Mainstreaming HIV/AIDS Progress and challenges in South Africa's HIV/AIDS campaign

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Despite a comprehensive national HIV/AIDS/STD Strategic Plan for SA, HIV prevalence has continued to increase, indicating inadequate implementation of the plan. The human rights approach was explicitly endorsed as being one of the guiding principles of the plan.

The targets for life skills education programmes are ambitious but achievable. Some provinces are already well ahead of these targets. Whilst condom availability has greatly improved, their use is less than ideal. The importance of STIs as a key HIV prevention strategy has not been fully grasped. The success of implementing VCT has varied greatly. During 2001 the provision of PMTCT services became a contentious issue. Following the Durban AIDS Conference, the DoH made a decision to implement a PMTCT 'pilot programme' in 18 sites. A key focus of the national strategy should be the implementation of a clearly defined package of treatment and care. The Pro TEST TB/HIV pilot districts have demonstrated the feasibility and effectiveness of doing this. Notwithstanding the need to improve the clinical care of patients living with HIV/AIDS, including the need to set up pilot antiretroviral treatment projects, Home Based Care networks will need to expand.

SA has created one of the most progressive and far-sighted policy and legislative environments in the world. Despite the existence of a well thought out plan, sufficient time, a large economy to draw on, a reasonable pool of skilled health and education workers and a sophisticated media, these policies and laws have not been adequately implemented and have not impacted significantly on the ground. Factors responsible for this include: poverty and inequality; a public sector undergoing restructuring at every level; a high turnover of staff; a lack of effective leadership; and a failure to mainstream HIV activities at all levels of society. The problems of leadership have been partially counter-balanced by a re-emergence of health activism and social action to combat the epidemic.

This chapter illustrates a number of areas requiring a mind shift including leadership; gender relations; health worker training and attitudes; and societal denial and stigmatisation. Underlying some of these problems is the lack of an effective human rights approach to HIV/AIDS. A large number of South African nurses, doctors, teachers, parents and persons living with HIV/AIDS have worked beyond the call of duty to deal proactively with HIV/AIDS. It is now necessary to ensure that this is complimented with a stronger institutional and societal response.

Introduction

Despite a comprehensive HIV/AIDS plan,[1,2] there has been a continuing increase in the prevalence of HIV in South Africa. This is an indication of the inadequacy of the implementation of the plan. Although the epidemic has been in our midst for over a decade, the country, with all its resources, is still far from having a response that is commensurate with the seriousness of the epidemic.

The spread of the disease has been facilitated by an AIDS campaign which, despite localised successes, is insufficiently mainstreamed. The campaign is fragmented and fractious; does not prioritise certain key interventions; and suffers from insufficient leadership from many sectors of society, most noticeably from national government. This chapter aims to characterise the state of the epidemic, describe some of the key HIV/AIDS activities underway in the country and analyse the reasons behind the campaign's inability to effect a sufficient impact on the epidemic.

A coercive approach to the epidemic is essentially one where attempts are made to force people to be tested, or to behave in a particular way. Prevention activities are portrayed as a war or moral crusade against an external threat, and people with the disease consequently feel isolated. The approach is discriminatory and often leads to the blaming and exclusion of people suspected of being infected. The judgmental tone of the coercive approach is often accompanied by individuals externalising HIV, and viewing it as someone else's problem, especially that of 'amoral' members of society.

The consensus that a coercive approach to controlling HIV drives it underground and encourages its spread, has led to a human rights approach in SA. This approach seeks to empower individuals and communities with the knowledge and means to avoid infection; strives to encourage the whole population to acknowledge their vulnerability to HIV; encourages a positive and informed willingness to undergo voluntary HIV testing and a response to infected persons which includes providing adequate care, support and treatment. As a consequence infected persons are likely to be treated with greater inclusion and dignity.

The human rights approach was explicitly endorsed as being one of the guiding principles of the national HIV/AIDS Strategic Plan (2000-2005)[2], and this review will evaluate progress within the spirit of a human rights approach.

