

Implementing HIV/AIDS services including ART in a rural resource-poor setting

Siyaphila La Programme - Lusikisiki, Eastern Cape



Activity Report 2003 - 2004

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Picture cover: First ARV patient, Nontsikelelo, with her treatment assistant, Fungiwe, on her first day of taking ARVs (November, 2003).

Acknowledgements

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Abbreviations

3TC	Lamivudine
ARV	Antiretroviral
ART	Antiretroviral Therapy / Antiretroviral Treatment
AZT	Zidovudine
D4T	Stavudine
EFV	Efavirenz
IQR	Inter-quartile Range
MSF	Médecins Sans Frontières / Doctors without Borders
NHLS	National Health Laboratory Service
NVP	Nevirapine
PMTCT	Prevention of Mother-to-Child Transmission
TAC	Treatment Action Campaign
TB	Tuberculosis
STI	Sexually Transmitted Infections
VCT	Voluntary Counselling and Testing

Background

MSF has worked in South Africa since 1999 providing medical care for people with HIV/AIDS. The first programme was implemented in Khayelitsha near Cape Town, the largest township in the Western Cape. The Khayelitsha programme was the first to provide dedicated HIV/AIDS services, including antiretroviral (ARV) therapy in a peri-urban resource-poor setting with high levels of infection. The Khayelitsha programme is run in partnership with the Provincial Administration of the Western Cape. Inspired by the impressive clinical outcomes and the acceptability of the programme by the community in Khayelitsha, MSF decided to set up a new programme in a rural setting in the country, in order to explore the particular challenges of delivering services in rural settings with even less developed health care infrastructure.

With this aim, in February 2003, MSF - in partnership with the Nelson Mandela Foundation - started operating in Lusikisiki, in the former Transkei (Eastern Cape Province). Lusikisiki, Flagstaff and Bizana make up the Qaukeni sub-district. Qaukeni is a local service area (LSA) of the Oliver Tambo district.

Lusikisiki has a provincial hospital – St. Elisabeth – and 12 primary care clinics which serve a population of about 150,000 people (figure 1). Clinics are between a 30 minute and one hour drive from the hospital. Antenatal HIV-prevalence is amongst the highest in rural areas of the country. Thirty-three percent of women testing during antenatal care are HIV-infected. It is estimated that today about 1,500 people are in need of ARV treatment in Lusikisiki.

The first months of the Lusikisiki programme were devoted to the implementation of basic HIV/AIDS services, co-ordinating with district and provincial authorities and supporting the Treatment Action Campaign (TAC) in building the community response to HIV.

In October 2003 the Department of Health of the Eastern Cape gave the go-ahead to MSF to start providing ARV therapy in Lusikisiki. The first patients were started on ARV therapy in late October 2003. In October 2004, the Lusikisiki programme was accredited as part of the national government ARV roll-out plan.

The present report aims to review key outcomes, strategies and future challenges after two years of experience providing HIV/AIDS care – including ARVs - in Lusikisiki.

