

AIDS IN UGANDA: YEARS OF CHAOS AND RECOVERY

I think AIDS is now part of us.¹

FROM RUMOUR TO DISEASE TO EPIDEMIC

Uganda is often associated in people's minds around the globe with Idi Amin and AIDS. This is unfortunate, but the suffering that Uganda has gone through in the decades of the 1970s and 1980s seems to have given it the resolve and strength to defeat both, and to arrive at the beginning of the twenty-first century as one of Africa's 'success stories' in a number of ways. But in July of 2003 as Idi Amin² lay dying in exile in Saudi Arabia and debate went on about whether to allow him (dead or alive) back into the country either to die or to be buried, fears were expressed that HIV/AIDS might come back, too, if vigilance was not exercised. During the height of Uganda's social chaos, when Idi Amin was being driven from power by the Tanzanian army, 'Slim', the Ugandan disease, had broken out into the general population from some isolated population(s) where it had clearly been endemic for some time. Some Ugandans had begun to recognise it, and gave it a name. Later they recognised that it was 'now part of us'. This recognition and the willingness to 'take ownership' allowed the struggle against AIDS to be built into the nation building process itself. Because Ugandans already had a 'native category' for AIDS at the beginning of the 1980s, *siliimu*, when the virus was finally identified in 1984, it could not be represented as a conspiracy or plot against the Africans by the West, as it was in South Africa. This, more than anything else, may have saved many Ugandan lives as the virus was tackled quickly and honestly.

Despite adversity, Uganda re-established peace, good governance and a strong civil society. This remarkable achievement is also closely related to, and partly responsible for, their achievement in meeting the AIDS crisis head-on that succeeding in bringing down the HIV prevalence rates over a ten-year period. The Museveni government was open to 'partnerships', as they called them, with all segments and sectors of Ugandan society. It was aware of and paid attention to cultural practices and beliefs, and showed resolve and direction in its political leadership. These have been central factors in their approach to AIDS. But, the political instability, warfare, pervasive violence and rape in the era before the establishment of peace in Uganda in 1986 are also responsible, in part, for the problem itself. As important as good government has been, however, the response of thousands of churches, schools, NGOs, CBOs and other organisations of the broader civil society must be acknowledged. They have been

¹ Interview with Namara Dinah, clinic sister and midwife, Kikyenkye Health Centre III, near Igorora town, Mbarara District. 16/7/03.

² Idi Amin Dada, who had been President of Uganda since overthrowing Milton Obote on 25 January 1971, was known as one of the bloodiest dictators that Africa has seen. Some 400,000 died under his rule, and the entire 'Asian' population (as those descended from original immigrants from India were called) of some 20,000 people was driven out in the early 1970s. He was forced to flee Uganda after an attack by Tanzania succeeded in replacing Milton Obote in the presidency. Amin died in Saudi Arabia on 16 August 2003.

supported by international donor agencies to great effect. These initiatives have been led by a number of extraordinary individuals, whose vision and dedication has been exemplary, too. Ultimately, it is the 'ordinary Ugandan', however, who had to change his or her behaviour in profound and significant ways to bring about the AIDS success story in Uganda. These shifts in sexual behaviour must be seen in the light of what amounted to a complete re-organisation of Ugandan society, cultural practices and values. These changes were supported by organisations that mobilised resources and personnel to educate and motivate the Ugandan people. And, these, in turn, were supported fully and efficiently by international agencies such as the WHO, USAID, and many others.

The story of AIDS in Uganda is thus a complex web of causes, factors, motives, and action that gained momentum over the last two decades of the twentieth century, and resulted in what became a fully-integrated, nation-wide response to AIDS on the part of all Ugandans at all levels and in all activities. Dr. Sam Okware³ led this response as Director of the National AIDS Control Program in the Ugandan Ministry of Health. Dr. Okware summed up the history in these words:

It started as a rumour. We discovered it was a disease. We found that it was an epidemic. We have finally accepted it as a tragedy.⁴

Although he had originally coined this succinct summary of the history of AIDS in Uganda in 1993, Dr. Okware was still offering it—with good reason—as a concise summary of the AIDS epidemic in 2003 when I heard it directly from him in his office in Kampala. Dr Okware's four sentences express an historical unfolding. First, rumours of a new and mysterious killer were eventually met with diagnosis of a disease. The disease spread rapidly as its causative agent, HIV, infiltrated the entire country. However, early recognition that this was an epidemic that could affect all parts of society led to mobilisation of government resources. Extraordinary political commitment from the top levels of government to freedom in an open society led to the enabling of civil society, and to 'partnerships' in dealing with the epidemic. The acceptance that this was a tragedy, however, motivated people at all levels of society, and from every village and town in what became one of the most coherent responses to a common threat ever mounted in Uganda, or perhaps Africa. Above all, *recognition* of the scope of the threat and refusal to deny its fearsome impact permitted effective responses to be mounted. *Acceptance* of the tragedy—like 'truth and reconciliation' after a bitter struggle—both legitimated and motivated a major reshaping of individual behaviours, and of culture and society.

