'OPI-PHOBIA' AMONG DOCTORS LEADS TO UNNECESSARY SUFFERING

Dr Francois Venter, President of the HIV Clinicians Society of South Africa, in full flow.
Picture: Chris Bateman

With palliative care the only option for tens of thousands of South Africans, ignorance of the efficacy and correct use of opioids among doctors and nurses and their continuing resistance to the prescription of these drugs are contributing to unnecessary suffering.

While it is known that all forms of cancer can create severe pain it is equally well proven, but poorly understood, that AIDS patients suffer severe pain.

So say two of South Africa's top palliative care trainers, Dr Liz Gwyther (also chairperson of the Hospice and Palliative Care Association (HPCA)), and Sister Sandie de Villiers, manager of the Pretoria Sun Gardens Hospice training department.

They are backed by the president of the HIV Clinicians Society, Dr Francois Venter, who called for an urgent review of existing drug legislation to enable the easier provision of opioids while removing administrative barriers and improving training.

The extent of the suffering and the gravity of any barriers to pain-relieving drugs are shocking when you consider two sobering studies, the first by the Actuarial Society of South Africa (ASSA), and the second by King's College, London.

The first estimates that just one-third of South Africans qualifying for antiretroviral treatment are receiving it, while the second calculates the reach of palliative care at 5% of people actually needing it. ASSA estimates there to be 537 803 South Africans of all ages with full-blown AIDS and not on ARVs.

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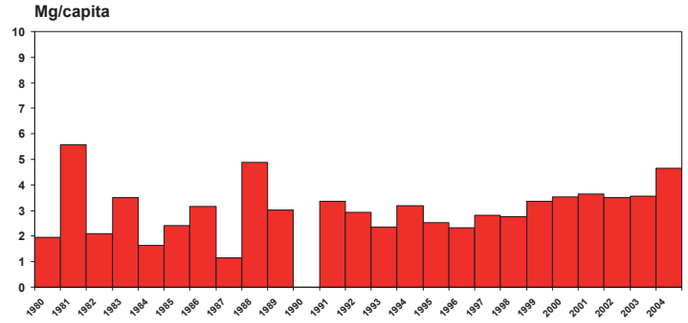
It also puts nearly half of all causes of death over the past year down to AIDS.

This conservatively puts the numbers of AIDS patients in severe pain who will inevitably die, into the tens of thousands. Additionally, one in six men and one in seven women in South Africa will get cancer during their lifetimes, regardless of social status.

Venter said doctors and nurses had an 'irrational fear' of opioids when it came to end-of-life medical care. He said far more aggressive palliative care



Mg/capita consumption of morphine, South Africa, 1980 - 2004

Source: International Narcotics Control Board; United Nations Demographic Yearbook
By: Pain & Policy Studies Group, University of Wisconsin/WHO Collaborating Center, 2006

This KwaZulu-Natal patient died at home of TB and AIDS-related symptoms after a long and painful illness.

Picture: Chris Bateman

was required while analgesic training needed to be taken more seriously by medical schools.

'We're hamstrung by legislation – if properly trained nurses were allowed to prescribe without a doctor that would be a huge step forward,' he added.

Contributing to denial of drug access to end-stage patients is another legal limitation, that of first-line drug dispensing to hospitals and clinics – a response in 2005 by government to widespread drug fraud and abuse.

In the State sector, morphine is mostly limited to provincial hospitals and in some areas only on a particular day of the week, even though it is on the essential drugs list for clinics as well as hospitals. Clinics with access have limited supplies and often dispense sub-optimal concentrations until they run out owing to poor logistics.

No drug option for bed-ridden patients at home

The main problem here is that patients must present themselves in person for their first prescription.

With most palliation in South Africa today taking place through home-based care, this makes it virtually impossible for hospice workers to access essential medicines from the formal health care sector. This leads directly to increased hardship for bed-ridden patients isolated at home, especially when it comes to the vital initial prescription.

A recent study at Chris Hani Baragwanath Hospital in Gauteng had shown that patients of all ages were more likely to be ignored if they complained of pain.