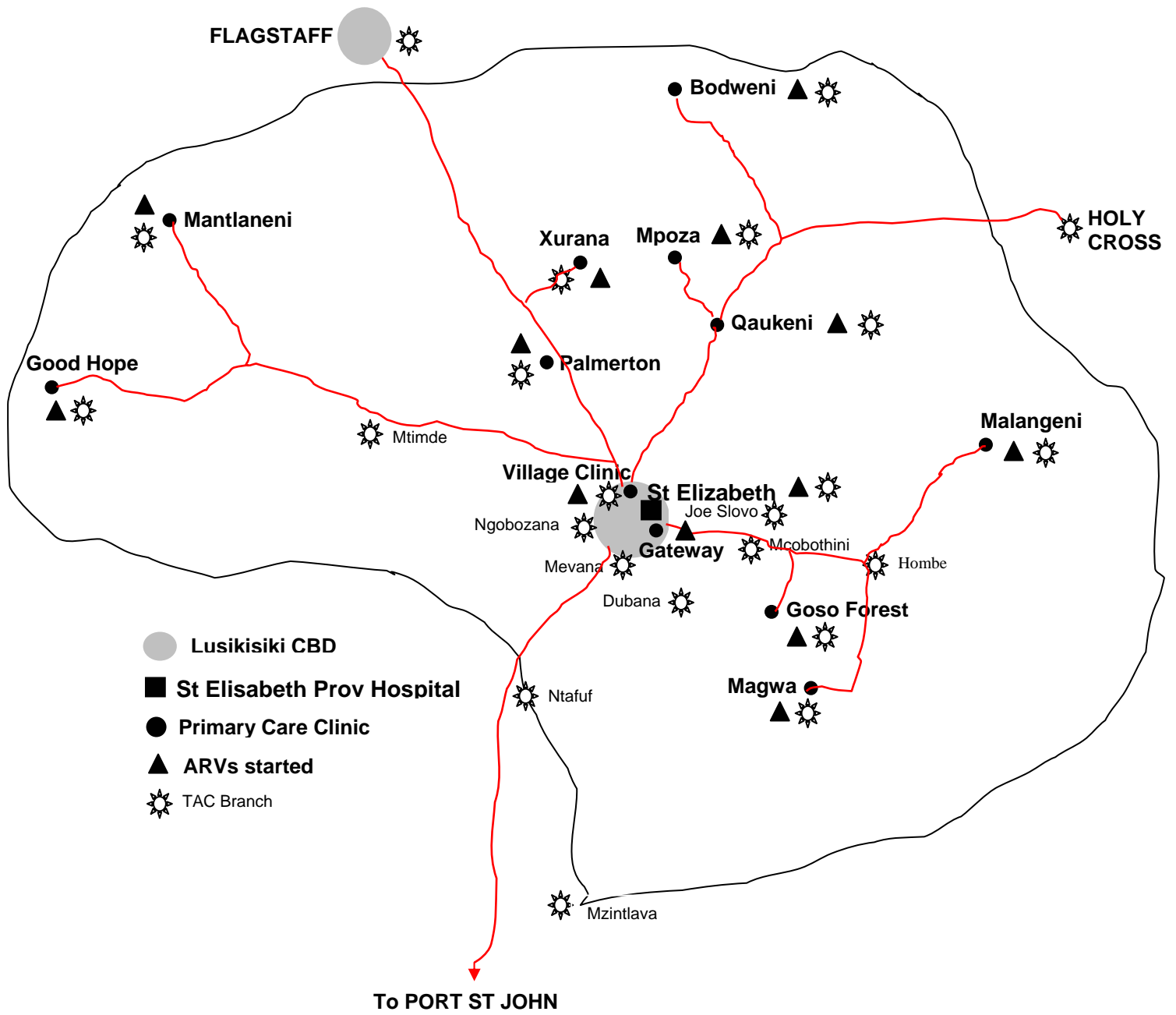


Figure 1. Map of Lusikisiki with detail of health services, ARV sites and TAC branches (updated on February 2004).

Voluntary Counselling and Testing (VCT)

At the beginning of the programme HIV testing was only available in the hospital and it was usually provided based on clinical indications rather than people coming forward for counselling and testing (VCT). Rapid tests and formal counselling were not available. Implementation and promotion of VCT was thus prioritized. Through selection and training of counsellors, supply of rapid tests and training of nurses to perform the tests, VCT was rapidly made available in all the clinics and in St Elisabeth's hospital. From the first month of the programme, about 600 people were getting tested in Lusikisiki per month. The number has doubled over 2004 (figure 2). Most of the people tested are adults. The demand for VCT services has been boosted by the community education work done by the Treatment Action Campaign. District authorities took over the VCT programme in mid-2004. The numbers of people testing dropped during the transition, but picked up again in the second half of the year.

The VCT figures show a very high HIV-prevalence in those testing. The median proportion of those testing positive in a month since the beginning of the programme is 42% (IQR=39%,44%), and this proportion has remained stable over time.

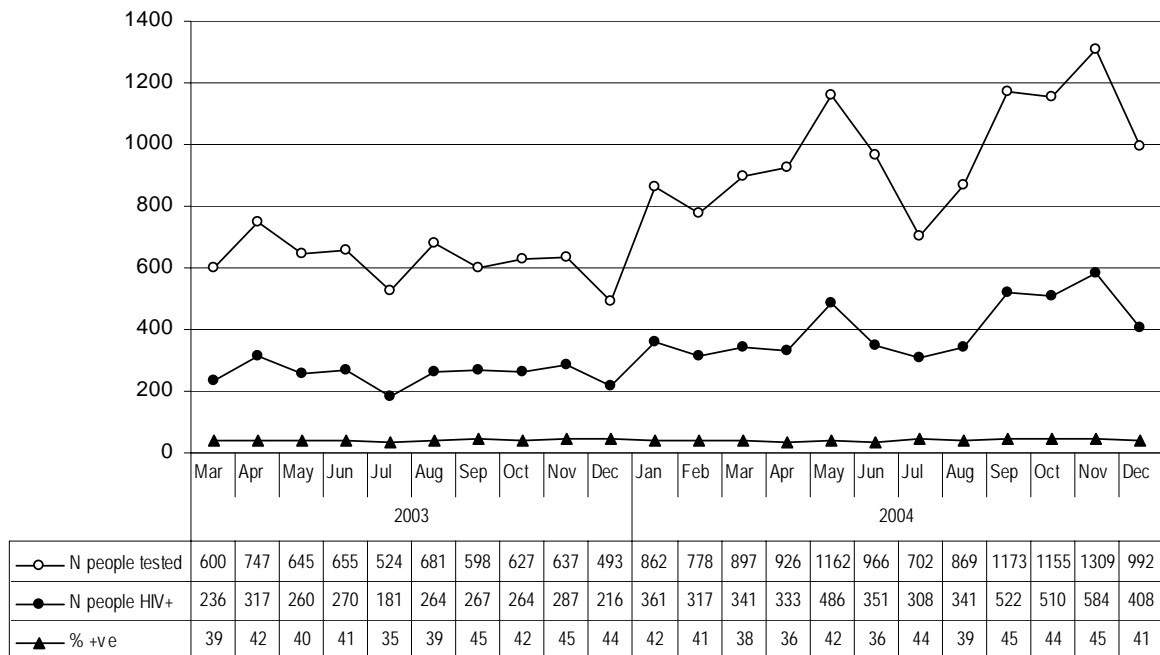


Figure 2. Monthly uptake of VCT and prevalence of HIV infection in all clinics and referral hospital since March 2003 until December 2004.

