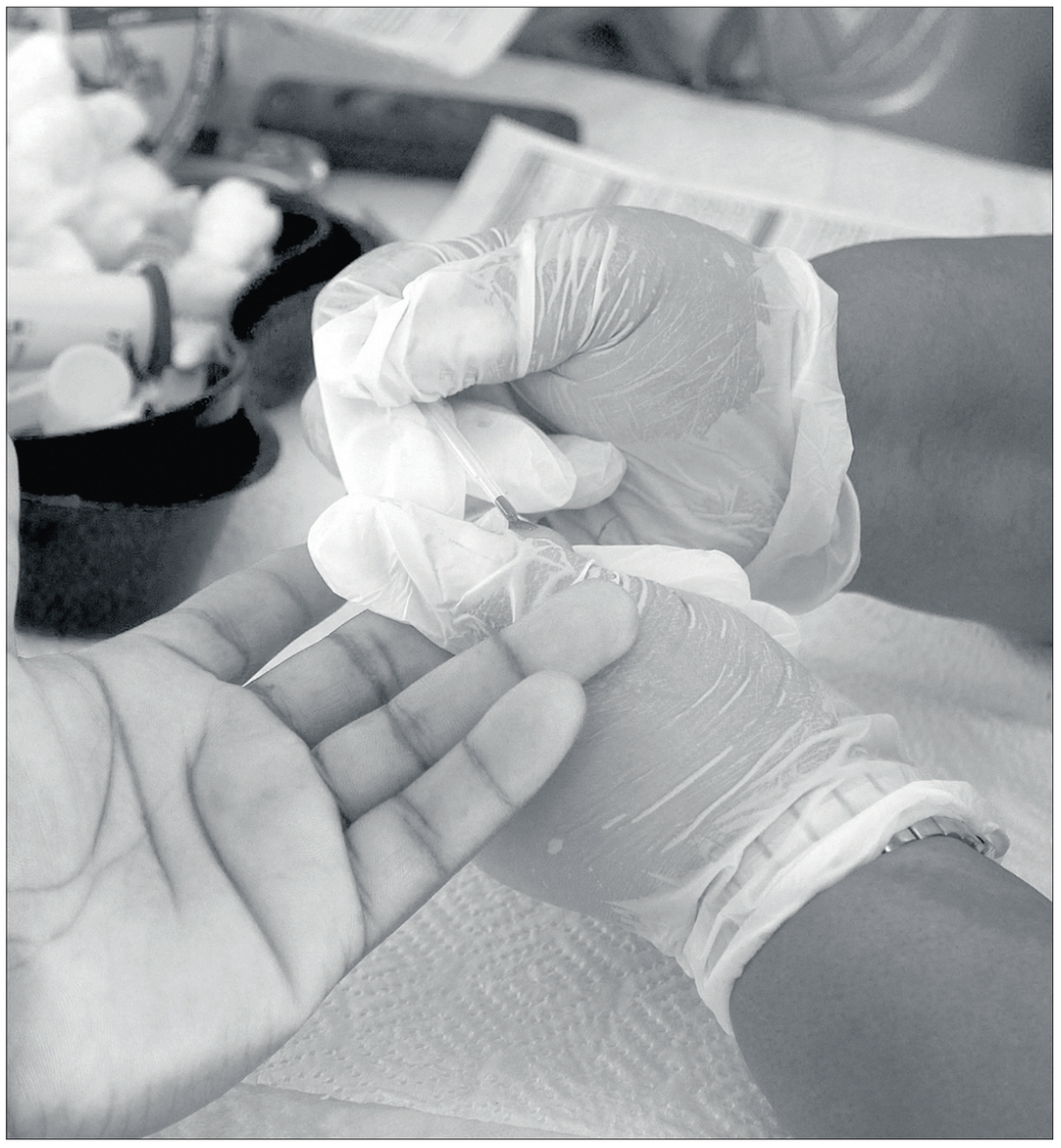
Aids gains must be maintained

There has been a great deal achieved in confronting the scourge of Aids, but there is more to do, and it is a shared responsibility, writes **Mark Cotton**



KNOW YOUR STATUS: Blood is drawn during an HIV test. PICTURE: KIM CLOETE

THE FIRST World Aids day was on December 1, 1988. Its goal was to draw attention to a new and terrifying global pandemic yet to unfold in South Africa.

At that time, I had just completed my first year as a junior specialist at Tygerberg Hospital in the Department of Paediatrics and Child Health and Stellenbosch University's Faculty of Medicine. I had returned to Cape Town after completing my paediatric training in Joburg, which included two years at Baragwanath Hospital, yet to be renamed Chris Hani Baragwanath Hospital, in Soweto.

Here I cared for two children who had acquired HIV through contaminated blood products. One of these, when in a general ward, was separated from the other children by curtains, either to protect him or everyone else from infection.

My four years of training, on reflection, prepared me for what was to come – caring for extremely ill hospitalised children from poor backgrounds. In those days, measles, a vaccine-preventable infection, was endemic. Children suddenly became very ill and many died quickly; others survived, but with damaged lungs. Tuberculosis and severe malnutrition were common.

At Tygerberg, childhood TB was common and serious. Children with TB meningitis almost always were recognised too late, with serious consequences for survivors.

Research from the 1950s had shown that TB meningitis was avoidable if children from houses where adults had TB were given simple and cheap TB-prevention medicine. Already I could see how research improved daily clinical care.

We all knew that HIV would reach us, but did not know when or what to expect. As a way of tracking HIV, anonymous surveys were conducted annually in public antenatal clinics in South Africa from 1990.

