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Unimagined community: sex, networks and AIDS in Uganda and South Africa

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THE 'TIGHTENING CHAIN' CIVIL SOCIETY AND UGANDA'S RESPONSE TO HIV/AIDS

'No one could see the link forming and stretching across the country,
a tightening chain that bound everybody together'

—Doreen Baingana, Uganda novelist, 2005

SYSTEM SYNERGIES

Uganda's approach converted the moralism of 'ABC' to the social ethic of 'zero grazing'. This allowed for the mobilisation of civil society, and for AIDS to be treated as a nation building exercise. The synergies brought about by a comprehensive and integrated response by government and civil society were largely responsible for the change.

It first became apparent in 1996 that HIV prevalence in Uganda, alone among African countries afflicted by HIV and AIDS, was declining. Data from sentinel sites in ante-natal clinics began to show that a sustained reduction in HIV prevalence existed in many (but not all) age groups and regions. This had begun to happen as early as 1989, but in aggregate, the decline was evident from 1992. The decline continued strongly for five years, until 1997, and then began to level out at around 8% overall approximating the power law curve. This represented a huge reduction from levels of 30% registered in western Uganda (Mbarara) and Kampala at the beginning of the decade. By 2003, prevalence remained much lower, in aggregate, than it had been ten years earlier, but by 2006 there were signs of 'message fatigue', and increasing in HIV prevalence again.[1] The influence of American policy, largely directed by the Christian religious right wing in the USA, has also led to declining emphasis on condoms and increased emphasis on the ill-defined concept of 'abstinence.' The slight increases in prevalence in 2006 were still not significant enough to say whether the decline in prevalence is permanent. Since the prevalence trend follows a power law curve, reflecting the network of sexual contacts, further decline is likely to be very slow if it occurs at all. Unlike other viral or bacterial epidemics, however, HIV prevalence is unlikely to trend towards zero in the near future. Indeed, a second rapid rise, paralleling the rise in the early 1980s or even a reverse of the network 'phase transition' or 'catastrophe event that seems to have occurred in 1992, is also a possibility. It is rarely possible to predict when a complex system like a sexual network (or stock prices, or

[1] Kiwawulo (2006) reports in *New Vision* (6 Nov. 2006) an increase from 10% to 25% in one year in Kawempe district. Mulondo (2006) reports that Museveni warns against complacence with HIV infections rising slightly. The Uganda AIDS Commission Director, Dr. Apuuli reports an increase in new infections from 70,000 in 2003 to about 130,000 in 2005, according to KaiserNetwork.org (http://www.kaisernetwork.org/daily_reports/rep_index.cfm?DR_ID=37396, report dated 22 May 2006, accessed 7 Nov. 2006). M. Merson (2006) notes, 'HIV prevalence is no longer on the decline and, in fact, may be increasing in some parts of the country and particularly in adults aged in their 30s', citing Wakabi 2006. See also Gray, Serwadda, Kigozi, Nalugoda, & Wawer 2006: 349.

global climate for that matter) might reach a 'tipping point' and show dramatic and rapid shifts in direction and rate of change. It is also impossible to predict shifts in opinion and policy that are affected by political and religious regimes. 'No one could see the link forming and stretching across the country,' the Ugandan novelist Doreen Baingana tells us about the spreading epidemic. These links are invisible until they are made apparent by experience of illness and death, and by careful analysis of the overall patterns and local manifestations.

What can be said, however, is that Uganda's success depended on what, over the years, has amounted to an extraordinary response by government and civil society to meet the crisis and to support appropriate changes in sexual behaviour that would have an impact on HIV prevalence. More than the individual effects of 'behaviour change'—the ABC and D of abstinence, being faithful, condoms and death—the synergies that developed between the configuration of the Ugandan sexual network and the degree of integration achieved in political, cultural, economic, social and medical response is probably the real cause of its 'success'. Because of the degree of integration of the response from civil society, economy and government it is also difficult to isolate any one 'factor'. It was the total system that changed. The Ugandan society changed in response to the HIV crisis and the sexual network changed in response to this response. The combination provided a positive feedback that led to a 'tipping point' at which HIV-prevalence plunged to a much lower level. In other words, the two systems, one sexual and private, the other social and public, interacted synergistically to produce a change at the system level.

Apart from being an HIV/AIDS 'success', Uganda's story is a remarkable case study in political and social development. As AIDS became a 'tightening chain that bound everybody together,' the common fear—always politically useful—was alloyed with hope for a new future. The government's integrated public response to AIDS became part of a highly successful nation building programme.

