J. biosoc. Sci. (2006) **38**, 7–28, © 2005 Cambridge University Press
doi:10.1017/S0021932005001008 First published online 14 November 2005

AIDS AND EVIDENCE: INTEROGATING SOME UGANDAN MYTHS

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Summary. Uganda is invoked as a metaphor for a host of arguments and insights about HIV/AIDS. However, much of what has been asserted about the country is not based on the available evidence. This paper reviews findings by epidemiologists and anthropologists, and draws on the author's experiences of researching in the country since the early 1980s. It comments on various myths about HIV/AIDS in Uganda, including myths about the origin and dissemination of the disease, about the links between HIV/AIDS and war, and about declining rates of infection. It shows that much less is known about Uganda than is commonly supposed, and it offers some alternative hypotheses for interpreting HIV prevalence and incidence data. In particular it draws attention to the importance of mechanisms for social compliance. It concludes by raising concerns about the current enthusiasm for provision of anti-retroviral drugs.

Introduction

When it comes to HIV/AIDS, Uganda has mythical status. Its name appears in almost every review of the pandemic in Africa, invoked as a kind of metaphor to support a wide range of contrasting arguments. The reasons for all the interest are two-fold. First, some of the very first cases of HIV/AIDS were diagnosed in the south-west of the country in 1982/3 and, since the latter part of that decade, assistance from international agencies has been actively encouraged by the government. There was no denying of the links between HIV and AIDS (in fact some of the early work establishing the link was carried out in Uganda), and the seriousness of the situation was quickly recognized. For these reasons Uganda has been the site of a considerable amount of externally funded research, one aspect of which has been to try to understand what might happen to the pandemic elsewhere. Second, from the mid-1990s it became apparent that in some Ugandan populations, rates of infection were stable or declining. Subsequently, declines have been observed in overall trends and by the turn of the century, Uganda had become established as the one place in Africa where high and rising HIV prevalence had been contained. From having a reputation as the worst affected place in the world, it has become a model for 'best case' scenarios.

https://doi.org/10.1017/S0021932005001008 Published online by Cambridge University Press

Partly because of this dramatic transformation in Uganda's status, remarkable assertions have been made about the efficacy of various public health strategies, procedures of governance and mass behavioural change, as well as about the nature of the trends in infection themselves. Uganda, it seems, is like a cloud in which commentators see whatever shapes they fancy. Journalists, politicians and aid agency staff have become prone to exaggerate and dramatize, and this has clearly affected some of the more academic analysis too. Working in the country as a social anthropologist for prolonged periods during the past twenty-five years, it has been hard not to be bemused by some well-established interpretations, and persistently surprised by the ways in which evidence is ignored, set aside or under-emphasized. This paper draws upon ethnographic knowledge acquired during this time (Allen, 1988, 1989, 1991a, 1991b, 1992, 1994a, 1994b, 1994c, 1996, 1997, 2005; BBC/Open University, 1996, 2002), and reflects on some of the most commonly articulated perceptions of the Ugandan epidemic. It argues that many conventional perceptions are incorrect or partial, and that in certain instances there are alternative hypotheses that might be fruitfully interrogated.

The evidence

Evidence, of course, is a loaded concept. Attending a recent international conference in The Hague on what is known about the global HIV/AIDS pandemic with respect to governance and security issues, it was striking how the experts and policy-makers contrasted two kinds of information – 'data' and 'anecdote'. The former essentially referred to quantified information, including rates of HIV incidence and prevalence, numbers of people raped or numbers of condoms distributed. The latter term was used for qualitative information about a particular place, such as researchers' accounts of the kinds of things rape victims say in South Africa or what happens to men who have sex with men in Thailand. A problem at this meeting, and also more widely, is that 'data' are given much greater emphasis, and 'anecdotes' tend to be set aside as perhaps interesting, but largely irrelevant when it comes to policy. A fetish for numbers is not unusual, but seems to be extreme with respect to HIV/AIDS. It is surely counter-productive. If declining HIV incidence is linked to behavioural changes in the most intimate aspects of social relations, then changes are required in understandings and expectations of accountability and duty – in other words, in what it means to act in a moral way. This is something that cannot be readily numerated, and even if trends in a population become apparent over time, detailed localized information is the most likely way to find out why they have occurred. The juxtaposition of 'data' and 'anecdote' also masks a great deal. 'Data' may be based on careful, longitudinal epidemiological population studies, or they may be no more than a guess, elaborated from the most flimsy information. Meanwhile, so-called 'anecdotes' may be the product of in-depth ethnographic field research, or may be no more than something said by an aid worker in a bar to a journalist. Usually it is not difficult to look more carefully at where evidence comes from, but perhaps it is naive to propose that this would be a good idea – too often the purpose of presenting both 'data' and 'anecdotes' about AIDS is merely to illustrate entrenched assumptions. In Uganda the problem is acute.

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Like other African countries, the national prevalence rates for Uganda are mainly derived from antenatal surveillance. Anonymous testing is carried out at selected clinics on blood drawn from first-time visits during a given pregnancy of women attending antenatal clinic. There are several well known problems with this method. These include the following: first, HIV-positive women are less likely to become pregnant than women who are HIV-negative; second, in African countries surveillance sites tend to be based in urban and peri-urban locations where rates are usually higher than in rural areas; third, data are not usually available with which to adjust antenatal surveillance for AIDS-related mortality; fourth, the method may lead to an over-representation of younger mothers and may not accurately reflect the prevalence rate in the 'sexually active population', and fifth, antenatal prevalence data may not be closely linked with rates of incidence (i.e. rates of new infection). It might be added that if anti-retroviral treatment becomes effective at reducing mortality, a rise in HIV prevalence should be assessed as a positive outcome.

Another problem that is commonly overlooked is that patterns of antenatal surveillance coverage vary hugely from country to country and region to region. In Botswana, for example, rural areas are relatively well resourced with clinics. According to the Botswana Family Health Survey of 1988, over 90% of women consulted a trained health worker during the course of pregnancy, and almost 80% delivered under the supervision of a doctor or bio-medically trained midwife (Government of Botswana, 1989). In Uganda, formal health facilities in many places are minimal. Over 80% of the population live in rural areas, 63% more than 5 km from a public or NGO clinic. Just 25% of deliveries actually take place in a health facility, and 60% of clinics have less than the assessed minimum staffing levels (Ministry of Health, 2005a; see Appendix note at end). In addition, fifteen of the 21 sentinel sites are in the south of the country. The six northern sites only began operating in 1993 and are clustered in the north-west. Only one site, at Matany in Moroto District, covers the entire north-east.

