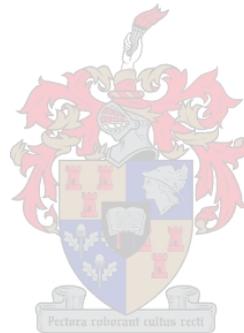


Beyond the Barriers: HIV Prevention and Treatment in the South African Public Sector – A Western Cape Science Communication Case Study

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Assignment presented in partial fulfilment of the requirements for the degree of Master of Philosophy (Journalism) at the University of Stellenbosch



Dr. George Claassen

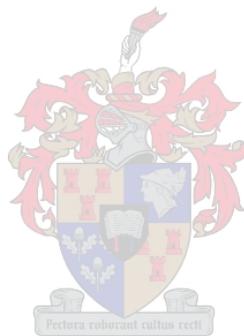
April 2005

Declaration

I, the undersigned, hereby declare that the work contained in this assignment is my own original work and that I have not previously in its entirety or in part submitted it at any university for a degree.

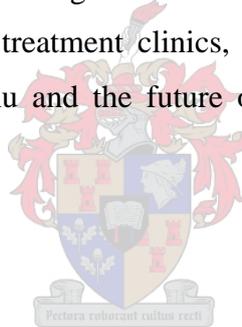
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Abstract

This work provides a comprehensive overview of the South African HIV/AIDS epidemic. It examines the historical and social background of the HIV/AIDS situation and looks at the importance of the media and science communication in combating the effects of the epidemic on society. This research explores the different forms of health communication and the varied benefits of each. Overall, it highlights positive media efforts that have helped redirect the HIV/AIDS epidemic within the social and political context of the HIV epidemic in South Africa. The second half of this work covers the challenges experienced in gaining public-sector antiretroviral treatment and the roles the media have played in informing and mobilizing society for these efforts. Through a community clinic ethnographic case study this work explores the current state of treatment clinics, social challenges experienced in the Usapho Lwethu Clinic of Gugulethu and the future of the HIV/AIDS epidemic in South Africa.



Abstrak

Hierdie werk verskaf 'n omvattende oorsig van die Suid-Afrikaanse HIV/VIGS epidemie. Dit ondersoek die historiese en sosiale agtergrond van die HIV/VIGS toestand en belig die belangrikheid van media en wetenskaplike kommunikasie in die bestryding van die effek van hierdie epidemie op die samelewing. Hierdie navorsing verken die verskillende vorms van gesondheidskommunikasie en die onderskeie voordele van elk. In sy geheel beklemtoon dit die positiewe pogings van die media wat gehelp het met die herkanalisering van die HIV/VIGS epidemie binne die sosiale en politieke konteks in Suid-Afrika. Die tweede helfte van die werk gee 'n oorsig van die rol wat die media speel in die beskikbaarstelling van inligting en die mobilisasie van die publiek en die stryd rondom die verkryging van antiretrovirale behandeling vir die algemene publiek. 'n Etnies-grafiese gevallestudie van 'n plaaslike gemeenskapskliniek word gebruik om die huidige toestand in behandelingsklinieke toe te lig asook die sosiale uitdagings in die Usapho Lwethu Kliniek in Gugulethu en die toekoms rondom die HIV/VIGS epidemie in Suid-Afrika.

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Introduction

The HIV/AIDS pandemic has caused economic and social devastation in many countries. It continues to put development at risk in nations such as South Africa, where the circumstances of the epidemic have been particularly challenging. This work explores different prevention methods and the role the media play in these efforts as South Africa addresses the spread of HIV/AIDS. A case study is provided of the successful awareness project, Soul City Institute, which promotes the power of entertainment education and the benefits of collaboration with the media. This paper also highlights the mass media's role in covering the politics of HIV/AIDS treatment and the additional economic barriers that keep many citizens of South Africa from receiving antiretroviral (ARV) treatment, coverage that has been vital to the fight to receive government-funded antiretroviral therapy. After society's long struggle to gain access to these anti-HIV drugs, the South African Department of Health is finally treating people in public-sector clinics. Lessons taken from non-profit trial clinics will be vital to proactively handle the many challenges of a successful national ARV treatment plan. The Usapho Lwethu 'Our Family' clinic in Gugulethu is one such clinic currently experiencing the difficulties of administering antiretrovirals in the unique social-economic conditions of peri-urban townships. One section of this research is dedicated solely to the documentation of the work of the Nyanga District and the Usapho Lwethu clinic. After exploring the social challenges of ARV therapy and the historical aspects of the situation in South Africa, the last section highlights the government's plan to treat its people, the problems encountered in their first year of treatment and includes a chapter on forecasts for the future of the South African epidemic.

Because of the availability of the national HIV treatment plan, the political struggle to gain access to treatment is less of a newsworthy topic despite the epidemic's raging presence. As a

result media are faced with the challenge of finding new angles to continue to cover HIV and treatment and prevention awareness. To some degree this responsibility has fallen on local, community-based media. Although community media's involvement in HIV/AIDS medical messaging has grown in the past years, educating society about the science and facts of HIV transmission, progression and treatment is not an easy task. A few organizations have been successful at educating and involving the community in health communication, and in doing so they have also shown the potential for community media to change behavioural patterns, increase dialogue and curb the growing epidemic.

Part I: HIV in South Africa: the historical and social background

Chapter 1: South African HIV/AIDS Circumstances

Poverty, high rates of infectious diseases, high infant mortality, gender inequality, ethnic conflicts and environmental challenges all contribute to the struggle for development on the African continent, especially in the years since individual nations began gaining their independence from colonial powers. Developmental problems affect many parts of the world and since resources to tackle these problems are scarce, it would be extremely beneficial to find a solution to address these issues. In fact, HIV/AIDS is now the leading cause of death in sub-Saharan Africa and has been a source of devastation to many nations and people on the continent (UNAIDS, 2002: 44). The average life expectancy in sub-Saharan Africa is forty-seven years instead of the sixty-two years it would be if there were no HIV/AIDS (UNAIDS, 2002: 44). South Africa in particular is considered the epicentre of the world's cases of HIV. The World Health Organization's current estimates claim South Africa has one-eighth of the world's forty million HIV positive people (Aids and business, 2004:68).

Mothers and Children

AIDS has had a particularly strong impact on children between the ages of one and five. Indeed, the majority of children in sub-Saharan Africa who are infected at birth or through breastfeeding will develop AIDS and die before turning five (UNAIDS, 2002: 46). South Africa is fortunate to have a Prevention of Mother-To-Child Transmission programme (PMTCT) underway; although a lack of governmental support and monitoring have risked its success. The PMTCT programme was established in June 2001 to stop the transmission of HIV from mothers to their children through a single dose of the antiretroviral, Nevirapine, which decreases the chances of passing HIV to a baby during birth by fifty percent (Thom, 2003b). But from the start this programme has been shrouded in controversy. Six months after the Medicines Control Council (MCC) approved the use of Nevirapine and approval was given to implement two pilot sites per province, there were few new PMTCT clinics (Thom, 2003b). Three provinces with committed provincial leaders and scientists were able to expand their PMTCT programmes, but outside the Western Cape, KwaZulu-Natal and Gauteng, the PMTCT clinics barely functioned and they did not expand. As a result, the Treatment Action Campaign, human rights group, filed suit against the government and won, forcing them to increase the number of clinics offering the PMTCT programme (Rickard, 2002). The South African government appealed the ruling but the Constitutional Court upheld it and shadows of controversy continued to grow around the PMTCT programme.

Two years into the PMTCT programme, reports were released claiming the programme a failure and blaming it on a lack of direction. For example, in the North West Province only 14% of antenatal patients were being tested for HIV at two pilot sites (Thom, 2003b). This translates to a horrifying figure of 86% of pregnant women not having the opportunity to prevent transmitting HIV to their babies. In the province of Mpumalanga there were no counsellors at non-pilot voluntary counselling and testing sites; thus pregnant women were not receiving any counselling about the PMTCT programme (Thom, 2003b). Without

PMTCT training, pregnant women will not learn the procedures and safeguards essential to the success of the programme.

Media personnel blamed the problems with the PMTCT programme on the government's disinterest in seeing a successful precursor to a national ARV programme (Thom, 2003b). 2003 reports claimed that national PMTCT staff members failed to attend "crucial" meetings and that some PMTCT provincial posts remained vacant for more than a year at times (Thom, 2003b). Additionally, poor follow-up on mothers and their newborns has left the programme with very little useful data to prove efficacy.

Caring for So Many Orphans

The toll of HIV/AIDS on South African families and parents is immense. Since the majority of people dying with AIDS are adults between the ages of 15 and 49, which is also the age group of people raising children, the number of orphans continues to rise (UNAIDS, 2002:190). In March of 2003, David Bourne of the University of Cape Town's School of Public Health stated that current estimates put 92% of the world's AIDS orphans in South Africa in 2010 (Trials for SA Aids vaccine to begin next year, 2003). The devastation of HIV and AIDS on families is unprecedented by any other disease.

The burdensome presence of HIV/AIDS usually means that the household and family unit will dissolve. A study in Zambia revealed that 65% of households fell apart when the mother died with AIDS (UNAIDS, 2002:47). As parents die with AIDS, their children are left to be cared for by grandparents or other members of the extended family. One grandmother in the township of Gugulethu, South Africa noted that she has lost all of her three children to AIDS and is now raising six grandchildren alone, two of whom are HIV positive (Yeager, 2003).

Before parents die though, the family is often stripped of assets and income as infected parents become unable to work because of illnesses or discrimination. This cycle whereby

families experience decreased income and increased care-related expenses, medical fees and funeral costs has further impoverished the already poor in South Africa. This is one area where community media could help change the effects of HIV/AIDS. Local media can provide human rights information to raise awareness about how to apply for social security for people living with HIV. Also, grants are available to people living with AIDS as assistance for them and their families while they are commonly unable to work. Most patients who attend clinics learn about the grant when they are diagnosed with advanced HIV, AIDS. However, there are many people who live behind the stigmas, do not attend clinics, and are ultimately unaware of their rights. By including this information in a weekly newspaper or on community radio programs, the media has the power to have a positive impact on the lives of those living with HIV and their families.

Affording School and the Cost of a Sick Workforce

Not only does HIV/AIDS harm families but also it tends to make it more difficult for poor families to afford sending their children to school. School costs take a backseat to health-care and food costs when a family member is sick because of HIV/AIDS and/or a breadwinner is out of work as a result of an illness. Additionally, children often stay home from school to care for an ill parent or family member, thus hindering children's educations. Children who themselves have HIV find it difficult to maintain good attendance as they face the plague of opportunistic infections caused by weak immune systems. Another problem caused by the death rate of HIV is the decrease in skilled teachers. Nationwide deaths among teachers in South Africa rose by over 40 percent in 2000-2001 (UNAIDS, 2002:53). But this is just one workforce harmed by the devastation HIV/AIDS has caused.

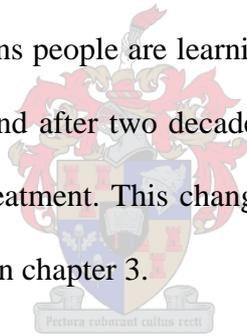
Indeed, the negative impact of HIV/AIDS on the workplace is not to be ignored as it sets back economic activity and developmental progress. In fact, since the majority of the global

HIV positive population is people in their prime working ages, the profits lost to increased absenteeism, increased staff turnover, loss of skills, loss of tacit knowledge and declining morale are extremely harmful to businesses. More people are missing work due to HIV-related illnesses, and as people die or are unable to attend work employers face the additional cost burden of recruiting and training new employees; not to mention that this also leads to declining productivity and supposedly reduced foreign investment. Health-care expenditures add one more cost to employers' already heavy burden, but there are a number of ways to make the best of the high HIV/AIDS rates in the workforce.

On the whole, HIV/AIDS means devastation for multiple aspects of a nation's wellbeing; however South Africa is fortunate to have companies that are leading the way for other businesses in educating and training their staff about HIV prevention and treatment. These proactive stances help dispel HIV/AIDS myths while building community and support networks within the workplace, thus sustaining a healthy morale as people deal with the illnesses and deaths of their peers. Additionally, some companies go so far as covering the cost of treatment for opportunistic infections caused by HIV, which inevitably keep HIV positive people from being at work. Some companies provide access to antiretroviral therapy, thereby increasing the lifespan and working ability of valuable employees. For example, Anglo American, a prominent South African mining company has focused on HIV/AIDS prevention since 1986 when they first surveyed their workers for HIV (Aids and business, 2004). They currently offer each employee regular HIV tests, counselling, and, if needed, antiretroviral drugs. Recent figures estimate that 2,300 employees receive drug therapy, and their families are offered testing and treatment as well. Of course, the mining industry is more able to afford treating their workers than some other industries, but according to Brad Mears of the South African Business Coalition on HIV and AIDS, "the cost of keeping someone alive is cheaper than letting someone die" (Aids and business, 2004).