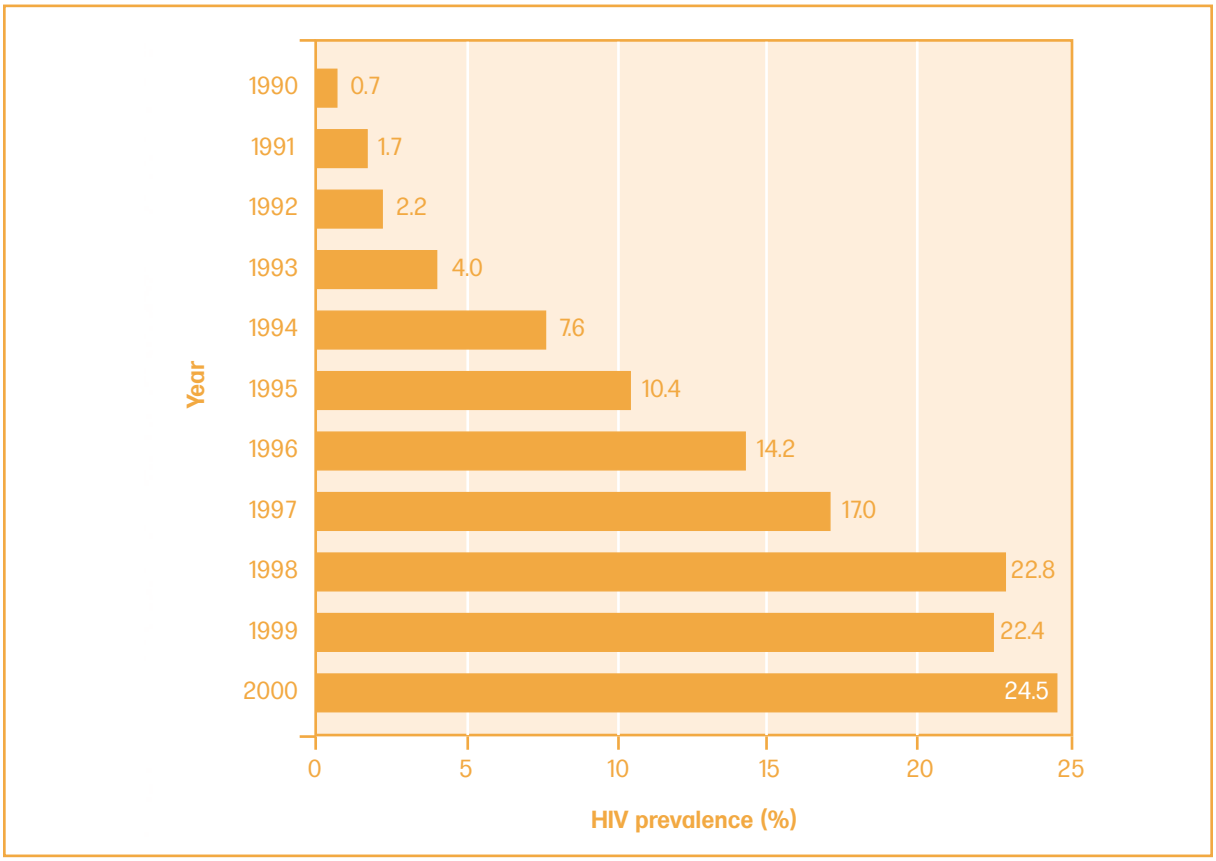
Describing the HIV epidemic

The HIV/AIDS epidemic may be characterised in three ways.[3] The first is in terms of **HIV infections**. Based on the antenatal HIV prevalence survey in October 2000 24.5% of all pregnant women were HIV positive. This translates to approximately 4.8 million South Africans and nearly 20% of all 15-49 year olds infected with the virus,[4] and indicates the enormity and

magnitude of the problem facing the country. The trend highlighted in Figure 1 suggests that the prevalence of HIV may be levelling off. However, since the antenatal survey measures prevalence (the total number of people infected with HIV), and not incidence (people recently infected), the levelling off reflects a combination of a reduction in the rate of increase of new infections, and of the increasing number of deaths due to AIDS.[a]

A positive finding of the antenatal HIV prevalence surveys is the decrease in the prevalence in the under 20 age group from 21% in 1998 to 16% in 2000. Because deaths due to AIDS are very uncommon among teenagers, the prevalence in this age group comprises mostly new infections. The reduction in prevalence may therefore reflect an actual reduction in incidence. This is corroborated by evidence that 55% of sexually active teenagers report always using a condom when they have sex,[5] and that syphilis prevalence rates have dropped from 11% to 5% in pregnant women over the past three years.

Figure 1: National HIV prevalence trends among antenatal clinic attendees in South Africa: 1990-2000[4]



a The Actuarial Society of South Africa 600 (ASSA600) model whose projections have this far been fairly accurate, projects that the HIV prevalence will stabilise by 2005/6.

The second way of characterising the HIV/AIDS epidemic is in terms of the number of people who are sick with **AIDS and who die from it.** AIDS related illness usually occurs several years after HIV infection. In 2000 it was estimated that 40% of all deaths in the age category 15-49 were due to AIDS. In some age groups mortality rates have increased by 350%[6] (see Figure 2), and average life expectancy in South Africa has decreased from 66 years to 47 years, due largely to AIDS (see Figure 3).[7] A further consequence of the AIDS epidemic is the doubling of the TB incidence in many parts of the country over the last three years,[8] and the large proportion of hospital beds occupied by patients with AIDS.[9]

The cost of AIDS to employers is likely to be large. Up to 40-50% of employees could be lost by some companies.[10] It is estimated that 70 000 new teachers, about the same number of teachers as those employed currently, will be needed by 2010.[11] In the health sector it is estimated that 5% of dentists and 23% of student nurses are HIV positive.[12]

Figure 2: Projected numbers of people living with HIV, sick with AIDS and the accumulated AIDS deaths (ASSA600)[6]