This was accomplished partly through the clear political direction provided by President Yoweri Museveni very early in the history of the AIDS epidemic, but it is hardly due to him alone. Government under Museveni also delegated effective authority to competent and motivated leaders in the Ministry of Health, in churches, hospitals and elsewhere, and helped to provide resources to facilitate their activities. Major international donors provided most of the financial resources, but very little of the actual implementation. Overwhelmingly, Ugandans themselves identified the problems, generated solutions, and integrated these into close knit networks of mutual support that brought to bear the concerted action of society at large. Since this is relatively rare in Africa, or in the world for that matter, it remains all the more remarkable.

EXPLAINING THE 'UGANDA SUCCESS STORY'

The 'Ugandan Success Story', as it has been called, is both encouraging and puzzling.

It is encouraging because Uganda shows that people—Africans in particular—can change their sexual behaviours sufficiently and in appropriate ways to meet a generalised, heterosexual, mature epidemic. In South Africa, President Thabo Mbeki feared that Africans could be accused of being sexually undisciplined and promiscuous. The Ugandan story should have put paid to this notion, but it seems Mbeki has not listened to this part of it. This has led to large amounts of donor funding flowing into the country for AIDS prevention programmes, including millions from the US 'President's Emergency Program for AIDS Relief' (PEPFAR) announced by George W Bush in 2003.[2] 'The Bush Administration basing its AIDS initiative on the success

[2] Loconte 2003.

of Uganda, which has experienced the greatest decline in HIV prevalence of any country in the world,' the conservative, Republican Party aligned Heritage Foundation announced in a briefing paper. According to this policy document, 'the best evidence suggests that the crucial factor was a national campaign to discourage risky sexual behaviors that contribute to the spread of the disease'.[3] But the Bush administration has also simplified and distorted this 'evidence' and its 'message.' The Heritage Foundation policy document declares that 'the White House correctly insists that U.S. AIDS policy be based on these lessons.' Accordingly, basis for US government policy under the Bush presidency is the following:

- High-risk sexual behaviors can be discouraged and replaced by healthier lifestyles.
- Abstinence and marital fidelity appear to be the most important factors in preventing the spread of HIV/AIDS.
- Condoms do not play the primary role in reducing HIV/AIDS transmission.
- Religious organizations are crucial participants in the fight against AIDS.[4]

While each of these 'lessons' is true to a degree, taken as a group they do not begin to account for the complexity of the reality and, together, cannot be held to be valid. This is especially true of the second point. Most of the evidence from Uganda both after and before the USAID pamphlet 'What Happened in Uganda' was published show that abstinence was, at best, a minor factor, and that marital fidelity is neither expected nor practiced by large numbers of people. Instead, the change in Uganda was a systemic change that involved synergies between behavioural and social changes, and changes in the configuration of the sexual network that 'stretched across the country, a tightening chain that bound everybody together.' To neglect this is to nullify the potential for success in other countries.

These simplifications are perhaps excusable, however, because the reasons for this change have been far from obvious. HIV is overwhelmingly a sexually transmitted infection that can only be controlled through limiting or stopping sexual contact among people, but changes in sexual behaviour, though necessary are not sufficient. It is also clear that Ugandans did not stop having sex. Uganda's birth rates did not fall during this period, and total fertility remains one of the highest in Africa. Despite the fact that large numbers of people have died of AIDS, Uganda's population has continued to grow through this time of AIDS.

Behaviour, especially sexual behaviour, does not change easily or in isolation. Patterns of sexual behaviour are generally quite stable. Thus, for sexual behaviour to have changed there must have been larger social, cultural, political and demographic factors that led to, motivated, and sustained these changes. Changes at the level of culture, social organisation, politics, ecology or demography are the 'distal' causes. These 'causers of causes' created an environment that both required change in personal sexual habits and practices (the proximate or immediate causes of the change in prevalence) and magnified their effect. In seeking reasons for the change in Uganda's prevalence rates, therefore, we can separate the more 'proximate' from the more 'distal' causes—that is, personal behaviour changes from the social and ecological context of these changes.

In order to prevent or control sexual infections sexual contact must be limited or prevented, an approach summed up in the slogan '**A**bstain, **B**e faithful to one partner, or use **C**ondoms'. The 'B' factor has also come to include reduction in the number of sexual partners (from two or more to one). None of these 'interventions', however, proves to be effective in itself.