A bias towards southern Uganda is also a limitation with the most robust data available on the country. Longitudinal, epidemiological, population surveys are the only reliable method of measuring the level of HIV infection within age cohorts and among men and women, making it possible to assess changes in rates of incidence. However, they require political stability and governmental support, and are expensive and time consuming. Very few studies of this kind have proved possible in Africa, even in high-prevalence countries such as Botswana. Of the three most important, two have taken place in the neighbouring districts of Masaka and Rakai in south-west Uganda (Rakai District is located just to the south of Masaka). Both these studies have tracked populations from the end of the 1980s in the part of Uganda in which HIV/AIDS has probably been endemic for the longest. The first diagnosed Ugandan AIDS cases were from Kasensero in Rakai, and for some time an unspecified local disease known as 'slim' had been linked to excess mortality. The two studies are run independently, and began to publish findings in 1995. The Masaka study monitored 10,000 people living in a cluster of fifteen villages. Results from the first five-year follow-up showed little change in overall seroprevalence (from 8·2% in 1990 to 7·6% in 1994). However, there was a highly significant drop noted among males aged 13–24 years (from 3·4% to 1·0%), and a less dramatic drop among females of the same

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age cohort (from 9·9% to 7·3%). This was the first report of a decline in HIV-1 prevalence among young adults in a general population in sub-Saharan Africa with high overall HIV-1 prevalence (Mulder *et al*., 1995). Soon afterwards, similar declines were also noted from the more heavily infected population tracked in Rakai, and subsequent results indicated that downward trends at both sites were being sustained (e.g. Mbulaiteye *et al*., 2002).

Although there had been some indications that HIV prevalence rates might be declining in certain parts of Uganda from 1993, it was the findings from the south-west in 1995 that transformed the country, almost overnight, from an HIV/AIDS disaster into an apparent success story. Sceptics might have pointed out that generalizing from the observed declines in the mainly rural south-west might not be appropriate. But such voices were largely ignored, and the trends in antenatal surveillance prevalence data from almost all sentinel surveillance sites during the remainder of the 1990s reinforced and sustained optimistic interpretations. The rates of declining prevalence at sentinel sites have varied substantially, with the steepest decline being recorded at some urban sites (Ministry of Health, 2003). At Mbarara, reported prevalence peaked at 30·2% in 1992 (the highest rate recorded anywhere in Uganda), declining to 10% in 2000 and then rising slightly to 10·8% in 2002. Median antenatal surveillance data from all sites in 1993 gave a national rate of just under 12%. This had declined to around 5% in 2000, and has subsequently risen to about 6%.

A further source of data relating to national rates of infection has also become available at the time of writing. In 2004/5 a 'sero-behavioural survey' was carried out under the auspices of the Ugandan Ministry of Health. A total of 18,000 women and men aged 15–59 were tested for HIV and interviewed about their knowledge, attitudes and practices. Only preliminary results have so far been made public (Ministry of Health, 2005b). According to this survey 7·9% of adult women are HIV-positive and 6% of men. People living in urban areas had an infection rate of 10·7% compared with 6·4% in rural areas. This is not the first seroprevalence study based on testing a random sample of the population. A survey in 1992 found a rate of 18%. However, the earlier surveys are not directly comparable, because coverage of areas outside of the south was very limited. An advantage of the new study is that it has attempted to sample populations from the whole country. The highest rates have been found in Kampala (9·2%), followed by what is termed the 'central region' – including Masaka and Rakai (9·1%), and the 'central north' (9·1%) – including Gulu municipality, from where the 'regional' population sample appears to have been taken (according to a personal communication with a locally based WHO staff member).

In addition to the population studies, the antenatal sentinel surveillance, and the recent national survey, there is a great deal of other information on HIV/AIDS in Uganda based upon studies of particular groups. It is of very variable quality. Much of it is based on so-called 'anecdotal' or 'qualitative' evidence, including anthropological fieldwork (for useful reviews of this literature, see Bond & Vincent, 1997; Lyons, 2004). Anthropological research in Uganda has mostly been linked either to clinical and epidemiological programmes or to projects supporting community resilience and participatory development. It has been particularly useful in highlighting the lived experience of the disease, and in investigation of changes in social

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relations. One study from the end of the 1980s, for example, noted that at Kitovu hospital in Masaka, two adults were required to look after each patient with AIDS, with probably a third delivering food (Bond & Vincent, 1997, p. 91). However, a problem with the applied anthropological studies of Uganda is that they have tended to be constrained by the need for quick results, have been unable to study sexual practices in sufficient detail (partly because it is not something that lends itself to participant observation methodology), and have also been limited to those places in the south of the country of primary concern to donors and biomedical investigators. There have also been several broader anthropological studies that have located the epidemic within the context of discussion and analysis of the livelihoods and social relations of particular groups (e.g. Wallman, 1996; Whyte, 1997), or have offered a critical commentary on established ways of thinking (e.g. Susser *et al.*, 1997; Whyte *et al.*, 2002; Allen & Heald, 2004). These have been less geographically restricted, but few in number, partly reflecting a general withdrawal of the discipline from engaging directly with HIV/AIDS in response to demands for targeted investigation with preordained conclusions (Heald, 2003).

So, from the various sources of information available, what can be claimed with confidence about the epidemic in Uganda? Qualitative evidence has described how AIDS-related morbidity and mortality have affected people, especially in the south and south-west. There has been relatively little of the kind of denial observed in southern Africa – although stigma remains an issue. For almost two decades there has been widespread awareness that HIV/AIDS is a serious problem. Ethnographic and other accounts continue to highlight the appalling consequences of the disease and suggest that its full impact has not yet been experienced, because of its unique epidemic curves (Barnett & Whiteside, 2002). Evidence that things are improving in terms of declining HIV incidence and prevalence is based on results from the population studies in Masaka and Rakai, and the data from mainly urban and peri-urban antenatal clinics, mostly located in the south. The extent to which these data reflect overall national rates of infection is open to question. Very little is known about HIV/AIDS rates in the north of the country. Nevertheless, it is clear that prevalence rates have not exploded since the early 1990s in the way that they have in southern Africa.

