

**The Complexity of Re-evaluating Antiretroviral
Therapy Eligibility Guidelines for HIV/AIDS
Patients in Uganda**

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Glossary of Acronyms

AIDS: Acquired Immunodeficiency Syndrome

ARV: Antiretroviral Drug

ART: Antiretroviral Therapy

CASA: Community ART Support Agent

CD4: Cellular Differentiation 4

Note: All CD4 cell counts are in cells per cubic millimeter.

CDC: United States Centers for Disease Control and Prevention

DNA: Deoxyribonucleic Acid

GFATM: Global Fund to Fight AIDS, TB, and Malaria

HIV: Human Immunodeficiency Virus

MOH: Uganda Ministry of Health

MUWRP: Makerere University Walter Reed Project

NGO: Non-Governmental Organization

NIH: United States' National Institutes of Health

NNRTI: Non-Nucleoside Reverse Transcriptase Inhibitors

NRTI: Nucleoside Reverse Transcriptase Inhibitors

PEPFAR: President's Emergency Plan for AIDS Relief

RNA: Ribonucleic Acid

TASO: The AIDS Support Organization

TRIPS: Trade-Related Intellectual Property Rights

UAC: Uganda AIDS Commission

USAID: United States Agency for International Development

WHO: World Health Organization

Background of Research

Abstract

When I first learned that the eligibility criteria for Antiretroviral Drugs (ARVs) in Uganda is to have a CD4 cell count of 200 or below, I was shocked. Actually, I think my exact response was, “So patients must have full-blown AIDS, severely weakened immune systems, and may be on their deathbeds before they can receive the drugs?” I knew little of the subject, other than that in the United States HIV-positive patients who are on drugs may avoid many of the opportunistic infections and complications that come from delaying treatment until the CD4 count is low. My initial confusion over a policy that appeared to have its priorities reversed served as the spark that propelled this project.

My goal was to understand the issues that surround eligibility for antiretroviral drugs. I wanted to learn everything I could about ARVs and how they are delivered. But I was especially curious as to who was able to receive ARVs, how and why. I felt that an understanding of the cultural, economic, political, and medical factors that influence eligibility guidelines would illustrate the rationale behind such policies and the barriers that exist to scaling up treatment for HIV/AIDS patients. A thorough understanding of HIV testing, counseling, care and treatment was necessary to put ARVs into context.

Assuming that the CD4 count eligibility guidelines should be higher than 200, my initial intention was to determine why this is not currently the policy in Uganda. While researching the topic, several crucial barriers to access of ARVs became obvious. These barriers, as will be outlined below, are multi-dimensional and require a multi-faceted approach to address them. However, the key concern is not whether the CD4 eligibility guidelines should be raised or whether barriers to access need to be overcome to improve treatment of HIV/AIDS, but rather how these two improvements may be integrated with one another.

The government of Uganda is currently re-evaluating its HIV/AIDS treatment guidelines, including CD4 cell count eligibility. Enormously relevant to this re-evaluation is consideration of Uganda’s ability to care for a larger population of eligible individuals when so many already face significant barriers to accessing care and treatment.

Research Setting and Methodology

The AIDS Support Organization (TASO) in Mulago, Kampala served as the home-base for my research. Most of my time at TASO was dedicated to participant observation in the various aspects of TASO including clinical examination, pharmacy, clinical outreach, and drama group activities. I also conducted informal interviews with various professionals, such as doctors, nurses and counselors associated with TASO Mulago. I chose to dedicate a significant portion of my time to learning about TASO as an example of an organization that provides a comprehensive care and treatment program.

From there, I branched-out to several NGOs and U.S. government-funded organizations. I had the privilege of talking with very knowledgeable and influential people in the field of HIV treatment affiliated with CDC, MUWRP, USAID, NIH, and Uganda Cares. A three-day visit to the Makerere University Walter Reed Project in Kayunga District, about one hour northeast of Kampala, afforded me the opportunity to learn first-hand about the MUWRP Youth Center in Kayunga and the projects it coordinates. I was also able to speak with several patients at various stages of HIV care, from those waiting to receive HIV test results to those who are seasoned ARV recipients.

Because so much of my research was conducted in the urban setting, it is by necessity a limited sample. But since my focus was not on the perspectives of clients, but rather an attempt to understand the issues affecting eligibility for ARVs, the key informants are medical professionals, especially those associated with organizations based in Kampala. Of course, the findings presented here are most relevant to Uganda, but potentially could apply to other developing countries of Africa as well, if the factors and conditions applicable to delivery of ARVs are comparable elsewhere.

Special Notes

1. All diagrams, illustrations and charts are my own work and analysis of data obtained.
2. This paper is written from the first-person perspective and frequently refers to the collective 'we.' This is intentional since it is my hope that those who read the following analysis will be inspired to reconsider policies and practices that may not be optimal in treating those infected with HIV/AIDS. This paper is written not only for the

millions who have in the past or continue to suffer, but for those fortunate enough to possess the agency to effect meaningful and lasting change.

Introduction

Overview of HIV

The battle against HIV/AIDS is unlike any other battle in history, just as it is unlike any other disease. Emerging on the world scene in the 1980's, HIV/AIDS has developed a great deal as an epidemic in that time. In the United States, it was stereotyped as a disease of only the four H's: homosexuals, Haitians, hemophiliacs, and heroin addicts. In Uganda, "Slim," as it was commonly referred to, was thought by many to have been the work of witchcraft. Untreatable and ultimately deadly, HIV/AIDS fostered a cycle of fear, stigma and discrimination.

While some of these misconceptions still exist today, great strides have been made in the effort to stem the spread of HIV, educate individuals and communities, reduce stigma and discrimination, and enable persons' living with HIV/AIDS to live productive and full lives through care and treatment programs. But as we continue forward with this fight, we must consider the unique aspects of the disease. First and foremost, the biology of the disease is such that it may lie dormant in an individual for many years without any symptoms, thus enabling the individual to unknowingly infect others. Also, the virus itself does not kill. Rather it weakens the immune system such that other opportunistic infections will eventually kill the patient. Secondly, one must consider the vast network of social influences and effects of the disease. Risk factors for HIV are not purely biological: socioeconomic status, profession, education level, race, gender, and sexual orientation all influence the chance of infection. The HIV pandemic has revolutionized society – threatening economic productivity, political stability, and family structure in the hardest hit countries. It has spurred radical changes in discussions of sexuality and romantic and sexual behavioral choices. And for our generation, it is a challenge in the struggle to reduce global inequalities.

Antiretroviral drugs (ARVs) as part of Antiretroviral Therapy (ART) have been in sub-Saharan Africa since 1997¹, but did not become widely available until years later. ARVs have extended the lives of people infected with HIV around the world and are generally regarded as a crucial tool for battling HIV/AIDS. Initially, people doubted

¹ Dr. Fred T. Muwanga. Personal Interview. April 23rd, 2008.

whether ARVs could be effectively delivered in developing countries, but many of the worries have since been disproved.

Viewed pragmatically, HIV/AIDS has its strengths and weaknesses, just as those battling the disease have demonstrated strengths and weaknesses. HIV/AIDS has won a few battles, and we have won a few. Right now we are in a stalemate: the prevalence of HIV/AIDS has leveled out.² Certain communities are experiencing a decline in infection, while others are on the rise. But a stalemate is not a victory; it is simply the proverbial “calm before the storm” when the fury of the pandemic can again be unleashed.

Uganda has been hailed as a success story in stemming HIV prevalence; but the latest survey estimated 6.4% of the population infected³. With a population of 28 million people, that means 1,792,000 are infected. And this is in just one small land-locked country. In order to fully comprehend what such a figure means, and what can or should be done about it, it is first necessary to examine HIV at the microscopic level.

Biology of HIV and the Action of ARVs

HIV, the human immunodeficiency virus, is transmitted through infected bodily fluids via unprotected sex, blood transfusions, needle sticks, or from mother-to-child during labor or breastfeeding. Once the virus is in the body it targets the cells of the immune system, specifically CD4 cells. CD4 stands for cellular differentiation 4 and is the name given to a type of receptor found on the white blood cells of the immune system.

