



# ANNUAL REPORT

MAY 2005-APRIL 2006

a model of palliative care in south africa

# Wits Palliative Care

## Our vision

Care, comfort and healing for all. We light the way for a pain free journey with dignity.

## Our mission

Wits Palliative Care does collaborative research, training and service delivery to develop equitable and appropriate palliative care services. It promotes best practice for palliative care throughout the public health sector.

## Our supporting values

- Provide excellent care and strive for continuous improvement
- Strive to maintain ethical and professional standards
- Respect, value and appreciate patients and colleagues
- Respond to the needs of the people
- Challenge ourselves to learn from our mistakes
- Build people through sharing knowledge and experience
- Find time to celebrate life

## Our slogan

Adding life to days, not just days to life.



Sandpit: exercise used to develop mission statement 2005



# Director's statement

Welcome to this annual report of Wits Palliative Care, a research syndicate of Wits Health Consortium and now an academic entity in the Department of Internal Medicine of the University of the Witwatersrand.

## The need for palliative care

Palliative care and hospice services have grown rapidly around the world, and in countries with a high HIV prevalence these services are deemed essential. But the UNAIDS 2004 global report found that palliative care is one of the most neglected aspects of HIV care, and also that while morphine is an essential medicine for HIV/AIDS care, access to it is limited.

Having identified the critical need for palliative care in South Africa, the N'doro Project, based at the Chris Hani Baragwanath Hospital in Soweto, started operating in 2003. Since then the project – now called Wits Palliative Care - has been at the forefront of developing and piloting a model of palliative care, providing community outreach palliative care to HIV/AIDS and cancer patients in the Soweto area, and providing training and conducting original research.

## Achievements despite many obstacles

The small but growing palliative care community faces many obstacles to our work of reducing the pain and suffering of people dying of AIDS, cancers and other fatal conditions

- A widespread lack of understanding of what palliative care is about
- A demand for cheap and quick-fix solutions or to implement solutions from the northern hemisphere
- Confusion between palliative care and NGO home-based care services
- Competition for resources, both government and donor
- Not being 'sexy' enough for donor funds and not being established in the state sector.

In addition, the palliative care community dares to face the most painful, traumatic and dehumanising side of an AIDS epidemic that defies contemplation, something that many feel more comfortable ignoring.

We feel justifiably proud of our achievements, and we are grateful to all the people who have chosen to work in this most demanding of settings. Nurses, doctors, social workers, pastors, people living openly with HIV/AIDS, counsellors and community leaders, anthropologists and physiologists, dentists and dieticians, have worked together to generate a dynamic and stimulating environment.



## A year of change and self-empowerment

2006 has seen intense work with successful outcomes for Wits Palliative Care, including in developing the capacity of all our staff. Clinical, research and communication skills have been absorbed with great enthusiasm, as together we have forged and lived our own organisational ethos, embracing change and self empowerment as defining features of who we are and what we do. This has been an important strength of this group, together with our great diversity of experience and skills, and our respect for one another.

## Thanks

I would like to thank all the following individuals, institutions and organisations for their help and support

- Our colleagues in the health service, and our local and international palliative care friends
- All the faculties of the University of the Witwatersrand that we have collaborated with, and the people in the departments of Internal Medicine and Family Medicine and the Wits Centre for Health Science Education who dared stick their necks out for palliative care
- The Hospice and Palliative Care Association of South Africa
- The management team (past and present) of the Chris Hani Baragwanath Hospital
- The National Department of Health and the Provincial and local health departments
- The South African Council of Churches
- Irish Aid
- The Dame Cicely Saunders Foundation

Finally, I would like to thank our patients and their families - they are our reason for existing - and our own families and friends, many of whom have contributed to improving our service through research and comments, and some of whom have become our best advocates. Their courage, love and strength in the face of unimaginable suffering has inspired and indeed lit the way for us to help each other on a pain-free journey with dignity.

The South African government acknowledges palliative care as a basic human right and we hope to make a significant contribution to realising that for all citizens.

**There is no second chance to improve the care of individuals who are dying.**



**Dr Natalya Dinat MD(Mos) FCOG(SA) MPhil Pall Med(UCT)**

Director of Wits Palliative Care  
University of the Witwatersrand

**“Compassion without wisdom is inefficient” – Euripides 485-406 BC**

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# Who we are

## Our story

In less than four years, Wits Palliative Care has grown from a small, one-person project into a recognised academic entity with 14 full-time staff.

### **2003: Establishing ourselves**

The N'doro Project, or a Model for Palliative Care in South Africa, started in January 2003 with a three-year grant from Irish Aid. Much of that year was spent doing formative work, getting buy-in and setting up our services. We established good working relationships with our colleagues in the clinics and at the Chris Hani Baragwanath Hospital where we are based. Support for our work was evident.

## 2004: Learning and change

We consolidated our good beginnings with successful training and service delivery in 2004, thus achieving the objectives of the pilot. Having established ourselves in Soweto and having gained the trust of patients and the caregivers, we strengthened relationships with the University of the Witwatersrand and the Hospice and Palliative Care Association of South Africa. 2004 was an exciting year, characterised by learning, critical review and evolutionary change for our organisation.

### Our home

Wits Palliative Care's offices are in the hectic outpatient department of the Chris Hani Baragwanath Hospital, and, since April 2006, we have an additional office in the hospital's learning centre. The Chris Hani Baragwanath Hospital is famous for being the largest in the southern hemisphere and serves mainly the 1.2 million people who live in Soweto. It is also a tertiary referral centre for the province, Gauteng, and receives referrals from neighbouring provinces and even from other countries. The hospital is part of the teaching academic complex of hospitals and clinics of the University of the Witwatersrand.

## 2005: Becoming independent

In January 2005 we became an independent research syndicate in the Wits Health Consortium. An independent review of Wits Palliative Care in August 2005 concluded that we had been successful in achieving our objective to provide access to quality palliative care within a human rights framework, noting that

- We had been highly successful in developing and delivering quality community palliative care services for the public health sector.
- We had trained a considerable number of health care workers, pastors and social workers.

Wits Palliative Care will support palliative care in the public sector in South Africa by providing academic input based on our ongoing hands-on clinical work.

- As a result of networking and lobbying, we had put palliative care firmly on the map as a vital component in providing support to HIV/AIDS and cancer patients, and their caregivers.

## 2006: Entering the mainstream

Our strategic planning meeting in July 2005, which included the active participation of 42 of our stakeholders, including Wits, government, NGOs, and patients themselves, agreed that the way forward was for Wits Palliative Care to become an academic entity, providing research and training in palliative care as a recognised academic discipline. They also agreed that the focus should be on the development of palliative care services for the public health sector.

The South African government's 2006-09 strategic plan prioritises the establishment of palliative care centres in each province, with full coverage by 2009. The Patients' Right Charter states that 'palliative care is a right for all'. There is no other academic entity in South Africa that is dedicated to training and research in palliative care and thus to improving palliative care services.

- **Training:** Wits Palliative Care will provide undergraduate, masters and postgraduate teaching in palliative care for students and health care professionals from around the world.
- **Research:** We will disseminate its research findings to practitioners, policy makers, users and the research community, and will establish a service and information centre for patients, carers, professionals, educators, researchers and the public.

“The organisation is like a beehive, it is industrious, creative, busy and active, where the workers feel ownership and responsibility for their individual activities”

– A quote from a team member during an independent review, August 2005



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Since palliative care cuts across most of the traditional disciplines of medicine, finding an academic home is not straightforward. International experience and wisdom suggest that the key issue is that one is welcome and that one's work is facilitated, and so internationally palliative medicine is to be found in different disciplines. Since April 2006, Wits Palliative Care has been based in the University of the Witwatersrand's Department of Internal Medicine, the largest department in its School of Clinical Sciences. This department is a leader in HIV/AIDS medicine, pulmonology and oncology.

## Sustainability

While the university supports our initiative, it has not been able to fund us. The faculty has faced significant budgetary cuts; government subsidies have been significantly reduced over the past 15 years, and the scope for self

sustaining support is limited. The shift towards short-term project-based funding in the tertiary sector has created a mismatch between what donors want to fund and what universities need.

