

ARVs bring hope to Pondoland

by Steven Robins

15.03.2004

An unconventional approach to health provision at the Medicins Sans Frontieres first rural HIV/AIDS programme in Lusikisiki has yielded impressive results.

Driving through Lusikisiki one is struck by the green rolling hills, the healthy looking cattle grazing in village pastures and the endless fields of maize. For those in the know, the extraordinary biodiversity of the area – with its over 1700 indigenous plants – is as impressive as the rolling hills and the maize fields. This high rainfall and fertile part of the picturesque Wild Coast is very different from so many other communal areas in South Africa that regularly experience drought.

But the statistics show that not all is well in Pondoland. The district, like so many parts of South Africa, has an extremely high HIV infection rate of 24% - high for rural areas in the Eastern Cape.

It also has an under-resourced provincial health department. As we drove past Lusikisiki's provincial hospital, St Elizabeth's, Herman Themba (Hope) Reuter, the MSF (Medecins Sans Frontieres) doctor responsible for Lusikisiki's HIV/AIDS programme, pointed out the shacks that served as the accommodation for the hospital's nursing staff. Further on we passed old shipping containers that comprised the main Lusikisiki Village Clinic. Dr Reuter spoke about the enormous capacity and resource problems facing the Eastern Cape health system and the difficulties of attracting and retaining nursing staff in such contexts. More than 50% of the hospital posts were not filled because of these problems. Only dedicated health professionals were prepared to remain in this deep rural part of the Eastern Cape Province.

The lack of HIV policy on ARVs did not deter the thirty-something doctor, who

immediately set about training nurses, local TAC volunteers and counsellors on HIV/AIDS treatment and voluntary counselling and testing (VCT).

A few months later there was a cohort of well-trained and committed health workers ready to embark upon treatment.

When MSF doctors and nurses and TAC activists began their ARV treatment 'trial' in 2000 in Khayelitsha, Cape Town, they were fully aware that they had their work cut out for them.

Government and public health sceptics seemed to have concluded that the public health system would not be able to implement what was portrayed as an unaffordable, complicated and inappropriate 'First World' AIDS treatment regimen.

By implementing an ARV programme in a working class urban African context, MSF doctors and nurses hoped to challenge those who believed that this medical technology was inappropriate for Third World contexts. As the findings of the studies of the efficacy of the Khayelitsha programme began to be released it became clear that ARVs could work in Africa.

Sceptics were still not satisfied. The next problem they posed was whether it would be possible to replicate an urban-based ARV programme in a rural site. Influential public health professionals and academics argued that a dysfunctional and under-resourced public health system, along with rural poverty and inadequate sanitation and poor nutrition in most rural areas, meant that the Khayelitsha programme could not be reproduced in most parts of the country.

Whereas the Health Minister's prescriptions of garlic, African potatoes and olive oil as alternatives to ARVs could be dismissed on strictly scientific grounds, the dire conditions in underdeveloped rural areas had to be taken seriously. It was with this in mind that MSF and TAC identified the Eastern Cape Province health district of Lusikisiki in Pondoland as their first rural ARV

site.

Their first line of attack was opportunistic infections (OIs). Prior to the arrival of MSF, nurses knew extremely little about HIV/AIDS, and had no training on treating people with HIV with the drugs already in their clinics .

Patients who presented typical HIV symptoms were simply sent back to their home villages and told to prepare themselves for death. With the arrival of MSF, clinic nurses were empowered with knowledge and drugs to treat thrush and a range of other OIs. This created a new sense of confidence amongst nurses, volunteers, counsellors and ordinary villagers.

Suddenly HIV/AIDS was no longer a death sentence. Treatment of opportunistic infections dramatically altered popular perceptions about this dreaded disease. Even though ARVs were not yet available in the local hospitals and clinics there was a palpable sense of hope amongst AIDS activists and health professionals.

Nurses were learning that it was possible to treat HIV/AIDS, and those diagnosed with HIV-positive were no longer seen as the walking dead. By the time national government announced its national ARV treatment programme in October 2003, Lusikisiki health workers were trained and ready.

Fast-forward to February 2004 and a group of counsellors discussing their experiences working in the area. Many of these HIV-positive counsellors tell of the initial disbelief amongst villagers when they publicly disclosed their status. Villagers claimed that the MSF counsellors were paid to say they were HIV-positive. How could they be HIV-positive when they looked so healthy? The treatment of opportunistic infections had created a dilemma for these counsellors.

As one counsellor recalled of her early counselling sessions: 'Some of the villagers would say to me, 'You look so fat and beautiful and your skin looks so smooth, how can we believe that you have this thing?'

Another counsellor based at St. Elizabeth Hospital spoke of how a taxiload of HIV-positive Umtata residents who had heard about MSF's treatment programme arrived at Lusikisiki demanding to be treated: 'Dr Themba examined them, gave an appropriate prescription for their problems but told them that they should go back to Umtata and demand ARV treatment from Umtata clinics which are designated ARV sites.' For MSF the problem was no longer that of challenging government over AIDS policies, but rather applying pressure on the health service to ensure that treatment policy was implemented properly.

The accounts from the counsellors revealed that the treatment of opportunistic infections (OIs) had contributed significantly towards breaking the silence and stigma surrounding HIV/AIDS. Dr Reuter, the nurses and the counsellors all spoke of the dramatically increased demand for treatment from Lusikisiki residents.

The demand for AIDS testing too was up, as was the treatment of OIs. TAC Treatment Support Groups were flourishing and HIV-positive T-shirts are visible in the streets of Lusikisiki town. This relative openness was largely the result of MSF's policy of encouraging disclosure in their counselling approach. Before someone was tested they were asked whom they would disclose their status.