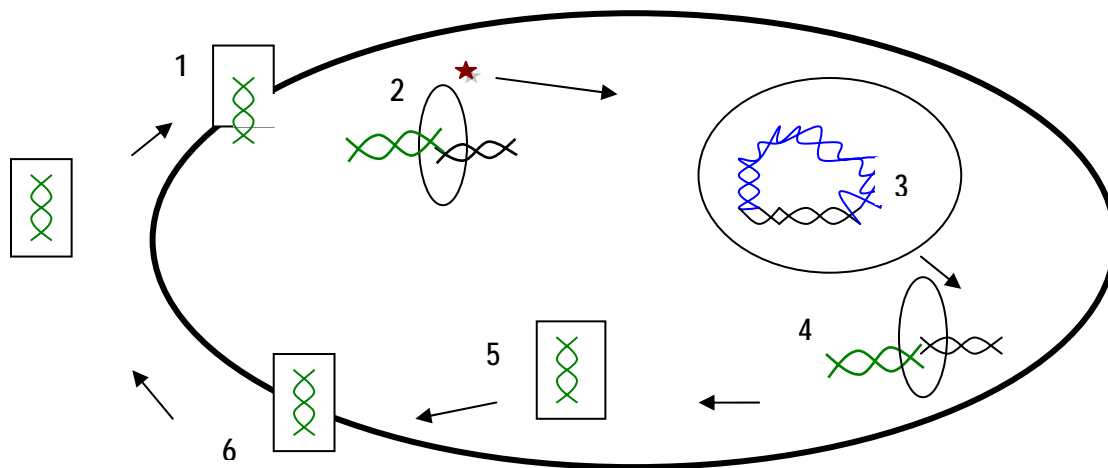
The diagram created below shows how HIV infects, lives, and replicates within the human body: 1) The HIV virus fuses with a CD4 cell, releasing its RNA (in green), or genetic material, into the cell. 2) An enzyme called reverse transcriptase helps “rewrite” the RNA into DNA (in black), so that it is compatible with the genetic material of the host cell. 3) The virus DNA enters the nucleus of the cell and actually inserts itself into the host cell’s DNA (in blue). It is now known as the provirus. Here it can lie dormant for many years. 4) When the host cell’s DNA is “read” through processes

² "Global HIV Prevalence Has Levelled Off." World Health Organisation. 20 Nov. 2007. United Nations. <<http://www.who.int/mediacentre/news/releases/2007/pr61/en/>>.

³ An Overview of HIV/AIDS in Uganda. Uganda Ministry of Health, 2007.

known as transcription and translation, the provirus is also “read.” Transcription is the process of “rewriting” DNA into mRNA to be transported out of the nucleus, and translation is the process of “reading” the mRNA and following the instructions to make proteins. The provirus contains all of the information necessary to make new HIV particles – the virus’ complete genetic material along with proteins and enzymes. 5) New complete viruses are assembled. 6) Then the viruses leave the cell where they can go and infect other CD4 cells.

HIV Lifecycle in the CD4 Cell



Not to scale

Ultimately, all Antiretrovirals work by preventing the formation of new viruses. However, different types of drugs act at different points in the HIV life-cycle. The most common types, and the ones that make up the first-line treatment in Uganda, are Nucleoside Reverse Transcriptase Inhibitors (NRTI) and Non-Nucleoside Reverse Transcriptase Inhibitors (NNRTI). These drugs act by preventing the enzyme called reverse transcriptase from “rewriting” the HIV RNA into DNA at the point starred in the illustration above.

Because the virus replicates so quickly and haphazardly, many genetic mutations result. When the mutation allows the virus to replicate, even in the presence of ARVs, the virus is now said to be drug-resistant. Obviously, this will result in a poorer outcome for the patient, not to mention that anyone subsequently infected with a drug-resistant

strain of HIV will have limited options for treatment. For this reason, it is recommended that drugs always be given in a combination of three so that the virus' replication is "attacked" from multiple angles. (In Uganda, the first-line treatment includes two NRTIs and one NNRTI.)⁴ Drug resistance occurs more readily when the drugs are not taken in a combination of three or when the drugs are taken incorrectly: at the wrong time or with interruption. The importance of supply interruptions and patient understanding of adherence will be discussed later.

⁴ Grace Oling. Personal Interview. April 15th, 2008.

The Current Status of ARVs

Views of ARVs

At the Positive Women's Network craft shop at TASO Mulago, I found a cardboard sign with a border of glued-on shells and written in glitter paint: "ARVs Gives Long, Long Live." Struck by the contrast of the innocence and simplicity of the message and the obvious implications of the seriousness of the subject, I bought it. I keep it as a reminder of the hope that is restored to those who are able to live meaningful and productive lives because of these life-saving drugs.

Of course, there are fears and hesitations associated with ARVs. One HIV-negative Ugandan friend told me, "The thing I fear most about HIV is the drugs you have to take. Imagine having to swallow pills every day for the rest of your life! Here in Africa we take each day as it comes. You can't do that if you are taking ARVs. Every time you leave the house you must carry your drugs. My auntie was taking ARVs and after ten years said she couldn't take it any more, she could always feel the pills in her throat, and so she just stopped taking her drugs."⁵ Issues such as pill-burden and side-effects are real challenges, and will be discussed in greater detail later in this paper.

But despite such reservations, I think it is safe to say that, overwhelmingly, ARVs are regarded with admiration and value. Not a single person that I encountered in the course of my research believed that ARVs were inherently bad. In fact, many talked of the ability of ARVs to restore a near-death patient to life and to thus turn around the life of that person and lives of his/her dependents. Patients currently taking ARVs were particularly positive when discussing the effects that ARVs have had on their lives.

Appendix A shows a poem encouraging hope for those who have HIV. The author says, "HIV/AIDS has three ways in which it can be maintained, First through Hope, second through everyone's support and last through ARVs."⁶ To those who have never faced death, as HIV/AIDS patients do, it may be difficult to understand their appreciation for ARVs. But as we can see, ARVs have truly been an inspiration to those struggling most with HIV.

⁵ Bridget Patricia Nazziwa. Personal Interview. April 20th, 2008.

⁶ Were, David M. "Hope."

Who Is Eligible

We have come a long way from the days when donors believed that ARV use would not be possible in Africa. Certain people believed that the high number of pills and the consistency with which they must be taken could not be adequately met in the African setting. People also raised concern over issues of adherence and subsequent drug resistance as well as prolonged costs of treatment. While all of these issues remain as challenges to varying degrees, the delivery of ARVs is well underway. But due to dependence on donors, resource limitations, and scientific evidence showing that starting ARVs at a very high or very low CD4 count has a poor outcome, there are specific treatment guidelines that determine who is eligible to start ARVs.

Currently in Uganda, ARV initiation guidelines set by the Ministry of Health are derived by the World Health Organization's recommendations for care in a resource-poor setting. An individual must be HIV-positive with a CD4 cell count of less than 200 per mm³. Other conditions such as a CD4 count of less than 350 along with active tuberculosis or pregnancy will also qualify an individual to receive ARVs. Where it is not possible to obtain a CD4 count, the WHO clinical stages are used to assess how advanced the HIV infection has progressed. In such cases, the patient is placed into one of four stages based on opportunistic infections and how he/she feels. (See Appendix B for an outline of the WHO Clinical Stages). ART is initiated in either Stage 3 or Stage 4. For best results, the entire clinical picture is evaluated, including a CD4 count, viral load count – that measures the amount of virus in the blood, and the WHO staging, as well as any particulars to the patient's life.

Procurement of Drugs

The method by which patients access ARVs is dependent on where they seek treatment. The drugs are usually given in one-month supplies, but this may vary. They are followed by a clinician who helps manage any side-effects of the drugs. CD4 counts are done at least every six months. Viral load counts, because of their cost, are done on an as-needed basis. ARVs may be administered either facility-based, where the patient

comes to a health center, clinic, or organization to pick up the drugs, or it may be home-based care, where an organization takes the drugs to the patient's community.

Ideally, ARVs would be given as part of a comprehensive care program known as ART, antiretroviral therapy, which includes the ARV drugs, counseling and support for living life, despite the infection, in a positive, uplifting fashion. The program of ARV delivery maintained by TASO Mulago is impressive. TASO attempts to help patients (or clients as they are referred to at TASO) live positively with HIV. Living positively includes support for healthy living, such as safe sex practices and proper nutrition, clean water, and using an insecticide-treated mosquito net. It also means adequate social and emotional support through counseling and connection with other HIV-positive individuals.⁷ Monitoring and easy access to drugs, whether through supplemented transportation costs or home-delivery, is critical to completing this impressive care and treatment program. All of this is done at little to no cost for the client.

It is to note that in 2004, Ugandan President Yoweri Kaguta Museveni announced that all ARVs would be free in the country for those who qualify. The cost to donors or others buying the drugs is currently around \$9-10 per month per patient for the lowest cost option drug regimen.⁸

The Issue of Need

Throughout the literature and discussions surrounding access to ARVs, the term "need" is often haphazardly used to describe people who qualify for ART within a certain community. For instance, the TASO 2006 Annual Report said the following:

"In spite of the big number of clients enrolled on the [ART] programme, there is still a huge unmet need as only about 30% of the TASO clients in need of ARVs are currently on the programme. Besides, TASO bases on the Ministry of Health criteria of a CD4 cell count of 200 as the eligibility cut off point. If, as some international organizations are recommending, the cut off point is raised to 350, then even more people will qualify for ART and the demand will go even higher."

