CHAPTER 5

AIDS

fear, stigma and hope
Cape Town, South Africa, 1999. “I was 18 when I first became pregnant.” Nokhwezi Hoboyi’s voice quavers as she recalls events of a decade ago. She went to a doctor in the South African township where she was living. “The doctor told me that I had ‘a rare illness’, she says.

She was too afraid to ask for more details, and the doctor did not elaborate. Later on, she gave birth to a boy, Bulelani. But her excitement about motherhood turned to anguish as Bulelani became sick. He died aged six months of whooping cough. Around this time Hoboyi was diagnosed with tuberculosis but, after a six-month course of treatment, she recovered. She then became pregnant again and gave birth to a girl named Nokuzola in 2002.

AIDS

fear, stigma and hope

It wasn’t until 1996 – 15 years after the disease was first described – that a cocktail of drugs turned AIDS from a death sentence into a chronic disease. The World Health Organization has taken a leading role in getting these medicines to people who need them.
The nightmare began again. Two months after her birth, Nokuzola was diagnosed with pneumonia. This time the doctors asked Hoboyi if they could test the baby for the human immunodeficiency virus (HIV) that causes acquired immune deficiency syndrome (AIDS) (see Box 5.1 Fact file: human immunodeficiency virus or HIV). It was the first time anyone had talked to Hoboyi about the disease, which she knew was a death sentence. She agreed to the test, and Nokuzola tested positive. She was given antiretroviral drugs (ARV) but did not improve. “That was really shattering,” says Hoboyi, holding back the tears. Nokuzola was so weak she had to be put on life support. A few months later, the doctor asked for permission to switch off the machines explaining that even if Nokuzola got better she would be brain damaged. “I was so depressed, and I was on my own at that time and I just agreed,” Hoboyi says. Nokuzola died. She was four months old. By this time Hoboyi had to face the reality of her own HIV status. She went to get tested and sure enough it came back positive. “It was then that I thought about that ‘rare illness’ the doctor talked about,” she says. She had been HIV positive for at least three years and had passed the virus to her babies without realizing it.

From mother to child

About two million children under the age of 15 were living with HIV globally in 2008, while these and many millions more were being raised in households impoverished by their parents’ HIV/AIDS sickness or death. Most of these children became infected in the womb, during birth or while breastfeeding – like
Nokhwezi Hoboyi’s first two babies – but the numbers of children infected in this way dropped steadily during the first decade of the 20th century with increased provision of services to prevent pregnant women and mothers from passing HIV to their babies.

When Hoboyi first became pregnant in 1999 such services were not available in her country. Yet, HIV had been present in southern Africa for about a decade and the virus had been circulating in other parts of sub-Saharan Africa for much longer (see Box 5.2 Origins of HIV). Among the first reports of the disease in the early 1980s were from Belgium, where doctors were confronted with Congolese patients arriving with symptoms that looked distinctly like a new syndrome being reported in the USA. The Centers for Disease Control and Prevention, which monitors outbreaks of infectious diseases around the world, was notified and in 1984 a team was sent to Zaire, now the Democratic Republic of the Congo, to investigate. At the Mama Yemo Hospital in the capital, Kinshasa, alone they found 38 patients with AIDS.

Similar scenarios were developing in neighbouring Rwanda, as well as in Burundi where Dr Teguest Guerma was the head of an international medical ward in the main public hospital of the capital, Bujumbura. The official response was as alarming as the disease itself. “The national authorities seemed to think that if the problem were ignored it would go away,” recalls Teguest Guerma, of WHO’s HIV/AIDS department in Geneva.

A wall of silence prevailed. People who tried to bring the problem to attention were punished. So great was the fear of the new disease that even people suspected of doing as much were punished. “A colleague from Antwerp was accused of telling a Newsweek magazine reporter that there was AIDS in the country,” says Teguest Guerma. “Even though the man had in fact said nothing, he was removed from the country within 24 hours. Meanwhile I was caring for people who were dying of AIDS every day.”