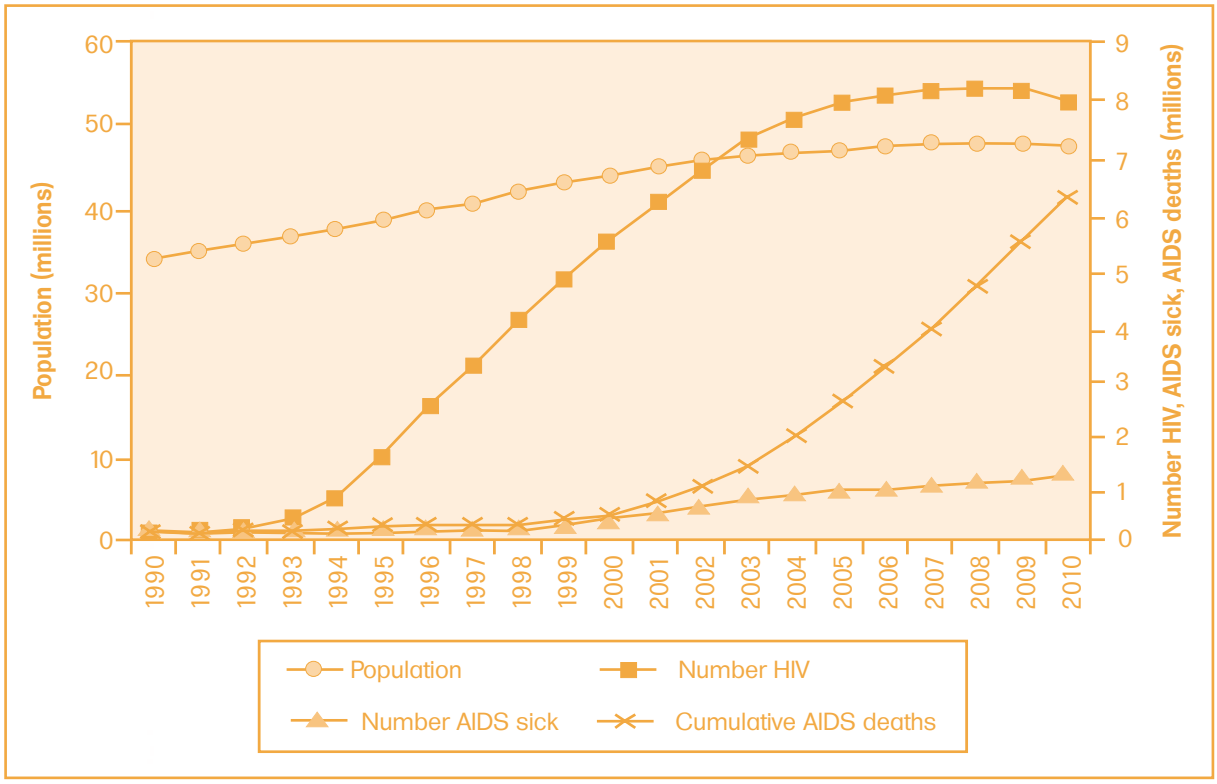
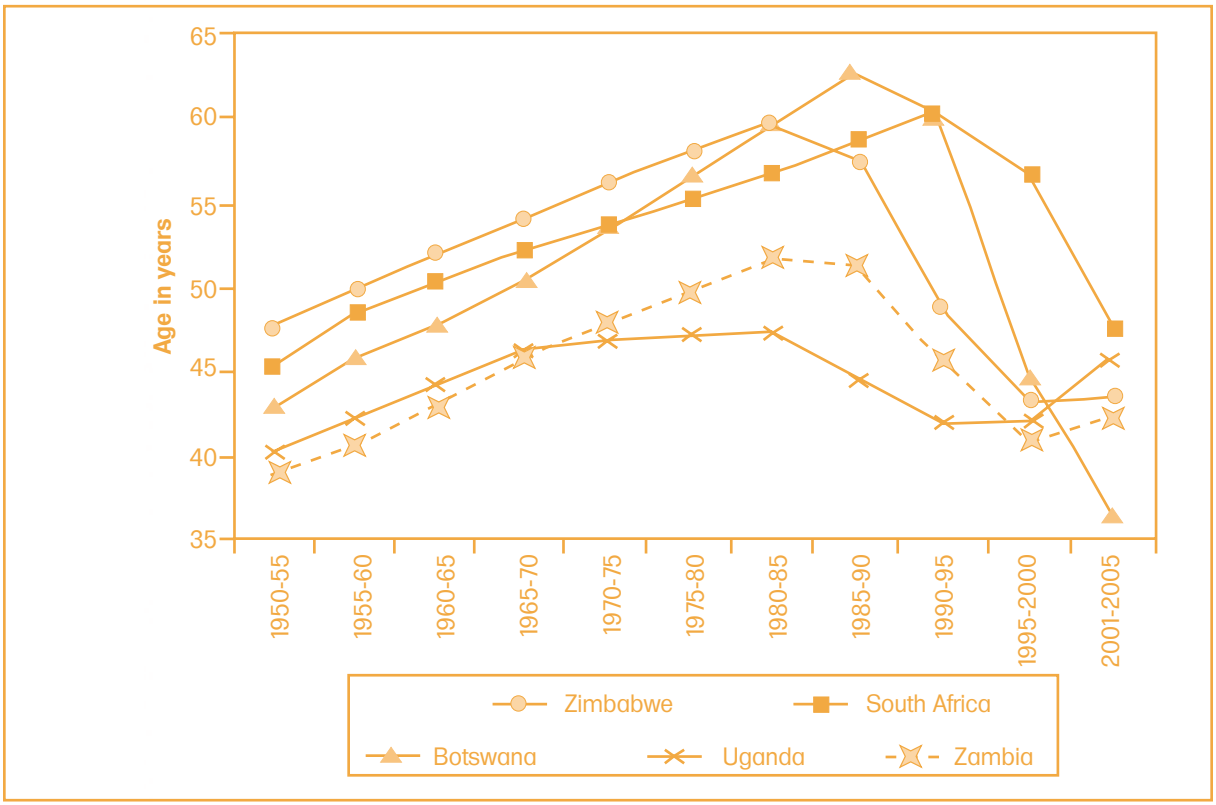


Figure 3: The impact of HIV on life expectancy in selected African Countries[7]



The third way of characterising the epidemic is in terms of the extent of **stigma, discrimination, blame and collective denial** in the country. In SA, this is demonstrated by the fact that while 4.8 million South Africans are infected with HIV only 0.5% believe that there is somebody infected with HIV in their family.[13] In the Northern Province 8% of youth do not believe in the existence of HIV/AIDS, whilst 61% assume that AIDS is not on the increase.[14] The difficulty those who are HIV positive have in disclosing their status is demonstrated by a survey of 726 HIV+ patients at two sites in KwaZulu-Natal, which found that 65% and 92%, respectively, had not told anyone of their status.[15]

The National HIV/AIDS and STD Strategic Plan for South Africa (2000-2005) and the National Integrated Plan (NIP)[2,16]

The National HIV/AIDS and STD Strategic Plan for South Africa, 2000-2005 (called National Strategic Plan) contains 37 objectives arranged in four priority areas: prevention, treatment, care and support, research and human rights. To ensure adequate prioritisation of the key objectives, the government launched the National Integrated Plan (NIP) in January 2000. The NIP is a joint venture between three Departments (Health, Social Development and Education), intended to implement three key interventions of the National

Strategic Plan: Life Skills education, Voluntary Counselling and Testing and Home/Community Based Care and Support. The three interventions are particularly targeted at children and youth and will receive R450 million over the next three years (and thereby consume the biggest chunk of HIV spending). This section of the chapter reflects on progress with these and other key aspects of the National Strategic Plan and NIP.

Life skills

The introduction of a formal life skills programmes in schools is envisaged to be the key intervention in the NIP. The goal of the programme is to 'assist youth to acquire knowledge, develop skills and establish values that will enable them to make responsible choices and grow-up healthy'.[16] The importance of this intervention is highlighted by the National Youth Survey that found:[13]

- 39% of sexually experienced girls had been forced to have sex when they did not want to
- 35% of sexually experienced boys agree with the statement that 'having many sexual partners means I am cool or hip'
- 16% of sexually experienced girls said that they have had sex in exchange for money, drinks, food or other gifts.

