

# Treating AIDS: Dilemmas of unequal access in Uganda

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## ABSTRACT

The price of antiretroviral (ARV) medicines in Uganda has fallen dramatically in recent years and more people are under treatment. By mid-2003 it was estimated that 10 000 people were taking ARVs. Drawing on participant observation, qualitative interviews, work with key informants and document reviews, we seek to map out the channels through which ARVs are being made available to people and to describe and assess the social implications of the present system of distribution. Four channels of access to ARV medicines were common in mid-2003: (i) Medicines were provided free in structured research and treatment programmes funded by donors, but only to those who lived in a defined catchment area and met inclusion criteria. (ii) Gazetted treatment centres provided drugs on a fee-for-service basis; these urban-based institutions account for the largest number of drugs dispensed. (iii) Private practitioners, mainly based in Kampala, provided discrete treatment for those who could afford it. (iv) Finally, medicines were 'facilitated' along informal networks, supplying friends and relatives on a less regular basis, sometimes for free, sometimes for cash. However, access to ARVs remains highly uneven. We argue that cheaper drugs make possible different kinds of access, different qualities of care, and a growing awareness of inequity. Because the price of drugs has fallen drastically, middle-class families now have the possibility of buying them. But this requires tough prioritising and many cannot follow the regimen regularly. Health workers must consider whether patients will be able to purchase the drugs or not. In a kind of popular social pharmacy, people assess who can and should and does get access to ARVs. Further research should examine the whole range of ARV access channels in different countries and the associated patterns of social differentiation and exclusions.

*Keywords:* Antiretrovirals, access, equity, Uganda, AIDS policy.

## RÉSUMÉ

En Ouganda, le prix des médicaments antiretroviraux (ARVs) a baissé au cours des dernières années et davantage de gens sont sur médicaments. Vers le milieu de l'an 2003, on a compté qu'environ 10 000 personnes étaient sur des médicaments ARVs. A partir de constatations faites pas les participants, les interviews qualitatives, le travail fait auprès des informateurs clés et des réviews, nous cherchons à tracer les canaux de distribution des ARVs mis à la disposition des gens ainsi que de décrire et d'évaluer les conséquences sociales de l'actuel système de distribution. Au milieu de l'an 2003, il y a eu quatre canaux d'accès aux médicaments ARVs: (i) Les médicaments ont été gratuitement fournis aux projets de recherche et de traitement qui étaient bien structurés et financés par des donateurs. Cependant, ce dernier était uniquement pour ceux qui habitaient le quartier désigné et qui répondaient aux critères d'inclusion. (ii) Les centres de traitement publiés dans le journal officiel du gouvernement fournissaient des médicaments à un prix. Ces établissements situés dans des milieux urbains

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comptaient le plus grand nombre des médicaments distribués. (iii) Les médecins du secteur privé, qui étaient en majorité à Kampala, dispensaient un traitement discret aux patients qui avaient des moyens financiers. (iv) Enfin, des médicaments étaient distribués par le biais des réseaux informels auprès des amis et des membres de familles de manière moins régulière à un prix ou bien gratuitement. Cependant, l'accès aux ARVs reste largement irrégulier. Dans cette communication, nous tenons l'argument que les drogues à prix bon marché favorisent des différents moyens d'accès, des différentes qualités de soin et une prise de conscience des injustices qui s'accroît. Puisque le prix des médicaments a trop baissé, des familles de la classe moyenne ont la possibilité d'en acheter. Néanmoins, ces familles sont amenées à mettre la priorité sur des médicaments et la plus part d'entre eux n'arrivent pas à suivre le régime régulièrement. Le personnel du service de santé doit s'assurer si les patients peuvent acheter des médicaments ou pas. Dans le cas d'une pharmacie socialement populaire, les gens évaluent qui peut, qui doit et qui a accès aux ARVs. Une étude plus avancée doit être poursuivie afin d'examiner toute une gamme de canaux d'accès des ARVs dans des différents pays ainsi que des tendances liées à la distinction sociale et l'exclusion.

*Mots clés : des antiretroviraux, l'accès, l'équité, l'Ouganda, la politique du SIDA.*

In the international media, differential access to AIDS medicine exemplifies global inequalities between wealthy and poor countries. Price cuts by the big multinational pharmaceutical companies, the advent of cheaper generics, action research programmes and donor support for treatment, offer ways of remedying these inequities. Yet even in countries that have benefited from such developments, equal access to treatment is still a long way off. The Uganda AIDS Commission estimates that only 10 000 people have access to the drugs, out of about 157 000 who should be taking them (Uganda AIDS Commission, 2003).

The fall in price has been dramatic: triple combination therapy cost about \$500 per month in mid-2000; in March 2003, the same treatment using the generic drug Triomune from the Indian firm Cipla cost \$28. But to put that price tag in perspective, the combined public and private spending on health care in Uganda is only \$38 per capita per year, as opposed to \$4 499 in the United States (UNDP, 2003). The vast majority of Ugandans cannot afford \$28 each month (and that figure is a minimum that does not include consultation, monitoring and drugs for other infections). The drop in price has created dilemmas for a minority who could never have considered treatment at the old price, but who have just enough resources to make the cheaper drugs an almost realistic option.

Solutions shape the way we see problems. In principle, affordable treatment in Uganda will change the meaning of AIDS (and of life!), as it has done in wealthy countries, where AIDS is something you live

with — if you can tolerate the drugs — and where mortality from the disease has fallen sharply. If treatment were available in poor countries, it is likely that people would be far more willing to be tested and to identify themselves as having the disease. Perhaps we are entering such a new phase in the cultural and social history of the disease in Africa. But the process is a rough and inequitable one — well suited to the kind of work ethnographers can do at the crossroads between historical forces and the complications of social agencies, be they local institutions, families or individuals. As drugs for AIDS become more common, they bring into relief the nature of health care in countries like Uganda — its dynamism, its unevenness, and the order in its disorder.