Although it remains disappointingly partial, evidence about the Ugandan epidemic has accumulated over time. However, this has not had such a direct bearing on analysis and policy as might be supposed. Anthropologists have often felt that their insights are ignored. But the findings of epidemiological studies too are taken out of context, set aside, or used selectively to support preconceived notions. Interpretations of HIV/AIDS in Uganda have taken on lives of their own, in which evidence of all kinds plays a secondary role.

Myths of origin and dissemination

Until the mid-1990s, Uganda was widely thought to have the highest HIV/AIDS rates in the world. There were no comparative data with which to support this view, but stories about a disease locally called ‘slim’ having killed people for a long time, the

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early diagnosis of AIDS cases, and the willingness of President Museveni's government to allow investigation and public discussion about the disease, all contributed to the idea that things must be much worse here than elsewhere. It also led to assumptions that HIV/AIDS had originated in south-west Uganda, or somewhere nearby, and played a part in fostering assertions about a 'black plague' with distinctly racist connotations (Chirimuuta & Chirimuuta, 1989). A host of speculative theories about how the disease emerged dominated the early debates, and have remained controversial (a good review can be found at http://www.avert.org/origins.htm). It is now generally accepted that HIV-1, the form of HIV found in Uganda, originated from a strain of Simian Immunodeficiency Virus (SIV) that has been observed in certain chimpanzees from west-central Africa. Exactly how the virus mutated and jumped species is unknown, and probably always will be, although hypotheses are still being presented with apparent confidence. The most widely publicized explanation has linked the origins of the HIV-1 epidemic with the testing of an oral polio vaccine given to about a million people in the Belgian Congo, Rwanda and Burundi in the late 1950s (Hooper, 1999). There has been a great deal of argument about whether or not this could have been possible, and some analysts, including Hooper himself, remain unconvinced by the various rebuttals (see, for example, Hooper's own website at http://www.aidsorigins.com). Even if he is correct, it can only be a partial explanation, as it relates to only one HIV sub-type (group M), but his work has fed conspiracy theories about unscrupulous governments and medics.

Leaving aside myths of origin, what about myths of dissemination? In the 1980s most knowledge about the spread of HIV/AIDS was associated with 'core' and 'risk' groups in rich countries. In Uganda the focus was truck drivers and sex workers (coyly referred to as 'barmaids'). Early seroprevalence surveys in Rakai District found a sample of lorry drivers to be 33% positive and 'barmaids' to be 67% positive (Carswell *et al*., 1989). These results were then assumed to be widely representative. For example, an Economist Intelligence Unit Country Report of 1990 quoted these figures as if they were rates for these high-risk groups for Uganda as a whole (Bond & Vincent, 1997, p. 90). In fact, data on rates among drivers and sex workers in other parts of the country have remained sparse. It is also far from clear that rates among high-risk groups are a bridge of infection to the population as a whole, because they may be socially contained or ostracized. Other studies have pointed to 'high-risk behaviours' or 'high-risk populations' in some border areas associated with intense trading activities and in urban centres (Lyons, 2004). Antenatal prevalence data indicate that this broader approach to risk is probably more insightful.

Another limitation with the risk group literature on Uganda is that, unlike comparable work on richer countries, non-sexual transmission of HIV/AIDS is under-emphasized or largely discounted. This relates to the most prevalent assertion of all about HIV/AIDS in Uganda – that infection is a consequence of heterosexual sexual intercourse. No sensible person denies that sexual intercourse is a major cause of infection. But what is the evidence that it has been as important as is generally assumed? In recent years, mother-to-child transmission has been given greater prominence, at least in part because there appear to be relatively cheap ways of limiting it. Nevertheless, transmission of HIV in Uganda and Africa as a whole is widely believed to be due overwhelmingly to unsafe, 'conventional' sexual contact. Is

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this a myth? Perhaps not, but it is certainly an idea that has accrued mythical elements.

The point has been put forcefully by a series of articles that appeared in the *International Journal of STD and AIDS* in 2003. In one of these papers, Gisselquist *et al.* (2003) examined data from studies of risk factors of HIV in Africa and proposed that the proportion from sexual transmission could be estimated. It is concluded that although data are frustratingly limited, they indicate that sexual transmission explains about 30% of HIV incidence. Among the epidemiological evidence that they investigated was the population study in Rakai, south-west Uganda. Here they noted that there was information about transmission between serodiscordant partners, and that it was less than a third of what would be necessary to sustain the epidemic. In a companion paper, bold statements were made about 'mounting anomalies' in the epidemiology of HIV, which might be explained with reference to other modes of transmission, notably poor medical hygiene such as the use of contaminated needles (Brewer *et al.*, 2003).

Not surprisingly, the response from international health agencies and many senior epidemiologists has been critical. A meeting was held at the WHO in Geneva to discuss the findings, focusing in particular on the argument about unsafe injections. Reportedly, the prevailing view amongst experts at the meeting was that the re-use of needles or syringes in the absence of sterilization is not sufficiently common to play a dominant role in HIV transmission in sub-Saharan Africa, and that sexual transmission was responsible for the majority of cases (WHO, 2003; Schmid *et al.*, 2004). However, the arguments of Gisselquist and his colleagues have not been rebutted in detail, and many of the issues they raised are surely worthy of further investigation. Anthropologists working in Uganda, for example, have repeatedly drawn attention to local healing and ritual practices involving cutting and incisions, as well as the very widespread re-use of needles and syringes (Allen, 1991b, 1992; Whyte, 1997). Systematic studies on needles and syringes were carried out in two areas of Uganda in 1992/93. At the research site in the east it was found that 63% of households possessed needles and syringes and that 21% had vials of injectable medicine at hand. In 25% of households at least one person had received an injection in the past two weeks, and 17% of injections were administered at home. The figures from the site in the west were even higher: 83% had equipment and 34% had vials of injectable medicine at home (reported in Whyte *et al.*, 2002, p. 108). The majority of home-administered injections in Uganda are intramuscular (chloroquine and penicillin), so the chance of HIV infection is low in any particular instance, but the scale of needle re-use must represent an accumulated risk. Moreover, I have found that more than one family member is sometimes injected with the same needle consecutively. At the very least it is reasonable to conclude that this problem is under-reported and under-emphasized. Similar points might be made about blood transfusions. These are now supposed to be screened, but from personal observations were manifestly unsafe during the 1980s.