The targets for the percentage of schools (primary and secondary) offering the life skills education programme are ambitious but achievable. These targets are 20% in 2000/2001 and an additional 40% in each of the subsequent two years. Some provinces are already well ahead of these targets. Gauteng for example, has implemented the programme in 84% of secondary and 76% of primary schools.[17]

However, the fact that some kind of 'implementation' has occurred says nothing about the quality of life skills education, the extent to which it has been internalised and practiced by all teachers, or the impact of the programme on youth behaviour. A review of the life skills programme in KwaZulu-Natal found that although two teachers per high school were trained as early as 1997, the 'lack of adequate initial teacher training, and/or ongoing teacher support' coupled with the fact that the subject was not recognised by other teachers meant that the programme's ambitious goals have 'fallen flat'.[13] James argues that "however well-intentioned and well-designed the training intervention was, it could not take root in a school setting where existing ideologies and practices were not likely to nurture it."[5]

A recent 'study tour' of HIV in rural areas, organised by the Health Systems Trust and the provincial DoH, visited a school which had been 'officially reached' by the life skills programme. The school had had one of its teachers extensively trained in life skills education. However, upon returning to the school, staff shortages and the lack of any on-going support or supervision

from the provincial office, effectively meant that no life skills programme had been properly implemented.[b]

The need for more commitment to a schools-based intervention is further highlighted by a Human Rights Watch study conducted in 2001 which found that 'sexual abuse and harassment of girls by both teachers and other students is widespread' in many South African schools. A 1998 Department of Health survey of rape victims found that 38% said a schoolteacher or principal had raped them.[18]

Other interventions that have recognised the importance of changing the behaviour and attitudes of the youth include the significant work done by Soul City and loveLife.

Access and use of condoms

The provision of condoms in the public sector in South Africa has risen from 6 million in 1994 to 250 million in 2000/2001. This is a huge increase in availability.[19] A recent prospective review of the fate of these free male condoms found that five weeks after distribution, 44% had been used in sex and only 9% had been lost or discarded.[20] These are very positive findings. On the other hand some reviews have found that many health facilities are only providing condoms on request, thus reducing their accessibility.[21]

Whilst the availability of condoms has greatly improved, some studies note that the use of condoms is less than ideal. A study conducted in the mining community of Carltonville revealed that men use condoms in less than 25% of contacts with non-regular partners.[22] The need to develop a regular system for the surveillance of risky behaviours has been recognised by the public health community and by the Department of Health. Some pilot Behavioural Surveillance Systems (BSS), have been set up but at present there is no BSS covering the country.

One of the reasons for the low usage of condoms may be the difficulty of accessing condoms in an inconspicuous manner: although 83% of sexually experienced youth agree that using a condom is the best way to avoid contracting HIV, 70% say that buying or obtaining condoms is very embarrassing.[13] So, although the condoms that are distributed are being used, not enough are used, and there remains a need to increase the availability and the social marketing of condoms.

One area of progress in the last 12 months has been the continued piloting of the female condom, which offers hope and protection to women. Experiences from the 27 female condom pilot sites have been generally successful, and the number of sites providing female condoms is being expanded to 117.[23]

b Dr Wendy Hall, Health Systems Trust, personal communication.

Improve the management of Sexually Transmitted Infections (STIs)

The control of STIs is one of the most cost-effective and important strategies for reducing the spread of HIV.[c] The Department of Health has organised a great deal of training on proper case management in the last few years. However, the importance of STIs as a key HIV prevention strategy has not been fully grasped.

The lack of appreciation of the public health importance of adequately treating STIs within the public sector is illustrated by:

- STI co-ordinators posts not being filled
- Lengthy periods where indispensable STI drugs are out of stock at clinics
- Poor adherence to national treatment guidelines
- Low numbers of STIs diagnosed.

Box 1: Case Study – Kopano, Free State

In order to improve the control of STIs, the national STI Initiative was set up to develop a number of best practice sites. Some successes and a number of lessons have been generated. In Kopano District, an integrated programme of joint planning with the District Management Team led to the formation of an STI Working Group and the introduction of three 6-monthly cycles of training and evaluation. The District STI Quality of Care Assessment (DISCA) tool[d] was used to evaluate the quality of STI services. In 18 months, the percentage of clinics providing correct syndromic treatment for STIs increased from 64% to 86%, and the number of partner contact slips that were handed out increased from 156 to 1 122.

A review of the factors behind these Kopano successes highlighted two key factors: firstly, the District Health System was better established in Kopano, and secondly, the members of the STI work group were highly motivated and their zeal drove the whole process.[24]

Previous reviews have also indicated that the quality of care of STI treatment in the private sector is generally poor.[25] Despite the fact that the private sector sees the majority of STI clients in the country there is no strategy by government to address this public health priority. This is a serious gap within the national HIV programme.

A symposium on the management of STIs within the private sector was held in November 2001 and attended by a variety of stakeholders including SAMA, the Health Professions Council, the Academy of Family Practitioners, the DoH and academic institutions. This symposium confirmed the need for action targeting the private sector.

c The control of STIs via the syndromic approach has been shown to reduce the spread of HIV by up to 40% (See Grosskurth H. Control of sexually transmitted diseases for HIV-1 prevention: understanding the implications of the Mwanza and Rakai trials. Lancet 2001; 353: 1981)

d The DISCA tool is a tool to assess the quality of STI services, and is divided into several sections covering access, infrastructure, routine data, staffing, training, management of STD syndromes.

The symposium also highlighted a number of important success stories that have occurred within the private sector such as the Lesedi and Carltonville projects that have been focused on the control of STIs within the mining industry. One of the innovations of these projects has been the use of a strategy called Periodic Presumptive Treatment (PPT). PPT involves the regular (hence Periodic) mass administration of a broad-spectrum antibiotic (azithromycin) to all women at high risk regardless of their clinical condition. In this project a well-defined high-risk group, *viz*. commercial sex workers, were given mass treatment with the purpose of treating symptomatic and asymptomatic STIs. While some people without an infection will inevitably be treated, in both Carltonville and Lesedi, the strategy has led to a 50% reduction in the incidence of STIs in the male populations of these towns. In Lesedi, it has been further estimated that the decrease in STIs could translate into a 46% reduction in the spread of HIV.[26]

Voluntary Counselling and Testing (VCT)

The elevation of VCT to one of the three key programmes in the NIP is based on a considerable body of evidence that shows that increasing the proportion of persons who know their HIV status will help reduce HIV transmission rates. At an individual level, undergoing the process of VCT is a powerful tool in effecting positive behaviour change. People who test positive are more likely to take steps to protect their partner, and people who test negative are more likely to take steps to ensure that they stay negative.[e,27-29]

Perhaps more important are the population level benefits. Currently less than 10% of those infected with HIV know that they are infected. The vast majority of HIV infections are therefore being transmitted by people who are unaware of their HIV positive status. The stigma and denial around HIV have resulted in most South Africans regarding HIV to be a problem of other groupings, and therefore very few South Africans see the need to be tested. A national VCT programme led by the leaders of all sectors of South African society would help to undermine the stigmatisation and denial that is helping to fuel the epidemic.