Chapter 2: Social Stigmas and myths- preventing testing and treatment

Talking openly about HIV and AIDS has historically been a global challenge. The virus, the syndrome it causes and the side effects have been taboo subjects in many cultures since the world first became aware of AIDS in 1981 (UNAIDS, 2002). As a result, many people choose the risks of transmission over being seen at a clinic or overheard making an inquiry about HIV/AIDS. There are many legitimate reasons why people have shunned talking about HIV/AIDS for so long. For example, being dislocated by one's family or losing a job are important enough to keep some from putting themselves at risk. Nowadays the rights of those living with HIV are protected. Employer discrimination is illegal in South Africa and thanks to community awareness interventions people are learning their rights. HIV/AIDS awareness has finally made it to the airways and after two decades of silence people are beginning to openly talk about prevention and treatment. This change is, in part, due to increased media attention and coverage as discussed in chapter 3.



Common Stigmas and Myths

HIV and AIDS are commonly misunderstood. Because people see how devastating AIDS can be to one's health, they often fear becoming infected. When this fear is coupled with a lack of knowledge regarding transmission and risk behaviours, myths often develop. The media has the potential to be a useful vehicle for eradicating myths, and several community media organizations, including Bush Radio's HIV projects, are paving the way for continued progress in this realm.

One South African myth says that having sexual intercourse with a virgin cleanses a man of HIV/AIDS (Jewkes, Levin & Loveday, 2003). Of course myths lead to a number of problems

and in this instance young girls are targeted for rape because of a myth. Additionally, dislocation is a common result of the myth that sharing plates and utensils spread HIV. One HIV positive woman noted having to use the community's public toilet rather than the toilet her family shared (Yeager, 2003). People with HIV have been forced to live in separate rooms or to move out of their homes because myths about transmission lead others to fear infection.

HIV has such negative stigmas that people often fear being seen at community HIV testing and health centres. They risk people spreading rumours that they are HIV positive simply by visiting the facility. These stigmas likely prevent people from presenting at HIV clinics to inquire about HIV facts and information (Lie & Biswalo, 1994). People fear that their families or friends will think they are HIV positive so they will not go get tested and risk the problems of discrimination that HIV myths cause. There was a time when people in South Africa commonly lost their jobs if their employers learned of a positive HIV status. Nowadays this discrimination is illegal and through organizations like the AIDS Law Project, it can be reported. But HIV/AIDS myths continue regardless of the progress being made by awareness campaigns and media efforts. There will always be things that are not completely understood by everyone, and people are bound to devise explanations for these things; thus there will always be myths. For example, when ARVs were introduced at the Usapho Lwethu clinic the people who received them first were those with extremely low CD4 counts, extremely compromised immune systems. Many of these people died before the ARVs could begin helping their bodies rebuild the immune systems and even those who were able to increase their CD4 counts risked the problems associated with fighting the opportunistic infections already present in their systems. These deaths sent fear into the community and made people question the benefits of ARV therapy and whether the treatment itself was the cause of the deaths. Counsellors and other members of the clinical team offer proper

explanations for illnesses and deaths when family members are available, but family members often do not come to the clinic to inquire about the details of the death. In other words, although stopping the spread of harmful myths is important it is not always feasible in terms of the system. As is discussed in Part III, one of the benefits of treatment counsellors like the Usapho Lwethu Sizophila team is that they assist the clinical team in handling myths and related social issues. Media have this ability as well, but it requires that journalists be knowledgeable about myths and the medical facts that counter them, and that these discussions be a part of health communication.

Part II: Media and HIV/AIDS

Chapter 3: The Role of HIV/AIDS Communication in Prevention

Global and national mass media have the benefit of a wide and often immediate reach in their coverage of HIV/AIDS reporting. As such, mass media have the potential to be a powerful tool in combating the pandemic and its threat to the survival of the human race. This section explores the roles of mass media, journalists and community media in keeping the public informed and involved with the HIV/AIDS pandemic, and it discusses the challenges faced in fulfilling their obligation to inform the public.

One of the biggest challenges to mass media is keeping the on-going HIV/AIDS crisis fresh day after day, story after story. It is additionally challenging to sustain successful HIV/AIDS education within the reports deemed newsworthy enough to be released. In fact, mass media has the tendency to provide only brief stories about statistics and scientific breakthroughs as their coverage of HIV/AIDS communication, which makes it difficult for people the world over to comprehend the reality of the pandemic much less learn the science of prevention.

In order to harness media's power to contribute to HIV/AIDS awareness and prevention, it must focus on its ability to connect the audience with the facts about the disease and the effects it has on humans and communities across the globe. The urgency of the public health situation demands mass education efforts focused on prevention because the general audience member "relies on the press for nearly all it knows about AIDS" (Brown, 1992:721). Still, many people require a humanization and demystification of the epidemic in order to truly comprehend the urgency of HIV/AIDS health messages and how the epidemic relates to them. If the audience does not feel vulnerable to the epidemic, then behaviours will not change and the information provided by the media will not effectively lower transmission rates (Bosch, 2003:195).

Around the turn of the millennium many academics and journalists engaged in open debates about the role of the media in HIV/AIDS efforts (Kiai, 2000; Bardhan, 2002). Some discussions acknowledged that "the AIDS/HIV issue needs to be understood as cultural phenomenon [and] that the media's role is a significant part of this culture" (Bardhan, 2002:222). It also reiterated that health communication is central to all prevention efforts. A number of suggested roles for effective mass media health communication of HIV/AIDS were thus outlined.

One of the primary functions of mass media is to educate people who are HIV negative and encourage them to remain negative, thus indirectly contributing to a decrease in transmission rates (Kiai, 2000). In South Africa the government sponsors mass media awareness campaigns for this very purpose. Advertisements promoting condom use and abstinence are visible in national and community newspapers.

It was also suggested that another function of mass media is to support people who are positive by providing information on how they can protect others from transmission and how to maintain hope through positive living (Kiai, 2000:41). Essentially, health communication

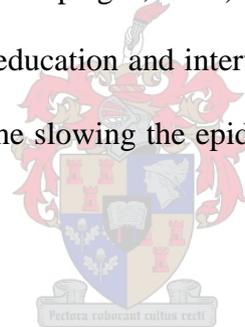
that provides this will need to address common stigmas and myths, which if executed successfully could contribute to an increased acceptance of those living with HIV. But this is no simple task. Reporting that debunks myths requires that journalists be knowledgeable about prevalent myths and be able to explain the complexity of scientific issues to readers. Reporters claim that scientists have a difficult time explaining these scientific complexities in terms that the reporters comprehend, which means that in turn the reporter has to take a challenging subject and turn it into something viewers/readers will understand (Diagnosing AIDS Media: Comments on coverage and campaigns, 2000). Since reporting on health communication requires a knowledgeable staff, it is helpful if they work with these complex health topics on a regular basis. This way journalists stay informed and keep up to date on social research and public health issues and have the time to find interesting ways to keep the public aware and informed.

Providing factual and accurate health communication regularly will discredit misinformation. Offering details on where to get tested and where and when to get treatment is another vital function mass media can offer community members. These logistics will need to be handled by regional mass media because it would otherwise not be useful in national media outlets. In developing nations these logistical details are vital as the inaccessibility and cost of treatment often destroys what little hope HIV positive people manage to maintain. Health communication that offers everything from nutritional advice to community support groups has the power to reinforce positive living.

Unfortunately, though, positive living topics are not commonly a part of mass media efforts, and despite the potential of mass media to perform these functions, it does not offer a continual HIV/AIDS educational presence. Chris Powell, audiovisual and public relations coordinator at the Geneva headquarters of the World Health Organization said, “the news media, especially the Western wire services, are generally reluctant to cover AIDS as an issue

in developing countries” (Bardhan, 2002:238). As the media see it, AIDS has become just another story (Bardhan, 2002:238). “Dealing with HIV/AIDS from here on is a long slog. Long hauls rarely make news except at the beginning and the end” (Bardhan, 2002:238). On the whole, HIV/AIDS mass media coverage is event driven. Conventional HIV/AIDS reporting tends to cover new drugs, international AIDS conferences, World AIDS Day, new scientific findings and updated statistical data (Stally, 2002). This broad reporting adds little to ones knowledge of when, why and where to get tested and/or treatment or why HIV/AIDS is relevant to members of the audience at all. It lacks the human element of the epidemic, to which more individuals could likely relate. But as one South African health writer puts it, “you cannot expect the media to simply play the role of AIDS educators” (Diagnosing AIDS Media: Comments on coverage and campaigns, 2000). Commercial mass media simply will not devote heaps of space to AIDS education and intervention because it is not newsworthy. This is a fundamental problem for the slowing the epidemic through the reach and power of the media.

South African Mass Media



As of 2002 HIV/AIDS coverage in South Africa was inadequate on many levels. Government Communications Information Service CEO, Joel Netshitenze said, “there’s very little reporting in the media about HIV/AIDS, which means we are failing our public responsibility” (South Africa: Media Coverage of HIV/AIDS Belittled, 2002). Thus any increase in HIV/AIDS coverage was welcomed. To this end political newsworthiness provided this increase and in doing so it drew attention to prevention and treatment efforts and the importance of the media’s role in this aspect of South Africa’s epidemic.

The politics of treating the estimated 5.3 million HIV positive citizens with antiretroviral drugs brought vital attention and media coverage of South Africa’s epidemic (UNAIDS, 2004). This coverage, in turn, initiated community dialogue about these issues. Few people

will dispute the claim that the media's coverage of the battle for public HIV drug treatment was a factor in winning support for government-funded treatment. Additionally, it has brought to the table countless other issues such as rape, domestic abuse, business's role in treatment, and educating children about prevention. It has publicized the health minister's and president's opinions about HIV and has cast a shadow on their need for dissidents as advisors. The headlines covered everything from President Thabo Mbeki knowing no one killed by AIDS to that of Manto Tshabala-Msimang's combative antics (Murphy, 2003; Berger & Geffen, 2004). Such headlines and undaunting coverage made HIV/AIDS a political issue and a topic that involved everyone affected by the epidemic. The downfall though is that the media coverage of Mbeki's denialism did not help to end the stigmatization of people with HIV/AIDS; rather his example showed that denial and stigmatization take place in all levels of society (Murphy, 2003). Additionally, claims about HIV not causing AIDS and nutrition being the best form of treatment for HIV/AIDS made the scientific facts about the epidemic confusing for many South Africans (I'll keep punting my concoction says Manto, 2003). As a result of the politics of antiretroviral treatment, mass health communication did not provide accurate and factual health information on a regular basis or prevention and treatment logistics. Until the South African government decided to offer antiretroviral treatment in public clinics, there was no uniform presentation of health communication for HIV/AIDS mass media, and the messages regarding treatment and antiretrovirals were often inconsistent. Government run media versus those that were independently owned offered differing coverage and information (Sidley, 2002). For example, the television series *Beat It!*, which provided information on HIV/AIDS treatment and healthy living, only aired on one independent regional station until 2002 (*Beat It! HIV/AIDS Treatment Literacy Series*, n.d.). Then, in 2003 (the same year the government decided to provide access to ARVs) South African Broadcasting Corporation television

channel 1 began airing the program nationally (Beat It! HIV/AIDS Treatment Literacy Series, n.d.).

As of November 2003, the Department of Health finally devised a plan to treat those in need of ARVs (Operational Plan, 2003). Many people expected that with the end of the political drama surrounding public access to ARVs, the general topic of HIV would also disappear from the news (End of the Aids Story, 2003). Fortunately and unfortunately, the government has not rolled out the ARVs gleefully and with great speed; thus the critical pieces about the government's misgivings remain. The fact of the matter is the delays are not good news for those people desperately in need of ARV therapy; however, because of the continued political attention, the HIV and AIDS issues have not completely fallen off of the tables of discussion. A sudden decline in HIV/AIDS newsworthiness would risk a decrease in public attention regarding the concerns of HIV positive citizens. As a result of the turmoil of the past four years, there now exist a multitude of organizations dedicated to reducing the problems of the epidemic, and groups like the Treatment Action Campaign are finding ways to get their message out. These grassroots mobilization projects combined with community radio stations like Bush Radio, community newspapers such as *City Vision* and even business advertisements contribute to prevention education, HIV awareness and discussions of other related social issues. For South Africa this means that the progress of communication will continue even without the mass media's coverage of the political drama, although it is likely that political debates about HIV/AIDS will not disappear completely.

Even though community media are making strides to contribute to the void left by mass media's HIV health communication, mass media journalists can still strive to effectively develop stories that sustain HIV/AIDS as a newsworthy topic. Human-interest pieces on HIV/AIDS could bring the voices of communities to media and contribute to reports worthy of regular coverage. By running human-interest features that are supported by an informative

presentation of transmission facts, mass media does have the potential to challenge risk behaviours. While we search for a cure, HIV/AIDS health communication has the power to make the difference for successful prevention programmes. Fortunately, there are a growing number of community media projects providing the coverage, support and educational information necessary to engage communities in dialogue and initiate behavioural change.