³ Dr. Samuel Ikwaras Okware, born 16 August, 1948 in Tororo, Uganda, is currently Commissioner Health Services, Department of Community Health in the Ministry of Health, Kampala. He received a Masters of Public Health and Epidemiology at the University of Minnesota in 1979 as a WHO fellow, after qualifying for a DPH (Public Health) and an MB ChB at Makerere University from 1968-1976. During the last years of the Obote and Tito Okello regimes he was Assistant Director of Medical Services, Public Health. In 1985 he became Director of the National AIDS Control Programme in the Ministry of Health, and Chairman of the National Committee for the Prevention of AIDS. In 1990, he was made Deputy Director of Medical Services in charge of Public Health, and from 1995, as Commissioner of Health Services (Communicable Disease Control and AIDS) continued to oversee the AIDS programmes together with all other communicable disease problems. From 1998 he has been Commissioner of Health Services for Community Health. See <http://www.health.go.ug/okware.htm>.

⁴ Interview: Dr. Sam I Okware, Ministry of Health, 25/7/03. Although Dr. Okware said this to me in July 2003, he was repeating words that were quoted by New Vision on 4 September 1993. See Iliffe 1998: 223 where they are quoted again.

TAKING SEX SERIOUSLY

In retrospect, and in the face of such an epidemic, Uganda's response may seem obvious. But recent history—and comparison with other countries—shows that many countries with problems of similar magnitude—or worse—have failed to mount anything like this level of response. Previous epidemics, such as the sleeping sickness (trypanosomiasis) epidemic in the 1940s in Uganda caused the deaths of an even larger share of the population.⁵ Today, more people die of malaria than they do of AIDS. These epidemics did not result in the sort of total response that the struggle against AIDS has done.

Why? First all, Ugandans take sex seriously. People in Uganda constantly confess to loving sex. Sexual networks are part of the social fabric. Customs and rituals in many ethnic groups prescribe sexual contact as part of the performance of duty. Ugandans value fertility greatly, and praise people with many children. Despite AIDS, fertility has not decreased. Indeed, many Ugandans say that life without sex is scarcely worth living.

Daily newspapers are full of a variety of tales of sexual intrigue, and stories of sexual styles, adventures, 'how-to' advice, love and betrayal. Today, there is almost no topic related to sex that is not discussed in the popular press, both in English and in indigenous languages. There are a number of popular newspapers, such as *Red Pepper*, that are simply about sex. Although they do not contain explicitly pornographic nudes, they come as close as they can without full nudity. They are sold freely on the streets for slightly more than the cost of a daily newspaper.

The Luganda-language daily, *Bukedde*, freely mixes articles about sex and sexuality, which constitute about 25% of the column inches, with other stories about Ganda life and culture.⁶ The issue for 5 July 2003, for instance, has stories about catholic bishops, sex games and the restored Ganda kingship. The leading front page spread is about transfer by the Ganda King (Kabaka) of the former residence of the Kingdom's Prime Minister (Katikkiro) to the State for use by the Joint Clinic Research Programme that provides research services on HIV/AIDS. The front page feature line '*Empaka z'okuzuula ebisambi bya mukazi wo*' introduces an article about a 'popular' party game in which women sit in chairs in a row with their legs uncovered or in short skirts and the men, blindfolded, feel their thighs and try to guess which one is their wife. Another front-page item, '*Abakazi abakuba abasajja baabwe baabano*' is a story and pictures of women who beat up their husbands/men, with six full colour photos of women beating men.⁷ On page 12, a special section is called "Ssenga" after the tradition of having an older woman teach young women 'how to please their husbands'. This contains short items such as "*Malaaya y'empa amaanyi*", a man's story of how he can only be aroused by prostitutes. This is followed by full page of wedding pictures under the "Ssenga" heading. There are also articles on 'Big Brother Africa' featuring the Ugandan participant, Gaetano, and his reality-TV romance with a South African woman.

The mix is also enlivened by full stories about a Ganda Cardinal welcoming newly ordained Catholic deacons in the Lubiri, the King's palace. All of this was explained to me as I sat eating and drinking—and reading *Bukedde*—with the school board of a Catholic girls school and the parish priest, Father Kalomba, in Rubaga, the heart of Ganda culture and the centre of the kingdom. Father Kalomba had just finished a speech to the school girls and their parents about

⁵ Interview: Dr. Sam I Okware, Ministry of Health, 25/7/03.

⁶ *Bukedde*. [Luganda language newspaper.] vol 10, no. 159, 5 July 2003. At the time, Uganda Shillings 600 = US\$0.30.