The NIP aims to have VCT offered in all health facilities within 3 years. It also aims to promote uptake so that 12.5% of the sexually active population has been be tested by 2004. The DoH has developed training manuals and a set of minimum standards for counsellors, and the provinces are responsible for implementation.[30,31]

Two positive innovations that have been introduced are the use of lay counsellors and rapid HIV tests. The rapid tests are done while the client waits, and as a result the proportion of clients getting their results has increased

e It is estimated that one HIV infection is prevented for every 10 persons undergoing VCT. Naidoo P. TB/HIV issues for the medium term development plan (Unpublished).

from between 10% and 80% to over 99%.[32] Lay counsellors help to reduce the workload of health workers, and the quality of the counselling they offer may be better than that offered by nurses.[33]

Setting up an effective VCT service requires a large number of different activities, such as a mentoring and support programme, an adequate information collection system, setting up of post test support groups, and the provision of a package of care to those who test positive. The success of implementing VCT has varied greatly. In most provinces, fairly large numbers of counsellors have been trained and 4-6 sites per district have been selected as sites for the implementation of the rapid tests.

The general failure of health workers to promote VCT has been a further challenge. Despite patients with TB (of whom nearly 50% are HIV positive) or STIs being in the high-risk category, few are offered VCT. A 1999 evaluation of HIV/AIDS Counselling concluded, 'the impact and reach of counselling (relative to its potential) is relatively narrow and limited…. counselling services in the main remain underdeveloped and under resourced, constrained by issues of competence, policy obstacles, lack of co-ordination and a lack of resources.'[33]

One way of providing further impetus to the VCT programme would be to expand the number of lay counsellors and the proportion of these that receive some form of remuneration. Provinces that are paying lay counsellors, or providing them with a stipend, have had more successful VCT programmes, and other provinces are considering adopting this strategy.[f]

The four original Pro TEST TB-HIV Pilot Districts provide examples of how to overcome the obstacles in the way of providing a prioritised package of HIV/AIDS/STI/TB prevention, care and support services. The priority components of this package are DOTS, VCT, STI syndromic management, condom promotion and providing basic HIV/AIDS clinical services. The sites are called Pro TEST because of the central aim of increasing access to a VCT programme as an entry point for access to a wider set of services and health promotion activities.

In the Central District of the Western Cape, when Pro TEST started in 1999, the district was testing 293 persons per quarter for HIV, which is equivalent to 0.4% of the adult population per year. Over the last 2 years the proportion of the adult population tested increased almost ten fold to 4% per annum. At this rate the departmental target of 12.5% in 3 years is attainable. Although staff encourage all high-risk clients, such as those with an STI or TB, to go for VCT, there has also been a steady increase in the numbers of clients who self-present. Encouragingly these now comprise 71% of those tested at Central District[34] providing concrete evidence of the population level benefits of an integrated package of prevention-care interventions based at clinic level.

f Personal interview with Thembela Masuku, National VCT co-ordinator, 3 October 2001.

Prevention of Mother-to-Child-Transmission (PMTCT)

During 2001 the provision of PMTCT services became a contentious issue. Following the Durban HIV Conference, the DoH made a decision to implement a PMTCT 'pilot programme' in 18 sites, two in each province. These sites began to implement services from the middle of 2001 onwards and all 18 were operational by the end of the year. In addition, Gauteng and the Western Cape[35] expanded the programme to other sites.

The programme is guided by a national PMTCT protocol that includes the administration of nevirapine, the implementation of revised obstetric practices and the provision of free formula for 6 months for those mothers who choose not to breastfeed. The purpose of these 'pilot sites' is to answer various questions about the implementation of the PMTCT programme.

By the end of 2001, 193 health facilities (hospitals, midwife obstetric units, community health centres and clinics) were part of the national PMTCT pilot programme. They covered approximately 6 090 antenatal bookings per month, which translates to about 9% of the total number of countrywide bookings.[36]

The rate at which pregnant women agreed to be tested for HIV was 51% in these sites. This translates to about 3 133 pregnant women being tested per month of whom about 30% are HIV positive. On the basis of these VCT uptake and sero-positivity rates, it is estimated that 6 343 HIV positive pregnant women were identified in the national PMTCT sites from the time of its inception to the end of 2001.

Towards the end of 2001 the Treatment Action Campaign (TAC) took the government to court to challenge the decision not to roll out the PMTCT programme beyond the 18 pilot sites for a minimum of two years. TAC argued that the PMTCT programme has been shown to be an efficacious, safe, affordable and cost-saving way of dealing with an aspect of HIV/AIDS, and should therefore be rolled out. In particular, TAC argued that no doctor at a public hospital should be prevented from giving nevirapine to mothers in need.

The government offered a number of arguments in its defence. These included the lack of resources and infrastructure to sustain a large rollout; question marks about the toxicity of nevirapine and concerns about the development of resistance.

In December 2001, the Pretoria High Court ruled that the government was 'obliged' to expand the programme and make nevirapine available as part of a person's constitutional right to health treatment. It gave the government until March 31, 2002 to create a comprehensive plan for dispensing the drug and reducing vertical transmission throughout the country.[37] The Minister of Health has since challenged this court ruling, although she has made it clear that the challenge to the court ruling 'is aimed at clarifying a

constitutional and jurisdictional matter'. The Minister also stated that the Department of Health would review its MTCT programme in January 2002 through a 'broader stakeholder consultation'.[38]

Treatment, Care and support

Prevention and care are inextricably linked. Concentrating on prevention alone is particularly 'inadequate in countries with high prevalence epidemics. Programmes which only offer condoms or counsel abstinence are woefully inadequate and cannot penetrate the inertia and sense of hopelessness that accompanies death and dying'. [39]

In addition to its synergistic relationship with preventive activities,[g] an affordable package of care is a basic constitutional right and vital to the success of the human rights approach to dealing with the epidemic.

