

## Overcoming Barriers to HIV/AIDS Treatment in Malaria Endemic Uganda

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### *ABSTRACT*

HIV/AIDS and malaria are the two most important global health concerns today, and the interaction between these two diseases has great implications for health care in sub-Saharan Africa. In addition to considering the biological interactions of these diseases, treatment programs for must take into account the cultural context of the patients. Uganda, which has had some success in reducing HIV, provides an excellent opportunity to study the interaction between HIV and malaria. Conducting an ethnographic study of a clinic in Uganda gives a greater understanding of the impact of HIV and malaria on individuals in the local community.

In the ten weeks of this study, participant observation revealed the services offered by a clinic and the patient utilization of these services in a specific cultural context. In addition, daily informal interviews and seven formal interviews provided a picture of the barriers that patients encounter when attempting to receive treatment and of the barriers that The Clinic and its staff encounter when attempting to provide treatment. These barriers fall into four categories: economic, environmental, social/political, and other. Interaction with foreign volunteers/expatriates, as well as with locals, provided an interesting contrast between emic and etic views of The Clinic. This study shows the complexity of providing treatment for HIV/AIDS and malaria in Uganda and the need for integrated services that address issues of transportation, nutrition, education, and stigma, as well as obvious health issues. Lessons learned from this study could be applied to similar contexts throughout the developing world.

## *INTRODUCTION*

The process of research involves constantly focusing and refocusing the scope of the research on the many layers of a problem. HIV/AIDS and malaria are health issues of global proportions, but we cannot hope to understand them without seeing them also as regional, national, local, familial, and personal health issues as well. Knowledge is not amassed by simply looking at smaller and smaller pieces of the puzzle; we must step back and contextualize these small pieces in order to see the bigger picture.

Researching the impact of HIV/AIDS and malaria in Africa provides a good picture of the statistical ramifications of these diseases, both in terms of the cost to human life and the economic burden. However, it does not give an understanding of what these diseases mean to the people infected and affected by them on a daily basis. As the physician and anthropologist, Paul Farmer, explains, “Anthropology concern[s] itself less with measurement than with meaning. As in mastering a language, one ha[s] to learn not just the literal meaning of words but also their connotations, and to grasp those one ha[s] to know the politics and economics, systems and histories of a place” (Kidder 2004). By studying the biology of HIV/AIDS and malaria, researching their human and economic costs, and investigating standard treatments, I learned the literal meaning of HIV/AIDS and malaria. However, in order to understand their connotations, I needed to go to a place that was dealing with HIV/AIDS and malaria in a very real sense. Uganda provided a prime location for the study of both HIV/AIDS and malaria.

Going to a successful, locally run, HIV/AIDS clinic in Uganda allowed me to begin to understand the greater context surrounding HIV/AIDS and malaria. While it is impossible to master a language in only a summer, through immersion one can gain the ability to communicate and navigate in a foreign environment. Similarly, while it would be overly presumptuous to

claim that after a summer at one clinic I have a full understanding of HIV/AIDS and malaria in Africa, conducting the ethnography of a clinic has allowed me to *begin* to grasp the politics, economic systems, and histories of these diseases.

Working with clinic staff, physicians, and patients provided the opportunity to glimpse the human face of HIV/AIDS in a malaria-endemic area. I strove to understand how and why patients came to The Clinic for care, what barriers they encountered in receiving treatment for their conditions, and how they attempt to overcome these barriers. What are the primary concerns of patients? What is a visit to The Clinic like for them? In addition, I wanted to know how The Clinic staff viewed patients, what barriers they encountered in providing patients with treatment, and how they attempted to overcome these barriers. Were the concerns of health care providers and of patients the same? By immersing myself in The Clinic's activities and talking openly with the people whom I worked with, I was able to address some of these questions. This case study is only a small piece of the great puzzle of HIV/AIDS and malaria, but it gives a human picture of the way that real people are fighting against and living with these diseases on a daily basis.

#### *DURATION, LOCATION, AND METHODS*

From May 30 to Aug 5, 2006, I conducted participant observation at the field site. The majority of time was spent at The Clinic, located at the intersection of two highways just outside of a major city in eastern Uganda. In addition, I made trips with clinic staff into the surrounding areas, including schools and villages, for home care treatments and VCT<sup>1</sup> programs. I conducted daily informal interviews with the clinic staff including lab technicians, nurses, doctors, counselors, local and foreign volunteers, the director, and Uganda Christian University students.

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<sup>1</sup> Voluntary Counseling and Testing

In addition, I conducted formal interviews with a midwife, a “doctor,”<sup>2</sup> and five clients. For two interviews I needed the help of an interpreter.<sup>3</sup> Verbal consent was asked for and confirmed before commencing all interviews. Informants were assigned a numerical code and were not listed by name in field notes. The clinic, all locations, and informants have been given pseudonyms in this report. During the duration of my stay I lived independently in a house in a small community approximately four kilometers from The Clinic.

