



SAVING THE PEOPLE OF THE SKY – ONE CHILD AT A TIME



Vibrantly positive – Izinhandane Orphanage housemother Elzeth Malherbe with her ART 'miracle' boys, Phiwe Chonco, 8 (left), and Ndumiso Majola, 10.

It's hard to imagine the feisty and robust Ndumiso Majola, now 10, crumpled and catatonic in Tugela Ferry Hospital for 4 years, his mouth covered with herpes sores, running boils on his arms and legs and suffering from tuberculosis.

Ndumiso is one of the four healthy children at the Izinhandane Orphanage – an impeccably provisioned and furnished two-bedroomed German-funded building intended as staff quarters to a home catering for 16 HIV-infected orphans.

That home, due for completion in August last year by agreement with KwaZulu-Natal's Department of Health, has yet to be built, delayed by bureaucracy and the political hangover of Pretoria's unseemly wrangle with the Global AIDS Fund.

All of the kids at the incipient orphanage are thriving in the embrace of full-time project manager, Elzeth Malherbe, a former local high school principal, but mainly because of

antiretroviral therapy (ART) and an unrivalled continuum of rural HIV care.

As admirable and inspiring as is the care of Malherbe and Dr Tony Moll, Tugela Ferry Hospital's Principal Medical Officer and the founder of the Philanjalo HIV/AIDS project, it meets an estimated 20% of this deep rural area's needs.

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Ndumiso's story perhaps best brings alive the dry statistic that 60% of Tugela Ferry's paediatric ward occupants are HIV-positive. Says Malherbe: 'When I got Ndumiso in April 2002 he was nearly dead. His CD4 cell count was 57 (now well over 800) and he was mute from depression – just a miserable little thing.'

At first Ndumiso would be discharged from the Tugela Ferry (also known as Church of Scotland) Hospital after 2 - 3 months, but he always regressed to his former condition and had to be re-admitted 6 months later. Then in June 2002 he began ART on drugs sourced overseas by a Belgian doctor, nearly 2 full years before the official South African ARV roll-out began.

'I would push him and 6-year-old Phiwe Chonco up the hill to the (nearby) hospital in a pram. They were so weak they couldn't walk,' Malherbe tells me over tea as 'her' two boys and pair of girls boisterously scamper about the house, teasing one another.

Malherbe slows them down with a loud but gentle admonition in English, the language that house rules dictate is spoken, even though she's a fluent Zulu linguist. All four children speak impeccable English and have a rapidly growing vocabulary.

Outside, a rain-muddied and swollen Tugela River flows serenely past, seeming to sound an ever-present ovation to this HIV/AIDS work, reassuring tens of thousands of Zulu families whose kraals dot the mountainous, lush thornveld up and downstream.

Ndumiso's particular hut was once occupied by just him and his 'Gogo' (grandmother), alongside the hut of an HIV-positive aunt, caring for six children, some of them her own. Then 'Gogo' suffered a stroke and the foster family grant was transferred, along with Ndumiso, to the aunt's family.

Explains Malherbe, 'We struck a bargain with the family and the social worker – that the grant continues to go to the aunt's family but the child (Ndumiso) comes here, to the orphanage – or he would have died'. Moll had told her that the child would not survive



Voluntary home-based carer, Ntombifuthi Mbatha (front), visits patient Qalangani Ngobe, her mother Tholakele and daughter Ayabonga, 3, on the banks of the Tugela River.

another hospital stay without daily close individual monitoring and care.

Philanjalo the backbone

Moll's HIV/AIDS project Philanjalo (meaning 'to be constantly well', fortuitously so named before the ARV roll-out), forms the backbone of Tugela Ferry's continuum of care at what is a vibrant and well-equipped 350-bed provincial district hospital.

Philanjalo's pivot is a prefabricated mobile home near the tuberculosis ward and serves as the HIV/AIDS clinic with 490 patients on ART (including 65 on a Yale University triple therapy study and 25 children).

This represents nearly 3 000 HIV-positive patients who have had blood drawn and CD4 cell counts done (a still-boxed CD4 machine lies luminously under a table in Moll's clinic consulting room, awaiting essential materials).

Bloods, drawn on a Tuesday, are sent by courier to the NHLS laboratory in Durban, with a turnaround time of 2 weeks.

The HIV clinic staff consists of six nurses, two counsellors, a data capturer and an all-important Gogo who represents patients and shoehorns in the most desperate, time and again, earning the tolerance and grudging admiration of overworked colleagues.

Philanjalo also runs the local 16-bed hospice, used with huge effect as a step-down facility for ARV patients needing

close monitoring in the initial difficult 2 or 3 months of ART and/or for stabilising pre-ART. These are patients who would almost certainly otherwise expire in the overburdened and understaffed main hospital.

No room to 'park'

'The hospital doesn't have the space to "park" someone like this,' explains Moll as he guides me from patient to patient in the hospice, outlining each one's symptoms, progress and background.

The hospital administrator aims for a minimum 7-day bed turnaround, preferably 4, but was averaging 11.

'Now, because of the hospice taking on such patients for up to a month, it's helped to bring hospital bed turnarounds down to between 4 and 7 days, and we've had miraculous recoveries, which is what keeps guys like myself going.'

One 'hospice' patient I saw had a CD4 cell count of 24 and was suffering three co-infections, all of which were being concurrently treated along with ARVs (which Moll claims some view as controversial). Says Moll, 'I'm trying to buy some time for her simply because I'm able to monitor her so closely. You can give them all-out treatment for these infections and they often succumb before you start ARVs – it's a last resort in a desperate situation and has worked in many cases where others have given up,' he explains.