In this period, I moved with my family to Denver, Colorado, to learn as much as possible about infectious diseases in children, especially HIV care and science. HIV prevalence was 1.7 percent when we departed, and had increased to 7.5 percent on my return almost five years later, at the end of 1995.

By 2002, 27 percent of pregnant women had HIV. We knew from research studies that one in three babies would acquire HIV. Breast-feeding was, and remains, an essential component of child health. Yet babies escaping HIV in the uterus or in the birth canal could acquire the virus through the very substance meant to ensure survival.

We did what we could, despite feeling helpless as critically sick children filled our wards. Some died quickly, while others recovered and came back again. We watched as their growth faltered. Parents often died and others filled in.

We looked for and treated TB in case it was present, and sometimes it was. We were just learning how TB and HIV could exacerbate each other. Both conditions affect the lungs and thrive on their failure. Sometimes we were right, and the children would get better for a while.

The early years were a struggle for more testing, antiretrovirals (ARVs) and infrastructure. Civil society was responding. The undue cost of medications entered the public domain. The 2000 Aids conference in Durban was pivotal. For the first time, it was realised that cost should not be an impediment for life-saving medications. Cost structures could no longer be hidden. Production expenses alone could define cost. There were no HIV clinics, as well as no treatment and, apart from condoms, no prevention.

From 2002, antenatal testing and prevention of parent-to-child transmission programmes were slowly introduced. The scale of the task was immense.

Consider the implications of a positive test in 2002: effective combination therapy was too expensive, so a positive test did not translate into life-saving care. HIV was linked to acts of intimacy with loved partners. The virus could reach the baby even before birth and, once born, through nurturing the child by breast-feeding.

Yet hundreds of thousands of pregnant women needed to be tested and helped to understand what this meant in a busy clinic where time and space were in short supply.

We were only starting to understand the implications of HIV in children. Although we had cared for extremely ill children before, by 2004 we learned that at least half of all infants acquiring HIV would be dead by two years of age.

Combination ARV therapy became available for all. We could measure CD4 counts and viral loads. A rapid HIV test was now available for adults, giving an answer within minutes.

We also knew that adherence to therapy was fundamental for success. Not a single dose could be missed. Could one sustain this rigour on a daily basis for the rest of one's life? Could a mother treat herself and her child every day? What about disclosure? When should one disclose to one's child or one's partner? Was it worth the risk?

Where are we today? We have collectively achieved a great deal. Mother-to-child transmission has been reduced from 30 percent to 2 percent. Effective medicines are available at a reasonable cost and funded by the Department of Health. Most important, more than 2 million South Africans are receiving treatment and living productive lives. Awareness of TB co-infection has increased, and at last infant and adult mortality are declining significantly. We can now focus on improving quality of life.

This progress has resulted from concerted engagement and can just as easily reverse. Despite reductions in infant HIV infection, we still initiate 10 newly diagnosed sick infants on ARVs every month.

HIV can develop resistance quite rapidly, especially when adherence wanes. We can run out of options. Second- and third-line medications are more expensive. Resistance testing, to help guide choice, is expensive and usually unavailable in the public sector.

For children, drug formulations are inadequate and choices even more limited. One cannot extrapolate dosages from adults to children; instead, drug levels need to be studied in children of all ages. One cannot even extrapolate from a term newborn infant weighing 3kg to a pre-term infant weighing less than 1kg.

We have seen the emergence of untreatable bacterial infections and extensively resistant untreatable TB. The same can happen for HIV if infrastructures unravel and gains are not maintained.

The role of civil society cannot be underestimated. In a shocking report just released ("Stockouts in South Africa – A National Crisis"), ARV and anti-TB stockouts occur frequently in South Africa.

HIV has stigma. Fear to disclose one's status impacts on adherence and affects relationships.

More and more children with perinatally acquired HIV are reaching adolescence. This branch of medicine is under-served. Few clinics are geared for these young people. In hospitals, sick adolescents are placed in wards with adults of all ages.

Medical issues, such as better drugs and tests, are relatively easy compared with influencing human behaviour. What drives individual choice, and how can you influence this process?

We know that HIV is adaptable, but so are approaches to understanding and combating its effects. Occasionally there are breakthroughs, such as the identification of the virus and its structure, the development of reliable diagnostic tests, and documenting that combination therapy can suppress viral replication to undetectable levels. Very often, progress is slow and incremental. Where answers are unclear, clinical trials are helpful to compare strategies. These can require significant infrastructure, and are expensive. Providing good data to inform practice is essential.

One example is our own contribution through the Comprehensive International Research Programme for Research in Aids, an initiative from the National Institutes of Allergy and Infectious Diseases in the US to foster "within-country" capacity for clinical research.

With colleagues from the Perinatal HIV Research Unit in Soweto and experts from the Clinical Trial Unit of the Medical Research Council in London, we could show that starting ARVs early was far better than the "wait and watch" strategy advocated globally at the time.

The word "cure" is now in the HIV vocabulary through two remarkable case studies. The first is the "Berlin Patient" who was cured after receiving two stem cell transplants for acute leukaemia, the donor cells selected with a variant resistant to HIV, and the second is the Mississippi baby, identified and treated by day two of her life. The latter concept also works in some adults luckily detected in the very early phases of infection. Such an approach is feasible in South Africa, and adds a new component to, and urgency for, HIV testing.

In conclusion, we can look back knowing that the HIV situation has improved – but we must also look ahead to ensure progress and maintain our gains.

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