In this article, we explore the dilemmas that AIDS treatment poses, as people learn about options, make painful choices and imagine the possibilities open to others as well as themselves. Who should have the drugs and who can get them? Our theme is that AIDS medicine is socially as well as pharmacologically active, in that it occasions reflections on social relations and distinctions. This happens within those families who are in a position to consider paying for treatment; and it happens as people experience programmes that offer treatment to some and not to others. Health care workers and ordinary citizens are increasingly confronting the reality of unequal access. For some this is a matter of moral concern; for others it is the normal order of things; for others still, it is a practical problem with which to deal, or to overlook while tackling more immediate difficulties. Our

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ambition is not only to document pharmaceutical policy and inequality (Farmer, 2001), but to show their significance for differently positioned Ugandans as they work out a vernacular view of social pharmacy.

### The social lives of AIDS medicines

Adopting a framework proposed by Appadurai (1986) and used as an expository device for following the movement of pharmaceuticals (Van der Geest, Whyte & Hardon, 1996; Whyte, van der Geest & Hardon, 2002), we can set the scene by tracing the life courses of ARVs as they enter Uganda and flow through alternative channels to sick bodies. We must enter a caveat, however. This is an account from one moment, mid-2003, in a complex and rapidly changing situation.<sup>(1)</sup> Although we have attempted to interview a wide range of role players — from people responsible for information, research and treatment programmes, to health workers and pharmacists — our view is inevitably partial and incomplete, like the views of the sick people, family members and colleagues whose concerns are presented in the sections to follow.

The ARV drugs available in Uganda originate as branded products from five multinational pharmaceutical firms and as generics from several Indian companies. Under an initiative from UNAIDS, the multinationals set up an autonomous organisation in 1999, Medical Access Uganda Limited, to ensure a steady supply of AIDS drugs to gazetted treatment centres, with a small profit margin to cover costs. When Indian companies entered the market with generics in 2000, they did not come in through this initiative, but set up distributorships at Kampala pharmacies. Two of the multinationals, Bristol Meyers Squibb and Merck, Sharp & Dohme (MSD) followed suit, establishing sales representatives dedicated to AIDS products at a Kampala retail outlet. In addition to the drugs imported through these established channels, others find their way from Europe through the hands of individuals who bring them in for themselves, friends or family, or perhaps to sell again.

Once in the country, ARVs flow out to sick people through four kinds of more or less well-demarcated channels. One way in which they are made available is through treatment and research programmes, funded by donors and provided for free. These include: prevention of mother-to-child transmission (PMTCT)

projects (integrated into maternity services at selected health units); a Centers for Disease Control (CDC) research project that will treat 1 000 adults and their eligible children in Tororo, eastern Uganda; the Developing Antiretroviral Therapy (DART) trial at two sites in the Kampala area, funded by Rockefeller, to provide drugs to 2 000 people; a Médecins sans Frontières project treating 100 patients in Arua, northern Uganda; and the Uganda Cares Initiative in Masaka, also with 100 patients as of early 2003. There are also other smaller projects which, like the larger ones, are localised and have strict eligibility requirements. Mainly branded drugs from the big multinationals flow to these projects through Medical Access. Because they are donor funded, supply is ensured for the life of the project at least, and there is fairly good control over the provision of the treatment.

A second channel provides drugs to gazetted treatment centres such as Nsambya and Mengo Hospitals, and Mildmay Centre. Most of these are fee-for-service, although some free drugs are provided through research studies. By far the most important is Joint Clinical Research Centre (JCRC), the oldest and largest AIDS treatment centre in sub-Saharan Africa. Growing out of an initiative by the Ministry of Defence to deal with the enormous problem of AIDS in the army, it developed a collaboration with the Ministry of Health and Makerere University. From its Kampala treatment facility in the beautiful grounds once belonging to the government of the kingdom of Buganda, it has provided ARVs to over 8 000 people since 1991. It recently opened clinical facilities in four other towns: Mbale, Mbarara, Masaka and Kabale. JCRC does 'intelligence work' to find the cheapest drugs. It purchases direct from the Indian firm Cipla, bypassing the distributor but, like the other treatment centres, it also provides brand name drugs for those who can afford them.

While the donor research and treatment programmes and the gazetted treatment centres are not government financed, they are very much government approved. Although they are scattered (huge areas of the country are not covered at all) and reflect the different priorities of donors and researchers, they have a public character and presence. They are located in buildings with signboards. They have a staff and provide jobs, maybe even vehicles with acronyms stencilled on the doors. They are announced at local council meetings,

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in religious services, and on the radio. They produce literature in the form of brochures, posters and reports. They have a professional character of the type that contributes to what a recent article in the *Lancet* called 'Preventing antiretroviral anarchy in sub-Saharan Africa'. The authors write that '... it is not just a matter of providing antiretroviral drugs, but also that they must be provided within a structured framework. There has to be a system to ensure regular procurement and distribution, good patient management, monitoring, and assessment' (Harries, Nyangulu, Hargreaves, Kaluwa & Salaniponi, 2001, p. 410).

The third channel, private practitioners, is far more discrete and less open to surveillance. No one knows exactly how many private physicians are treating patients with ARVs, but David Bagonza, the sales representative for MSD, says his company was selling to 40 private clinics as of mid-2003, almost all in the Kampala area. The Ministry of Health and the National Drug Authority are supposed to monitor the distributors to insure that they sell to physicians in established clinics, rather than lay individuals. But once someone has a prescription, it is possible to have it filled without continuously consulting a doctor — this opens the door for more creative and less systematic use of medicine.