[3] Loconte 2003.

[4] Loconte 2003.

Condoms may be used incorrectly, or may fail. Few people are exclusively faithful to one other person throughout their sexual life-times. And few people envision abandoning sex altogether. There are important temporal dimensions as well. When one begins sexual activity (and thus ends the implied 'abstinence' from childhood) partly determines the age structure of HIV epidemics. When and how multiple sexual partners are encountered—within polygynous marriages, through 'casual sex' (whether married or not), with commercial sex workers, and so forth—also has implications for spread of HIV. The apparent simplicity of the 'ABC message' then, is an illusion.

How behaviour changed

A great deal of research has shown that there was significant behaviour change during the 1980s, that is, during the time when sexual behaviour would have had to change if this were to account for the decline in prevalence beginning in 1992. It is clear, too, that behaviour continued to change through the 1990s. No single change, however, can fully and unequivocally account for the change in prevalence: the change itself took place at a systemic level. Unfortunately, the uncertain impact of any or all *single* factors has made it possible for political and religious groups to assert their views using partial evidence, or by simplifying what is in fact a complex system.

The USAID pamphlet[5] entitled What Happened in Uganda: Declining HIV Prevalence, Behaviour Change and the National Response, led the way both in showing overall decline in HIV prevalence but also in simplification of the context and complexity.

[5] Hogle et al. 2002.

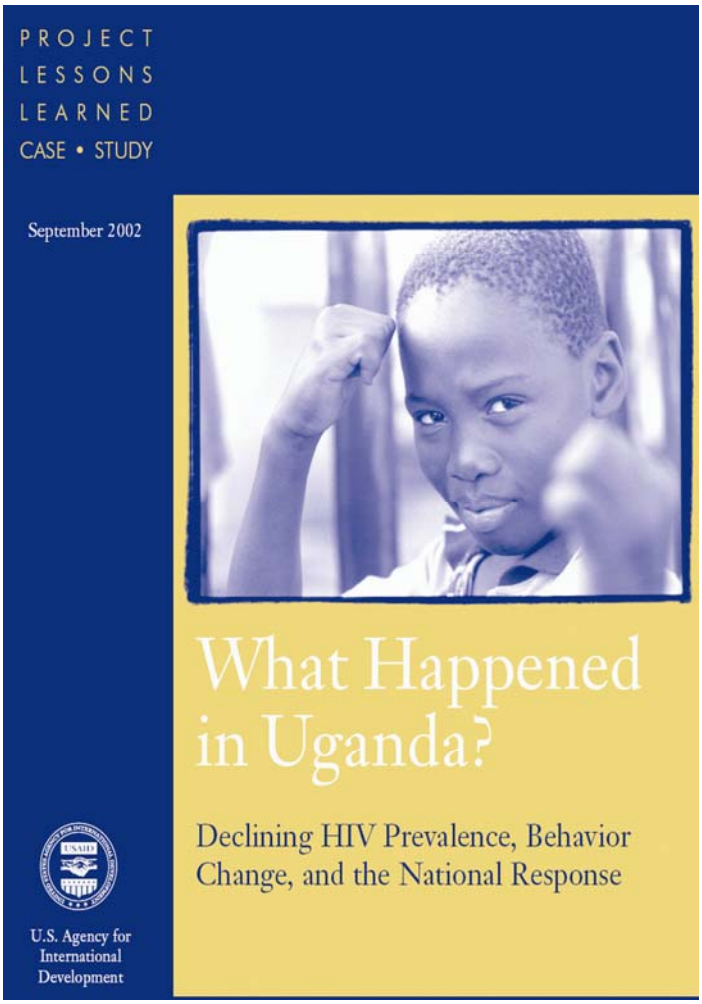


Figure 4.1. The USAID pamphlet that popularised the 'ABC Approach' and gave simplified reasons for HIV prevalence decline in Uganda.

