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January 28, 2004
HRC Summer Fellowship: final report

This summer, I was fortunate enough to be able to spend 8 weeks in Kampala, the capital city of Uganda, working with a team of American and Ugandan researchers studying access and adherence to HIV medications. Uganda is located in the eastern part of sub-Saharan Africa--within the epi-center of the global AIDS epidemic--but the life-extending antiretroviral cocktails that have been available to people with AIDS in the US since 1996 have only recently become available there. An estimated 600,000 of Uganda's residents are thought to be infected with HIV (UNAIDS/WHO 2002 Update), and as of December 2000, 850,000 Ugandans had died from AIDS (Ismail et. al. 2003). This deaths have resulted in an extremely high number of orphans, with nearly 900,000 children under the age of 15 having lost one or both parents to AIDS by the end of 2001 (UNAIDS/WHO 2002 Update).

In the industrialized world, effective antiretroviral treatments for HIV have been available since 1996. This year marked the introduction of a new class of drugs (protease inhibitors) which, when combined with at least two other antiviral drugs, produced a drug "cocktail" that was extremely effective at reducing patients' viral loads (the number of copies of the HIV virus in the blood)—often to undetectable levels—and also raised their CD4 counts ("t-cell" counts) significantly, thus boosting their immune systems and improving their ability to fight off the opportunistic infections that eventually kill most people diagnosed with AIDS. These medicines have provided many Americans and Europeans living with HIV with a "new lease on life" and have raised hopes that HIV may become a manageable, chronic disease rather than an inevitably fatal one. Currently there are 23 antiretroviral medications available in the US, almost all of which remain under patent protection. These drugs are extremely expensive, often costing close to $1,000 a month, but in the US a combination of state and federal programs has made them available to even the poorest patients (for example, homeless in SF can get ARVs but not housing).

In Uganda, where the average income hovers around $30 a month, these medications are prohibitively expensive. Until recently, there were no antiretroviral medications available in the country, and often no affordable drugs to treat opportunistic infections such as cryptococcal meningitis that were killing many Ugandans with AIDS

(this is treated with fluconazole, an antifungal known in the US as Diflucan, where it is a common treatment for yeast infections). This situation has started to change over the last 2 years, as generic drug manufacturers in India have begun to export "copycat" antiretroviral treatments to developing nations such as Uganda. The legal status of these drugs is tenuous, as they are technically in violation of the international patent laws that protect brand-name pharmaceuticals. During the Clinton administration, a group of multinational pharmaceutical companies tried to sue the generic manufacturers and the countries that were importing from them (such as South Africa) in order to prevent the manufacture and sale of "copycat" versions of drugs that they held the patents to. Fortunately, international pressure led to the dropping of this suit, and a series of decisions by the World Trade Organization have made the manufacture and sale of these cheaper (but equally effective) ARVs possible. As a result, effective HIV therapy is now available in Uganda for about $30 a month in the form of "Triomune," a twice-daily tablet that contains a combination of three antiretroviral medications. However, even though this is much cheaper than the patented versions of these medications sold in the US, because $30 is also the average monthly income in Uganda, these medicines remain prohibitively expensive for most Ugandans (and for most people throughout southern Africa).

I went to Uganda to assist with some research that is seeking to understand the impact of the arrival of these medications on the AIDS epidemic in Uganda. I spent my summer working with a research project called Adherence Monitoring Uganda (or AMU), a joint effort of the University of California San Francisco and Makerere University in Kampala. "Adherence" (formerly called "compliance") is medical jargon for how well a patient takes his or her pills—i.e., whether or not they take all their doses, the proper dosage, at the correct time, with or without food, etc.

What does "adherence" have to do with human rights? The answer to this question lies in the political context in which this research is being carried out. In the politics of international health, Africa has been marked as profoundly dysfunctional—so dysfunctional, that to provide Africans with antiretrovirals has come to be seen as not only difficult, but as dangerous. Such portrayals of Africa have a long history. In his book On the Postcolony, African historian and postcolonial theorist Achille Mbembe argues that:

Africa is never seen as possessing things and attributes properly

> *part of "human nature." Or, when it is, its things and attributes are generally of lesser value, little importance, and poor quality. It is this elementariness and primitiveness that makes Africa the world par excellence of all that is incomplete, mutilated, and unfinished (Mbembe: 1).*

It is this image of Africa as somehow not "properly human" –of Africa as, to repeat Mbembe's words, "incomplete, mutilated, and unfinished"—that links the issue of adherence to questions of human rights, for unfortunately, such negative images of Africa are alive and well in international public health discourse. Crucially, this neo-colonial rhetoric of incomplete humanity is voiced in expert opinions on the ability of Africans to adhere to antiretroviral pill regimens.

