinical audit using a scientifically and locally validated tool.

Challenges

Policy, regulatory and implementation challenges include:

- The lack of a detailed national policy framework and budget for implementation of palliative care.
- The failure to enact Section 56(A) of the Nursing Bill in order to allow palliative care trained nurses to deliver palliative drugs.
- The need to clarify the scope of disability grants.
- The lack of clear guidelines for prognosticating diseases and death.
- The need to train district nurses and clinical associates in palliative care.
- The need to provide accredited undergraduate education in palliative care in all medical, nursing and allied health professional training institutions.
- The lack of transport for severely ill patients.



Wits Palliative Care staff

Lessons learned

Lessons learned from implementation of the Wits Palliative Care Programme include:

- People need to know that palliative care services are available. The centre has increased referrals through participation in local radio talk shows and a dedicated helpline. By making palliative care an acceptable service, the project is also helping to reduce the stigma and discrimination associated with HIV and AIDS.
- Effecting change in an environment as complex as a health system requires both a multifaceted approach and a focused intervention with clear outcomes.
- Developing a scientifically and locally validated way of measuring impact has been crucial in demonstrating the viability and impact of the Wits approach.
- Identifying and involving all key stakeholders from the start has been crucial to success. One example of this is involvement of the pharmacy department, which has helped to ensure access to morphine.
- Having a clear organisational focus, including a vision and strategic objectives, and realigning organisational structures, has supported rapid and effective implementation of the Wits Palliative Care Programme.
- Creating a supportive and equitable working environment for staff is essential for effective implementation of palliative care.

- Retaining staff in the public, NGO and academic sectors is a challenge as private sector salaries are more competitive. This is particularly an issue for young black graduates, who often have student debts or are supporting an extended family.
- The effectiveness and impact of training is enhanced by tailoring training to the working context of nurses, doctors and allied professionals, and by the inclusion and assessment of practical skills.
- Ongoing training, peer review and recognition of good performance, together with careful and sensitive introduction of clinical audit and performance feedback, contribute to better results.
- Institutionalising and sustaining good practice in training and service delivery requires attention to be given to issues such as governance and institutional culture as well as to clinical practice.
- Informal carers for the sick and dying are mostly elderly women or young girls. Providing palliative care services at home as well as respite care reduces the burden on elderly women and allows girls to go to school. Increasing government responsibility for provision of palliative care services also helps to mitigate poverty, since it is often the poorest who provide care for the dying.
- Sustainability – Public sector provision of services and funding for staff is also critical to sustainability.