⁷ Inside headline, pg 14. "*Abakazi abakuba abasajja kibook*, 'Women whip their men', *Bukedde* vol 10, no. 159, 5 July 2003.

the need to control sexuality, and to use condoms where abstinence had failed. There could be no doubt that sexuality was part and parcel of Ganda life and sense of identity in which Catholicism, marriage, sex games, and politics of HIV/AIDS were all blended together in this Luganda-language daily newspaper. While this is no different than the content of glossy European women's and men's magazines such as *Cosmopolitan* or *Maxim* that are available in Uganda, *Bukedde* is a popular 'family' daily newspaper aimed at Ganda 'traditionalists' and Catholics. Although articles emphasised the value of marriage, and of tradition and Roman Catholicism, there could be no doubt about the importance of sex and sexuality in daily life.

Second, sexual networks of lovers, wives and husbands are fundamental to the social order. Many people we interviewed insisted that this has not changed. They felt that the worst aspect of the HIV epidemic was the limitations that it had put on sex. Dr. Okware spoke to us of his concern to 'make the world safe for sex again'. All Ugandans admit that many aspects of this sexual culture have changed for the better and for good. Numbers of partners and therefore the size and reach of networks of sexual contacts have decreased, they asserted. Cultural practices that involve penetrative sex such as 'cleansing' rites after death and circumcision, together with wife inheritance and 'wife sharing' among brothers have all but stopped. 'We have changed our culture absolutely,' says Professor Musisi, UAC Commissioner and director of the Makerere Institute of Social Research, 'but what do we put in its place?' 'This culture had to change,' she said, 'but we do not want to lose everything,' pointing—somewhat ironically—to the pervasive influence of American popular culture in particular.

Third, Uganda was determined and able to mount an early and effective response after vast devastation over the previous 15 years. This was led by President Museveni, but he was capably supported by a number of exceptionally capable medical doctors, initially, including Dr. Sam Okware, Dr. John Rwomushana⁸ and Dr. Kihumuro Apuuli⁹, among others. Later, the struggle was joined by many of the leading ministries of government, and by the major hospitals and their staff including government hospitals such as Mulago in Kampala, and mission hospitals such as Lacor Hospital in Gulu, or Rubaga in Kampala.

POLITICAL COMMITMENT AND SOCIAL MOBILISATION

Political commitment from the top was critical but probably not sufficient to explain the effectiveness of Uganda's response. It could not have happened without a strong sense of commitment from virtually every organisation of civil society, and from individuals across the country. Why and how did this happen?

There are a number of factors that seem relevant. Uganda has a high level of literacy and there are good schools throughout the country. While there are many local languages, English is the national language and it is widely and well spoken throughout Uganda. These factors made it possible to communicate effectively and quickly with the country of approximately 24 million people. In the south, especially, Uganda has a heritage of hierarchical political organisation stemming from the history of early kingdoms dating from the 16th century. President Museveni, soon after taking power, quickly organised the country into a hierarchy of Districts, counties, parishes and villages that is not unlike Napoleon's thorough re-organisation of France after the Revolution. Uganda was never a colony, so its political order was maintained—though transformed—during the sixty or so years as a Protectorate of Britain. Museveni was able to draw on these traditions.

⁸ Prof. John Rwomushana is director of Policy Advocacy & Knowledge Management at the Uganda AIDS Commission at the Uganda AIDS Commission (2006).

⁹ Dr. Kihumuro Apuuli is currently (2006) Director General of the Uganda AIDS Commission.

Religious communities are also well integrated and less fragmented than in many other African countries. The majority of Ugandans are Roman Catholic and Anglican (Church of Province of Uganda). Islam has been firmly established in Uganda since the late nineteenth century. It is also a fundamental part of Ugandan culture and is thoroughly Ugandan. Approximately 25% of Ugandans are Muslim.¹⁰ There are very few 'independent' or African syncretic sects in Uganda. Because of this, the churches and Islamic communities were able to act in an integrated fashion, and to reach the large majority of Ugandans.

Finally, the determination to repair the country after the ravages of civil war, the 'liberation' by Tanzania that attacked Uganda in 1979 in order to re-install the corrupt previous president Milton Obote, and mismanagement of government, gave Ugandans a sense of purpose. AIDS stood in the way of re-development of the country and had to be countered if these goals were to be met. The struggle against AIDS was coupled with a political and economic agenda of reconstruction and development and this enlisted the support of the entire country.

Ugandan history, then, over the past two decades is a story of sex, death and life's transcendence of adversity.

