The history of AIDS in Uganda

The history of AIDS in Uganda can be divided into three distinct phases.

The first stage saw the rapid spread of HIV through urban sexual networks and along major highways from its origin in the Lake Victoria region. Doctors in this area had become aware of a surge in cases of severe wasting known locally as 'slim disease', as well as a large number of fatal opportunistic infections[2]. In 1982, the first AIDS case in Uganda was diagnosed[3] and the link between 'slim disease' and AIDS was clinically recognised. It was not until 1986 when the Ugandan civil war ended and President Museveni was firmly in power that the country had a major HIV prevention programme. By this time the country was in the midst of a major epidemic, with prevalence rates of up to 29% in urban areas[4].

The programme promoted the ABC approach - abstain, be faithful, use condoms.

Uganda's first AIDS control programme was set up in 1987 to educate the public about how to avoid becoming infected with HIV. The programme promoted the ABC approach (abstain, be faithful, use condoms), ensured the safety of the blood supply and started HIV surveillance[5]. Strong political leadership and commitment to tackling the rampaging AIDS epidemic was a key feature of the early response to AIDS in Uganda.

Prevention work at grass-roots level also began in this era, with a multitude of tiny organisations educating their peers about HIV. One of the first community-based organisations formed was TASO, The AIDS Support Organization, which was run by sixteen volunteers who had been personally affected by HIV/AIDS. TASO later became the largest indigenous AIDS service organisation providing HIV/AIDS services in Uganda and Africa, providing emotional and medical support to many thousands of people who are HIV positive[6].

The second phase of the Ugandan HIV epidemic ran from 1992 to 2000. During this period the HIV prevalence fell dramatically, from a peak in 1991 of around 15% among all adults, and over 30% among pregnant women in the cities[7], to around 5% in 2001[8].

It is thought that the government's ABC prevention campaign was partly responsible for the decline in prevalence. However, as treatment was not widely available in Uganda during this time the high numbers of AIDS-related deaths also contributed to the reduction in the number of people living with HIV.

The Ugandan government's prevention initiatives continued throughout the nineties with high levels of funding from both the government and international donors such as the World Bank[9]. In 1998, the government ran a trial to test the feasibility of rolling out effective anti-AIDS treatment to people in developing countries.

Presidents George W. Bush and Yoweri Museveni

The third phase of HIV/AIDS in Uganda has seen the stabilization of prevalence during 2000-2005, and reports of a slight increase in prevalence from 2006[10].

Free antiretroviral drugs have been available in Uganda since 2004. It is thought that the availability of drugs to treat HIV may have led to complacency as AIDS is no longer an immediate death sentence; this may have contributed to the suspected rise in new HIV infections.

Many experts have also speculated that Uganda's shift in prevention policy away from ABC towards US-backed abstinence-only programmes may also be responsible for an increase in risky behavior, as comprehensive sex education and condom promotion are no longer mainstream.

Why might HIV prevalence have declined?

The number of people living with HIV in Uganda fell dramatically during the 1990s. The interesting questions are what caused this decline, whether other countries can adopt similar methods, and whether the lower rates of transmission are sustainable.

The drop in HIV prevalence in Uganda in the 1990s cannot be attributed to a single factor. It is likely to have been a result of both a fall in the number of new infections (incidence), and a rise in the number of AIDS-related deaths.

Deaths: It has been suggested that the high number of AIDS-related deaths in the 1990s may have been largely responsible for the decline in the number of people living with AIDS in Uganda during this period[11]. The reason so many people died in this decade is that there was no available treatment to delay the onset of AIDS, and high numbers of people infected with HIV in the 1980s were reaching the end of their survival period. In 2000 the Ugandan health ministry estimated that 800,000 people had died of an AIDS-related illness since the beginning of the epidemic[12].

However, the high death rate alone may not account for the significant reduction in the number of people living with HIV in Uganda. Many other countries in sub-Saharan Africa experienced similar patterns of HIV incidence and death but did not experience a similar decline in prevalence.

