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# Looking back on HIV: Where did it all begin?

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Twenty years ago, in 1997, I wrote the following piece reflecting on the *Mothusimpilo* project, an early attempt to understand and help to manage the epidemic of HIV in South Africa. Names have been changed to protect individuals. An excellent discussion of the early stages of the epidemic and the response to it can be found in *Side Effects: The Story of AIDS in South Africa* by Lesly Lawson (1) and in *Letting Them Die: Why HIV/AIDS Prevention Programmes Fail* by Catherine Campbell (2).

*We cannot afford to allow the AIDS epidemic to ruin the realization of our dreams. Existing statistics indicate that we are at the beginning of the AIDS epidemic in our country. Unattended, however, this will result in untold damage and suffering by the end of the century.*
Chris Hani (1942–1993) Maputo AIDS conference, Mozambique, 1990.

It is a dry day in Carletonville, the biggest gold mining complex in the world. The year is 1996. We are sitting in a shack in a hot-spot, an informal settlement next to one of the deepest mines in the world. This is a place where migrant men seek intimacy and comfort. Tony is interviewing sex workers for a film about HIV/AIDS in a mining community. Lena, who has lived and worked in Carletonville for six years, talks about her life. “I originally come from Zimbabwe. I had done my O-levels, actually up to an extent of form three. When I was supposed to go to form four no one was there to pay for me the school fees. I decided to do the border jumping to South Africa. That was early ninety-one. And I tried to get job in South Africa in town. I failed to succeed till I had to meet other girls in Soweto whereby I had to come with her here in Leeupoort. All we do we are selling beer for the owners of the houses, that means you take beer to the bush there, you sell, they give you two cases, you sell two cases a day and as you are selling the beer you are also selling yourself at the same time.”

Nokuzola, who introduced us to Lena, is a diminutive nurse with energy to spare and a mission to help her community deal with the epidemic that is gathering momentum all around us. Her father worked on the mines and she was born in Carletonville, a place that she knows and loves. While working as a nurse for one of the mining houses Nokuzola saw, long before we did, the impact that AIDS was having on her world. Solomon, a social worker, also spent many years in Carletonville among the mine workers who migrate to Carletonville from all over southern Africa. Solomon and Nokuzola joined forces with epidemiologists and scientists in an attempt to show that HIV can be managed and controlled. The community gave the project a name: Mothusimpilo ‘working together for health’. The project was funded primarily by the British Government, with some support from regional health authorities. It aimed to counter the attitude of nihilism that followed the neglect and denial that were the initial response to the epidemic of HIV by all sectors of South African society.

The project has two components, intervention and evaluation. The intervention aims to reduce the levels of other sexually transmitted infections (STIs) which act as co-factors for HIV transmission, and to promote the use of condoms. The evaluation is intended to show how well the intervention works by quantifying its impact on disease transmission.

With compassion and understanding, Nokuzola spent a year training sex workers in Carletonville to act as peer educators among their colleagues and their clients. She taught the women about HIV and STIs. She taught them to do role-plays and short dramas to convey their messages. They used songs to speak to the audiences that gather wherever they go. Lena was one of Nokuzola’s first recruits. One year after we met Lena, she died of meningitis.

*Health impacts of the mining industry*

At the end of the nineteenth century, the discovery of the world’s largest and richest gold reef started a process that was to transform South Africa from a rural agricultural society to one based on the extraction of minerals. The political and social consequences were profound and the tremors of that great upheaval continue to be felt in the new South Africa. Although the gold is plentiful, the ore is of low grade and, buried kilometres below ground. The big machinery used to mine metals in other countries is unsuitable for the Witwatersrand seams, which are narrow and rise and fall steeply underground. So every day three hundred thousand men descend to loosen the ore with drills and dynamite, then scrape it down the falling slopes into hoppers that carry it back to the surface. For

every ounce of gold five tons of ore is taken from the ground, and for every ton of ore a hundred tons of air is pumped through the mine so that men can breathe.

In the early days it was not easy to persuade rural men to leave their land and their families; in 1912 the Chairman of the Chamber of Mines explained "he [the native] cares nothing if industries pine for want of labour when his crops and home brewed drink are plentiful" (3). Over the years punitive hut taxes and land wars persuaded men to leave their homes and families and come to Egoli: Johannesburg, the City of Gold. In the 1940s, the Apartheid government needed to ensure the continuity of the labour supply while keeping men away from the bright lights of the city. The Chamber of Mines was instrumental in writing and developing the pass laws that defined the nature of South African society for so many years. The pass laws have gone, but the light of democracy has yet to penetrate the stopes and tunnels of the gold mines.