THE FIRST DECADE OF AIDS IN UGANDA

Idi Amin came to power in a coup d'état early in 1972, driving President Milton Obote into exile in Tanzania. Famous for his own sexual exploits and many wives, his rule ushered in a period of economic chaos and decline, as well as untrammelled brutality and pervasive rape. Many informants agreed that the prevalence of rape during these periods, and during the wars that punctuated the political process, led to greatly increased HIV prevalence. "Sex is a very important part of war ... rape, and so on," said Dr. Sekatawa, a statistician at the Institute for Statistics and Applied Economics. "[It is used] To demonstrate conquest or something. Unfortunately, it [also] increases HIV."¹¹ Everyone, especially women, agreed that they had lived in fear of rape under Amin and Obote. "During Amin's time, life was so bad. Amin's soldiers used to take people [away to rape] in a car boot. I was one. People lived in fear,"¹² said one woman from western Uganda. Men agreed. A man from northern Uganda commented "Soldiers are injectors of AIDS because they don't ask."¹³ "They take you by force," echoed his friend. Another man from western Uganda said "Between 1979-1986 men would freely rape women. ... It would only become a problem when the rapist was caught in the act. In such a case he would only be fined [pay a penalty]."¹⁴ Soldiers were especially guilty of this, and rape by soldiers became virtually 'normal'.

War, however, also seems to have curtailed 'ordinary' sexual activities and opportunities for many. Mrs. Goretti, a community counsellor in Kikyenyekye, a village about 30 km north of Mbarara, said that rape was commonplace during this period, but "People did not have time to have [normal] sexual relationship as a result of war. People were more concerned about their

¹⁰ Kagimu, Marum, et al., 1998: 215. The percentage of Muslims was greatly increased during the Amin regime when considerable economic incentives were offered to convert. The businesses and properties confiscated from Indians and Europeans after 1972 were preferentially handed out to political supporters and to Muslims by Idi Amin.

¹¹ Interview: Dr.E. Sekatawa, ISAE, Makerere Univ., 4 July 2003.

¹² FGD: Ibanda country, Kabingo cell, Mbarara District, Born Again Christian Women, 45-60 y.o. 16 July 2003.

¹³ FGD: Naguru, Kampala, male 36-73 y.o. 8 July 2003.

¹⁴ FGD: Kakoba, Mbarara, Males 35-64 y.o., 17 July 2003.

security and for their children.’¹⁵ Soldiers, however, ‘had multiple partners because they were mobile and every where they went they had partners.’ Mrs Goretti distinguished clearly between the disruption of ‘normal’ sexuality in marriage, and in bars and other places of entertainment, and rape during the wars and misrule of Amin and Obote. ‘People did not have sex so much because they were in confusion’, she said. ‘It was the time Museveni was fighting Obote’s government. This gave no opportunity for people to engage in sexual intercourse.’ Shortages of everything and curfews imposed by government seem to have brought to a close a period of relatively free, uncoerced, sexual expression in the late 1960s and 1970s. Instead, women came to accept rape by soldiers as almost a normal and expected part of their lives. Men who could afford to also sought sex outside the home.

When Tanzanian and Ugandan forces attacked Amin’s regime in 1979, the Tanzanian soldiers were also accused of rape, but many young women welcomed the cash brought by the soldiers. Older women in Igorora village, Mbarara District, western Uganda—an area that has been in the path of several military campaigns—made a distinction between the relatively well behaved Tanzanian soldiers, who often married the girls from the region (and took them back to Tanzania), and Idi Amin’s troops who simply raped at the point of a gun.

Respondent C: The *Bakombozi* [Tanzanian soldiers, literally ‘liberators’] were not raping girls; this was the good thing about them.

Respondent A: It was Amin’s group which used to rape women

Respondent B: Aren’t *Bakombozi* the same as Amin’s soldiers?

Respondent C: No, the *Bakombozi* are from Tanzania and were different from Amin’s soldiers. Those of Amin would use force. Like the way we are here [a group of women sitting and talking], if they came, they would cock their guns and if we went to the bush they would follow us and rape us.¹⁶

This was a period of mayhem and disarray. Mulago Hospital, the principal hospital in Kampala was looted by Amin’s troops as they fled, while Amin’s government workers looted the Ministry of Health on their way out.¹⁷ Five major hospitals had been destroyed during the fighting.¹⁸ Cash and goods were exchanged for sex, but many respondents who mentioned it commented that there was considerable prestige associated with going out with a soldier. They had money and power. After the defeat of Amin, the Tanzanian government returned Milton Obote to rule after elections that were widely believed to have been heavily rigged in favour of Obote’s party, the UPC. The second period of rule by Milton Obote, known as ‘Obote II’, proved to be at least as brutal and corrupt as that of Idi Amin’s. Both Idi Amin and Obote were from the northern half of Uganda, and were resented by the people of the south whose culture and languages were considerably different. Despite this, there was a great sense of relief when Amin was deposed, and this led to rejoicing associated with a period of sexual license. A group of middle aged professional women in eastern Uganda described it in the following way:

Respondent 1: After the fall of Amin there was a lot of excitement. Originally people were like prisoners, so thereafter they felt free. There was a lot of socialising; drinking, and people had many sexual partners. Schoolgirls had sexual affairs with the *Bakombozi*. Some schoolgirls got married to them. Some school girls had sugar daddies.