### *THE CLINIC*

The Clinic is a community based HIV/AIDS NGO, established in 1998. Its mission statement is “to prevent the further spread of HIV and mitigate [the] personal [and] community impact of AIDS through provision of quality medical care and counseling services to the infected and affected population” (The Clinic website). The Clinic offers a wide range of programs to its clients and community.

Its greatest effort is for awareness and sensitization about HIV/AIDS through radio advertisements, post-test group performances, community mobilizers, and VCT for HIV. At least once a week, The Clinic does testing in the surrounding areas including schools and villages. Another main focus of The Clinic is providing medical care to all members of its community. Services include DOTs,<sup>4</sup> home based care for HIV positive clients, and a new antenatal clinic.

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<sup>2</sup> The word “doctors” appears in quotations because they are clinical and public health specialists, not MDs. These “doctors” have received the equivalent of a “bachelors in medicine.” They prescribe medicine and treat uncomplicated cases of illness; however, they have minimal training in procedures and refer complicated cases to the hospital. Patients, health workers, and staff refer to these individuals as doctors. This is common in health care facilities throughout the developing world.

<sup>3</sup> Female students from Uganda Christian University in Mukono acted as interpreters

<sup>4</sup> Direct observed therapy, short-course for tuberculosis (TB) patients

The main diseases treated are HIV/AIDS and malaria. While The Clinic does not provide ARVs<sup>5</sup> itself, bi-weekly it transports clients to another clinic for HIV treatment.

The Clinic, furthermore, reaches out to its community by sponsoring those affected by, but not infected with, HIV/AIDS. The Shadow Idol Club is a youth group that addresses issues of HIV/AIDS and reproductive health. The program also pays for two years of vocational schooling for OVCs.<sup>6</sup> Finally, the clinic organizes IGAs<sup>7</sup> for the caretakers of OVC, primarily grandparents, so that they may become self-sufficient.

### *BARRIERS TO TREATMENT*

Having discussed the services offered by The Clinic and the health issues that they deal with, I now move on to discuss barriers. Patients must overcome barriers to receive medical treatment, and likewise, the clinic must overcome barriers to provide treatment. By talking to patients and working with clinic staff, I gathered a variety of stories that illustrate these barriers and the attempts to overcome them. Barriers, which apply to both the clients and The Clinic, generally fall into the categories of environmental, economic, social/political, and other factors outside of the control of the individual or organization (Figure 1: Barriers to Treatment).

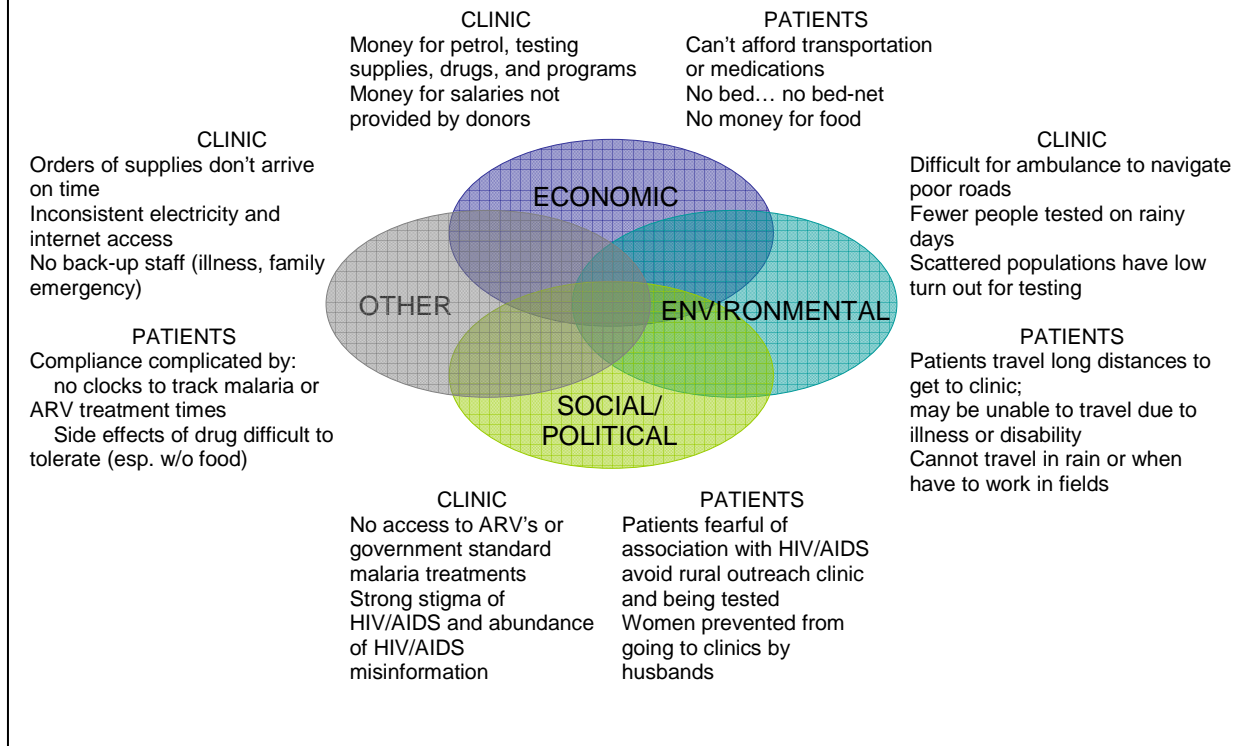
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<sup>5</sup> Anti-retrovirals; medication to treat HIV