Whatever the merits of the argument about transmission of HIV by unsafe medical practices, it is hard to avoid the conclusion that the almost exclusive emphasis on sexual transmission has been more than simply a response to the available evidence. It is also odd, given the emphasis, how little information about sexual

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practices has actually been collected. In Uganda virtually nothing is known about anal sex or homosexual sex. Both are basically taboo subjects in the country itself, and it is almost as if international researchers have not wanted to ask 'indecent' questions. Information about heterosexual vaginal intercourse too seems to be mainly based on assumptions. There have been reports about dry sex and violent sex, but no careful analysis of how and why sexual practices change, and how and why they differ between partners and from area to area. Significantly, orgasm is a word that does not appear in the academic literature on Uganda – in marked contrast with *Red Pepper* and other Kampala-based newspapers, in which just about all aspects of the sex act are something of an obsession.

On the one hand, it seems that academic research on the sex act in Uganda, as in Africa more widely, is constrained by a perceived need to be both sensitive and circumspect. On the other hand much of what has been claimed is based on little more than speculation, and is sometimes affected by very misleading assumptions about a homogeneous African sexuality. One particularly influential model has been the work of the demographer J. Caldwell and his associates. Ethnographic accounts from all over Africa, including Uganda, are mined for anecdotes about local customs of marriage, kinship and fertility to show that the core of African society is its emphasis on ancestry and descent (Caldwell *et al*., 1989; Caldwell & Caldwell, 1990). This, it is argued, means that reproduction for the lineage will normally be privileged over safe sex. Some aspects of Caldwell's work are thought provoking, but the fall-out has been that the very thing that gives good ethnographic research its power, namely its engagement with the complexities of the local, are subsumed into generalizations. As Suzette Heald has observed, this has had pernicious consequences. It involves disregard for the particularity of moral norms and encourages a new pathologizing of Africa (Heald, 2003, p. 217). Amongst other things, it has deflected attention away from the dismal failures of public health programmes towards lazy and misinformed ideas about 'traditional culture' acting as a barrier to behavioural change.

Myths about war and HIV/AIDS

Another hypothesis put forward in the early years of the epidemic was that HIV/AIDS spread in Uganda as a result of war. It is an idea that has taken on a new significance since the turn of the century, and requires close scrutiny here.

Following the Tanzanian invasion of 1979 there were civil wars in various parts of Uganda, with fighting initially concentrated in the south-west and in the Luwero region immediately to the north of Kampala. Rape by soldiers and forced population displacements were common. Following the capture of power by Museveni's National Resistance Army, the areas of fighting shifted to Gulu and Kitgum in the north, where it is still occurring. In the late 1980s there was a perception in southern Uganda that AIDS was partly a legacy of the upheavals inflicted upon the people by northerners and Tanzanians. A paper published in 1991 by Smallman-Raynor and Cliff looked at the available evidence for this thesis and compared it with two other established hypotheses: that AIDS had been spread by truck drivers passing through towns or by labour migrants. At the time there were no longitudinal HIV prevalence rates. The authors used Ugandan Ministry of Health data up to the end of 1989 on

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the 12,444 diagnosed AIDS cases, and related these to reported places of residence. From this an 'incidence rate' was calculated by using the 1980 census. This rate was then analysed with reference to recruitment rates into the Uganda National Liberation Army (UNLA), based on reported 'tribal' composition of the army in November 1979. Smallman-Raynor and Cliff took pains to emphasize that the evidence from which they were working was at best sketchy, but tentatively concluded that military-associated factors were more significant than the other explanations (Smallman-Raynor & Cliff, 1991).

There are obvious problems with the case presented. All the data sets used were highly problematic (for example the mechanisms for diagnosing AIDS patients varied widely across the country). It is also debatable that the numerical proxies used were adequate. Even if it is accepted that ethnic patterns of recruitment in the UNLA could be a proxy for the effects of military activity, as the authors themselves note, the ethnic composition of the UNLA altered radically in the course of the early 1980s. Moreover, the rates of infection in the general population of Rakai must have been high well before the Tanzanian invasion passed through the area in order to explain the excess mortality associated with 'slim' in the early 1980s. The argument in the paper that civil war spread the disease from the south-west to the rest of the country is driven by the rates of reported AIDS cases in Kampala and Gulu. But these rates might be explained by non-military movements of populations both before and after the Tanzanian invasion. The high Gulu rate might have been due to non-military movements of people under Obote and Okello, and by the movement of non-combatants following the fall of the Okello government. It might additionally reflect the fact that there had been many Acholi soldiers in the UNLA, and they might have played a significant role in spreading the disease in their home district. But whether they actually did so is unknown. There is some evidence that they were ostracized (Allen, 1991a). Also, if war was the main cause of the disease spreading, it seems strange that the reported rates in Luwero and West Nile (Arua and Moyo Districts) were relatively low. This is where fighting was most intense during the early to mid-1980s. In sum, there are no data in the paper to indicate that the collective actions of soldiers themselves drove the epidemic, which is not to say it was not important, just that there was no evidence to draw upon. The data used to assess the alternative explanatory models were similarly flawed, so not much weight can be given to the conclusions. Essentially the paper was a pioneering piece, which aimed at opening up the HIV/AIDS risks from war for further investigation. However, much more than this has been read into it.

In recent years there has been growing international concern and interest in the connections between AIDS, security and armed conflict. This has been largely a response to perceived threats in rich countries and to the revelations about HIV rates among UN peace-keeping forces, but there has also been an acceptance that in some parts of the world, notably in Africa, war may be driving the pandemic (see, for example, UNICEF, 1996). One indication of this was UN Security Council Resolution 1308 of July 2000 which officially recognizes 'that the HIV/AIDS pandemic is . . . exacerbated by conditions of violence and instability'. Unfortunately, good evidence remains sparse. In this context, the paper by Smallman-Raynor and Cliff has taken on a significance that the authors could not have anticipated. A

https://doi.org/10.1017/S0021932005001008 Published online by Cambridge University Press

striking example can be found in the widely cited flagship World Bank report called *Breaking the Conflict Trap*. Citing the article by Smallman-Raynor and Cliff, the authors suggest that a far reaching claim might be made: 'the origin of the global pandemic is a consequence of a particular civil war'.