¹⁵ Interview: Mrs G Goretti, Community Counsellor, Kikyenyekye, Mbarara. 16 July 03.

¹⁶ FGD, Igorora, Mbarara, female, 46-60 y.o., 16 July 2003.

¹⁷ Iliffe 1998: 150.

¹⁸ Iliffe 1998: 151.

Respondent 2: Our people integrated a lot with *Bakombozi*, they became girl friends and boy friends and produced children with those people.

Respondent 3: Almost every woman was involved with the *Bakombozi*. They seemed to have money and yet people were very poor. Schoolgirls, married and unmarried women got sexually involved with the *Bakombozi*.¹⁹

In the early 1980s, a resistance movement, composed mainly of people from the southern kingdoms, and led by Yoweri Museveni, broke away from the army and began a four-year long war against Obote II. This was also the time that AIDS was first recognised in south-western Uganda. Museveni's resistance army was, at first, based in south-western Uganda where AIDS or *siliimu* ('Slim') was already endemic. From there, they moved to an area known as the Luwero Triangle, north of Kampala. In July 1985, another army General, Tito Okello, overthrew the Obote II regime. Okello's grasp of power, however, was short lived. Museveni's National Resistance Army made a final push to topple this regime in early January, and took Kampala on January 25th 1986.

On January 29 1986, Yoweri Museveni was declared President. He immediately promulgated the '10 Point Plan' that promoted institutions of civil society, the rule of law, human rights, and political freedoms, together with ambitious plans for development based on a mixed economy relatively free from government control. Even more importantly, these promises were kept, and in the peace that followed, tens of thousands of new businesses, NGOs, CBOs and other organisations sprang up across the countryside. USAID, among a few other donors, had resumed support for Uganda in 1980 after the return of Obote, primarily in the areas of agriculture, medical relief and training. It had suspended aid to Uganda during Amin's rule, and again briefly after Okello's coup. With the installation of Museveni's government, international aid began to move into Uganda once again to help restore the war-torn social and economic infrastructure.

During the 1980s, like the 1970s, Ugandans remember that, apart from rape, sexuality was 'rampant'. Both men and women had many sexual partners according to a large number of informants.

In the early 80s, ideally in this culture, people had multiple partners. This is acceptable in Uganda for men to have many wives. This was happening all the time. That started to change with HIV. We also had wife inheritance and girls getting married very young, especially if poor or if not going to school. They get married to older men.²⁰

Many believed that this was a consequence of the severe economic hardships for many, with what wealth there was concentrated in the hands of a few, mainly male, businessmen (especially traders, and smugglers), military and government personnel, and land or property owners. Young girls with few prospects were often willing to have sex with these men for money or other forms of support for themselves and their families. This was a consequence of poverty, but was not entirely coercive. A group of relatively poor women from the Kampala suburb of Kifumbira, for instance, were asked if girls in the mid-1980s could choose to abstain from sex. They all agreed, 'Not when he has showed you *Omutwaro* [ten thousand Shilling note, currently = US\$5.00].'²¹ Sexuality was often seen as a legitimate 'commodity', tradable value or service that could be exchanged for other goods and services.

¹⁹ FGD: Bumulyanyuma, Mbale. Women (professional) 31-65 y.o.; 17 July 2003.

²⁰ Interview with Dr. Cissy Kityo Mutuluza, Deputy Director (Clinical and Research), Joint Clinical Research Centre, 5 July 2003.

²¹ FGD: Kifumbira, Kampala, female, poor; 9 July 2003.

When Museveni came in, if you can remember, he used young soldiers - the *kadogos* ['small ones/boys', Kiswahili] who came with money. Obviously, they would also come and move around with their guns freely in discos and interact with people. Afterwards a lay person [non-military] seeing a *kadogo* with money, especially women, would be forced to go with them. Women were forced due to poverty. So they earned their living from the *Kadogos*. The *Kadogos* were also excited in having sex with these elder women, now they could pull out whatever [money] the women could demand.²²

During the previous regime, soldiers were feared greatly, but Museveni's army attempted to create an atmosphere of trust and acceptance of soldiers—what many people referred to as the 'demystification of the gun'. Most people saw this as a return to normality, and even 'sexual behaviour normalized.'²³ For women in one of the discussion groups in Mbale, this implied

Somebody would go where he was supposed to go. A girl would go with a boy, not necessarily a man with money, social life became confined within the age groups. There was a lot of freedom of association.²⁴

But they also agreed that this freedom under the new government meant, for many, sexual license as well. One woman in eastern Uganda explained it.