⁷ Simon Sunny Wejuli. Personal Interview. April 22nd, 2008.

⁸ Dr. Alice Namale. Personal Interview. April 25th, 2008.

While it is true that more people will qualify if the CD4 cut-off for eligibility is raised, just because certain individuals are not currently eligible does not mean that they are currently not in need.

According to the Centers for Disease Control and Prevention (CDC) a normal CD4 count is between 500-1500. Once a CD4 count falls below 200, a person is at great risk for opportunistic infections and is, thus, said to have AIDS: Acquired Immunodeficiency Syndrome.⁹ In 2006 the International AIDS Society – USA Panel re-evaluated the four critical aspects of ARV therapy: when to start, what to start, when to change therapies, and what to change to. In an ideal situation, that is, one with unlimited resources, the recommendation is to begin Antiretroviral therapy when the CD4 count is between 200 and 350.¹⁰

In December 2007, a study conducted in Cote d'Ivoire concluded that patients “who started antiretroviral therapy before CD4 counts fell below 350 cells/mm³ experienced significantly improved treatment outcomes with fewer deaths when compared to those who started treatment later.”¹¹ This finding may even challenge the 350 cutoff which is supported in some quarters. According to this same article, some patients who begin ARVs die within the first few months of treatment because they are already so sick when ARVs are started. Additionally, the incidence of mortality was shown to be greatly reduced the higher the CD4 count was when patients began antiretroviral therapy. Of course, this could also be due to the fact that patients were not as sick when they first joined the study. But most importantly, this study was conducted in a resource-poor setting, demonstrating that success with ARVs is not only found in developed countries. This suggests that perhaps ARVs should be given not as a reaction to, but rather as a prophylaxis measure.

Literature from the CDC says that the evidence is strongest in support of beginning ART once CD4 counts fall below 200, but ideally should be given below 350.

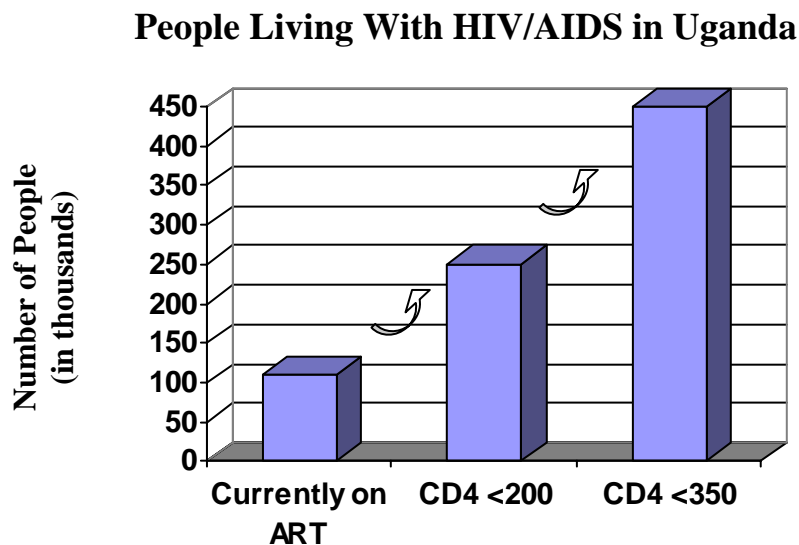
⁹ Centers for Disease Control and Prevention. United States Department of Health and Human Services. <www.cdc.gov>.

¹⁰ "Treatment for Adult HIV Infection. 2006 Recommendations of the International AIDS Society -- USA Panel." *Journal of the American Medical Association*.

¹¹ Moh, R. "Incidence and Determinants of Mortality and Morbidity Following Early Antiretroviral Therapy Initiation in HIV-Infected Adults in West Africa." *AIDS* 21 (2007): 2483-2491.

Despite the fact that studies have shown that “delaying treatment until the CD4 T-cell decreases to below <250 cell/ mm³ should be avoided,”¹² there is no analysis suggesting that any discrepancy exists between the developed and the developing world.

In 2005 the WHO estimated that between 120,000 and 230,000 “needed” to be on ARVs in Uganda. 75,000 of those actually were receiving these life-saving drugs. With 175 sites providing ART in 2005, and a total budget of over \$18 million¹³, one can only wonder how and why so many people do not receive needed treatment. The graph below, showing current data obtained through interviews, presents the question: Is it even possible to raise the CD4 eligibility cut-off, when there is such a barrier already to the delivery Antiretroviral drugs?



Why We Should Care

The book “Global AIDS: Myths and Facts” by Alexander Irwin, illustrates the reasons why we should even care about these disparities between those in need of ARVs and those receiving them. First, Irwin explains how in our ever-shrinking world, we are no longer separate societies. The plagues of one corner of the world can reach the other side of the world in record time due to the transit of goods and people. In terms of

¹² Centers for Disease Control and Prevention. United States Department of Health and Human Services. <www.cdc.gov>.

¹³ "Uganda, Epidemiological Fact Sheet on HIV/AIDS and Sexually Transmitted Infections." Dec. 2006. World Health Organization.

national and global security, a peace-keeping force that is afflicted with a disease such as HIV/AIDS will not be able to effectively maintain order and stability in the future. “A heavy burden of disease among a country’s population is strongly correlated with political instability.”¹⁴

The economic impacts of the disease are obvious when considering that “Africa is losing its teachers and doctors, its civil servants and farmers, its mothers and fathers.”¹⁵ According to Irwin, “Rapidly declining household economic conditions can lead to hunger, domestic conflict, lost educational opportunities, forced migration, family disintegration, and the economic exploitation of those who normally depend on others for income – especially children and the elderly...Stemming the disease’s devastating socioeconomic effects is not charity, but a necessary investment in the global economic future.”¹⁶

An often overlooked fact is that the investment in antiretroviral drugs may actually save health systems money in the long-run by avoiding extended hospital stays, necessary treatment for opportunistic infections, and burdens on the family and community when a patient is no longer able to provide for the household. Furthermore, fighting HIV/AIDS will also help control other infectious diseases, particularly tuberculosis.

Quite apart from the scientific and economic reasons for earlier and more extensive use of Antiretrovirals, there are compelling ethical reasons for public policy to seek to mitigate as much suffering as possible if the resources exist to do so.

¹⁴ Irwin, Alexander, Dorothy Fallows, and Joyce Millen. *Global AIDS: Myths and Facts. Tools for Fighting the AIDS Pandemic.* Cambridge, MA, 2003.

¹⁵ Sachs, Jeffrey. *The End of Poverty: Economic Possibilities for Our Time.* 2005

¹⁶ Irwin, Alexander, Dorothy Fallows, and Joyce Millen. *Global AIDS: Myths and Facts. Tools for Fighting the AIDS Pandemic.* Cambridge, MA, 2003.

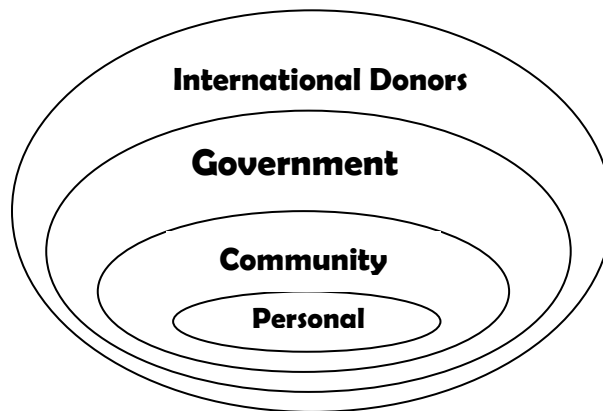
Factors Affecting “Scaling-Up” of ARVs

Barriers Encountered on the Ground

The issue of eligibility for Antiretrovirals is distinct, but not isolated, from the issues that surround access to the life-saving drugs in a setting such as Uganda. When looking at the statistics of those who need drugs, it may seem that simply providing the drugs is an obvious solution. “Scaling-up” treatment is the term given to initiatives that increase the number of people accessing Antiretroviral Therapy (ART). This would call upon pharmaceutical companies to lower costs and donors to pledge more money. But an examination of what is happening on the ground reveals a different story – one that places responsibility in the hands of people at all levels of society.

Before eligibility criteria can be discussed, it is necessary to understand what barriers to access of drugs exist for individuals living with HIV/AIDS. Unfortunately, there is no one single culprit that accounts for the thousands in Uganda that do not have access to care or treatment, or if they do access care, it is sub-optimal care. There are barriers at every aspect of society from the individual to the international donor. As the various obstacles are discussed on the follow pages, the issues work their way from the most personal to the most general. Even as one challenge is addressed and overcome, there may still remain a larger issue that threatens access to ARVs. It is only by looking at the whole picture that we can even begin to tackle the issues that challenge our efforts to provide treatment.