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**Box 5.2. Origins of HIV**

Most researchers believe that the human immunodeficiency virus (HIV) was originally derived from a virus infection of chimpanzees that passed to humans in the early decades of the 20th century, somewhere in West or Central Africa. Nobody knows quite how this happened, but scientists believe that, after hunting monkeys, humans may have become infected with an ape virus when eating or butchering their catch. Once it entered humans, the virus is thought to have mutated into what we now know as HIV.

But the pandemic probably only got started once people infected with the virus migrated in adequate numbers to Africa’s big urban centres. It is thought that this might have happened as far back as the 1950s; in 1998 a sample of frozen blood taken from a man who died in 1959 in Kinshasa in Zaire, now the Democratic Republic of the Congo, was found to contain the virus. This is the earliest known sample of HIV.

The end-stage of infection with HIV, known as acquired immune deficiency syndrome or AIDS was not described by doctors until 1981, when they observed unusual cases of disease in homosexual men in Los Angeles, USA. A couple of years later, in 1983 and 1984, scientists at France’s Pasteur Institute and the USA’s National Cancer Institute identified HIV as the cause of AIDS.
As in other countries, people with HIV in Burundi were being stigmatized because of the disease, and were in many cases left to die. Part of this reaction was simply due to fear. In the early years of the epidemic, people did not know how HIV was transmitted or how infectious it was. “Even the hospital staff would not come near the AIDS patients,” remembers Teguest Guerma, who was left to feed and clean patients single-handed.

While AIDS was starting to spread in Burundi, it was already a full-blown epidemic in Uganda. As early as the mid-1980s, the global focus of the pandemic was shifting to this eastern African state, where people spoke of a new disease they called ‘slim’.

One person who witnessed the Ugandan epidemic firsthand was Noerine Kaleeba, a forthright woman who ran the school of physiotherapy at Mulago Hospital in Kampala. Kaleeba’s husband, Christopher, became infected with HIV after receiving a blood transfusion in Uganda, but the first time he knew anything was wrong was during a stay in the United Kingdom in the summer of 1986. Kaleeba heard that Christopher had been diagnosed HIV positive and was very ill and flew there to be with him. Then when she heard that WHO had appointed someone to head up the first global programme on AIDS, she left her dying husband on a desperate impulse to go to the headquarters office in Geneva and get the cure.

Looming pandemic

In 1986, WHO took centre stage in the global battle against HIV/AIDS. At a news conference in November that year, WHO’s director-general, Dr Halfdan Mahler, warned of the looming global pandemic and acknowledged that “we stand nakedly in front of a very serious pandemic as mortal as any pandemic there ever has been” (see Box 5.3 Epidemic or pandemic?).

Admitting that WHO had not taken the disease seriously enough, Mahler said the Organization was now committed to combating the epidemic – one
that was “knocking unpleasantly on the doors of Asia” and had infected nearly eight million people, although at the time it was believed to be more than 10 million. Calling for an anti-AIDS effort, at the core of which would be science-based policies and strategies for combating the disease, Mahler insisted that there be a strong emphasis on educational campaigns. The programme was to focus on creating an international network among scientists to share information, and promote research into drugs, vaccines and other therapeutic and preventive health measures.

To head the programme, Mahler appointed Dr Jonathan Mann, who had first encountered the reality of AIDS in Zaire in 1984 (Photo 5.1). Mann was given a budget of US$ 5 million a year and an office at WHO’s headquarters in Geneva. It was into this cluttered office that Kaleeba walked in 1986. She was told by Mann’s secretary that without an appointment she could not see him, at which Kaleeba burst into tears. It was at that moment that Mann walked in.

For the next four hours Mann talked with her. There was, he said, probably nothing he could do for her husband, but her country was a different matter. He urged her to return and fight the prejudice, the ignorance and denial that had become attached to this disease.