New infections: It is likely that the number of new HIV infections in Uganda peaked in the late 1980s, and then fell sharply until the mid 1990s. This is generally thought to have been the result of behavior changes such as increased abstinence and monogamy, a rise in the average age of first sex, a reduction in the average number of sexual partners and more frequent use of condoms[13]. Uganda's entire population was mobilized in the fight against HIV and everyone was made aware of the consequences that risky behavior could have for their country.

President Museveni encouraged input from numerous government ministries, NGOs and faith-based organizations. He relaxed controls on the media and a diversity of prevention messages spread through Uganda's churches, schools and villages.

HIV education in school, Uganda

This frank and honest discussion of the causes of HIV infection seems to have been a very important factor behind the changes in people's behavior that allowed prevalence levels to decline. Music and educational tours by popular musician Philly Lutaaya (who was the first prominent Ugandan to openly declare he was HIV positive) also spread understanding, compassion and respect for people living with HIV[14].

Much of the prevention work in Uganda occurred at grass-roots level, with a multitude of tiny organizations, often made up of people living with HIV educating their peers. These groups worked to break down the stigma associated with AIDS, and encourage a frank and honest discussion of sexual subjects that had previously been taboo.

The sheer scale of the HIV epidemic in Uganda is also thought to have been a major driver of behavior change and the reduction in the number of new infections. The epidemic was very visible: in the 1990s the majority of Ugandans knew somebody who had died from AIDS and in 1995, 91% of Ugandan men and 86% of women knew someone who was HIV positive[15]. Many villages experienced high numbers of deaths

each month, houses were standing empty, funerals were frequent and grandparents were increasingly becoming carers for their orphaned grandchildren. As anti-AIDS treatment was not yet widely available in the 1990s, many people equated AIDS with a death sentence and it is believed that fear drove a change in behaviour.

The current situation

The current HIV prevalence in Uganda is estimated to be 5.4% amongst adults[16]. According to the Uganda HIV and AIDS Sero-Behavioural Survey, the number of people living with HIV is higher in urban areas (10.1% prevalence) than rural areas (5.7%); it is also higher among women (7.5%) than men (5.0%)[17].

It is feared that HIV prevalence in Uganda may be rising again; at best it has reached a plateau where the number of new HIV infections matches the number of AIDS-related deaths. There are many theories as to why this may be happening, including the government's shift towards abstinence-based prevention programmes, and a general complacency or 'AIDS-fatigue'. It has been suggested that antiretroviral drugs have changed the perception of AIDS from a death sentence to a treatable, manageable disease; this may have reduced the fear surrounding HIV, and in turn have led to an increase in risky behaviour[18].

The impact of AIDS on Uganda

AIDS has had a devastating impact on Uganda. It has killed approximately one million people, and significantly reduced life expectancy[19]. AIDS has depleted the country's labour force, reduced agricultural output and food security, and weakened educational and health services. The large number of AIDS related deaths amongst young adults has left behind over a million orphaned children[20].

"If someone in Uganda tells you they haven't been affected by HIV/AIDS they're lying."*Jennifer Bakyawa, a Ugandan journalist*[21].

A woman and her baby in an ART Clinic waiting room at Kisiizi Hospital in Uganda

Women are particularly affected by the epidemic in Uganda, representing 59% of those infected with HIV/AIDS in the country[22]. Ugandan women tend to marry and become sexually active at a younger age than their male counterparts, and often have older and more sexually experienced partners. This (plus various biological and social factors[23]) puts young women at greater risk of infection; in fact, young women in Uganda are nine times more likely than young men to contract HIV[24].

AVERT.org has more about women and AIDS.

People living with HIV & AIDS in Uganda not only face difficulties related to treatment and management of the disease, but they also have to deal with AIDS related stigma and discrimination. Stigma and discrimination towards those affected by AIDS are visible at all levels of society from families and local communities to the government. President Museveni himself supported the policy of dismissing or not promoting members of the armed forces who test HIV positive, and in 2001 he suggested that a rival presidential candidate was unsuitable for office because he was allegedly infected with the virus. Discrimination has also been reported in the private sector, including mandatory HIV testing for new employees. As well as hurting those affected, such attitudes are a major hindrance to prevention and treatment efforts[25].

