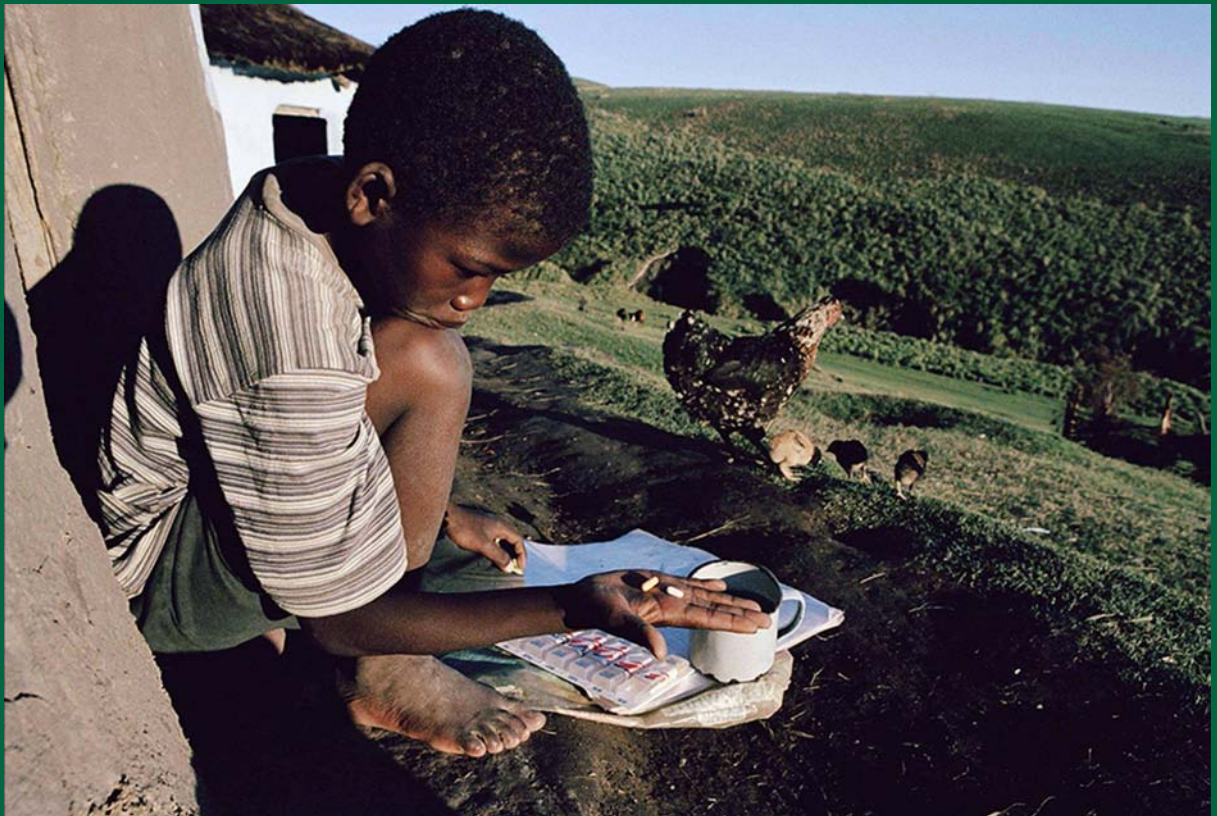


ACHIEVING AND SUSTAINING UNIVERSAL ACCESS TO ANTIRETROVIRALS IN RURAL AREAS

The Primary Health Care Approach to HIV Services in Lusikisiki, Eastern Cape



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FOREWORD

In 2003 the Nelson Mandela Foundation and Médecins sans Frontières (MSF) identified a need to support HIV/AIDS care in rural areas and approached the Provincial Department of Health of the Eastern Cape to offer their assistance. We were happy to receive their support and asked them to help us in one of the most difficult rural areas with a great need for support. As well as being an impoverished rural area struggling with a poorly resourced health service, Lusikisiki has traditionally been a place where the mines used to recruit migrant labour which has had a negative impact on family structures and has led to a high level of HIV. At that time half of deaths among adults were associated to HIV.

Working with MSF, an organization that has a lot of experience from other countries in delivering HIV/AIDS care at the clinic level, gave us the confidence to test this primary health care approach. This was very clearly the most appropriate model for Lusikisiki where the rural population is dispersed and where access to hospitals is more difficult.

The benefits of working with an NGO partner, with the extra resources they can bring and their flexibility to move quickly, became clear very quickly. A number of easy improvements ensured that by the time the National Operational Plan for Comprehensive HIV Care was launched in late 2003, the clinics were ready to start providing antiretroviral therapy: within two weeks the first person was initiated on antiretroviral therapy.

As government we have benefited from the training of nurses to manage medical problems of people with HIV and the development and support of community care givers to do health promotion and provide VCT services.

This experience has confirmed that decentralized HIV/AIDS care is the optimal model for rural areas, and that treatment can be effectively initiated at the clinic level, with supervision by a mobile team. The involvement of the community is an important way to enhance efficiency and effectiveness by alleviating staff shortages within the system and supporting patients to achieve good adherence.

A particular effort to address HIV has been warranted by the high levels of mortality in the community. At the same time, we have seen many benefits to the primary health care services as whole, with improvements in clinic services, including infrastructure, laboratory services, drug supply, training, staff motivation, and patient satisfaction.

This is a model that we are very keen to roll out to other rural areas and to share it with other provinces.

Nomalanga Makwedini
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SUMMARY

The chronic shortage of health care workers is recognized as a major bottleneck to scaling up antiretroviral therapy, and this has the biggest impact in rural areas where the human resource crisis is most acute. There is a need to develop innovative, effective delivery models, particularly for rural areas with weak health systems.

The HIV/AIDS programme in Lusikisiki, a partnership between Médecins sans Frontières (MSF) and the Department of Health of the Eastern Cape, has managed to achieve universal access to antiretroviral therapy in one of the most under-resourced and disadvantaged areas of South Africa without compromising on quality.

There are currently 2,200 people receiving antiretroviral therapy in Lusikisiki, which represents universal coverage of the need for the last year. To achieve this rapid scale up in the face of a chronic shortage of health staff, a model of care was developed along three lines: task shifting to mobilize existing human resources; the creation of additional capacity through the establishment of new posts (in particular adherence counsellors) and a strong community engagement to support the health system; and concerted efforts to improve clinic infrastructure.

From the outset, antiretroviral therapy was provided at the clinic level, avoiding ‘down-referral’ from hospital to clinic which creates a bottleneck in treatment enrollment. The availability of multiple entry points for testing and treatment, together with the proximity and acceptability of services has led to a much faster enrolment of people on treatment, good clinical outcomes, and excellent patient retention.

The delivery of ARVs has required attention at several levels that has also benefited the general level of care provided at the clinics. The strong community ownership of and participation in health care delivery has also had a major benefit in supporting the general quality of health services.

Following a gradual handover of resources and responsibilities to the Department of Health, Médecins sans Frontières is now withdrawing from Lusikisiki. To sustain the good outcomes and high coverage achieved to date will require sustained investment and innovation.