Kaleeba returned to Uganda in 1987 where she established the AIDS Support Organization (TASO) and found a powerful ally in the country’s new president, Yoweri Museveni. Unlike many heads of state before and since, Museveni tackled AIDS head on, speaking frankly about the causes and calling for compassion. The government developed a strategy to combat AIDS — A B C or ‘Abstinence, Be faithful to your partner, but if you can’t manage the other two, use a Condom’. There was humour in it. There was humanity. TASO groups took the word into remote areas, even performing plays to demonstrate the importance of safe sex for people who were illiterate. Later, TASO activists were key in helping to roll-out treatment across the whole country, one of the first sub-Saharan African countries to attempt this (Photo 5.2).

Similar programmes were repeated elsewhere, notably in Thailand, where the virus had started to spread in the mid-1980s. Fuelled partly by Bangkok’s sex trade, Thailand’s epidemic was also fed by a large population of injecting drug users, most of them in prison. The virus spread fast in 1987 when 37 000 prisoners were granted an amnesty and released. The infection spread through sexual contact as well as exposure to blood or blood products, injecting drug-use and mother-to-child transmission.
The country’s prime minister in 1991, Anand Panyarachun, appointed Dr Mechai Viravaidya to tackle the epidemic. Viravaidya had been promoting the use of condoms since the 1970s for family planning purposes and had gained the nickname ‘Mr Condom’ for his promotional activities that included condom-blowing contests for children. Viravaidya directed radio and television networks to run a half minute of AIDS education spots for every hour of broadcast (Photo 5.3). There was also an education campaign, largely targeted at sex workers. Condoms were distributed free to every brothel in Thailand on the understanding that any brothel not using them would be shut down (Photo 5.4). The campaign produced dramatic results, reducing HIV infection among sex workers by around 90% over the following decade. Thailand proved that a targeted information campaign, backed by a supply of condoms, was a powerful weapon against HIV.

Fighting the stigma

At WHO’s Geneva headquarters, Mann realized that effective treatment for HIV would only be part of the solution to the epidemic. He saw AIDS as a social issue as much as a medical one (Photo 5.5). Like no other disease, AIDS provoked the strongest reactions, and led to the worst injustices of stigmatization and exclusion. For these reasons, he put the greatest emphasis on the human rights aspects of the pandemic.
Organizing a series of meetings at WHO, Mann succeeded in creating a consensus among global AIDS experts against the compulsory testing for HIV, and above all against the exclusion of people with HIV from employment. He also lobbied for their right to be insured, and to be able to travel, bringing in human rights activists to support his cause. No one was to be excluded because – as he told the World AIDS Summit in London in 1988: “Silence, exclusion and isolation – of individuals, groups, or nations – create a danger for us all.”

Mann went on to create the WHO Global Programme on AIDS, which became one of the largest programmes in the Organization’s history. “He was so charismatic and inspiring that people who listened to him were easily persuaded to follow his ideas,” remembers Teguest Guerma. Within four years of Mann entering that narrow cluttered office at WHO’s Geneva headquarters, the Global Programme employed 280 people, and commanded an annual budget of US$ 109 million. In WHO terms, it was very big. But then so was the challenge.

Indeed, 1987 ended with the pandemic being debated on the floor of the United Nations General Assembly, where it devoted a whole session to the disease. As a result, the General Assembly committed to mobilizing resources worldwide in the struggle that was to be led by WHO.

The pandemic had been doubling each year since the beginning of the decade, and by the end of 1987 was already affecting between five and 10 million people. The decade closed with reports of the first home-grown HIV cases in China.

It was at this crucial juncture that WHO faltered. In 1990, Mann resigned. Some saw his resignation as a protest against the failure of the United Nations and governments worldwide to respond adequately to the pandemic, others cited personal reasons. Mann’s departure marked the beginning of the end for the Global Programme on AIDS. But even without his departure, WHO’s response to the challenge posed by HIV needed to be examined. “Despite the success of the Global Programme on AIDS, there were some criticisms,” says Dr Kevin De Cock, former director of WHO’s Department of HIV/AIDS. “Some felt, for example, that coordination with other United Nations agencies, who all had their role to play, was less than ideal.”