This simplified picture cannot be empirically supported despite its appeal to policy makers. The 2002 pamphlet states in the first sentence that it 'is not intended to provide a definitive explanation for Uganda's AIDS prevention successes during the 1980s and 1990s,' but it has subsequently been taken to be sufficiently definitive to serve as a basis for policy and to justify the allocation of US$ 15 billion for further programmes. More detailed evidence shows that prevalence exhibits marked regional, sub-regional, temporal, and cohort variation. In other words, while HIV *prevalence* peaked *overall* in 1992 and then declined, this was only true of the aggregate population. The reality is more complex. For instance, Whitworth et al., in a decade-long longitudinal study in rural Masaka District from 1989 to 1999 shows that no single age-group or gender follows exactly the same trend shown in he USAID publication.[6] During this period prevalence fell for females aged 13-19, 20-24, and 40 to 44, but increased for those aged 30-34 and 35-39 in the set of rural communities studied.[7] Peaks occur at different times, and trends are different for different age groups in this study. Similarly, the Ugandan data from ANC sentinel survey sites across Uganda show many different regional trends. For instance,

[6] Whitworth et al. 2002.

[7] Whitworth 2002: 1048; Kamali, Carpenter, Whitworth et al. 2000.

prevalence began to decline in Jinja as early as early as 1990, while at Matany decline did not begin until 1994.

It is likely therefore, that no single factor, or single 'behaviour change' factor can account for the initiation of the decline and its continuation. Indeed, there are likely to be different causes for different age groups, regions, and genders. The initial decline, due—directly and indirectly—to mortality at first, was then sustained by significant and major behaviour change in all categories ('A', 'B', and 'C'). Directly, mortality probably reduced prevalence since those who were HIV-positive died, reducing their proportion in the population. This has been referred to as the 'D' factor (in 'ABCD'). Indirectly, mortality also seems to have driven the behaviour change since many Ugandans watched close friends and family die during the late 1980s and early 1990s in significant numbers. Mortality, therefore, was also significant in the cultural environment as a motive for behaviour change.

The impact of AIDS mortality on sexual behaviour change was probably greatly enhanced by a number of important cultural practices. First of all, most deaths occurred in homes, and AIDS sufferers were cared for by their families. Second, Ugandans bury the dead within their living compounds. Graves of family members are often prominent features of the domestic space (see Figure 4.2). Unlike people in many other countries, Ugandans generally do not use public or municipal cemeteries. When I travelled to Mbarara in Western Uganda to conduct research there in June 2003, I had the opportunity to visit the grave of our old family friend, Kamondo, and his family (Chapter 1). The importance of the visual and visceral impact of Ugandan burial practices on behaviour change was brought home to me most forcefully as we stood by his grave after reminiscing about old times. His parents were still alive then, and they also remembered those days of thirty years ago, the time before AIDS when Kamondo was still present in his family home, and as our families got back in touch with each other over the Internet, the significance of his presence/absence could not be doubted.

Thus, mortality from AIDS had a daily visual impact as the living were forced to look at the graves of family members who had died of AIDS. Finally, AIDS orphans are cared for by relatives of the deceased in 99% of all cases. Death from AIDS placed a very significant burden on the living that had to incorporate AIDS orphans into their families, and continue to care for them.



Figure 4.2. Kamondo's grave in the family homestead, with his wife and two of his children. (photograph by R. Thornton)

Condoms may not have been a major factor in initiation of prevalence reduction in the population since they were not available in large numbers before 1992 when the decline in prevalence had already begun. However, they were and are used increasingly through the remainder of the 1990s to the present, and have probably contributed to the continuing decline in prevalence.

Abstinence, similarly, cannot be isolated as causal. Although it was consistently mentioned by all informants in focus groups and key-informant interviews, almost no one gave any concrete examples of abstinence, and most expressed considerable scepticism about whether abstinence was really possible. Appeals for abstinence could only have played a role in delaying sexual debut among youth[8] and in the abandonment of wife inheritance (since widows did not automatically go into a new sexual union). Long term abstinence was never mentioned as desirable. Indeed, those who are entirely abstinent (the very young, the elderly, priests, and for those practicing it for religious reasons) are clearly not part of the sexual networks that transmit HIV and are irrelevant to the epidemiology of HIV. The numbers of abstinent people are probably insignificant in the total population, and the period of abstinence is small relative to an entire lifetime, and therefore unlikely to have a statistically noticeable effect.

Discussion of AIDS was not published in the popular press in Uganda until April 1985, and not discussed as a sexually transmitted disease caused by HIV until the following year. A mysterious disease known as *siliimu* or 'Slim' was, however, already a wide-spread rumour by 1985, though it was not yet connected with HIV or sexual transmission at this time. This is only 7 years between the first *possible* public knowledge of AIDS in Uganda and the beginning of the decline in prevalence. By the end of the 1980s, however, knowledge of AIDS was almost universal, and has remained so. The relationship between knowledge about HIV and AIDS and actual behaviour change, however, remains as problematic in Uganda as elsewhere.