The fourth channel is hardly a channel at all, but a web of capillaries through which ARVs seep out to those in need. People who are 'in the system' help relatives and friends to obtain the drugs at lowest possible cost. One pharmacist confided that he had 15 patients he was facilitating in this way. Another revealed that the drugs were sometimes sold without a prescription, and that pharmacists must take on the task of counselling and advising even though they have not been trained to do so.

Whether anarchy, or at least disorder that is convenient for some, will set in remains to be seen. What we know about the social lives of other drugs in Uganda is that they are lively (Whyte, *et al.*, 2002). All kinds of prescription drugs are available over the counter or from someone's satchel in small shops and storefront clinics, at bus stages, and in the homes of health workers. Will ARVs be diverted from their enclaved positions under the monopoly of health professionals in quasi-public institutions?(2) Such valuable commodities, needed desperately in a poor

country where people look for any way to make money, will provide a strong challenge to the kind of structured framework called for by the authors of the *Lancet* article.

### **Inclusion criteria: what about me?**

The lives of drugs flow in channels that carry them mainly to the urban, the more prosperous and the better connected. The lives of most people are rural and constrained by poverty. They are unlikely to have a chance of getting ARVs unless they happen to reside in the catchment area of a project giving free treatment. The channel that brings ARVs to donor-funded projects and to beneficiaries is well demarcated. Research projects must have explicit inclusion and exclusion criteria; donor projects and programmes have defined target groups and procedures for becoming a beneficiary. They are localised, linked to an institution with a catchment area, and usually meant for a certain category of people.

A prime example is the PMTCT programme, supported by UNICEF and other donors, so far in place at 18 government hospitals. The plan is to scale up so as to eventually include maternity units at all government facilities, although a major problem in access is that over two-thirds of births take place at home. Mothers who attended antenatal clinics are counselled about the possibility of receiving a free dose of the ARV nevirapine(3) at onset of labour, and a dose for the newborn baby, which can reduce vertical transmission by about 50%. Mothers wishing to participate must take an HIV test; the medicine is only given to those who test positive. It can save the baby but has no effect upon the mother, for whom no treatment is offered. This requires women to confront distressing information, which will be made known to hospital staff, with differential consequences for themselves and the child. As one woman speculated: 'I would like to know my status if this will prevent my baby from getting infected, but on the other hand I fear knowing that I am among the dead and I am to experience much suffering of AIDS, so I would not want to know my HIV status for fear of those deep thoughts.' (Pool, Nyanzi & Whitworth, 2001, p. 608).

A majority of women so far have made the difficult decision to test: of 54 000 attending antenatal clinics at the 18 hospitals between April 2002 and January 2003, 77% were given information about the

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programme, 65% agreed to test, and 12% tested positive. The co-ordinator of the research component of the programme, Loyce Ariinatwe, told us that the possibility of getting a drug to save the baby was the decisive factor for women, who say: 'It has been documented (that the drug can save the baby's life) ... if I die and leave my child healthy, it's a blessing from God.' But at the same time, they ask: 'What about me? Why are you giving the child and leaving us?' At Mulago Hospital in Kampala, women ask about ARVs and the policy in this programme is to tell them where they are available and at what price. They are terribly disappointed to learn how costly they are: 'It is too much ... we have that hope but how many can afford?' Social pharmacy cuts across the most intimate of all relations — that between mother and child. The ARV is for the baby; as Loyce pointed out, the mother can only lick the free milk powder that was also intended for the child.

The solution to this dilemma is a new programme, PMTCT+, in which the plus stands for free ARV therapy for the mother, and also for the baby should it be found positive despite the preventive doses. But PMTCT+ is only beginning, with support from other donors in a few restricted locations. If you do not happen to live in a selected area, and do not attend an antenatal clinic during the project period, you are left to fish in the other channel, the one where ARVs are sold to those who can afford them.

The inequality of access to free therapy is illustrated in another way by recent developments within The AIDS Support Organisation (TASO). In 2002, TASO decided to subsidise ARV treatment for its counsellors. This famous organisation has been a pioneer in promoting openness, positive living, and AIDS education by people living with AIDS. Its eight district centres are places where AIDS can, and must be, talked about, where people can share experiences and get advice from other people living with AIDS. Facilitating ARV treatment for counsellors introduces a deep distinction in that commonality of experience. Most clients of TASO have no chance of obtaining the same treatment. The steering committee of TASO Mbale felt this was wrong and the manager of TASO Tororo commented that it was a challenge now to struggle to get ARVs for TASO members as well as employees. One person speculated that the staff were not 'shouting' demands on behalf of their clients because they feared losing their own privileges,

perhaps in a scheme of cost sharing where both they and their clients would have to pay.

In the event, donor-funded research and treatment projects have linked up with TASO branches in Entebbe, Masaka and Tororo to provide medicines and clinical care to clients who meet established criteria. In Tororo, the US CDC have recruited the first 32 of a planned 1 000 adults for a 3-year study (ARV treatment is promised for life for study subjects, but is not yet funded beyond the study period). ARV drugs will be delivered weekly by motorcycle to people's homes by a fieldworker (with a US Embassy identity tag). The researchers have thought carefully about inclusion criteria: membership of TASO, CD4 count under 250; sleeping seven days a week in the surveyed household. Priority for admission to the study will go to those still surviving from a previous CDC study, then to members of the TASO Drama Club, and then chronologically in order of length of membership — those who joined TASO first get first chance. What is unclear is the effect this will have on those who are not part of the study. Part of the plan is to provide public education about ARVs; a flock of 30 motorcycles will be plying routes on the district's dirt roads and paths. Awareness of ARVs will be raised exponentially. Yet most HIV-positive people in the district are not members of TASO; not even all of TASO's 7 000 – 8 000 members will be given drugs; and not even all sexual partners of the study subjects can be included. The question 'what about me?' is bound to arise as the project takes shape. Welcome as this project is, it shares with other donor-funded treatment initiatives a limited lifespan and access criteria that exclude many people. They are left to the 'public-private mix-up' that constitutes health care obtained from government facilities, fee-for-service clinics and retail drug outlets.