The reality was that after almost a decade of coping with the pandemic, the needs of affected countries had become greater than any one agency could handle. “There were other agencies within the United Nations who had
developed or were developing programmes relating to their particular mandates,” says Dr Andrew Ball, WHO senior strategy and operations adviser with the HIV/AIDS Department. “This was notably the case with the United Nations Development Programme (UNDP), which had a clear development agenda, along with the United Nations Children’s Fund (UNICEF) with its commitment to children and maternal issues. “AIDS needed a response that went beyond the challenges faced by the health sector,” says De Cock. “In some places it was a development issue, an issue of poverty. There was a lot of pressure to develop a multi-sectoral response.”

That pressure culminated in the establishment of the Joint United Nations Programme on HIV/AIDS (UNAIDS) in 1996. Headed by Dr Peter Piot – who had studied some of the first AIDS cases in central Africa when he was working in Belgium in the early 1980s – UNAIDS yoked together six agencies belonging to or affiliated with the United Nations system. Its mandate was to coordinate all of the AIDS efforts.

With UNAIDS now in the driving seat, WHO’s role in AIDS control became less clear. Geneva-based staff who had worked in the WHO Global Programme on AIDS under Mann were either released or reassigned to UNAIDS. “It took several years for governments to sort all that out,” recalls Ball, who joined WHO in 1991. “We really had very little presence for a time.” De Cock puts it more bluntly, “It does seem that when UNAIDS was established WHO got out of the (AIDS) business.”

Meanwhile, the global picture of the pandemic was darkening. In 1998, at the International AIDS Conference in Geneva, UNAIDS presented the first set of authoritative surveillance numbers for the pandemic that showed that over the previous three years, while the scientific community had been congratulating itself on the advances WHO made in HIV

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**Box 5.4. Elusive vaccine**

Health workers draw a lot of hope and inspiration from the fact that, using an effective vaccine, humanity was able to completely wipe out the devastating disease of smallpox. But smallpox is still the only disease that has ever been eradicated by human efforts and finding a vaccine against HIV is a major challenge.

Why? Vaccines often work by showing the body’s immune system a part of the virus or a weakened version of it, so that the next time the body encounters it, it can react straight away. Unfortunately, two forms of HIV exist: HIV-1, which is derived from a chimpanzee virus and HIV-2, which originates from another monkey virus, that of the sooty mangabey. HIV-1 – the cause of most of the world’s HIV infections – alone has 10 different subtypes. HIV is extremely adept at rapid mutation.

An effective vaccine would, therefore, need to protect humans against a rapidly evolving and changing virus. Making a vaccine is extremely challenging when the body does not already mount an effective protective response itself to natural infection, as is the case with HIV infection, which persists for the rest of an infected person’s life. An important vaccine trial was abandoned in 2008 because it appeared to actually increase the likelihood of infection with HIV. For now, an AIDS vaccine remains a hope for the future.
treatment, HIV infection rates had doubled in 27 countries. Globally, people were becoming infected at a rate of 9000 per day.

Piot sought to engage governments worldwide, underlining the gravity of the situation and bringing economic and security considerations into discussion of the pandemic. People listened. The worsening situation in South Africa alone was sufficient to get people’s attention.

A cocktail of drugs

Meanwhile, scientists had also been working on ways to fight the virus, and by the mid-1980s the first ARV drugs had become available. In September of 1986, pharmaceutical company Burroughs Wellcome & Co. announced the results of tests which had demonstrated that Zidovudine, a drug originally developed to treat cancer, slowed the progression of the AIDS virus. For five years a diagnosis of AIDS had been a virtual death sentence. Now, finally, it could be treated (see Box 5.4 Elusive vaccine). The bad news was the price – annually around US$ 10 000 per person. Under pressure from activists, the company eventually cut the price by 20%, but it was still out of reach for people in poor countries. It later emerged that the drug caused major side-effects and the virus was developing resistance to it. However, there was a solution.

In the mid-1990s triple drug ‘cocktails’, combining different drugs including Zidovudine, emerged as a highly effective treatment. Again, the price soon put a dampener on the celebrations. The cocktail was going to cost each patient US$ 20 000 per year. But whatever the problems associated with the triple cocktail, it marked a turning point in the fight against HIV. Not only was it possible to limit new infections through educational campaigns that focused on the use of condoms (Photo 5.6), it was also possible to lengthen lives through treatment (see Box 5.5 Incurable but treatable). AIDS was now a chronic disease that could be managed with the right medication.