Levels on Which Barriers to Access Exist



Poverty

The dictionary defines poverty as “the state or condition of having little or no money, goods, or means of support. Synonyms include: indigence, insufficiency and destitution.”¹⁷ But underlying the definition of poverty is the fact that its ramifications infuse themselves into all aspects of living: education, health, security, to name a few. And while poverty’s devastating effects can be felt in various ways throughout society, it is how poverty affects individuals that is of particular concern to care and treatment for people living with HIV/AIDS.

Poverty is a driving risk factor of HIV infection. As the saying goes, “Why worry about dying of AIDS in ten years when I will die in ten days of starvation?” For those who struggle to survive because they do not have enough food or a safe place to sleep, a disease that may kill them years down the road will not be a priority in their lives. This can cause people to engage in HIV-risky behavior, (e.g. prostitution) despite the risk of HIV infection.

For those who are already infected, poverty may be a significant factor preventing of HIV testing. And even if an individual knows his/her HIV-positive status, poverty is an obstacle to accessing care and treatment. Consider the hypothetical example of a single mother, who already knows that she is HIV-positive, who is working to support her children. In order to access treatment, several things must happen. First, she must go to a health facility or organization that offers HIV/AIDS care. She must arrange for child-care for her children and then spend money for transportation to and from the health center. She will then spend much of the day, if not the entire day, waiting to see doctors, nurses, and counselors. Not only is she incurring personal costs, but she is also losing a day’s income that might be necessary to put food on the table that evening. And this is only the initial visit. She will need to return to receive the results of her CD4 cell count. If ineligible for ARVs, she will still be put on Septrin prophylaxis, requiring her to return frequently for drug refills, and continued counseling, monitoring and CD4 cell counts. If she is eligible for ARVs, an even more involved process of counseling ensues in

¹⁷ ""Poverty"" Dictionary.Com. <<http://dictionary.reference.com/browse/poverty>>.

preparation for beginning ART in addition to the continued monitoring and drug refill requirements. Once started on ARVs, issues of poverty and the priority of needs may affect an individual's ability to adhere to drugs.

But even in an area where home-based care eliminates many of the issues described above, other factors such as misinformation and stigma and discrimination prevent individuals from seeking care, as described below.

Social Influences

Community attitudes can serve as a great supporter or great barrier of HIV care and treatment access. Societal influences in the form of misconceptions and misinformation and stigma and discrimination pose a significant risk to the lives of those infected with HIV.

Religious groups discouraging the use of condoms may be contributing to the spread of the virus, and the same groups' insistence that prayer should be used for healing instead of drugs is not uncommon. According to one nurse at TASO¹⁸, men in Kampala would say that "HIV is only during the day" so that come nightfall, they could engage in HIV-risky behavior without the explicit fear of infection. One young person in Kayunga District told me that many people believe that ARVs are only for the rich, and as such those with limited financial means will seek traditional remedies as opposed to treatment at a health facility.¹⁹ Even some culturally common ways of keeping track of the time of day may lead to poor adherence when taking ARVs. For instance, an informant at TASO told me of the client who planned to swallow her ARVs when the rooster would crow. But what would happen if the rooster was stolen by a neighbor, or was slaughtered when a visitor arrived? Or the case of the client who would swallow his drugs when the shadow from the tree in the yard reached a certain level, but what if there is no shadow on a cloudy day? Or a patient may not properly take his/her own drugs if the patient thinks he/she is helping others in the home by sharing the drugs.²⁰

But perhaps most dangerous to those already infected is the belief, mentioned by multiple informants, that ARVs "will make you die sooner." The result of patients

¹⁸ Grace Oling. Personal Interview. April 15th, 2008.

¹⁹ Richard Oleja. Personal Interview. April 17th, 2008.

²⁰ Grace Oling. Personal Interview. April 15th, 2008.

becoming severely ill or dying shortly after starting ARVs is that many people misunderstand the true effect of ARVs. Because ART is initiated at a CD4 cell count of 200 or below, the immune system is already severely compromised.

And since it may take up to a year for the ARVs to have an effect of building back up the CD4 cells, opportunistic infections, or even death that would occur regardless of ARVs may be incorrectly attributed to the ARVs themselves.

Additionally, a phenomenon known as IRS or Immune Reconstitution Syndrome, which is a possible result of ARVs, can be also be cited as ‘proof’ of the dangerous and harmful intentions of those delivering ARVs. According to Grace Oling, the Assistant Medical Coordinator of TASO Mulago, IRS occurs when opportunistic infections that have been dormant in the body are suddenly attacked by a now-improving immune system and thus the individual feels sick as the body tries to rid itself of these infections.²¹

But no matter how knowledgeable the patient, stigma remains a major hurdle. Sources of stigma are difficult to identify, but may be linked to the mode of transmission and the fact that it is culturally taboo to openly discuss sex, or the association of HIV and death as a remnant of the days when treatment was not available. Whatever the case, people fear discrimination from disclosure of an HIV-positive status.

Keeping up with the rigorous course of a care and treatment program may be too difficult for those who do not wish to disclose their status to close family and friends. As Grace Oling further explained, people at TASO initially rejoiced when ARVs first began to be used. But now it has led to numerous other problems, including efforts to avoid the stigma of HIV infection. For example, a patient who was formerly without hope of recovery may be able to return to a normal life with the help of ARVs. He or she may then decide to move to a new community where no one will know of his/her HIV status and thus he/she will be able to find a new husband or wife and start a new family without ever disclosing his/her HIV-positive status.

Stigma also greatly affects correct adherence to drugs. As for adherence, Grace Oling said:

²¹ Grace Oling, Personal Interview. April 15th, 2008.

“Of course when someone is having stigma and swallowing ARVs, they will swallow in hiding. The moment that someone is hiding they will not adhere. They will need to wait for people to go away, or will go to the toilet. Someone will take it at awkward times. But if someone has disclosed, then it is very easy. Stigma is still there, some will say “Why do you come to our homes with marked [TASO] motorcycles” With recovery, stigma is coming back. Someone’s hope is raised once more; I will get another man once more. Someone says I will get another job. Someone will start hiding again.”

Mis-Management

On a broader level, poor management jeopardizes any progress achieved to increase access to ARVs. In Uganda, the national government fills the intermediary role between the general population and the donors. Reinforced largely by the international community’s praise for Uganda as a success story in the battle against HIV/AIDS, the Ugandan government has been placed in a unique position for either progress or deterioration in their fight against the disease.

Two examples of poor management and accountability have caused many people who should have been receiving ARVs to be neglected. The first is the story regarding the former Minister of Health, Jim Muhwezi, where \$47 million from the Global Fund was channeled into over 400 fictitious NGOs.²² While Minister Muhwezi lost his job, he spent only one night in a private jail cell, and is still living in a comfortable home, sending his children to foreign universities, and \$37 million remains unaccounted for. Secondly, the National Medical Stores, which are responsible for distributing ARVs, announced at the end of last year that nearly a million dollars worth of ARVs expired in the stores. This shows the absence of an effective system to monitor the drugs that are available and that are being distributed to those who should be receiving them.

The latter example is reflective of the relationship between the Uganda AIDS Commission (UAC) and the Ministry of Health (MOH). As articulated by one doctor wishing to remain anonymous, efforts of time, resources and energy are duplicated

²² Witter, Willis. "Uganda Shaken by Fund Scandal." Washington Times 21 June 2006. <<http://www.aegis.com/news/ads/2006/AD061085.html>>.

because the MOH is supposed to provide ‘health for all’ but UAC wants to oversee everything pertaining to HIV/AIDS. While MOH’s role is “support and supervise,” UAC “runs the show.”²³ The lack of coordination between the two agencies is one such example of well-intentioned but ineffective efforts resulting in patients who should be receiving drugs actually “slipping through the cracks”. Even when not intentional, poor management is causing dangerous supply interruptions. The Head of HIV/AIDS Department at Bwera Hospital told me that they experience stock-outs of drugs for two to three months at a time, as frequently as three times a year.²⁴ Not only is this psychologically discouraging to those in need of medication, but it is also dangerous because of the possibility of drug resistance mutations of the virus developing while the drugs are unavailable.

The book, “Global AIDS: Myths and Facts” attempts to dispel and disprove why ten major myths regarding HIV/AIDS are not true. Regarding corruption as a barrier to treatment, it says:

“Cronysim, bribery, and embezzlement hamper the AIDS fight in many countries and communities. Yet ... evidence shows that efforts to fight corruption and direct resources efficiently towards AIDS control are gathering momentum today, particularly in Africa...International institutions such as the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM) have incorporated strict new monitoring and accountability mechanisms to ensure proper use of resources as anti-AIDS efforts are scaled up...some developing countries grappling with stubborn cultures of corruption have already managed to implement highly effective HIV/AIDS programs. Evidence from Thailand, Uganda, and Brazil shows that countries do not need to wait until systemic corruption has been eliminated before implementing large-scale programs against HIV/AIDS with success. Corruption and HIV/AIDS can be battled simultaneously.”