### Health workers and referral: the blanket sign

Most people, even if they have heard about ARVs, do not know where to get them. One source of information is the health worker. The women whose babies were to be saved by nevirapine at Mulago Hospital, were told that they could buy treatment for themselves — which most could not afford. But this information is not always provided, either because health workers themselves do not know, or out of sensitivity to the predicament of poor people.

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Some of the most striking and poignant examples of this point come from health workers in public facilities, who must decide whether to tell their patients that life-saving medicine is available. At the paediatric immunity clinic of Mulago, many of the patients are orphans brought by family members who have already exhausted their resources caring for the now dead parents of the children. The nurse at the clinic said that they did not normally mention ARV treatment to these families: 'Just caring for an HIV-positive child is difficult. We can't mention ARVs which they cannot afford..and we can't tell the children about ARV medicine — that would be cruel.'

The head of the Department of Medicine, Dr Harriet Mayanja, at the same hospital explained that they do not have ARVs on the ward, because most people cannot afford them and they do not want the spectacle of the lucky ones going to the dispensing window of long life, while others look on hopelessly: (4) 'On our ward, we use the "blanket sign" in order to decide whom to inform about where they can buy ARVs. Our patients bring their own bed linen. You check the blanket, the bed sheets, how the patient and family are dressed, whether they are wearing shoes or rubber slippers. Do they bring a nice thermos flask, a basket of food with a crocheted cover, a radio? Do they ask for a private room? Or is the patient using old sheets, or maybe a woman's gown because they can't afford a blanket. On the bedside table, is there only a plastic mug with the cold porridge provided by the hospital? It's not fair to suggest treatment costing 60 000 shillings a month to someone who has not been able to afford sheets at 8 000 shillings in the past five years.'

The blanket sign as a test of financial means is evocative in Uganda, where a common way of describing poverty is to say that husband and wife have to sleep under the woman's only gown.

This situation is part of the general 'bring your own' pattern that characterises public health care in Uganda. Both in-patients and out-patients are routinely required to bring everything: a school exercise book for recording their diagnosis and treatment, a disposable hypodermic needle and syringe, rubber gloves and a plastic sheet for maternity, IV sets and fluids, and food. Hospitals and health centres regularly tell families that needed medicines are out of stock and ask them to purchase them from

nearby drug shops. With their high price and presumed life-saving properties, ARVs are a high-profile example of something with which most Ugandans are well familiar.

Even when patients are referred to AIDS treatment clinics, they are often disappointed that the expense is greater than expected. The AIDS Information Centre (AIC) in Kampala provides counselling, testing and treatment of opportunistic infections. It has now started to give information about ARVs; patients are told that the price of ARV treatment at JCRC is \$28 a month. Some who are able to follow up on the referral, return to the AIC doctor, bewildered and discouraged that the cost was far higher. This could be because of necessary tests, the inclusion of other drugs for opportunistic infections, and the prescription of ARVs other than Triomune, the cheapest generic, presumably for medical reasons. This uncertainty about what one will actually have to pay is again characteristic of health care in Uganda. The problem is not only cost, but the unexpected extra cost for which it is difficult to plan. Unless one can find a sponsor, as have a few of the volunteers at AIC, the financial headache is a family pain. For AIDS care is not an individual matter between a patient and a health care provider, but a concern of families.

### **Painful priorities in families: affording the next dose**

With women bearing an average of seven children,(5) Ugandan families of procreation are large — extended families are truly extensive. And as every Ugandan knows, part of the practice of relatedness is giving and receiving assistance. About 80 - 90% of Ugandans live in rural areas, but agriculture seldom produces much cash surplus, so people face major problems in acquiring cash to pay school fees, build a house, and get medical care, not to mention buying commodities for daily needs. A crisis, such as someone needing an operation, may require a family member to sell a goat or cow or even a piece of land. Any member of a family in paid employment has to balance his or her own living expenses, the needs of relatives, and hopes to accumulate a few savings. Ugandan colleagues of ours working at the university almost always pay school fees for children of less well-off siblings. In the era of AIDS, people take orphaned nieces, nephews and grandchildren into their homes and support them together with their own children. 'High dependency ratios' is the social work jargon for what is idealised as

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the supportive African extended family and experienced by people with jobs as an often burdensome obligation.

People of all economic backgrounds depend on family help in dealing with illness. AIDS is different because of its long duration and the fact that it often strikes more than one person in a family. As the staff at the paediatric immunity clinic recognised, families with a member needing ARVs have already been burdened by caring for long and demanding illnesses, and possibly by the cost of funeral expenses and fostering orphans. Only families with relatively good resources consider undertaking costly and lifelong treatment with ARVs. Even for them, the burden is often too heavy. Almost everyone who has contact with middle class Uganda has examples of family efforts and family dilemmas in paying for ARV treatment. Three themes are woven through these situations.

*Treating AIDS means withdrawing support to other relatives for other important life projects.* Even when the sick person has an income and could afford to buy medicine, he or she must make priorities about other expenses. And that means considering and prioritising social relations.

