



Hope on the Horizon

HIV IN SOUTH AFRICA

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World AIDS Day is on 1 December and for many in the West, it is marked by little more than calls for 'action' by politicians and international aid organisations. By 2 December, life returns to normal and the issue is placed again on the back burner until the next year. For others around the world, especially those in Africa, AIDS is more than just a single-day event. Fewer and fewer people on the continent remain untouched by the illness, having lost family and friends over the years to a disease that is entirely preventable and treatable. For them, 1 December is an occasion to remember those who have been lost and as a reminder of the importance of swift and strong action to ensure that AIDS' future in Africa is a short one.

In the beginning...

Human Immunodeficiency Virus (HIV) spreads through the exchange of bodily fluid, chiefly during sexual intercourse or if using unsterilised injecting equipment. The virus can remain dormant in the human body for a number of years, but if left untreated, it begins to compromise the immune system, leaving the body defenceless against what are known as opportunistic infections: tuberculosis, meningitis, cancer, influenza and a host of others, all of which are deadly for an HIV-infected person.

HIV made its first appearance among humans in Central Africa during the 1950s. Although there has been heated debate about the scientific origins of the virus, it is now generally agreed that HIV was originally a primate disease, but transferred to human population as a result of the consumption of monkeys by certain isolated communities within the Great Lakes region of Africa. At first, HIV could not be passed from human to

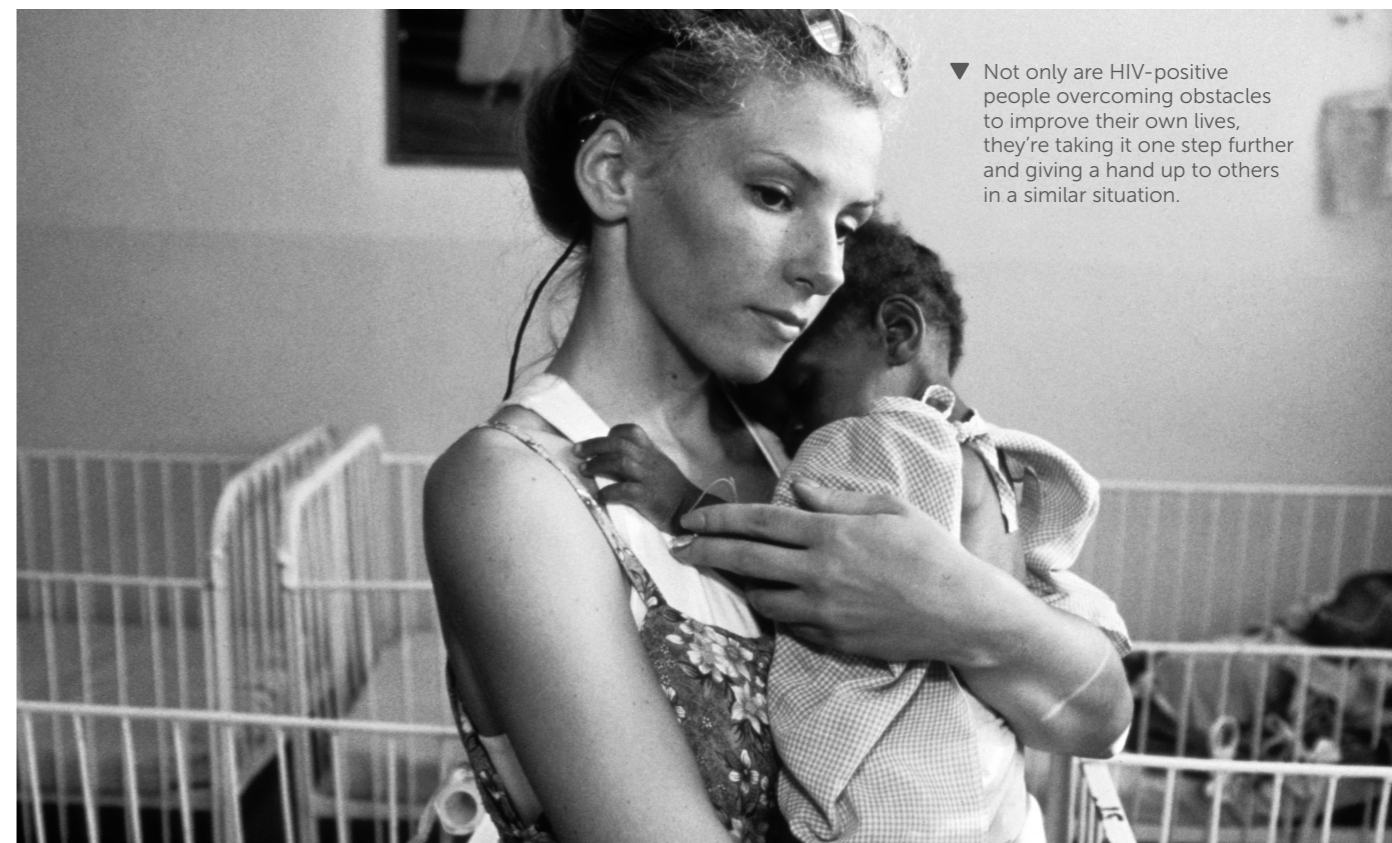
human, but the virus began to mutate as thousands came in contact with infected blood through the unsanitary mass-immunisation campaigns taking place across the continent during the 1960s and 1970s. Before long, HIV had evolved into its current form and was spreading with frightening ease through the sexual networks of central Africa and travelling with transport workers east and south into the informal settlements and refugee camps of Kenya and the mining communities of South Africa.