Prevention of Mother to child transmission (PMTCT)

Simultaneously with VCT a PMTCT programme following the national guidelines was initiated. The idea was that where possible, VCT should provide a direct benefit to the person testing. Initially this program was started by MSF in six different LSAs including Lusikisiki. The management of PMTCT in all six areas had been handed over to the Department of Health by April 2004.

Developing a routine follow-up service for people with HIV

Previously HIV-infected people only made use of medical services for acute illnesses. Following an increase in the numbers testing HIV-positive through the expanded VCT service, the urgent for a “wellness service” emerged. Nurses were trained in the management of opportunistic infections and the provision of cotrimoxazole prophylaxis. Some new drugs like acyclovir, griseofulvin and amitriptyline were introduced. A folder system was developed to be able to keep good clinical records on each patient. Within a few months each clinic could provide an HIV-specific service as part of their comprehensive service. Distribution of condoms also became a routine activity at clinics with the help of clinic committees.

Initiation of ARV treatment

Initially, ARV treatment was only provided in the clinics. The hospital started enrolling patients in April 2004.

Patient enrolment onto ARV treatment follows a similar procedure to the one initially followed in the Khayelitsha programme. Candidates to start ARV treatment undergo a preparedness process through several sessions with the counsellors and the nurses. Patients are required to select a person close to them who will act as their treatment assistant. A home visit is performed to verify physical address and do a brief evaluation of the social support received by the patient. A selection committee comprised of clinic staff, service users and other community members anonymously reviews clinical and social issues for each candidate and determines if they are ready to start ART or if they should be referred back to counselling and education.

Figure 3 shows the evolution of enrolment of patients onto ARVs in Lusikisiki’s hospital and clinics. The clinics initiated treatment enrolment in October 2003, whilst the hospital started later. To illustrate the distribution of ARV patients in the district, figure 4 presents detail of the number of patients per clinic in December 2004. All but two of the clinics had less than 25 people on ARVs. Village Clinic had enrolled a much higher number of people (124). Being located in Lusikisiki town, this clinic not only serves its residents, but also people from remote areas of Lusikisiki with poor clinic access, as well as others coming from neighbouring towns like Flagstaff, Bizana and Port St John where ARVs are not yet available.

By the end of December 2004, a total of 551 people were on ARV treatment in Lusikisiki, 6,7% of them being under the age of 14 (N=37).

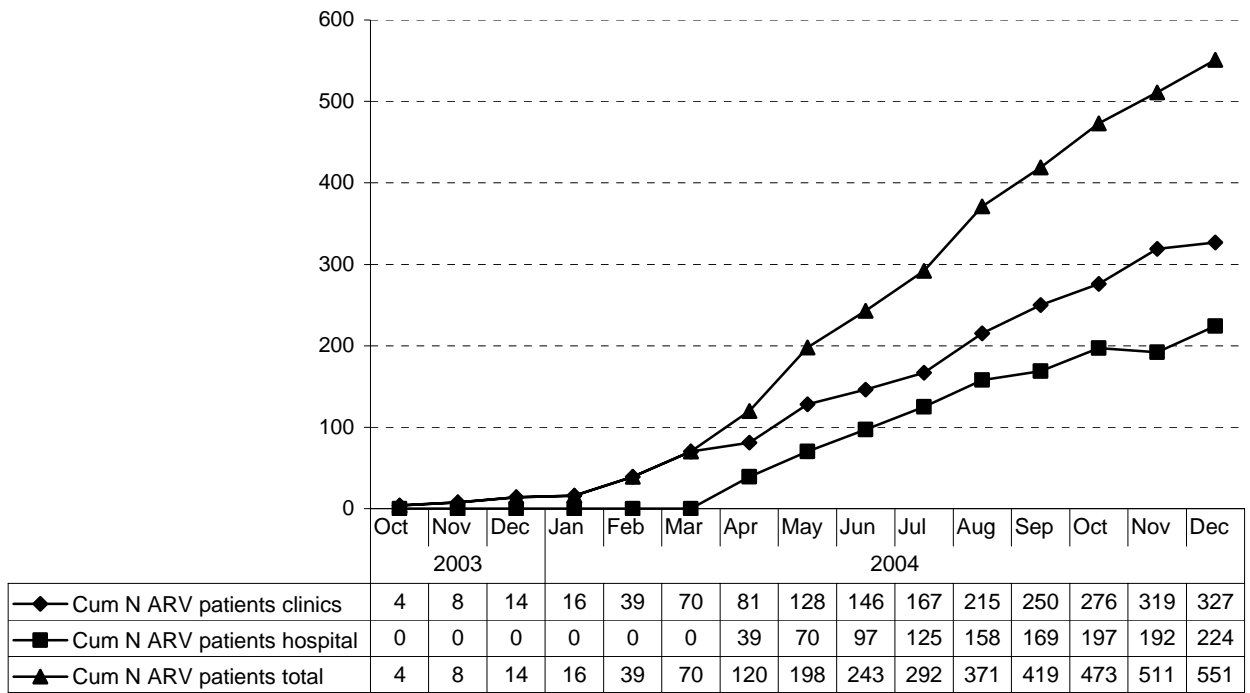


Figure 3. Cumulative number of patients on ARV treatment from October 2003 to December 2004 in the 12 primary care clinics, in the hospital and total.