The compliance study carried out in connection with the UNAIDS Drug Access Initiative in 1998–9 included 20 people who were financing their own ARV medicine. Even these people, who were well-off by Ugandan standards, reported that they considered obligations to family members when budgeting for their drugs. Some explained to relatives why they had to stop helping them with school fees and other expenses; others did not. However, patients reported that it was not easy for them to decide stopping or reducing financial support because extended families, fictive kinship institutions, neighbours, and close friends were social assets, and were always mobilised or united when a disaster struck. So there was a fear that they would also lose such support in the future (Kisuule & David, 1999, p. 59). One patient at the AIDS Information Centre remarked to the doctor that she might be on ARVs if she was not paying school fees for her younger sister. People speculate about whether taking a child out of school would enable them to buy drugs and improve enough to keep a job so they could continue giving at least some support. They worry about using all their resources to buy drugs, not being able to continue after they run out of

money and then dying, leaving their children with nothing. The price of social relations and life chances is brought sharply to consciousness in such situations.

*Because more than one family member is often sick, treating AIDS means choosing whom to help.* Dr Peter Solberg of the CDC project used the technical term ‘triage’ for the terrible decisions that must be made: ‘I’ve heard many cases of difficult choices — how to triage if there’s not enough money for treatment for a couple.’ The choice is not always made explicit. We know of one instance where a very sick woman was refused help by her husband, only to learn later from a relative working in an AIDS treatment centre that he was on ARVs himself.

Sometimes families do pull together and find enough resources for all, at least for a while. A friend told of how they raised money for her sister-in-law, the husband and their son to access ARVs. George and Lisa wed in 1990 and had been blessed with three children. When their last-born child fell ill, failed to respond to treatment, and died in 2000, they could hardly grasp the tragedy and the terrible thoughts for the future of the family. When they tested for HIV, both George and Lisa and their second born were HIV-positive. George worked for one of the most powerful companies in Kampala and was doing well. Although he was from a prosperous family and had close relatives living outside Uganda, he was stressed, afraid of losing his job, and fearful that other people would learn about his HIV status. He and Lisa both started using ARVs, but he still kept his diagnosis a secret until his financial status was in jeopardy. He lost the good job and the family depended on Lisa’s income. In 2002, George fell ill with signs and symptoms of AIDS; his condition was no more a secret. It was rumoured that both George and Lisa had stopped using ARVs because they could no longer afford them. At this point family meetings were organised every Sunday by George’s family, later involving Lisa’s relatives as well. Resolutions to fundraise and purchase ARVs for all three were passed, medical check ups were done at JCRC, and George improved enough to get another job.

The financial and emotional costs of treating AIDS force people to conceptualise and make explicit assumptions about relationships that usually remain implicit. George and Lisa’s relatives formalised this process through weekly meetings. Our colleague Mary

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explains how her family network financed one of her cousins' ARV treatment for a period when the cousin was very sick. Now the cousin has recovered, is working as a tailor, and is paying for her own treatment. 'It's a miracle,' Mary says. 'She was dying and now she is even paying school fees for her children.' Another member of the family is also HIV-positive and in need of ARV treatment, but she has not managed to mobilise resources from the family network. Mary remarks: 'That one — she is not responsible, she doesn't understand ARV medicine, she never finished school and doesn't have a job. How do you start to help a person like this? And where do you stop? ... People have to prioritise their resources: Do you pay ARV medicine for a sister forever and give up paying school fees for your child?' Mary is weighing up not just her relationships to her cousins, but their characters and their likelihood of resuming responsibilities within the family. Unusually, she put her deliberations into words. Many people prefer to keep silent about such painful decisions, and just let things take their course, as if there was no decision to make (Mogensen, 2003).

*People who are ill and unable to support themselves must consider the burden that ARV therapy might impose upon their families.* From the point of view of the sick person, being so highly dependent is often a distressing situation. Some would rather die. One of our young Ugandan colleagues fell sick with the sort of meningitis which is very common among AIDS patients. At the hospital where she was admitted she was started on ARV drugs by the doctor. The meningitis had made her disoriented and she had not understood the implications of the medicine. She was a very proud person and when she realised that she would have to receive help from others for the rest of her life to stay alive, she made the decision to stop the medication and go back to her parental home in northern Uganda. That is where she died.

Another Ugandan colleague told of his cousin who was HIV-positive and developing AIDS. The cousin's wife was also sick, and the family decided to hold a meeting to plan how to raise money for ARV medicine. A few hours before the family was to assemble, the cousin hired a taxi to Bujagali Falls on the Nile. He threw himself into the wild water and drowned, leaving the family the easier task of supporting only one sick person and the children.

Papa M is a retired government official, a wealthy and well-educated man by local standards. He lives in a large home with his three wives and some of their 22 children and grandchildren. Three of his daughters knew that they had been infected with HIV. One died in 1998, before less expensive ARV medicine was available in Uganda. Another daughter, Prisca, started to lose weight after her husband died in 2000. When we discussed the cost of ARV treatment, Papa said: 'Even if we can't afford this in the long run we have to try it — we have to try it. She might pick up and survive. If she dies we will know that we tried everything possible.' She moved back to her parents' home, and her father and some of her brothers and sisters were buying the ARV drugs every month at a branch of JCRC in Mbale town, 30 km from the home. But after some months, Papa began to worry about 'the arrangement' of buying drugs in Mbale. How long would it be sustainable? He is retired and had imagined that at this stage in his life, the adult children would be taking care of the old parents — both financially and otherwise. Papa mobilised funds from daughters and sons for their sick sister, but most of them were incapable of helping in a significant way, having many children themselves for whom to care. When a third daughter Lovisa, who had moved in to help care for sister Prisca, fell sick, she decided not to stay at home: 'It is too hard for mother to see our sister Prisca being sick. It reminds her of how our other sister died ... The medicine helps, but it puts pressure on mother. She worries about how they will get the next dose, money, transport ... So I decided to move where she can't see me and worry about me.' Meanwhile, Prisca had many side-effects from the medication. Papa M said that he suspected she lost the morale to take the drugs. She died on Easter Sunday 2003. The family was again in great pain, and Papa commented that it was depressing to have spent so much money and put great expectations in these new drugs, which proved to be worthless for his daughter. He did not talk about the third daughter who is also HIV-positive, but from his facial expressions it was clear that his worries continued. Lovisa's sensitivity about being a burden to her family increased accordingly.