Uganda began a public debate about 'slim'/AIDS in the media from 1985. The government of Tito Okello, who took power after the fall of Obote and before the Museveni government came to power, was the first to initiate steps to control the disease. Dr. Samuel Okware led the first initiatives. Although President Yoweri Museveni was not the first to discuss AIDS publicly, nor the first to make it a matter of public debate, his government moved swiftly after 1987 to develop a comprehensive response that eventually involved all part of society.

President Yoweri Museveni, came to power in January 1986 and made a significant contribution to AIDS control programmes by his early acknowledgement of the problem, and the clarity of his messages about it. His primary contribution, however, was indirect. He enabled the growth of civil society and freedom of the press, and delegated authority to deal with AIDS to the Ministry of Health where competent and motivated people began to design and implement highly effective responses after 1987.

Ugandans generally still believe in marriage, and marry early. The influence of the Christianity and Islam cannot be doubted, but neither can they be credited with making a significant difference by themselves. The important role of faith based communities was part of the synergistic integration of the many other forms of social organisations in Uganda. Marriage and early age of marriage, however, do not necessarily mean that faithfulness to a single partner is the norm, nor that numbers of partners would be reduced as a consequence. Marriage, in fact, may be a kind of sexual licence that heralds the debut of sexual access to many partners, especially for men, but also for women whose husbands are away or travelling. This was especially true in the period before the 1990s. A 1988 study of 15-24 year old school-attending

[8] Kamali, Carpenter, Whitworth et al. 2000.

youth in Jinja found, for instance, that 75.6% of married males and 26.6% of the married females in the sample had more than one sexual partner.[9] Faithfulness in marriage seems to have increased, and practices such as 'wife sharing' and widow inheritance were all but abandoned by the middle 1990s.

Churches and mosques were central in providing information about AIDS and HIV (IEC), and in providing elements of the ABC message. This was facilitated by the fact that Ugandans overwhelmingly belong to three principal religions, Roman Catholic, Church of Uganda (Anglican) or Islam. Only small percentages —1-2% in most surveys in the 1980s or early 1990s—belonged to other churches or to no faith, but this is changing rapidly with conversions to 'born again' and Pentacostal religious groups largely backed by American supporters.[10] Unlike countries in southern Africa, in particular, there seem to be almost no African syncretic or 'independent' churches. This facilitated tremendously the communication of messages related to HIV, AIDS and sexuality.

Although something like 25% of Ugandans are Muslim, there appears to be good communication between Islamic leaders and Christian leaders, and broad agreement on HIV/AIDS issues. The relative unity of religious organisations in Uganda, and their early involvement in information, education and communication interventions from the 1980s is one factor that greatly enhanced campaigns concerning behaviour change, especially towards delay of sexual debut, faithfulness in marriage, and partner reduction. Churches did not at first (1980s and early to mid 1990s) support condoms, but by the middle of 1990s, Christian and Islamic leaders had agreed not to interfere in promotion of condoms, and sometimes to promote them. (Some ten years later, however, under pressure from religious fundamentalisits and the US government PEPFAR programme, many of the religious leaders had reversed their positions on condoms.)

One of the most striking factors in Uganda's approach to AIDS, however, has been the early and comprehensive inclusion of all parts of society in control programmes. Uganda quickly implemented HIV monitoring at sentinel sites, and developed educational programmes that reached all schools. Government agencies and civil society organisations co-ordinated activities between government departments, universities and research institutes, hospitals, churches, labour and employer organisations, NGOs, and other community based organisations (CBOs). By the late 1980s—still early in the epidemic—Uganda had developed a national strategy. By 1992 it had implemented a national co-ordinating agency based in the Office of the President, and established AIDS control programmes in all major ministries became responsible for implementation of education and control measures in their areas of concern. The governmental approach was distributed and decentralised. All levels of government, in all regions, districts, counties and parishes were involved. This approach has gradually incorporated virtually every size and type of organisation in the struggle against AIDS. The intensive, directed and focused participation by all aspects of society must be acknowledged as one of the most important factors in Uganda's success. This does not, however, fully explain the fact that Ugandans have responded to these myriad initiatives.