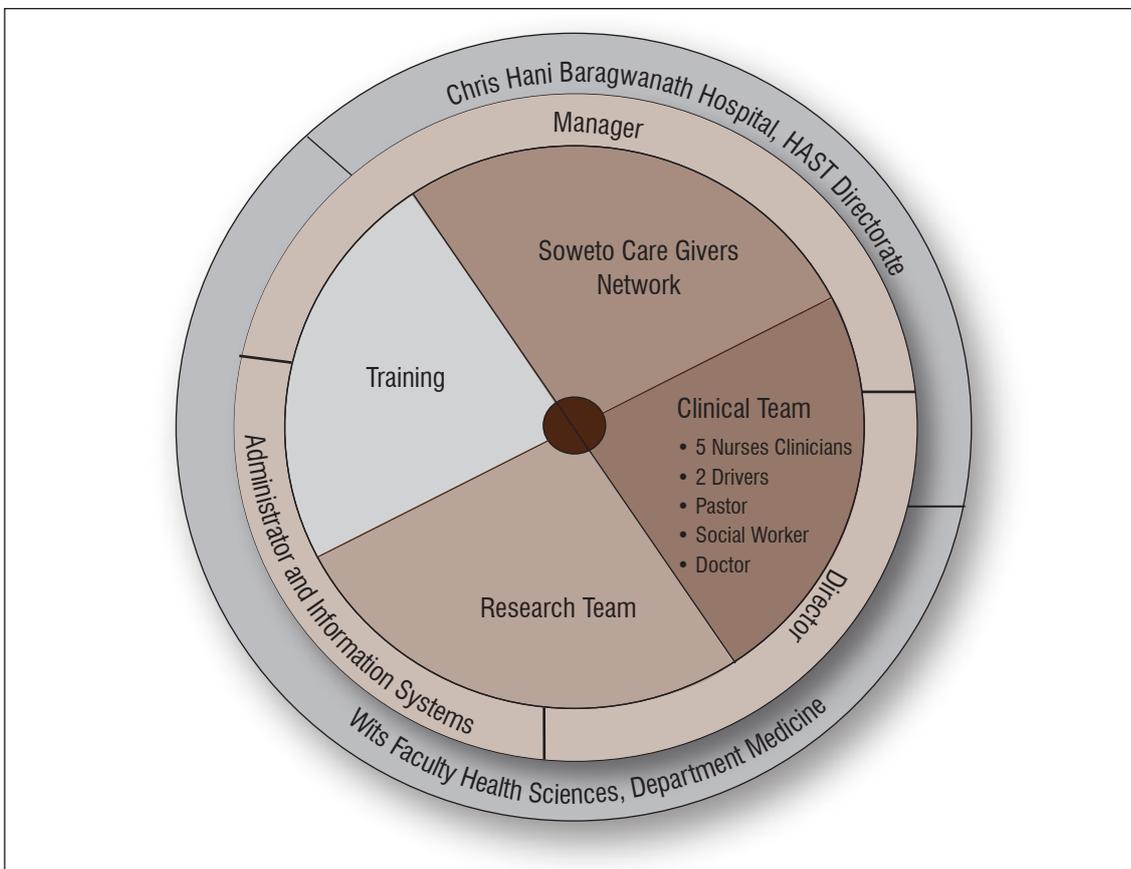
A parallel option, pursued from the outset, is that our service and training activities be supported by the provincial Department of Health in partnership with the university. This has received support from the MEC and at the senior management meeting of the department, and is also supported by Chris Hani Baragwanath Hospital, which has found that our service is cost effective in that it protects hospital beds. Posts have been promised for our whole clinical team, and negotiations around details continue. When the arrangements have been finalised, we will then be able to focus our energies on fund raising for research, more training in non-academic settings and on creating a Centre for the Study of Palliative Care.

The funding partnership between government and the university is a landmark for Wits Palliative Care and sustainability is on the horizon.

# Our organisation

The core of our organisation is the clinical team. Coordinators from the Soweto Care Givers Network, the training coordinator and the researchers (both in-house and from collaborating organisations) work closely with the clinical team. All are supported by a management and administrative team. Financial and HR support is provided by the Wits Health Consortium.

The organogram below shows the organisational structure and its relationship with Wits University and Government.



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The clinical team consists of five nurses, one social worker, one pastor, two drivers and a doctor who provide a multidisciplinary, nurse-led service. A multidisciplinary team is essential for providing a holistic service and we have worked hard to move away from traditional hierarchical structures to 'flat' structures, where each is clear about their role and responsibilities.



## A typical day for the nurses on the clinical team

“Each morning, one of the nurses meets the hospital team to receive new patient referrals and give clinical reports on patients in the community. Others prepare the files and the routes, and receive new referrals from other sources.

By about 9am we are out seeing patients in the community. We examine them and recommend treatment. This is reviewed and written up by the doctor.

We talk to the family and teach them how to look after their loved one. We counsel and listen. We refer people to other services and resources: one patient may need a priest, another a placement in the hospice, and another a referral to a social worker for a child. If a patient has died we visit the family to provide bereavement care and assess the conditions for serious social problems. We are back by 4pm. We write up our notes or do this the next morning.

On Thursdays we teach the medical students and take them with us on our patient visits. Sometimes we train other nurses and people from other disciplines. On Fridays we have a staff meeting, a clinical meeting and a debriefing, and do staff development activities.”

## Our drivers are not just drivers

Our team’s drivers have been doing palliative work in addition to driving, including counselling patients and families, and teaching male patients to use a urinary catheter. In addition, our drivers are responsible for providing emotional support to their colleagues, the nurses, when they experience distress. Our drivers also attend team-building meetings and our weekly clinical meetings, where their input is valued.

The whole organisation has been involved in running the pilot model and so has been involved in its evolution.

We have held four team-building sessions, which focused on a year’s programme. These were essential not only for personal growth and preventing burn out, but also for organisational growth and more effective outcomes. This has been particularly important in meeting the demands of the new health care principles of “batho pele”- people first



Pro Charmane

## Not just a driver – but a palliative driver

My name's Pro Charmane and I have worked for Wits Palliative Care since 2003. Prior to joining the unit I worked in the taxi industry. When I was recruited to the unit as a palliative care driver I had no idea what palliative care was. I thought that I would just be driving the palliative nurses from patient to patient; I never anticipated that I would meet or get involved with patients myself.

3 years on I have learned a great deal. I now understand what palliative care is. I have progressed from not just being a driver, but a palliative care driver. I have learned a number of lessons on my journey from driver to palliative driver as follows:

- Being a non professional working with a professional team of nurses with many years experience is not easy. I have had to learn to be strong and to earn the respect of my colleagues.
- The African cultural system is very patriarchal and there are issues which a man would never discuss with women. This includes sexual issues, money etc. Over the time I have worked with the unit I have been required to speak to male patients about these and other issues. This has made a great deal of difference to the service that the palliative team are able to provide.
- As well as listening and giving practical help I have also helped one male patient with changing his colostomy bag. This was under the guidance of one of the nurses who knew from the way that he was behaving that he was not happy for her to do this. He was much happier to have this done by another man and I was happy to help him.
- The environment in which the palliative care nurses work is stressful and as well as helping

male patients I also have to listen to and support the nurses when they need to talk about particularly stressful cases.

- There are many people in Soweto who are living in poverty and occasionally the team come across people who are in a very difficult situation. We visited a mother who was sleeping and in pain. There were 3 children. While the nurses were busy with the mother I could see that the children were hungry. I felt I had to do something, so I took them to the shop to buy something to eat with my own money.

Since working in the unit I have been able to learn new computer skills and about palliative care. I have also been involved in training future doctors at Wits University. I have learnt a lot since I have been a palliative driver, but know that I could do more if I undertook formal training in communication and counselling skills.

I keep a daily logbook of the kilometres that I travel every day. I also make sure the petrol, oil and water are checked every day before we go out to visit patients. I make sure that the car is regularly serviced and that it is in good working condition e.g. that the tyre pressure, windscreen wipers, indicators etc. all work. I report any problems straight away to ensure the smooth running of the palliative care service. As a palliative driver you need to be both strong and mature. I know I have these qualities and that I add value to the palliative care team.

# Our reason for being

“To cure sometimes, to relieve often, and to comfort always” a 16<sup>th</sup> century aphorism summarised the purpose of medicine. But in the pursuit of scientific cures, relief and comfort have been neglected well into the last century.