The provision of treatment, care and support for HIV/AIDS in public health facilities remains inadequate. A baseline evaluation of services conducted in the Pro-TEST TB/HIV pilot districts found few clinical HIV/AIDS activities. For example, 'no prophylactic regimens were offered to people living with HIV, and there was no standardised management of HIV-related opportunistic infections'.[h]

This situation appears to be the norm around the country as suggested by a recent review of the management of HIV in children which found that only 20% of clinic staff had heard of, and under 10% of clinics had a copy of, the National Treatment Guidelines.[i] A mere 33% of clinics said they were providing appropriate (co-trimoxazole) prophylaxis.[j,40]

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g As described in the VCT section, increasing the proportion of the population receiving counselling and testing is vital to limiting the epidemic. A meaningful package of care offers people a powerful life or death incentive to be tested. Without it people have little incentive to be tested.

h Our failure to gear our PHC clinics up to provide the package of care has led to patients going straight to hospitals with all the increased costs associated with this. One survey found that 80% of HIV outpatient visits could have been seen at a primary care site (Kinghorn A, Lee T, Karstaedt A *et al*. Care for HIV-infected adults at Baragwanath Hospital, Soweto. S Afr Med J 1996; 86 (11):1490-4.)

i These guidelines came out in mid 2000, three years after the first meeting of the authors in October 1997.
The failure to adequately distribute these Treatment Guidelines is all the more significant if we consider how poorly HIV is dealt with in the National PHC Standard Treatment Guidelines (STGs). A nurse or doctor consulting these guidelines would find nothing when it came to managing HIV in children and more on the management on gingivitis than HIV when it comes to adults. They would also learn under drug treatment that 'there is no curative treatment for this disease.' These STGs were, however, published 3 years ago and the process to update them should be initiated in 2002.

j The urgent need for training is backed up by the findings of a recent survey of 236 health workers in KZN (superintendents, doctors and nurses), which found that 96% felt there was a need for HIV/AIDS training in their institution. (Pawinski, R. 2001. Unpublished)

Another recent survey in hospitals found that nearly all physicians interviewed were unhappy about the lack of clinical protocols to deal with both the clinical and ethical aspects of care.[41] It is thus not surprising to hear of incidents of discrimination that HIV/AIDS patients have experienced at the hands of health workers.[42]

The current absence of guidelines leads to HIV care being rationed in 'inconsistent and often unfair ways', and places tremendous stress on frontline health workers.[43] The responsibility for this behaviour lies not with the individual health workers, but with a system that has not yet adequately provided its workers with the guidelines and skills to provide effective care.

A key focus of the national HIV strategy should therefore be the implementation of a clearly defined package of treatment and care. The Pro TEST TB/HIV pilot districts have demonstrated the feasibility and effectiveness of doing this. In these sites, for example, evaluations of the impact of training have noted remarkable improvements in the care provided to HIV infected persons, and also in the attitude of persons living with HIV and their openness about HIV.

It is against this backdrop, that the decision by the national and some provincial DoH's to enter into a partnership with various non-governmental organisations to dramatically expand the training of PHC and hospital based staff in the package of care should be applauded.[k]

Both health workers and the public need assistance in distinguishing between persons with AIDS near death and HIV positive persons for whom simple and cost effective treatment and care can be provided to restore health and improve the quality of life. As one doctor put it, "our whole system is shoving persons into HBC."[44]

The question of antiretrovirals

Although an expensive treatment programme, combination antiretroviral (ARV) drug therapy represents one of the greatest pharmaceutical developments in the history of medicine.[45] Hopefully it will be possible to determine the compromise point between what is affordable and the cost of an adequate package of care. The Abuja Declaration and Framework of African Countries for Action for HIV/AIDS, of which South Africa was a key author and signatory, recommends that Health Sector expenditure be increased to 15% of total expenditure.[46] In South Africa, this would amount to an extra R2-R5 billion for the health budget, in addition to the potential to tap into the Global HIV/AIDS Fund and the private sector.

k One of the major bodies responsible for this training will be IAPAC (International Association of Physicians for AIDS Care). IAPAC has been responsible for the highly successful training of health workers in the Diflucan Partnership Programme (where health workers were trained in the use of fluconazole for the management of opportunistic infections).

While such an additional injection of funds would necessitate a significant proportion being spent on preventive activities and other health care and welfare needs, including a basic income grant, it may be possible to afford some form of ARV programme. An ARV treatment programme tailored to our circumstances, could, for example, provide ARVs to 250 000 persons per year at a drug cost of R0.5 billion/year (or R2 000 per person per year).[l,m,47]

The case of Brazil may be illustrative. Although the number of people who are HIV+ is much smaller, in terms of levels of poverty and inequality Brazil is similar to South Africa. Through its commitment to dealing with HIV within a human rights framework, it has made the provision of ARVs a central component of its programme, and has managed to more than halve the expected increase in HIV infections over the past 6 years.[48] Even excluding the benefits of the averted infections, the ARV treatment programme in Brazil has been shown to be cost saving.

The positive impact of ARV treatment on TB control is also of equal importance. A recent study in the Western Cape found that triple ARV therapy could reduce the risk of HIV positive persons developing TB by a factor of 9.[49] In addition, ARV treatment is significantly more cost effective than a significant number of interventions currently offered by the public health sector[n] and a there is a strong case for establishing a few pilot sites per province.

In November 2001 the National Health Summit discussed the issue of ARVs extensively and recommended that pilot projects using ARVs to treat children and adults should be set up in the public health service.