Zikhona, a twenty-year old TAC activist, spoke of how she had been awarded a bursary to study medicine in Cuba. Upon being told that the Cubans insisted on medical examinations she went to get tested for HIV/AIDS. She was devastated when she discovered her HIV-positive status. Only after testing for a second time – this time receiving counselling by an MSF counsellor did she accept the results. She disclosed to her high school teachers, fellow students and members of the community.

Zikhona was regarded as Lusikisiki's star student. A teacher offered to pay for her ARV treatment however her immune system is still strong and there is no need for the drugs. Following meetings with Dr Reuter and other MSF and

TAC activists, Zikhona joined TAC. She is openly HIV-positive and does workshops in schools and churches throughout Lusikisiki.

At workshops for local teachers she is often told that she should go home because children cannot teach teachers anything.

'Why do MSF send children to educate us about this disease?' However, once she begins speaking the teachers are usually quick to realise that she is much older and wiser than her age and youthful looks suggest. Her knowledge of HIV/AIDS is impressive and this wins over the teachers.

Another catalyst for this open attitude towards HIV/AIDS in Pondoland was the Cape Town 'stand up for our lives' march on Parliament in 2003. A large contingent from the newly formed TAC branches in Lusikisiki came back from the Cape Town march highly motivated and aware that they were part of a national social movement. Many of the key HIV-positive TAC activists realised that their personal experiences were similar to thousands of other South Africans. They were no longer alone.

In just over a year, Lusikisiki has been transformed from a place where HIV/AIDS was a taboo topic, to a place where hundreds of HIV-positive people are open about their status and flocking to the clinics.

Rather than opting for the protection of privacy and confidentiality, MSF and TAC chose to push the disclosure line. All of this in the heartland of rural Pondoland, a place portrayed by government officials as characterised by conditions of chronic poverty, illiteracy and ignorance. Government and public health sceptics had assumed that these were insurmountable obstacles to the implementation of ARV programmes.

Post-apartheid South Africa has provided MSF with an ideal opportunity to challenge mainstream biomedical and public health approaches to HIV/AIDS in the Third World. The emergence of TAC as a grassroots based social movement created the conditions for MSF's empowering vision of health citizenship. TAC's massive support base provided MSF with the necessary

political legitimacy and credibility to intervene in South Africa. This partnership has been extremely strategic in rural Eastern Cape. .

Professor Rene Fox, a sociologist of MSF, notes that whereas in the past MSF had sought to be neutral and non-partisan in its interventions, the conditions in South Africa forced the organisation to take a more overtly political stand.

Given TAC's civil disobedience campaigns, court cases and street demonstrations, MSF could not afford to treat its South African mission as 'business as usual'.

Shortly after starting to provide generic ARVs to patients at the beginning of this year, there are already successes. After three months on ARVs, Bomikazi, a young women who was asked by her stepfather to leave his house because she had become too sick for him to look after her, is now healthy and has found employment. She has a partner again after many months of being too ill to even think about sex.

Together with Dr. Reuter and Zikhona we visited Bomikazi at her mother's 'RDP' house in Joe Slovo, a new low-income housing scheme on the outskirts of Lusikisiki. Bomikazi told us how she was extremely ill when she arrived at the clinic. She tested HIV-positive, and after she disclosed her status to her family was forced to use separate plates and eating utensils. She now lives with her sister who is very supportive. Bomikazi asked Dr. Reuter whether it would be wise for her to have a baby with her new partner. This triggered a lengthy and lively discussion about whether it made sense to get pregnant with a man she had only known for three months: Would her new boyfriend stick around once he knew she was both pregnant and HIV-positive? Bomikazi responded that she wanted a child even if it meant she would end up raising the baby on her own. In any case, she said, most of her female friends were single mothers. The conversation covered topics such as men who absconded responsibility upon pregnancy, domestic violence, secrecy and disclosure, trust and support groups, and the TAC's goals and strategies

for achieving gender equality in relationships. Dr. Reuter was interested to know whether TAC helped young women navigate their way through this gendered battleground. It appeared that while young women such as Bomikazi are considerably more empowered than their mothers, gender inequality is still deeply entrenched and part of everyday life in Pondoland.

These conversations between Dr. Reuter and his patients reveal an approach to HIV that goes well beyond conventional medical practice. This method challenges the aura of expertise, authority and paternalism that characterises most public health encounters between doctors and nurses and their patients. Engaging openly with issues of gender relations, sexuality, marriage, and pregnancy breaks down the traditional hierarchies and barriers between the health expert and the passive and docile patient. Perhaps this accounts for the successes of the Lusikisiki programme. But could this approach be replicated in more conventional public health settings? Sceptics suggest that it could work in the cities, but not in conservative rural communities. MSF's decision to start an ARV programme in rural Eastern Cape was an attempt to test these assumptions.

Choosing Pondoland as the second MSF ARV site was bound to be an enormous challenge. No doubt the sceptics will once again argue that the successes of the Lusikisiki programme are a result of the specific contributions of MSF and TAC, and that ARVs are unlikely to succeed in other rural sites. A more useful response is to investigate what it is that MSF and TAC are doing in Khayelitsha and Lusikisiki, and whether these methods can be used and adapted in other ARV rollout sites.

It would appear that the decision to opt for a nurse and community-driven treatment programme was a key factor in MSF and TAC's successes in Lusikisiki and Khayelitsha.

Sceptics continue to question whether an overstretched and under-resourced public health system could reproduce this model without the involvement of organisations such as MSF and TAC.

But MSF staff insist that these ARV programmes are not exceptional and they can be replicated, with adjustments, elsewhere.