Mining is dangerous work: men die when the rocks burst, develop silicosis from breathing the dust, and the incidence of tuberculosis among them is one thousand times higher than it is in Europe. If they return home, it is often with broken and diseased bodies. The 1980s brought the portents of an epidemic that poses yet another threat to miners' health. First diagnosed in American gay men, then in Haitians and haemophiliacs, AIDS appeared in East Africa with a focus in Uganda. Researchers moved fast. The HIV virus was identified, its routes of transmission clarified, and its epidemiology quickly understood. But in Africa the epidemic spread and infections multiplied. As viruses go, HIV is relatively inefficient: it spreads slowly and kills slowly. But it kills with near certainty. Factors that promote HIV infection include migration, high rates of other STIs, social unrest and the breakdown of social structures. The list reads like a description of conditions in South Africa, which now has the highest rate of new infections in the world.

*Going underground, and going after women*

Charlene, a social scientist, spoke to miners so that we might better understand their lives. A man told her "Every time you go underground you wear a lamp on your head. Once you take on that lamp you know that you are wearing death. Where you are going you are not sure whether you will come back to the surface alive or dead." And another: "The dangers and risks of the job we are doing are such that no one can afford to be motivated with life so the only thing that motivates us is pleasure." A third: "There are two things to being a man: going underground, and going after women".

Living in single sex hostels for much of their adult lives, far away from their families, mine workers seek sex with multiple partners to affirm the masculinity that sustains them underground. Nyama-ya-nyama (flesh-to-flesh) heightens intimacy and pleasure, so the men are reluctant to use condoms and HIV is passed from men to women and back again, from men to their wives in distant rural areas, from women to others living in Carletonville and so to young people who will never grow old.

In Carletonville, as in many other places in South Africa, one in four adults are already infected. For every two men that are infected, three women are infected. Here the disease is spread most frequently through heterosexual contact, although many gay men were already infected and many died. But in a country where people enjoy greater wealth, have better services, and possess more skills than any other country in Africa, the initial response to the epidemic was imperceptible. Within five years, half-a-million South Africans will die annually from AIDS-related diseases, one million children will have been orphaned, life expectancy will have fallen by twenty years, and three-quarters of our hospital beds will be occupied by people with HIV. Many of the gains so painfully won in 1994 will be lost.

The experience of Thailand shows that with commitment, resources, and imagination, ways can be found to manage the epidemic. The experience of Uganda shows that it is never too late to significantly reduce the spread of HIV/AIDS. Those who study epidemiology tell us that each person who contracts HIV will, on average, infect only seven other people in his or her lifetime so that if transmission can be reduced by seven times, the epidemic will go into decline.

*The Mothusimpilo project*

The Mothusimpilo project was an attempt to show that in South Africa too, the epidemic can be tamed. The most immediate need is to reduce the levels of other STIs. In Carletonville one in four adults have syphilis, gonorrhoea or chlamydia. Robert, an authority on STIs runs a clinic for one of the mining houses in Carletonville. He notes wryly that he sees more gonorrhoea in one week in Carletonville than is seen in Scandinavia in a year. While these other diseases greatly increase the transmission of HIV they can be treated with modern antibiotics. Where infection rates have been reduced among sex workers, rates have also

fallen among mine workers. But victory can be transient, and there is an increase in Herpes simplex Type 2, a viral STI that can be treated symptomatically but not cured. Herpes amplifies HIV transmission.

In the medium term, ways have to be found to ensure that people use condoms when they have sex. Changing peoples' behaviour is never easy, all the more so when it involves the most sensitive and intimate aspect of their lives. Lena's friends know that seven out of ten of them are already HIV positive. Because Nokuzola taught them about HIV and STIs, they understood fully what that meant. Their response "Some of us will die but we must protect the others. Everyone must use condoms." Their hard lives had not robbed the women of compassion, but the high stakes make them intolerant of breaches in this code of conduct. Women who don't use condoms could be threatened or beaten by their peers.

The sense of solidarity and the harsh discipline seem to have worked, and attitudes among both the sex workers and their clients were changing. Fewer men demanded sex without condoms, and fewer women allowed it. Lena told us that before the project started "For example, I will take a man for maybe twenty Rand with condom and you take a man thirty Rand without condom." For one dollar more a woman would gratify a man's desire for "flesh-to-flesh" and risk her life. Later she said "sometimes I get more customers because I use condom on twenty Rand and that one is taking on a high money, the high money you can't get the profit at a high speed rate. But then right now I think we are facing great changes. People, there under the trees, just waiting there, and when I look at them they just show me the condom. I know that one, that one wants the job."

