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# HIV/AIDS Treatment and Care in a Long-Term Conflict Setting: Observations From The AIDS Support Organization (TASO) in the Teso Region

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**HIV/AIDS Treatment and Care in a  
Long-Term Conflict Setting:  
Observations from The AIDS Support Organization (TASO)  
in the Teso Region**

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Location: TASO Soroti

SIT Uganda Spring 2008

## **Dedication**

To all the people living with HIV/AIDS in Teso, who continue to live strongly despite decades of suffering from continuous war, displacement and neglect. May the world come to recognize the struggles that you live with.

## **Acknowledgements**

There are so many people to whom thanks is owed, it would not be possible to acknowledge them all even if time and space allowed. Primarily, I would like to thank the clients of TASO Soroti, who so willingly welcomed a stranger into their communities and allowed so many questions to be asked of them. Many thanks are also due to the staff at TASO, without whom none of this research would have been possible. From the manger, to the staff in the counseling and medical departments, to pharmacy workers and filing clerks, so much gratitude is owed to all of you for your time, assistance, explanations and willingness to answer the questions of a newcomer.

Thank you so much for all your work.

Eyalama noi anu aswam kon.

## ABSTRACT

Since its emergence in the early 1980s, HIV/AIDS has come to infect 33.2 million people world wide, over two thirds of whom (68%) reside in sub-Saharan Africa<sup>i</sup>. While great strides have been taken in terms of global awareness, research, treatment and care accessibility, the epidemic remains severe and many of those infected, especially those in sub-Saharan African nations, face the continued challenges of stigma and discrimination, limited medical resources, insufficient care, insurmountable costs and great distances to treatment area. When the individual case of Uganda is examined, it is encouraging to note that HIV prevalence has declined significantly since the early 1990s (now approaching a stabilized prevalence of approximately 7.1%<sup>ii</sup>) and that government and NGO support for persons living with HIV/AIDS (PLWHA) continues to grow. However, a stabilized HIV occurrence in conjunction with a rapidly increasing population equates to more new infections every year and a growing population of HIV positives nationwide. One area of Uganda that is experiencing high incidences of HIV infection, but has received little support is the Teso region, which is comprised of Amuria, Kaberamaido, Katakwi, Kumi and Soroti districts. HIV/AIDS care and support in this region is complicated by a variety of political, social and geographical complexities. The area has experienced over thirty years of continuous civil conflict stemming from on-going cattle rustling by Karimajong warriors, local militia activities and, more recently, attacks by the Lord's Resistance Army (LRA). During the course of these conflicts, almost 500,000 people have been relocated into internally displaced peoples (IDP) camps, where vulnerability to contracting HIV is significantly increased. The implementation of education, prevention, treatment and care services is difficult due to continued insecurity (despite some resettlement successes), inaccessibility and the huge client volume needing not only medical attention, but also counseling and sustainable livelihood activities. In addition to these challenges, this area has experienced widespread flooding during the past nine months, which has lead to widespread crop failure, property destruction, malnourishment and even further displacement.

The objective of this practicum period was to observe the practices of The AIDS Support Organization (TASO), which is the oldest, indigenous HIV/AIDS comprehensive care program in Uganda, and to identify the specific challenges and needs of this area as

it continues in a post-complex emergency state. Throughout this period a variety of research methodologies were employed. Observations of the counseling, medical and projects departments in their operations both at the center and in outreach settings provided the majority of the data. This was supplemented by a series of interviews and focus group discussions with TASO clients, staff and number of key informants about the area. Interviews and other data collecting activities were limited by actual volunteer work, such as administrative assistance with reports and presentations, distribution of drugs and foodstuffs, filing clerk work and laboratory tasks, including blood draws, HIV tests and record keeping.

This period provided invaluable insights not only into the operations of TASO but also into the challenges of implementing HIV/AIDS care in an ongoing conflict setting, with continued complexities of remote, displaced populations and widespread natural disasters. Although many factors were uncovered that are driving the epidemic in this area and prevent proper treatment and care, the most significant include widespread polygamous practices leading to multiple sexual partners, the lifestyles of many IDPs make them vulnerable for contracting HIV, the general lack of income for proper nutrition, medical treatment and transportation to care centers, and social attitudes such as widespread despair as well as continued stigma and discrimination against PLWHA. Due to the wide spread poverty in this area and lack of funds for transportation to treatment centers, there is a huge need for continued and expanded outreach care especially to IDPs and those who continue to be affected by cattle raids and the recent floods. At this point staff and resources are completely exhausted though more outreach programs are required and there are great demands for TASO services including counseling and medical treatment as well as need sustainable livelihood activities and community groups. There is a lack collaboration with local partners, which has weakened the area's referral system and in some cases has caused a duplication of services. Although TASO has achieved a great deal in the face of these challenges, the Soroti program itself would benefit from a variety of minor organizational changes that could eliminate inefficient uses of time and resources and allow more clients to be reached.