> The hypothesis, for which credible evidence exists, but which is far from proven, is that the conditions of war enabled what would otherwise have been a routine, localized outbreak to spiral out of control. Even if we attach only a small likelihood to this explanation being correct – say 10% – then one-tenth of the global cost of the AIDS pandemic should be added to the estimated global cost of civil war . . . Epidemiological research on the spread of HIV/AIDS points out that the initial spread of HIV is closely associated with the war in Uganda in 1979 ... The spread of AIDS from the south to the north of Uganda exhibited the same route as the one Idi Amin's soldiers followed. . . .' (Collier *et al*., 2003, pp. 41, 47)

Leaving aside the confusion between Amin's soldiers and the soldiers of the invading UNLA – to which Smallman-Raynor & Cliff's data refer – this is a quite astonishing interpretation of their paper, a kind of updating of the origins myths discussed above. But the World Bank report is not the only recent publication to stress the significance of war for HIV/AIDS and to highlight the significance of the Tanzanian invasion of Uganda. The influential anthropologist and human rights activist Alex de Waal refers to the invasion in a piece graphically entitled 'Fucking Soldiers'. He argues that: 'The risk-embracing nature of military life makes a mockery of safe sex messages . . .', and that 'A big part of the blame for Africa's AIDS epidemic must fall on wars, soldiers and cultures of militarisation' (de Waal, 2002). De Waal recognizes that the evidence base is weak – no more than a 'compilation of anecdotes and snatches of data'. Nevertheless, the arguments he presents carry weight, not least because they appear to be 'common sense'. They are echoed in many aid agency and media accounts, and have now become so common in reports on HIV/AIDS in Ugandan war zones that observers and activists have accepted the links between militarization and high infection rates as an established fact. Thus, the current HIV/AIDS situation in the north is contrasted with the apparent achievement in containing the epidemic in the south.

In 2004, for example, World Vision, an agency that has been working in the war zone for many years, claimed that Uganda's

> . . . protracted civil war threatens to unravel the country's dramatic improvements as AIDS rates skyrocket in the country's northern region . . . [T]he 18-year war between the Ugandan government and the rebel Lord's Resistance Army (LRA) . . . has increased the HIV rates in parts of the north to 11·9% – nearly double the rest of the country . . . Many women, especially those in the displacement camps, find that they can only get food, soap or money in exchange for sex. Girls who are abducted by the LRA are often given to commanders as 'wives' and sex slaves. Those who 'night commute' and sleep in the cities to avoid abduction are often raped there. (World Vision, 2004a, b)

World Vision's analysis was immediately seized upon by the main international media organizations, and repeated as an objective assessment of the situation, based on in-depth local level knowledge. For example, the BBC reported that 'doctors say' that, 'About half the girls who escape from the rebels are found to be HIV positive,' (BBC, 2004; see also Reuters, 2004a, b; IRIN-UNOCHA, 2004). Somewhat similar points have also appeared in many other reports and articles (e.g. Dolan & Bagenda,

https://doi.org/10.1017/S0021932005001008 Published online by Cambridge University Press

2004) and, during fieldwork in 2005, I found that assumptions about HIV/AIDS escalating out of control were being taken for granted among most aid workers and government officials working in the war-affected region.

There is no doubt that the situation in northern Uganda is appalling, and has been for a long time. There have been dreadful abuses and disease-related mortality has been reported to be very high (MSF, 2004; Allen, 2005; WHO, 2005). However, is there really evidence that the war is pushing up HIV incidence rates? The straightforward answer is that no incidence rates have been recorded in northern Uganda, but antenatal prevalence rates suggest that incidence might be going down, not up. World Vision makes the point that the war has increased the HIV rates in parts of the north to 11·9%, which is nearly double that in the rest of the country. It is a point that local informants reiterate and has appeared in numerous newspaper articles. It is presumably based on the antenatal sentinel surveillance at Lacor hospital near Gulu, which recorded a rate of 11·9% in 2002. This was indeed the highest rate at any surveillance site in the country for that year. The rate was more than double the national average, but it is misleading to interpret this as being double the rate in the rest of the country. Several other sites also had high rates. At Mbarara in the south-west it was 10·8%. Also the rates at Lacor have not been on an upward trajectory. Since it became an official surveillance site in 1992, rates have declined from 27·1% (Accorsi *et al.*, 2001, 2005; Fabiani *et al.*, 2003). Indeed, the decline in antenatal prevalence recorded at Lacor is one of the steepest recorded anywhere in the country (Ministry of Health, 2003, p. 10).

As has been noted above, there are problems with reading too much into antenatal data. They are not a good indicator of overall adult prevalence. Nevertheless, the trend at Lacor is dramatic. There are, moreover, other data available at Lacor that are equally positive. The hospital has run tests on a sample of all in-patients referred to the hospital. Most of these people are already very seriously ill. The rate of those with HIV has declined from 74·2% in 1994 to 44% in 2002. In addition, in some years all TB and cancer cases have been tested. Among cancer cases, HIV rates declined from 21·2% in 1997 to 13·2% in 1999. Among TB cases, HIV rates fell from 57·7% in 1994 to 44·6% in 1999. They have risen steeply to 69% in 2002, but this is explained by the fact that the hospital changed its admission procedures to only accept terminal cases as in-patients.

From the Lacor data it seems likely that incidence rates were higher in the past than they have become since the mid-1990s, indicating that the upheavals of the 1980s, including the migrations from the south of Uganda following the overthrow of Okello in 1986, may indeed have been a factor. The war in the area from 1986 up until the early 1990s may also have contributed, although it is unclear how much. The declines in reported prevalence at Lacor since the mid-1990s may be partly explained by high AIDS-related mortality, but the evidence of that is unclear. Malaria and infectious diseases of childhood are reported to be the primary disease burden by staff at Lacor hospital (Accorsi *et al.*, 2005). In the general population, AIDS-related mortality is likely to be high among adults, but there seems to be no evidence that it is higher than in other parts of the country.