<sup>6</sup> orphans and vulnerable children

<sup>7</sup> income-generating activities

## BARRIERS TO TREATMENT FOR PATIENTS AND THE CLINIC



### STORIES

The Shadow Idol Club is the most direct way that The Clinic reaches out to youth and gives them the opportunity to lead their peers. Simon was one of the group's leaders. His parents died several years ago, at least one from AIDS. He and his younger sisters had been receiving food from the World Food Program since then. Unfortunately, the program was ending its support of his family in a few months. Simon was attending vocational training, paid for by The Clinic, to become a brick maker. However, The Clinic could only support his education through a basic level certificate,<sup>8</sup> and in order to be competitive in the job market, Simon would need to receive an advanced certificate.<sup>9</sup> Simon wanted to give his sisters a chance

<sup>8</sup> Two years of education

<sup>9</sup> One more year of training/apprenticeship

at an education and at opportunities that he could not have since he was forced to become a child-head-of-house. However, without a sponsor for his advanced certificate, he will barely be able to make enough money to feed and clothe his family, let alone to pay for their school fees. Despite all of these challenges and the grim prospects ahead of him, Simon was a great leader for the Shadow Idol Club. He led the group as it reviewed HIV/AIDS information, he taught younger members traditional dance used in school presentations, and he spoke for the group when decisions were made. Being a leader gave Simon a sense of belonging and a sense of hope for the future. Simon's situation is not unique in Uganda, where more than one million children are estimated to be orphaned as a result of AIDS. However, his determination to make a better life for himself and his family combined with the support of The Clinic give Simon a chance at a better future.

Home care visits are one of the most important ways The Clinic attempts to overcome barriers to care. On one of these visits, we stopped to see Rose, a woman living in the prison staff barracks. Rose was extremely ill and suffering from AIDS. She was very thin and trembling uncontrollably. The nurse explained that she had been on ARVs for six months. When Rose first started treatment, her T-cell count was thirty-five, and she was suffering from severe skin infections. She was relieved that the skin infections had improved, but she was still so weak that she could not walk, or even stand, on her own. Rose reported feeling worse since she started taking the ARVs, perhaps a result of side effects from the drugs, but with encouragement she continues taking the medications. The nurse could only give Rose a few 'over-the-counter' medications including vitamin B6, Dexona,<sup>10</sup> and milk of magnesium. The

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<sup>10</sup> The nurse explained that Dexona was "for her nerves" to help stop the shaking. She explained that Rose was shaking because the HIV had attacked and damaged the nerves. According to [www.free-pharmacy.com](http://www.free-pharmacy.com) Dexona is a corticosteroid that relieves inflammation. It is used to treat certain forms of arthritis; skin, blood, kidney, eye, thyroid, and intestinal disorders (e.g., colitis); severe allergies; and asthma.

nurse believed that Rose's T-cell count had improved; however, when I asked about Rose's prognosis, the nurse replied, "I'm scared." Rose knew that she should go to the hospital, but she did not have to pay for transportation or for treatment. Interestingly, when greeting Rose with "Osiibye oty?" (How are you?), she responded "Bulungi" (Fine). Despite The Clinic's efforts to provide treatment to home-bound individuals like Rose, there is a limit to the care they can provide, and without the more-advanced medical intervention available only at a hospital, Rose will likely not recover. When one barrier to provide care is overcome, it seems The Clinic runs into another.

Judith, a 32-year-old divorced woman, came to The Clinic to be treated for a persistent cough which turned out to be pneumonia for which she needed to be hospitalized. On the day of her interview she was barely able to speak and was coughing up sputum into a handkerchief.<sup>11</sup> She took her first trip to the ARV clinic the day after the interview. Judith had known that she was HIV positive and used The Clinic's services since 2001, but she had not tested her children. She does bring her children to The Clinic when they get sick, which is almost always with malaria. She lives near The Clinic, feels the services are very affordable, and says she has no difficulties using its services. Her primary concerns were related to her occupation, rather than her health. Judith previously worked at Nytil, a textile factory down the road from the clinic, but the cotton fibers irritated her lungs, so she quit that job. She now works for a school kitchen, but that job requires a lot of heavy lifting. She is concerned about the lifting, because when she feels weak or sick, she cannot lift things for the work, but she is still expected to. Judith would like to find a new job, but she cannot leave her current job until she finds a new one. It is interesting that despite being close to The Clinic and reporting neither financial nor transportation barriers to receiving care there, Judith did not seek medical treatment for her cough until it was so severe

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<sup>11</sup> Interview was only conducted at the insistence of nurses and the patient.

that she need to be admitted to the hospital. If people don't visit The Clinic until they are extremely ill, there is little that The Clinic can do to help them directly.