## What is palliative care?

Palliative care approaches every person anew as a unique physical, emotional, social and spiritual whole. Palliative care affirms life and regards dying as a normal part of life, intending neither to hasten death nor prolong life. It focuses on

- Relieving symptoms and enhancing the quality of life for the patient
- Supporting the family and those close to the patient.

Wits Palliative Care uses the World Health Organisation’s 2002 definition of palliative care:

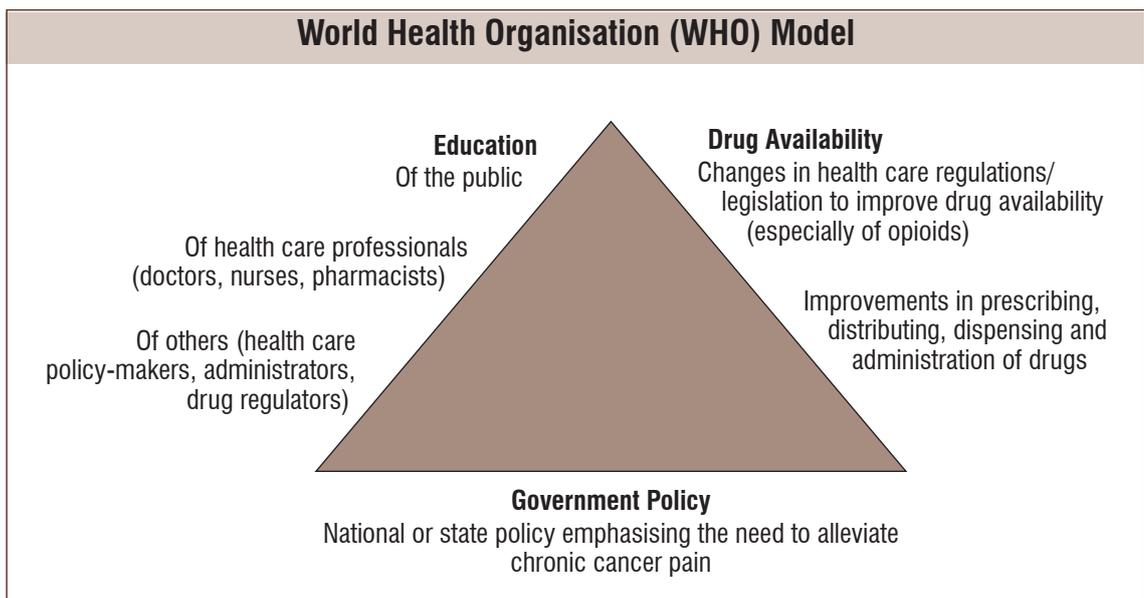
“Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”

The same definition goes on to state that palliative care for adults

- Offers a support system to help patients live as actively as possible until death and to help the family cope during the patient’s illness and in their own bereavement
- Uses a team approach to address the needs of patients and their families

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The hospice movement in South Africa pioneered the palliative care cause. The time has now come to take palliative care into the South African public health sector so that everyone can have access to a dignified, pain-free and symptom-free death.

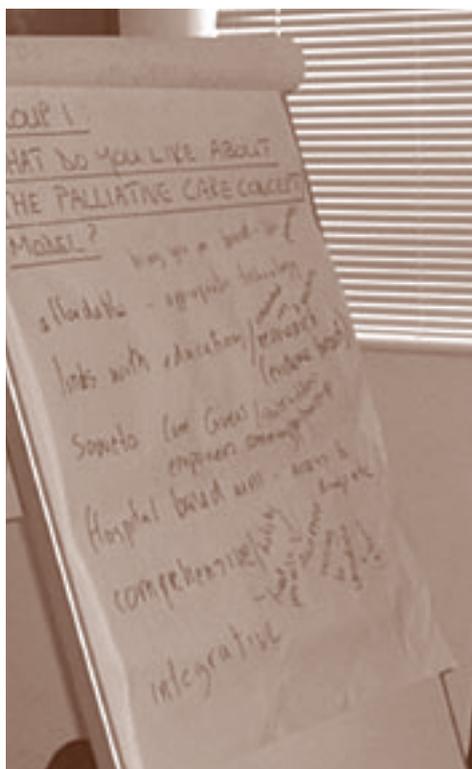


- Enhances quality of life, and may also positively influence the course of an illness
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

## Why is palliative care so important in South Africa?

### Protracted, painful deaths are prevalent

More and more people in South Africa are dying of HIV/AIDS – an estimated 600 people a day. HIV/AIDS is the leading cause of death in this country and accounted for more than 30 per cent of deaths in 2002. Cancer is the fourth leading cause of death. More than 80 per cent of people with cancer seek medical help late, and cancer now accounts for 7.1 per cent of deaths. Death from illnesses such as HIV/AIDS and cancer



take a long time, are painful and are often accompanied by a large degree of suffering. But government health care services have previously emphasised curative and preventative medicine, and health care practitioners, especially doctors and nurses, have until recently not been taught how to care for people who are dying – how to ameliorate pain and other symptoms and reduce suffering in general.

## Government recognises the need for palliative care

In recognition of the critical need for palliative care to be available to the majority of South Africans, the Department of Health has made palliative care one of the objectives of its strategic plan. Palliative care is also in the Patients' Rights Charter and the national HIV/AIDS care and treatment plan deems it an essential service in the care of HIV/AIDS.

Prior to the N'doro Project, palliative care was only provided on an ad hoc basis in a few hospitals (mainly using donor funding) and mainly by the Hospice and Palliative Care Association. There was limited training in the undergraduate curricula, and no national guidelines, norms or standards for the public sector.

### A global problem

The lack of palliative care – service delivery, training and research - is not unique to South Africa. Indeed in their 2004 annual report, UNAIDS found that palliative care is the most neglected area of health care and treatment. Meanwhile, only 5 per cent of people who need ARVs internationally have access to them and more than 20 million people have died from HIV/AIDS. The increasing burden on women as carers and patients threatens global development goals.

## The N'doro Project responds

Following a situational analysis and based on international lessons, the N'doro Project set itself up to develop a model for palliative care in the public health sector in South Africa.

Over the last four years, we have drawn on international best practice, our clinical experiences and our research findings to evolve our model. It is based on the visionary

concept of the WHO Cancer and Pain Control Programme of the 1990s. But while the WHO programme described how resources should be allocated *between* so-called curative and palliative treatments, especially in developing countries, our model supports the government's 10-point plan by describing how palliative care can be *integrated* into the public health services.

### The N'doro project's goals

#### Our primary goal

Reduce the pain and suffering of people with HIV/AIDS and cancers, and of their families, by increasing access to quality palliative care in the public health sector.

#### How we will approach our goal

Pilot a model for palliative care in Soweto at district level in order to

- Test feasibility of nurse-led, community outreach palliative care in a public health setting
- Coordinate and support existing services in the delivery of palliative care
- Monitor and document the experience for best practice.

#### Other goals

- Increase the numbers of health care workers practising palliative care principles by establishing a sustainable training capacity.
- Establish a coordination mechanism between NGOs and public health facilities at a district level which may be replicated and is self-sustaining.
- Develop policy and advocacy in palliative care.
- Provide quality palliative care and develop evidence-based palliative care, and document the experience for other settings.

### Defining features of the N'doro palliative care model

- Ensures equity and cost effectiveness since palliative care is delivered in the public sector
- Integrates a palliative care service into primary health care services as the mainstay of palliative care
- Ensures quality of care by a simple up and down referral system and works easily across all clinical specialties
- Advocates nurse-led multidisciplinary teams
- Networks public sector services to district level NGOs



# What we do

## Wits Palliative Care activities

- Service delivery
- Training
- Research
- Community liaison
- Policy and advocacy

Delivering a palliative care service is the major activity of Wits Palliative Care. But in the process of alleviating the suffering of our patients, we are also a best practice programme. It is through our palliative care work on the ground that standards for best practice are tested and refined and clinical training and research happen.



Relevant research and training is the new imperative for academic institutions in the young democracy of South Africa. Our palliative care service delivery is a main pillar informing our research agenda and training priorities. Being in the academic realm also ensures that our work can be peer reviewed and allows great opportunities for collaboration nationally and internationally.

Ensuring meaningful and two way links with the 'community' (in this instance service users and their families) is another mechanism to ensure relevant research and training.

Provision of peer reviewed and quality research and training and clinical experiences can maximise the benefit of our work through informing policy and assisting in advocacy in palliative care.