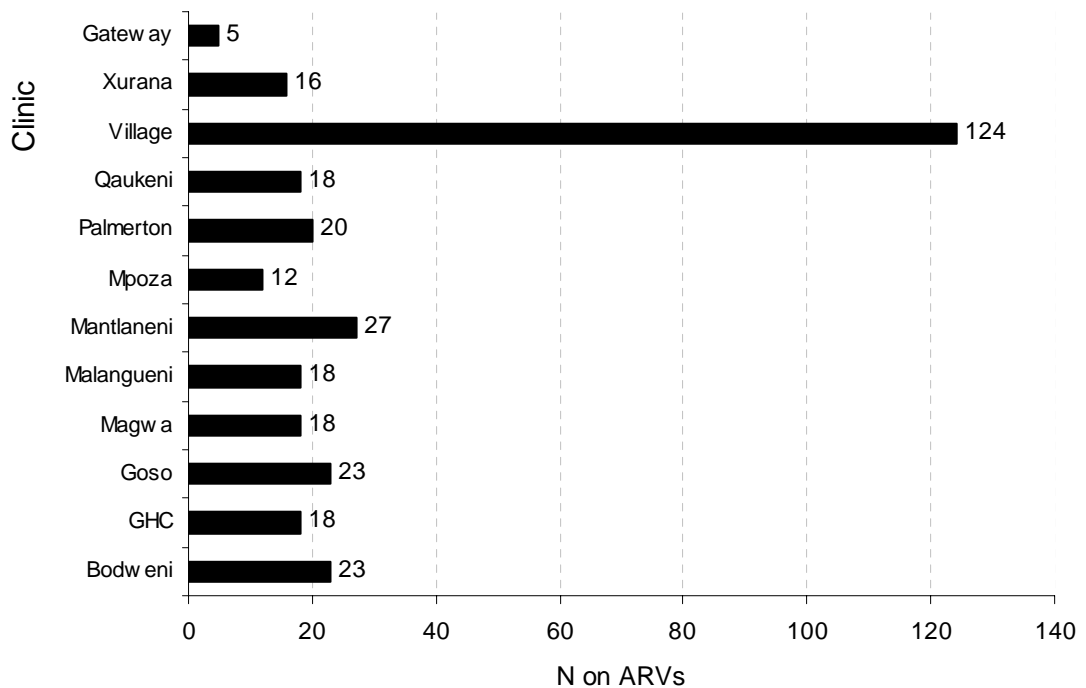


Figure 4. Number of patients on ARV treatment per clinic by the end of December 2004.

Adherence support

In order to ensure that ARVs work well and are effective for as many years as possible, patients must adhere to the medication. The decentralised model of care of the Lusikisiki ARV programme, providing treatment and counselling at primary care clinics, has advantages for adherence support. It brings the ARVs close to the population served rather than expecting the patients to travel long distances to reach secondary or tertiary hospitals.

Adherence in Lusikisiki is supported using a model adapted from the Khayelitsha ARV programme. With a patient-centred approach, patients are encouraged to take responsibility for their medication and their own health. The model comprises thorough patient education on the benefits and side effects of ARV treatment prior to treatment initiation, and continuous support with participation in support groups, self-nomination of a treatment supporter and the availability of adherence counsellors for one-to-one sessions. Adherence to tablets is verified by regular pill counts on return dates at clinics. Pill boxes and printed material are provided as adherence-aids.

Clinical outcomes after six months on ART

This section summarises the profile and clinical outcomes amongst the cohort of adult patients who by December 2004 had been on ART for at least 6 months (N = 147). All patients included in this analysis were treated and followed up in the primary care clinics.

Three out of every four patients in the cohort are women (76%), a slightly higher proportion than in Khayelitsha for the same follow-up period (table 2). The median age of these patients at treatment initiation is 31 years (IQR 28–39). Women start ARV treatment at slightly younger than men (32 and 35,5 years of age, respectively). The median CD4 cell count at baseline for these patients was 80 cells/ μ l (IQR 31-137).

Patients eligible for ART were started on the first-line regimen recommended by the National ARV protocol: Stavudine (D4T), lamivudine (3TC) and nevirapine (NVP) or efavirenz (EFV) (ratio 2:1, NVP vs EFV).