Home Based Care (HBC)

HBC was designed as a way to implement effective and affordable community-based care and support. It involves shifting care for the dying from hospital to people's homes, and from health professionals to family and community members. According to national policy, HBC is applicable to all terminal conditions, not just AIDS. Unfortunately, there are as yet no clinical guidelines for determining when patients with differing illnesses should be treated in this HBC setting. The programme is based on collaboration between the DoH and the Department of Social Development. The division of the interventions between the two departments is illustrated in Table 1.

l This would include tapping into the Global HIV/AIDS Fund and the private sector.

m An internal DOH document calculated that the state is spending R3,6 billion on the hospitalization of AIDS patients this financial year.

n Triple ARV therapy is more cost effective than many therapies for non-HIV disease, such as radiation therapy for early breast cancer, treatment of raised cholesterol, and kidney dialysis (Freedberg 2001).

Notwithstanding the need to improve the clinical care of patients living with HIV/AIDS, in the absence of antiretroviral treatment, HBC is an appropriate and necessary response to the epidemic. Whilst HBC is a vital component of a treatment and care approach, it must not be the only component. It is essentially a form of palliative and supportive care and can only be justified as an adjunct to affordable treatment.

Table 1: The key components of the HBC strategy [44]

Department of Social Development	Department of Health
Social relief e.g. food parcels	Training volunteers on the medical care of infected persons
Social grants e.g. disability grants	Providing care kits
Foster placements	Training on palliative care
Training volunteers on care and support	

Much progress is being made in the roll out of HBC. The Departments of Health and Social Development have completed a national audit of all the existing Home Based Care operations; they have produced HBC guidelines, manuals for trainers and learners; and have appointed a HBC co-ordinator in each province. The plan is to build a series of HBC teams, where each team is capable of providing care to a catchment population of 17 000 persons. By March 2002 there should be 300 such teams in place and 600 by March 2003. It is estimated that 2 400 teams will be needed to provide 'full coverage of vulnerable communities'. A HBC costing study by the DOH and the Department of Social Development has calculated that a country-wide HBC programme would cost between R1.1 billion and R1.45 billion per year.[44] R904 million has been earmarked for HBC and VCT over the next three years.

Human Rights

It is widely accepted that openness and acceptance of HIV/AIDS and breaking down denial will only be achieved by campaigns to protect and advance the human rights of people living with HIV and AIDS. This has become known as 'the AIDS paradox' – by protecting the rights of people with HIV, you reduce the risk of infection to uninfected people.[o] The fourth priority area of the National Strategic Plan aims to deal with the promotion of human rights.

One of the objectives is to create a legal and policy environment that protects the rights of all persons affected with HIV and AIDS, and by mid-2001, South Africa had created one of the most progressive and far-sighted policy and legislative environments in the world. Policies exist for education,[50,51]

o This is described as a paradox because it is the opposite to the traditional public health response to infectious diseases, where a limitation of rights is often seen as justifiable in the interests of containing epidemics.

the workplace, HIV testing and counselling[30,31] and the management of patients with HIV and AIDS.[52] In addition, there is a national Patients Rights Charter.

Unfortunately these policies and laws have not been adequately implemented and have not impacted significantly on the ground. Stigma and poor access to justice deter people from seeking redress for institutional human rights violations. Women's dependence on male partners together with the lack of support services and shelters prevent women from taking steps to protect themselves from risk of infection. In the workplace, there is evidence that unfair discrimination, albeit unlawful, continues to take place.

Access to specialised legal services is minimal. A number of NGOs exist to deal with AIDS and human rights abuses (e.g. the AIDS Law Project, Black Sash and Legal Resources Centre), but are wholly insufficient in number and capacity. Statutory human rights commissions, notably the Human Rights Commission (HRC) and the Commission for Gender Equality (CGE), despite occasional tentative forays into the arena, have not taken up clear campaigns around HIV as a human rights issue.

Explaining the inadequacy of our response

In 1994 South Africa developed a multi-sectoral HIV/AIDS plan based on international and local experience and supported by all the major constituencies. Despite the existence of this well thought out plan, sufficient time, a large economy to draw on, a reasonable pool of skilled health and education workers and a sophisticated media, our antenatal HIV prevalence increased from 7.6 to 24.5% over the ensuing 7 years.

Responsible factors include:

- The depth of poverty and inequality, which accelerate the spread of HIV
- A public sector that has been undergoing restructuring at every level (both in terms of transformation from its apartheid past as well as in terms of devolution of authority to local government[53])
- A high turn-over of staff within the health sector and the concomitant loss of institutional memory.[54]

A further contributing factor which has been especially evident in 2001, has been the lack of effective leadership. The 2001 United Nations General Assembly Special Session Declaration on HIV/AIDS indicated that the first action required to mount 'an effective response to the epidemic' is the development of 'strong leadership at all levels of society'. Leadership, it noted, 'involves personal commitment and concrete actions'.[55] Strong and enabling leadership is necessary to both mobilise all sectors and direct their activities.

Uganda, under the leadership of President Museveni, is a good example of

the importance of political leadership in helping a country make a mindshift in terms of behaviour. HIV prevalence in pregnant women in urban areas of Uganda dropped for eight consecutive years from 30% in 1992 to 11% in 2000.[56]

In SA national leadership has not been weak, but some of it has been misguided. Most damaging has been the on-going questioning by the President of whether HIV causes AIDS. The President has incorrectly asserted that 'a virus cannot cause a syndrome'. The contradictions of simultaneously promoting VCT and 'breaking the silence' on the one hand, while publicly questioning the very existence of AIDS and the validity of HIV testing inevitably causes confusion. Given this apparent fudging of the issue, the results of a recent youth survey in the Northern Province (NP) and the Free State (FS) are not surprising: 8% and 6% of 16 to 30 year olds in the two provinces did not believe in the existence of HIV/AIDS or thought it was like any other disease and 61% in the NP and 43% in the FS think that AIDS is not on the increase.[14]

The expensive, time-consuming and highly damaging 'Presidential Aids Advisory Panel' (PAAP) was 'designed to generate the best possible collective advice to the South African government'. The panel did not reach any consensus as to the cause of AIDS, and many of its members found the whole process a waste of time and resources. In addition, the high profile panel ended up giving a platform to the discredited views of a small group of pseudo-scientists, known as 'AIDS dissidents', who continue to deny the scientific evidence that the HIV virus is the underlying biological cause of AIDS and that AIDS is largely responsible for the rise in adult and child mortality in Africa. Some of the statements of the dissidents in the 134 page report ('AIDS does not exist' and 'AIDS would disappear instantaneously if all HIV testing was outlawed and the use of antiretrovirals drugs was terminated') are indefensible.