In some ways, South Africa was a special case. The epidemic’s explosion coincided with the transition from apartheid to a democratic system. When Nelson Mandela was released from prison in 1990 – four years before he became president – around 1% of South African adults were HIV positive, but by 2005, the epidemic peaked with an estimated 18% of people aged 15–49 years infected. Infection rates across southern Africa reached similar
levels. Moreover, it did not help that Mandela’s successor president Thabo Mbeki, cast doubt on whether AIDS was caused by HIV.

In 1999, based on the advice of people who questioned whether the virus caused AIDS – known as HIV denialists – Mbeki refused to support the procurement and provision of ARV drugs in government hospitals, even though there had long been sound scientific evidence to show that these medicines could block the majority of cases of mother-to-child transmission and could lengthen the lives of people with HIV.

At the 13th International AIDS Conference in the South African city of Durban in July 2000, Mbeki publicly questioned whether AIDS was actually caused by HIV. The response from the delegates was stunned silence and, later on, a statement called the Durban Declaration – signed by 5000 physicians and scientists at the conference – affirming that HIV was indeed the cause of AIDS.

It was also in Durban that the idea of a global fund for AIDS was first mooted by Kofi Annan, who was United Nations secretary-general at the time, and others. As Annan saw it, even with pharmaceutical companies lowering prices, ARV drugs were always going to be too expensive for the poorest nations. He proposed that a global fund be established that would buy the drugs at cost and make them available free to nations most in need.

At the African Summit on HIV/AIDS, Tuberculosis and Other Infectious Diseases in Nigeria a year later, Annan called for spending on AIDS to be increased tenfold in developing countries. He also proposed setting up “a war chest” of US$ 7 to 10 billion. That same year, global leaders came together at the United Nations General Assembly’s first-ever special session on HIV/AIDS.

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**Box 5.5. Incurable but treatable**

Once someone has been infected with HIV, they will carry the virus for the rest of their life. But although it is an incurable condition, it can be treated with antiretroviral or ARV medicines, giving patients extra years or decades of life, provided they take their ARV medicines as prescribed and drug resistance does not develop.

One of the most common definitions of AIDS – acquired immune deficiency syndrome, the disease caused by HIV – is that it occurs when someone’s CD4 count (short for cluster of differentiation) falls below 200 per microlitre of blood. CD4 cells are a part of the immune system, which the virus infects and kills. When these cells drop below that critical level, the body is almost completely unable to defend itself against other diseases.

Although the virus cannot be removed from the body, ARVs work by slowing down the replication of HIV and reducing the detectable level of HIV in the blood. That keeps the CD4 count higher for longer and thus the patient’s immune defences are stronger. That, in turn, means that the patient’s body is better able to defend itself from what are known as ‘opportunistic infections’, ones that take advantage of the HIV-positive person’s weakened immune system and ones that often contribute to his or her death. Among the most common opportunistic infections are bacterial pneumonia and tuberculosis.
AIDS. Once again the pandemic provoked an extraordinary response. The delegates committed to raising the funds Annan called for by 2005. In the end, they managed to raise US$ 8.3 billion. It was an enormous jump in funds committed to the one disease. A year later, the Global Fund to Fight AIDS, Tuberculosis and Malaria was established to provide funds to poor countries for the treatment of people with those diseases. Since then, it has attracted at least US$ 20 billion in pledges, a large part of which are for HIV/AIDS. Never has so much money been pledged in such a short space of time for one disease.

WHO’s grand plan

WHO was once again able to bring its expertise to bear on the problem of HIV/AIDS. “What really brought WHO back into a prominent position was the issue of treatment,” says De Cock. Getting essential medicines to people in remote areas was something WHO knew a lot about. Since the ground-breaking smallpox eradication campaign in the late 1950s, WHO had developed strategies to achieve precisely this kind of objective, and so drew up a plan called the ‘3 by 5’ initiative. At the time of its launch in December 2003, around 400 000 people were receiving ARV medicines in low- and middle-income countries. The Organization pledged to bring ARV drugs to three million people by the end of 2005, by advising governments of poor countries which drugs to buy and how to distribute them, training health-care workers and advising clinics on the treatment of HIV.