At the moment of printing this report, 76 of the 6 month follow-up viral load results have been received. Besides deaths (N=28), the rest of missing results are due to missing viral load tests (N=21) and results not received yet from the laboratory (N=19), patients' referral to other treatment sites (N=2) and discontinuation of therapy (N=1). Of the 76 patients with completed 6-month viral load results, 91% show undetectable levels (below 400 copies/mL). Table 1 shows gains in weight and CD4 cell count after 6 months on ART.

<i>Baseline</i>	<i>After 6 months on ARVs</i>	
<u>Median weight (N = 147)</u> 51 (IQR 45-59,5) kg	<u>Median weight (N = 116)</u> 60 (IQR 52-68) kg	<u>Median weight gain (N = 116)</u> 5 kg
<u>Median CD4 (N = 147)</u> 80 (IQR 31-137) cells/ μ l	<u>Median CD4 (N = 116)</u> 258 (IQR 203–397) cells/ μ l	<u>Median CD4 increase (N = 116)</u> 196 cells/ μ l

Table 1. Changes in CD4 cell count and weight after 6 months on ART as compared to baseline.

For comparison purposes, table 2 includes outcomes observed in the Khayelitsha clinics after the same follow up period. The median age and gender ratio of people starting ART is similar in both settings, as well as the weight gain after 6 months of ARV treatment. The baseline CD4 cell count of the Lusikisiki cohort is double than the one observed in Khayelitsha.

All patients	N = 287
Median age	31 (IQR 28-37) years
Women	201 (70%)
Median CD4 cell count at baseline	43 (IQR 13-94) cells/ μ l
Duration of follow up (all)	13.9 (IQR 9.2-18.1) months
Patients with viral load < 400 cps/mL after 6 months	89.2%
Mean CD4 cell count gain after 6 months	199 cells/ μ l
Median weight gain after 6 months	5.0 kg
Survival at 6 months	88.1%

Table 2. Baseline characteristics and clinical outcomes of patients receiving ARV treatment in the Khayelitsha HIV/AIDS clinics (published in *AIDS* 2004, 18: 887-895).

Regimen durability

The occurrence of side effects was minimal. Three patients changed due to side effects. Two patients changed to AZT due to peripheral neuropathy and one patient changed to lopinavir boosted with ritonavir due to lactic acidosis. No serious side effects were observed.

Patient retention and survival

No patient was lost to follow-up. From the 147 who had completed 6 months of therapy by December 2004, 28 died and 3 stopped treatment in the Lusikisiki clinics. One of them decided to stop treatment three weeks after initiation. Today he is still alive and sometimes visits the clinic. Two further patients moved away from Lusikisiki - one to Pretoria and one to Kokstad - and were referred to those respective sites where they continue therapy.

The survival rate (80,9%) is slightly lower than the one observed in Khayelitsha after 6 months of treatment (88,1%). All these deaths are due to HIV related opportunistic infections with bad prognosis at the moment of treatment initiation (table 3).

Drugs used: Simplifying ART and minimizing cost

Of the 551 people on ART treatment by December 2004, 152 receive a 3-in-1 fixed dose-combination (FDC) containing stavudine, lamivudine and nevirapine. This formulation is imported from Cipla (Triomune®) at a monthly cost of R126 per patient. It considerably simplifies administration since patients only take two pills to complete their daily requirements of ARV medication. The cost of this formulation is 2,3 and 2,5 times cheaper than the lowest possible prices available in SA for the loose formulations in the private sector (R298, Cipla-Medpro; R318 Aspen Pharmacare).

Triomune® is still awaiting registration at the Medicines Control Council (MCC). MSF currently obtains authorisation from the MCC to use Triomune® in Lusikisiki on a patient-named basis. Triomune® is included in the list of drugs whose quality has been pre-qualified by the World Health Organisation.

All other patients receive individually formulated combinations of the same drugs from a range of sources, with a total daily pill burden of 5 or 6 tablets.

	<i>CD4</i>	<i>Weight</i>	<i>Cause of death</i>	<i>Time on ART (months)</i>
1	1	30	Kaposi Sarcoma	M-1
2	1	35	Disseminated TB	M-1
3	28	67	Diarrhoea, TB	M-3
4	108	50	PCP	M-3
5	33	62	TB	M-2
6	96		TB	M-6
7	130	41	MDR TB	M-4
8	42	40	Sudden death	M-1
9	80	27	Wasting syndrome; TB	M-1
10	9	43	TB	M-1
11	91	40	Disseminated TB	M-1
12	169	38	Extra pulmonary TB	M-2
13	136	55		M-1
14	46	38	TB	M-2
15	33	37	LRTI	M-1
16	28	39	PCP/TB	M-3
17	0		Kaposi Sarcoma	M-5
18	11	39	CMV	M-4
19	42	51	Cryptococcal meningitis	M-3
20	174		MDR TB	M-1
21	8	51	Kaposi Sarcoma	M-4
22	55	35	Shortness of breath, TB	M-0,5
23	84	55	TB (re-infection)	M-1
24	102	52	TB	M-2
25	23		Advance immune-suppression; poor compliance	M-2
26	66	43	Traditional herb intoxication	M-4
27	68	51	Extra pulmonary TB	M-1
28	188		Status epilepticus	M-3

Table 3. Baseline CD4 count, weight, cause of death and time from treatment initiation to death of all patients on ARVs who died.