“Slowly, I learn about the importance of powerlessness. I experience it in my own life and live with my work. The secret is not to be afraid of it - not to run away. The dying know we are not God.

All they ask is that we do not desert them”

Sheila Cassidy, a British Hospice Doctor, in her memoir, 'Sharing the Darkness'

## Service delivery

### Home visits

This year, we accepted 189 new patients, and at the end of April 2006 we had 314 patients. Our patients received from 1 to more than 30 visits, a median of 5.9 visits per patient. It is intuitive that a better quality of life can be achieved if a patient receives more visits. By international standards, 5.9 visits per patient is an achievement, since there are institutions in the USA who recently 'celebrated' the achievement of 10 days palliative care before death.

### Increase of 28 per cent in the number of contact visits

Our team made 2,833 home visits this year. The number of contact visits has improved by 28 per cent above last year of which 86 per cent were contact visits, meaning the patient was found to be at home during the visit. We are implementing strategies to decrease the number of non-contact visits further, but 14 per cent of non-contact visits is acceptable for the mobile and indigent population we mainly work with. In general patients do try their best (and indeed have gone to extraordinary measures) to contact us if they have had to move house. Our achievement of 3.25 contact visits per nurse per clinical day is within international norms for community palliative nursing. This is despite

the fact that visits are often more time consuming because they are used for teaching purposes and for research and careful monitoring and evaluation. There is also no compromise on quality care in order to achieve quantity of indicators.

Why have we succeeded in improving our rate of contact visits?

- Our team is now established and highly trained.
- Despite our increased teaching load, the team is more efficient.
- The number of referrals has increased.
- Our systems are working more efficiently.

## Deaths

96 of our patients died this year, mainly those with cancer. The government's ARV programme is taking off, and more and more of our patients are getting better after taking ARV medication, no longer needing pain and symptom relief.

We enhance the quality of care we are able to provide by making a bereavement visit when a patient dies, even when this is on the same day they were referred to us.

## Out-patient clinic

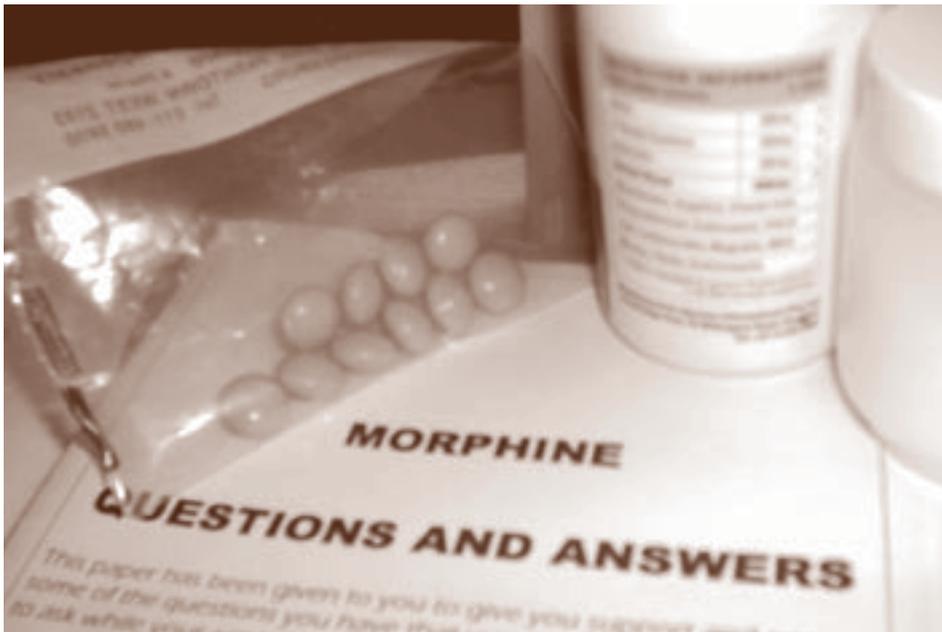
As it becomes more widely recognised that palliative care is not only for terminally ill patients we are receiving more and more referrals from various outpatient clinics for palliative services and opinion. Also because many of 'our' patients are going from bedridden to mobile to symptom-free on ARV therapy we have opened our own out-patient clinic. Based at Glynn Thomas House, it runs as a daily drop-in clinic, so providing an integrated 'one-stop shop' at Bara.

We receive patients from all specialties, and training in the palliative approach will ensure that in future our clinic is only used when a specialist palliative opinion is needed. We encourage telephone consultations to support non-palliative doctors and nurses to provide a palliative approach in their work. Nevertheless, we urgently need extra staff to run the clinic.

## Transport

Our drivers do an average of 250 km per week around Soweto to deliver our services to our patients – that is 1,000 km per month per vehicle.





### The difference that one more car would make

We do not provide patient care outside of Soweto due to resource constraints. Currently our outreach service relies on two cars. To maximise the number of patients we can reach, we divide the clinical team (eight, plus two drivers) into two and have divided Soweto into eight routes. We do two routes per day. This means that we cannot attend to patients who are not on the route for that day, and it also makes clinical training difficult.

The clinical team cannot work to maximum efficiency in two cars. Just one extra car, if it could carry up to seven people, would increase the number of visits and enable emergency visits.

### Effective pain and symptom management

This year, we attempted an analysis of pain scores. This is not straightforward: as one pain is treated, the patient's condition deteriorates and there are new pains. However, analysing the

pain scores over time, we have found that 88 per cent of patients with moderate or severe pain had their pain significantly reduced. Palliative nurse clinicians are able to mitigate most of our patients' pain and symptoms. Our major challenge was ensuring that the correct drugs were accessible from the government pharmacies.

### Taking fatigue seriously

We were able to mitigate the most common and degrading and debilitating symptoms of AIDS, such as chronic diarrhoea, coughs and candidiasis. We were even able to mitigate symptoms which are distressing but currently difficult to manage, such as fatigue and weakness, through simple support and skilled communication. Our research found that fatigue is a very distressing symptom, but is highly stigmatised because people are perceived as being lazy and good for nothing. By educating the family and community that this is part of a disease we have brought comfort to the patient.

## The wide range of social work

In June 2005, our social worker resigned for personal reasons, and due to the uncertainty of sustained funding we did not appoint another. This has negatively impacted on the quality of care we are able to offer.

Our social worker saw 37 cases in May and 28 in June 2005. Over the previous year the average was 28 visits a month. Her work was wide ranging, including dealing with emotional trauma and mental illness related to HIV and its effects on the household, working with child protection services, and taking measures to alleviate poverty, like giving food parcels to 300 needy families. She also met regularly with the region's social workers and was on the Soweto Care Givers Network's steering committee. She was particularly interested in group work for children whose parents are terminally ill.

## Pastoral care

In November 2005, the contract for our pastor was completed. While his work was considered essential, we were unable to renew his contract due to lack of funding. However, we are now able to access pastoral care from people we have trained in our clinical pastoral courses.



**“Dear loving Sister, you possess a real nursing heart that every nursing person should have”**

**One of our patients wrote a letter to us**

## Service delivery challenges and responses

### Drug availability and drug scheduling

The uninterrupted supply of drugs is of key importance to maintaining the quality of care for patients with chronic conditions such as HIV/AIDS and diabetes. This has been an issue at the clinic level, although the hospital pharmacy ensured no stock-outs of morphine. We need to secure the drug supply and we need short-acting morphine tablets. We have found that the majority of pain and symptoms can be mitigated with a core formulary of 12 palliative drugs, all currently available on the Essential Medicines List. An important barrier to access of these drugs is non-implementation of Section 56 of the recently promulgated Nursing Act. We recommend implementation of this section which allows for certain nurses in specified conditions to prescribe specified drugs in the absence of a medical practitioner.

### Transporting the very sick patient

Dying does not always follow a simple downward trajectory and palliative care should not always be delivered at home, as in palliative emergencies and on others occasions when it is appropriate that patients come to a hospital. Currently, ambulance services are overwhelmed and palliative patients are not a priority. In the absence of adequate transport services for patients, we need ambulance services to be made available for palliative emergencies and for transporting terminally ill patients who are desperately poor to a shelter or hospice. Leaving people to die at home when for example, they share a bed with their child, or live alone, is entirely inappropriate.