Community Media

The community media approach to HIV/AIDS awareness has the potential to offer a reliable source for locals to gain medical facts about transmission, HIV progression, treatment and human rights. Community participation and involvement in education is empowering because it offers people a forum to discuss their own concerns, questions and myths. It brings the issues of HIV/AIDS up close and personal in an environment people commonly feel comfortable in, their own neighbourhood. For example, Bush Radio hosts an off-air component in which they actually visit schools and initiate dialogue about HIV/AIDS topics such as myths. They present health facts to young members of the community in a manner that they can relate to and they bring the information directly to the audience. Discussions about the importance of getting tested and when to get treatment have the potential to lift the spirits of people who feel condemned to the AIDS epidemic. In providing information about access to treatment, community media help build a positive approach to living with HIV. People learn that there is hope for a life with HIV and in changing this perspective media can eradicate the stigma that having HIV equals death.

The urgency of the HIV/AIDS pandemic is not declining in correlation to mass media coverage of it. Thus, it needs to remain on the public and media agendas in order to slow its forward progression. The challenge remains that “the on-going nature of the issue does not lend itself well to the everyday pace (and constraints) of the newsmaking process in most cultures” not to mention that mass media have historically failed at providing successful

prevention awareness (Bardhan, 2002:239). For example, the *Cape Times*, a daily newspaper published in Cape Town, regularly reports on HIV/AIDS but the focus is hard news rather than educational health information. A recent article entitled “Mandela calls on South Africa to protect its women, children from AIDS” focuses on Mandela’s public statement but lists no resources for how to go about doing this (Mandela calls on South Africa to protect its women, children from AIDS, 2005). Some mass media institutions have developed standards and policies about HIV/AIDS coverage. Several large news organizations have even assigned specific reporters to only cover a health beat, which should provide for knowledgeable reporting of the different facets of HIV/AIDS health communication (Bardhan, 2002:239).

The news agency, *Health-e*, produces news with a focus of “public health policy and practice” in South Africa (http://www.health-e.org.za/about_us/index.php). It offers both print and audio features to newspapers, magazines and radio stations. The agency’s recent print releases included a number of articles on government spending, the politics of President Mbeki’s and the government’s reactions to HIV/AIDS, vaccine breakthroughs, and updated South African AIDS statistics (Cullinan, 2005a; Cullinan, 2005b; Cullinan, 2005c; Thom, 2005). None of these articles offered information about prevention or education (Cullinan, 2005a; Cullinan, 2005b; Cullinan, 2005c; Thom, 2005). The broadcast pieces they put together are more focused on health education than the print media, which was primarily brief news coverage. Of *Health-e*’s three most recent broadcasts one addressed the benefits of testing early, which could have implications for real people’s plans to get tested (Bodibe, 2005a). Also, there was a report on the controversies and myths of condom use and the protection condoms offer if used correctly, which was also explained in the piece (Bodibe, 2005b). It included interviews with one young man and one young woman who explained their personal difficulties with condom negotiation. The report highlighted an important health issue, but it concluded with no new information or reference for where listeners could

get further advice on the topic; while it was a good vehicle for creating dialogue, it failed to provide access to assistance for these problems. Certainly, South Africans benefit from coverage like that provided by mass media and agencies like *Health-e* news, but for powerful educational information citizens will most likely need to look elsewhere in the media.

Because of the overall decline in mass media HIV/AIDS health communication it is vital that community media continue to address prevention, education and the socio-cultural aspects of the epidemic. Additionally, community media have greater potential to release in-depth, community-oriented reports that are likely to be of more interest to locals than global mass media health communication. Creative media relations (such as those described in the following section on Bush Radio) engage communities in HIV/AIDS health communication and therefore have a good chance of shaping local discourse, attitudes and behaviours. As community radio stations develop better research skills to study the effects of their health messaging, they will hopefully find that indeed there is evidence that these forms of health communication are making a difference.

South African community health communication

Radio awareness and mobilization

Since some 98 percent of South Africans regularly listen to radio, HIV/AIDS related radio programming has the potential to reach many people (Singhal, 2003:12). By being rooted in the community, radio can inform and educate residents about HIV/AIDS while addressing local needs and the availability (or lack) of HIV/AIDS services. This kind of media can mobilize the community to take action and to cope with the effects of the epidemic. However, according to the Open Society Foundation for South Africa, at present the majority of community radio stations are not successful at handling these powers. They attribute this to the poor quality of programmes stemming from inaccurate information, poor formative

research, poor broadcasting quality, poor community involvement and an overall poor understanding of the epidemic and its effects (Brief report on the HIV/AIDS Community Radio Stakeholders Meeting, 2003). In an effort to improve these conditions the Open Society Foundation for South Africa developed a pilot project to be tried at a sample of stations. The project was designed to assist community radio stations in producing and broadcasting quality HIV/AIDS programmes. It proposed the establishment and training of children's radio groups so that children can produce their own programmes in response to the epidemic. Creative ideas like this will engage young people in awareness and prevention, which could eventually slow the progression of the epidemic as this generation becomes sexually active. Western Cape radio programs like those by Idasa, Radio Zibonele and Bush Radio offer examples of stations addressing HIV/AIDS health communication at the community level.

Idasa, the Institute for a Democratic South Africa, provides both local and national radio programmes about HIV prevention, awareness, treatment and other related social issues such as domestic violence and rape. Idasa is a larger, financially stable organization and for these reasons it has been able to successfully devote itself and staff members to HIV/AIDS education and in-depth community awareness research and projects. Also, since Idasa contributes reports to smaller community radio stations, it offers some HIV/AIDS programs in multiple languages and can reach diverse audiences.

Radio Zibonele is a regional station that broadcasts from the township of Khayelitsha to approximately 120,000 listeners (Making Waves: stories of participatory communication for social change, 2002). In 1992 a collaborative project utilizing community health workers was started to treat minor ailments and promote health education in the community. It was called Zibonele, a Zulu and Xhosa word meaning to 'take care of yourself' (Medical Research

Council of South Africa, 2000). One year later, Radio Zibonele was started as a way of spreading the project's health messages out into the community. At first the radio station used homemade equipment and broadcast out of an old container truck to about 20,000 listeners (Medical Research Council of South Africa, 2000). At that time the broadcasts were illegal because the government owned the airwaves and Radio Zibonele was unlicensed, but in 1994 the Independent Broadcasting Authority issued the station permission to broadcast.

In the beginning Radio Zibonele aired for two hours every Tuesday morning. After 1995 the station gradually increased its broadcast time to nineteen hours a day five days a week. Radio Zibonele is now a full-fledged station whose programming is aimed at Xhosa and English speaking black listeners. Broadcasts are a mixture of music and talk radio and offer coverage of sports, local and national news and even children's programmes. Radio Zibonele still offers messages about health care and remains dedicated to community health education and HIV/AIDS awareness that started it.

One of the key elements of Radio Zibonele's community media role is its philosophy that locals should take full part in programming. As such each year the Khayelitsha community elects a board of directors to oversee and monitor the operations of the station. Mabee Mdlalosi, Zibonele's project manager, claimed Radio Zibonele "integral to the development of the community" (Urban health and development bulletin, 2000). He said, "it enables a greater number of individuals to receive messages about health and other important aspects of life from the people to the people" (Urban health and development bulletin, 2000).

Bush Radio is another community station that is founded on community involvement. In fact, it offers skills training to volunteers and even lobbied for the establishment of a community radio organization of South Africa (<http://www.bushradio.co.za/history/frameset.htm>). Still

today the station continues to be a successful resource for community education, especially regarding vital issues such as HIV/AIDS.

Recently, Bush Radio offered a number of HIV/AIDS community projects. The Schools AIDS Education Project (SAEP) included both on-air and off-air outreach components. SAEP on-air broadcasts cover HIV/AIDS facts and information to educate young people and adult listeners. This programme airs daily in a timeslot after regular school hours. The off-air component of the SAEP has the 'Bush Radio Team' going out into the townships twice a week with an outside broadcast unit to speak to students and young people about what they know and want to know about HIV/AIDS.

Another project, Youth Against AIDS 2000 (YAA2000) included youth workshops in the townships of Gugulethu and Mitchell's Plain. They focused on raising HIV/AIDS awareness beyond the mass messages of abstinence and using condoms. Because of the interest YAA2000 participants showed for the use of rap music during a creativity workshop on HIV/AIDS awareness, Bush Radio created the HIV Hop project. HIV Hop is based on the utilization of rap as a medium for youth engagement in HIV education. The focus is less on basic HIV/AIDS education and more about broader social issues that contribute to the epidemic such as culture, traditions and socio-economic trends. As a result of its success, HIV Hop developed into a five-week on-air HIV Hop campaign, which experienced a strong response from the community and is discussed in greater detail in the following chapter.

Creative awareness projects like these that include members of the community in the health communication goals of local radio stations have proven to be very successful. The amount of callers that phoned in during the on-air programmes showed that members of the communities were listening and wanted to be involved. The roots of Bush Radio, being based on the importance of community participation, have become a strong centre for people to rely

on for health information and education while addressing the challenges of prevention, awareness and acceptance in a their own neighbourhoods.

Community Print Media

In the Western Cape there are a number of regional and community newspapers, all of which offer varying kinds of HIV/AIDS coverage from personal stories to government-funded condom advertisements. *City Vision* is one such regional newspaper distributed throughout the black townships of the Cape metropolitan area. This weekly paper is free and offers articles written by people living in the townships. Its focus is on crime, corruption, HIV/AIDS and other major issues of importance to the community. *Blits*, another community newspaper of the Western Cape metropolitan area offers an additional presence for print health communication. Produced by the large newspaper, *Die Burger*, *Blits* is a freesheet that it contains newsworthy articles, weather, train timetables, and also educational information and advertisements on HIV/AIDS.



Business Initiatives

Corporations have also joined in on raising awareness, and many now offer HIV testing, counselling and other support services for their employees. Vodacom, one of South Africa's telephone communication giants, promotes activism regarding the HIV epidemic on their website. It suggests ways people can assist those affected by HIV/AIDS, orphanages and women of domestic violence. This corporate website offers everything from inspirational poems to rape counselling and information on the latest on HIV/AIDS vaccine trials and initiatives (<http://www.speakout.org.za/medical/main.html>). Other businesses such as BP Gas Company are including HIV facts in their advertising campaign. One magazine advertisement had a section about the importance of businesses in stopping the spread of HIV through voluntary counselling and testing and treatment for employees, which reminds employees

that they have a right to get tested and receive treatment. Corporations like Impala Platinum Holdings and Transnet are making contributions to programmes such as the South African AIDS Vaccine Initiative, whose 2004 annual budget was R70 million (Caelers, 2004:10). Media reports of such contributions draw attention to positive actions and remind others to join in.

Human Rights Mobilization

Human Rights initiatives such as the Treatment Action Campaign (TAC) hold community awareness workshops in areas heavily affected by HIV/AIDS. The TAC has offices in townships outside of cities like Cape Town and Johannesburg. It is well known for its events where people living with HIV speak about their experiences and offer an example of living positively with HIV. The TAC often holds these events in schools and in community centres. Members are most known for their role in the political battle to gain treatment and their mobilization efforts, but they also remain visible and active in education. The TAC uses a portion of its funding to print posters and brochures that promote awareness about important and commonly misunderstood topics. The TAC's educational posters colour the walls of clinics and community centres. They explain how to eat to promote one's health while living with HIV, HIV drugs and the processes of therapy, and PMTCT programmes and how one can prevent his/her child from becoming infected with HIV.

One of the TAC's most useful and important skills in fighting the spread of HIV and its destruction is raising community awareness. It holds marches and rallies for HIV causes, and members are seen as a strong community mobilization group. On the opening day of Parliament on the 14th of February 2003, the TAC held a march through Cape Town that led to the building where President Mbeki was addressing Parliament. Members wore the world-famous tee shirts that read "HIV Positive" and through the TAC, thousands of people came

out to show support for a national ARV treatment programme. Even now, after the government decided to offer ARVs to the public, the TAC continues to bring the news and politics of HIV treatment to marginalized areas where people are affected and willing to get involved in the cause. Additionally TAC acts as a watchdog over government projects for HIV/AIDS. This is traditionally the role of the media, but as a dedicated mobilization and awareness campaign TAC takes advantage of the media attention their watchdog efforts earn them.

TAC has taken on the task of generating community media coverage of key HIV medical and human rights information for marginalized communities in the Western Cape. According to Colwyn Poole, a TAC spokesperson, “the problem is not that there is a complete void of HIV/AIDS medical information it is just that now news is more policy orientated” (personal communication, 2005, 18 February). He also said the TAC is trying to make information on human rights, prevention, and social security and medical programmes available to HIV positive people. As such, TAC is shifting the messages it offers the media to be more practical and useful for positive living. For example, in 2002 eTV, a relatively small, independent television company based in the Western Cape aired a series called Beat It! Treatment Literacy Series. It was created by the Treatment Action Campaign to provide information on treatment and living positively. The series discussed ways to obtain antiretroviral drug treatment (at that time it was only available in private clinics) and the benefits and possible side effects of ARVs. Jack Lewis, the producer, said he felt treatment needed to be addressed urgently at that time because it was an issue the government was avoiding in its awareness campaigns (Sidley, 2002:448).