I. BACKGROUND

Lusikisiki (population 150,000) is part of the Qaukeni Local Service Area (health district) in the Eastern Cape Province. It is one of the poorest areas of one of the poorest provinces in South Africa. A recent survey showed that the Eastern Cape had seven of the ten poorest municipalities in South Africa. The two municipalities which together make up the health district to which Lusikisiki belongs (Qaukeni and Mbizana) were in this group.¹ Up to 80% of the population live below the poverty line (defined as household expenditure of R800 per month).

Not surprisingly, the general level of underdevelopment is also reflected in the health services. A survey in 2003 of national primary health care facilities showed that only 5% of clinics had a full complement of 25 marker drugs of the Essentials Drug List. These drugs are amongst the most important and commonly used drugs. Only four out of every ten facilities had adequate consultation rooms and waiting areas; eight in ten facilities required urgent structural repair.²

In December 2002, Médecins Sans Frontières (MSF), in partnership with the Nelson Mandela Foundation, approached the Eastern Cape Provincial government with the view to developing and testing a model of HIV service delivery that would be appropriate to rural populations in South Africa. They agreed on Lusikisiki as the site for the programme. This programme started in January 2003.

An assessment done among the 12 clinics in Lusikisiki at that time showed that electricity was only available in a third of clinics (4 of 12) and the supply of electricity was unreliable in half of those; only 8% (1 in 12) had running water or a phone, and none had a fax machine. Half (6 in 12) lacked nursing accommodation. Only 40 % of nursing staff posts were filled, and those nurses that were there were poorly supervised. The high workload and poor infrastructure kept staff morale low, further undermining the services.



¹ Hemson D, Meyer M, Maphunye K. Rural development: The provision of basic infrastructure services Human Sciences Research Council, January 2004. Available at: <http://www.sarpn.org.za/documents/d0000683/index.php>

² J Roberts, The National Primary Health Care Facilities Survey 2003, Eastern Cape, p41+46

Many medications needed for managing opportunistic infections had been added to the national Essential Drug List in 2003 but had not yet been introduced to clinics in the Eastern Cape. Other essential drugs were also frequently out of stock, with up to sixty Essential Drug Lists drugs missing at some clinics. Attention was given to ensure continual availability of priority drugs like cotrimoxazole, amitriptyline, acyclovir, and steroid ointments, while strengthening the whole supply chain.

It soon became clear that nurses were already overburdened with other responsibilities and struggled to cope with the extra workload that HIV management represented. During the first months of the programme, a doctor visited all twelve clinics on a rotational basis undertaking consultations and providing training to nurses on HIV testing, services to prevent mother to child transmission, and the management of common opportunistic infections. The first staff employed by MSF were adherence counsellors who took on some of the workload of the nursing staff. This, together with the early provision of drugs and training for the treatment of opportunistic infections helped improve the quality of care, which in turn improved nurse motivation.

In October 2003 the National Department of Health gave the go-ahead to provide antiretrovirals and the first people were started on treatment. On 10 December that year the ARV program was officially launched by ex-president Nelson Mandela. By mid-2006, less than 3 years later, around 2500 people had been initiated onto ARVs.

II. PROGRAMME SERVICES AND OUTCOMES

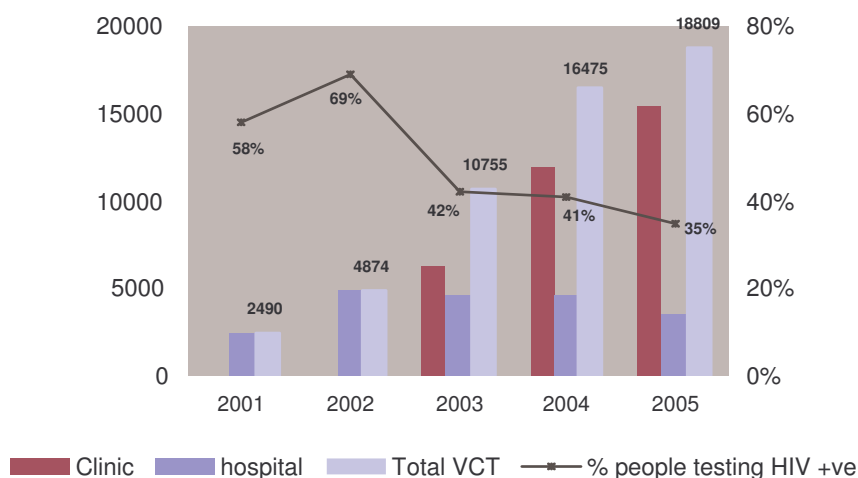
Voluntary counselling and testing

Before 2003 HIV voluntary counselling and testing (VCT) was only available at the hospital (St Elizabeth Hospital). When VCT services were made available at clinics there was a dramatic increase in the number of tests performed, from 4874 in 2002 when only the hospital was involved to 18,809 in 2005 (Graph 1). This rapid increase is largely due to increased proximity and capacity, with clinic capacity gradually reinforced through the employment of community health workers and expansion of space (counselling rooms) to do testing. It also reflects the success of the ARV programme – people test because they know they can be treated – and the work at community level to encourage people to know their status.

In total, 46,039 people have been tested in the last three years. This represents almost two-thirds of the adult population of Lusikisiki. While it can be expected that many of these are duplicates (people who have tested more than once), it still points to a high level of VCT coverage. As is expected with an increase in coverage, there has been a decline in the proportion of people testing positive (69% in 2002 vs 35% in 2005) but the absolute numbers testing positive has increased.

The early rapid increase in VCT was made possible by the fact that testing was done by the counsellors in the clinics. This was well accepted by the community, and quality control was satisfactory.

Graph 1: VCT Done in Lusikisiki and percentage of people testing positive.



Condom distribution

Condom distribution is fundamentally a logistical problem. In Lusikisiki distribution significantly increased when the driver of the mobile team was tasked to distribute condoms in the surrounding community while the nurses attend to patients. Since the beginning of this year, a monthly average of 110 000 condoms are distributed via 450 distribution points in the community, mainly shops and schools. Condom distribution is also supported by community groups, in particular the Treatment Action Campaign (TAC). In addition, a condom promoter from the community works in each of Lusikisiki's 12 clinics. Female condoms are now also being provided by the Department of Health. They are very well accepted by the community, as evidenced by a constant shortage of supply.

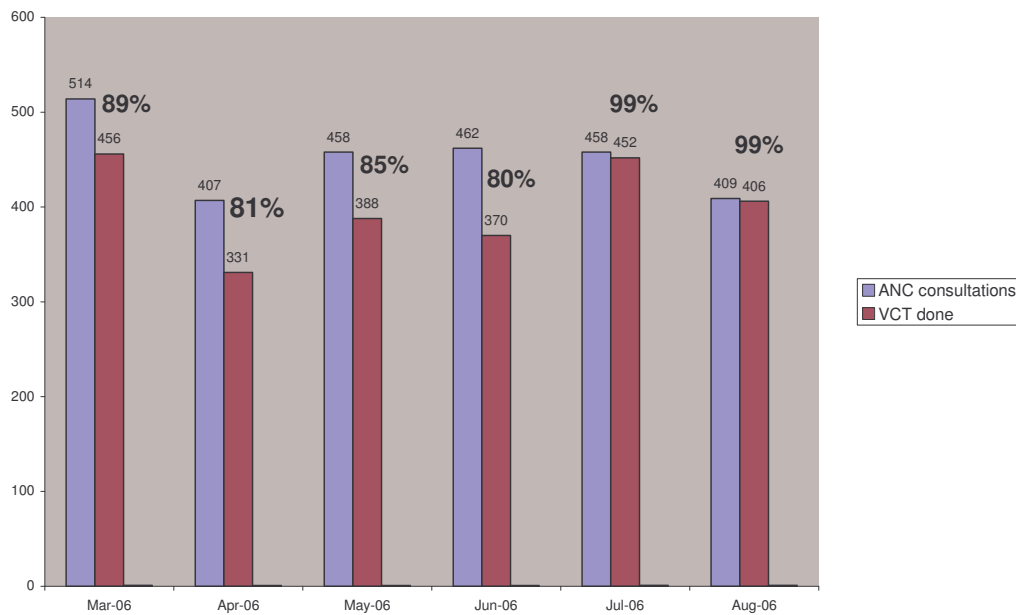
Prevention of Mother-to-Child Transmission of HIV