²³ Female Doctor in Kampala. Personal Interview. April 24th, 2008.

²⁴ Bwambale Joshua Kakuhi. Personal Interview. March 24th, 2008.

While the general argument is noble, the supporting examples have been made irrelevant by the Global Fund scandal, mentioned above, which took place two years after the book's publication. It is interesting to note that Uganda is specifically mentioned as a success among African nations. There is evidence of corruption involving policy-makers, those who handle the mass influx of funds from donor organizations and countries, as well as those whose job it is to serve at the front lines in the battle against HIV/AIDS, including physicians, clinics, and pharmacies.

Lack of oversight has led to corruption trickling down to the lower-levels of policy implementation as well. Several sources informed me that in order to even see a doctor at Mulago, a supposedly free government hospital, one must bribe a series of individuals. The experiences of one such informant trying to support her HIV-positive cousin are worth repeating in her own words:

“Now my cousin is 22 years, we don't know how she got infected. We don't know if she was born with the disease or got, but she is HIV positive and on drugs. When she broke down and fell sick we started her on drugs...But her immune system became more weak, she got pregnant. She miscarried, told it was side effect because of the drug. She was never the same, got rashes, she looked like that for almost a year. Our family decided to try [another location], that maybe they would give her a better combination. But they refused to admit her claiming that she used to take her drugs from [first site of drug delivery]. That's where she has to go. We had to bribe a doctor. The doctor we bribed gave her a file, gave her a number and they registered her. So she began taking drugs from Mulago. But they had to pay the doctor. She was given a combo of 6 drugs – we were paying the doctor a total of over 500,000/= for her to get the drugs each month. We used to find that doctor in town and give the money. He would send them to people in town, saying call this number. We would give the envelope to this person. Then we would call the doctor and he would tell us you come to [his place of work] around 6:30 and would give the medication in a small bag. Over time we stopped interacting [there] because he said it was too dangerous, we met him elsewhere. After two months she got the four drugs for free, then they told

her one of the specific drugs, a vitamin, was out of stock she couldn't have it free. But the doctor gave her an option, telling her it was in the clinics and wrote down the names of the clinic. And bought the drug there – 50,00/= extra per month. When she asked the doctors when the drug would come back, she was told it was out of stock. There were so many people who wanted it and they think that she isn't the neediest, yet she really needed it. That particular doctor who was getting us the drugs migrated to the US, he got a job in the US and when he left we got in touch with another doctor... We give him money and he does the same thing for us. We have his bank number, we transfer the money there, when he sees that the money is there he gives us the drug. That's how bad it is.... Now as her caretakers, we are getting our hands tied. Because I tried to investigate how much the combination of ARVs is to an ordinary person. I almost collapsed. It's 130,000 Ugandan shillings a month for the combination. So what does that mean? If she stops receiving the drug for free, because even me I cannot afford that. So she has to just survive until her CD4 goes low, she dies and we bury her. Unless the doctors do what they have promised to do.”²⁵

This individual also told me that it is possible to buy the drugs without ever testing positive for HIV. She knows this to be the case, because she has done it. She described for me a time when she went to a doctor in private practice saying that she wanted to get a prescription for ARVs for her cousin. After explaining that all patients must go to a government facility to get a CD4 cell count, and that ARVs cannot be prescribed without this information, the doctor offered names of clinics that sell the ARVs. Once my informant described the condition of the patient, this is what happened:

“So this is what he did: He has this very big medical book about treatment of HIV. He opened it, read through, he pulled out from his drawer a medical form from Mulago hospital and then he wrote for me the prescription. Then he told me, there is a case of a patient that exactly has such signs. So probably he thinks

²⁵Female Ugandan Living in Kampala. Personal Interview. April 30th, 2008.

that will [work], so he asked me, “Do you think she has had such treatment.” So I was like, “I don’t know.” He was like, “Then fine. You can go and try giving this patient this.” Then afterwards he was like, “I actually don’t know if I really have to give you this because under the medical profession it is not allowed a person to give a prescription when you have not seen the patient.” Then I was like, “Fine,” because it’s not like you have to give it to me and I don’t want you to do something out of your profession. So I was ready to go, I was walking out and he said, “Come, because it seems you really need this.” And said, “I need it but I don’t want to go against what your profession says.” He said, “Okay, how much are you going to pay for it.” Then I told him I didn’t have money. Then he was like, “Why did you then waste my time?” He was getting annoyed. ... “You know what I am doing is against my profession, something can happen to me.” And then I was like, “But I don’t want to do something against.” ... So I was like, “I have 30,000.” He said, “30,000 is nothing.” “Then I was like, that’s the most I have.” Then he said, “Make it 50.” Then I coughed it up and made it 50, so he gave me the prescription. ... The name you see here is just the name of one of his patients, but Helen is just a fake name. Just to alter the name. I think he put a different name because he was afraid of being held liable. And if he put the name of my cousin, he would be easily prosecuted in a court of law... So I went to a pharmacy near the Old Taxi Park, whose name I will leave as X. At the pharmacy there was a lady. I simple gave her this [indicating to the prescription] and she “Oh, Lamuvidune we have. And even the second.” And this is what was so funny about this pharmacy. Like all its drugs were on the shelves up and in the open. But the pharmacist reached these drugs from the under cupboards, like you would not easily see.”

The drugs cost my informant 500 Ugandan shillings each, for a total of 15,000/= for 15 days. My informant went on to explain that she never had to prove she was the patient, the identity of the doctor was never confirmed, and at no point was she counseled or informed on how to take these drugs. Furthermore, when the pharmacist realized that

she did not have the tablets in the correct dosage that the doctor had written out, “she had the audacity to change what the doctor had written!”

“You can have [a prescription] from any clinic, no one is going to question you. Even if it’s a fake clinic, as long as the prescription is properly written, you can go and get the drugs...Anyone can acquire the ARVs in any way they want.”²⁶

Appendix C includes both the prescription and the receipt from the pharmacy mentioned in the anecdote described above. Upon further research, I realized that the two drugs obtained by the informant, Lamivudine and Stavudine, represent only two thirds of the necessary three-drug combination therapy standard for HIV treatment around the world. Even more alarming is the fact that Stavudine is no longer recommended by Uganda’s Ministry of Health²⁷ and other health organizations around the world.

Such an example describes ARV anarchy caused by corruption. Where donated drugs are smuggled from hospitals (such as the informant told me she believes these drugs were) and distributed with absolutely no oversight or responsibility, massive problems may ensue. Of course, while corruption may be commonplace, it is by no means universal. I witnessed one doctor giving money from her own wallet to a client in need of money for transportation home after her appointment.

Dr. Alice Namale of CDC Entebbe told me that many of the issues associated with management of ART delivery is because of a “lack of strong leadership from our own people.”²⁸ Bridget Nazziwa, a law student at the Uganda Christian University in Mukono summed up these problems very well when she said, “The biggest problem in this country is management. No matter how poor or bad the policies may be, it all begins with the management.”²⁹

²⁶ Female Ugandan Living in Kampala. Personal Interview. April 30th, 2008.

²⁷ Dr. Susan Kizaala. Personal Interview. April 25th, 2008.

²⁸ Dr. Alice Namale. Personal Interview. April 25th, 2008.

²⁹ Bridget Patricia Nazziwa. Personal Interview. April 20th, 2008.

Organizational Limitations

Even with good intentions on the part of policy makers and implementers, structural and human resource limitations severely disable attempts to provide HIV care and treatment.

Constantly recited in my interviews were three areas of resource needs: 1) Human resources. While the clinic burden has greatly been reduced because of ARVs, the hope that is provided by ARVs has also spurred more people to seek testing and then treatment. Much of the care of HIV/AIDS patients is individualized, and as such requires the time of counselors, physicians and nurses, not to mention the laboratory and pharmacy staff necessary to support treatment centers. Simply put, there are too many clients for the number of staff available. 2) Space limitations. Overcrowded waiting rooms have spilled over into the hallways. Testing, counseling and examination rooms in some facilities may be separated by only a thin curtain. 3) Expensive and/or Inaccessible Laboratory Equipment. This refers specifically to machines used to make decisions regarding a patient's eligibility to begin ARVs. Depending on the location, and the donor supporting the health facility, a CD4 machine may be either very easy or very difficult to access.