The Beat It! series provided the public with personal documentary stories of people living positively with HIV/AIDS and expert advice and explanations of medical terms and processes. It also used texts to highlight key points. Beat It! host Siphon Paddy Nhlapo is

himself HIV positive, which provided a spokesperson with whom the public could relate. Siphso also works for the National Association of People Living with AIDS and offered the audience the benefits of information sharing and community support networks.

The Treatment Action Campaign is itself not a media agency but it is focused on raising awareness around key HIV/AIDS issues that prepare communities to “respond creatively to people living with AIDS in [their] environment” (<http://www.tac.org.za>). Because of these intentions TAC is involved in many aspects of community media and mass media. For example, TAC managed to draw attention to key HIV/AIDS issues through the course of accessing treatment to prevent mother-to-child transmission. Members staged sit-ins when TAC was lobbying for public-sector access to antiretrovirals, which also generated daily news reports. TAC holds marches and public rallies in cities during important political events such as the Durban AIDS Conference in 2003. All of these events draw media attention to awareness issues such as human rights laws and grants for people living with HIV, the need for treatment and living positively with HIV. At the height of the struggle to access affordable HIV/AIDS drugs, Zackie Achmat flew to Thailand and brought back 5000 capsules of the generic version of Diflucan, a drug used to treat thrush (The AIDS rebel, 2003). In Thailand, this generic version was available for twenty-eight cents per capsule, whereas Pfizer was selling the patented form for as much as eighteen dollars a capsule. This sort of action attracts media attention and as a result the big picture gets spelled out in lights for all of South Africa to see via mass media coverage. It is an ingenious way of using the media to keep people informed. Although TAC is not a media organization it is certainly doing its part to raise awareness, unite and mobilize society to stop the spread of HIV and to create a positive image of living with HIV.

Non-profit medical organizations such as Médecins Sans Frontières have been providing treatment to people very ill with AIDS while the government debated making ARVs

available. Clinics like the one in Khayelitsha promote awareness and the importance of testing early and staying healthy for as long as possible without ARVs. These clinics, though few, offer HIV education to the community through the word of mouth of patients, counsellors and community health workers.

The Hannan Crusaid “Usapho Lwethu” clinic in the township of Gugulethu has a unique method of employing HIV positive people already on ARVs as counsellors. They help doctors teach new patients about drug therapy and staying healthy. This method of HIV prevention and communication is effective as it utilizes people who are themselves members of communities in need of HIV knowledge and prevention facts. They commonly speak the languages of the community and act as support structures for patients in a way that doctors often cannot. The Hannan Crusaid clinic is discussed later in this piece but for now it is important to note that although there are only a few, trial clinics provide a great deal of information and resources to prevent further spread of HIV and the deaths of those living with HIV/AIDS. The Hannan Crusaid clinic held a community awareness session for traditional healers to learn about ARV therapy and its benefits. Since traditional healers are commonly visited by community members the treatment of HIV and its side effects, it is vital that traditional healers understand how ARVs work and what patients should and should not do while taking ARV drugs. Traditional healers need to be included in treatment efforts and receive as much information as they can regarding HIV and AIDS. This communication and education will foster a strong support network essential to successful ARV therapy.

Edutainment Initiatives

The use of communication to bring about social change has become more commonplace in developing nations in recent years. The education entertainment strategy is perhaps one of the most documented successes of the communication field. In fact, education entertainment,

increasingly referred to as “edutainment,” purposely designs and implements a media message to both educate and entertain. It has been successful in influencing awareness, attitudes and behaviours about social issues, and it has even shifted social norms and served as a social mobilizer and media advocate (Singhal, 2003:2). Media strategies that attempt to promote awareness and social change need to appeal to audience members, and be commercially viable and socially responsible, which requires significant social research and planning for an effective edutainment campaign (Singhal, 2003:3). Since hard to reach people are becoming more accessible through satellite and cable television, VCRs, multimedia and economic progress, the mass media have a better chance at spreading edutainment at a low cost.

Edutainment offers entertainment media the opportunity to promote public discussion and move audience members to consider new patterns of behaviour. In regard to the prevention of infectious diseases, the edutainment option provides media an opportunity to play a more prominent role in eradicating serious social ills. It validates the need for socially responsible, wholesome entertainment, which, according to a study on what viewers prefer to consume, would be the majority’s choice of entertainment programming (Piotrow, Kincaid, Rimon II & Rinehart, 1997).

Making the edutainment model successful requires careful planning and structure, the first step of which is drawing up an ethical framework of the specific issues to be addressed in the project. Also, a values grid is useful to keep the focus on the behaviour and social changes encouraged or discouraged by the edutainment plan. It is suggested that the values grid and ethical framework be approved by government, religious and media officials as a pledge of support for the educational values and social change they promote. This ensures cooperation

and thus fewer obstacles to the project's success while also providing it with credibility by having influential backing (Singhal, 2003:8).

Preliminary research with the intended audience is a big part of designing an edutainment programme. Formative evaluations offer information on what is and is not known by the intended audience. These social evaluations can also determine the needs and preferences of the community, which will sharpen the design of the programming and make it more appealing as it needs to be both educational and entertaining if it is to be beneficial. In fact, the messages of the programmes are what will promote the learning necessary to bring about social change. Role models that the audience can relate to and who can give individuals a sense of self and collective efficacy, thus encouraging new patterns of behaviour, must present these messages (Bandura, 1997 cited in Singhal, 2003:10).

The effects of entertainment education are greater when various supplementary activities are part of an integrated communication campaign (Singhal, 2003:10). Multi-media broadcasts offer additional benefits as the various images support one another, and the audience will thus receive the intended messages through different mediums. As is described in the next chapter, the Soul City initiative in South Africa provides a great example of the benefits of a multi-media campaign.

Chapter 4: Soul City and HIV Hop Edutainment

In 1992 the Soul City Institute for Health and Development Communication was established as a non-governmental organization to utilize the power of mass media for the benefit of health education and development. As its first project, Soul City introduced a prime-time television drama series broadcast on South Africa's popular television channel, SABC. Soul City now includes a radio drama, which is broadcast in nine different languages, covering all regions in the nation. The Institute also produces some 2.5 million educational booklets

designed around the characters of the programmes. It hosts campaign activities such as the Soul City Search for the Stars, recruiting new talent for the following year's shows, and the Soul City Health Care Worker of the Year Awards, which recognize outstanding grassroots community health workers.

Soul City programmes focus on health related issues such as maternal and child health and HIV prevention. The thirteen-part Soul City television drama series includes topics like HIV treatment, alcohol abuse and violence prevention. The Soul City Institute has managed to make the programmes relative to common people who can empathize with the characters, their lives and their choices. Each Soul City series has different health and developmental themes particular to that season. For example, the 1999 Soul City 4 series addressed domestic violence as a core issue. It included information about the 1998 Domestic Violence Act (DVA) and put it in the context of the characters lives. In one episode Matlakala, the wife of the respected Thabang, is distraught and depressed about the domestic abuse she endures. With the help of her friends, her community and a telephone helpline, Matlakala learns about her legal rights. She later files and wins a judicial case against Thabang for domestic abuse. Not only does she act as a role model for other women of abuse, Matlakala's actions provide women plausible coping strategies and information about their rights.

During the Soul City 4 season the DVA had the potential to empower abused women, but there were many delays in implementation of the Act (Singhal, 2003). The Soul City television series brought attention to the new DVA and informed people about it in an indirect manner. In addition, Soul City partnered with the National Network on Violence Against Women to launch an advocacy campaign that included a 24-hour toll-free domestic violence line for counselling and referrals. The phone number was provided on the programme and subsequent surveys showed the attention produced positive results. In one

survey thirty-nine percent of viewers noted that they knew about the telephone helpline for domestic violence (Singhal, 2003). In fact, there were over 180,000 calls answered by the helpline in the five months following the Soul City broadcast season (Christofides, 2001). The helpline reported that there were a large number of calls that actually went unanswered due to funding constraints restricting the number of available lines. In one province telephone records showed some 95 percent of calls unanswered during peak times (Christofides, 2001). As a result of these statistics, officials provided increased funding for additional phone lines and made the service permanent.

Overall, Soul City's edutainment has proven to be beneficial in changing social norms and actions regarding domestic violence. During one episode of the 1999 series Matlakala's husband beat her inside their home. Community members gathered around the home, banged pots in solidarity with Matlakala, and showed Thabang that they were protesting his abuse. This banging of pots and rallying outside a scene of domestic abuse has actually been reported in numerous South African communities after the programme aired (Singhal, 2003). It is this kind of activism that shows how powerful edutainment can be.

In the interest of involving children in their edutainment efforts, Soul City Institute and SABC added the multimedia intervention, Soul Buddyz, to their list of programmes. A 2000 study showed that Soul City reaches 67% of the African and Coloured youth of South Africa (Singhal, 2003). The Soul City Institute also provides interactive learning packets to students across South Africa in grades seven, eight and nine. The materials are based on the Soul City television dramas and cover HIV/AIDS, mother and child health, water and sanitation and violence against women.

Soul City has commissioned multiple independent evaluations of their materials and programmes. These surveys show that the Institute has become an effective vehicle for health

promotion and social change. In fact, Soul City is indicated as South Africa's most effective HIV and AIDS educator (Ten Years of Soul City, 2002). Additionally, its success as a drama series is confirmed by the many Avanti Awards Soul City has received, including the Avanti Gold Award for South Africa's Best Television Drama in 2000 (Ten Years of Soul City, 2002).

HIV Hop- Rapping Edutainment

Much like Soul City initiatives, HIV Hop is a media project that offers HIV/AIDS education through entertainment. As previously noted, Bush Radio created HIV Hop as a way to target youth with messages about HIV/AIDS and to attract young community members to participate in awareness education. The lyrics of HIV Hop explore issues of sexuality and HIV/AIDS and also alert people to key issues while advising youth to modify high-risk behaviours (Bosch, 2003:175).

Bush Radio team members began the project by researching current levels of knowledge, attitudes and behaviour as well as uncovering prevalent myths. Their findings then led the way to deconstruct the myths and inform young people about safe sexual practices and the facts of transmission and treatment. After this initial research, Bush Radio's outside broadcast crew began visiting schools once a week to raise the profile of the project and hold "teen town meetings" to uncover the challenges and problems of conventional educational campaigns (Bosch, 2003:186). Doctors and public health representatives were often invited to speak and address student's questions. HIV/AIDS related social issues encompassing everything from the male ego to domestic violence were discussed.

The next phase of the HIV Hop campaign was comprised of a radio show intended to raise the importance of community responsibility in AIDS education. By involving diverse members of the community in awareness campaigns, there is a potential to reach more people

with the messages. A Bush Radio listener called in to the HIV Hop show and made a similar point that “a lot of people don’t know what AIDS is about, so if you talk to them in slang that they understand then you will approach them in a better way and they will understand better” (Bosch, 2003:177).

The radio show experienced a high volume of calls from all over the Cape Town area. One emcee called in to express how inspired he was by the HIV/AIDS issues being discussed on the show and then he went on to rap a rhyme he wrote about prevention (Bosch, 2003:189). Raps written by community members covered many aspects of awareness and HIV/AIDS prevention. Debunking myths, a vital aspect of prevention, makes for a powerful rhyme. The following is a portion of a rap emcee Mr. Devious wrote about myths:

You can’t get AIDS from going to the dentist or sharing the same glasses
You can’t get AIDS from cutting your hair or breathing the same air
Or sharing cutlery with a person with HIV hopefully I’ll make you see
Having sex while standing does not prevent infection
neither does pulling out your penis before ejaculation
So go ahead and laugh at this
You can still get AIDS if you have sex and pee afterwards
That’s my verse
If you confused, rewind and go back ‘til you understand the lyrics in this rap
Get that?
(Bosch, 2003:193)

Local emcees like Mr. Devious were invited by Bush Radio to attend workshops and be present during broadcasts. As a result, members of the hip-hop community participated to increase their popularity and their knowledge of the medical facts. This way they were able better address basic misconceptions about the virus and help to end stigmas in their lyrics. The following rap ends by reminding listeners that they, too, are at risk.

You think you’re different coz this virus didn’t show up on your test
I’m seen as evil by people who know I’m depressed
I’m already lying on the ground and they’re kicking me in the chest
I’m walking around fighting for dignity in distress

Is it ignorance or prejudice leaving the people vexed
You best believe what you read take a peep at the stats
One thousand six hundred people's infected daily
Not only by sex but needles injected maybe
You need to take the test yourself then check your attitude
Coz someone in your family even you might have it too
(Bosch, 2003: 195)

Research shows that many South African youth underestimate their risk for contracting HIV and that a “higher perceived vulnerability and anxiety about personal risk is linked to greater intended and actual behaviour change” (Bosch, 2003:195). Raps like the last one are reminders that everyone all sexually active people are vulnerable and there is no safety in perceiving HIV/AIDS as a disease that only affects others. Powerful words presented in a manner that community members relate to also stimulate debate and reflection about the topics among audience members. In this way HIV Hop united youth and provided community building around awareness. Hopefully young people hearing and memorizing these powerful lyrics will internalize the messages and be able to make positive lifestyle choices and offer guidance on preventing disease. Unfortunately there were no comprehensive mechanisms to evaluate the effectiveness of the project, but from the support and turnout for events like the World AIDS Day HIV Hop concert in 2001, creative entertainment education has the power to be extremely successful.