MSF started providing services for prevention of mother-to-child transmission (PMTCT) as part of antenatal services in the clinics in February 2003 and within 2 months all clinics were offering services in accordance with the national protocol. In August the following year, MSF proposed an improved PMTCT intervention with the following aims: improve uptake rate of HIV testing amongst pregnant women; implement improved protocol of AZT from 28 weeks of pregnancy complemented by single dose nevirapine (introduced successfully in the Western Cape in 1999³); introduce PCR infant testing at six weeks; and reinforce outcome monitoring. While this protocol change was requested and supported locally and ethics approval to piloting this approach was granted by the Walter Sisulu University of Mthatha, final approval for this improved intervention was withheld by the Department of Health.

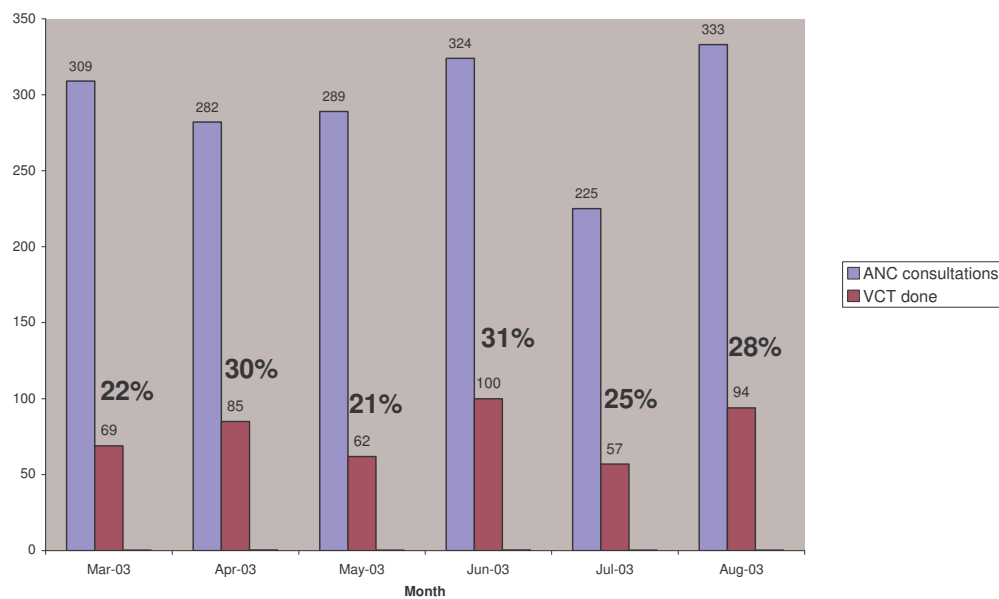
³ Coetzee D, Hildebrand K, Boulle A, Draper B, Abdullah F, Goemaere E. Effectiveness of the first district-wide programme for the prevention of mother-to-child transmission of HIV in South Africa. *WHO Bulletin* 2005. 83;7:489-94.

MSF's efforts then focused on improving uptake rates by offering VCT at entry to antenatal care services, and introducing simplified testing and monitoring (PCR for infant diagnosis and new registers). The overall aim was to prevent childhood HIV infections, but there were several other advantages: raising awareness and knowledge about HIV, increasing coverage of VCT, enabling early management of opportunistic infections, and ensuring rapid access to antiretroviral therapy for those in need (because it is available at the same clinic). Uptake of VCT increased from an average of 26% from the period March - August 2003 (data from the first six months of the programme) to 89% in the same period of 2006 (Graphs 2a & b).

Graph 2b: VCT done at ANC consultation March - August 2006



Graph 2a: VCT done at ANC consultation March - August 2003



The PMTCT programme has managed to achieve reasonable results using the standard PMTCT protocol. Accurate reporting on outcomes has been fraught with difficulties, but since the introduction of dry blood spot sample collection in December 2005, testing is possible at clinics at an early stage, so it is now possible to report on transmission rates. A count of the last 100 consecutive results from the two busiest clinics in July and August 2006 showed that 12% of HIV-exposed newborns tested positive. This is an expected rate with the present protocol, but could be further reduced using a more effective ARV regimen for PMTCT.

HIV/TB integration

Tuberculosis is the number one killer of people with HIV/AIDS. As in all provinces of South Africa, TB incidence in the Eastern Cape is high, at 675 per 100000 people. Despite strong investment from the government in ongoing support and training and DOTS the treatment completion rate for the Eastern Cape is only 70.5% for smear positives.⁴ The completion rate for smear negatives, which represents over two thirds of TB in people with HIV/AIDS, is unknown.

The provision of antiretrovirals (ARVs) has had a number of direct benefits on TB management. ARVs reduce the chances of an HIV-infected person developing TB by up to 80%. In addition, a patient-centred approach to adherence with a high level of peer-education and empowerment is providing important lessons for improving adherence to TB treatment. These and other issues were highlighted at an expert meeting organised May 2005 that brought together academic experts, programme managers, senior Department of Health officials, and over 60 primary health care nurses to discuss improvements in TB care in the Eastern Cape.⁵ This meeting succeeded in mobilizing attention around the need to improve services in the province.

One of the outcomes of this meeting was the clear need to improve diagnosis. A fluorescent microscope was introduced at the beginning of 2006 and this has allowed for more rapid and sensitive method of diagnosis compared to light microscopy, resulting in around 110 additional people with TB being picked up each month (average of 1110 tests done each month; positivity rate is 25-30% compared to 15-20% previously). Diagnosis for children has also been improved by making Tuberculin skin testing available at the clinics.

Due to the high rate of TB co-infection and increased mortality, high priority has been given to improving the TB program and integrating TB care with HIV services. This has been successful up to a point, with improvements in staff requests for confirmatory diagnosis (culture and chest x-ray), cotrimoxazole prophylaxis, and number of people with TB who are offered (and take up) VCT. In general in South Africa, TB treatment is done at clinic level, whereas ARVs are provided at the hospital. This results in a separation of treatment provision, support strategies, and monitoring, and a need to refer service users between health centres, all of which is overcome by the *de facto* integration that results from providing ARVs at the clinics.