Many patients are unable to afford transport to the nearest clinic and may be too frail to attend the clinic, relying on home-based carers in the employ of the government, NGOs or the Hospice Palliative Care Association (HPCA).

Doctor prescriptions, when they are written, sometimes go unfilled for weeks owing to poor drug administration and availability at clinics.

Dr Natalya Dinat, head of the academic unit of palliative care at Wits University, said most opioids in South Africa were used in the relatively small private sector, either peri-operatively and for palliative care – or in sub-therapeutic doses. She said 'opi-phobia' was well documented with most practitioners ignorant of proper administration.

Joan Marston, paediatric palliative care co-ordinator for the HPCA, described the under-diagnosis of pain in children, who formed 43% of the country's population, as 'huge'. She said doctors were 'petrified' of using morphine on terminal children.

Gwyther explained that this was chiefly because doctors and nurses were not trained in pain assessment, which was 'particularly challenging' in pre-verbal children.

Dinat said a recent study at Chris Hani Baragwanath Hospital in Gauteng had shown that patients of all ages were more likely to be ignored if they complained of pain.

She quoted a saying popular among palliative care workers: 'Many cancer (read *and AIDS*) patients could die free from pain and with dignity if a few of the myths about opioids died.'

All interviewees agreed that besides infrastructural issues, doctors and nurses needed urgent education around pain assessment, management and the prescribing and administration of opioids.

De Villiers, who has over 20 years' experience in palliative care, says the lack of understanding of the mechanism of pain is frequently to blame for the reluctance to prescribe. 'There's a lack of understanding of how chronic pain and morphine work and I've encountered strong resistance to it by doctors. Often they won't prescribe it or because of where you are in South Africa, you just can't get it.'

Gwyther says that, even in hospitals, 6-hourly medicine rounds mean that the

This bed-ridden rural Eastern Cape AIDS patient has little or no chance of accessing pain-killing morphine.

required 4-hourly dosing with morphine is not followed so that patients are condemned to 2 hours of pain every 6 hours. Nor is the recommended 50% increase in morphine dose for uncontrolled pain instituted. If these simple guidelines (WHO guidelines for cancer pain relief) are followed, says De Villiers, pain control is highly achievable with proper training.

Most Third World patients uncurable at diagnosis

Both said their comments came in a context in which palliative care cannot be considered a luxury. Most patients in developing countries were, for reasons of manpower, logistics, culture and infrastructure, incurable at the time of diagnosis.

Pain relief in developing countries would remain the only effective, humane and realistic alternative to curative therapy for 'years to come'.

De Villiers said that historically Africans had not been valued enough to be given 'a decent quality of life, never mind a decent quality of death'.

'Suffering has become so common that we seem to be immune to it,' she said, adding that palliative care was often deemed unnecessary because of the total lack of any health care to large numbers of people in Africa.

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Hospices in South Africa are playing a pivotal role in educating people about criteria for getting onto ARVs, where these roll-out sites are and how to get onto a programme.

Many a creative solution has been found by HPCA workers when a life is at stake or the suffering 'gets too much'.

This includes, in one graphic example of lack of access, asking a *compos mentis* dying patient to sign a statement donating their morphine and then asking a pharmacist to countersign it.

De Villiers says that at Sun Gardens, one of the country's most sophisticated hospices with 500 home-based patients and a 7-bed inpatient facility, they access morphine through the Pretoria Academic Hospital – when a patient is referred to them.

A problem however arose when doctors referred patients to Sun Gardens for home-based care but declined to hand them over medically to hospice doctors and then declined requests for morphine. This left the hospice doctors, who were the closest 'hands on' link to the patient, legally hamstrung.

De Villiers says that pain relief is very cheap and all that is needed is a drug dispensing licence and some basic understanding of the physiology and pharmacology of pain relief. 'You actually don't need a medical degree – sure, there are some very real concerns about availability, but you can have it sitting in trunks and when you have resistance from doctors and nurses you simply won't get access – we need political buy-in.'