Prossy is an HIV positive, 28-year-old, born-again Christian woman without any children. She speaks English very well and wears pants.<sup>12</sup> When she was living in Kampala, Prossy developed such a severe case of oral thrush that she could not eat, and her family, who lives in the area, brought her back to The Clinic. She began taking ARVs at a near-by center and is continuing her treatment both there and at The Clinic. Prossy has very strong religious convictions, and after referring to a Bible verse that mentions God cleaning the blood, she explained “so you see, HIV was there, and God can clean the blood and make you again negative.” Prossy thanks God for her health and for the medicines through which he acts. She reconciles the importance of faith and medicine saying, “We are all sinners. HIV can infect anyone and God can cure anyone. But, we have to take care of ourselves [too].” Prossy is greatly pleased with the services offered at The Clinic, emphasizing its affordability, the friendliness of the staff, the fact that patients actually get to see the doctor, and that The Clinic has medicines that other hospitals/clinics do not. When asked about the wait at The Clinic, she said it was not bad, even though the interview took place at four o'clock in the afternoon, after she had waited all day to see the doctor. Prossy provides an example of someone whose strong faith in God does not conflict with seeking out modern medical treatment. The use of faith communities in the effort to control HIV/AIDS is an area that was not explored during this study, but that has great potential for future research.

Mirembe is an elderly woman who said that she is “sixty-five.”<sup>13</sup> Mirembe lives with her mother, and has been abandoned by her only child. Mirembe now knows that she is HIV

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<sup>12</sup> It is extremely rare for women outside of the capital city to wear pants. The female university students volunteering at the clinic were reprimanded for wearing pants and told that they must wear skirts to work.

<sup>13</sup> Elderly people tend to say that they are 65 when they know that they are old, but do not actually know their age.

positive, but her child left her before she knew her HIV status. Mirembe has no source of income, so when she needs treatment at The Clinic she “digs in the garden of a neighbor”<sup>14</sup> for a day to make enough to pay for the clinic fee. On the morning of her visit she wakes before the sun comes up, “prepares some little food, and foots to the clinic” from the other side of the forest. Mirembe was not able to estimate the amount of time it takes her to make the trip, but the translator suggested that it would take four and a half to five hours for this slow moving woman to walk from her village to The Clinic. Mirembe knows that she should be tested for her T-cell count, but the test is not offered by The Clinic, and she cannot afford the 2000 Ush<sup>15</sup> (US\$1.10) it costs elsewhere. Mirembe also knows that she has goiter,<sup>16</sup> but she cannot afford the treatment for it either. Mirembe’s main concern is her appetite. She says that with the medications her stomach “pains” her. There is often not enough food, but sometimes she is not hungry even when there is food. Her main wish would be that The Clinic would reduce the cost of treatments so that she would not have to dig and could afford transport. Of the women interviewed, Mirembe had the greatest barriers to care. Even the smallest fees for transportation and care are barely surmountable for her. Unfortunately, she lives far enough away from The Clinic that it is difficult to include her in the Home Care rounds.

Ruth is a 29-year-old woman with two children, ages five and three-and-a-half. Although she is being treated for TB, she has not been tested for HIV<sup>17</sup> because she says she cannot afford the test. Ruth takes her children to a clinic closer to her house when they get sick.<sup>18</sup> However, this other clinic does not offer treatment for TB, so Ruth must come daily to the clinic to receive

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<sup>14</sup> A ‘garden’ is more appropriately translated as field.

<sup>15</sup> Ugandan Shilling, when in the field 1,000 Ush = ~US\$0.55

<sup>16</sup> Goiter is a swelling in the neck due to an enlarged thyroid gland often caused by iodine deficiency.

<sup>17</sup> It is extremely common for people suffering from TB to have a compromised immune system resulting from HIV infection.

<sup>18</sup> Typically with malaria

her TB tabs.<sup>19</sup> Her primary concern is money, because “the [TB] tabs need food.” Ruth is separated from her husband because, “we quarreled a lot, and he did not take care of me when I was sick. He got a new wife, so I left.” Since she has been on her own, Ruth has had greater difficulty getting enough to eat for herself and her children. Ruth is a good example of a quotation attributed to Paul Farmer: “Giving people medicine for TB and not giving them food is like washing your hands and drying them in the dirt” (Kidder 2004).

Betty is 34 years old and has four children. Her children do not live with her because she says, “I could not manage them.” Betty tested positive for HIV at TASO,<sup>20</sup> but decided to receive treatment from The Clinic because “at TASO we are too many! It is taking a long time to see the doctor”. In comparison, at The Clinic she is able to see the doctor quickly.<sup>21</sup> She felt that “there are no problems getting care for those of us who are ‘positive’ ... the wait is long sometimes, but we get good care.” Betty lives and works at a Catholic parish near The Clinic. Prior to moving to the parish, she lived and worked alone in the major city, and life was very difficult for her. It was at this time that she became sick and had to place her children in the care of relatives and the local orphanage. She says that now, although she does not make a lot of money, she is living well. She sleeps under an ITN,<sup>22</sup> eats well, and does not worry about her health or her wellbeing. Her primary concern is for the future of her children. What will happen to them if she dies? Who will pay for their school fees? Betty’s story shows the role of faith communities in providing shelter and a new start for people struggling with HIV.