Efforts have recently been made by the clinic supervisors to encourage nurses and community caregivers to test people with TB for HIV, and as a result the percentage of people with TB knowing their status has increased from 45% in July to 75% in September

⁴ Health Systems Trust. Last available data for 2003. www.hst.org.za

⁵ TB in the world of HIV. Report of a Rural Conference jointly organised by the Dept of Health of the Eastern Cape, Nelson Mandela Foundation, and Médecins Sans Frontières. Médecins Sans Frontières, Lusikisiki, May 2005. Report available on request from resourcec@mweb.co.za

2006. This is an average figure for 11 of the 12 clinics in Lusikisiki. In the remaining clinic (Gateway) TB and HIV services are managed separately; partly due to this separation of services the percentage of people with TB knowing their status is only 29%.

The goal must be that all people with TB know their status, given that in general around two thirds of people with TB who take a test are found to be positive. Data on HIV infection among TB patients are poorly collected, but a snapshot from Village Clinic -one of the busiest clinics - shows a high percentage of co-infection. Nearly all patients on TB treatment (98%) agreed to be tested for HIV in the period from May until September 2006. Of 137 TB patients who tested, 113 tested positive and 24 tested negative, i.e. 82.5% positivity rate. There are 3 people on MDR TB treatment; all are HIV positive.

Antiretroviral Therapy

Antiretroviral therapy was first provided in October 2003 and by the end of August 2006 2190 people were currently on treatment, including 110 children. All people testing HIV positive are strongly encouraged to come to the clinic every two months (WHO stage I&II) or monthly (WHO stage III&IV) for clinical examination, family planning, and group support activities. Treatment is offered to all HIV-positive people with CD4 below 200 according to national protocol, with CD4 count and viral loads done at baseline then every six months. Apart from monitoring individual progress, these data also provide an indication of the overall effectiveness of the programme. Service users are divided into cohorts according to the date of starting ARVs, and cohorts are then compared within and between facilities.

A review of outcomes of people who have been on treatment for more than 12 months (Table 1) shows that service user retention is much better at clinics: only 2% of people are lost to follow up compared to 19% at the hospital. This higher drop-out rate at hospital can be due to sicker people starting treatment (higher early mortality), having to travel further, less preparation of ARV users, and less effective follow up of defaulters by adherence counsellors.

Outcomes in terms of gain in CD4 count and reduction of viral load is also much better in the clinics. The programme has also demonstrated that children can be treated successfully at the clinic level without the need for a paediatrician. Mortality in the hospital (13%) at first appears to be lower than the clinics (16%). However, mortality and lost-to-follow up combined is much higher in the hospital (32% versus 19%); it is not possible to know how many people lost-to-follow up have died but the number can be expected to be high.

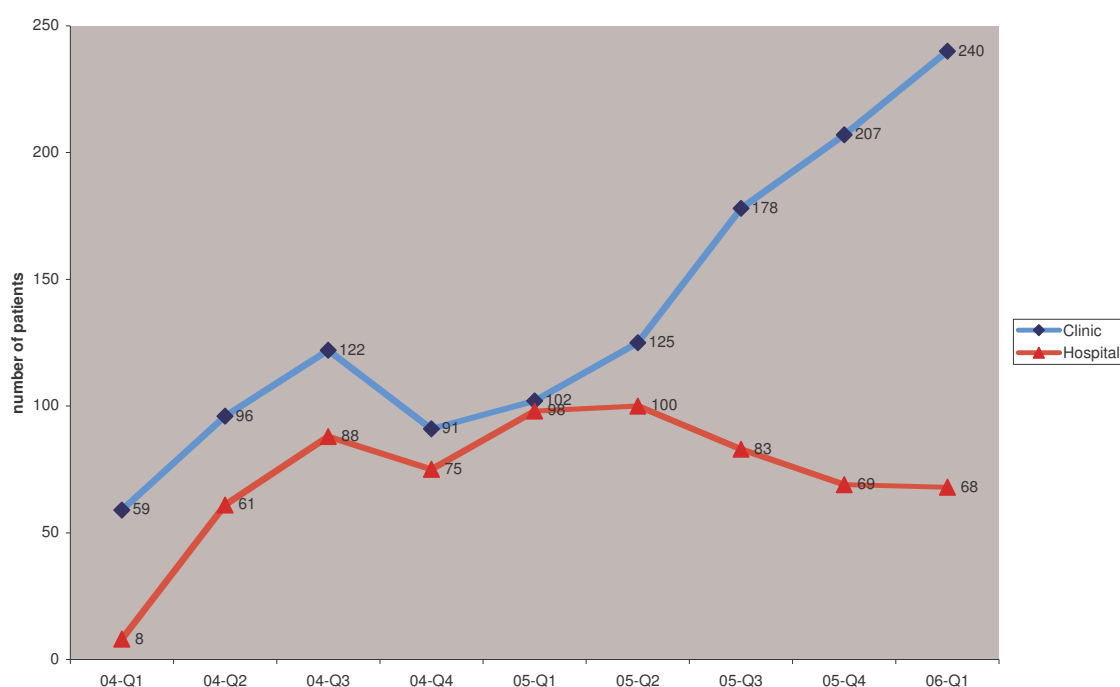
Table 1: Outcomes at clinics and hospital

| | Clinics | Hospital |
|-------------------------|-----------|-----------|
| Number of patients* | 595 | 430 |
| Remaining on treatment | 482 (81%) | 289 (67%) |
| Deaths | 100 (17%) | 58 (13%) |
| Lost to follow up | 13 (2%) | 83 (19%) |
| CD4 >200 | 87% | 75% |
| Viral load undetectable | 90% | 78% |

* People starting treatment between January 2004 and July 2005 who have all completed at least 12 months of treatment

During the first year of the programme ARV enrolment increased at a similar pace in both the hospital and clinics. But after a year enrollment at the hospital reached a plateau and then began to decline, suggesting a saturation of services. In contrast, enrollment in the clinics continues to increase (Graph 3). Enrolment is increasing faster in the clinics because of multiple service points and because services are integrated into general consultations and not dependent on specific staff. The much lower number of people who are lost to follow up and the faster enrolments at the clinics are a clear indication of service user preference to follow treatment at sites close to where they live. These indicators also point to the more ‘user friendly’ services provided by clinics that are part of the community and supported strongly by community groups.

Graph 3: Enrollment in clinics and hospital



NB: This graph shows the number of patients newly enrolled into treatment for each quarter. Numbers are not cumulative.

Overall coverage (treatment as a proportion of need) is impressive: according to established modelling, the programme had achieved 95% coverage of patients entering stage IV for 2005. This is substantially higher than any other estimate using the same comparator, bearing in mind that the number in need of care is greater than those entering stage.⁶

This increased coverage means that people arriving at the clinics are far less sick. At the beginning of the programme many people were so sick they have to be carried to the clinic, and every day there would be several new arrivals ‘by wheelbarrow’. This is hardly seen today, and the fact that the programme is ‘catching up with the backlog’ is reflected

⁶ This calculation is derived from the ASSA Model (www.assa.org.za/aidsmodel.asp), which counts all new people who reach stage IV as requiring ARVs. It calculates all people entering Stage IV and requiring treatment in 2005; it does not cover the backlog of people needing treatment that would have accumulated in previous years, or those with CD4 counts below 200 who have not had a stage IV illness.

in the statistics: in early 2004, 50% of service users at the hospital and 40% at clinics arrived with a CD4 less than 50; by the end of 2005 this had dropped to 16% at both hospital and clinics. Because people are arriving with a better immune status, clinical management is easier, freeing up the time spent on each person so that more people can be seen.