South Africa's first medically recorded case of HIV surfaced in 1983, but doctors didn't initially appreciate or understand what this would mean for the history of their country and ultimately the entire continent. HIV was, at this time, almost exclusively restricted to the black-dominated townships of Cape Town and Johannesburg, therefore the disease barely registered on the radar of the apartheid government and many white South Africans still associated it with the

American gay community, where the HIV virus received its first media coverage, rather than as a South African issue. Due to this intentional ignorance, the virus was able to spread virtually unabated and undetected throughout the entire region of southern Africa.

Lacking leadership

By 1995, when the newly-elected ANC government began to collect information on HIV prevalence rates, almost 11% of the population was found to be infected and a national pandemic was declared. Although the ANC drew the majority of its supporters from the communities most affected by AIDS, its policy towards the issue was surprisingly deficient. When asked about why he failed to act strongly on the issue of HIV during his time, as leader of the ANC and president of South Africa, Nelson Mandela was quoted as saying, 'I wanted to win and I didn't talk about AIDS,' and then 'had not the time to concentrate on the issue,' after being elected. This lack of action allowed the



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infection rate to spiral out of control, reaching five and a half million people, or just under 20% of the population, by 2005, a level at which it has stayed since.

Although the Mandela administration could be accused of neglecting the HIV epidemic, the South African government under Thabo Mbeki would do far worse than ignore it. They would actively, if unintentionally, make it worse. Mbeki based many of his policy decisions on the work of American scientist Peter Duesberg. Duesberg belonged to a group of academics known as 'AIDS denialists', who believed that the HIV virus did not cause AIDS and, furthermore, that deaths attributed to AIDS in Africa were mostly misdiagnoses. Other 'AIDS denialists' would build on these ideas, some going so far as to claim that the American government was responsible for introducing HIV into Africa in an effort to curb population growth on the continent. As ridiculous as these claims may seem, in the absence of any widespread education about the reality of the HIV epidemic in South Africa, many people were not in a position to distinguish truth from lies.

As a result of the accompanying epidemic of misinformation, few people bothered to get tested for HIV and those who knew

their status failed to take proper protection or attempted to treat their infection with herbal remedies or traditional medicine that proved woefully ineffective. Government policy concerning AIDS has improved slightly under Jacob Zuma, but his notorious comments about taking a shower to 'wash off' the HIV virus show that even the president of South Africa does not have access to the accurate information that could save thousands, if not millions, of lives.