## ENVIRONMENTAL BARRIERS

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<sup>19</sup> Ruth was treated for TB (tuberculosis) and it improved, but then came back. She describes going to the clinic daily to get her TB medications, making it very likely she has been enrolled into the clinic’s DOTS program.

<sup>20</sup> The AIDS Service Organization, a national HIV/AIDS Organization in Uganda with offices in the major cities

<sup>21</sup> Even though a quick visit takes a minimum of 2 hours

<sup>22</sup> Insecticide Treated Bed-net, the primary means of malaria prevention

With over 80% of Ugandans living in rural areas, and 51% of residents living greater than five kilometers from a clinic (UBOS website), simply getting to a clinic can be difficult, especially for those who are very ill or disabled. In addition, dirt roads can make transportation to The Clinic near impossible when it rains. Also, patients may be unable to take the time to go for treatment when they are needed in the fields for planting and harvesting.

The Clinic attempts to meet these environmental barriers to treatment and testing by providing home care visits and outreach testing. Clinic staff pay weekly visits to a blind woman to ensure that she is receiving her ARV medications. Other home visit routes stop at the prison and rural fishing villages. Sometimes the roads are in such poor condition that the ambulance cannot use them, and, especially on rainy days, the home care visits may not be able to run. Despite their best efforts to cover a large area with outreach programs, there are some areas, such as where Mirembe lives, that The Clinic's outreach can not financially justify traveling to.

During outreach VCT, The Clinic's staff is able to counsel and test over 100 individuals, and many more are educated about HIV/AIDS through loudspeaker announcements and performances by the post-test group. However, testing trips can easily be delayed or canceled when rain makes the roads impossible to use. It is not only more difficult for The Clinic to make it to the testing site, but even when they do set up a testing site, members of the community are much less likely to come out in the rain to be tested.<sup>23</sup> Sparsely populated areas also have low turn out for testing.

## ECONOMIC BARRIERS

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<sup>23</sup> When a testing site was set up prior to a rainstorm, only 64 people were counseled and tested, despite being in a relatively well-populated area. Typically over 100 people are tested per session.

Uganda is very much a developing country. The gross national income per capita is (486,000 Ush) US\$270 and 84.9% of the population lives below the poverty line<sup>24</sup> (WHO, World Health Statistics, 2006). Seventy-eight percent of the country's residences are rural (UBOS, Main Report, 2002). Only 61% of the population has access to safe drinking water and 17% are without access to toilet facilities. Less than 8% of residents have access to electricity, and even those that do are subject to 'power sharing' and on average have access to power only 50% of the time.<sup>25</sup> Almost all households (97%) use charcoal or firewood for cooking, and only 17% of residences are constructed from permanent roof, wall, and floor materials. As a result of living in rural areas, a full 50% of households do not have any access to health care facilities (WHO, Health Action, 2006 and UBOS website).

Individuals must overcome economic barriers to reach even the most affordable treatment. Some, like Mirembe, work the fields of other Ugandans to make "some little money" so that they can come to the clinic and receive treatment. Others, like Judith, are trapped working in debilitating jobs in order to provide for their families. Patients also attempt to save on transportation costs by walking or getting a ride from family so that they only have to pay The Clinic's small fee. In addition to difficulties getting to The Clinic and paying the clinical fees, patients also may find it difficult to afford preventative measures recommended to them, such as ITN for malaria, or to fulfill the doctors recommendations such as eating more food, getting meat, and/or taking iron supplements.

The clinic attempts to minimize the economic barriers for those seeking its services. In addition to providing treatment to the community for a minimal fee, The Clinic attempts to help patients overcome economic barriers to care through their home based care and VCT programs.