Three quotes from three different types of "experts" in demonstrate this point. First, the pharmaceutical industry. The following quote is from the Pharmaceutical Researchers and Manufacturers Association, the leading industry group for the brand-name pharmaceutical industry. Predictably, this group has been one of the most vocal opponents of providing generic antiretrovirals to Africa, as any loosening of patent protections on medication is a threat to their market share. Their campaign against generics has been largely successful, partly because they have been able to couch their position in terms of public health, rather than in terms of profit. They have done so by utilizing the discourse that Mbembe criticizes, a discourse of "elementariness and primitiveness" that facilitates the portrayal of Africans primarily as petri dishes for breeding resistant virus, rather than as human beings dying for lack of access to treatment (from the PhRMA website):

> *Rather than curing or treating a patient, drugs taken improperly or sporadically—as is often the case in impoverished societies where adequate public health systems and sufficient infrastructure are lacking—lead to new strains of viruses that defy existing medications.*
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> *Unfortunately, few developing nations until now have made public health programs a priority. In the case of HIV/AIDS, "the therapies require taking a dozen or more pills every day at precise intervals without fail, plus high-tech monitoring for viral resistance, plus still more drugs to control side effects," says National Journal. "Try that in African town with dirty water and mud roads" (Pharmaceutical Researchers and Manufacturers Association web site; world.phrma.org/challenges.html).*

Such views are propagated not only by the pharmaceutical industry, but also by groups intended to serve the interests of developing nations, such as the U.S. Agency for International Development (or USAID). My second quote comes from USAID chief administrator Andrew Natsios, the Bush administration's top-ranking foreign aid official. In June 2001, Natsios told a Boston Globe reporter why he thought that funds from the newly-formed Global Fund for AIDS, TB and Malaria should be spent on AIDS prevention but not on antiretroviral treatments:

> *Natsios, who spent a decade in aid work in Africa, said many Africans "don't know what Western time is. You have to take these (AIDS) drugs a certain number of hours each day, or they don't work. Many people in Africa have never seen a clock or a watch their entire lives. And if you say, one o'clock in the afternoon, they do not know what you are talking about. They know morning, they know noon, they know evening, they know the darkness at night.*
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> *"I'm sorry to be saying these things, but a lot of people…advocating these things have never worked in health care in rural areas in Africa or even in the cities," Natsios said.*
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> *(Boston Globe 6/7/2001 p. A8)*

Lastly, and perhaps most unfortunately, these views can be found among some African health officials. My third quote is brief, and comes from the South African Minister of Health who in June 2001 stated that "in settings of high illiteracy patients would not take their antiretroviral drugs correctly, thus promoting and spreading drug resistance" (Tusiime 2003).

It should be noted that although the idea that poverty = poor adherence = dangerous drug-resistant strains of HIV was the conventional wisdom in public health, at the time that these statements were made (in 2001) there was very little actual research done on adherence to ARVs in Africa (quite simply, because there were no ARVs available for anyone to adhere to—thus these policies were successful not only in preventing patients' access to these medications, but also in monopolizing knowledge about ARVs in Africa to their own unfounded conventional wisdom by preventing research that might have proved them wrong).

The above quotes are loaded with a number of problematic assumptions, which contrasted greatly with what I observed during my fieldwork:

First: "The regimens are too difficult." The generic regimen available in Uganda consists of only one pill, taken twice a day. In the US, most regimens are more complex

and involve a higher "pill burden" (i.e. more pills per day). However, in many cases the complexity of these regimens is an artifact of patent protections, not of scientific necessity. Many drugs that could be combined into a single pill (or fewer pills) are not, because each drug in the combination is owned by a separated pharmaceutical company.

Second: "The roads and infrastructure don't exist to transport the medications." It's true that many of the roads, even in urban areas, are not paved. It is also true that reliable distribution is a legitimate concern. However, speaking as someone who had never been to the third world before this summer, I think that it is very easy for those of us who are used to 1st world levels of infrastructure to assume, out of culture shock, that organized transport and distribution of goods would be impossible in a country such as Uganda where many roads are not paved, many roads are not mapped, and "street addresses" are largely non-existent. I have two rebuttals to this point. Firstly, as any traveler in the developing world may notice, a "lack of infrastructure" has not stopped the distribution of goods—most notably Coca-Cola, which seems to have penetrated into even the most remote parts of the world. Secondly, and more directly related to my fieldwork is the story of one man I interviewed who was working as a driver, a job that sometimes caused him to be away from home for several days at a time. I asked him if he'd ever missed his HIV medication, and he told me of a time when he almost missed a dose because he left on a job driving someone from Kampala to Mombasa (several hours away in Tanzania). He took his morning dose before he left, but forgot to bring his pills with him. However, rather than miss his medication, he called his wife (also HIV+) and had her put his medication on a minibus taxi bound for Mombasa. The medication arrived that night, in time for his evening dose.