Strengthening primary health care for the implementation of ARV treatment

Nurse based ARV programme

In a setting like Lusikisiki, with a high prevalence of HIV infection and a rural population which mostly accesses primary care clinics, implementation of HIV/AIDS care and ARV treatment at rural clinics is critical in terms of proximity to patients and promoting long term adherence. Nevertheless, the scarcity of human resources in the health sector is a major barrier to the implementation of a decentralised model of care. Health services in Lusikisiki are delivered almost exclusively by nurses. Many nursing posts are vacant (30 in St Elisabeth hospital and 25 in the clinics early in 2004), and the number of vacancies has not been reduced in the two years of MSF's presence in the district despite the fact that Lusikisiki has a nursing school which trains about 30 nurses per year. Only those retiring or taking long-term leave are formally replaced.

In order to be able to implement comprehensive HIV/AIDS care in these circumstances we opted for a decentralised model based on nurse-delivered primary care. Nurses based in the 12 rural clinics were trained in VCT, treatment of opportunistic infections and ARV management. Their work is supported by mobile teams each comprising one doctor or one specialised nurse employed by MSF. Mobile teams do weekly visits to all clinics and do on-site training and monitoring of the clinical work, progressively empowering the local staff. In addition, the role of community workers has been redefined as described below.

Adherence counsellors: The backbone of the ARV programme

Crucial to the success of the Lusikisiki programme is the involvement of *community health workers*. These are community members trained in specific tasks that support the implementation of HIV services. The concept of community workers has already been used by the provincial department of health to overcome the human resources shortage in delivering essential health services. The department's *clinic volunteers* are trained to educate communities about immunisation, breast feeding, family planning, sexually-transmitted infections (STI's), and to be directly involved in TB and HIV management and home-based care. In 2004 MSF trained clinic-volunteers in VCT prior to the district taking over the VCT programme.



Pic 1. MSF counsellors are the backbone of the ARV programme.

The introduction of the ARV programme required the creation of two new categories of facility-linked community workers: adherence counsellors and pharmacy assistants.

Adherence counsellors were recruited from community volunteers already supporting the implementation of HIV/AIDS services. They received on-site training for one year. Their tasks include preparing patients for ARV initiation, ensuring adherence to the medication and following-up patients with adherence problems. They are essential to the successful outcomes of the programme, currently constituting the backbone of the HIV services. Each clinic has one adherence counsellor, except for Village clinic and St Elisabeth's hospital which have two.

Pharmacy assistants are another essential category of community workers. They fill critical shortfalls in the existing pharmaceutical services in the district, improving dramatically their effectiveness. Pharmacy assistants were also recruited from community volunteers already



Pic 2. Doctor and pharmacy assistant do home-visit.

involved in the programme, and incorporated in the clinic and hospital teams. They are trained and supervised by the district and hospital pharmacists, and have received additional training in ARVs from MSF. Their responsibilities include managing the stock of drugs in the clinics including ARVs as well as drugs for TB and other opportunistic infections. They are responsible for ensuring minimum stock levels, maintaining stock cards, placing orders and following up on deliveries.

Decentralised drug management

The initial phases of the Lusikisiki programme required an intensive effort to improve drug supply and management. Stock-outs of essential drugs, including TB drugs, were common to the extent that the inefficiency of the pharmaceutical system was considered the second largest constraint after human resources. MSF pushed for the addition to the clinic stock of key drugs to treat HIV related conditions, including acyclovir, fluconazole, betametasone and starter packs for post-exposure prophylaxis. Supply of some HIV/AIDS related medicines from the provincial depot in Umtata has not yet been consistent, and MSF has had to continue supplying some of these drugs.

The introduction of pharmacy assistants has been critical in improving the pharmaceutical services.

Laboratory services for diagnostics and monitoring

Following negotiations with NHLS (National Health Laboratory Services) and provincial authorities, a flow-cytometer was installed in the laboratory of St. Elisabeth's hospital to perform CD4 cell counts. The laboratory technicians were trained by NHLS. The turn around time for CD4 cell counts at clinics is two weeks.

Viral load tests for Lusikisiki patients are currently being performed at the new laboratory in the *Nelson Mandela Academic Hospital* in Umtata. A district vehicle collects specimens and delivers results on a weekly basis. MSF assists with transport of specimens through the mobile teams. The turn around time for viral loads is six weeks.

Developing management capacity at district level

The District Administration is a key partner in the programme. Since the beginning of the HIV/AIDS programme. It has strengthened the management in the Lusikisiki clinics by employing two new primary health care supervisors. An additional three are responsible for the other two local service areas (Bizana and Flagstaff). The post of *HIV programme manager* that has been vacant since April 2004 has also finally been filled. MSF participates in a number of management committees at district level, including the *HAST* committee (HIV/AIDS, STD, TB) and the HIV steering committee. To support health administrative capacity, MSF hired a part-time administrator to work in the district office.