Part III: The Social Challenges of Treatment: The Nyanga District and the Usapho Lwethu Clinic

Chapter 5: The Nyanga District

This section sets out to discuss social issues and the context of life in townships across South Africa. It also establishes the relevance of violence and its effect on antiretroviral therapy, the difficulties of treating a population where stigmas and social discrimination surrounding

HIV/AIDS remain important issues, and the challenges for treatment in economically constrained areas. Beating the HIV/AIDS epidemic will be done with successful HIV/AIDS treatment and prevention practices. This section outlines one region where treatment is being offered in a pilot clinic and discusses the challenges of treatment experienced there.

In the peri-urban township of Gugulethu, South Africa the Usapho Lwethu ('Our Family' in Xhosa) clinic has just entered its second year of providing community-based Highly Active Antiretroviral Therapy (HAART). Gugulethu is a township located in the Nyanga District, which has an estimated population of 350,000 and is situated in the Cape Flats just outside of Cape Town (Statistics, 2002). Nyanga is primarily comprised of black South Africans, many of who originated in the Eastern Cape and migrated to the Cape Town region in search of employment. There is a predominance of Xhosa persons, which has determined the common language in Nyanga, but the community has a diversity of ethnicities and religions.

Housing in Nyanga is comprised of formal block dwellings and informal houses made of varying combinations of metal, wood and cardboard. Some of the informal houses are located in informal settlements and 'squatter camps.' There are often no formal addresses in these settlements, and streets are mostly dirt roads determined by the random placement of shacks rather than proper urban planning schemes.

Houses of patients at the Usapho Lwethu clinic range in occupancy from one person to thirteen people living within a one-room dwelling. Clinic demographic findings show that 61% of patients live in block or brick housing, 32% live in metal shacks and 7% live in cardboard dwellings (Yeager et al., 2003). The demographics also note that 53% of patients do not have running water in their homes, 19% of patients have no electricity and 74% of patients do not have toilets within the dwelling (Yeager et al., 2003). Conditions of extreme poverty exist in many townships. According to Statistics South Africa's 2002 labour force

survey, the official unemployment rates for black South Africans are 37% for black men and 41% for black women. This high level of unemployment has many effects on the community. For example, in areas of high unemployment the lack of money often translates into a lack of food and subsequently nutritional deficiencies, which affect one's overall health and wellbeing. The lack of money and resources also makes it difficult to afford travelling to and from one's clinic, which is a factor in getting people on ARV therapy.

The statistics are staggering. People living in informal settlements are most at risk of HIV with a prevalence of 21.3% (Department of Health, 2002). Black women are most susceptible to HIV infection with seropositivity rates estimated at 26%. Black men have seropositivity rates of 19% (Department of Health, 2002). The prevalence of HIV infection in South Africa is considerably higher (five times higher) among black women than compared with Asian, coloured or white women (Department of Health, 2002). This is particularly relevant in regard to the demographics of the Nyanga District and the lessons of the Usapho Lwethu clinic.

The other epidemic facing the population of the Nyanga District is that of tuberculosis (TB), with notifications greater than 700 per 100,000 people (Department of Health, 1999). The high prevalence of TB becomes a problem in an immune-compromised population where patients commonly have evidence of TB on lung x-rays. Since drug resistance has made TB difficult to treat effectively, it is challenging to diagnose active TB versus scarring from previously treated TB. There is a need to recognize and treat TB prior to commencing ARV therapy in the severely immune compromised, due to the risk of overwhelming immune reconstitution-associated TB. Starting antiretroviral therapy (ART) in patients also undergoing TB treatment tends to lend itself to an overwhelming pill burden thereby complicating treatment adherence. In the face of this dual epidemic, the clinical challenges of

ART alone are enormous. Poor socio-economic conditions in an overcrowded community only compound these growing epidemics.

Chapter 6: Clinical Methods and Research Results

The Usapho Lwethu clinic utilizes an easily replicable primary-care model of ART delivery, based on one medical officer, one nurse and a group of therapeutic counsellors. At Usapho Lwethu, the group of counsellors is called Sizophila, which is a Xhosa word meaning ‘we are healthy.’ All the therapeutic counsellors are HIV positive themselves and some are on ARVs. Every patient is assigned a therapeutic counsellor at the first visit to the clinic. One of the counsellors’ primary responsibilities is to increase patient ARV literacy. They educate new patients during weekly treatment readiness sessions. Weekly topics cycle through HIV progression, antiretroviral drugs and the process of therapy, and the importance of adherence and healthy living. When necessary, counsellors provide this information in the homes of their clients too unwell to make the weekly trip to the training sessions. The therapeutic counsellors are part of the clinic team and through their social assessments they assist in team discussions and decisions regarding the readiness of patients to begin treatment.

Requirements to start ART at the Usapho Lwethu clinic state that a patient must attend at least three treatment readiness sessions. They also must have disclosed their status to their sexual partner, or if that person is not available then to at least one other person who can assist with treatment support. Each patient must meet the biological requirement of having a CD4 count of or below 200 and/or having experienced an AIDS defining illness as defined by the World Health Organization. Due to the possible teratogenicity (birth defect risk) of one of the clinic’s first-line antiretroviral drugs, Efavirenz, the female patients agree to use contraception and ensure condom usage with partners prior to beginning treatment. If they cannot guarantee contraception they are offered a pregnancy-safe alternative antiretroviral.

The Usapho Lwethu clinic also utilized the services of an anthropologist, who conducted an ethnographic study of the clinic and the counsellors while visiting patients in their homes. Seven therapeutic counsellors were key informants in this study. Patients became familiar with the anthropologist while preparing for treatment at the weekly treatment readiness sessions. This venue allowed for interaction with patients in an informal setting which further helped to make them comfortable with the anthropologist's presence in their homes. It also allowed for additional observation of patient's questions and fears about treatment, concerns regarding social myths and personal experiences with issues such as disclosure. Through these observations and those of clinic meetings, the social concerns that caused delays in getting patients treatment ready or those that led to adherence problems were recorded. The relevant observations were then investigated further through two focus group sessions and individual interviews with counsellors.

Importance of Home Visits

Home visits provide an invaluable resource as they establish the basis of the clinic team's non-medical knowledge about patients. They provide insight into the circumstances in which patients will take their drugs, the extent of their social support structures, and whether or not disclosure has taken place. Home visits also offer patients a comfortable environment for getting to know their counsellors on a peer-level and further fostering a friendship unlike that of many clinical counselling relationships. Home visits discount certain myths and other social stigmas by providing family members (and even friends and neighbours) with factual information about transmission, ways to live positively, ART and its side effects.

The visits also offer families an accessible resource for asking questions about HIV and ART, which may reduce discrimination within the home and community. One local woman noted that even though her family accepts her HIV status enough to let her stay in their home, their

ignorance about transmission keeps her from being able to help with such tasks as baking bread or cooking (Yeager, 2003). She explained that the family also thinks she should remain home rather than being active or having a social life despite the fact that she is clinically well. This stigmatisation further handicaps people living with HIV and derides their sense of belonging and normalcy (Muyinda et al., 1997). Social discrimination also burdens the mental health of patients focusing on getting well (Berkman, 1995; Muyinda et al., 1997; Wojcicki & Malala, 2001). If HIV is to be seen as a “manageable, chronic, clinical condition” rather than a death sentence, the interactions of home visits are vital toward creating a greater societal understanding of this disease (Ekambaram, 2003: 31).

Chapter 7: Barriers to Successful ARV Therapy

Identifying Medical Myths

At the start of the anthropological research it was rumoured by some members of the Gugulethu community that antiretrovirals themselves were killing people. Patients who heard these myths were asking questions about this in treatment readiness sessions. One woman said that while waiting in the hall to see the clinic doctor she heard people saying that the clinic’s drugs had recently caused the death of a patient (Yeager, 2003). These myths perpetuate fears and untruths about the realities of treatment and possibly even deter new patients from returning to the clinic. Other research has shown that the social consequences of HIV/AIDS, such as stigmatisation and rejection, often keep people from being tested (Lie & Biswalo, 1994). There may be other factors that have kept some patients from returning for their second appointment; however, myths and fears most likely contribute. For those people living with HIV/AIDS these social consequences may be of great enough concern to keep them from being seen at an HIV clinic where they could possibly receive treatment.

In an effort to dispel myths, the clinic's therapeutic counsellors share with families the biomedical explanations of patients' illnesses and when necessary, patients' deaths. For example, when one patient died of the opportunistic infection, cryptococcal meningitis, rumours spread that the death was because ARV drugs are poisonous and cause patients to become crazy. In actuality, the patient died of an exacerbation of pre-existing cryptococcal meningitis during immune reconstitution in the first few months of ART. Cryptococcal meningitis may present with confusion and signs of dementia, which would thereby explain the 'craziness' myth. But in the case of extremely unwell patients, immune reconstitution is a challenging aspect of ART, especially in an area so burdened by diseases such as TB, which can also cause problems for patients through immune reconstitution.

The counsellor of the patient with cryptococcal meningitis helped the family understand the symptoms of the infection, the actual cause of death and what the Usapho Lwethu clinic and the local secondary hospital had done to treat it. In people with advanced HIV or AIDS, diagnosing and treating opportunistic infections prior to beginning ART is key, but often difficult. Immune reconstitution during the first few months of ART may lead to the worsening of opportunistic infections that were previously undetectable due to the damage caused by HIV to the immune system. This is especially true when public sector nursing staff lack proper education about ART and its side effects as well as those of opportunistic infections. Upon hearing that she had to visit the local hospital for a specialized test, one patient expressed dissatisfaction by replying that going to that particular hospital "is a one-way ticket" (Yeager, 2003). Because so many community members with advanced AIDS disease have died at the local hospital, patients comment on it as a final resting place rather than a centre for receiving helpful medical care.

These worries about gaining proper treatment in community hospitals are a reality. One patient's family specifically preferred to take care of the patient at home rather than admitting him to a local hospital. The clinic doctor had recommended that the patient receive intravenous fluids and the twenty-four hour attention of hospital staff while in such a state of ill health. However, the family refused due to their reservation about how HIV positive people are discriminated against and treated in public health centres.

Hospitalisations

Usapho Lwethu doctor, Dr. Catherine Orrell, noted that she has also become frustrated with the level of care for HIV/AIDS patients. One of her patients was referred to the local community hospital for basic antibiotic treatment of bacterial pneumonia. The patient and her baby waited to be seen for 18 hours in the emergency ward. However, later in the night, having never been seen, the mother died. She never received the antibiotics that could have prevented her death. Certainly there exist many cases where people with HIV/AIDS are untreated due to discrimination. It is also likely that this particular casualty unit is under-resourced and overcrowded, which would also have contributed to this woman's unnecessary death.

When Usapho Lwethu patients are admitted to local hospitals for additional assistance, such as is the case with some opportunistic infections, the counsellors often visit to make sure that their clients are receiving their ARVs properly. The clinic team has repeatedly noted problems with patients' ARVs while in local hospitals. Entire bottles of ARVs have gone missing while patients were in the hospital. On more than one occasion, the nursing staff have been unable to answer correctly when questioned by Usapho Lwethu doctors about the particulars of patients' ARV dosing schedules. Perhaps this problem, like that of the many

patients who die of easily preventable deaths, is as much related to ignorance of ART as it is to discrimination and the notion that death is inevitable if you have HIV/AIDS.

In some instances family members or friends have offered to bring the patient's ARVs to the hospital every day so that they know their loved one is getting the ARV medications properly. This type of support is rare though because many family members are overburdened by caring for other family members or children. Making daily or twice daily trips to the local hospital for ARV support is simply too expensive and/or time consuming for some families. Regardless, since hospital staff handle other forms of pill administration, ARV pill distribution could be easily incorporated. Further education for hospital staff regarding ART, more specifically the reasons for adhering to a strict pill-taking schedule, should help correct these problems. After one year of working together with the Usapho Lwethu clinic, officials at the local community hospital referred to in this research are trying to resolve these problems. However, the same issues will need to be addressed more efficiently and on a much larger scale if a national treatment plan is to progress successfully. Also, non-discriminatory structures need to be in place to support the work of doctors administering ART. This is just one essential component necessary to resolve the medical challenges of treating extremely unwell patients.

Social Support

A supportive social structure is another crucial element for someone on ART. This is an important factor in helping a patient prepare for treatment and is also an additional reason that home visits are vital. According to patient comments many of the counsellor-patient relationships have developed into much-appreciated friendships. One patient said, "I can't wait for my counsellor to come visit. Just yesterday I was telling my mother that I wondered when she would come again." The support given by the therapeutic counsellors is based on a

peer-relationship, which coupled with home visits does provide additional social support to patients on ART. However, anthropological research verifies that in-home support is also a fundamental element to successful ART. In fact, research shows that people who are isolated are at increased risk for mortality, which is particularly relevant in regards to the stigmatisation of people living with HIV (Berkman, 1995; Muyinda et al., 1997).