### Overwhelming suffering

HIV/AIDS is not just an illness, but also a social ill. HIV/AIDS impacts on poverty and poverty impacts on HIV/AIDS. The resulting suffering is enormous and overwhelming. Our links with faith-based organisations and NGOs through the Soweto Care Givers Network have helped us mitigate some of this suffering.

### Social grants and disability grants

We have helped many patients access the appropriate government grants, and these have helped alleviate the suffering that illness and poverty brings. But we have found that illness affects not only the poverty-stricken ill themselves but also their families. Our work as health care service providers would benefit from having a trained paralegal person who can access the appropriate grants for both patients and their families.

## Training

“Nothing would have more immediate effect on quality of life and relief from suffering - not only for patients, but also for their families - than implementing knowledge accumulated in the field of palliative care.”

**Dr Jan Stjernsward, WHO**

Palliative medicine is now the eleventh largest medical specialty in the world. Increasingly, its importance in medical education is being recognised. Unlike most medical disciplines which have become super-specialised and compartmentalised palliative medicine cuts across disciplines and should be available at all levels of care, especially at the community or primary care level.

Our training is guided by both the WHO model for an effective national palliative care programme and by the experiences of other training initiatives in South Africa.

We have

- Learnt and applied current methods in medical and health education
- Developed and used bold, innovative methods suitable for South Africa today
- Applied the principles of adult education, outcomes-based education, community education and participatory education
- Successfully used and contributed to multi-media and electronic interactive learning.

## Expert input

In establishing a sustainable training capacity in our organisation, we are fortunate to have worked with various excellent organisations and individuals, including palliative medicine consultants from Caerdas Trust, Oxford University, the Kings College London, and through an exchange programme with the WHO Palliative Demonstration Centre in Kerala (India).

We have divided our training into four main areas of activity

- Training generalist health care practitioners (mainly primary health nurses and GPs). Provision of palliative care for this category will not be their core business, but basic palliative skills will be integrated into their daily work (a palliative approach)
- Training health care practitioners with a special interest in palliative care (for example a gynaecologist-oncologist, surgeon, or anaesthetist). This would be via diplomas and higher learning.
- Training palliative workers who have allied health or non biomedical skills (for example pastors, physiotherapists, social workers, dieticians, art therapists)
- Training ourselves as palliative specialists

In addition, we educate policy makers and the public through our advocacy work.

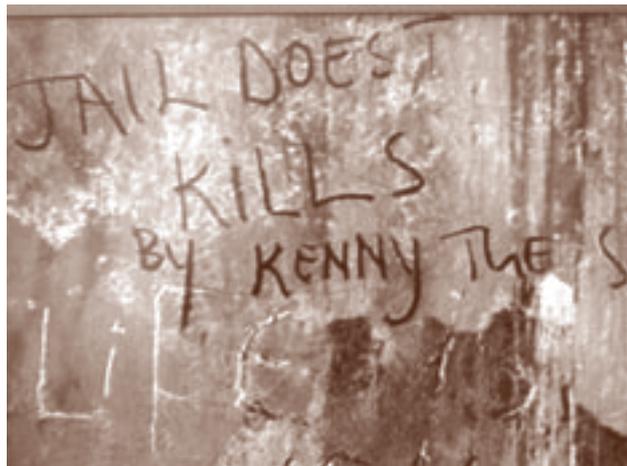
## Training health care practitioners

It is common opinion that 80 per cent of palliative care could and should be delivered by trained general health care practitioners who apply a palliative approach. We have requested to provide yearly training for primary health care nurses in Soweto. We have taught GPs in the Masters of Family Medicine degree.

## Training is not an end in itself

Government and international agencies have identified the lack of human resources and skills as the biggest barrier to delivering effective health care. But training should be tailored to what is envisioned for particular national health services and cannot be separated from policy and health systems work or from research. We contribute to the development of policies and take part in discussions in several forums. Our training is designed to respond to the South African context, though it is applicable to and can be adapted for other developing countries.

All health care practitioners should have a basic competency in palliative care.



## Palliative care for prisoners

Having been approached by the Johannesburg Correctional Services Centre, the largest prison in South Africa with more than 16,000 inmates, we have embarked on a long-term programme of training courses and clinical mentorship so that the prison can provide palliative care. Our first three-day course in 2005 trained half the prison's health service. Feedback indicates that the need for palliative care and for on-the-job training is clearly recognised.

## EXCERPT AND QUOTES FROM MEDICAL STUDENTS' PORTFOLIOS AT WITS UNIVERSITY

"Why do the doctors not know about pain relief?"

"We are the first to be taught palliative care ...I had to teach my consultant about the pain ladder, I need to be sure I have it right!"

"Palliative teaching is a perfect summation and completion to a medical course because it gives us the tools to treat the untreatable"

"In Mr N the original pain management needs to be modified greatly, a step II drug should not be given with a step III . What I have gained from this experience is mostly on a spiritual level. ...best described as 'there may be joy, love, forgiveness and truth as well as pain and suffering"

"Physical pain... in my opinion she should have been given morphine and not dextropropoxyphene"

"(Patient M)...with the dedicated palliative care team caring for him I can appreciate what that does to assuage his fear"

"I am afraid ... of the manner in which I die, I am afraid of suffering and of my family knowing that I am suffering"

"My aunt who died of breast cancer would have benefited from the palliative care team"

"Later during the week I noticed Mr K was in pain, I checked his regime ... he started demanding a reason for why it has taken so long to diagnose him.... but surely he was not blaming me... strange what you realize when you let your emotions get the better of you"

"Things R taught me. I visited R daily, he gave me great insight on what it feels like to be dying and allowed me to walk in his footsteps as he took his journey... the dying have the right to be free of pain"

## The graduate entry medical programme at Wits (GEMP)

Wits now offers entry into the third year of its MB BCh degree for suitably qualified graduates who are interested in qualifying as medical doctors. The MB BCh years III-VI are now also integrated into this GEMP.

Since the inception of the GEMP in 2003 Wits Palliative Care has provided training in palliative care in the first three years of this graduate entry medical programme (GEMP), in the form of lectures and exam questions, and symposia. We provide a compulsory clinical attachment in the final year.

## Reaching an adequate standard in palliative care now compulsory for medical undergraduates

In January 2006, a landmark decision was made to incorporate our palliative care training course as a mandatory, assessed clinical attachment for the more than 200 final year medical students in the University of the Witwatersrand's Faculty of Health Sciences. Graduating doctors of the class of 2006 will all have the knowledge, skills and attitudes to practice a palliative approach.



Our clinical attachment runs over six weeks and students spend a total of 20 hours at various palliative care sites. We provide theory lectures with inputs from other institutions, and students clerk patients and write a learning portfolio based on a patient. They are also formally examined on the course.

At the end of April 2006, we were half way through the third rotation of GEMP students, and 63 students have completed and passed the course. An unexpected bonus was that some students were asked by their seniors in other disciplines, including consultants in medicine and surgery, about the correct approach to pain relief in palliative care. We have also been approached by various departments to provide palliative training.

### Problem-solving approach to training

In September 2005 we provided a half day workshop for the whole GEMP III class of 200. We used an innovative problem-solving approach with great success. The class was split into 14 groups. With access to books, the internet, nurses, social workers, a pastor and doctors, each group had to solve a particular problem in palliative care, ranging from basic science issues to clinical problems to communication needs. They had to present their learning to one another and an expert panel.

The Wits Centre for Health Science Education rated this learning experience highly and holds it as an example of how training should be done. Students appreciated the independence they were given in a controlled and safe setting.

Wits Palliative Care has been asked to extend this to a whole day training each year and to share our methods with other departments.



“The programme is very relevant to my ministry. It really enlightened and empowered me.”

#### Other activities in the faculty

- Last year two elective students joined us and highly rated their palliative experience.
- Wits Palliative Care contributes to various faculty committees, highlighting palliative care.

#### Training for non-specialists

Intermediate palliative care is defined as palliative care which is provided in the primary health care or non-specialist setting by staff who have a special interest and training in palliative care.

Ongoing education and training and clear links with specialist centres are essential for intermediate palliative care to be effective. The training we have provided so far has had a lasting and knock-on effect: treatment protocols are being used and we have yearly requests for updates.

“I wish the programme could be on TV or announced on radio so that more pastors can know about it.”