When a CD4 count machine is not available, the clinicians make decisions based on the WHO Clinical Stages. While these generally match up to a CD4 count that corresponds in terms of the strength of the immune system, it is not uncommon to find discrepancies. It is possible for the CD4 to be high, but the patient presents with severe opportunistic infections. Or the patient may appear totally healthy but have a severely compromised CD4 cell count. In fact, according to Dr. Steven Reynolds of the Infectious Disease Institute, using clinical factors alone will miss 50% of people who would otherwise qualify for ART.³⁰ As mentioned earlier, the best results are obtained when clinical factors and a CD4 cell count are considered together. Another issue is the infrequency with which viral load tests are performed in Uganda. This measure of how many copies of the virus are in the patient's blood, coupled with a CD4 cell count, is a good indicator of how the immune system is fairing, both before and during treatment

³⁰ Dr. Steven Reynolds. Personal Interview. April 25th, 2008.

with ARVs. The viral load test is expensive in Uganda, and is thus only done for more medically complex cases.

Sustainability

If enough hard-work and dedication were invested into the HIV/AIDS treatment system of Uganda, mixed with a little luck, perhaps many of the barriers previously discussed could be solved over time. But as it currently stands, we cannot hope that people living with HIV/AIDS will have access to life-saving drugs and care in the future if Uganda continues to be nearly totally dependent on foreign donor support.

A physician with the Makerere University Walter Reed Project told me that “95% of the HIV budget in Uganda is from donors. [The remaining] 5% includes things such as administration and security, but in the actual sense they are not putting in a coin.”³¹ This absence of more domestic commitment of resources does not bode well for Ugandans. The current situation puts the lives of Ugandans at risk of the whim and potentially changing priorities of policy makers thousands of miles away. If the United States put trade sanctions on Uganda, people would start “dropping dead,”³² I was told.

Donors in general love numbers, and seem to measure their successes in quantity not quality. It is easier to boast of the number of people treated with ARVs, instead focusing on the comprehensive nature or sustainability of those numbers. For example, the World Health Organization’s “three by five” campaign to put three million people on ARVs by 2005 was an admirable goal, but all of these people needed to be provided a commitment of ARV supplies for the rest of their lives, not just for the next few years.

The fact that ARVs must be taken for life is probably the biggest challenge facing sustainability of care and treatment programs. But there are many more costs associated with a good quality program; as outlined in the chart of Appendix D. As noted, a comprehensive and home-based care system, such as the one that TASO offers, is the best care and treatment program, but is the least sustainable. And no matter how valuable and extensive the program, such as the PEPFAR supported program in Kayunga District

³¹ Dr. Fred Magala. Personal Interview. April 16th, 2008.

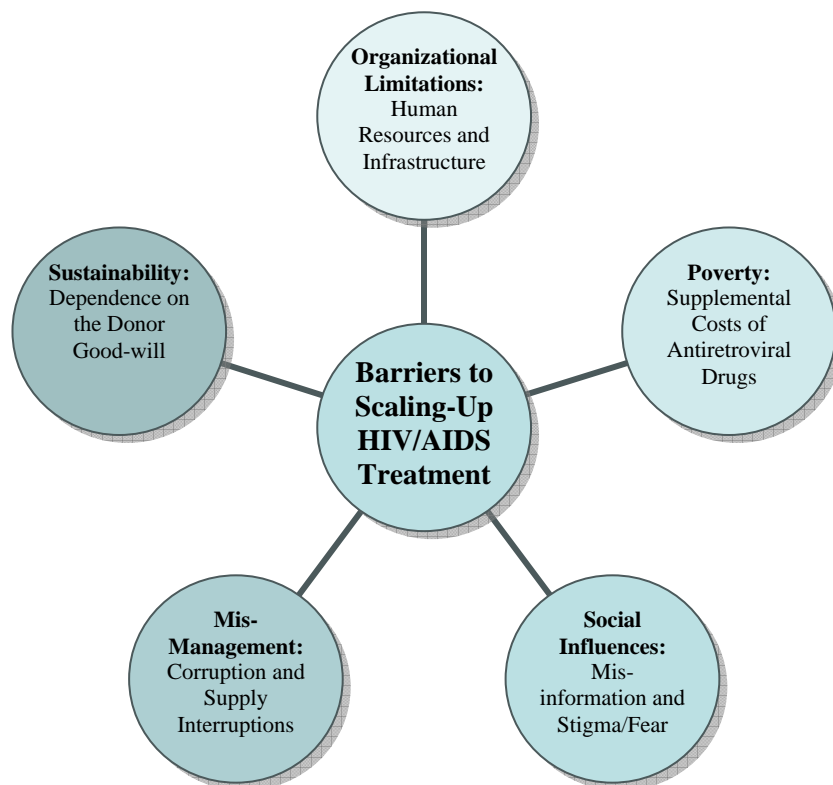
³² Dr. Fred Magala. Personal Interview. April 16th, 2008.

focusing on HIV prevention, testing and treatment, “there is no donor program that is sustainable” forever.

As the fight against HIV/AIDS continues it is simply unacceptable for a country that has been hailed as a leader in the battle against the disease to be so dependent on the money, technology, and resources of other countries.

Eligibility Guidelines

Any effort to increase access to treatment, as argued for earlier, must not shy away from any of these challenges: whether on the individual, community, governmental, or international level. Together they form an integrated web of issues that must be dealt with if the scaling-up of treatment is to be achievable. The issue of eligibility for ARVs permeates the efforts to combat the disease. Consequently, when considering eligibility for ARVs, all barriers to access of ARVs must be taken into account.



Solutions

In addressing and combating the barriers discussed above, there are several possible solutions, some already well underway. Naturally, every challenge requires personnel, money, and patience. The challenges may seem monumental, but there are options for revolution.

Efforts to alleviate poverty are among the best solutions for minimizing the individual barriers to access of ARVs. Of course this is easier stated than accomplished and something that those committed to eradicating poverty been struggling to achieve. The United Nation's Millennium Development Goals, and Uganda's Poverty Eradication Action Plan must be given the support that they have requested in order to be successful.

Education and the dissemination of information regarding HIV/AIDS is the best way to combat misconceptions and stigma in the community. Fortunately there have been countless efforts to overcome these hurdles. For instance, the Uganda Network on Law, Ethics and HIV/AIDS attempts to fight discrimination, especially in the workplace, that is faced by people living with HIV/AIDS. TASO's drama group also strives to sensitize the community to issues pertaining to HIV/AIDS. TASO also sponsors an ART-related support line that is open to any individual with a question regarding ARVs. Signs posted all over TASO and other health centers talking about the benefits of ARVs and how to properly take them for positive living are written in both English and the vernacular.

A new idea to compensate for limited human resources is "task-shifting". As the NGO Uganda Cares explains, it is a strategy of using "expert patients" to act as counselors and basic care technicians for fellow patients.³³ Community ART Support Agents, also known as CASAs, of TASO are one such example of task-shifting to combat many of the societal barriers to accessing HIV care and treatment. These individuals are clients of TASO who are taking ARVs and have medically responded well. Their role is to educate their communities about ARVs, show people the effects that ARVs can have on one's life and support fellow community members on ARVs. They wear T-shirts with slogans such as "Stigma Kills...Talk Openly about HIV/AIDS" or "Am on ARVs...and In Your Community." The idea of "Positive Prevention," or encouraging already HIV-

³³ Dr. Mina. Personal Interview. April 24th, 2008.

positive persons to engage and educate their communities about HIV prevention is being employed across Uganda already.

International agencies should take up the cause of improving Uganda's HIV/AIDS approach. Naturally, they should work with the already existing government structures, but also examine such areas as: the overlap between the Uganda AIDS Commission and Ministry of Health, the supply and distribution chain of ARVs between donors, pharmaceutical companies, the medical stores and health centers. Additionally, donors should take a more hands-on approach to oversight of funds and then follow up with concrete reprimands for those countries that do not use the funds honestly.

Donors should also work with the public and private sector of recipient countries to develop tangible expectations on a timeline that moves the recipient country towards greater self-dependency. For example, Quality Chemicals has teamed up with the Indian pharmaceutical company, Cipla, to begin manufacturing ARVs that will be available for distribution in June 2008. Manufacturing the drugs closer to their destination will reduce costs, and will allow much-needed drugs to be produced without violating the World Trade Organization's Trade-Related Intellectual Property Right's Agreement (TRIPS), which allows pharmaceutical companies to hold patent rights over drug formulas for a certain period of time to off-set research and development costs. It will also create a new job market and training center for the industries of Uganda. The new plant just opening in Kampala is the first of its kind in the region.³⁴

We must also look ahead to possible problems in the future. The pharmaceutical companies have historically been targeted by human right's activists to lower the cost of life-saving drugs, such as ARVs. Responding to these calls, the companies have complied. But second-line drugs remain very expensive in Uganda, and although the current first-line regimen appears to be sufficient for the time-being, the future is far from certain.. While recognizing that pharmaceutical companies will need to achieve a certain level of profit in order to continue investing in the development of drugs, activists must keep applying pressure on pharmaceutical companies to work with governments and donors to make the necessary drugs affordable to those who need them. Also, research

³⁴ George Babumba. Personal Interview. April 28th, 2008.

into better drugs, such as those that reduce pill-burden by delivering the drugs in a weekly pill for instance, or drugs with fewer and milder side-effects, will revolutionize adherence for patients taking ARVs.