HIV prevention in Uganda

Uganda is often cited as a rare example of success in a continent facing a severe AIDS crisis. The country is seen as having implemented a well-timed and successful AIDS prevention campaign, which has been credited with helping to bring adult HIV prevalence down from around 15% in the early 1990s to around 5% in 2001[26].

Praise for Uganda's prevention efforts has waned in recent years, with particular criticism leveled at US-backed abstinence campaigns. There are indications that Uganda's HIV prevalence may once again be on the rise[27].

The approach used in Uganda has been named the **ABC** approach - firstly, encouraging sexual **A**bstinence until marriage; secondly, advising those who are sexually active to **B**e faithful to one partner; and finally, urging **C**ondom use, especially for those who have more than one sexual partner.

Abstinence

Abstinence is the most controversial area of Uganda's HIV prevention campaign. Although it has always been part of the country's prevention strategy it has come under scrutiny since 2003 following significant investment of money for abstinence-only programmes from PEPFAR, the American government's initiative to combat the global HIV/AIDS epidemic. It is felt that PEPFAR has shifted the focus of prevention in Uganda from the comprehensive ABC approach of earlier years.

PEPFAR is channelling large sums of money through pro-abstinence and even anti-condom organisations that are faith-based, and believe sexual abstinence should be the central pillar of the fight against HIV. Abstinence-only is also being encouraged by evangelical churches within Uganda, and by the First Lady, Janet Museveni[28].

This money is making a difference - some Ugandan teachers report being instructed by US contractors not to discuss condoms in schools because the new policy is "abstinence only"[29]. Dozens of billboards around the country have sprung up promoting only abstinence to prevent HIV infection and sometimes discouraging condom use. Some leaders of small community-based organisations also report they are aware that they are more likely to receive money from PEPFAR (which is the largest HIV-related donor to the country) if they mention abstinence in their funding proposal[30].

"PEPFAR really shifted the emphasis to A and B [Abstinence and Being faithful] just because of the amounts of money being put into these programmes"*Sam Okware, senior Health Ministry official and architect of Uganda's ABC model. –* [31]

Stephen Lewis, while UN Special Envoy for HIV/AIDS in Africa, said that PEPFAR's emphasis on abstinence above condom distribution is a "distortion of the preventive apparatus and is resulting in great damage and undoubtedly will cause significant numbers of infections which should never have occurred"[32].

An educational sign promoting abstinence in a Ugandan primary school

Pro-abstinence-only organisations are increasingly using Uganda as an example to indicate the success of their methods. But this is inappropriate, since the multiplicity of prevention methods used in Uganda mean that the decline in HIV prevalence was certainly not due to abstinence-only messages.

Abstinence *is* an important part of an HIV prevention programme, but it should not be promoted at the expense of encouraging condom use.

"We are still hopeful that America, being a strong and well-meaning country, will not go down in history as a country which exported ideas at the expense of people's free will to choose." [33]*An HIV-positive Ugandan man*

Be faithful

Being faithful to your partner – or 'zero grazing' - was the dominant message of early HIV prevention campaigns led by President Museveni. The term "zero-grazing" comes from the agricultural practice of tying livestock to a post, restricting them to a zero-shaped section of grass.

Models of the epidemic and surveys from the late 1980s to 1990s show that encouraging fewer sexual partners was effective - the World Health Organisation reported that between 1989 and 1995 the number of Ugandan men reporting three or more non-marital sexual partners fell from 15 percent to 3 percent.[34]

Unfortunately, the early emphasis on avoiding casual sex appears to have lost its impact in recent years. A 2006 study by the Ugandan Ministry of Health found an apparent increase in multiple partnering. The proportion of sexually active Ugandans who reported having had two or more sexual partners in the previous 12 months increased from 2 to 4 percent between 2000-01 and 2004-05 among women, and from 25 to 29 percent among men[35].

Use condoms

Condoms were not heavily promoted and distributed during the early years of the AIDS epidemic in Uganda as the president felt that they offered false hope that the epidemic could be stopped without curbing multiple sexual partnerships. It was not until the mid-nineties that condoms were widely distributed. The number of condoms delivered and promoted by international groups rose from 1.5 million in 1992 to nearly 10 million in 1996[36].