Let me give you an example, for a young lady like I was. I was confined in the village [in the early 1980s], so when Museveni came in I got freedom of moving from Mbale to Kampala and there I met people I had never seen, those who do not look like people in the village. They had a lot of money. So I was caught up in a trap.²⁵

She made it clear that this 'trap' was the lure of sexuality, 'sugar daddies', good food, fashionable clothes, and the city life of night spots, bars, and the sex that went with this.

When Museveni took over power, the situation was that people were really happy of the government and were assured of peace, and then the soldiers had to move in the villages freely and there were some parties organized. ... When they heard that Museveni had taken over the leadership and especially when they arrived in Mbale here, there were so many ceremonies being organized such as the "*kadodi*" dancing, discos were organized even in rural areas ...everywhere. Soldiers had to leave the barracks and they were just moving, interacting with people freely in communities, telling them that don't fear, we have come to rescue you.²⁶

Upon Museveni's ascendancy, then, sex also became part of the general rejoicing.

It was the rejoicing part of it that resulted into women interacting and finally moving out with *kadogos* because of the poverty and the *kadogos* were the source of money. As they rejoiced, the women got money from the *kadogos* in exchange for sex.²⁷

The period of rejoicing lasted for a couple of years and was associated in many people's minds with the realisation that AIDS was a serious threat, and that many people were dying. In Museveni's own camp, it quickly became clear that HIV had infected many of his top echelons.

²² FGD: Bungokho, Mbale, youth, 18 July 2003.

²³ FGD: Bumulyanyuma, Mbale, Women (professional) 31-65 y.o.; 17 July 2003.

²⁴ FGD: Bumulyanyuma, Mbale, Women (professional) 31-65 y.o.; 17 July 2003.

²⁵ FGD: Bumulyanyuma, Mbale, Women (professional) 31-65 y.o.; 17 July 2003.

²⁶ FGD: Bungokho, Mbale, youth, 18 July 2003.

²⁷ FGD: Bungokho, Mbale, youth, 18 July 2003.

In 1986 when they went to Cuba, early 1987, they had captured power early January 1986, a high percentage were tested in late 1986 and 18% were positive and none were sick.²⁸

Those ones started dying in 1995, 1996. That cohort may be they had not got the disease while in the bush but may be it was part of the celebration of 1986. So we heard one story. So when he came from meeting Castro, that is when he called everybody and started campaigning.²⁹

Even before Museveni's presidency, however, AIDS had begun to raise alarms. The first AIDS case was identified in Uganda in 1982, almost as soon as the syndrome was identified in the USA among homosexuals and intravenous drug users.³⁰ Medical practitioners in San Francisco and New York City began to note the emergence of previously rare infections and cancers in men in 1979 and 1980. Pneumonia caused by the bacteria *pneumocystis carinii*, an infection that usually occurs in birds, and Kaposi's sarcoma, a type of previously very rare skin cancer that produces black or dark coloured nodules on the skin, seemed to be occurring together and in greater numbers. The Centre for Disease Control in Atlanta, Georgia, published the first notice of this emerging phenomenon on 5 June, 1981, in the journal that they published, *Morbidity and Mortality Weekly Report*, and a second notice in the following month. Reported cases of the new diseases and their apparent connection to homosexual men began to attract increasing attention. By then, it was becoming clear to Ugandans, especially those who were resident around the shores of Lake Victoria in Masaka and Rakai districts that what they had already begun to call 'Slim', or *siliimu*, was increasing rapidly, with more and more people dying of the disease. In the early 1980s too, infections and diseases that were now being grouped under the 'syndrome' label began to appear elsewhere in the world. Dr. Anne Bayley reported cases of Kaposi's sarcoma in Zambia.³¹ Soon cases were identified in most European countries, in Brazil and Mexico, and in surrounding African countries such as Rwanda and Zaire (now Democratic Republic of the Congo). Isolated instances appeared even in Australia and New Zealand. By 1982, it was beginning to be recognised as a global phenomenon with serious potential for epidemic spread.

In fact, it was already spreading rapidly in the increasingly international gay or male homosexual community which had developed its own sexual culture that permitted and often encouraged rapid change of partners and promiscuous sex. One person in particular, a gay male flight attendant, Gaetan Dugas from Quebec in Canada, today has the distinction of being known as 'patient zero'. Gaetan Dugas had infected at least 40 of the 248 men who were showing symptoms of AIDS by the middle of 1982.³² Mr. Dugas himself estimated that he had sex with at least 250 men a year, just short of one new partner a day. In his travels as a flight attendant, he may have spread the virus to the far corners of the world. It is likely, too, that he had been infected in the 1970s because his Kaposi's sarcoma was already well advanced by 1982.³³

²⁸ Interview with Jessie Kagera, AIDS Advisor to the President; Interview July 2003 conducted by Daniel Halperin, USAID.