Given the South African government's history with HIV, it is unsurprising that the nation now has the worst HIV epidemic in the world. There are 69% of adults who say that they have taken an HIV test, but 20% of those are not interested in knowing the results and 48% would not disclose the result to family or friends if they knew it. Around 28% of young adults did not use protection the last time they engaged in 'high-risk' intercourse, or, unprotected sex. Over half of all orphans in South Africa today have lost their parents to AIDS.

Picking up the pieces in Khayelitsha

Since the government has built themselves a reputation of unreliability, the burden of education, prevention and provision of

treatment has fallen on the shoulders of non-governmental organisations, one of the oldest and most established being the Treatment Action Campaign (TAC). Founded in 2000, the organisation was created with the intention of advocating for the rights of HIV-positive people, especially in terms of access to treatment and preventing discrimination.

Mary-Jane Matsolo, TAC's policy communication and research coordinator, spoke to me from her office in Khayelitsha about the importance of her organisation's work in the impoverished neighbourhoods of Cape Town. According to Matsolo, one of TAC's main goals is to raise awareness about HIV and prove to the community that those who are HIV-positive are just as deserving of respect and dignity as anyone else. They have also branched out to handle domestic abuse and gender equality as well. Currently in Khayelitsha, TAC is partnering closely with Medicines Sans Frontiers (MSF) to train Treatment Literacy Practitioners (TLPs) who then go out to public clinics to teach the staff about how to educate their clients about the prevention of mother-to-child transmission of the HIV virus, the proper use of condoms, and the extreme importance of correct usage of anti-retroviral medication.



▲ Rights and Life-skills education co-ordinator Ronnie Ngalo, from the organisation Molo Songololo, teaches youth in Khayelitsha about HIV; 21% of people here are HIV-positive.

TAC also sponsors a team of Community Health Advocates (CHA) who walk down the streets of townships like Khayelitsha, knocking on doors distributing condoms and talking with people about their right as South African citizens to access treatment for HIV. Through the CHA programme, Mary Jane says that TAC has been able to reach thousands of people, providing accurate information and education to 75% of Khayelitsha's population. Matsolo explained that, at first, many people were sceptical about hearing what TAC had to say, partly because of all the misinformation floating around and partly because they were hesitant to place their trust in the organisation when they had been let down by others so many times before. Over time, however, TAC's impeccable record of following through with the cases they take on has given them a reputation for accountability and reliability.

The endemic poverty in townships like Khayelitsha makes TAC's job even more difficult, says Matsolo. HIV-positive people (especially those who are not on treatment) are more prone to contracting infections and will suffer more acutely from them than someone who is HIV-negative. The lack of proper sewage systems, easy access to clean water, and ventilation within homes – combined with horribly crowded conditions – means that informal settlements are breeding grounds for the types of bacteria, which can be lethal for those with compromised immune systems. Extreme poverty also curtails access to proper education, meaning that there are few channels that organisations like TAC can use to distribute the information about HIV/AIDS, which has the potential to save lives.

TAC has a history of strong opposition to the South African government, especially in terms of their response, or lack thereof, to the epidemic ravaging their country. When asked what she thought the government's biggest failing in AIDS policy had been, Matsolo answered that it was their failure to 'recognise the scourge.' Due to the government's failure to act on the issue of HIV, TAC has been regrettably forced to expend resources, energy, and time lobbying the government to fulfil its obligations, as laid out in the constitution, to South African citizens. Along with campaigning for an increase in expenditure on HIV-related issues, TAC has been a plaintiff in a number of precedent-setting lawsuits against the government. One of the most significant ones highlighted by Matsolo was the 2008 ruling obligating the government to provide Nevirapine, the drug most commonly used to prevent HIV transmission to unborn children, for pregnant women. Without organisations like the TAC, many of Cape Town's poorest would be left without the vital information necessary to protect them against HIV infection.

More than just medication

Non-governmental organisations also spearhead some of the most significant work being done in the treatment of HIV/AIDS as well. Dr Paul Roux – paediatrician, professor at the University of Cape Town, and co-founder of Paediatric AIDS Treatment for Africa (PATA) and the Kidzpositive Family Fund – spoke to me from his office at Groote Schuur Hospital in Cape Town about his work improving the quality of treatment for HIV-positive children both in South Africa and around the continent.