Within the context of major social mobilisation, Uganda also led the way in voluntary counselling and testing for HIV. This began too late to explain the decline in HIV prevalence in the early 1990s, but has clearly been a major factor in sustaining a behavioural response in many individual Ugandans.

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[9] Turyasingura 1989.

[10] Van Dijk 2000; Meyer 2004; Rice 2004, Epstein 2005.

Ugandans in all walks life have clearly responded by changing their sexual behaviours, and all of the 'factors' were probably significant in reducing the number of sexual partners over the period of the epidemic, and this, in turn, had re-shaped the sexual network at the systemic, national level.

Thus, the 'Ugandan Success Story' cannot easily be attributed to any single cause, or to any type or category of social actor. Personal decisions to change sexual behaviour were made in the context of near universal fear of the consequences of HIV, comprehensive social and cultural support for change, and integrated management of all institutional interventions.

The validity of the Uganda prevalence curve

The USAID 'ABC' study in 2003 was motivated by clear and impressive data that HIV prevalence in Uganda had begun to decline in 1992. This 'curve' was impressive and demanded explanation … if it was real.

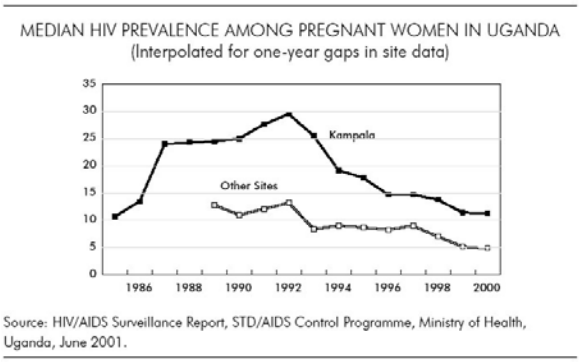


Figure 4.3. The 'Success Story' graph (Hogle et al. 2002)

The data was obtained from sentinel survey sites at Ante-natal Clinics (ANC) in Kampala and six other sentinel sites at Rubaga Hospital (in Mmengo, Kampala, Nsambya Hospital (Kampala), Jinja (Central District), Fort Portal (Kabarole District in the western Uganda), Mbarara (Mbarara District, south western Uganda) and Gulu (Gulu District, northern Uganda). The data was collected and summarised in the HIV/AIDS Surveillance Report of the STD/AIDS Control Programme of the Ministry of Health.[11] HIV prevalence data for 15-19 year-old pregnant women shows a similar decline from 1991, from an average around 30% in 1991 to around 5% in 2000. Prevalence data for this age cohort is a good *proxy measure for incidence* because people of this age will have presumably been infected only recently, and will not have progressed to the point of AIDS illness and death. Since similar trends exist in all of the ANC data, it appeared that most of the decline was due to the lower rate of new infections (incidence) rather than to overall mortality. This in turn suggests that this data is both valid and consistent. Several studies that examined prevalence and incidence over a ten year period in south-western Uganda confirm this suspected declining trend for *incidence*.[12]

This decline had become evident in 1996.[13] This trend has continued to be observed, and is again summarised in the USAID 'Project Lessons Learned Case Study: What Happened in Uganda?' and in other documents.[14] These reports concluded that the decline in HIV

[11] Ministry of Health, Uganda 2001.

[12] Whitworth, Mahe, Mbulaiteye et al 2002; Kamali, Carpenter, Whitworth et al. 2000.

[13] Asiimwe-Okiror, Opio, Musinguzi, Madraa, Tembo, and Caraël 1997; Lyons 1996; Kagimu, Marum, et al. 1996; among others.

[14] Hogle et al. 2002; Bessinger et al. 2002.

prevalence was largely due to 'a complex set of epidemiological, socio-cultural, political, and other elements that likely affected the course of epidemic in Uganda',[15] and that these were often absent in other countries where HIV prevalence has continued to rise.

Attributing causes to the statistical decline in prevalence

But, the attribution causes for these declines is not obvious. Dr. Emmanuel Sekatawa in the Makerere University's Institute for Statistics and Applied Economics, told us in 2003 that a new national prevalence study was in the advanced planning stages, but, while the study "will try to account for changes in prevalence, [there] is going to be a problem of attribution [of causes]. Evaluation and monitoring were not built into [any previous] programmes." Dr. Sekatawa is as keen as others to try to account for the apparent decline, but as a statistician, is extremely cautious about whether this is possible given the available data. "We can't account for the decline," he said. "We don't know how much was due to condoms. We believe that all interventions contributed, but we can't specify which ones. [We] do not even know where condoms go when they come into country … urban or rural. [We] do not know what worked."[16] On a pad of paper in front of him, Dr. Sekatawa drew a graph of a decreasing exponential trend, asymptotic to a line above the x axis, and asked: 'What will bring it down lower?' He shrugged his shoulders.