²⁹ Interview with Jessie Kagera, AIDS Advisor to the President, Interview, July 2003, conducted by Daniel Halperin, USAID.

³⁰ Uganda AIDS Commission 2002; Kagimu, Marum, et al. 1996; Barnett and Whiteside 2002:28-29.

³¹ Bayley 1983.

³² Barabasi 2002:123; Shilts 2001.

³³ Barabasi 2002: 124.

Seventeen confirmed cases were reported to the Ministry of Health in 1983, but this considerably underestimated the impact of the disease in the areas in Rakai District along the shores of Lake Victoria and on the Tanzanian border where it had begun to hit hard.³⁴ By this time it was known widely as ‘slim’, because people lost weight precipitously through loss of appetite, gastro-intestinal infections and diarrhoea. A group of Runyankole and Rukiga speakers (western Uganda groups) in Kampala told us it was first called ‘*Omunywengye*’ in their language.

I know *Omunywengye* very well because I had an in-law who had that disease, he lost weight and his mother-in-law used to put banana leaves under his bottom to trap the watery diarrhoea. That was in 80s, they said it was munywengye, then he died.³⁵

There were other names for it as well, such as ‘rough cast’ (the rough cement plaster applied to brick and cement walls), or *Mukenenya* (Luganda) meaning someone who was reduced in size or ‘drying up’, or *Ziridde*.³⁶ As it reached the northern parts of Uganda it was called ‘Wild cat’ (*Etawoi* in Ateso, a language spoken in northern Uganda around Lira and Kitgum, or *oridi*, ‘something that squeezes you down, squashes you.’³⁷ A number of Acholi men commented,

‘There is still not a name for AIDS in local languages.’

‘No one can exactly explain why [there is no African name]. People were calling it ‘slim’, ‘*asein*’ in Ateso, meaning you have lost weight until you are like this [showing a squeezing motion with his hands].’

‘It was called ‘slim’ by that time [early] 1980s. No other new names.’

‘In some places, in local languages like Acholi, [it is called] *Acui* [meaning] “you just become thin”.’³⁸

In Luganda and other Bantu languages in the southern part of Uganda, the word ‘AIDS’ is still not used in IEC campaigns: *siliimu* (Luganda) or *akakooko ka siliimu*³⁹ (‘Chronic disease of Slim’, Runyankole) is used instead. The KiSwahili word, *Ukimwi*, coined in the late 1980s by the Swahili Language Institute at the University of Dar es Salaam, is not used in Uganda.⁴⁰

Ed Hooper, a journalist whose 1990 book, *Slim*, was one of the first extensive reports on the disease, asked a local health assistant, Jimmy Ssemambo, ‘When was the first time that you came across Slim?’ Jimmy responded, ‘During 1982, when I was just posted here, I visited a place called Lukuny on the lake; there I happened to come across a case, which I at first suspected to be TB ... it was a woman.’ According to Hooper, the health assistant realised that it had been ‘Slim’ two years later ‘when a large number of people died in Gwanda, another

³⁴ Kagimu, Marum, et al. 1996.

³⁵ FGD: Kifumbira, Kampala (Ankole& Kiga, Western Uganda), male 22-54, 11 July 2003.

³⁶ FGD: Kifumbira, Kampala.female, poor, 9 July 2003.

³⁷ Interview: Dr. Sam I Okware, Ministry of Health, 25/3/03.

³⁸ FGD: unemployed men (mostly from the north, Acholi, Lango); Naguru (slum), Kampala, 8/7/03; English language.

³⁹ This phrase was seen on a billboard in Mbarara advertising the services of the Counselling and Testing Service.

⁴⁰ *Ukimwi* is an acronym in KiSwahili, standing for *Ukosefu wa kinga mwilini*, literally, ‘a shortage of protection in the body’.

parish here.’⁴¹ Several focus group discussion (FGD) respondents claimed that it must have been present even earlier. One said,

I remember back then, around 1979, coming to 1980, I had a sister who died of the same symptoms; up to now we can recall how she died. So I think the thing began a long time ago. But people are believing they were being bewitched. That is when it started. The symptoms are the same as the things we are seeing today. You can imagine that this is what she might have died of.⁴²

Another recalled:

Me I learned of it in 1980 when I lost my mother. They called it AIDS. She was a medical superintendent. After the burial they said this disease has just come called AIDS. People were doubting. Some say she was bewitched.⁴³

Still others remarked,

I remember that when my father was working in Nsambya [army] barracks, I used to see how people were having sex. I knew Okware who went with the banning of his father in London. When he explained how his father died in London, he was black, thin. That was in 1980.⁴⁴

Or,

[That was] when we discovered it was a killer disease from America. Historically, they say it started a long time ago, but no one was yet experiencing it. One from our family, in the late 70s, the man died, but no one knew the cause. So they gave the woman to another. The whole family got down [died].⁴⁵