Ivan, a young man in rural Tororo, told how he was planning to get an HIV test, because he had started falling sick, and his former girlfriend had died recently. He said he would not be shocked if he tested positive, but still hesitated to do the test because it

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would bring a lot of conflict in the family. One of his brothers who works in Kampala had told him that he would help him with money for treatment if he tested positive, but Ivan was worried about getting the rest of the money for treatment: 'I do not fear the first 150 000 shillings for making those first tests, but it is the monthly expenses of drugs I fear ... We are from a somehow rich family with many children, but we are just disorganised and there is too much disagreement. If my family would not help me when they knew my problem it would kill me very fast. So that is why I fear to make that test.'

These family situations do not involve priority setting once and for all, but rather continuing processes unfolding over time as circumstances change and one set of problems overshadows another. When a relative is desperately ill, it is usually possible to mobilise help. But after the first few months on ARVs, if the patient improves, the family again feels the weight of other obligations and stops contributing to purchasing the drugs. The long-term commitment to buying ARVs is difficult for individuals and families to maintain in situations where needs are so abundant.

The medical consequences of these family dilemmas are non-adherence to treatment regimens and the 'antiretroviral anarchy', with dangers of developing resistance, that experts fear. Although there is little systematic research from Uganda on adherence in the 'natural' situation of people paying for therapy, it is thought that the main reason for not adhering to ARV treatment is inability to sustain the cost. Cissy Kityo, the Research Co-ordinator of JCRC and a doctor with great experience in fee-for-service clinical care, asserts that cost is the main constraint to using and adhering to ARV treatment. In a retrospective review of 577 patient charts from January 1998 to June 2001, JCRC found that, despite the fact that most patients were from urban areas and high socio-economic status, only a quarter were 80% or more adherent to treatment. About 60% were lost to follow-up. They did not return for continuing treatment, presumably because they could not afford the next dose of drugs (presentation by C Kityo on 9.26.02).

Health workers regularly confront the realities of patients not being able to pay for treatment, and families who have some means struggling to balance the cost of the next dose against all the other needs. At the same time, we found a recurring conviction

that well-placed people could afford them or get them through connections.

### Connections, secrecy and status: those big people

Most people in Uganda do not know ARVs by name, nor what exactly they do, nor where they can be obtained. But we have often heard people say, in a general way that 'those big people get medicines to prolong their lives'. People who are better informed also relate the drugs to social position. When Betty Kyaddondo asked people attending a clinic at the AIDS Information Centre what they knew about ARVs, their responses revealed the social character of the drugs. One young woman said: 'My boyfriend used to talk about people using expensive drugs to cure HIV while he worked as a driver at the president's office. He would say that people using these drugs get cured of HIV, but kept lamenting at the exorbitant costs'. Another woman, a teacher, told Betty: 'In 2000, a friend at the school told me about drugs that cure HIV. She said these drugs are sold in pharmacies in Kampala and cost about 700 000 shillings a month. She said in order to buy the drugs you must produce a bank statement because it is an indicator that you will actually afford them. I have not interacted with anyone using them, but I heard about some ministers taking them and they are doing well.'

What these examples show is that medicinal knowledge is social knowledge, or at least it is linked to people's image of the kind of society in which they live. But the political imagination about social status and access to medicine has one particular feature that is especially striking: the conviction that the elite takes medicines secretly. This comes out most clearly in discussions with professional 'insiders' following the epidemic or providing treatment.

From one point of view, secrecy is simply understandable discretion. David Bagonza, the sales representative for MSD, noted that only some of the big businesses subsidising AIDS treatment for their employees have made public announcements about the programmes.<sup>(6)</sup> 'Many others have not announced because they are not offering treatment to all employees. If you want to provide for free, you want to treat your most valued employees, not casual labourers. One of the big hotels treats trained workers, but not the unskilled ones. They do it silently because in the contracts, some have medical coverage and some don't'.

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From the point of view of patients, secrecy may be about the desire for confidentiality. Bagonza seemed to see this as a natural desire of elite people: 'Many people want confidentiality — like government officials, army officers. This kind of patient wants privacy. They prefer private practitioners, they don't want to go to treatment centres'. He gave an example of the means by which confidentiality could be insured: 'A big army officer used to get drugs every month and ask us to put them in different containers — unmarked tins — so his wife would not know.' Cissy Kityo of JCRC puts a somewhat different slant on this desire for privacy: Stigma increases with socio-economic status. Wealthy and well-connected people do not want to associate their symptoms with HIV or to disclose their status. They fear to attend JCRC because it's known as an AIDS clinic. They want to spend the shortest possible time at the clinic because they don't want to be seen. They prefer to see physicians outside of working hours. They give false addresses and identities. Doctors are the worst offenders.

For her, secrecy is associated with denial, an unrealistic and unhealthy attitude in patients. But she also sees how social differences mean that some people have more face to save than others.

That secrecy is a political and moral issue is the argument put forward by others. There are two issues here. One is the question of whether state money is being used clandestinely to favour the few. The other is the matter of the role of openness and solidarity in the fight against AIDS.

A few years ago, a Ugandan researcher presented a paper on the current state of HIV/AIDS in the country. During the discussion the researcher noted that some Ugandans in leading political and military circles have had discreet access to ARV treatment for many years, despite the high cost of medicine and testing. Other elites were also known to receive treatment. Pressed for details about this group, the researcher replied with one bitter word: relatives!