III. PROVIDING ARVS AT THE PRIMARY HEALTH CARE LEVEL

The World Health Organisation is promoting a radical departure from traditional models that depend on specialist personnel. Instead, task shifting is promoted to enable nurses to prescribe and dispense antiretroviral therapy and engage community workers to deliver a wide range of HIV services. WHO has made it clear that it supports a public-health model of service delivery that uses standardized, simplified and decentralized systems in order to maximize the involvement of primary health and community-led care.⁷

The Lusikisiki programme is a practical application of these principles. Scaling up treatment has depended on three approaches: (i) task shifting to mobilize existing human resources; (ii) the creation of additional capacity through the establishment of new posts and a strong community engagement to support the health system; and (iii) concerted efforts to improve clinic infrastructure.

Mobilizing existing human resources

The shortage of skilled health workers (nurses, doctors and pharmacists) is recognized as one of the most significant constraints to making ARVs accessible, especially in rural areas. The Lusikisiki programme has dealt with this in two ways: firstly, by ensuring decentralization to clinics (involving more sites means involving more people in HIV care) and delegating tasks as much as possible (task shifting); secondly, by making extensive use of the available human capacity by engaging lay workers, community structures, and HIV service users.

Task shifting

The National HIV/AIDS plan is founded on the principle of universal care and equitable implementation.⁸ Lusikisiki, like many rural areas, faces a chronic shortage of health workers at all levels, in particular doctors. With 14 times fewer doctors in Lusikisiki than the national average, the only way to ensure equitable access to treatment is by establishing models of delivery that do not rely on doctors.

If appropriate training, mentoring and supervision are available at the clinic level it is possible to delegate much of the running of the ARV programme to primary health care staff. In Lusikisiki, this process of task shifting has resulted in greater access to and uptake of essential HIV services.

Table 2 outlines the roles of the various team members in the Lusikisiki programme compared to more traditional functions. As the table shows, the workload for individual patients is 'top heavy' in the traditional model, and this results in a bottleneck for ARV initiation and clinical management. In Lusikisiki, tasks have been pushed down as much

⁷ Taking stock: Health worker shortages and the response to AIDS. WHO, Geneva, August 2006. Available at: <http://www.who.int/hiv/pub/advocacy/ttr/en/index.html>

⁸ Operational Plan for Comprehensive HIV and AIDS Care, Management and Treatment for South Africa. National Department of Health, South Africa 19 November 2003. Page 17.

as possible to move away from an overreliance on the most sparse human resources in the system.

All clinics receive regular (monthly or bimonthly) doctor visits with the objective of supporting the overall service rather than managing individual cases. Nurses receive extensive preparation in HIV management, including staging and initiation of ARV therapy in uncomplicated cases and routine follow-up. In the two larger clinics they are supported by pharmacy assistants on drug management.

The traditional model of community care givers is to do community-based health promotion. In Lusikisiki they work in the clinics, taking on some of the nurses workload (including VCT, opening of HIV folders with social history, transferring lab results into folders, conducting support groups). Given the nature and magnitude of the HIV epidemic, it is critical to educate service users to empower them to take responsibility for their own treatment, rather than relying on the community health worker going to community to enforce directly observed treatment. Defaulter tracing is done by support group members who come from the same rural village as the person who missed their appointment. These support group members are appointed by the adherence counsellors and are given training on approaches to ARV adherence.

Table 2. Comparison of the traditional roles of health staff in HIV/AIDS care compared to the Lusikisiki programme.

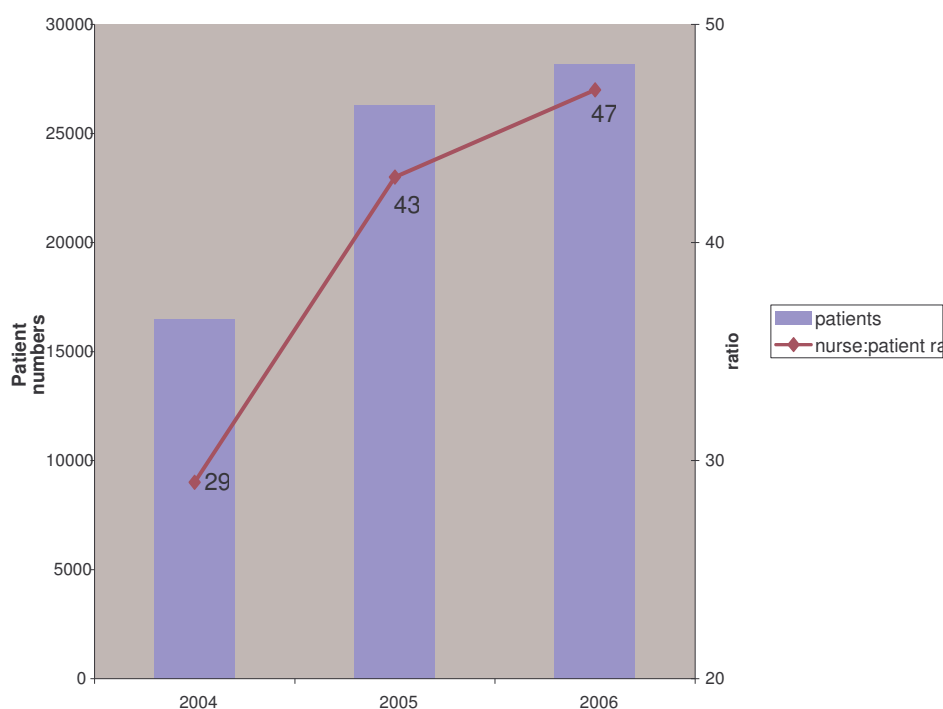
| Category | Roles in Lusikisiki | Traditional Roles |
|--|--|--|
| <i>Doctors</i> | Mobile team Clinic supervision and mentoring Part of multi-disciplinary team | Patient consultations: OIs, staging, ARV initiation. Visiting doctor remains apart from clinic staff |
| <i>Pharmacist</i> | Hospital pharmacist provides coaching to pharmacy assistants | Manages drug supply Responsible for overseeing prescriptions |
| <i>Nurses</i> | Manages OIs Clinical staging Initiates and monitors ARVs Prescribes ARVs | Supports doctor Does VCT Prepares for ARVs Monitors ARV users Data collection Manages drug supply Supervises community care givers |
| <i>Adherence Counsellors</i> | Preparation for ARVs Empowers ARV users (not DOTS) ARV support group Data collection (ARV registers) Mentors community care givers Defaulters tracing | Not utilized |
| <i>PharmacyAssistant</i> | Manages drug supply Dispenses medicines Adherence checks? | Not utilized or limited role (dispensing medicines only under strict pharmacist supervision at the hospital) |
| <i>Community Care Givers</i> | VCT HIV support group Data collection (VCT registers) | Health promotion DOTS (recall of defaulters) |
| <i>Support groups, community committees, activists, people with HIV/AIDS</i> | Preparation for ARVs Health promotion in community Recall of non-adherers Identifies, reacts and overcomes bottlenecks for smooth service delivery | Not utilized |

The traditional picture of home-based care has also been revised. Because care is provided at clinic level and is generally accessible, it is assumed that if a person is so sick that they cannot come to the clinic they should be seen at a hospital rather than cared for by the lowest trained cadre of our health system.