Lacor hospital, it should be mentioned, is located near the largest urban centre in northern Uganda. If patterns observed in antenatal rates in other parts of Uganda are

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anything to go by, it might be anticipated that antenatal rates would be much higher than in more rural locations. There is some evidence for this from antenatal surveillance that has been carried out by an Italian NGO between 2002 and 2004 at the two main hospitals in Kitgum town, a much smaller place than Gulu, and at Kalongo in Pader District, which services largely rural areas. Prevalence rates vary from 4·6% to 9·9%, with the lower rates being recorded at Kalongo. These rates are based on surveillance of 14,570 women who chose to participate in a 'prevention of mother to child transmission' programme. So it is likely that these rates too are significantly higher then the rate in the adult population as a whole. Interestingly, they suggest a similar pattern to that recorded by a comparable programme in peaceful locations in central Uganda – at Hoima town a rate of 8·1% was recorded while in rural Kigorobya the rate was found to be 4·3% (Ciantia, 2004).

Drawing on fieldwork in 2004/5, an alternative hypothesis seems appropriate about the war in northern Uganda. From the mid-1990s most people living in the war zone have been compelled to reside in IDP camps. These camps are controlled by the Ugandan army and administered through a system of camp commanders and the directly elected local councils. Movement in and out of the camps is restricted, and there are curfews from soon after dusk. It is hard to move far from the camps during the day, even for purposes of cultivation, because there is a threat of attack from the LRA or the local soldiers may suspect collaboration. Sanitation and housing is very poor, with thousands of people being confined in small areas. There is very little privacy, and social interaction is quite tightly regulated, making sexual activities almost impossible to hide. There is also a considerable amount of AIDS awareness. Soldiers interviewed are amongst the few people who openly use condoms. Women who spend time at the barracks are well known and are generally considered to be the soldiers' wives. Around 80% of the population are now living in these camps, and in Gulu, Kitgum and Pader Districts people have been living in them for the best part of a decade. There are also striking differences between Gulu town today and the situation in the late 1980s. In the late 80s, for example, it was common for bars and lodges to be frequented by sex workers. This is no longer allowed to occur. While not disputing that there are cases of rape and transactional sex, there does not seem to be evidence that it is as systematic or as widespread as some accounts have indicated. Rather, social control mechanisms have been imposed, partly for security or military reasons, and partly also because of HIV/AIDS awareness. This has made the spread of the virus by such behaviours less likely.

It should also be mentioned that both the UPDF (the Ugandan army) and the LRA have rules about their own sexual activities. The UPDF have been encouraged to use condoms and rape is, in theory, a punishable offence. It does happen, but many of the soldiers working in the war zone are locally recruited and they are stationed at the same locations for several months. They become integrated into local networks of accountability. Also, contrary to some reports, the LRA has not raped indiscriminately. Abducted girls are given to combatants and senior commanders as a reward. The girls become these men's 'wives' and are expected to produce children. Other men are not supposed to touch them. A few women reported that they had not been raped or 'married' during their period of abduction, but had been used as servants because they were suspected of having AIDS. Given the statements made by World Vision

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and reported by the BBC, staff at the agency's reception centre in Gulu town were interviewed about HIV and AIDS cases. The clinic at the centre had no means of testing for HIV, and had no data on those returning from abduction being HIV-positive. However, some of the other reception centres have arranged HIV tests at one or other of the hospitals. The results are kept confidential, and have not usually been collated to give a rate of infection for this specific group. An exception is the Rachele centre in Lira town, where almost everyone who might have been exposed to infection is counselled and tested. The rate of those found to be HIV-positive is less than 1%.

There is no doubt that atrocious sexual abuses have occurred, but there does not seem to be evidence that military activities and rape are driving the HIV/AIDS epidemic. On the contrary, at least in recent years, militarization and the imposition of social controls may have been a factor in rates declining. War might be a reason for rising rates, but it is just as likely to be a reason for rates falling. As several authors have recently pointed out from evidence elsewhere in Africa, it depends on local circumstances (e.g. Speigel, 2004). Finally, evidence from northern Uganda indicates that the highest HIV rates are at urban centres. This suggests that when the mass of the population is finally released from the IDP camps they may become vulnerable to HIV infection if they head for the towns in search of work.

Myths about declining rates

Since the mid-1990s myths about the origin and spread of HIV/AIDS in Uganda have been joined by myths about their decline. One of the most common is that HIV/AIDS rates in the country have fallen from 30% to less than 6% in a decade. It is a claim that continues to be made – the US global AIDS co-ordinator repeated it again during a visit to State House in Uganda in May 2005 (New Vision, 2005). For reasons already discussed, it has to be set aside as nonsense. Nevertheless, it is clear that Ugandan rates have not risen in the way they have in southern Africa. The usual explanations for this relate to policy interventions, and Uganda has become a benchmark for what governments, international agencies and activists should try to do elsewhere. But what is the evidence that it is policy interventions that have made the difference? It turns out that there is surprisingly little.

Although it is often ignored, a crucial point in assessing HIV/AIDS policy in Uganda is that the epidemic in significantly older than in southern Africa. This is important for two reasons. First, it is reasonable to expect that HIV/AIDS, like any other epidemic, will run a natural course. Its virulence within a particular population will decline over time. How long this will take with HIV/AIDS is unknown, but it is possible that the declines in infection rates noted in parts of Uganda may reflect such a trend. It needs to be borne in mind that most of the Ugandan population reside in relatively stable rural locations, and this may have contributed to less genetic proliferation of the virus (there appears to be little of the virulent HIV-1 Clade C). Second, a disease locally referred to as 'slim' had already been causing deaths for some time in south-west Uganda before those infected were diagnosed as having HIV/AIDS in 1982/3. Experience of AIDS-like symptoms and excessively high mortality was already quite widespread in some places. This alone may be a reason

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for some of the declines in recorded prevalence. It is also quite possible that behaviour had already begun to change in the south-west of the country as soon as the link with AIDS was made, and before the national HIV/AIDS programme was set up in 1987/88. This seems to be an implication of the Rakai and Masaka population studies, which indicate that incidence must have been stabilizing for certain age cohorts for some time (Parkhurst, 2002).

So it could be that policy measures had relatively little to do with the apparent Ugandan success. There is, however, evidence that some of the campaigns have been very effective in changing attitudes and perceptions. Although it is hard to show that they directly changed behaviour, they did quickly increase awareness of the disease in Kampala and southern parts of the country. As in Botswana, which introduced programmes at about the same time, the symptoms of AIDS were often incorporated into local bio-moral interpretations of affliction. But, unlike Botswana, the diversity of Ugandan society mitigated against a cohesive alternative explanation of the disease. Various, relatively small-scale cults of affliction emerged, but there was less resistance to the formal public health care messages. Indeed, one of the most remarkable aspects of the HIV/AIDS campaigns in Uganda is the way they have involved everyone including international agencies, NGOs, government ministers and journalists, to pop stars, Catholic priests, local councils and soldiers. There has indeed been a considerable degree of mass mobilization. Not surprisingly, the combination of apparently declining HIV rates has been associated with this level of activism, and various myths have sprung up about how it has been possible. Perhaps the most important have been those associated with 'ABC' and those about leadership.