While strides have been made to combat these many levels of inequalities of access to treatment, there is still much to be done. According to the book Global AIDS, “The Ugandan government’s effective leadership against HIV/AIDS has paid off in terms of heightened public awareness, changed behaviors, and lower infection rates.”

Undoubtedly, President Museveni’s acknowledgement that HIV is a threat to his country has helped Uganda battle the epidemic. While other African leaders, namely South Africa’s Thabo Mbeki, have denied that HIV causes AIDS, Museveni’s response has allowed NGOs and governmental organizations to carry out efforts for HIV/AIDS education, prevention, treatment and care. Billboards and public health messages are seen on almost every street corner in Kampala and I did not question a single person in the course of my research that lacked at least some knowledge of HIV/AIDS. But it would be a grave mistake for anyone to assert that the Ugandan government’s efforts have “paid off” without acknowledging the challenges that still lie ahead. Knowledge can, but does not always, lead to a change in behavior. Whether by choice or by circumstance, individuals are still infected with HIV even if they know how to protect themselves. But even with such a heavy burden in mind, there is the possibility for change.

Moving Forward

Current Debate Regarding Public Policy Changes

This report is not intended to examine all of the biological ramifications of earlier initiation of ARVs. But all of my research has let me to conclude that, medically speaking, there is no compelling reason to *not* increase the CD4 eligibility cut-off level. As Uganda currently debates the issue, it seems that the principal question to consider is not whether the guidelines should be changed, and thereby increase the group of people eligible for ART, but rather whether this should be done concurrently or only after Uganda addresses the many barriers to access for those who are currently eligible. However, this central question raises many subsidiary considerations. For example, although it is a medically sound course of action, is it advisable to increase the number of people who qualify for ARVs, when there are so many who already do qualify but are not receiving the drugs because of the many barriers described above? Can the number of ART-qualifying patients increase while the issues of access are addressed concurrently?

On the one hand, a greater number of people “in need” of ARVs may ensure the distribution of available resources to more individuals. While more people will be assisted, the neediest will likely receive a smaller portion. If the system cannot handle the current numbers eligible for ARVs, is over-burdening the system fair to patients, healthcare providers or donors? Working on development of infrastructure, educational systems, and transparency of government will contribute more to access of drugs in the long-run than simply focusing on breaking down barriers to HIV/AIDS treatment.

However, several arguments on the other side of the debate also have merit. If people are not accessing health care for any of the aforementioned reasons, that is a separate issue from what is medically advisable. Those who are accessing care should be able to begin ARVs as soon as medically possible, and not be held back by the people who are not accessing care but are assumed to be more “in need.” Furthermore, support for health system improvements may rise to meet the challenge as more people are qualified for ART. Improvements in the areas of development of infrastructure, educational systems, and transparency of government may be accelerated when attached to a concrete goal, such as the scaling up of HIV/AIDS treatment.

Although these are important questions, refraining from proceeding with treatment for the current eligible population before fully addressing the problems that affect access to drugs would nonetheless be the incorrect course of action. Despite all the failings and obstacles in the current system, there are people whose lives are owed entirely to the health care they have received and the ARVs that strengthened their immune systems. It is now the issue of expansion of ARVs in the most effective manner that must be debated.

Further Research

As we face this next frontier of the epidemic, I believe it is imperative that considerable debate be given to the issue of when and how to scale up access to antiretroviral drugs for people living with HIV/AIDS. Beyond addressing the barriers to access, future research should be focused on the continuing debate of whether or not the eligibility guidelines can be changed concurrent with addressing the issues that affect access. It may be helpful to look at other countries and settings – both in the developed and developing world – to serve as a comparison and springboard for action in Uganda.

As I continue my formal and informal education, I hope to explore further the complex issues related to the provision of appropriate medical care for those infected with HIV/AIDS. I am inspired by the words spoken to me by a young adult in Uganda, with the hopes of improving access to ARVs for her fellow Ugandans. She said:

“I believe it all begins with us...I wish we can have nationalistic feelings towards our country...If you have nationalistic spirits in your heart, even if you’re given thousands of dollars for your fellow Ugandans, you will not embezzle it, you will help your fellow Ugandans. But because of lack of nationalism, who cares? ... But now when we are eating, or embezzling funds, we always say, “For Me and My Stomach. I don’t care.” That thing is going to bring this country down...I first want to let people love their country. This is your image, this is what you are. Protect it, respect it, love it. The rest will follow, simple.”³⁵

³⁵ Bridget Patricia Nazziwa. Personal Interview. April 20th, 2008.

Conclusion

I began this project thinking that at the end, I would have a completely clear idea of what needs to be done – and that this paper would largely be a call-to-action on the part of the privileged to assist the plight of the poor and disadvantaged by fighting some easily-identifiable evil, whether it be government, donors, or the pharmaceutical industry. But the conclusions are much more complex. It is not a straightforward determination to decide whether ART should be initiated at a CD4 cell count of 200 or 350 in a resource-poor setting such as Uganda.

Nor should the monumental obstacles to better treatment, obscure the rather remarkable work that is getting done everyday in spite of the obstacles. One only needs to ask what it was like “before” to know the magnitude of difference that ARVs make.

But the answer for improvement is much more complex than a simple rallying cry of “ARVs for all!” The task is more daunting and harder to communicate effectively when the chant is expanded to “ARVs, nutrition, safe water, free medical care, school fees, adequate personnel and infrastructure, end of corruption, and alleviation of poverty for all!”

The solutions are not simple. But perhaps that is the essence of a global village – of one world. We all share responsibility. But we all have the power for change as well.

Bibliography

Primary Sources

- Bridget Patricia Nazziwa. Personal Interview. April 20th, 2008.
- Bwambale Joshua Kakuhi. Personal Interview. March 24th, 2008.
- Dr. Alice Namale. Personal Interview. April 25th, 2008.
- Dr. David Serwadda. Personal Interview. April 29th, 2008.
- Dr. Fred Magala. Personal Interview. April 16th, 2008.
- Dr. Fred T. Muwanga. Personal Interview. April 23rd, 2008.
- Dr. Mina. Personal Interview. April 24th, 2008.
- Dr. Steven Reynolds. Personal Interview. April 25th, 2008.
- Dr. Susan Kizaala. Personal Interview. April 25th, 2008.
- Female Doctor in Kampala. Personal Interview. April 24th, 2008.
- Female Peer Educator in Kayunga. Personal Interview. April 17th, 2008.
- Female HIV Positive Patient Not on ART. Personal Interview. April 18th, 2008.
- Female HIV Positive Patient on ART. Personal Interview. April 18th, 2008.
- Female Receiving HIV Test in Kayunga. Personal Interview. April 17th, 2008.
- Female Ugandan Living in Kampala. Personal Interview. April 30th, 2008.
- George Babumba. Personal Interview. April 28th, 2008.
- Grace Oling. Personal Interview. April 15th, 2008.
- Idi Abiriga. Personal Interview. April 17th, 2008.
- Innocent Abaho. Personal Interview. April 22nd, 2008.
- Kakitahi, John T. "Introduction to Public Health Practice in Uganda." School for International Training. Makerere University, School of Public Health, Kampala, Uganda. 3 Mar. 2008.
- Male Counselor and Peer Educator in Kayunga. Personal Interview. April 17th, 2008.
- Male HIV Positive Patient Not on ART. Personal Interview. April 18th, 2008.
- Male HIV Positive Patient on ART. Personal Interview. April 18th, 2008.
- Male Receiving HIV Test in Kayunga. Personal Interview. April 17th, 2008.
- Richard Oleja. Personal Interview. April 17th, 2008.

Rufina Barigo Oloa. Personal Interview. April 24th, 2008.

Serwadda, David. Lecture. School for International Training. Makerere University, School of Public Health, Kampala, Uganda. 3 Mar. 2008.

Simon Sunny Wejuli. Personal Interview. April 22nd, 2008.

Secondary Sources

Asingwire, Narathius, and Swizen Kyomuhendo. "Attacking Africa's Poverty." *Turning the Tide: How Openness and Leadership Stemmed the Spread of HIV/AIDS in Uganda*. 2005. 343-369.

Bartlett, John G. *Antiretroviral Therapy, HIV Primary Care Guide 2004*. Centers for Disease Control and Prevention, United States Department of Health and Human Services. 2004.

Bugembe, Anthony, Raymond Baguma, and Esther Kyabaki. "Africa's AIDS Disaster Could Have Been Avoided." *The New Vision* 31 Mar. 2008.