#### Pastoral counselling

Our courses on pastoral counselling have been well received and are in demand. The courses have both theoretical and practical components, and include patient visits. In 2005/06, 29 pastors attended our courses. We have had numerous requests for this training in Limpopo, Northern Cape and Gauteng.

#### Training materials

- A manual for medical students on counselling (which has become prescribed reading for GEMP IV students, and has also been used by postgraduate students in Family Medicine)
- Curricula and manuals for nurses, pastors and undergraduate medics
- Multi-media material for Mindset, already reaching thousands of health care practitioners
- An accredited e-learning course for doctors, acclaimed for its teaching methodology and design

## Training highlights for 2005/06

- Provided an introduction to palliative care for 27 social workers at Chris Hani Baragwanath Hospital
- Trained 781 primary health care nurses and doctors
- Trained 31 health care practitioners in the correctional services
- Ensured specialist training for a doctor, seven nurse clinicians and two social workers
- A one month clinical exchange for 2 doctors from India
- Provided hands-on training for provincial departments of health in Limpopo and Northern Cape to set up palliative care services in these provinces
- Taught on the Masters in Family Medicine course
- Examined a Masters in Medicine thesis and co-supervised student research.

## Summary

- More than 6 months training: 10 health professionals
- 4 week training: 29 pastoral care givers, 60 nurses
- 3 day training: 800 student doctors
- 3 hour training and information sharing: Mind Body and Spirit International Palliative Conference 500, Pefpar Conference: 300; Mindset television: 14,000; medical meeting: 62 postgraduate students

Our training materials are used in many other countries, including Tanzania, Mozambique, and Cambodia.

Evaluations of our training sessions have rated it highly for content, style and relevance, and our e-learning module has been internationally acclaimed for its teaching methodology and design. We have been asked to repeat courses and expand courses for nurses, doctors and other health professionals.



In the future, we hope to use telemedicine for education as well as for distance clinical support.

## Becoming a better palliative care team

We are proud that each member of our clinical team understands palliative care in all its complexities and with all its challenges.

Two of our nurses are currently doing the specialist palliative care course at the Hospice and Palliative Care Association, and we have in turn become involved in the HPCA course as external examiners.

The doctor on our team was awarded the MPhil in palliative medicine by the University of Cape Town. Her original research directly informed the N'doro model and the external examiners recommended submitting the work to peer reviewed journals.

Our two drivers have been trained in palliative care for lay persons, and have provided invaluable services in our multidisciplinary team.

Our data capturers and administrators have been found to be excellent teachers at the university on community and communication aspects of palliative care.

Our excellence in training for palliative care is well recognised and we are in demand.

## Training for the clinical team in 2005/06

- Specialist training in ARV therapy
- Bedside training for complex palliative problems
- Visits to other hospitals
- Visits from international palliative care practitioners
- IT training
- Training on teaching methodologies and assessment methodologies

Palliative care challenges many usual practices. Non-hierarchical teams, holistic, patient-centred care, working alongside non-professionals and respecting patient decisions, are often new experiences for many health care workers. Audit cycles, significant event analysis, and stakeholder forums have helped us bridge the gap between theory and our practice.

Not everyone is suited to providing specialist palliative care. It requires a calling, not only knowledge. But all health professionals can and should provide basic palliative care

## Research

“[B]ecause we are so poor, we cannot afford not to do research. ... I see no way out of our vicious cycle of poverty except through the means that science and technology has placed at our disposal.”

Jawaharlal Nehru (1889-1964)

“[R]esearch in developing countries is the crucial element in translating theoretic knowledge into practical innovations and drugs to improve health.”

Dr GH Brundtland, Director General of the World Health Organisation, 2000

Developing countries carry over 90 per cent of the disease burden, yet less than 10 per cent of global spending on health research goes to research on these diseases.

Our research priorities include basic science research, clinical research and health systems research. We are also interested in the economic evaluation and costing of various models of palliative care.

## Collaborations and partnerships

Palliative care takes account of the fact that patients not only suffer medical symptoms, but also have emotional, social, spiritual and

existential problems, and that social care services and family contexts are complex. Palliative solutions need a multidisciplinary approach to research: oncology, nursing, psychiatry, neurology, rehabilitation medicine, general medicine, health services research, psychology, anthropology, medical sociology and ethics all play a part.

We have been part of successful research collaborations across the schools of the University of the Witwatersrand's Faculty of Health Sciences, notably with the School of Public Health on a clinical randomised controlled trial on palliation of oral lesions, and with the School of Physiology on its internationally leading research on HIV-related pain. We have also collaborated with

departments and projects in other faculties, such as anthropology.

Beyond Wits, research collaborations have been established with:

- King's College London; the University of Cape Town; University of Manchester
- Wits Hospice; HPCA
- Chris Hani Baragwanath Hospital; 23 primary health care clinics in Soweto
- Soweto Care Givers Network,
- African Palliative Care Association
- Neighbourhood Network for Palliative Care, India
- Population Council
- Four health Districts in Limpopo and Northern Cape
- Southern African Migration Project

Two new collaborations are in the process of being established: the proposed combined HIV/TB/palliative care clinic at the Chris Hani Baragwanath Hospital is an approved partnership between these services and the Gauteng Department of Health

## Research for action

Disseminating our research forms part of our research for action cycle. To this end, Wits Palliative Care publishes in peer reviewed journals, makes formal presentations at international and national conferences, initiates and contributes to debates in the media, and participates on committees (academic and community) and advisory groups (government and hospices).

Presentations at conferences are an important forum for disseminating our research and the lessons we are learning.

## Wits Palliative Care research themes

### Improving services by measuring outcomes and evaluating services

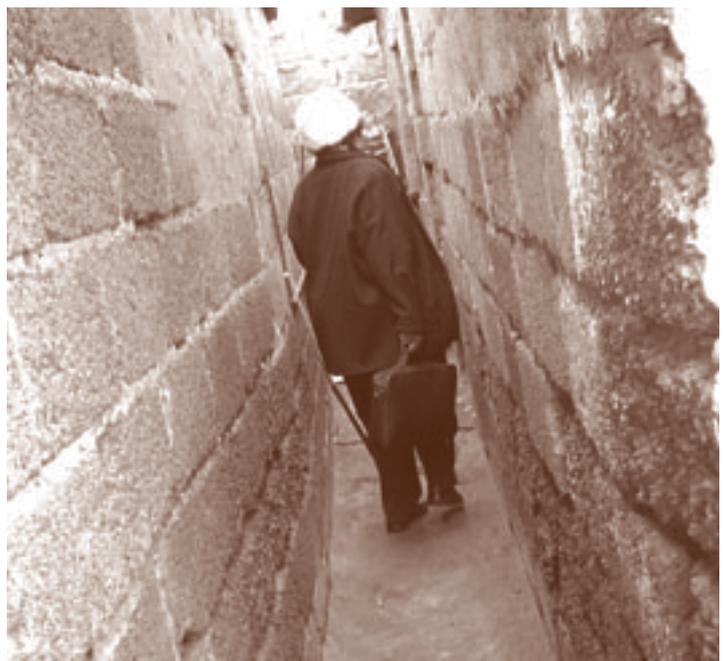
Research in this area is already underway and will contribute to developing standards, models and measures for more humane, dignified and cost-effective care, feeding into government policy and the funding of hospice, cancer, supportive and palliative care services.

### Palliative care in HIV/AIDS

More than half of our patient base comprises people with HIV/AIDS, but there is a dearth of evidence on what works in terms of palliative care. We have already done research in this area, including a large study on the meaning of death and dying in Soweto, and will continue to as a priority. We are well placed at the epicentre of the pandemic and have well established links with adult and child ARV clinics.

### Effective and affordable palliative drug therapies for the public sector

### Service development models for the public sector



## Sr. Sophia Tsepetsi



Sr. Sophia Tsepetsi

### Comment:

#### Clinical skills

As a primary health care nurse and palliative consultant, I am able to manage pain by using morphine which is a schedule 7 drug. This has to be monitored at home and titrated according to WHO steps of the pain ladder.

For the symptoms I have to use adjuvants for bone pain and for the offensive smell I have to use appropriate emmollients which removes the smell, which is most uncomfortable to the patient and carer.

This can only be done by a chief professional nurse who is also a trained palliative specialist.

#### Counselling skills

As a psychiatry nurse I have an in-depth knowledge to be able to counsel the patient and family. More especially to explain about the diagnosis and prognosis – which is both painful and distressing to patients and family and me as a carer if I am not well trained and experienced.