Reinforcing nurse-based care

Nurses are the main professional backstop of the ARV programme. Through task shifting, nurses are given more responsibility while being relieved of many menial tasks that distract from patient care. In Lusikisiki every professional nurse is able to evaluate eligibility for ARVs and monitor progress on ARVs. This is in keeping with the primary care principle that all services should be available at all times, avoiding a scenario in which service users must wait for a specific ‘HIV day’ or a specific ‘HIV nurse’. In fact, without this approach, clinic-based ARV services would not have been possible as no extra people were employed to run HIV services in the clinics. While overall numbers of service users in the clinics have almost doubled, from 16465 in April 2004 to 28191 in April 2006 the number of professional nurses (30) has not changed (Graph 4).

Graph 4: Lusikisiki nurse:patient ratio



The nurse-patient ratio (number of patients seen per nurse per clinical work day) has increased from 29 in 2003 to 47 in 2006; this compares to a national average of 29.4.⁹ Such an increase would clearly have been impossible to manage without task shifting.

To ensure sustainability, nurses who have completed sufficient training and are actively involved in HIV care should be appropriately rewarded. (Panel)

⁹ Health Systems Trust. Best available data from 2005. <http://www.hst.org.za/healthstats/149/data>



Nurse shortages a priority concern for the Eastern Cape

In 2003 the Eastern Cape Department of Health set itself an ambitious operational plan in 2003 which stated that by March 2008 nearly 150,000 people should be on ARVs across 80% of all health care facilities. Eight in ten fixed clinics in the Eastern Cape are rural clinics (67% situated in rural areas, and 13% located in towns but providing services to rural areas). The Eastern Cape Department of Health operational plan for 2003 states:

“Alternative models for implementation of ARVs in the Eastern Cape will need to be considered. A nurse-based approach which utilizes clinical nurse specialists who have undergone special post graduate training for treating clients with antiretroviral therapy, would be a good model worth considering for rural areas.”

In 2005, 37% of nursing posts in the Eastern Cape were vacant. Several actions need to be taken to improve the situation:

- There should be an adequate budget for a full complement of clinic staff. Currently the Eastern Cape Department of Health is under budgeting by 37%¹⁰ This means prioritizing primary health care services in budget considerations.
- Vacant nursing posts need to be advertised; this includes advertising for senior nursing posts so that promotion paths are opened up, increasing motivation
- Adequate support staff (drivers, clerks, pharmacy assistants) must be recruited to ensure that nurses spend their time being nurses
- The basic salary of nurses, which is very low, should increase;¹¹ and accreditation and increased remuneration of nurses trained and experienced in HIV should be explored; the great disparity between non-urban settings should be reflected in rural allowances, with maximum allowances paid to staff working in places like Lusikisiki that are the most challenging
- Nursing accommodation must be built or renovated to meet acceptable standards

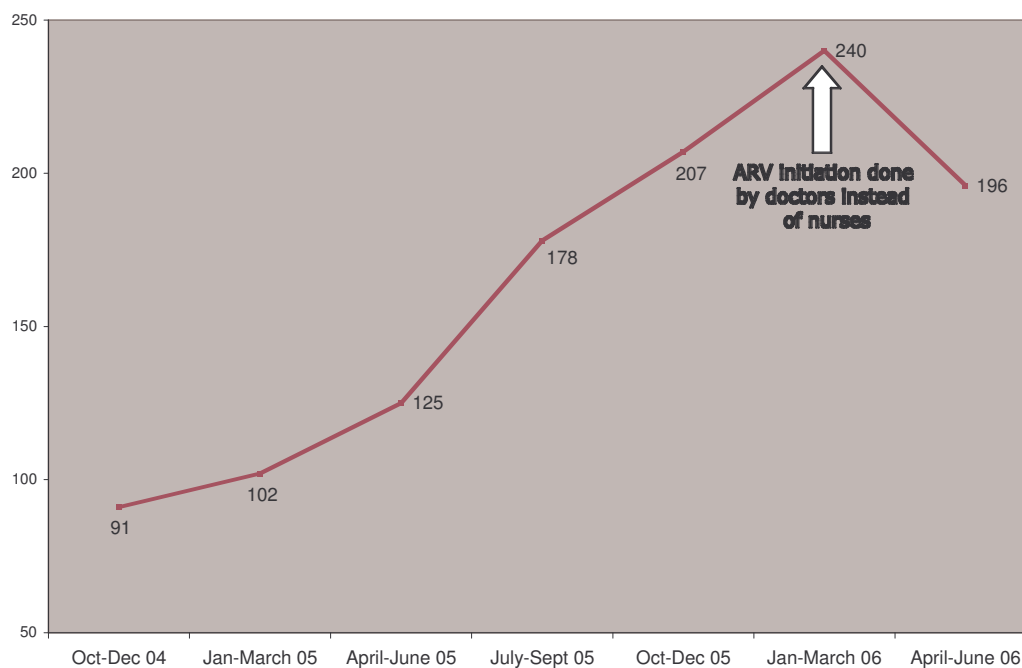
¹⁰ Public Service Accounts Monitor, Eastern Cape Dept of Health Monitoring Brief for 2004/5 Financial Year. Page 7. www.psam.org.za

¹¹ Breier M, Wildschut A. Doctors in a Divided Society: The Profession and Education of Medical Practitioners in South Africa. Human Sciences Research Council, Cape Town, April 2006. Page 17 www.hsrcpress.ac.za

To better control the standard of the training of nurses in the long term it would be useful to develop a post-basic training curriculum for HIV (similar for example to psychiatric nursing) and reward nurses who have done this training with a higher salary, possibly via a scarce skills allowance. This training should endorse nurse initiation of ARVs.

The fact that initiation of treatment by nurses has been central to achieving high coverage is demonstrated clearly by the below graph (Graph 5). In April 2006 the Department of Health passed instruction to the clinics that nurses were no longer allowed to initiate treatment, insisting that this must be done by doctors. This resulted in an immediate downturn in enrollment rates. Confronted with this negative trend in September the Eastern Cape Department of Health reverted this decision.

Graph 5: Quarterly enrollments at clinics



Creating new capacity

Adherence counsellors: backbone of the primary care approach

At the centre of the Lusikisiki model are the adherence counsellors. Acting effectively as clinic-based health promoters who represent the interests of the community, they are the glue that holds to the system together. Adherence counsellors are lay workers, recruited from among community health workers and people with HIV/AIDS, who receive training through workshops and onsite mentoring. Within a few months they are able to manage all the key processes for running a primary health care based HIV service, including VCT provision, service user support, treatment preparedness, facilitating support groups, arranging follow-up visits, teaching people on ARVs to package pillboxes, addressing problems in adherence, and collecting and collating statistics. Adherence counsellors work closely with other community actors: volunteer workers (community care givers), various support groups, adherence and clinic committees and treatment activists (See

Table 3) The fact that they do not wear uniforms is a reflection of their being part of the community rather than the clinic hierarchy.