Training

Since the beginning of the programme an intense capacity building effort was needed at all levels of health services addressing the multiple aspects of a comprehensive HIV treatment and prevention programme. MSF organised training sessions targeting the following staff categories:

- Nurses and doctors from Lusikisiki and other health districts received clinical training in prevention of mother to child transmission, opportunistic infections and ARV treatment.
- Adherence counsellors
- Pharmacy assistants
- Clinic volunteers
- Programme managers at district level
- Programme managers of other ARV treatment sites in the Province

To build sustained technical support, a training project in collaboration with the *Ukwanda* Centre for Rural Health based at the University of Stellenbosch was developed.

Simplified data management

All clinics as well as the hospital have been supplied with appropriate registers for facility-level data collection. A paper-based system was strongly preferred given the rural setting. Apart from not requiring any new technology, the nurses are able to readily draw on the registers to assist in individual patient management and facility performance monitoring. This facilitates quick on-site adjustments and empowers the nurses. Data collection and input into a central database is performed on a monthly basis by members of the mobile teams.

The Infectious Disease Epidemiology Unit of the University of Cape Town (School of Public Health and Family Medicine) has provided important support in designing a system for data collection and clinical monitoring adapted to a rural setting.

Networking with other local programmes

Having been the first site to provide ARVs in public clinics in the Eastern Cape, the visibility and good early outcomes of the Lusikisiki ARV programme has attracted other programmes into the area. There is a close working relationship with *Masangane* programme, which is already treating 60 patients in Queenstown and Maluti. Columbia University assists the implementation of HIV/AIDS services in Flagstaff and Bizana, the other areas in Qaukeni, depending on the district administration based in Lusikisiki. These programmes are preparing to provide ARVs. MSF has also given support to the clinical staff of Rietvlei Hospital and Madwaleni Hospital in preparing for the implementation of ARV treatment.

Anglo-Gold has agreed to donate its well-equipped and under-utilised clinic in the centre of Lusikisiki town to the department of health. Village clinic, the busiest primary care clinic located in the outskirts of Lusikisiki, will move to the Anglo-Gold facility early in 2005. This will benefit all services provided, including HIV/AIDS services.



Pic 3. Village Clinic Health Care workers will soon move to premises donated by Anglo-Gold.

Community Mobilisation: Partnership with the Treatment Action Campaign (TAC)

Community response and treatment literacy

Following the model of community partnership implemented in Khayelitsha, MSF's strongest partner in developing a community response to HIV/AIDS in Lusikisiki is the Treatment Action Campaign (TAC). Since the beginning of the ARV programme in Lusikisiki, TAC has recruited and trained seven volunteers as treatment literacy practitioners. These volunteers together with an elected district working committee lead twenty-two branches throughout the district (see distribution in figure 1). The branches are closely associated with the primary

care clinics. This experience was presented as an oral communication to the International AIDS conference in Bangkok (abstract N. WeOrE1337).

TAC's branches are responsible for creating a community response to HIV through increasing people's understanding of HIV/AIDS and the services available to them, as well as ensuring community support for the HIV/AIDS programme. TAC has launched an aggressive community reaction against discrimination and stigma which is already having a remarkable effect in promoting openness and facilitating discussion about HIV infection.

Monthly plans for treatment literacy workshops and community events are developed and approved by the TAC district committee. Those are co-ordinated with MSF to review priorities and ensure common strategies.

Treatment preparedness and adherence support

Branches work closely with adherence counsellors in the primary care clinics to ensure patients' understanding of ARV therapy prior to starting treatment, and helping create a supportive environment around them. As patients have been on treatment for longer durations, branches help identify and respond to barriers to adherence. Being situated at community level and consisting of community members, branches can respond to adherence problems within community structures, a level adherence counsellors struggle to reach. This grassroots involvement of people, shifting responsibility and ownership to them, has been essential in achieving high acceptability of the HIV services.

Mobilizing the youth

Since HIV infection happens largely amongst youngsters, TAC's work during the early stages of the Lusikisiki programme has targeted the age group between 12 and 25 years of age. The aim was to build on the openness facilitated by the better access to dedicated HIV services and improved community awareness about HIV infection and treatment,



A network of 50 condom (both male and female) distribution points has been developed with a special emphasis on reaching the youth sector. This was implemented together with training and awareness workshops. The impressive outcomes of this condom-distribution programme were debated at the Bangkok International AIDS conference in July 2004 (abstract N. ThOrE1378).

Pic 4. Youth Mobilisation of TAC on Youth Day (16 June 2004).

Campaigns

Besides translating TAC national campaigns into local events, a number of campaigns have been generated to respond to local needs. These include an ongoing campaign to engage with the issues that make nurses leave after short periods of service in Lusikisiki. Particularly, TAC has demanded an improvement in the living conditions of nurses. Other campaigns have lobbied for new clinics to be built in underserved areas, and the registration of fixed-dose combinations by the Medicines Control Council.

Recently, TAC has started to mobilize the community against sexual abuse. Support groups for rape survivors have been started. Some of their members conduct home visits to new victims in the area to provide support and counselling. This helps families deal with the consequences of rape and helps to follow legal processes. Demonstrations at court and a police station have highlighted the neglect in the prosecution of the perpetrators.