The disease or syndrome was first suspected to exist in Uganda in 1982⁴⁶ or 1983.⁴⁷ Recalling their own family histories, numbers of informants believed that people had died of ‘slim’ even earlier than that, however. Dr. Anthony Lwegaba, District Medical Officer in Rakai District, first reported a local epidemic around Kyotera town in Rakai to the Ministry of Health in November 1984. He speculated that the newly identified syndrome known as AIDS ‘may not be new in Africa’ and may even have originated in Africa.⁴⁸ A cancer specialist, Charles Olweny, published a report in a medical textbook in 1984 citing AIDS as a possible explanation for Kaposi’s sarcoma, a previously rare skin cancer that was being seen in Rakai District and a

⁴¹ Hooper 1990: 38.

⁴² FGD: unemployed men (mostly from the north, Acholi, Lango), Naguru (slum), Kampala, 8/7/03; English language.

⁴³ FGD: unemployed men (mostly from the north, Acholi, Lango), Naguru (slum), Kampala, 8/7/03; English language.

⁴⁴ FG: unemployed men (mostly from the north, Acholi, Lango), Naguru (slum), Kampala, 8/7/03; English language.

⁴⁵ FGD: unemployed men (mostly from the north, Acholi, Lango); Naguru (slum), Kampala; 8/7/03; English language.

⁴⁶ Hooper, 1990.

⁴⁷ Schopper, Doussantousse et al, 1995: 171.

⁴⁸ Iliffe 1998, p. 222; citing A M T Lwegaba, ‘Preliminary report of ‘an unusual wasting disease’ complex nicknamed ‘slim’, a slow epidemic in Rakai District, Uganda’ (November 1984; Photocopy of typescript, Ministry of Health Library, Kampala, Uganda).

Mulago Hospital in Kampala.⁴⁹ The HIV-1 virus was first isolated in 1983, and blood testing became possible. Wilson Carswell, an expatriate surgeon at Mulago, sent blood samples of patients suffering from Kaposi's sarcoma to Britain for testing. All proved to have the HTLV-3 (later called HIV-1). A team including Dr. Carswell, with Ugandans David Serwadda, Nelson Sewankambo, and Roy Mugwera visited Rakai and Masaka to do further tests. They found that patients with 'slim' were infected with HTLV-3, and they speculated that it was transmitted by sexual contact. They published their results in 1987.⁵⁰ By then, several other articles had appeared about AIDS in the international medical literature, including Serwadda et al. 'Slim disease: a new disease in Uganda and its association with HTLV-III infection' in *The Lancet* in 1985, and Wilson Carswell et al., 'AIDS in Uganda: a special report by the Clinical Committee on AIDS', in *Health Information Quarterly* in 1986.⁵¹ Publications occur months or years after the discovery they announce, however. Although it is difficult to fix a precise date on the definitive identification of AIDS as a disease caused by HIV (HTLV-3 as it was called then), it appears to have occurred in late 1984 or early 1985.

It is clear then that HIV was already well established in the Ugandan population in the 1970s, if not earlier, and that it had already begun to travel the world. Ugandans in the villages around Lake Victoria where it first began to emerge with a vengeance had already identified it and given it a name, Slim in English, and *siliimu* in Luganda and other local languages such as Kinyarwanda, Chiga, Kinyankore and Kinyoro, among others. Numbers of people have told me that people were already dying by 1980 of the disease known as Slim or *siriimu*, but this was in retrospect in 2003. Nevertheless, the death of their kin—mothers, sisters, fathers, as in the stories cited above—was not remembered as just any death, but as a death of a certain type. The classification and knowledge of the causes of death was not yet known by medical science; these were Ugandan terms for Ugandan knowledge.

Ugandans thus created an indigenous category for the disease by naming it and recognising it as a feature of their own family histories and community problems. Indeed, in Rakai and Masaka Districts, especially, in south-western Uganda and in the cities of the Buganda heartland, Jinja and Kampala, HIV was already endemic. The fact that it had already entered the cultural consciousness, oral history and vocabulary of the people in this region meant that it was also already part of their ideas about health, illness, disease and death, that is, part of their medical culture. Because it was an indigenous category *before* it came to be identified by Western medical practitioners and scientists, Ugandans seem to have been much more willing to accept the consequences of the emerging epidemic. They seem to have taken ownership of it promptly, and this, as much as anything else, is probably responsible for their ability to deal with it more effectively than any other country that we have so far seen.

⁴⁹ Iliffe 1998: 222, citing Olweny in Parry 1984.

⁵⁰ Iliffe 1998: 223 (n. 7), citing Sewankambo, Sewankambo, Carswell, et al. 1987: 9.

⁵¹ Iliffe 1998:223 (notes 11, 12), citing Serwadda et al. 1985, and Carswell, Mugwera, Sewankambo, Kigozi, and Goodgame 1986.