Nevertheless, there are several factors that are likely to have been involved. The USAID report[17] summarises the 'key elements … in roughly chronological order' that may have led to this decline as follows:

- High level political support with multi-sectoral response set the tone;
- Decentralised planning and implementation for behaviour change communication (BCC) reached both general population and key target groups;
- Interventions addressed women and youth, stigma and discrimination;
- Religious leaders and faith-based organisations have been active on the front lines of the response to the epidemic;
- Africa's first confidential voluntary counselling and testing (VCT) services;
- Condom social marketing has played a key but evidently not the major role;
- Sexually transmitted infections (STI) control and prevention programs have received increased emphasis;
- The most important determinant of the reduction in HIV incidence in Uganda appears to be a decrease in multiple sexual partnerships and networks.

Other, independent study has produced strong support for the reality of the situation suggested by these statistics. For instance, the AIDS Control Project (ACP) in Kabarole District, funded by the German aid agency GtZ, was conducting sentinel surveillance in ANCs every six months from 1991 to 1995 at three sites: Fort Portal, a semi-urban roadside trading centre and a rural community. These data were compared with population surveys conducted in 1993, 1994, and 1995 to determine the representivity of the ANC data. Using this data they concluded that trends seen in ANC data were in fact representative of the whole community, especially in semi-urban and rural communities. For women aged 15-20 there was a constant decline in both HIV and syphilis rates between 1991 and 1996, with declines from 30% to 10% in Fort Portal, from 18% to 9% in the trading site, and from 10% to 5% in the rural site. However,

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[15] Hogle et al. 2002: 3

[16] Interview: Dr. E Sekatawa, ISAE, Makerere University, 4 July 2003.

[17] Hogle et al. 2002

prevalence of HIV infection among women aged 21 to 45 rose during this period, though they appeared to be stable in the road-side trading site and the rural community.[18] This study concluded that the AIDS control project was producing significant results, especially in the area of behaviour change, due to the combination of multiple factors including IEC campaigns; care and counselling; STD treatment; condom education, procurement and distribution; training and capacity building. Although appearing seven years before the USAID report, the 1996 report referred to here came up with many of the same explanations for the apparent decline that had only recently begun to register clearly in the data.

In both these reports, and in Ministry of Health reports, the data from the sentinel sites is usually generalised across the country as a whole. Since the sentinel sites are mostly distributed across southern Uganda, and since absolute numbers of respondents is not available from the Ministry of Health,[19] it may be the case that this data cannot be generalised, and is not valid. However, the consistency of trends across most of the sentinel sites, both across sites and across age cohorts within sites, suggests very strongly that this data is valid and therefore probably generalisable across the country. This of course masks potential 'hot spots' of prevalence and incidence, and does not permit a dis-aggregation of descriptive statistics for different regions or risk groups. In other words, Uganda as a whole probably does indeed present a clear 'success story'—but this does not mean the problem is solved, or that there are no significant populations where HIV incidence and prevalence continue to increase.

Contextualising the data

The positive results in achieving lower HIV prevalence has been achieved with a tremendous amount of personal and often selfless dedication by large numbers of people at all levels of government, business and civil society.

The countrywide prevalence curve represents statistical summaries and therefore does not show regional and temporal differences. The epidemic progressed rapidly across the landscape, and has progressed to older persons over time. For instance, the epidemic clearly began in the south western part of the country and spread rapidly eastward, and then to the north. Prevalence rates in the northeast are still much lower. Matany, in the Moroto District in north eastern Uganda reached a peak of only 7.5% two years later than other sentinel sites in the south and central regions, and declined with the others to below 2% in 2001.[20] ANC data for Nsambya, Rubaga (in Kampala, Central Region), Jinja (Central) and Mbarara (Western) all show higher prevalence rates from 1989 to 2001, while Tororo and Mbale in the Eastern Region show consistently lower rates. All exhibit the same trend, peaking at about the same time (except Matany) and falling to similar prevalence rates between 5% and 10% by 2001.