The momentum of condom distribution was lost in 2004 when the Ugandan government issued a nationwide recall of the condoms distributed free in health clinics, due to concerns about their quality. Millions of condoms were incinerated, and by mid-2005 there was said to be a severe scarcity of condoms in Uganda, made worse by new taxes which made the remaining stocks too expensive for many people to afford[37].

Some experts, including Stephen Lewis, believe that America was largely to blame for the shortages. Mr Lewis said "there is no question that the condom crisis in Uganda is being driven and exacerbated by PEPFAR and by the extreme policies that the administration in the United States is now pursuing"[38].

In June 2006, the Ministry of Health announced it had, with assistance from the World Bank, imported 80 million re-branded condoms for free distribution[39].

Conflicting messages and problems with distribution appears to have had an effect on the number of people using condoms. UNAIDS found that condom use during sex with non-regular partners was reported by 20%, 39%, 47% and 35% of women in 1995, 2000, 2004–2005 and 2006, respectively, and by 35%, 59%, 53% and 57% of men[40].

Prevention-of-mother-to-child-transmission (PMTCT)

The Ugandan Ministry of Health began offering a free prevention-of-mother-to-child-transmission (PMTCT) service in a small number of antenatal clinics in January 2000. The trial PMTCT programme included counselling and rapid testing for all women attending antenatal clinics and treatment to both mother and child following a positive diagnosis.

The results of the programme after two years were fairly positive, although there were large disparities in mother-to-child-transmission rates in different areas, which were largely dependent on the number of staff at each facility[41]. The drugs Combivir plus single dose nevirapine are used for PMTCT in higher level facilities, while the lower level health facilities with fewer resources continue to use single dose nevirapine only[42].

The number of PMTCT service delivery sites was expanded between 2005 and 2007 with emphasis on providing services to rural populations. The number of health facilities providing routine HIV counselling and testing for pregnant women increased, raising the uptake of HIV testing to 80% of all women attending antenatal clinics[43]. The proportion

of HIV positive pregnant women receiving antiretrovirals for PMTCT increased from 12% in 2005 to 34% in 2007[44].

According to the latest figures, 25% of new HIV infections in Uganda occurred through mother-to-child-transmission, which is approximately 25,000 infants[45]. There are an estimated 100,000 children living with HIV/AIDS in Uganda[46]. In Uganda's 2008 national plan, PMTCT has been placed high on the agenda with a target of halving mother to child transmission by 2012[47].

AVERT is calling for a greater global effort on preventing mother-to-child transmission in our Stop AIDS in Children campaign.

HIV testing in Uganda

Recognising the vital role that testing plays in preventing the spread of HIV, Uganda was the first country to open a voluntary counselling and testing (VCT) clinic in sub-Saharan Africa[48].

In 1999 the Ugandan Ministry of Health started a voluntary door-to-door HIV screening programme using rapid tests in an effort to reduce the spread of HIV. This effort was intended to make HIV screening services accessible to more people, especially in rural areas where there were neither modern laboratories nor electricity to run standard HIV tests[49]. It has been suggested that in Bushenyi district, door-to-door testing contributed to a radical reduction in HIV prevalence in the early 2000s: from 8% to 3.1% in three years[50].

A community based AIDS information centre provides HIV testing for adults and children

Uganda has also begun to implement routine or 'opt-out' testing (whereby anybody who enters a healthcare facility is tested for HIV unless they specifically ask not to be) in some healthcare settings. Trials of routine testing had overwhelmingly positive results, showing that this style of testing identified those infected at an earlier stage of their

infection (before they were symptomatic) and therefore increased their survival rate[51]. A study in two large Ugandan hospitals with a high HIV burden found a high rate of routine testing uptake with only 5% of people refusing the test[52].

In 2007, HIV testing and counselling was available in 45% of health facilities in the country, and 15% of people aged 15 years and above had received HIV testing and counselling in the previous year[53]. As an estimated 80% of Ugandans remain unaware of their HIV status it is vital that testing is stepped up to prevent further transmission[54] [55].