Leadership on HIV/AIDS was again questioned with the release of the Medical Research Council's Report on AIDS mortality in South Africa. This study, found a large increase in young adult deaths (up to 350% in some age groups) and noted that this pattern has never been observed anywhere in the world, except for AIDS affected populations in Southern Africa (See Figure 2). The report also estimated that 40% of 15-49 year old deaths last year were due to HIV/AIDS, and projected that that by 2010, AIDS would account for a total of 5 to 7 million deaths in South Africa.[6] Certain sectors of government, such as Statistics South Africa, chose to criticise the methodology (which was scientifically sound) of the report rather than its underlying and horrific message.

Part of the damage caused by the raised profile of the 'dissident viewpoints' has been to lose the important connection between the social and biological factors responsible for ill-health. In this regard, President Mbeki needs to continue emphasising the social, environmental, nutritional and economic

factors that play a massive role in disease and mortality patterns. However, much would be gained if the government collectively stated in clear and unequivocal terms that the HI virus was the underlying, infectious agent that causes AIDS.

Another feature of South Africa's inadequate response to the epidemic has been the failure to mainstream HIV activities at all levels of society. Dealing with a disease of the scale and complexity of HIV/AIDS requires the full participation of all elements of society. Mainstreaming refers to the taking ownership of, and adequate prioritisation of, HIV/AIDS interventions in the day-to-day activities of all sectors of society. The lack of leadership beyond the role of the President is also noted in other sectors, particularly amongst the business sector.

Attempts to harness a greater degree of multi-sectorality to combat the epidemic had previously been assured through the inclusive nature of the National AIDS Council of South Africa (NACOSA). However, in January 2000, a new body was launched – the South African National AIDS Council (SANAC) - to lead the national campaign. Unfortunately the body has proven to be largely invisible and ineffective. Many of the members selected to the SANAC steering committee were uninspired choices with little experience in the HIV/AIDS field.[57] In addition, the five working groups of SANAC which had each tabled concrete strategic plans in March 2001, have still not received any feedback from SANAC.

The failure to mainstream HIV/AIDS is also evident within government departments. A recent DoH publication indicated that 'the status of HIV/AIDS in national government departments is dropping constantly'. There seems to be 'HIV/AIDS fatigue in many departments.'[23] At National, Provincial and District level, HIV units have, until recently, been weak in terms of budgets, staffing and status. Although at the provincial level many Provincial AIDS Units are now being headed up by Directors, at the district level, many HIV/AIDS/STD co-ordinators still feel that they get little support from the other members of the health management team.

This same 'HIV/AIDS-is-somebody-else's-problem' approach is often echoed at a facility level. One provincial HIV Director noted, "as long as HIV is viewed as an added priority, it is susceptible to being sidelined in budgeting and management. AIDS must be built into the core business of departments instead of competing with other priorities." Whilst new staff, such as lay counsellors, will be required in some of these interventions, most of the HIV interventions should be integrated into the day-to-day duties of all PHC staff and be managed at the district level.

Remembering the positive developments

The problems of leadership have been partially counter-balanced by a re-emergence of health activism and social action to combat the epidemic. Organisations such as the Treatment Action Campaign (TAC), the SA Council of Churches, the AIDS Law Project and trade unions have been mobilising communities and the media to take up the fight against HIV/AIDS in a more urgent and pro-active manner, especially around issues of treatment. They have played an invaluable role in raising the profile of HIV/AIDS and helping to provide a more open and caring society for those afflicted by the disease.

Significantly, this HIV activism has had positive spin-offs on other spheres of health and social development. For example the crucial role played by health activists in supporting the government when multi-national drug companies took it to court, helped to educate the public about the politics of AIDS 'profiteering' and the greed of pharmaceutical companies.

Equally important, though less commented on, are the thousands of managers and frontline service providers working in government departments, NGOs, CBOs and the private sector who are battling to provide a decent service for the communities they serve in the face of the mounting human tragedy of premature death, human suffering and loss of dignity, poverty, psychological despair, the break-up of families and the cruel loss of parental care.

Conclusion

Evaluations of countries with successful HIV campaigns have shown that the axis of any effective response is a prevention and treatment programme that draws on the explicit and strong commitment of leaders at all levels and that is built on a community and multisectoral response that mainstreams HIV/AIDS. This commitment is vital to effect the necessary mind shift in all sectors of South African society. This chapter has illustrated numerous problem areas where such a mind shift is necessary:

- **Leadership**: The lack of clear and unambiguous messages about the link between HIV and AIDS and the resistance to planning for the roll out of PMTCT services reflects a problem with leadership which needs to be addressed.
- **Gender relations**: Nearly 2 out of 5 (39%) sexually experienced teenaged girls report having been forced to have sex. Only 25% of men use condoms with irregular partners. Many of our schools provide an environment that is not conducive to a life skills programme.
- **Health worker training and attitudes**: Basic STI and HIV/AIDS care remains sub-optimal. Many health workers are unwilling to offer clients VCT. Health workers have received very little training and guidance around HIV care.

- **Societal denial and stigmatisation**: Only 0.5% of South Africans believe that there is someone infected with HIV in their families. Up to 92% of persons who test HIV+ are not able to tell their partners their serostatus.

Underlying some of these problems is the lack of an effective human rights approach to HIV/AIDS. Despite a wonderful policy and legislative environment, the disease continues to be externalised as someone else's problem. Many initiatives could assist in effecting a mind shift towards a more positive approach. A previously noted example illustrated how training health workers in the HIV package of care leads to changes not only in health workers care of HIV infected persons, but also their attitude to persons living with HIV and their own openness about HIV.[58]

Uganda's experience illustrates that even a rampant HIV epidemic can be brought under control. A large number of South African nurses, doctors, teachers, parents and persons living with HIV/AIDS have worked beyond the call of duty to deal proactively with HIV/AIDS. It is now necessary to ensure that this is complimented with a stronger institutional and societal response.

We know what needs to be done, the challenge, as Nelson Mandela puts it, "is to move from rhetoric to action and action of an unprecedented intensity and scale."[59]

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