In the future, a one-stop rape service will be developed in the hospital that can deal with the legal, medical and social needs of victims.

Visibility of the Lusikisiki HIV/AIDS programme

The impressive early outcomes of ARV therapy in a rural and under-resourced area such as Lusikisiki, as well as the innovative organisation of the services has been a focus of media attention since the beginning of the programme.

Several stories in the *East Cape Herald* featured Lusikisiki, as well as in depth reports in the *Sunday Independent*, *Mail and Guardian* and *You/Drum/Huisgenoot* magazines described the Lusikisiki programme. An SABC's *Special Assignment* programme featured the Lusikisiki response to HIV/AIDS as compared to other nutrition-based approaches which have been the subject of controversy in the country. The SABC's *Siyayinqoba - Beat It* documentary has also reported on some of the components of the Lusikisiki HIV/AIDS programme. Internationally, Lusikisiki also featured in a full article and on the front page of *Newsweek* magazine during the last International AIDS Conference held in Bangkok (issue of 19 July 2004) as well as in a BBC TV documentary.

Local media has also been used for educational purposes. Regular radio programmes have been broadcasted on Unitra Community Radio and occasional reports on *Umhlobo Wenene*, especially the youth programme *Apha nalapha*. Lusikisiki was also used as a case study at the People's Health Summit hosted by the Treatment Action Campaign (July 2004).

The programme coordinator was awarded the RUDASA's (Rural Doctors Association of South Africa) rural doctor of the year award.

Conclusions

Contrary to what was expected, stigma and discrimination in Lusikisiki does not seem to be a major barrier for people to get tested for HIV, since a high and growing demand for VCT was observed from the beginning of the programme and the services available are working at full capacity.

The high monthly prevalence of infection observed since VCT was made available nearly two years ago (42%, IQR 39%,44%) indicates the devastating magnitude of the epidemic in Lusikisiki.

The excellent follow-up and good early clinical outcomes of the ARV programme are a direct consequence of the implementation of a decentralised model of care relying on nurses and community workers in rural clinics.

Outcomes are comparable to those observed in the Khayelitsha ARV programme for the same duration on ART. This is remarkable given that infrastructure is substantially poorer in Lusikisiki as compared to Khayelitsha.

The role of community workers has been crucial to bridge the deficiencies of the existing infrastructure.

Adherence counsellors are the backbone of the ARV programme. Besides their responsibilities of patient preparation and support, they play a critical role in balancing clinical work with community activism.

As previously observed in Khayelitsha, community involvement and activism has been critical for the acceptance of the dedicated HIV/AIDS dedicated services in Lusikisiki. This has facilitated a demand-driven programme, where service users take responsibility for the services, respond to bottlenecks, promote adherence, follow-up patients missing appointments and help identify barriers to accessing the clinics.

Weaknesses and limitations of the programme have tended to be due to health service rather than patient or community issues. Innovative approaches have been developed to some of the health service constraints. The sustainability of this programme depends on formal recognition of the changes to the services that were required in order to provide comprehensive HIV/AIDS care

Challenges

In order to implement comprehensive HIV/AIDS care including ARV treatment in all 12 rural clinics, the Lusikisiki programme adopted a decentralised model, challenging the tendency to implement such programmes in secondary or tertiary hospitals. The major constraints are the scarcity of health professionals and weak management capacity, particularly related to drug supply.

Critical for the implementation of a decentralised model has been the support of the mobile teams, in terms of clinical work and support to drug supply. These posts do not currently exist in the public sector which creates a limitation in terms of sustainability of the programme.

The failure to increase the number of nurses in the district has resulted in a chronically under-staffed service. Filling those positions becomes particularly urgent given the expected increase in attendance to health services anticipated as a result of HIV/AIDS service provision.

In addition to nursing staff, it is critical to review and officially recognise the roles played by the different categories of community workers. In part, they cover some of the tasks that should be performed by nurses. They also carry out activities that are new and specific to an ARV programme, such as adherence counselling. The positions of clinic-based counsellors and pharmacy assistants should be created within the public sector, since the success of dedicated HIV/AIDS services is largely reliant on them.

Pharmaceutical supply has improved substantially since the beginning of this programme with the addition of new HIV related drugs to the essential drugs list (EDL) for primary care (such as acyclovir) as well as the increase in available stocks of critical drugs like co-trimoxazole. MSF nevertheless continues to provide some of the drugs used for opportunistic infections and most of the ARV drugs. A plan for the progressive hand over of the drug supply responsibility to the provincial depot has been discussed with the Department of Health, and the progress of this will be closely monitored in 2005.

Lusikisiki 01/03/05



Madiba talks to people on ARVs in Lusikisiki.

"The name Siyaphila La is an appropriate one for this site. It means 'We Are Alive.' The HIV positive people we see here today are alive, they are healthy, and they are happy. What we see is proof that there is life after HIV/AIDS. Let us work together to send that message to communities across South Africa and around the world."

Nelson Mandela, during his visit to *Siyaphila La* programme, December 2003