Adherence counsellors help support a range of activities related to HIV/AIDS in the clinics. At the same time they advocate for the rights of service users and participating in decision-making about health services. Within their group, adherence counsellors are held accountable for the number of enrollments per month, adherence (as indicated by viral load) and number of service users lost-to-follow up every six months. The very low rate of lost-to-follow-up in the clinics is (2%) is largely thanks to the work of the adherence counsellors.

While the critical role played by adherence counsellors is recognized by clinic staff and service users, their function is not accommodated by Department of Health staffing structures or budgets. In Lusikisiki a community based organisation has recently been formed (HIV/AIDS Adherence Counsellors Organisation; HAACO) to ensure their role is sustained in the long term.



Promoting adherence by encouraging service user empowerment

A patient-centred approach is very different from the traditional directly observed treatment that relies on direct monitoring to ensure people take their medicines. It became quickly obvious that there would not be enough personnel to ‘police’ people in this way and in Lusikisiki the goal has been to empower ARV users to become responsible for their own health with medical monitoring from the clinic. This model was first piloted with very good results by MSF in Khayelitsha, Cape Town.¹²

The starting point is to provide training on HIV and recognition of HIV-related conditions, common HIV medication and their side effects, and an understanding of the

¹² Promoting adherence to antiretroviral therapy: the experience from a primary care setting in Khayelitsha, South Africa. Coetzee D, Boule A, Hildebrand K, Asselman V, van Cutsem G, Goemaere E. *AIDS* 2004;18:S27-31

rights of service users under the Patients Rights Charter. People on ARVs were asked to appoint their own treatment assistants, and these were trained in basic HIV/AIDS care. This turned out to be a highly effective form of raising awareness in the broader community as people would engage in a practical way to increase awareness/openness about HIV infection and helping their friends and family members, as opposed to passively receiving information on billboards and radio programmes.

Community support

Engaging the community in HIV/AIDS care is a proven way to enhance programme quality, in terms of clinical outcomes, adherence rates, and retention.¹³ In Lusikisiki, the community interacts with the HIV services in a number of different ways (Table 3). These groups act to mobilize demand for VCT and ARV within the community while at the same time pushing for access to care and treatment within the health system.

Table 3: Community groups supporting HIV services in Lusikisiki

| Group | Who | What |
|--|---|--|
| <i>General support group for HIV positive people</i> | All people testing positive are invited; family members may also attend. 20–60 people meet weekly at each clinic. | Learn about HIV, prevention and treatment (OI, ARV); provide peer support, disclosure, partner testing; do home visits when problems are identified; support advocacy campaigns. |
| <i>ARV support group</i> | All people qualifying for or on ARVs. Treatment assistants may also attend. Slight overlap with general support group. | Preparation for ARVs; support for side-effects; adherence; general support; recall for non-adherers. |
| <i>Treatment Action Campaign</i> | Voluntary association of HIV positive and negative people. 21 branches in major communities and one linked to each clinic. | HIV awareness and prevention; treatment literacy at clinics, schools, community meetings; advocacy for Dept of Health to provide equal services; condom distribution. Human rights and right to health care approach. |
| <i>Adherence committee</i> | Co-opted committee made up of 2 TAC activists, 2 community care givers, 2 clinic committee members, 3 ARV support group members, 1 clinic staff and 1 adherence counsellor. Care is taken to ensure representation from each surrounding village. Members meet monthly. | Decision on potential ARV users (anonymous) where clinic team cannot decide on readiness of a person for ARVs; review and follow up of non-adherers. The committee is a way to keep community responsible for good outcomes. |
| <i>Clinic committee</i> | Elected yearly by community. 8 – 14 members from different villages. Meets monthly. | Represents service users who feel they have been badly treated; appoints community care givers; advocacy for better infrastructure and drug supply, monitors HIV program and condom distribution in community. |
| <i>Community Care Giver</i> | Appointed by clinic committee and paid a stipend by the Dept of Health. | Currently five : two do VCT; one supports sputum collection; two do home visits and recal non-adherers |
| <i>Individual people with HIV/AIDS</i> | Motivated individuals | Learn about HIV and are keen to share experiences and support other members of the community. This is an ad hoc but significant contribution. |

¹³ Zachariah R, Teck R, Buhendwa L, Labana S, Chinji C, Humblet P, Harries A. How can the community contribute in the fight against HIV/AIDS and tuberculosis? An example from a rural district in Malawi. *Trans Royal Soc Trop Med Hygiene* 2006. 100, 167.



These groups overlap both in terms of support provided and membership – for example, a person with HIV/AIDS can be a member of TAC, a participant in an ARV support group, and a member of the adherence committee. This overlap encourages an exchange of ideas and problem-solving approaches.

Proactive drug supply management: pharmacy assistants

Drug supply was initially a major stumbling block, with regular shortages of key medicines. Considerable community pressure was put on the district authorities to improve the situation. The Treatment Action Campaign (TAC) developed a drug monitoring tool, reporting out-of-stock drugs to people at management level. Pharmacy assistants were recruited by MSF to dispense medicines, check orders and take a proactive approach to low stocks, thereby relieving the clinic nurses of a considerable workload. It is a matter of considerable pride for the programme that not a single ARV user had to go without ARVs, and there have been no delays in initiating treatment for adults due to shortage of medication. However, there is sometimes a delay to starting children on treatment, as the system does not allow for a buffer stock of paediatric ARVs.

Improving the system

Simplified monitoring and evaluation

As HIV is a chronic illness it was important to develop tools for monitoring clinical and programme outcomes over time. Good monitoring and evaluation systems hold people accountable and are a tool to constantly improve quality. In Lusikisiki a simple paper-based monitoring system was developed. Each service user keeps their own health record ('health passport'), where all clinical and prescription information is entered. In Lusikisiki a second record was introduced in the clinics that provides an overview of patient history, opportunistic infections, laboratory results (including 6-monthly CD4 and viral load measurements) and antiretroviral regimen. In the absence of clinic clerks, these results are

filed by the counsellors. Program monitoring is done through quarterly cohorts, using the ARV register. Quarterly summary sheets are completed to calculate number of service users (death, transfers, lost to follow up, remaining in care), numbers with CD4<50 and >200, and numbers with undetectable viral loads. Adherence counsellors play a crucial role in this, recording all lab results in the ARV register and filling in quarterly reporting form, thus relieving the nurse of some of the administrative burden. To strengthen clinic supervision, clinic supervisors have been employed and visit each clinic once every two weeks. A paper-based evaluation tool has been developed that evaluates outcomes that quickly point out areas in the clinic that need extra support.¹⁴

Improving laboratory services

When the program started there was no possibility to do CD4 counts in Lusikisiki and blood was sent to Cape Town for CD4 measurements. Thanks to support from the National Health Services Laboratory (NHLS) a flow cytometer was installed in St Elisabeth hospital (the first in the Eastern Cape), presenting an immediate challenge of ensuring efficient flow of specimens and results between clinic and hospital. This was initially ad hoc and chaotic: in some clinics service users were asked to donate money (2 Rand) to pay for a taxi; elsewhere clinic staff would tell them to take laboratory samples to the hospital themselves. A car was at one point supplied by the Department of Health but was diverted to other uses (during a measles outbreak the car was used for immunisation and no specimens were collected for more than a month). Finally, an NGO was subcontracted by NHLS to courier samples by motorbike. So far, this system is functioning well. Telephones have been installed in all clinics and those with electricity also have a fax. This has greatly improved specimen collection and returning of results. Despite greater logistical constraints the clinics retrieve a greater percentage of CD4 tests results compared to the hospital.¹⁵ However, there is still room for improvement.