Patients who have family members or friends who are willing to help them take their treatment when they are unwell or hospitalised are more likely to remain adherent. For example, a counsellor noted that she was concerned about one patient's children who are not only unsupportive, but also verbally abusive. Just prior to the patient commencing therapy the counsellor conducted a home visit where the patient's adult children made negative remarks about their mother's HIV status. All of these children live with the mother but until recently none were willing to assist her with treatment or fill her pillbox every week. The comments sparked concern in the counsellor who decided initially to conduct weekly home visits for extra support and to help with filling the pillbox. During one of these visits the counsellor noted that the patient's tablet counts were incorrect. In this case the counsellor has already noted that there is a lack of support in the home and that it might contribute to non-adherence.

Patients who receive support and care in the home have a healthier environment for the promotion of wellness than those that are isolated (Berkman, 1995). In his article about the role of social relations in promoting health, Berkman noted that social support must provide a sense of belonging and intimacy and must help a person be more competent (Berkman, 1995). There are examples of patients who have very good home support and despite grave health matters, continued to persevere beyond clinical predictions. Fortunately for the patient described above, regular home visits from the counsellor have put her at less risk for failing

ART. In part due to conversations with the counsellor, the patient's oldest son is now helping with the pillbox.

Alcoholism

Counsellors have noted alcohol concerns regarding a number of patients. During the month of patient screening that precedes treatment, counsellors get to know patients and visit them in their homes. Despite all of the visits and efforts, it is unusual that counsellors pick up on alcohol issues during screening. Rather it is more common that problems with alcohol are discovered as therapy progresses and counsellors continue to visit patient's homes. Sometimes counsellors notice other signs of non-adherence such as missing clinic appointments and, when following up on these issues, discover that the patient is drinking. Patients who get drunk are at risk for noncompliance because they may forget to take their pills or pass out and miss doses. Also, alcohol contributes to immune suppression and may result in unnecessary stress on the liver, pancreas and other organs.

Alcoholism seems to be one of the problematic social ills challenging the ART programme. Not one member of the team is prepared to counsel patients for alcoholism. To add to this dilemma, local doctors commented that the social services that are meant to handle this issue are not functioning.

Complex Gender Dynamics

Disclosure

Disclosing one's HIV positive status is essential to being able to take ARVs properly. Often patients' family members help them remember dose times and this type of support is essential in cases where patients are extremely unwell. None of this is possible without disclosure. Telling a partner or family about testing positive for HIV is not an easy task. For women, the

social pressures to have a male partner and the prevalence of gender violence make disclosure increasingly difficult in communities like Gugulethu.

Abandonment and abuse are common reasons that keep women from disclosing their seropositive status. The fear of being abandoned is a reality in communities where women typically possess a lower economic status than men. Being single and possibly raising children alone further compound-economic strains (Campbell, 2000). However, economic support is not all that is at stake in being abandoned. According to Campbell, a woman's social worth is directly connected to having a male partner (Campbell, 2000; Jewkes et al., 2003). Single women are commonly socially isolated because they are seen as potential partners for the many men who manage multiple relationships (Jewkes et al., 2003). In this society, abandonment receives special consideration when women (and men) consider disclosure. But when patients are faced with needing to disclose in order to receive potentially life-saving medicines, the balance tends to shift.

With the assistance and support of the therapeutic counsellors, patients are finding disclosure to be much easier than expected. One patient shared his own positive experience with disclosure during a treatment readiness session. Through the smiles of other patients it was clear that this man's positive experience was relieving and encouraging. Still, studies have found that many women fear that partners will react violently to disclosure and that indeed HIV-infected women are at increased risk for partner violence (Population Briefs, 2001).

Interviews allude to the complications of condom negotiation. Women find themselves afraid of abandonment while understanding the need to protect themselves from reinfection. This situation makes it difficult to ensure the use of condoms, which can potentially decrease the positive accomplishments of therapy while also putting the partner at risk for HIV infection and ARV drug resistance. It is a difficult battle for many patients. One patient whose four-

week pill counts showed noncompliance explained that her boyfriend refused to believe that she has HIV. He also refused to use condoms and since the patient did not want to put him at risk of drug resistance, she had not been taking her ARVs regularly. Her non-adherence resulted in her doctors interrupting her ART until she can overcome all the issues resulting in poor treatment compliance. Unfortunately, this will be a difficult challenge for the patient as there are emotional issues attached to the relationship and yet she is aware that this might be her only chance to receive ARVs. For some patients, being extremely unwell is enough motivation to help with disclosure and condom negotiation. But what will happen when patients regain their health through ART? With mortality seemingly less of a daily concern, will patients sacrifice condom usage in order to have a partner or even possibly to have a child?

Violence

Gender violence and domestic abuse also add to the social dilemmas that contribute to adherence concerns. For example, a patient explained that after an ordeal with domestic violence she refrained from going home for a few days, and therefore did not take her antiretrovirals because they were inside her home. Noncompliance, or missing a couple days of ARVs, can lead to the development of viral resistance. All patients are taught this prior to starting treatment. However, as seen through this patient's experience, personal agency is affected by violence regardless of knowledge about the importance of adherence.

Representatives of the South African Medical Research Council explain the violence in South Africa as a result of the “decades of apartheid State-sponsored violence and reactive community insurrection” (Jewkes et al., 2003). They connect past violent acts of older generations to the current situation because violence is commonly the first response for resolving conflict (Jewkes et al., 2003). Certainly, South Africa has a history of being a

violent society and it remains a part of life even today. The manifestations of this history show themselves in the prevalence of gender violence and domestic abuse in communities like Gugulethu. Police estimate only 1 in 35 rapes are reported in South Africa (Shifman, Madala-Routledge & Smith, 1997). Even though there are many rapes that go unreported, the Human Rights Watch has recorded the highest figures for rape in a country not at war (Human Rights Watch, 1995).

Previous social research has found that violence against women makes them particularly at risk for HIV infection as forced sexual intercourse with an infected partner can directly result in HIV transmission. Also, the fear of being abused may keep women from asking a partner to use a condom, which has implications for transmission and reinfection. Violent practices against women in South Africa have been termed “endemic” (Wood et al., 1998: 234). Social research documents that gender violence is “widespread, common and deeply entrenched” (Vogelman and Eagle, 1991).

Methods used to document domestic and gender violence are often inaccurate. Few women actually report, so the quoted statistic may be inaccurate. This is partially the result of the phenomenon of women viewing abuse as a way of being “educated” or “corrected” by a man (Population Briefs, 2001). In many cases gender violence has become normative and commonly accepted instead of challenged (Vogelman & Eagle, 1991). This acceptance of violence as normal is in part due to the inaction of police when a woman comes forward to report a case.

A study of gender violence in the Western Cape region noted that police officers recognize that they are relatively unprepared to help women who report incidences of rape (Women’s Media Watch, 2002). In addition to police inadequacies, police complacency regarding rape

cases is commonly reported (Wood et al., 1998). In fact, rape has the lowest rate of conviction of any form of assault (Shifman et al., 1997).

A personal account of a woman in the Nyanga District noted that the local officers were friends of her abusive boyfriend. She believed that this was the reason that nothing was done when she filed a report. Making attempts to end gender and domestic violence by educating women of their rights is relatively futile in environments where officers of the law seem burdened by their duty and are known to act on special favours. Changing the way gender violence is viewed by both men and women, will only begin with proper law enforcement and a judicial system that will back it.

Condom Negotiation

The presence of gender violence in South Africa has serious implications for HIV prevention and treatment. For example, safe sex negotiation can sometimes be a hazardous endeavour. A 1998 qualitative study of Xhosa-speaking adolescent women in Khayelitsha (a neighbouring township demographically similar to Gugulethu) showed that “male violent and coercive practices dominate their sexual relationships” (Wood et al., 1998). In fact, “being beaten was such a common experience that some...perceived it to be an expression of love” (Wood et al., 1998). This prevalence of violence has an effect on a woman’s ability to negotiate condom usage and protect herself not only from acquiring HIV but also from reinfection when on HAART.

The use of condoms is also vital to the protection of the sexual partners of patients on ART. By not condomising, partners are at risk of acquiring HIV but also of acquiring a non-naïve virus. This means that a person who would have no clinical history of being on ART could have HIV virus that has already developed some drug resistance. Unfortunately, patients’ honesty regarding condom usage is subjective. For example, to her doctor a woman might

say that she is using condoms with her partner because she knows that this is required by her ART clinic. However, the realities of condom usage might be very different. Patients are more likely to admit to their counsellors that they are having difficulty enforcing the use of condoms, and these conversations have been the primary means by which the clinic team has learned of such issues. In fact, counsellors have noted on numerous occasions that a patient alluded to occasional condom usage or problems with negotiation. It is difficult to truly know whether fears of intimate partner violence, denial by the partner or what other factors contribute to having unprotected sex while on ART. Certainly knowledge about reinfection alone is insufficient in ensuring condom usage.

Recent studies note that men often relate masculinity to having “flesh-to-flesh” sex (Wojcicki & Malala, 2001). Webb’s work suggests that some men believe regular flesh-to-flesh sex necessary for good health (Campbell, 2000). This cultural construction of masculinity means that refusing condom use might be part of this machoism. Furthermore, violence as a means of achieving flesh-to-flesh sexual contact would not be out of the realm of accepted practice. According to Wojcicki and Malala, women’s low economic status determines a dependency on men and often makes attempts at negotiating safe sexual behaviour unsuccessful (2001). The likelihood that people will engage in health-promoting behaviours is influenced by the extent to which they feel in control of other aspects of their lives and the extent to which they live in a supportive social environment (Berkman, 1995; Campbell, 2000). The prominence of gender violence has serious implications for enforcing all aspects of ART, especially condom use.

Part IV: The Future of HAART in the Public Sector

Chapter 8: The Health Minister’s Plan

Late in the afternoon of Friday, August 8th, 2003 the Government Communication and Information System issued an unforeseen press release that read, “Cabinet decided that it should, as a matter of urgency, develop a detailed operational plan on an antiretroviral treatment programme” (Thom, 2003a). After the four year long debate between the South African government and relentless human rights organizations, the press release came as a surprise to everyone. Nonetheless, the pledge to develop a national ARV treatment plan was made and the previously dim future of South African’s 5.3 million HIV positive people was lit with the idea that ARVs could one day be available to the public. Today’s challenge, though, is how the government is handling the roll out of ARVS in a health system that already has flailing mismanaged programmes such as the PMTCT programme. This chapter explores these problems aside the government’s moves to manage the rollout and the media’s coverage of their first year’s attempts.

Meditating realistic concerns while lacking governmental proactive measures

There are many understandable reasons the South African government including President Thabo Mbeki, Health Minister Manto Tshabalala-Msimang and other officials, drag their feet on a national HIV treatment plan. However, it would have served the people waiting for ARVs well if the government had attempted to address the fledgling health care concerns while debating for instance, the connection of HIV and AIDS (Parsons, 2004). But what is done is done and now South Africa is faced with numerous hurdles in front of a successful ARV rollout. For starters, previous government efforts such as the PMTCT, HIV prevention programme for survivors of rape and the Voluntary Counselling and Testing programme have been poorly monitored and thus less successful than they can be. Dr. Nono Simelela, Director of the TB, STIs and HIV/AIDS Directorate in the Department of Health noted in a December 2003 interview with *Health-e* reporter Khopotso Bodibe that the fast-track process they took

for these programmes is partly to blame for the problems they have had (Bodibe, 2003). He explained that with the PMTCT programme the Department of Health selected sites and they just went in and set up the programme and let them run their course. Dr. Simelela stated, though, “the lessons we learnt from [the PMTCT] programme have really informed how we do [the national ARV programme]” (Bodibe, 2003:1).

Service delivery is a very real threat to vital health care programmes in South Africa because the national health system is based upon a decentralized, provincial-oriented plan. Each of the nine provinces has differing levels of health care abilities, due in part to economics, location and proximity to universities and, thus, doctors, research and trial projects. As a result of this structure, some provinces have been much more successful in administering nationally funded health programmes. Provinces such as Gauteng and the Western Cape were able to reach programme goals in PMTCT but others such as Mpumalanga are still lagging behind (Bodibe, 2003:1; Thom, 2003b). This raises the important issue of national support and monitoring for the ARV programme as a vital element to its success.