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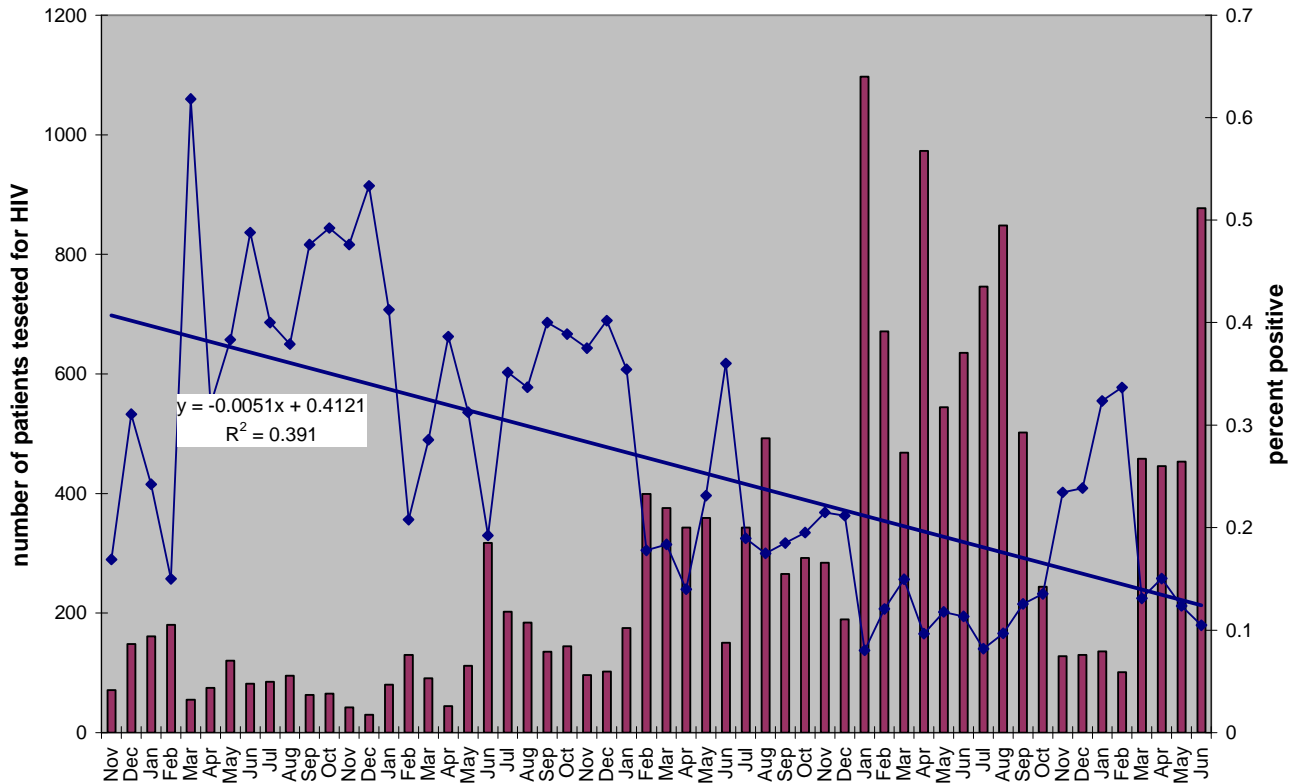
<sup>24</sup> Percent of population living on less than \$1 a day (less than 2000 Ush)

<sup>25</sup> An area is supposed to have power for 24 hours, and then not for 24 hour; however, the power-sharing rarely maintains this regular schedule.

By going to the community, The Clinic saves patients the cost of transportation. Also, no one is refused treatment on home care visits and testing for HIV is free on outreach programs.

Unfortunately, The Clinic has not had a constant source of funding. Despite the Director's constant applications for funds from the Ugandan Government, International NGOs, and individual donors The Clinic's budget is always smaller than is necessary to meet the needs of the population it serves. Home care visits and outreach testing are two of the most expensive services offered by The Clinic and are the first programs to be scaled back when funds become short. Having to pay for petrol, bus rental, and testing supplies each VCT trip costs no less than 500,000 Ush (just under US\$280). While that may seem like a small cost, when the funds received by the clinic dropped in June 2004 and again for several months starting in November 2005, there was a corresponding decreased in the number of HIV tests for the next several months (Graph 1: HIV Testing).

**Graph 1: HIV Testing (monthly)**



Home care visits can also be limited by the cost of petrol and medications. At the start of field work, home care visits were only running one day a week, but at the start of July when more funds became available, home care visits went out six days a week.<sup>26</sup> In an attempt to minimize cost but increase accessibility, The Clinic is opening an outreach clinic about fifteen kilometers away. The Outreach Clinic is more cost effective than home care visits to the areas it serves, but it is running into a different sort of barrier—a stigma of association with HIV.

## SOCIAL/POLITICAL BARRIERS

<sup>26</sup> When home care visits first return to an area where they had not gone in a while, few people come to the ambulance to receive treatment. The nurses explained this could be for two reasons: 1) People didn't expect the ambulance to come, so they were out in the fields or in town. They will expect it next week, and be there. 2) The clients in the area are now dead.

The stigma of being associated with HIV is a significant barrier to HIV care and testing. While education campaigns and radio advertisements help to make people more aware of AIDS/HIV and to the services that The Clinic provides, it also subjects The Clinic to the stigma associated with HIV. At the time of this study, The Outreach Clinic had been opened for several weeks, but very few people were utilizing its services. Staff explained that the issue was not that people were unaware of its existence,<sup>27</sup> but that members of the community were afraid to go to The Outreach Clinic for fear of being associated with HIV. Even with home care visits, fear of stigma makes some clients ignore the ambulance and hide in their homes when it comes to their village.

Another social issue faced by patients, especially women, is that husbands may refuse to allow their wives to receive treatment. As previously discussed, husbands may be concerned about being stigmatized for being married to an HIV positive wife, so they may prevent her from registering at The Clinic. A woman may not tell her husband about her HIV status and not receive treatment if she thinks that he will react poorly. Wives are always expected to produce children, so they cannot insist that their husbands use condoms, even if they know that they are HIV positive and suspect that their husband is too. Husbands may also refuse to be tested themselves. Many Ugandans express fear of being diagnosed with HIV/AIDS and feel that since there is no cure, they are better off not knowing their HIV status. The Clinic strives to overcome HIV/AIDS stigma and misinformation through radio advertisements, outreach programs, and education at secondary schools. They emphasize that there is still hope for people living with HIV and that treatment is available. People on the street in the major city would walk up to the ambulance and thank The Clinic's staff for spreading a positive message about HIV.