No training, no morphine

Says Estelle du Toit, a professional nurse and the nursing director of the Matlosana Hospice in Klerksdrop, 'our biggest problem in the North West is that we don't have palliative care trained doctors. So most of them have a phobia for morphine.'

She says the only time her patients are prescribed morphine is when they have cancer *and* an oncologist treating them.

'The HIV clinicians never prescribe it – unfortunately we don't have our own medical practitioner here and the doctors at the State hospital won't prescribe morphine.'

With nearly all her charges State patients drawn from the

towns of Klerksdorp, Stilfontein, Hartebeesfontein and Orkney and surrounding townships and countryside, those with cancer have little difficulty in accessing morphine.

However, she says that for end-stage AIDS patients, acquiring morphine was 'virtually impossible'.

Using morphine with her end-stage pain-racked patients was often 'miraculous'.

She described an incident where one of her nursing colleagues could hear a cancer patient screaming in pain as she approached the house. She arrived to find neighbours holding her down.

'We admitted her here, administered morphine and within 24 hours she was peaceful and the pain was under control,' says Du Toit.

According to HPCA records, uptake of palliative care increased from 10 089 people (25% of them with AIDS) in the 1998/99 financial year to 47 535 patients in the 2005/06 financial year (69% of them with AIDS).

Dr Venter said reluctance to prescribe morphine was an international trend, even in developed countries. Several studies had shown that pain was under-treated even in the developed world. 'God help us in the developing world,' he added.

He challenged the 'excellent people' in palliative care in South Africa to design an instrument by which the efficacy of home-based care could be measured, citing Uganda where the quantities of morphine used were the instrument.

Referring to one of the motivations behind existing legislation, Venter said he had never seen a morphine addict among health care workers, 'pethadine sure, but not morphine'.

He was worried that because of home-based care and some of the palliative care courses, 'we've tended to de-medicalise end-of-life care. As well as nappy-changing and the mopping of brows, we need to dish out drugs. We're sitting here wringing our hands about things like respiratory depression, which is so very rare…instead of alleviating pain,' he said. Without medical intervention, psycho-spiritual support becomes difficult, if not impossible. Venter said another reason doctors were reluctant to prescribe opioids was that it required a signed motivation and increased paperwork.

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MCC Registrar 'willing to probe'

Ms Mandisa Hela, Registrar at the Medicines Control Council and head of the Medicine's Regulatory Authority, expressed willingness to meet with any top pain relief protagonists in order to eliminate as many barriers to pain relief as possible.

'First prize is obviously doctor, nurse and patient education, so they are not afraid of using morphine as a pain killer,' she said.

While she cautioned that safety was a top priority, she said South Africa could motivate to the United Nations Narcotics Control Board (NCB) for increased quantities of relevant opioids 'provided our request is solidly motivated'.

In the past high schedule drugs had sometimes been sent by the NCB to countries with weak regulation, 'resulting in untold problems'.

Hela agreed that the principle of 6-hourly dosing in hospitals 'simply doesn't hold', and suggested doctors investigate the newest formulations of self-injectable morphine that could be used by home-bound patients under supervision.

'Where there's proper home-based care I don't see why self-dosing isn't possible,' she added.

While a 30-day prescription was currently required from a doctor, there was a 'down referral system', where medication could be prepared at a 'higher standard' before being sent on to a clinic.

She disagreed that morphine use was a reliable indicator of home-based care efficacy but said she 'cannot dispute' the contention that tens of thousands of patients were suffering and dying in unnecessary pain because of barriers to accessing opioids.

Wits University's Palliative Care Unit has developed a unique self-learning course called 'An introduction to palliative care in HIV/AIDS and cancer'. Available free online and on CDRom, it is worth 8 CPD points and can be completed in 3 hours.

Website: www.free-learning.org, e-mail: training@witspalliative.co.za and telephone (011) 933-4916 (ask for Nozipho).

The learning module is WHO endorsed and gaining international recognition.

Chris Bateman