The researcher was not against helping relatives — a practice considered moral and indeed necessary. The bitter tone was reserved for the way that public funds were being channelled secretly, by those in power, to their own relatives. There are clear overtones here of class and ethnic politics — 'the rich people from the

west' (the researcher was from central Uganda) — but perhaps also a reluctant recognition that, in today's Uganda, the entitlements of citizens are few and far between. To paraphrase Chabal and Daloz (1999), Uganda 'works' even though many of the initiatives of the Ugandan state do not. Seeming weaknesses of the state provide opportunities for covert practices that are to the advantage of the powerful.

Access to valued goods and services is often a matter of connections — they are crucial, be they to relatives and tribesmen, co-religionists or simply 'old boys'. All connections however are not of equal significance. Most people agree that the demands of kinsmen are moral, even when they are excessive. Likewise, one ought to help a fellow tribesman or co-religionist, and one ought to remember old connections such as those formed at school. As such these sorts of connections resemble entitlements — not always honoured but still honourable (although they are often cause for criticism or irony when people like the researcher above comment about how the powerful help their kinsmen and tribesmen).

Another set of connections, having to do with politics, individual profits and patronage, is far more ambiguous, covert and suspect. Here we enter the world of patrimonial relationships and rewards for service described by Chabal and Daloz. There are no entitlements, merely utility and the pursuit of advantage. Suspicions of access to ARV treatment, given as patronage to a political ally or military supporter, are bitter for those outside the circle of connections and, at least in the eyes of the outsider, bitterness clings to the treatment even when it is converted into the moral world of kinship obligation, into helping someone else's relative.

Whereas many Ugandans talk generally, and often cynically, about the politically well-connected and wealthy, AIDS professionals and activists specifically criticise their fear of coming out of the closet. Not only do they have access to AIDS treatment that is beyond the reach of most citizens, but they have no solidarity with others, saving their own skins and keeping their HIV status secret. This is the theme of one of the most outspoken critics of the current pattern of access to drugs.

Major Rubaramira is the principal AIDS educator in the Ugandan army as well as the founder and leader

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of an NGO called NGEN+ (National Guidance and Empowerment Network of People Living with HIV/AIDS in Uganda). He is open about his HIV-positive status, which he discovered in 1989. He has been on ARV medications for several years, which he must 'find' himself, some of which he gets from contacts in Europe forged through his activism. A still-serving officer, Rubaramira was together with President Museveni in the original 'war in the bush' which brought the NRM to power. He has become a political figure in Uganda, thanks mostly to his publicly expressed disgust at President Museveni's attempts to smear his opponent as HIV-positive during the recent presidential campaign. In 2002, Rubaramira told us that there were perhaps 1 000 Ugandans who receive medicine at any one time from different government sources. This includes army officers, politicians and members of the Movement — the ruling 'non-party' — as well as their family members. Rubaramira insists that this has been the case for a number of years. 'But no one talks about it. These are all big people and getting medicine makes them support the government.' For Rubaramira, the worst part of the whole affair is: 'They are silent, they will not admit that they are HIV-positive, and that is very wrong for them and for others.'

Rubaramira is highly critical of current Ugandan AIDS policy and in particular of the unwillingness of the country's leaders to press for the resources to make ARV medicines generally available. For him this is an issue of equity — without help the poor will never be able to afford such medicines. But he also stresses a pragmatic point: with public access to treatment, people will be more willing to be open about their own HIV status — and openness is the key first step towards behavioural change. The misuse of public trust and public resources is not in itself so unexpected (it is 'just politics', after all). Worse than the cheating are the hypocrisy and the secrecy which have become commonplace among HIV-positive elites. AIDS for Rubaramira is truly a crisis in Uganda, and secrecy is the behaviour which encourages the continuation of the pandemic.

The moral ideal asserted by Rubaramira was evident in the account given by a colleague of her friend, widow Namwandu. After losing her husband, Namwandu tested positive in 1992 and went to TASO where she was very active. At TASO she made contacts with development workers coming from

abroad on study tours. These 'good friends' facilitated ARVs for her. Like Rubaramira, she became part of an international network through which medicines flowed. As our colleague said: 'These "Poles" (her pronunciation of PLWAs – people living with AIDS) have many advantages because of their outside contacts. These people, the Rubaramiras, they share experiences, have so many contacts who give them donations. They get free drugs. But the good thing, they carry the message to all parts of the country.'

It is not so much that people resent wealth and advantage as such. New hotels and resorts, fine office blocks and the like are generally applauded as signs of progress. Even the modern house in a rural neighbourhood is progress (Whyte & Whyte, 1998). What is objectionable is secret consumption and selfish unwillingness to affirm relations with others by sharing and helping. What is morally admirable, at least in the eyes of enlightened AIDS professionals, is the willingness to speak out and stand with others in the struggle against the disease. In this respect, the views of people like Major Rubaramira harmonise with a deep theme in dealings with misfortune: the morality of open public affirmation of relationships and the ambiguity and potential evil of secret use of medicines for purely selfish ends (Whyte 1988, 1997). Just as medicines (both African and cosmopolitan) have the possibility of secret use in the local rural communities where we have done our fieldwork, so people imagine that ARVs can be taken without regard for sociality. As long as they are so expensive for ordinary people, the image of the powerful man getting them covertly through connections can only be a bitter one, and raises questions about morality.

### Conclusion

We entitled this article 'Treating AIDS'. Perhaps we have failed our title by focusing on ARVs. Treating AIDS is so much more than ARV medicines. It is ensuring proper care for tuberculosis, skin disorders and all the other opportunistic infections that make people suffer. It is good food (what people call 'soft food' like passion fruit juice, milk and eggs), something that many families feel is difficult to provide for chronically ill members. It is emotional support and nursing care and all the rest. Even regarding medicines, there are so many others that people need before ARVs. Many public health specialists, and many on the front lines of AIDS care in Uganda, think the media attention to ARVs has

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distracted from all the other problems of delivering health care to people with AIDS.