Critics initially lashed out saying that by concentrating on treatment, WHO was no longer interested in prevention. But WHO maintained that prevention and control went hand in hand. By the end of 2005, the programme had reached about 1.3 million people while it took two more years to reach the three million originally targeted. “If every target we set was met just two years late, the world would be a better place,” says De Cock. Meanwhile, WHO Director-General Dr Margaret Chan called it, “a remarkable achievement for public health” that proved that “with commitment and determination” people living in poor countries could be “brought back to economically and socially productive lives”.

With an unprecedented level of funding and increased commitment on the part of governments to control the pandemic, providing treatment to
people who needed it became a key focus. A response that was ultimately to benefit people like Nokhwezi Hoboyi. Antiretroviral drugs given to a woman during pregnancy and delivery, and administered to her baby following birth, can reduce the rate of mother-to-child transmission of HIV by two thirds in non-breastfeeding populations. Breastfeeding complicates the picture, with the risk of the virus being passed on in the mother’s milk. Until recently mothers with HIV infection faced a stark choice – whether to breastfeed their baby and risk infection with HIV, or avoid breastfeeding altogether and risk death from malnutrition and diarrhoeal diseases. Since 2009 WHO has recommended exclusive breastfeeding in the first six months unless safe replacement feeding was available (see Box 5.6 The HIV breastfeeding dilemma), but research published in 2009 has led to new recommendations on breastfeeding if the mother or the baby takes antiretroviral drugs to reduce the risks.

Antiretroviral drugs for pregnant women who are HIV positive have been used in some wealthy countries since the early-1990s, but it took until the end of the decade for the medicines to start to be distributed in the poorer parts of the world. Now, with help from WHO and its partners UNAIDS, UNICEF and the United States President’s Emergency Plan for AIDS Relief (PEPFAR), many countries have pledged to deliver ARV drugs to prevent transmission to at least eight in 10 pregnant women with HIV by 2010. Since its launch in 2003, PEPFAR has provided funding to buy ARV drugs that have prevented transmission of HIV from mothers to 340 000 babies. Through PEPFAR, the USA government has pledged a whacking US$ 32 billion for HIV from 2004 to 2011. The other major funder of HIV programmes is the Global Fund.
Progress has been made, particularly in southern and eastern African countries, which is where most newly-infected HIV-positive children live. In this area, the supply of ARVs to pregnant women to prevent them infecting their babies has increased more than fourfold, from one in 10 in 2004, to 4.5 in 10 by 2008.

So far, Botswana is the African country providing pregnant HIV-positive women with the best access to ARV treatment. Before its government began providing these drugs, almost four in every 10 babies exposed to HIV became infected. Now the figure is below one in 10. Rwanda, Thailand and Zambia have all had similar successes, and these countries are inspiring efforts globally since a rallying call to action by UNICEF. In 2008, more than 628,000 pregnant HIV-positive women living in low- and middle-income countries received ARV drugs to prevent them infecting their babies – a 17.5% increase on the previous year.

The picture changes

In 2004, only 9% of HIV-infected pregnant women received ARV treatment to prevent transmitting the virus to their babies. In 2008, the figure was 45%. The increase in provision of treatment to pregnant women mirrors the steady increase to more and more people with HIV who need the medicines – spurred by WHO’s 3 by 5 campaign and the contribution of partners, such as PEPFAR and the Global Fund. While the overall picture may be encouraging, there is still a great deal to be done.

Governments, NGOs and faith-based organizations say they are expanding such services, but they still only reach a limited number of women and their infants. And for the many children who do become infected with HIV, medicines are not always available and, when they are, they are rarely those designed for children. More mothers are receiving treatment to prevent HIV transmission to their babies, but the world is far short of reaching the eight mothers in every 10 ‘coverage target’ set for 2010. “Wider coverage has been hampered by the inaccessibility of some areas, a problem which is aggravated by weak health systems,” explains Teguest Guerma.