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<sup>27</sup> Members of The Clinic's mobilization team had gone to the area for weeks before the clinic opened and advertised via loudspeakers.

Unfortunately, there are many people who hear the messages and ignore them. Overcoming stigma is a difficult and arduous task.

The Clinic also has to deal with political issues. Politics, especially as aid agencies switch from directly-funded programming to “basket funding,” can determine the size of the clinic’s budget. The status of being an NGO<sup>28</sup> means that The Clinic does not have the same degree of access to government standard medications, such as ACT<sup>29</sup> to treat malaria, as government clinics. The Clinic must make do with the medications it receives from donor agencies.<sup>30</sup> The Clinic can do little to overcome these political barriers other than to continue to request funding from many donors and use whatever funds it does receive to purchase the most cost effective medication and sponsor the programs that benefit the greatest number of people. By investing the fees collected by clients toward the further development of The Clinic, The Clinic strives to be self-sustained, just as it encourages self-sufficiency for its clients through programs such as IGA and OVC vocational education.

#### OTHER FACTORS OUTSIDE OF THE INDIVIDUAL/ORGANIZATION’S CONTROL

In addition to environmental, economic, and social/political barriers there are additional barriers to receiving care, which are beyond the control of the individual. Methods to overcome these barriers take creativity and patience. Patients may have difficulty complying with their medication for treatment of TB, malaria, or HIV because they cannot read written directions and do not have watches to time doses. However, there is a striking regularity to the rhythm of daily life in Uganda and the majority of people are well aware of how to tell at least approximate time.

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<sup>28</sup> Non-governmental organization

<sup>29</sup> Artemisinin-based combination therapy; the first line treatment for malaria in Uganda as recommended by the WHO and Uganda Ministry of Health

<sup>30</sup> This tends to be SP tablets and chloroquine injections, which are less effective medications and may cause adverse reactions with antibiotics that HIV patients frequently take.

In addition, patients could be taught how to use radio programs, mosque prayer calls, or other daily signals to remember to take their medications.<sup>31</sup>

The side-effects of both ARVs and TB treatments may also be difficult for patients to tolerate, even under the best conditions. Side effects can be especially difficult to tolerate without adequate nutrition. Unfortunately, under-nutrition is common in Uganda. A counselor explained to me that the children at the ARV clinic were crying, not because they were sick, but because they were hungry. He would like to start a program for food donation to these children; however, The Clinic cannot afford to sponsor such a program at this time, and even if it could, it is very difficult to determine which patients really need food donation. It is almost impossible to be sure that food actually gets to the family members who need it most. Patients are tempted to avoid the side effects and stop taking medications as soon as they start to feel better;<sup>32</sup> however, if patients understand the importance of taking the full treatment of their medications and receive constant encouragement, they are more likely to continue taking them.

The Clinic must also attempt to manage barriers beyond its control, such as inconsistent delivery of supplies, the unpredictability of electricity and a lack of back-up staff. Sometimes, even when The Clinic orders its supplies well in advance, they are not ready when The Clinic staff goes to pick them up. There is little that The Clinic can do to overcome this barrier. During the course of the study, The Clinic had to cancel a VCT trip because testing supplies did not arrive on time. Uganda as a whole is suffering from a power shortage. Luckily, due to its location next to the national power source, The Clinic is relatively unaffected by this problem, but they can lose power for any length of time at any given moment. If it could afford one, The Clinic might purchase a generator, but the petrol to run the generator is also costly. At the start

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<sup>31</sup> While I heard volunteers talk about this method being used in other clinics to help patients keep a schedule for their medications, I did not witness its implementation at The Clinic itself.

<sup>32</sup> This is a common problem, even at HIV clinics in the US.

of the study The Clinic was staffed and open twenty-four hours a day, but it does not have enough staff to maintain this schedule. The director had to cut back the hours of operation of The Clinic until he could afford to hire more staff. The Clinic experiences a similar strain whenever a primary staff member becomes ill or has a family emergency. Because there is no back-up staff, The Clinic functions at a lower capacity and offers fewer services for the period of time that the staff member is gone. With the myriad of barriers that The Clinic must overcome to provide care, it is surprising it manages to stay open.

*EMIC/ETIC Table*

Looking at The Clinic from the outside it is easy to be blinded the inadequacy of its services; however, seeing it from within the system in which it functions, The Clinic becomes a model for overcoming barriers to health care. Some of the “problems” may be good practices; others are beyond the control of The Clinic, and they manage them as best they can. There are still some areas where The Clinic could work to improve the quality of its care, but overall, it is doing a fine job providing medical care to the poorest of the poor with very limited resources.