There is also a temporal factor: the epidemic is progressing into older age groups. Rates of decline have been highest in the youngest sampled age groups (15-19 y.o.) and the 20-24 year olds, while prevalence is higher in older age groups (25-29, 30-34, 35+). Declines in prevalence in older age groups are also generally slower, if they exist at all. The Mbale ANC data in the eastern part of the country even shows an *increasing* prevalence trend for 25-29 year olds, for instance.[21] A 10-year study of HIV prevalence in rural southwestern Uganda[22] shows a

[18] Kagimu, Marum et al. 1996.

[19] To my knowledge, it appears that the raw data is held to be confidential.

[20] Ministry of Health, Uganda 2002, HIV/AIDS Surveillance Report 2002: 7.

[21] HIV/AIDS Surveillance Report 2002: 8-9

[22] Whitworth, et al. 2002.

decreasing trend among male and female 20-24 year olds *beginning in 1989*, when the study began. Prevalence in this age group *decreased* from 21.1% to 8.2% ($p < 0.001$) for females over the ten years of the study from 1989 to 1999, and from 7.7% to 2.2% for males. Prevalence *increased most rapidly*, however, for 30-34 year old females (11.5% to 20%, $p = 0.03$) and slightly less rapidly for 35-39 year old females (9% to 14.7%, $p = 0.06$). This increase for women in their thirties is at least partly due to a 'cohort effect' in which a 'bulge' in prevalence for younger age groups moves through age groups as the population ages. For men, however, the *trend was in the opposite direction*, with a decline from 19.5% to 16% for men 30-34 years old during this period. No male age groups showed an increasing trend, with the exception of men aged 20-29, but none of these trends were statistically significant. Prevalence also increased for 25-29 year old females during the period from 14.5% to 17%.

Overall, however, 'seroprevalence in adults of all ages fell from 7.8% at the first survey round (1989/1990) to 6.4% at the 10th survey round (198/99), a highly significant reduction ($p < 0.0001$).'[23] This is largely because of falling prevalence for males of all ages, and low and declining prevalence for females under 19, and over 40 years old. *Overall*, too, there is an aging trend in the population with the median age of HIV infected women rising from 26 years to 30 years, and for men from 32 years to 35 years old.

None of this data[24] for any age group, male or female, shows the pattern of the trend shown in the USAID publication 'What Happened in Uganda',[25] and elsewhere. Peaks occur at different times, and trends are different for different age groups and for males as compared with females. Dr. Sam Okware, a pioneer in the struggle against AIDS and the person responsible for the Ministry of Health surveillance reports acknowledges that there are likely hotspots that are not sampled. The refugee camps in the north, where large numbers of people who have fled from the depredations of the LRA are likely to have higher than 'normal' prevalence rates, and many rural areas are not sampled adequately or at all.[26]

Thus the geographic and temporal progress of the HIV virus might yet come up with some surprises. This does not negate the validity of the other data that probably does represent a good part of the population adequately.

There is strong evidence in the interview and ethnographic data[27] that shows that knowledge of HIV transmission and AIDS was disseminated as early as the second half of the 1980s and that this did indeed lead to changes in behaviour, but that this was complex, involving many non-governmental actors as a broadly based civil society that began to emerge as early as January, 1986, when Museveni came to power. Communication about the modes of transmission of the HI virus, about the fact that it was incurable and would lead inevitably to death, and about the prevalence of AIDS in the population, was communicated informally, in the press, and on the radio from the beginning of the Museveni government, and possibly even before, even in the dying days of the Obote II regime. Knowledge emerged from many sources, with many different interpretations during the early to mid 1980s, and seems to have pervaded the whole of Uganda (especially southern Uganda) very early in the epidemic. Today, there is virtually 100% awareness of the disease, its causes, and prospects. This is not so say there is consensus:

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[23] Whitworth, et al. 2002: 1048.

[24] Whitworth, et al 2002.

[25] Hogle et al. 2002.

[26] Interview with Dr. Sam Okwari, Commissioner of Health Services, Community Health, MoH, Kampala. 24/7/03.

[27] Asiimwe, Kibombo, & Neema 2003; Kirby 2004; Thornton 2003b.

there is not. There is, however, pervasive knowledge and direct experience that has penetrated all aspects of life in Uganda. It has led to significant changes in behaviour in many ways, including modes of social organisation, modes of governance, politics, the economy, and culture. As a mid-wife in a rural village in Mbarara distict told us, 'I think AIDS is now part of us.'[28]

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