In recent years, the HIV/AIDS pandemic has not been as big as some thought it would be. In 2007, UNAIDS and WHO, estimated that 33 million
people were living with HIV – fewer than the previous estimate for 2006 of 40 million. The sharp downward revision was due to better methods of gathering figures. Those revised figures confirmed what many experts already thought: the pandemic had peaked in the late 1990s, when more than three million people were becoming infected every year.

In 2008, there were an estimated 2.7 million new infections, representing an average of 7400 new infections per day. Meanwhile, deaths from AIDS-related illnesses are declining because of ARV treatment. Meanwhile, the overall number of people living with HIV is increasing not only because of continuing new infections, but also because people with HIV are living longer (see Box 5.7 How big is the AIDS pandemic?).

Both UNAIDS and WHO believe that the number of new infections is decreasing. In 2004, AIDS was the sixth biggest killer in the world. In 2030, WHO projects that it will be in tenth place. The fact that the pandemic appears to be losing some of its momentum does not mean that the disease is about to go away. More people with HIV have the treatment they need to make this fatal, incurable disease a chronic condition for which they must take medicines every day – as people with diabetes or high blood pressure do. Meanwhile, campaigners continue to fight the stigma and discrimination that resulted in a reluctance to speak about AIDS openly, or at all particularly at the beginning.

**Box 5.7. How big is the AIDS pandemic?**

Since it first appeared AIDS has killed more than 25 million people and continues to kill around two million people a year. As of 2008, an estimated 33 million adults and children were infected worldwide – a number that is still growing.

These and many other statistics on the AIDS pandemic are estimated by WHO and UNAIDS every year. These figures are used by public health professionals and policy-makers to work out how well – or badly, as the case may be – they are responding to the disease.

Falling numbers of people living with HIV could mean two things: that more people are dying or that fewer people are becoming infected with HIV. Higher numbers of people with HIV might mean that the number of new HIV infections has increased and/or that the people who are already infected are receiving antiretroviral therapy and are living longer. However, it’s worth bearing in mind that only detailed analysis of data provided by HIV surveillance systems and programme data will bring any clarity to these issues.

Data on the number of people living with HIV are usually expressed in terms of ‘incidence’ and ‘prevalence’. Incidence is the number of people who have become newly infected by unit of time, usually expressed by year. For example, in 2008 an estimated 2.7 million people became newly infected with HIV around the world.

Prevalence reflects the number of people in a population with a disease in a given time frame, including those who already had the disease and those newly diagnosed. For example, in 2007, there were an estimated 30.8 million adults aged 15–49 years living with HIV at the global level, while in sub-Saharan Africa the number of adults aged 15–49 years infected were estimated at 20.3 million.
Healing power

It was that same silence that kept Nokhwezi Hoboyi in the dark about her HIV status. But even if she had known that the ‘mystery illness’ her doctor spoke of in 1999 was HIV, it is unlikely that she would have had access to treatment. In 1999, only some private hospitals and mining health facilities in South Africa provided ARV medicines to people with HIV and few, if any, provided these to pregnant mothers with HIV. If she had been living in a wealthy country, the preventive treatment for pregnant mothers may well have been available to her.

For Hoboyi the healing began when she was referred to the Treatment Action Campaign (TAC), a South African NGO, which was founded by AIDS activist Zackie Achmat in 1998. Achmat made headlines around the world, when, in protest at government policy on ARV drugs, he refused to take the life-saving medicines for months until in 2003 the government promised to provide ARVs to all South Africans in need.

“At TAC, I saw that I was not alone, and I met people who told me that they had been living with the virus for years,” Hoboyi says. Given new hope, Hoboyi became interested in learning more about the disease and became an AIDS activist. In 2007, she became pregnant again. This time she was able to take ARV medication and gave birth to a son by Caesarean section, whom she named Qhayiya. He was tested for HIV at six weeks.

Hoboyi wept the day the results came back. Qhayiya tested HIV negative.