Etic/Emic Table	
ETIC* VIEW OF The Clinic	EMIC** VIEW OF The Clinic
Consistently lacking in Basic Medical Supplies (gauze, topical antibiotics, ACT malaria treatments)	"When I go to [the clinic] I get the medicines I need to make me better."
Run out of medications and/or test supplies	Breakdown in delivery/availability, not funding
No safety procedures (no sharps container, administer injections on unclean skin)	
Nurses unaware of the risks of drug interactions	Doctors are aware of drug interactions, but are forced to prescribe drugs with potential interaction because of availability.
Overabundance of injections given (primarily for malaria and infections)	Patients prefer injections to treat malaria. Doctors also say injections provide higher compliance, quicker treatment, and fewer side effects
No "real doctors" at the Clinic	Clinics are commonly staffed by Clinical and Public Health professionals. Qualified to treat “simple cases” and to refer complex cases. Patients refer to them as "doctor".
Records in disarray, Only Client records kept at the	Outpatients keep their own records - allows them to get

clinic	treatment anywhere
Patients wait for a very long time to see doctor, to get lab tests, and to leave with treatment	"When I go to TASO (or the government hospital) I wait all day and night to see the doctor, but I know when I come to [the clinic] I will see the doctor, go to the lab, and get treatment on the same day."
Sometimes staff sitting around with nothing to do	Staff takes lunch hour, and patients do not (usually) come during this time
Staff can seem disinterested and brusque with patients	Staff is happy at the clinic. Despite not being paid in months, only 2 staff have quit since the clinic opened. "The doctor and nurses are very good here... they treat us well"
Many clinics in the area – patients have many options	Patients can't afford the fees for treatment at other clinics. "I walk all morning to come here... it is the closest to where I live. I cannot pay fees"
The clinic is well known (and respected) in the area	Clients have come from as far away as Kampala and Busia. Radio adds have increased awareness of HIV/AIDS as well as the clinic and its services
The clinic is doing the best it can with limited resources (staff, funding and access to medication). It is making an impact on the community.	The clinic serves a great need for the community providing HIV/AIDS education, reducing the stigma of HIV, providing treatment and support to HIV positive individuals as well as OVC, and providing comprehensive medical care to the community as a whole at a very affordable price.
	Staff is very proud of the number of people they've tested

\*Etic views come from Westerners who are in Uganda long/short term. These include: a volunteer nurse from Netherlands, a volunteer medical student from US, a volunteer undergraduate from US, a year-long volunteer from Germany, and priests/nuns from US.

\*\*Emic views come from Ugandans associated with the clinic. These include: the director, "doctors", nurses, counselors, other clinic staff, university students, patients, and clients.

## CONCLUSION

The Clinic provides a strong case study for HIV/AIDS treatment in a malaria endemic area. The barriers faced by patients and The Clinic clearly demonstrate the need for the coordination of HIV and malaria treatments with larger issues such as nutrition, employment, education, and infrastructure. As members of The Clinic's community work together to overcome economic, social/political, environmental, and other barriers, it becomes clear that the ultimate success in fighting HIV/AIDS is tied to overall development. As with the Millennium Villages, "success in any single area, whether in health, or education, or farm productivity, depends on investments across the board" (Sachs 2005). The problems faced by The Clinic are

complex, and the solutions to them are also multifaceted. The Clinic very early on realized that they needed to offer a variety of services and programs ranging from youth to elderly, from awareness to treatment, and from home care to the clinic. All of these programs are important in the fight against disease. Without proper nutrition, the medications do not work as well, and the side effects can be unbearable. Without economic independence, it is difficult to afford travel and treatment. Without proper infrastructure, transportation of patients and medical supplies is hindered. Without education, youth will not know how to protect themselves, and the stigma surrounding HIV/AIDS will continue to worsen.

In the future, The Clinic hopes to expand its services. At the time of this study they had begun construction on a new building. The Clinic currently spends a great deal on rent, and owning its own building will decrease costs in the long run and bring The Clinic closer to its ultimate goal of being self-sufficient. With money saved from client fees, The Clinic has been able to complete construction of the walls and roof of the new building. When it opens, the staff hope to have a maternity ward, a library, and may even be able to offer ARVs. The director is constantly hopefully about the future of The Clinic. He and his staff are committed to not only keeping The Clinic's doors open, but also to expanding its services. Despite the barriers that they must overcome, the greatest of which can be summed up into a single word—funding—there is little doubt that The Clinic will grow as it continues its fight against HIV/AIDS. Researchers should continue to work with clinics like this one to gain a greater understanding of their needs and the best way to battle infectious disease.

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## ABBREVIATIONS and ACRONYMS

ACT	artemisinin-based combination therapy
AIDS	acquired immunodeficiency syndrome
ARV	antiretroviral (drugs)
DOTS	directly observed treatment, short-course
HIV	human immunodeficiency virus
IGA	income generating activity
ITN	insecticide treated bed-net
NGO	non-governmental organization
OVC	orphans and vulnerable children
TASO	The AIDS Support Organization
TB	tuberculosis
UBOS	Uganda Bureau of Statistics
USH	Ugandan Shilling
VCT	voluntary counseling and testing
WHO	World Health Organization