Centers for Disease Control and Prevention. United States Department of Health and Human Services. <www.cdc.gov>.

Currier, Judith S., and Lindsey R. Baden. "Getting Smarter -- the Toxicity of Undertreated HIV Infection." *The New England Journal of Medicine* 355 (2006): 2359-2361.

Etyang, Jude. "\$10m Order for First Batch Ugandan ARVs." *The East African: Business Week*. 28 Jan. 2008 <http://www.busiweek.com/index.php?option=com_content&task=view&id=4667&Itemid=9>.

"Global HIV Prevalence Has Levelled Off." World Health Organisation. 20 Nov. 2007. United Nations. <<http://www.who.int/mediacentre/news/releases/2007/pr61/en/>>.

"Guidelines for the Use of Antiretroviral Agents in HIV-1-Infected Adults and Adolescents." Panel on Antiretroviral Guidelines for Adults and Adolescents. 29 Jan. 2008. United States Department of Health and Human Services. <<http://www.aidsinfo.nih.gov/ContentFiles/AdultandAdolescentGL.pdf>>.

"HIV Classification: CDC and WHO Staging Systems." AETC: National Resource Center. July 2006. AIDS Education and Training Centers. <http://aidsetc.org/aidsetc?page=cm-105_disease#t-4>.

Irwin, Alexander, Dorothy Fallows, and Joyce Millen. *Global AIDS: Myths and Facts. Tools for Fighting the AIDS Pandemic*. Cambridge, MA, 2003.

Karugaba, Mary. "Soroti Stuck with Expired Drugs." *The New Vision* 4 Mar. 2008. <<http://www.newvision.co.ug/D/8/13/614913>>.

"Medications to Fight HIV/AIDS." AIDSinfonet.Org. New Mexico AIDS Education and Training Center. <http://www.aidsinfonet.org/factsheet_index.php?catnum=400>.

Moh, R. "Incidence and Determinants of Mortality and Morbidity Following Early Antiretroviral Therapy Initiation in HIV-Infected Adults in West Africa." *AIDS* 21 (2007): 2483-2491.

Mugerwa, Yasiin. "Uganda: MPs to Probe Drug Body Over Expired Stocks." *The Monitor* 4 Mar. 2008. <[://allafrica.com/stories/200803032089.html](http://allafrica.com/stories/200803032089.html)>.

An Overview of HIV/AIDS in Uganda. Uganda Ministry of Health, 2007.

"Poverty" Dictionary.Com. <<http://dictionary.reference.com/browse/poverty>>.

"Quality Chemicals Industry, HIV Drug Plant, Uganda." Pharmaceutical-Technology.Com. 2008.
<<http://www.pharmaceutical-technology.com/projects/qualitychem/>>.

Sachs, Jeffrey. The End of Poverty: Economic Possibilities for Our Time. 2005.

TASO 2006 Annual Report. The AIDS Support Organization. 2007.

"Treatment for Adult HIV Infection. 2006 Recommendations of the International AIDS Society -- USA Panel." Journal of the American Medical Association.

"Uganda, Epidemiological Fact Sheet on HIV/AIDS and Sexually Transmitted Infections." Dec. 2006. World Health Organization.

"Uganda Gov't Releases Final Report on Global Fund Scandal." Xinhua News Agency 10 Apr. 2007.
<<http://www.reliefweb.int/rw/rwb.nsf/db900sid/SHES-725Q2W?OpenDocument>>.

Wainberg, Mark A. "Generic HIV Drugs -- Enlightened Policy for Global Health." The New England Journal of Medicine 352.8: 747-750. <<http://content.nejm.org/cgi/content/full/352/8/747>>.

Were, David M. "Hope."

Witter, Willis. "Uganda Shaken by Fund Scandal." Washington Times 21 June 2006.
<<http://www.aegis.com/news/ads/2006/AD061085.html>>.

World Health Organisation. <www.who.int>.

APPENDIX A

APPENDIX B³⁶

**Table 4. WHO Clinical Staging of HIV/AIDS for Adults and Adolescents (Interim Definitions)
Primary HIV Infection**

- * Asymptomatic
- * Acute retroviral syndrome

Clinical Stage 1

- * Asymptomatic
- * Persistent generalized lymphadenopathy

Clinical Stage 2

- * Moderate unexplained weight loss (<10% of presumed or measured body weight)
- * Recurrent respiratory infections (respiratory tract infections, upper respiratory infections, sinusitis, bronchitis, otitis media, pharyngitis)
- * Herpes zoster
- * Minor mucocutaneous manifestations (angular cheilitis, recurrent oral ulcerations, seborrheic dermatitis, prurigo, papular pruritic eruptions, fungal fingernail infections)

Clinical Stage 3

Conditions for which a presumptive diagnosis can be made on the basis of clinical signs or simple investigations

- * Severe weight loss (>10% of presumed or measured body weight)
- * Unexplained chronic diarrhea for >1 month
- * Unexplained persistent fever for >1 month (intermittent or constant)
- * Oral candidiasis (thrush)
- * Oral hairy leukoplakia
- * Pulmonary tuberculosis within the last 2 years
- * Severe presumed bacterial infections (eg, pneumonia, empyema, pyomyositis, bone or joint infection, meningitis, bacteremia)
- * Acute necrotizing ulcerative stomatitis, gingivitis or periodontitis

Conditions for which confirmatory diagnostic testing is necessary

- * Unexplained anemia (hemoglobin <8 g/dL)
- * Neutropenia (neutrophils <500 cells/ μ L)
- * Thrombocytopenia (platelets <50,000 cells/ μ L)

Clinical Stage 4

Conditions for which a presumptive diagnosis can be made on the basis of clinical signs or simple investigations

- * HIV wasting syndrome, as defined by the CDC (see Table 3, above)
- * Pneumocystis jiroveci (formerly carinii) pneumonia
- * Recurrent severe or radiologic bacterial pneumonia
- * Chronic herpes simplex infection (oral or genital, or anorectal site) for >1 month
- * Esophageal candidiasis
- * Extrapulmonary tuberculosis
- * Kaposi sarcoma
- * Central nervous system toxoplasmosis
- * HIV encephalopathy

Conditions for which a confirmatory diagnostic testing is necessary

- * Cryptococcosis, extrapulmonary
- * Disseminated nontuberculosis Mycobacteria infection
- * Progressive multifocal leukoencephalopathy
- * Candida of the trachea, bronchi, or lungs
- * Cryptosporidiosis
- * Isosporiasis
- * Visceral herpes simplex infection, cytomegalovirus infection (retinitis or organ other than liver, spleen, or lymph node)
- * Any disseminated mycosis (eg, histoplasmosis, coccidioidomycosis, penicilliosis)
- * Recurrent nontyphoidal Salmonella septicemia
- * Lymphoma (cerebral or B-cell non-Hodgkin)
- * Invasive cervical carcinoma
- * Visceral leishmaniasis

³⁶ "HIV Classification: CDC and WHO Staging Systems." AETC: National Resource Center. July 2006. AIDS Education and Training Centers. <http://aidsetc.org/aidsetc?page=cm-105_disease#t-4>.

APPENDIX C³⁷

³⁷ Female Ugandan Living in Kampala. Personal Interview. April 30th, 2008.

APPENDIX D

COSTS OF A SUSTAINABLE CARE & TREATMENT PROGRAM

| | Testing | ARVs | Counseling/Education | Monitoring | Positive Living |
|-------------------------|---|---|---|---|---|
| Personnel | <i>Phlebotomist Educator/Counselor</i> | <i>Pharmacist Physicians/ Nurses</i> | <i>Counselors Trained Educators</i> | <i>Laboratory Technicians, Phlebotomist, Physicians/Nurses</i> | <i>Supportive Family/Friends</i> |
| Physical Space | <i>Private area for result delivery</i> | <i>Pharmacy space, exam rooms</i> | <i>Private rooms for counseling, group workshop space</i> | <i>Laboratory space</i> | <i>Safe, clean living conditions</i> |
| Equipment | <i>Testing Kits</i> | <i>Pharmacy equipment</i> | <i>Educational materials</i> | <i>All laboratory equipment</i> | <i>Basic Care Package</i> |
| Time | <i>At least 2-3 hours for transport, education, testing, and result delivery and counseling</i> | <i>Refill of drugs – at least a full day for a patient once a month</i> | <i>Varies depending on patient and his/her needs</i> | <i>Varies depending on tests performed, frequency of test, etc.</i> | <i>For life</i> |
| Additional Costs | <i>Transport for either client or home-care provider</i> | <i>Transport cost, drugs to manage side-effects, etc.</i> | <i>Transport costs, continuing education</i> | <i>Maintenance of equipment, transport of samples, etc.</i> | <i>Nutrition desire for education, families, income, etc.</i> |