Philanjalo also supports the TB DOTS programme with a vehicle and two staffers, began a drop-in HIV/AIDS advice centre in Tugela Ferry Village (now transformed into the State 'Sinozwelo' Drop In Centre that acts as a child day care and nutrition centre and offers HIV rapid tests, counselling and advice on State disability and foster grants).

Sinozwelo ('we have empathy') provides food parcels for 100 families, alternating the handouts from week to week to reach 400 families, beefing up the Izinthandane Orphanage NGO food parcel programme that feeds 18

households (73 people) for a month at a time.

Disability grants a vital tool

Moll, besieged with patient requests for the vital R740 disability grant, took matters into his own hands and successfully got permission from the Department of Social Welfare to authorise them. He seems ruthlessly strict on the clinical disability criteria, and once a patient is adjudged well enough to work again, he stops the grant. Very often this financial support can mean the difference between life and death when it comes to nutrition at the critically vulnerable, disabled stage.

In the 5 1/2-hour period I spent with Moll he saw 22 HIV-positive patients in his clinic, authorising disability grants where appropriate, making calls to employers in Gauteng to organise (with patient permission) work-friendly clinic attendance and ARV adherence and warning couples about the risks of multi-strain HIV infections.

An evocative human tapestry is woven as women and their infants are advised to be tested, husbands or partners are given results and strict ARV adherence training sessions are organised with a family member or close friend identified for support.

The HIV patients include a gunshot victim, several alcoholics, and TB sufferers in every manifestation imaginable. Each case is treated on its merits.



Eunice Malinga, 26, of Tugela Ferry, had a CD4 count of 19 in September 2003 and weighed just 46 kg. Today she is vibrantly healthy and revels in her HIV negative-born daughter, Mbali, 3.



Moll interrupts a patient with a baby on her back who is gushing her heartfelt thanks for the disability grant now putting food on her table with, 'well, you must take your pills, because I don't want you dying fat!' She grins widely, acknowledging the vital import of the message.

Come a long way

Moll says he diagnosed his first AIDS case in December 1989. By 1997 Tugela Ferry ward rounds involved stepping over patients lying on the floor to get to those in standard hospital beds. Recalls Moll: 'We came together under a tree at tea-time and asked ourselves where all this was taking us.'

The health department wasn't coming up with a solution and referral didn't help.

'So we decided to get the community on board and develop home-based care.'

Local resources consisted of Durban's Sinosizo ('we have help') Project and Doctors for Life (DFL) who conducted Philanjalo's first home-based care training. Moll and his colleagues translated the DFL training into Zulu and wrote their own manual, adapting it to local conditions.

Since then they have trained 250 home-based caregivers in the community, including voluntary counselling and testing once the HIV rapid test kit became available (2001) and created a best practice model for ensuing provincial government programmes.

Prevention of mother-to-child HIV transmission began with the advent of nevirapine the following year and the Tugela Ferry Hospital became one of the first six provincial pilot sites.

It also became one of the first four accredited ARV sites in the province, with Moll and his colleagues well ahead of the game with the Yale University ARV therapeutic study having started in October 2003, 6 months ahead of the State roll-out. 'That gave us a huge advantage in terms of confidence

because we saw with our own eyes how ARVs worked – people who were once very sick were carrying wood and picking crops again within 3 - 6 months. Government asked us where our social workers and pharmacists were – we said we don't have any but we're doing it!'



Shirley Shabalala travelled over 200 km from Bergville to Tugela Ferry Hospital where she was admitted to the hospice. Dr Tony Moll introduces her to a calendar with her ARV drug dose stapled to each day.

On 24 March last year the ART programme 'officially' kicked off at Tugela Ferry – the first deep rural site in KwaZulu-Natal and possibly the country — with the ever-alert BBC in attendance, giving it a tiny but unprecedented window of worldwide publicity. Noses were out of joint in Ulundi and Pretoria as the government's 'big announcement' was only scheduled for a week later.

Today they seem to have got over it with South Africa acknowledged as having the most ambitious public ART programme in the world, in spite of the ongoing and often acrimonious debate around the speed of its implementation.

Home-based care triumphs

Yet it is home-based care that is arguably Philanjalo's greatest victory in the face of such odds – one that current wisdom believes to be the only answer to overflowing hospitals.

An *Izindaba* visit to the homes of three of home-based care volunteer Ntombifuthi Mbatha's 27 charges revealed how ARV is fast changing the stigma surrounding the pandemic. Each of the young women, two of them with HIV-negative children, was ARV-adherent, healthy and spoke of how well their families and communities accepted them upon learning of (or witnessing) their HIV/AIDS status.

'Even when I was very sick, my friends remained my friends and my family encouraged me to check my status at the clinic,' says Qalangani Ngobe, 24, who matriculated 4 years ago.

She began ART 15 months ago (CD count was 109) and her weight has crept up to 41 kg from a low of 39 kg. 'At first the pills made me dizzy and I had diarrhoea and vomiting. Then came the headaches. Now I have nothing except my legs feel a bit numb with sharp pains under my feet,' she says brightly.

I ask Ntombifuthi Mbatha how involved the local tribal chiefs are with HIV/AIDS care and awareness in the valley. She says they are 'very quiet' and 'don't really play a leading role'.

How come she does home-based care for no remuneration whatsoever? 'It's in my heart to help. We are believers and I want to give people hope,' she responds simply.

A Christian theme runs strongly through the entire rural community, with treatment literacy trainers often using biblical metaphors to drive their message home.

One such, Gogo Mbongwa, stridently urges her ARV students, 'now if you vomit up the pills or get diarrhoea or have problems, come to the hospital. It doesn't matter how busy or short-tempered we are — you keep tugging on our clothes until you get our attention, just like that woman did with Jesus – and you saw how she was healed!'

Chris Bateman

Pictures in article: Chris Bateman