Viral load, TB culture and drug sensitivity testing is done at Mthatha (about 180 km away). Initially there were problems in communication of results from Mthatha to Lusikisiki and on to the individual but this has been resolved by computer links that allow printing of results in the hospital in Lusikisiki. Now around 80% of results routinely get to the individual. Community caregivers help with tracing any results that are not received.

Infrastructural improvements

Clinic infrastructure improvements were essential for the Lusikisiki programme to succeed: the increase in VCT uptake required more rooms to do counselling; reporting of lab results was facilitated by installing fax machines, but these would only work in clinics with reliable electricity and telephone lines; nurses will not stay in the programme if their accommodation is uninhabitable. Since the beginning of the programme, dedicated attention to these issues has increased the number of clinics with a reliable electricity (16% to 50%), water supply, (0% to 58%), telephone (0% to 75%) and fax (0% to 50%). Building and renovation works have improved the number of clinics with acceptable nursing accommodation (0% to 50%) and counseling space (0% to 50%)

¹⁴ The monitoring tools used in the Lusikisiki programme are available on request: resourcec@mweb.co.za

¹⁵ Herron T, Bandezi N, Bedelu M, Reuter H, Mofokeng N. Effective outcomes from decentralizing ARV care to nurse-managed clinics in rural South Africa. XIV International AIDS Conference, Toronto, August 2006. Abstract TUPE0246.

IV. CONCLUSIONS

The primary health care approach to providing HIV care in Lusikisiki has achieved very high coverage without compromising on quality of care. Uptake of testing and treatment is much faster because these services are offered at clinic levels because there are more service points that are more readily accessible. In addition, because clinics are part of the local community, they are more user friendly, thus people seek treatment earlier and stay on treatment longer. Integration has helped to spread the load amongst all staff, while decentralisation helps spread the load amongst clinics. This is shown by the higher enrollment rate and low rate of lost to follow up in the clinics compared to the hospital.

Task shifting has proven its effectiveness in Lusikisiki. Two critical elements that permitted a dramatic increase in enrolment were reliance of lay counsellors to do voluntary counselling and testing and nurses to initiate ARV treatment. However, nurse initiation of ARVs is not clearly supported by Department of Health policy and a clear policy is needed to promote this is needed.

Adherence counsellors, community health workers, and empowered service users are the key elements behind programme success – a success reflected in highly satisfactory clinical outcomes, excellent retention, low mortality, and universal treatment coverage. The community plays an active watchdog role in ensuring that programmes run smoothly at many levels, from drug supply to reporting of laboratory results. This independent, energetic advocacy for the rights of service users is an essential part of the health care system that cannot be taken for granted. It must be supported and sustained.

The delivery of ARVs has required attention at several levels that has also benefited the general level of general care provided at the clinics. Improvements in drug supply, diagnostic services, monitoring, staff training, and infrastructural improvements have all contributed to improving the overall quality of primary health-care services. The strong community ownership of and participation in health care delivery has also had a major benefit in supporting the general quality of health services. The experience in Lusikisiki has been that far from being a detriment to health care services as some have suggested,¹⁶ the provision of antiretroviral therapy is having a positive effect on the general quality of primary health care.

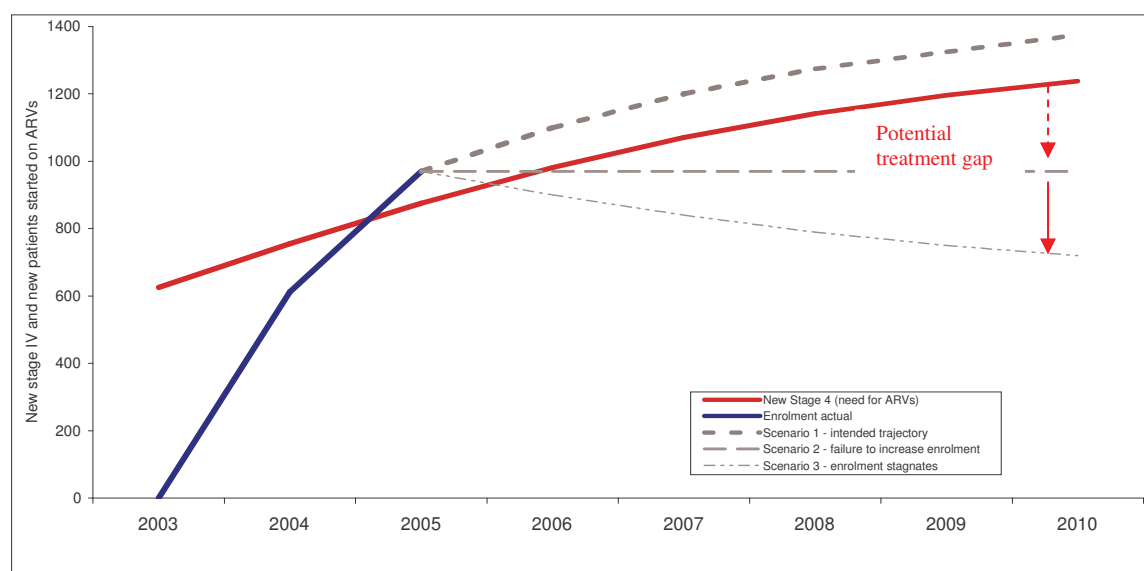
¹⁶ McCoy D, Chopra M, Loewenson R, Aitken J-M, Ngulube T, Muula A, Ray S, Kureyi T, Ijumba P, Rowson M. Expanding access to antiretroviral therapy in sub-Saharan Africa: avoiding the pitfalls and dangers, capitalizing on the opportunities. *Am J Public Health* 2005. 95;1:18-22.

V. MOVING FORWARD

The enormity of the HIV crisis and need to constantly improve models of care is a major challenge for the public health service. External NGOs, with the freedom of flexible budgets and human resources, can be a crucial catalyst to get programmes off the ground. Once a new program is running smoothly the Department of Health can then take over the routine management of the program, and this is happening in Lusikisiki with the withdrawal of MSF in October 2006. This withdrawal has been a carefully planned process with a gradual handover of responsibilities and resources over a period of 18 months.

However, ensuring sustainability in the face of increasing need will require increased resource inputs from the public sector and creative approaches to implementation, including continued support for task shifting and community involvement. While the Lusikisiki programme has performed well up to now, concerted efforts must be made to ensure that rate of enrollment continues to increase in order to prevent the treatment gap from widening (Graph 6).

Graph 6: Projecting the treatment gap in Lusikisiki



Modelling done using ASSA 2003 model

Increasing treatment coverage is a pressing concern across South Africa, and the main rate limiting step is initiation. The current practice in many places of ‘down referral’ – initiating treatment at the hospital, and then passing them on to the clinic – creates a bottleneck in treatment and an unnecessary shuttling of service users, prescriptions and lab results between institutions, all of which can lead to a break in confidence among service users. The innovative approaches taken in Lusikisiki have been a response to an overwhelming need for services that are poorly staffed and equipped. This model is not simply a substitution for suboptimal staff levels in rural areas. It represents the ideal principles of running a district health system and should be promoted as a model for best practice.