HIV treatment in Uganda

Uganda was the setting for one of the first test programmes in Africa distributing life-saving antiretroviral (ARV) medication. The programme began in 1998 with the aim of assessing the feasibility of setting up and running an antiretroviral (ARV) drug clinic in a resource-poor country. The patients involved had to pay for their medication, although at reduced prices. After the study was complete, the Ugandan Ministry of Health used the lessons it had learned to set up its National Strategic Framework for HIV/AIDS[56].

It was not until June 2004 that Uganda began to offer free ARV medication to people living with HIV as part of a five-year pilot programme. The initial consignment was funded by the World Bank, with future drugs to be paid for by a Global Fund grant of US$70 million and large grants from America's PEPFAR initiative[57]. Although the initial drugs roll out was fairly slow, within two years 41% of those in need were receiving HIV treatment[58]; this increased to 56% in 2006[59].

The waiting room at an ARV Clinic in Uganda

The momentum of scaling up HIV treatment in Uganda was put in jeopardy following the suspension of funds from one of the country's key donors. In August 2005, the Global Fund to Fight AIDS, Tuberculosis and Malaria suspended the disbursal of money Uganda's grants after financial irregularities were discovered[60]. It was found that management of Uganda's grants was generally poor, and that significant sums of money had been diverted to activities not related to combating the HIV/AIDS[61]. Grant

disbursement was restarted in November 2005, and in 2008 the Global Fund signed Round Seven of funds pledging $254m for HIV/AIDS over the next five years[62].

According to the government, the number of people on treatment rose to 110,000 (including 8,532 children) - or around half of those in need - by February 2008, with around 1,000 new patients being put on the drugs per month. This rate may slow as the national programme faces problems with getting the drugs to those in need, including delays in procurement and distribution, poor storage and weak quality control, stock-outs and a chronic lack of staff[63].

Dr Elizabeth Madraa, manager of Uganda's AIDS Control Programme reports that "The management of the whole supply chain is very weak and problematic… We are now moving slowly as a result of the stock-outs because if we spread out rapidly and ran out of drugs, it would be disastrous"[64].

Uganda aims to relieve the drug supply problems by producing its own generic drugs. The drugs will be produced by a pharmaceuticals factory in Kampala which, at full capacity, will produce two million tablets a day. The ability to produce generic drugs will make anti-HIV drugs cheaper and more widely available. Ugandan officials estimate that generic drugs will cut the price from US$9-15 to between US$2-9 per patient per month[65].

Targets have been set of 240,000 people on treatment by 2012[66], and 342,200 by 2020. When setting treatment targets Uganda must think about sustainability, as 95% of the ARV programme is currently donor funded, mainly by PEPFAR[67].

In 2004 the government and international donors initiated a programme to scale up the delivery of HIV treatment to internally displaced populations in the war torn north. By 2007, an estimated 39% of people in need of HIV treatment in the northern region were receiving it[68]. Providing HIV treatment in this region has not been easy due to inadequate infrastructure and frequent drug shortages. Initially there was a severe shortage of health workers; shifting tasks to staff with less training, and involving people living with HIV as "expert patients" has alleviated some of the pressure[69].

The way forward

Uganda is at an important crossroads in the history of its AIDS epidemic. After a dramatic reduction in HIV prevalence following an early comprehensive HIV prevention campaign, there are signs that the number of people living with HIV in the country may be starting to rise again.

In order to avoid this, Uganda needs to take a serious look at infection trends and behaviour to identify why this rise may be occurring and how to remedy it. Experts believe that complacency and the 'normalisation' of AIDS may be leading to an increase in the risky behaviour that early prevention campaigns sought to reverse.

"People now think that because we have had HIV for so many years, it is a normal condition among the population."*Kihumuro Apuuli, director of Uganda Aids Commission (UAC)*[70].

Uganda clearly needs to revive and adapt its HIV prevention programme, moving away from abstinence-only initiatives to a comprehensive programme that incorporates not only abstinence, fidelity and condom use, but also HIV testing and PMTCT.