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Dr Roux worked as a general paediatrician at Groote Schuur for before seeing his first case of AIDS in a child in 1998. He said that at first doctors would spend hours with each HIV-positive child, but as the numbers began to increase the doctors became overwhelmed. Now at any given time, 25% of children on Dr Roux's ward are suffering from an HIV-related illness. During the first years of the epidemic, the children would often arrive on the ward in very poor condition: malnourished, and with any number of opportunistic infections. The older children and teenagers were often worse-off than the babies as they had gone longer without treatment. Since 2003, with the help of international donors, Dr Roux has been able to provide ARV treatment for the children on his ward and things are improving, slowly but surely.

Despite the fact that the South African government finally instituted the extremely belated ARV roll-out in 2004, the standard of care in most hospitals is still lacking in many respects. Almost all of Dr Roux's patients who have transferred out of Groote Schuur have come back, complaining about the treatment they were receiving elsewhere: exorbitant wait times, unfriendly doctors, and lack of treatment continuity. At Groote Schuur, they do things differently. Their treatment approach, sponsored by Kidzpositive, is known as G25 'Ways of Caring'. On ward G25, they work towards a 'comprehensive' treatment model where patients can develop a strong relationship with a team of health care practitioners who stay with their case the whole way through.

There is also a seven-day-a-week, 24-hour open door policy on the ward. This is an extremely important part of effective care for HIV-positive people not confined to a hospital ward, especially those living in extreme poverty. For those lucky enough to have a job, they are often forced to choose between standing in line for hours to collect life-saving drugs and going to work. The G25 model prevents their HIV status from defining the structure of their life, which is important for financial reasons, but also in terms of maintaining personal independence and dignity.

As a result of operating separately from the government, NGOs have a much greater degree of freedom in that they can experiment with concepts and initiatives that would not potentially be feasible on a larger scale. For instance, one of PATA's foundational concepts was an annual conference, the 'PATA Forum' in which doctors, nurses, counsellors, community practitioners and experts from over 20 different African nations meet and exchange stories and ideas.

Dr Roux is very enthusiastic about the benefits of taking a multinational approach, both in terms of what community practitioners can learn from experts and what experts can learn from those working on the ground. Doctors speaking at a PATA Forum were able to educate community workers about the advances made in the prevention of mother-to-child transmission of HIV, while community workers from the Eastern Cape were able to help doctors at Groote Schuur hospital set up a home visit programme for their clients.

What comes next?

Organisations like TAC, Kidzpositive, PATA, and a host of others are making progress every day in Cape Town and all around South Africa and it is because of them that South Africans and the world at large can see a light at the end of the tunnel in the fight against HIV. Even though their line of work can be infuriating, frustrating and terribly sad, both Matsolo and Dr Roux relish the opportunity to speak about hope. Their experiences have been very different, and their ideas about successes reflect that, but both speak about the extreme resilience of the human spirit in the face of adversity.

When asked about his biggest success since beginning work with HIV patients, Dr Roux replied without hesitation that it was the fact that 75% of teenagers currently being treated by his organisation have remained on first-line antiretroviral treatment. He has helped these young adults to overcome the massive hurdles of poverty and stigma, enabling them to flawlessly adhere to their treatment regimen, thus giving them the opportunity to live much longer, much healthier lives.

Not only are HIV-positive people overcoming obstacles to improve their own lives, they're taking it one step further and giving a hand up to others in a similar situation. For Matsolo, this is the most rewarding part of her work.

'My number one success,' she said, 'is the people who come to this organisation basically one foot in the grave and the other one just clinching on to life and they came to the organisation and they learned and they sucked everything that we taught them like a sponge and now they are living it. They've managed to turn their lives around... and they are going out there and sharing their personal life stories and helping a total stranger.'

Every year, on 1 December, people around the world need to stand up and speak out about what is arguably the single most pressing issue to face the continent of Africa in the last fifty years. HIV is not something that can be dismissed as 'somebody else's problem'; this disease is crippling South Africa and it is crippling the continent. There is promise on the horizon though and we may be losing the battle, but we can still win the war! ☺