I have to touch on the issue of death and dying and make them understand that it is a necessary end to a human being and this has to be welcomed with strength and hope and dignity. The family has to be involved and supported throughout – not on a once off – one day issue, but over a long period .

### Case Study:

Female patient of 64 years diagnosed with cancer of the womb.

The patient was admitted to Palliative Care on 25. 02.05 presenting with

- Backache
- Abdominal pain
- Smelling discharge
- Social Problems

She lived in a shack alone – no child – no carer. She was very ill, depressed and had nothing to eat because she did not have a social grant.

#### Plan

- Pain & symptom control
- Seek next of kin and counsel and educated her about the disease.
- Educate the patient about medicine / diagnosis and prognosis.
- Referred to Social Worker for purposes of the disability claim for the patient
- Engage home based carer to help the patient with the cleaning and house chores and general hygiene

#### Way forward

- The patient was admitted to community palliative care and seen on a weekly basis for Improvement
- Education on her medication
- Support

Social worker saw to it that the forms were filled in for the disability grant. Family meeting set up and family were highlighted as to the state of the patient / the need for care and family involvement.

Relevant medication for pain was ordered – which helped to control the pain. The relevant medication for discharge was ordered and it really worked.

Although disease is slowly progressing the patient is now pain free and has no problems with food and she is with her family who now accept her as she is and if she should die.

In the year under review, we have made presentations at, among others

- The XVI International AIDS Conference, Toronto
- The Pefar Enhancing Care conference
- The Mind Body and Spirit international palliative conference
- The Population Council symposium on re-positioning care and support in the era of treatment

Wits Palliative Care is involved in formative and original research, relevant to the palliative care problems facing the users of the public health system in South Africa.

Our topics have included

- Palliative care in the public sector in a high HIV/AIDS prevalence setting in South Africa
- Integrating palliative care into the formal health care system
- Pain management in palliative care community service delivery
- Effective pain management for HIV/AIDS
- Gender, volunteerism and networking
- Pastoral training in palliative care

There is a detailed list of our publications and conference presentations at the end of this report.



Sr. Sizakele Nkosi

## Sr. Sizakele Nkosi

### Comment:

I am a highly skilled, experienced and qualified palliative nurse.

I am professional and dedicated to my patients at all times and in all circumstances.

Since in Palliative Care – we use an holistic approach – and our team currently has no social worker – I used my clinical skills in diagnosis and symptom control and my people, counselling and networking skills in placing this patient successfully into a suitable environment at Takalani Home.

### Case Study:

Our Patient (L.S.) is a 26 year old mentally retarded lady living with epilepsy.

The patient was sexually abused by a strange man who infected her with HIV

The patient is not on treatment. The family is not ready to take her for ARV's.

Patient's mother is an alcoholic who doesn't take care of the patient.

The patient has two sisters, who are the main carers and are both working.

During the day the patient is left alone, she goes around Soweto without supervision. On two occasions in July, she slept out, without the family knowing her whereabouts.

The patient has advanced AIDS and needs 24 hour supervision – especially since she is retarded.

Safety was a big issue. I arranged for an urgent family meeting, which was held on 17/07/06. The patient's safety was discussed and the need to get her into a place of safety.

I contacted the social worker at Takalani who promised to get a placement for her.

The patient was admitted to Takalani on 02/08/06 and the family was very happy.

The family were advised to visit her regularly in the home and the patient will be followed up for palliative care by the Wits Community Palliative Care Team.

# Community liaison

## The Soweto Care Givers Network: “With love we will conquer”

In 2003, Wits Palliative Care initiated the Soweto Care Givers Network, which now represents about 70 NGOs working in Soweto with people infected and affected by HIV/AIDS and other terminal illnesses.

The AIDS epidemic is so engulfing that an effective response demands partnerships.

In 2005/06, through imbizos and the work of a new, elected steering committee, Wits Palliative Care sought to bring all the relevant NGOs together and involve them in building the network. A VSO development worker was seconded for two years to guide this process, specifically to mentor a local person to lead it. We have developed key organisational and planning documents and are in the process of formal registration of the Soweto Care Givers Network as an NPO. NGOs have started to register as members of the network.

This kind of work is particularly slow, requiring great sensitivity and a keen understanding of the environment, but with robust foundations and a common goal we know that - as our motto states – with love we will conquer.

### Two main objectives for 2005/06

#### Improve linkages between organisations

- Information has been collected from 59 relevant NGOs and a database and website are under construction.
- Two editions of a newsletter have been distributed to about 400 NGOs and government officials.
- Relationships are being developed between both NGOs and statutory organisations.
- Links are in place with the departments of health, social development, home affairs and social security.

#### Capacitate NGOs to provide more effective care

We have done a skills audit of a cross-section of organisations and have identified some that are being well managed to help capacitate others. We have also identified common skills gaps. We will work with NGOs to develop a plan to use the skills we have and to bridge the gaps.



# Policy and advocacy

Palliative care is still in its infancy, so it is essential to make sure that policy makers have the correct facts. In addition, dying has long been a taboo subject in the medical profession and there are many myths and misconceptions around palliative care, euthanasia, and the safety of morphine.

Wits Palliative Care has reached hundred of researchers, policy makers, funders, service providers and government officials through our training, our research presentations, and our public education activities.

The Hospice and Palliative Care Association's research and education committee.

We serve on government advisory committees for palliative care and are part of government's expert group on disability grants.

## Working with government

The National Department of Health has adopted a 10-point strategic plan for 2006-09 to implement the national health system's priorities for 2004-2009. The establishment of palliative care centres in all provinces is defined as an objective, funded from government's strategic health programme. By 2009, government wants palliative care centres in all the provinces.

## The Palliative Care Society of South Africa

The Palliative Care Society of South Africa was formed in June 2005 with the aim of promoting palliative care issues, providing training in palliative care, and promoting the sharing of expertise, knowledge and experience. The society has the vision of being the voice for palliative care in South Africa and to network with other palliative care societies in Africa and internationally. Membership

### **The most important policy, implementation and regulatory challenges for palliative care in the public sector**

- Enact section 56(A) of the Nursing Bill for palliative trained nurses to deliver palliative drugs
- Develop clear clinical guidelines for prognosticating diseases and death
- Train district nurses and clinical associates in palliative care
- Clarify the scope of disability grants
- Uplift the community care workers programme
- Provide undergraduate palliative training at all institutions
- Facilitate the transfer of information.



Wits Palliative Care is lobbying with the Hospice and Palliative Care Association and the Palliative Care Society of South Africa for a parliamentary hearing on palliative care.



is open to anyone who is interested in palliative care or is working in a palliative care setting. This is an individual membership and individual persons may join in their own right.

Wits Palliative Care was invited to the inaugural meeting of the society. Our project manager currently serves on the steering committee and will provide administrative support until the constitution of society has been ratified by members and a new steering committee elected.

Activities in 2005/06 included actively recruiting members, and the ongoing electronic distribution of the society's newsletter.

## Public education

Our public education work of various kinds has reached thousands of people.

### Public education work

- More than three hours: 500 people
- Less than three hours: 15,000 people
- Newspapers and television: 52 million (All Africa broadcasting channel)

We partner other organisations and groups in providing training for funders, universities, campaigns, and government departments

- Common Purpose, which has trained thousands of leaders internationally, told us "I couldn't find anyone in the history of Common Purpose that was rated 99 per cent by the participants."
- And the USAID reported "Your staff was fabulous at the Quality of Care conference."

### Gender and home-based care

In 2005/06, our doctor and social worker were invited to contribute to the strategic planning workshop of the organisation, Men as Partners. By initiating a debate on gender as an issue in home-based care (informal as well as formal), we highlighted the feminisation of poverty, girl children staying from school to care for their parents, and the quadruple burden of women. This led to a discussion on practical strategies for increasing the involvement of men in home-based care. The Soweto Care Givers Network has maintained links with this organisation.