The debate about ABC in Uganda is in itself something of a myth. It has been claimed that the Ugandan model of HIV/AIDS control is due to an integrated strategy based on 'A for abstinence (or delayed sexual initiation among youth), B for being faithful (or reduction in number of sexual partners), and C for correct and consistent condom use, especially for casual sexual activity and other high-risk situations' (USAID, 2004). Actually, use of the ABC acronym seems to have originated in Botswana, where it failed dismally (Heald, 2002). Certainly I saw no sign of it in Uganda between the 1980s up to the mid-1990s, and veteran AIDS campaigners in Uganda have been reported as stating that they had never heard about it until 2001 (Human Right Watch, 2005, p. 5). Claims about its relevance in Uganda seem to originate from USAID. But even if the term was not actually used in awareness campaigns, it does capture two of the main approaches to encouraging behavioural change in Uganda – on the one side promotion of abstinence and faithfulness, and on the other the promotion of condoms.

In recent years this combination of potentially complementary strategies has opened up into a fierce, polarized conflict. It has been prompted by both large amounts of money being made available by the US Government for HIV/AIDS control programmes, and a simultaneous shift away from support for condom promotion (one member of staff at Mulago hospital in Kampala observed to me that ABC now means 'Anything *But* Condoms'!). Some of those appalled by the new approach have castigated anyone who questions the significance of condoms in reducing rates of infection as right-wing Republican stooges. In response, there have been assertions about the Ugandan HIV prevention strategies being undermined by

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'infuriated UN condom-pushers' (AIDS and Anthropology Bulletin, 2003; Green 2003, 2004; Life Site, 2005). On both sides of the divide there has been a fair amount of myth-making. The adopting of positions for ideological, financial and political purposes has once again had a tangential connection with what has happened on the ground in Uganda itself. Human Rights Watch, for example, in a generally excellent discussion and analysis of HIV/AIDS in Uganda, has felt the need to criticize the current emphasis on abstinence by some powerful groups as a 'life-threatening' shift, orchestrated and funded by the US (BBC, 2005; Human Rights Watch, 2005).

A problem is that, whatever one thinks about the usefulness of condoms, they were largely absent from the Ugandan scene until the mid-1990s except in some urban locations. In the late 1980s President Museveni had been involved in an informal alliance with the traditionally Catholic Democratic Party. Partly for this reason, but also partly because of his own beliefs and attitudes, condoms were not vigorously promoted. Indeed, Museveni and other ministers made speeches denouncing condoms as un-African and raising doubts about their efficacy as a form of protection. Over the years this line has been moderated, but Museveni has continued to down-play the importance of the barrier method (e.g. New Vision, 2004). He has argued that the Ugandan 'success' has been to do with the promotion of 'family values', and the First Lady has explicitly associated HIV/AIDS declines in Uganda with abstinence and the Christian faith (e.g. Museveni, 2003). It is a position that makes them rather popular with certain Republican politicians in the US, but it is not simply a sudden change of policy in response to demands from US aid donors. The slogans used in the early awareness campaigns included 'love carefully', 'love faithfully' and 'zero grazing'. As late as 1991, donated condoms were being kept in stores in Entebbe because of government resistance to their distribution. This subsequently changed, and by mid-decade there were rural condom distribution points in certain places, but there is little evidence that they were having a significant effect.

In 1996, I investigated condom use in and around Kasensero (the village in Rakai District where the first Ugandan cases of AIDS had been diagnosed). I found that most informants had no knowledge of how to use them correctly, and that only fishermen were asking for them regularly (BBC/Open University, 1996; Allen & Heald, 2004). At the same time, results from the two population studies in the south-west of the country confirmed that condom use was not an important factor in the noted declines in incidence. They both indicated that a much more likely cause was later age of sexual debut in girls (Mulder, 1996a, b).

Recently a group of US-based scholars have taken issue with such an interpretation, or rather have suggested that the situation may have changed since the mid-1990s (Wawer *et al*., 2005). Using results from the population study in Rakai they find that high AIDS-related mortality accounts for most of the recorded declines in prevalence between 1994/5 and 2002/3. They also find that during this period incidence did not decline overall. Nor did it do so in young adults or in adolescents. Reported age of sexual debut declined in both sexes, and the proportions of young adults reporting sexual activity, non-marital relationships and multiple partners increased. However, reported condom use increased (e.g. from 19% to 38% in males aged 15–16). They concluded that there had been no increase in abstinence or faithfulness, and that the stable incidence rates were associated with increased use of

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condoms. Although at the time of writing only an abstract of this study has been made available, the fact that it was presented by an eminent group of epidemiologists at an important international conference has meant that it has been reported widely and taken seriously. It has been interpreted as showing that abstinence programmes are failing and that condom use should be encouraged (e.g. Reuters, 2005).

However, it could be that a rise in age of sexual debut and a decrease in casual sexual activity had occurred before 1994 in Rakai, as monitoring up to that point suggested, and that sexual activity amongst some groups changed as condoms become more readily available. This would not be surprising. Studies from elsewhere in Africa suggest that increased availability of condoms coincides with such behaviour (Allen & Heald, 2004). Also, reports by anthropologists and others working in the area have continued to suggest that condom use remains inconsistent and too low to be a significant factor in keeping incidence rates down (Green, 2005; Mosley, 2005). So another interpretation of the latest results from Rakai could be that the increased stress on condoms from the mid-1990s has had the effect of undermining earlier messages about abstinence and faithfulness. In other words, it has been counter-productive. Elsewhere in the country, for example in the north, condom availability has remained very low. Yet antenatal prevalence rates have continued to decline. Caution may be required in interpreting these data, but they too suggest that highlighting the value of condoms in response to pressure from certain Christian and right-wing interests may lead to unhelpful exaggerations.