The ARV programme will require highly technical monitoring and evaluation at a number of different levels, starting at the facility level. Take, for example, the pharmacy responsibility at a public primary care hospital like the Gugulethu Community Health Centre that house the Usapho Lwethu clinic. Any prescriptions written at the hospital (save the ARVs which are privately purchased by Hannan Crusaid, a non-governmental foundation that donated the ARVs to the HIV clinic) were dispersed by the hospital pharmacy. If it were that ARVs were housed in the general pharmacy and were not managed well, a black market for ARVs could develop, which would in turn result in a growing population of people with drug resistance. This is one reason monitoring is so important; drug resistance could potentially ruin any advances made by a national ARV plan and should be prevented through impeccable

monitoring procedures. Additionally, if by chance ARV ordering was inadequately handled at the pharmacy and there happened to be drug shortages, patients could potentially go without drug thereby risking adherence and making drug resistance more likely even in patients attempting to be adherent. The Comprehensive Management and Treatment Plan outlined the need for more trained pharmacists to administer ARVs and for secure facilities (Cabinet's decision, 2003:5). According to a November 2004 comment by the head of the national Department of Health's Directorate on HIV and AIDS, Rose Mulumba, there is a plan in the works that will prevent hospitals and clinics in the country from ever running out of antiretrovirals. She referred to a "multimillion-rand tender for sustainable procurement of drugs" as still outstanding but in the final stage (Naidu, 2004:3). If this government system works as planned then at least at one level there will be a safety in place to ensure an adequate drug supply.

Currently, though, supervisors at primary care facilities do not have the skills or the capacity to handle the gigantic task of monitoring (Barron, 2003:3). Without adequate information systems and use of information from these systems there is every likelihood that an ARV programme will not achieve what it is meant to do. According to Dr. Simelela, the Department of Health is going to make sure the budgets are in place and fully provided and that the training is complete for this programme to have the proper staff to manage and monitor it (Bodibe, 2003). Hopefully, the lessons learned through the problems of the PMTCT programme will be useful to the success of the ARV programme.

The South African Government gave the title of the Comprehensive Management, Treatment and Prevention Plan for HIV and AIDS for the system they devised to roll out ARVs. One of the restrictions they put in place to safeguard the success of the Comprehensive Treatment Plan is the system of accreditation. Every service point must first get accreditation before

going ahead with treatment (Operational Plan, 2003:24). The service points are defined as “a group or network of linked health facilities within a clearly demarcated geographical area called the health district” (Cabinet’s decision, 2003:4). Each service point must first be equipped with all the necessary resources such as a project manager and a trained team of clinicians, nurses and counsellors, access to trained laboratory, pharmacy and nutritional staff, a secure pharmacy, enough rooms to ensure patient confidentiality in treatment and counselling, 24-hours a day access to care within the vicinity of the service point and many additional standards for service (Cabinet’s decision, 2003:4). The Department of Health agreed to provide for technical assistance and financial resources to assist the service point managers and staff in meeting the accreditation requirements in a timely fashion. Accreditation requires being investigated by the Department of Health to ensure the ability to “effectively screen, diagnose, treat, care for and effectively monitor the progress and safety of HIV-positive patients” (Operational Plan, 2003:24). The accreditation system was devised because of the complexity of administering antiretroviral drugs safely and effectively and the call for improved monitoring at the national level in regard to the previous problems of the PMTCT programme (Operational Plan, 2003:24).

According to KwaZulu-Natal’s Department of Health Director, Dr. Chris Jack, each of the province’s eleven health districts had at least two ARV accredited sites by the end of November 2004 (Operational Plan, 2003:24). This is very important progress for KwaZulu-Natal as it houses South Africa’s highest prevalence of HIV and AIDS (Operational Plan, 2003:24). However, as of September 2004, of the more than twenty accredited sites only nine were actually administering ARVs, which leads one to question what is causing the delays (Bailey & Caelers, 2004:1).

KwaZulu-Natal is home to several ARV pilot projects that have been underway for the past few years and it is fortunate to have a prominent university and noteworthy scientists. Dr. Hoosen Coovadia, a leading South African AIDS scientist from the University of Natal and Dr. Salim Abdool Karim, Director of the HIV Prevention and Vaccine Research for the Medical Research Council and professor at Columbia University, are two of the many HIV/AIDS researchers who have taken active roles in ARV studies and are publishing their findings and opinions in noteworthy national and international journals (Cohen, 2000; Karim, 2000). Having resources like these researchers certainly contributes to the success of the province's ARV treatment. But for less prepared provinces, those without universities, pilot clinics and hordes of involved researchers and doctors, greater efforts will be needed to get necessary ARV clinics open and functioning properly.

Infrastructure

The existing infrastructure of the South African health system is one of the greatest challenges to ensuring the adequate delivery of antiretrovirals. This very point was perhaps one of the speedbumps that slowed the government's decision to rollout ARVs. Basic infrastructure elements including water, sanitation, electricity, communication and consultation rooms, are insufficient. In the first year of the Usapho Lwethu clinic (2002) at the Gugulethu Community Health Centre there were no extra rooms available in which to see patients when an extra doctor was available to assist the clinic. Counsellors did not have a private area to speak with their patients and sometimes had to conduct affairs in the presence of other patients or in the same room where the doctor worked. Also, in its first year of operation there were a number of occasions where the clinic had no electricity. Once there was a period of a week where no electricity was available because someone had vandalized the outlets in the hallways and stolen their electrical covers. Doctors checking for signs of

active tuberculosis on x-rays had no electricity for the x-ray light box and had to hold the chest x-rays to the window. These kinds of infrastructural inadequacies compromise the level of care patients receive, and conditions need to improve in order to provide a successful ARV programme. The Gugulethu Community Health Centre and the Usapho Lwethu clinic are not alone in these problems. At Natalspruit Hospital in Gauteng the ARV clinic shares a space with another department, limiting the days they can operate, and only one doctor is available to see patients one day a week (Naidu, 2004).

There is a substantial risk in offering ARVs at primary care services that are already underfunded and understaffed. According to Dr. Peter Baron, the Director of the Initiative for Sub District Support of the Health Systems Trust, “virtually every primary facility has unmet primary care needs” (Barron, 2003:1). Dr. Barron believes that adding on an ARV programme without addressing the under funding of the primary care system, will “exponentially increase the under funding on primary care” (Barron, 2003:1).

Funding raises a number of problems for the primary care facilities and the people attempting to gain health care in them. For example, underfunding results in rationing, which can have adverse effects on the quality of the health care provided at these facilities. Rationing commonly also causes a quota system whereby patients are turned away, often after waiting for hours to be seen, and then told to come back on another day. But patients beware, one cannot just show up on any random day as rationing also causes many clinics to only run on certain days of the week and/or offer some services only on limited days during the week. According to Dr. Jeff Wing of the ARV clinic at Johannesburg General Hospital, they can disperse ARVs only on Tuesdays and Fridays despite being “relatively well staffed” (Naidu, 2004:3). They do, however, offer patient screening, testing and counselling five days a week (Naidu, 2004:3).

Many services are not offered in all primary care facilities, and patients are forced to attend different locations, thus causing great inconvenience to often unwell patients and delays in treatment due to poor communication between facilities. The time lost in sending a patient to another facility can add up to vital health risks for patients. Consider this mock example. A patient receiving ARVs is suspected on Monday of having cryptococcal meningitis (a disease that is often deadly because of immune reconstitution) and is told to see a special doctor at another facility for tests not available at the primary care clinic in the patient's township. The next time the special doctor sees patients is on Wednesday and so the patient goes home and waits until Wednesday to spend the entire day travelling to the other doctor, waiting to be seen and then travelling home. Friday, the next day the patient's primary ARV clinic is open, the patient waits hours to be seen only to find out that the results have not arrived yet and is asked to come back on Monday. In this example an entire week is lost to a system resulting from rationing. The clinic in the township does not have the funding for the equipment or the specialized staff to offer the tests the patient needs. Thus, the selective basis of primary care coupled with the other inefficiencies of underfunding often indirectly result in deaths that can be prevented.

Introducing ARVs in this system of rationing is going to be extremely problematic. The Usapho Lwethu clinic faced many of these problems as they attempted to provide ARVs in a public sector HIV clinic. Except for the ARVs, the clinic was solely funded by the government and was run similarly to the other HIV clinics in Nyanga. The Usapho Lwethu clinical goals were to show that successful ARV therapy is possible with the infrastructure available nationwide and to provide evidence that a national ARV plan can work. However, the well-connected project supervisors often made things possible that would otherwise have not been available if it were not for the importance of the success of the pilot clinic. "Miracles" like finding open beds at hospice centres will not always be feasible in a national ARV

programme and for this reason it is vital that primary care funding be increased to combat the rationing at the primary care level and to fully support the needs of the ARV treatment plan. The system of accreditation should improve some of these previous problems. For example, a service point is only supposed to be accredited if it provides consultation, treatment and counselling rooms to ensure patient confidentiality and it is to have “linkages with community resources and other support organisations to complete the continuum of medical care and support services” (Cabinet’s decision, 2003:4). The Operational Plan set forth by the government does read that there is a need for “additional capacity in the national health system” (Cabinet’s decision, 20003:3). Originally the plan pledged over R750 million to upgrading systems in the healthcare infrastructural areas of “drug distribution, patient information systems and monitoring of reaction to the drugs” but whether this is being done and to what degree remains to be seen (Cabinet’s decision, 20003:3).

Ensuring equality of ARV services in underprivileged areas

There are additional concerns that the government roll out will further the inequality of services in primary care. “The districts with the greatest social, economic and health problems have the poorest infrastructure and the lowest level of resource provision” (Barron, 2003:2). According to Dr. Simelela, the issue of equity was raised sharply in the early Cabinet debates. Back in 2003 he said the government is focusing strongly on how the weaker provinces allocate their ARV programme money to ensure that these challenged areas are able to provide the services that will be more easily available in urban areas (Bodibe, 2003). However, after the first year of the Comprehensive HIV and AIDS Care, Management and Treatment Plan it is evident that each province is not progressing at the same pace. In fact, Rose Mulumba, head of the national Department of Health’s Directorate on HIV and AIDS, said “lack of capacity” was a problem delaying the rollout, “especially in poorer

provinces” (Naidu, 2004:3). She also noted that the treatment plan has made great accomplishments this year because it started “off the ground, creating new systems and structures and building capacity where there had been none” (Naidu, 2004:3).

According to Nhlanhla Ndlovu of the Institute for Democracy in South Africa (Idasa), there has been steady progress in the ARV programmes where there is strong leadership (Smetherham, 2004:4). But media reports claim that health officials in some of the poorer provinces are unaware of the urgency of the HIV and AIDS pandemic and without the proper leadership and support, it will be much more difficult to get ARV service points functioning in a timely manner (Adams, 2004:2). Additionally, since these areas typically have a lack of treatment literacy and many of the stigmas surrounding HIV and AIDS remain unchanged, there needs to be a much greater effort to prepare communities for the opening of ARV service points so that they will be more effective when they do get accreditation (Naidu, 2004; Roll-out or cop-out on AIDS drugs, 2004).

Not Enough People to Treat the Millions

The lack of human resources is a big part of the problems facing the Department of Health in its attempts to make ARVs available nationwide. There is an absolute shortage of skilled personnel in the public health sector, especially in rural and disadvantaged urban areas, which happen to be the places hardest hit by the HIV/AIDS epidemic. It will be extremely difficult to run an ARV programme by the already overworked staff and there simply is no other answer than to bring in additional doctors, nurses and support staff. But the problem remains that these people do not appear from nowhere; they need to be trained, which, according to Dr. Barron, can take four to seven years (Barron, 2003). The Human Sciences Research Council stated in a 2003 report that over the next ten years there would be shortage of 20,000 nurses (Human Sciences Research Council, 2003). Gauteng health department spokesperson,

Popo Maja, said it takes time to fill the human resource needs. “Posts have to be advertised and candidates have to be interviewed. We need to appoint people who are qualified” (Green, 2004:2). The Operational Plan suggests that national and international experts be mobilized to assist in the design and delivery of training for new staff members (Operational Plan, 2003:26). It also advocates the “increase utilization of private sector health professionals in the national health system, incentives to attract health professionals to underserved areas and measures to retain health professionals in the public sector” (Operational Plan, 2003:26). Still, one year later it remains to be seen what the logistics are for these big ideas and what is actually being done to accomplish the goals set forth in the Plan.

Media Reporting on Progress of Plan

The August 2003 announcement to roll out ARVs set the end of September as the deadline for the government to release their plans for the national programme. In November of 2003 the Department of Health actually did so, and following the tradition of setting unobtainable goals, it named what many see as an unrealistic target of treating 53,000 people by the end of March 2005 (Adams, 2004:2). The plan also claimed there would be 53 new “service points” in operation by the end of 2004, one in each of the nation’s health districts, and, indeed in August there were already 85 accredited points in operation but not in every service district (Adams, 2004:2).