Third: "People are too poor and uneducated to take these medicines properly, so to provide them with medications would be inviting the development of dangerous, drug-resistant strains of HIV." Until recently, this belief was pervasive despite the fact that almost no research had been done on adherence to ARVs in Africa (because there were no ARVs available there for anyone to adhere to). This is perhaps the most egregious assumption underlying these quotes, not only because it is so wrong, but because it allows for the denial of treatment in the name of public health. Although the blatant ethnocentrism of Natsios' quote hardly justifies a response, I will say for the sake of argument that Africans do indeed understand how to tell time. In fact, the level of concern expressed by Ugandans with AIDS over the timing of their doses was far beyond

any concern that I have ever witnessed in my many years of working with people with HIV in the U.S. Both the AMU staff and several Ugandan doctors told me that patients had called them concerned that their Triomune might stop working if they failed to take it at exactly 7pm, and instead took it at 7:10 one night. Even those without clocks are diligent about the timing of their doses. When I asked what he thought of the Natsios comment, one doctor in rural Uganda told me of an elderly patient of his who timed her ARV doses to the news broadcasts on the radio, which air at 8am and 8pm. Transistor radios, he said, are almost universally owned even in rural areas. This same doctor had conducted focus groups with his HIV patients on issues related to adherence. At one point he asked them whether they felt that their lack of education made it more difficult for them to take ARV medications. Their response, he told me, was incredulous: "You don't have to be able to read in order to want to live."

Given these observations, it is perhaps not surprising that quantitative research is also showing very high rates of antiretrovirals among Africans with HIV. The AMU study has shown average adherence rates of over 90%, as have studies conducted in South Africa. By comparison, the average adherence rate to antiretrovirals in the US is about 70%. (Apparently, it is Americans who experience greater difficulty with "Western time" than do Africans). As a result of these high rates of adherence, those who have been able to access ARVs have experienced dramatic improvements in their health. These improvements are visible not only in their drastically reduced viral loads, but also in their quality of life. All the Ugandan patients I spoke with described a greatly improved quality of life as the infections, rashes, and debilitating fatigue of AIDS began to disappear, and they regained strength, energy, and hope. Those who were in danger of losing their jobs due to illness were able to continue working, while those who had lost their jobs because of AIDS began to search for new work.

Yet, the availability of these medications is a double-edged sword. Although the health benefits of the drug appear nothing short of miraculous to patients who were near death prior to treatment, the burden of paying for these pills introduces new challenges. As I said earlier, although the cheapest generic regimen is only $30 a month, this is equivalent to the average monthly wage in much of Uganda. For this reason, these medications remain out of reach for a vast number of patients. For example, I was told that doctors judge whether or not they should even bother to tell a hospitalized AIDS patient about the ARVs based on the quality of the bedding that their family brings them

in the hospital. Hospitals in Uganda are unable to provide bedding, and so it was not uncommon to see families with bedrolls walking around the hospital grounds. Thus, if a patient's family brought her a high-quality blanket, the doctor would raise the possibilty of prescribing ARVs out of hope that the family would pay for it. If a family brought only a sheet or failed to bring a blanket at all, doctors had little hope that the patient would be able to afford antiretroviral treatment.

For those who can afford them, the burden of raising an extra $30 a month every month, indefinitely (for unlike most medications, antiretrovirals presumably must be taken for the rest of one's life) poses serious problems not just for patients but also for their family members. Frequently, patients paying for Triomune were not able to educate their children, as the money they would have spent on school fees instead went towards medication. Many patients I spoke with were dependent upon other family members to pay for their antiretrovirals. One woman in the study had to stop her medications because her grandmother, who had been paying for her pills, died and she could not afford to buy them herself. Another woman's mother had had to sell a goat in order to pay for her daughter's pills. Other patients became unable to pay when they lost their jobs. Thus, in a sense, poverty does cause poor adherence—but not because the poor can't take medications properly, but because they can't afford to buy them.

While this statement seems obvious enough, it is not this interpretation of poverty that has determined international health policy. Instead, rather than being seen as simply as a lack of money, poverty—and in particular, African poverty—has been seen, as Mbembe puts it, as lack of "human nature," as an "elementariness and primitiveness" that allows the West to speak presumptively in Africa's "interest." In this way, the fight for equal access to treatment in Africa should be recognized as an issue not just of health care, but as a question of human rights.