Lastly, some points need to be made about leadership and mass mobilization in Uganda. President Museveni himself has been closely associated with promulgating the idea that he and his government have achieved great things in the campaign against HIV/AIDS. It is a claim that is generally accepted; even by those who disagree about particular strategies, or who take into account other reasons that might help explain the declines in reported infection rates. There has clearly been a considerable amount of myth-making here. It actually took a while for Museveni's government to accept the seriousness of the situation. In April 1987, J. Carswell, one of the team of doctors that had been involved in diagnosing AIDS in Rakai in 1982/3, was expelled from the country for talking too openly to journalists (Putzel, 2003). Nevertheless, it is certainly true that by the late 1980s the President was fully engaged in AIDS awareness promotion and that, in contrast with Botswana, his government, together with relevant agencies, succeeded in communicating about HIV/AIDS to the population at large in ways that were not resisted (Allen & Heald, 2004). In August 1991, a survey of around 1400 informants was carried out in the relatively cut-off Moyo District, located in the north-west of the country, where I had been living since 1987. It found that more than 90% of respondents had heard of AIDS, about 30% knew of someone with AIDS and over 60% believed that 'sex with many people' was a cause of transmission (Schopper, 1991). At least in part, this remarkable acceptance of the health messages was because condoms were not a primary focus of the campaigns, and alliances had been formed with religious leaders, traditional authorities, elders and the newly introduced and directly elected local councils. As elsewhere in Uganda, the AIDS campaigns played a part in processes of supporting authority systems, reinforcing ideas about moral probity and institutionalizing patrilineal hierarchies.

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In this respect, President Musevini's own claim that the Ugandan 'success' was based on traditional family values is much more than just rhetoric. Rather it seems to have been a deliberate strategy, with ramifications that have barely been perceived by most analysts. In Moyo District, councils tried to control activities of young people at dances, monitor the movement of certain women (and occasionally certain men), and mediate in various kinds of disputes. These disputes often related to payments of bride-wealth, or to the sexual activities of women for whom no bride-wealth had been paid. In some instances the councils were prepared to act violently, for example by forcing certain individuals to leave a neighbourhood. They also became involved in hearing cases where someone, usually a woman, was accused of *inyinya* (witchcaft/poisoning). On a number of occasions they executed or tortured a person found guilty, sometimes with the active support of soldiers stationed in the vicinity. Once HIV/AIDS messages started to spread, with the Catholic Church in the district playing a leading role and echoing the President's call for sexual restraint, local council activities appeared to have governmental and church support, and to be in the interests of public health. Indeed, the term *inyinya* started to be used for people who might be infected (Allen, 1989, 1991b, 1992, 1994b, 1997). The HIV/AIDS campaigns were thus integrated into and helped invigorate local institutions, not necessarily in ways that many analysts would expect.

Uncomfortable conclusions

Interrogating evidence and myths about HIV/AIDS in Uganda leads us to uncomfortable conclusions. Much less is known about the epidemic than is asserted. Even basic questions about what exactly has affected incidence and prevalence rates remain unanswered. Many theories, such as those about risk groups, sexuality and military activity, can be shown to be largely speculative. It is also possible that policy measures have had a relatively marginal effect. To the extent that they have, condom use does not seem to have been particularly important, although this may have been changing in some places, notably in the more urbanized parts of the south. Limitations on sexual contact might be more significant in affecting overall trends, although this too probably varies in different parts of the county.

Where changes in patterns of sexual contact have occurred, they may have been linked with social control procedures. In the IDP camps in the war zone of the north constraints on daily life are extreme, and they seem to be linked to declining rates. Elsewhere in the country, the regulation of social activities by local councils, patrilineal hierarchies, religious leaders and other groups may have sometimes played a similar role. It underlines an important point that is curiously absent in most of the AIDS literature on Uganda. Behavioural change rarely happens because of information alone. It occurs when information is combined with effective mechanisms of social control, sometimes including enforced compliance. In Africa, most people cannot simply choose a different way of life. They live in circumstances in which individual agency and opportunity is very limited. For women, constraints on their actions can be extreme. When it comes to sex, they are rarely in a position to freely opt for 'abstinence' or 'condoms'. Rather they live their lives according to locally accepted social and moral norms. Ignoring this fact is to indulge in wishful thinking,

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and it is something that may prove alarmingly counterproductive if it is extended to treatment with ARVs (anti-retrovirals). This unfortunately seems to be the case.

A new myth has emerged in Uganda that anti-retrovirals can provide adequate treatment for AIDS. President Museveni has been making speeches calling on people to come for testing now that treatment is available, and a host of aid agencies have jumped on the anti-retroviral bandwagon. But this treatment remains very limited, and there are massive problems with unequal access and with monitoring. Although some programmes run from clinics have established methods for ensuring that patients adhere to treatment indefinitely, many drugs are obtained privately with little or no medical advice. Anti-retrovirals have become available at private pharmacies, and even reputable hospitals, such as that at Lacor near Gulu, have what is termed a 'cash and carry' window. Staff at Mulago, the main government hospital in Kampala, complained to me in mid-2005 that both generic drugs and brand drugs are flooding into the country from a wide range of formal and informal sources. A consequence is resistance and genetic mutation of the virus. Already many patients are arriving at Mulago with forms of HIV that do not respond to first-line treatment procedures. It is possible that one reason HIV rates have not exploded in Uganda in the way that they have in southern Africa is because genetic mutation has been more limited. The current unregulated enthusiasm for ARV treatment should therefore be a cause of concern, not complacency. The Uganda 'success story' is not written in stone. It is a mistake to assume it will last forever.

Acknowledgment

Research and writing of this paper was supported by a grant from the UK's Department of International Development to the Crisis States Research Centre of the London School of Economics.

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Appendix

The Ugandan Demographic Health Survey (DHS) of 2001 gives slightly higher figures for biomedically assisted deliveries and an extraordinarily high figure for women accessing antenatal care from a trained health worker (over 90%). Districts in the central north of the country were not covered in the survey. However, even allowing for a southern and urban bias, there seems to have been a problem with the way it was organized. The categories of 'midwife' and 'nurse' were not treated separately in the questionnaires. The survey claims that just 1% of Uganda women receive antenatal care from 'traditional birth attendants'. If this is really so, I must have inadvertently interviewed almost all of them! The full text of the DHS survey can be found at http://www.measuredhs.com/pubs/pdf.

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