On World AIDS Day, last year Nokuzola and her team took to the streets of Carletonville, accompanied by a township Michael Jackson who mimed condom use with enthusiasm and a lascivious grin. The songs and play-acting were imbued with a characteristic and hardy spirit that may yet prevail in the fight against HIV/AIDS. The women distributed condoms as they marched through town singing "No matter what/the people say/the condom is/the Number One". Although their profession is not legal they have a police escort, a delicious irony that is lost on no one. Traditional healers in extravagant dress, some with condoms tucked into their headbands say "Listen" and the people around them do.

It took two years to raise enough money from the United Kingdom to support the Mothusimpilo project, during which time a million more South Africans became infected with HIV. The South African government remains slow to mobilise, perhaps because its health service, distorted by the years of Apartheid, provides some of the best tertiary health care and some of the worst primary health care in the world. The mining industry is still locked into an ideology in which the long-term costs of chronic diseases are externalised and borne by the families from which the men come. The trade unions are fighting fires as they try to protect jobs while unemployment runs at about thirty percent and the country struggles to compete in uncertain world markets. Nonetheless, epidemiologists know that the trajectory of an epidemic is best blocked early, and that each Rand invested in prevention now will save many more Rands in years to come.

Yet South African health policy-makers still prevaricate while South Africans remain uninformed and ignorant, and the World Health Organisation and the United Nations AIDS Programme watch aghast at the progress of our epidemic. Margaret, who runs an STI clinic in a run-down, inner-city suburb of Johannesburg, observes: "It is a very curious fact that the national AIDS plan is recognised world-wide as one of the best. …it was accepted by the new cabinet in 1994 and since then virtually none of it has been implemented. …we have been planning since 1992 for this epidemic …we're endlessly planning, we must be the most over-planned AIDS programme pretty much in the world. … there has to be a move away from lip service". When asked "what is the Health Department doing to mobilise communities?" the Minister of Health answers: "I don't think it is an appropriate question to ask the Health Department, I think we should say what is the country doing to mobilise against this campaign. And secondly, you should be asking what is the government doing, not the Health Department AIDS is really not a health issue. It's only a health issue towards the end when people are ill and needing help. But the infection is really a social issue. It's an economic issue, so it's an issue that affects everybody."

*HIV is a public health issue*

It is difficult to understand South Africa's underwhelming response to what must surely be the greatest threat to the reconstruction of our country. The abolition of Apartheid ensured that the essential humanity, rights and privileges, which must be accorded to all as equal citizens, were recognised in law. The current South African government is now challenged to realise these rights and privileges so that the right to health is

not just an article in the constitution, but leads to the provision of access to health services and the mounting of appropriate responses to diseases such as HIV and tuberculosis. Perhaps at the heart of the inertia lies our difficulty in conceptualising HIV as a public health issue. When HIV is viewed as a disease that threatens individuals, we are easily led to regard it as an affliction of 'bad' people only: sex workers, migrants, gay men or any category of 'other' that suits our prejudice. We are tempted by extravagant theatrical productions such as Sarafina II, or miracle cures such as Virodene, which, we believe, will change individual behaviour or save individual lives. But HIV has already infected too many people for the epidemic to be dealt with in this way. If, on the other hand, we regard HIV as a public health issue, other things follow. The response must involve the education and mobilisation of communities so that accepted norms of behaviour can be redefined, we must target our efforts in ways that will minimise the spread of disease in the community as a whole, and we must work with and support those at highest risk though they be the poorest and most marginalised people in our communities.

When Lena was hospitalised with AIDS, her colleagues visited her, took her food, and washed her. Had she fallen ill before Mothusimpilo started, she would have died alone. The project made it possible to trace her parents in Zimbabwe, and Nokuzola and the other women each contributed R100 to hire a vehicle. Together they took her body back to Harare. The journey was fraught and customs officials kept them at the border for two days before a doctor could be found to sign the necessary papers. Nokuzola said "Listen girls, Lena's family do not know what she was doing for a living, so while we are in Harare there will be no drinking and no working". Everyone behaved well, and Lena's elderly father was saddened but moved that the daughter he had not seen for six years had at last come home. They told him that she died of meningitis. Lena had been a role model to her sister Angie. Lena had encouraged Angie to work hard, to finish school, to get a good education. Angie told Nokuzola that she is about to go to America on a Fulbright scholarship.

We hope that the Carletonville project will help both to inform government policy on managing HIV/AIDS and to provide lessons for projects elsewhere. Our focus has chanced upon a particular mining town. Carletonville may be a 'hot-spot' now, but HIV infection rates there mirror those that will surely follow in other South African communities if we do not find ways to manage the epidemic. Having lost friends and colleagues, we feel the first breezes of the gathering storm. One day our children will know whether we rose to the challenge or turned away.

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