There are very few people for whom ARVs are a realistic option in Uganda today. However, one of the reasons why we chose to write about them is that, beyond the pharmacological properties that have changed the epidemic in wealthier countries, they have such powerful symbolic potential. As concrete things, they objectify relationships in both subtle and dramatic ways. Hope, concern, solidarity, power, money, selfishness are all enacted as those tablets and capsules move between people. Within families, the virtues of care are most clearly demonstrated by buying medicines for the sick person (Meinert, 2001). On a global scale, claims of medical apartheid in refusing to make ARVs truly accessible in poor countries are accusations of injustice and immorality.

Access to ARVs in Uganda illustrates the social meanings of medicines with painful clarity. They not only move people to conceptualise and weigh their relations to immediate relatives, but to envision social relations and distinctions on a national and even international scale. Research and treatment projects with their inclusion and exclusion criteria, health workers who silently assess the financial capacity of their patients, families who have to choose which lives to support, and activists who call for social justice — all are caught up in dilemmas that can be expressed in terms of access to medicines.

As global pharmaceuticals, ARVs have captured the social and political imagination more powerfully than almost any other kind of medicine. At the same time, they are caught up in a process of fetishisation that is the fate of any *thing* that so effectively objectifies a possibility. Providing things — the adequate supply of cheap or free medicines — is not sufficient. Ensuring their proper use through flexible and efficient systems of delivery and care is the real problem, and it is one that cannot be solved by pharmaceutical companies or international agreements on property rights and trade.

The advocacy and lobbying efforts that have brought down the price of ARVs and ensured the possibility of producing and importing generics are immensely important. So are the exemplary projects that demonstrate that ARVs can be delivered effectively to poor populations in developing countries, such as the

high-profile efforts in Khayelitsha in the Western Cape (MSF, 2002) and the Clinique Bon Sauveur in Haiti (Farmer, *et al.*, 2001). What our review of access dilemmas in Uganda points to is a further step. There is a need to examine the whole range of delivery channels and access possibilities on a national basis. There has been little research on the implementation of AIDS treatment and how it might be scaled up for a whole country (but see Teixeira, Vitoria & Barcarola, 2003). As the price of drugs falls, and if donors and politicians do make decisions to prioritise treatment as a concomitant of prevention, it will be essential to know how treatment and care can be delivered effectively not only in small projects with good resources, but for everyone (Barfod & Ullum 2003, pp. 68–69).

In the long run, we believe that medicines for AIDS should be free to those who need them. The fall in price makes it more feasible for governments and other agencies to purchase and supply them. In the short run, or rather in the process of moving toward the goal of equitable care, cheaper drugs make it possible for different kinds of access, different qualities of care, and a growing awareness of inequity. Uganda is an excellent example. The very qualities of openness to initiatives from different quarters that have made it a leader in prevention (Parkhurst, 2002) have encouraged a variety of treatment projects and possibilities. However, there is not yet an adequate national policy on ARV drugs (Okuonzi, Karamagi & Kyomuhendo, 2003), and the public health care system remains woefully incapable of providing equitable and effective care for all citizens. The dilemmas we have described here show the painful realities of ‘social pharmacy’ at one historical moment.

### Acknowledgments

This work was carried out as part of the Tororo Community Health (TORCH) Project, a collaboration between Child Health and Development Centre, Makerere University, the Institute of Anthropology, University of Copenhagen, and the Institute of Epidemiology and Social Medicine, Århus University. It was funded by DANIDA, under its Enhancement of Research Capacity Programme. We are grateful for many discussions with colleagues at Makerere, and for the generosity of those who gave us their time and shared their concerns.

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### Footnotes

<sup>1</sup>A useful report on Access to ARVs in Uganda (Martinez-Jones, and Anyama 2002) was compiled for Oxfam, with lists of accredited treatment centres and prices of all the ARVs available on the market. But just 1 year later, prices have already fallen further, and new initiatives have changed the picture.

<sup>2</sup>A hint of what could happen came with the fluconazole scandal in 2002. Pfizer had donated a large supply of this drug, which though not an ARV, is even more expensive and is used in the treatment of meningitis and fungal infections commonly affecting AIDS patients. The drug was distributed to government hospitals, but not long after it was found — marked a gift from Pfizer — in private pharmacies in Kampala. The Ministry of Health came down strongly, but just a half year later in May 2003, another sticky situation was reported in the newspapers. National Medical Stores had negotiated a favourable price reduction on Combivir and two other ARVs from GlaxoSmithKline and was preparing to re-export them to Europe, despite an outcry about the damage this could do to Uganda's image vis à vis other drug companies and donors. The deal was stopped by the Ministry of Health.

<sup>3</sup>The nevirapine is being donated to the Ministry of Health for a period of 5 years by Boehringer Ingelheim.

<sup>4</sup>Her colleague was quoted elsewhere on the same point: 'Why should we tell patients about ARVs when they will not be able to buy them? It will just make them more depressed.' (Martinez-Jones and Anyama, 2002)

<sup>5</sup>Total fertility rate for the age group 15 – 49 was calculated at 6.9 for the country as a whole (ORC Macro, 2001).

<sup>6</sup>Among those who have announced that they will subsidise all or part of ARV treatment for employees with AIDS are: *New Vision* newspaper, Bank of Uganda, Stanley Chartered Bank, the Civil Aviation Authority, National Water and Sewage, Shell, Total, Coca-Cola, and various embassies. The Uganda Business Coalition and the Uganda Business Council have been active in promoting AIDS prevention and care in the corporate world.

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