However a February 2004 article published in the Mail & Guardian newspaper noted insufficient human resources, lack of training of health care workers, lack of treatment literacy, delays in the procurement of the drugs and the need for specialised equipment as the primary problems being reported for the delays (Roll-out or cop-out on AIDS drugs, 2004). But we knew these issues existed before the plan was devised so it raises the question of what was and what is now being done about these problems.-

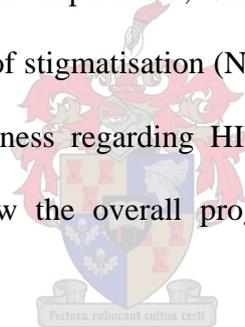
The first year of the government's treatment plan saw unwavering press coverage about the delays and problems experienced. This media coverage indirectly put pressures on the government to follow through on its pledge to create a successful treatment programme. Human rights groups continue to critique the progress being made and directly try to influence the actions of the health officials. Their complaints are that there is too little guidance from government leaders to make the programme successful and timely. They also believe that treatment targets and timelines should be made public knowledge (Parsons, 2004). In early November of 2004, the Treatment Action Campaign led a national protest demanding that the government be candid about what it was doing in the fight against AIDS (Parsons, 2004). They blame the slow pace of the antiretroviral rollout on lack of supervision to implement the plan and most likely want transparent timelines so they can put greater pressure on the government when the Department of Health does not make its targets (Naidu, 2004). As Ms. Mulumba of the Department of Health noted in a press statement in November 2004, "communications around the rollout" have been one of the "key challenges" to its progress (Naidu, 2004:3). Perhaps there is more to TAC's call for government transparency, especially since there still seem to be mixed messages from Health Minister Manto Tshabala-Msimang and since there are still provincial health officials who do not "understand the HIV and AIDS pandemic" (Adams, 2004:2). Improving communication will only improve the success of the national plan and the likelihood that the people who desperately need treatment will get it in time.

Hopefully other nations will learn from the mistake South Africa made in waiting to dedicate efforts toward the improvement of their health infrastructure until the Cabinet forced the Department of Health to design a treatment plan. A great portion of the first year of treatment was spent bringing just a small number of locations up to the initial standards necessary to run an ARV programme successfully. Imagine how many people could be on treatment now

if the government focused on preparations for treating people back when South Africa's epidemic was made notable by Nelson Mandela's presidency in the 1990s.

Chapter 9: Projections for the Future of HIV/AIDS in South Africa

As evidenced in the previous chapter there are a number of concerns regarding the successful treatment of South Africa's 5.3 million HIV positive people. In spite of all the efforts there remain many areas that need great attention. Take for example the Limpopo province, which as of November 2004 only had 130 patients receiving antiretrovirals. Phuti Seloba, the Spokesperson for Limpopo's health department, said that few people were requesting treatment due to the social concern of stigmatisation (Naidu, 2004:3). Rural areas continue to lag behind in awareness and openness regarding HIV and AIDS, and the discrepancies compared to urban areas will slow the overall progress of the national treatment and prevention plan.



By the end of 2004 Rose Mulumba said "the government [is] on target to meet the March 2005 deadline of providing antiretrovirals to 53,000 people. So far we are providing the treatment to more than 11,000 people" (Naidu, 2004:3). She went on to say that the South African government has achieved in three months what Botswana managed in three years.

Additionally, the progress of certain provincial health departments is not going unrewarded. The Western Cape saw its 5,000th person to receive antiretroviral treatment in October 2004. That same month they were given a R430 million grant from the Global Fund to be dispersed over a period of five years. This is the first unconditional grant the Global Fund has given to any of 120 countries, and the money will go directly to the province, which is a first for

South African international aid (Caelers, 2004:1). According to Dr. Fareed Abdullah, head of the Western Cape's HIV/AIDS programme, two-thirds of the grant will go to treating the 12,000 people in need of life-prolonging ARVs in their province by the end of 2005 (Caelers, 2004:1). They also plan to initiate peer education programmes in all high schools and primary schools, and there are already 2,000 young people in training for the programme managed by the provincial education department (Caelers, 2004:1). Abdullah said the grant will double the number of hospice beds in the province's fourteen hospice centres, and it will fund community-based and non-governmental initiatives to assist in the overall health and well being of people living with HIV (Caelers, 2004:1). This could mean availability of vital social services like alcoholism treatment and counselling, domestic violence support, and job training and placement for patients who regain their health and no longer qualify for governmental AIDS grants. As was highlighted in the chapter on social challenges to ARV therapy, these problems will need to be addressed by provincial governments in order to fully administer ARVs successfully and the Western Cape Province will likely set the standards for how to link these non-governmental, community-based initiatives. The commitment Western Cape doctors and health officials invested in supporting pilot projects like the Usapho Lwethu clinic and the proposal to the Global fund is being rewarded in ways they could have only imagined. Eric Goemaere, head of Médecins Sans Frontières' South African mission in Khayelitsha, said "[The grant] makes real something an organisation like mine thought was a foolish idea a few years ago" (Caelers, 2004:1). It gives a sense of hope to the dedicated health professionals and people living with HIV and AIDS in the Western Cape. Fortunately the South African AIDS Vaccine Initiative (SAAVI) has provided similar dedication to the South African epidemic.

Vaccine Initiatives

The South African AIDS Vaccine Initiative was established to develop and test vaccines in a coherent coordinated manner, creating standards for how the country will handle all vaccine trials (The Next Steps, 2002:1). Malegapuru William Makgoba, a former president of the Medical Research Council, said “we don’t want to find people doing research in our own backyard and not being held accountable,” which he said has been a problem historically with research and clinical trials in South Africa. By making it a requirement that all vaccine studies go through the SAAVI, the MRC is protecting citizens by ensuring a highly coordinated and accountable system. Still, although SAAVI works very closely with the MRC, it is the MRC that wields the power of approving all new vaccine trials.

In 2003 two phase I vaccine trials commenced in sites in Durban and Soweto, making South Africa the first African country to run multiple clinical trials and the first country in the world to run trials of subtype C vaccines (Highlights, awards and recognition, 2004). Since HIV subtype C accounts for over 90% of infections in the southern African region, vaccine trials that address subtype C are vital to developing a vaccine that will help South Africans (Background and Establishment of SAAVI, 2004). Most trials to date have been developed for the subtype B virus (Background and Establishment of SAAVI, 2004). This first trial includes 48 people in South Africa and 48 people in the United States (Keeton, 2003).

The different phases of vaccine trials have specific standards as to how many people can participate in each trial. As one phase proves safe, the vaccine study moves on to the next phase and will include more participants. Phase II trials can include up to 400 low and high-risk volunteers. By the time phase three trials are ready to commence, from 5,000 to 10,000 volunteers will be needed, and preparing thousands of people for a vaccine study is not a simple task. The first step, getting people to test for their HIV status, can be a challenge. Often, people go to voluntary counselling and testing only when they start showing

symptoms of HIV. But in order to prepare for the more advanced vaccine trials people need to be willing to know their status. Fortunately, since ARVs will soon be available in many areas of the nation, the thinking that learning one's status is like getting a death certificate will hopefully begin to change. Vaccine studies need healthy, HIV negative individuals who are willing to be seen at the HIV clinic on a regular basis. In communities where stigmatisation is still an issue this means vaccine study staff members devote great amounts of time to community awareness, preparation and promoting early testing so that they can recruit enough HIV negative individuals in time for a vaccine trial. T-shirts that read, "Knowledge is Power- Know your status +/-" are being handed out at awareness street parties in one potential vaccine trial site, Masaphumelele, in the Western Cape (Yeager, 2003). This site is being prepared as one of four communities where phase III trials will eventually be held. Researchers in charge of this project have dedicated two years to setting up a HIV clinic, offering voluntary counselling and testing, and educating potential participants about vaccine trials. They sought out private funding to offer ARV therapy in the HIV clinic while waiting for the decision to roll out ARVs nationally (Yeager, 2003). All volunteers who participate in the vaccine study receive risk-reduction counselling and condoms to prevent HIV. Half of the participants will be given the vaccine and the other half will be given a placebo, but these vaccine studies are double-blind, which means that neither the participants nor the doctors know who gets what. Confidential records of this information are kept, though, so that it can be utilized for research and data purposes when the trial is complete (Keeton, 2003).

In August 2004, the Nelson Mandela Foundation and the SAAVI announced a new partnership focused on an AIDS vaccine for adolescents. Providing a vaccine for adolescents is extremely important to slowing the spread of HIV since "young people between the ages of 15 and 24 account for half of all new HIV cases in the world" (AIDS Vaccine Advocates,

2004:1). It is also a difficult endeavour as adolescents are often excluded from clinical trials due to ethical, legal and logistical concerns. Michael Warren of the AIDS Vaccine Advocacy Coalition said “although the inclusion of adolescents raises challenging issues, these are all solvable issues- and they must be solved if we are to develop a vaccine that can reach those most at risk of HIV in a timely way” (AIDS Vaccine Advocates, 2004:1). The AIDS Vaccine Advocacy Coalition praised South Africa’s initiative to include young people in the battle to beat the spread of HIV. They noted that two pharmaceutical companies are already conducting international trials of STD vaccines among adolescents, which is paving the way for the inclusion of young people in AIDS vaccine research (AIDS Vaccine Trials- Getting the Global House In Order, 2004).

Certainly the future of the SAAVI will be exciting, challenging and expensive. The scientific endeavour of finding an effective vaccine to prevent new HIV infections is in itself incredible, yet once this feat is achieved the struggle will shift to being able to manufacture and administer the vaccine successfully. These challenges will keep the SAAVI occupied for many years. Currently the SAAVI is investing in the people and biological processes required to build capacity for manufacturing the vaccine (South African AIDS Vaccine Initiative, 2004). They are also looking ahead to the data management needs generated by vaccine trials. With increased funding the SAAVI plans to invest in sophisticated data systems and qualified and trained personnel to process the data (South African AIDS Vaccine Initiative, 2004). Fortunately, the SAAVI was set up as a public-private entity, thus receiving funding from the government and any business or private groups that want to contribute. In 2004, private sector funding contributed immensely to the SAAVI. Impala Platinum Holdings and Transnet donated a combined R4 million to the R70 million 2004 budget (Caelers, 2004:10). Businesses like these realize the importance of effective disease control and eradication and

urged other South African business to come forward and invest in a future AIDS-free South Africa (Caelers, 2004:10).

Unlike the structure of the ARV programme, the Vaccine Initiative is “managed almost centrally” (The Next Steps, 2002:1). SAAVI has made it so that all vaccine trial sites in South Africa talk to each other and even participate in tasks together. Then, once every quarter, SAAVI reports to the board of the MRC and the Department of Health, thus completing the circle of information with politicians and health officials so that doctors, researchers and leaders are all able to participate in a forum to share ideas and common problems. But such a thorough system is rare in the South African political and health landscape. We can only hope that the progress made by the success of the SAAVI will set the stage for other programmes like the ARV plan, and that they too will receive such monitoring and support as is provided in the leadership of the SAAVI.

What happened to Ubuntu?

Until there is a united front against HIV/AIDS in all facets of governmental leadership, attacks on the Health Department and the ARV programme’s failures will likely continue. In August of 2004 Health Minister Manto Tshabalala-Msimang acknowledged that South Africa is “just a developing country” and the presidential target of supplying 53,000 people with ARVs by March of 2005 will probably not be met (Adams, 2004:2). She went on to state that, “if you say to the nation that you are providing ARVs, then you will wipe out all of the gains made in the promotion of a healthy lifestyle and prevention” (Adams, 2004:2). This statement sounds reminiscent of the days when President Mbeki uttered his opinion that “poverty causes AIDS” and the Health Minister publicly debated whether or not HIV caused AIDS and how important nutrition is to curbing the devastation of the epidemic (Tregrove-Jones, 2001:3). Zackie Achmat of the Treatment Action Campaign thus reminded the media

to note that the “lack of political leadership stemming from the government’s ‘denialism’” is the weight holding back the progress of the rollout (Naidu, 2004:3). Manto commented in one interview “I’m not sure whether 53,000 people would want to go on ARVs. Some will probably want to stick to their nutrition regimen and traditional medicines” (Adams, 2004:2). Statements like these send mixed messages to the South African people, potentially making them question whether ARVs are truly safe, especially if the health minister continues to reinforce nutrition over the proven efficacy of ARVs.

In addition to TAC’s recent calls for a more transparent HIV/AIDS treatment plan, they have taken a proactive stance and joined forces with other prominent organizations like the Institute for Democracy in South Africa (Idasa), multi-national company Anglo-American, the Southern African HIV Clinicians Society, the University of Cape Town School of Public Health and Family Medicine and Médecins Sans Frontières to monitor the government’s ARV programmes (Smetherham, 2004). This new monitoring forum hopes to be able to communicate the successes and problems of the treatment programme to the South African public. But as Fatima Hassan of the AIDS Law Project made clear, the forum wants to “work with government to ensure the programmes succeed, rather than to be antagonistic” (Smetherham, 2004:4). An expert watchdog forum might prove rather useful in South Africa since the government has had such a difficult time ensuring successful health programmes before and since the infrastructure is so unprepared to offer ARVs.

As is apparent from the challenges faced in the past four years of struggling to gain access to treatment and the obstacles of the first year’s comprehensive treatment and prevention plan, political leadership is the key to a positive future for South Africa’s HIV and AIDS epidemic. Fortunately for South Africans, the vaccine initiative appears to have full governmental

support. It is just a matter of time before an effective vaccine curbs the infection rate and the pandemic takes the desperately needed u-turn.

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