# Our team



Father S Abrahamse  
Palliative Pastor



Pro Chamane  
Palliative Driver



Natalya Dinat  
Doctor and Director



Nina Du Toit  
Manager



Barbara Green-Thompson  
Training Coordinator



Victoria Kenosi  
House Keeper



Edith Mahlke  
Palliative Nurse -  
Clinician



George Masiteng  
Palliative Driver



Gerti Monkoe  
Palliative Clinical  
Coordinator



Keletso Mmoledi  
Palliative Research  
Coordinator



Sophie Mokhosi  
Palliative Nurse -  
Clinician



Sizakale Nkosi  
Palliative Nurse -  
Clinician



Laura Ross  
Soweto Care Givers  
Network



Charles Sekwati  
Soweto Care Givers  
Network



Sophia Tsepetsi  
Palliative Nurse -  
Clinician



Nozipho Zwane  
Data Capturer

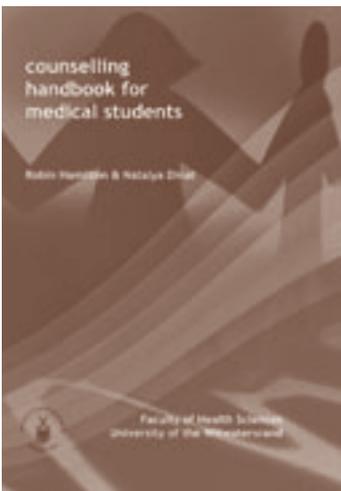
# Research, publications, conference presentations, newspaper articles television programmes

## Completed and ongoing research 2005/06

All our research has ethical approval.

TITLE	DESCRIPTION OF THE RESEARCH	RESEARCHER/S (INDIVIDUAL/S AND THEIR INSTITUTION/S)	TIMEFRAME (WHEN BEGUN, WHEN CONCLUDED, WHEN PUBLISHED)
An evaluation of a pilot of palliative care in Soweto: the N'doro Model	This a retrospective record review of clinical activities for the purpose of research	Wits Palliative Care	Ongoing study, which started in 2003 Various conference presentations
Impact of palliation on oral lesions in HIV positive patients.  It described the prevalence and extent of mouth pain and impact on the quality of life in people with HIV/AIDS and showed effectiveness of a mouthwash.	A clinical Randomised controlled trial	Yolande Malele. School of Public Health, University of the Witwatersrand collaborative trial. Dr Dinat was a co-supervisor	2004-2005 Presented and submitted for publication
Domestic workers, migrancy, the workplace and HIV/AIDS	A cross sectional survey of 1100 domestic workers in Johannesburg	Original research collaborative study between Wits Palliative Care and Southern African Migration Project. Principal investigators; Dr Dinat and Dr Peberdy	2003-2004 Presented at conferences and published in the DSA
Living and Dying of AIDS in Soweto	A qualitative study to inform development if palliative services in Soweto (the N'doro model)	This is original Research, Principal investigator; Dr Dinat	2003-2005 Presented at conferences and submitted for publication
Encompass - improving care through the prevention of suffering	This is an international, multi-centred study looking at outcome measures for palliative care services	Collaboration with the Palliative and Policy unit of Kings College London, and the African Palliative Care Association and Wits Palliative care	April 2006-April 2008

# Publications



Measurement of palliative care outcomes in Sub-Saharan Africa: multi-professional clinical perspectives on tool utility and acceptability. Harding. Dinat. Mpanga Sebuyira. Submitted to Journal of Palliative Care Feb 2006

The Soweto Care Givers Network – facilitating community participation in palliative care in South Africa. Dinat N, Ross L, Ngubeni, V. Indian J Palliative Care. June 2005. Vol 11. Issue 1

Pain and symptom control in HIV disease under-researched and poorly managed- Letter. CID. 2005: 40 (1 February). Harding, Easterbrooke, Dinat, Higginson

Worlds of work, health and migration; Domestic workers in Johannesburg. Development Southern Africa. S Perbedy, N Dinat. 2005

Illness trajectories for AIDS BMJ.Com Rapid response for Murray et al. 330(7498)1007-1011 Dinat N.

The N'doro Project of Wits Palliative Care, South Africa. N Dinat BMJ.com. Africa edition. October 2005

Palliative care - a clinical approach for adults with HIV/AIDS. The Southern African Journal of HIV medicine. August 2003 Dinat N, Russell AJ

Counselling manual for Medical Students. R Hamilton and N Dinat. 1<sup>st</sup> ed. 2006

Book review. Learning from HIV and AIDS. N Dinat. Aids Care Feb. 2006

E-learning module – palliative care for adults with AIDS and Cancer. 2004

Informed consent and your rights. Video, Wits for researchers

MIRA trial information video. 2004

Sexual assault - evidence collection. Video, South African Police. 2003

Besser M, Paruk F, Dinat N. Changing Obstetric practices in the context of HIV: an evaluation of service provision in the National PMTCT learning sites. December 2002. Health Systems Trust.

## Conference presentations

Understanding the meaning that fatigue, a common symptom in AIDS, has in a high HIV prevalence setting in South Africa. Dinat, Harding Submitted to XVI International AIDS 2006

Palliative care in the public sector in a high HIV/AIDS prevalence setting in South Africa. Dinat. Submitted to XVI International AIDS 2006

Interactions between morphine and metoclopramide on morphine-induced anti-nociception and metoclopramide-induced motor dysfunction in rats. Peter R Kamerman, Nicole Becker and Linda Fick. School of Physiology, University of the Witwatersrand, South Africa

The N'doro Model – integration of palliative care into the continuum of care of HIV/AIDS. Nina Du Toit. Invited speaker at Enhancing Care meeting. Feb 2006

Pain and Symptoms in HIV and Cancer- prevalence, management options and measuring impact. S Tsepetsi. Invited speaker at Enhancing Care meeting. Feb 2006

Interpretations of community participation in palliative care. N Dinat. Invited speaker. International Workshop on Patient rights. Manchester University. Feb 2006

Prevalence and Risk Factors for HIV Infection in Zimbabwean and South African Women: Preliminary analysis of the MIRA trial screening population. Meehan A, Chidanyika A, Naidoo S, Didier L, Ramjee G, Chipato T, Dinat N, Blanchard K, team MIRA, Padian N: The XV International AIDS Conference; Bangkok, Thailand; 2004.

Putting medical care back into home based care- the N'doro model. The 6th International Conference on home based care for people living with HIV/AIDS. Oral Presentation, Dakar 2003

The impact of food insecurity in home based care: the case of Soweto, South Africa. Skhosana, Struthers, Dinat. SAHARA conference, Cape Town. 2004

AIDS conference skills building workshop. Palliative care for Adults with HIV/AIDS and Cancers

The burden of living with HIV and dying of AIDS in Soweto. N Dinat. Mind, Body and Soul, International palliative care conference. Dec 2005. Oral presentation

Impact of palliation on oral lesions in HIV patients. Y Malele. Mind, Body and Soul, International palliative care conference. Dec 2005. Oral presentation

Experiences of pain relief in home visits. E Mahlake, N Dinat. Mind, Body and Soul, International palliative care conference. Dec 2005. Oral presentation

Pastoral training in palliative care. S Abrahamse. Mind, Body and Soul, International palliative care conference. Dec 2005. Oral presentation

We are not drivers, we are palliative drivers. and the Soweto Care Givers Network. P Chamane, G Masiteng, L Ross. Mind, Body and Soul, International palliative care conference. Dec 2005. Oral presentation

The N'doro Model, lesson learnt. N Dinat. Mind, Body and Soul, International palliative care conference. Dec 2005. Oral presentation

## Newspaper articles, television

Palliative care – 3 min SABCA. Health Matters March 2006

Palliative care – 35 min talk show. Siyanqoba, Beat it Feb 2006

Living until you die. Mail and Guardian 18/11/2005

Dying with Dignity. Sowetan 10/2005

The MCC are mixing up issues. Putting the record straight on nevirapine. Mail and Guardian July 13 2004

Death with Dignity. Mail and Guardian July 16-22 2004

Seattle Times: Nation and world. The Schiavo Case 2004

The Hindu: Kerala News. Involve community in fight against AIDS. 28/11/04

The Hindu: Kerala News: do you know your status? 1/12/04

Indignation of a sickening scandal. Star newspaper. July 31 2003

# Financial statement

Funds received from Irish AID	
Total received	2,906,358.42
Expenditure	
Personnel and administration	2,112,080.98
Capital purchases	130,466.41
Activities	532,276.91
Total expenditure	2,774,824.30
Carry over	131,534.22

36

Support from Public Health Sector	
Drugs	
Facility	