## **LIST OF ACRONYMS**

AIC	AIDS Information Center
AIDS	Acquired Immune-Deficiency Syndrome
ART	Anti Retroviral therapy
ARV	Anti Retroviral
ASTU	Anti-Stock Theft Unit
CASA	Community ART Support Agents
CBO	Community Based Organization
CDC	Centers for Disease Control
CDDP	Community Drug Distribution Point
FP	Family Planning
HBHCT	Home-based HIV Counseling and Testing
HC	Health Centre
HIV	Human Immunodeficiency Virus
IDP	Internally Displaced Person
IGA	Income Generating Activity
LRA	Lord's Resistance Army
MOH	Ministry of Health Uganda
NGO	Non Governmental Organization
NRM	National Resistance Movement
OCHA	United Nations Office for the coordination of Humanitarian Affairs
OI	Opportunistic Infection
PEPFAR	President's Emergency Plan for AIDS Relief
PLA	Person Living with AIDS
PLWHA	Person Living with HIV/AIDS
PMTCT	Prevention of Mother to Child Transmission
STI	Sexually Transmitted Infection
TASO	The AIDS Support Organization
UN	United Nations
UNAIDS	United Nations Joint Programme On HIV/AIDS

UNHCR	United Nations High Commissioner for Refugees
UPA	Uganda People's Army
UPDF	Uganda People's Defense Force
USAID	United States Agency for International Development
VCT	Voluntary Counseling and Testing
WHO	World Health Organization
WFP	World Food Programme

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## **INTRODUCTION**

The purpose of this six-week practicum period was to examine the practices of delivering HIV/AIDS care and support to displaced peoples living in a post-complex emergency setting. This study period allowed time to investigate the specific medical and social support needs of persons living with HIV/AIDS in an extended period of armed conflict. This research sought to uncover what are the challenges to delivering medical care and antiretroviral therapy (ART) to these individuals, what types of medical complications are they vulnerable to, what are the social challenges that prevent further improvements in treatment and care, and what factors in this particular setting are continuing to drive the epidemic. These questions were specifically examined throughout a period of study with The AIDS Support Organization (TASO) in the northeastern Teso region of Uganda, which is comprised of Kumi, Katakwi, Amuria, Kaberamaido and Soroti districts. During the past forty years this an area which has been strongly affected by cattle rustling, local revolutionary movements, the insurgence of the Lord's Resistance Army (LRA) and, most recently, widespread flooding. These factors make the Teso region a unique area in Uganda as it has been compromised by a series of social, political and natural emergencies, the affects of which have been compounded further by the growing prevalence of HIV/AIDS. Due to the social, political and geographical complexities of this area, HIV/AIDS treatment, care and prevention require specific strategies for targeting those who have been affected and displaced by these emergencies. Further development of such outreach methods is crucial as the epidemic continues and the growing potential for further political unrest and natural disasters.

## **OBJECTIVES**

Throughout the period of practicum study at TASO Soroti the following objectives were address:

- To observe the operation of TASO activities with specific attention to outreach programs in the post-emergency setting of the Teso region
- To evaluate the challenges facing HIV/AIDS treatment and care delivery in a present and post-armed conflict context and identify the factors that are driving the epidemic in this area

## **BACKGROUND**

### **HIV/AIDS in the World: Focus on Sub-Saharan Africa**

Since its emergence in the early 1980's, the HIV/AIDS epidemic has infected 33.2 million people worldwide and has affected the lives of far more<sup>iii</sup>. Although the reverberations of the epidemic have been felt around the globe, nowhere has the virus had such a devastating impact than in sub-Saharan Africa, where some 22.5 million HIV positive adults and children live, according to the 2007 AIDS Epidemic Update as published by the United Nations Joint Programme on HIV/AIDS. In 2007 alone, some 1.7 million people in sub-Saharan Africa became infected with HIV, accounting for 68% of all new infections<sup>iv</sup>. In addition to the number of new cases reported, another alarming trend is the number of children who are living with HIV/AIDS worldwide. In 2001 there were 1.5 million HIV positive children and as of 2007, there are over 2.5 million. Nearly 90% of all children living with HIV/AIDS reside in sub-Saharan Africa<sup>v</sup>.

The impact of HIV/AIDS around the world especially in sub-Saharan Africa has been staggering. A huge bulk of the disease burden rests on the health sector: bed occupancy has grown, co-infection rates of tuberculosis and HIV have risen dramatically, infant and young child morbidity and mortality rates have increased and the associated work load has overwhelmed already struggling health workers across the continent. HIV/AIDS has had a huge impact on labor and human capital. With reduced life expectancy, increased expenses stemming from medical and burial costs, time lost to care for the sick and an increased number of orphans and child-headed families the net result has been low labor productivity, poor output, poor income and poor GDP. There has been widespread reduction in agricultural production, yields and sales, which have led to increased food insecurity and higher rates of malnutrition. Increased poverty at the household level due to economic losses from expenditure on the sick is resulting in stagnation of development and an inferior quality of life for many<sup>vi</sup>.

Despite these disturbing trends, the current epidemiologic assessment has some encouraging elements as it suggests:

- The global prevalence of HIV infection is remaining at the same level, although the global number of persons living with HIV is increasing due to ongoing accumulation of new infections with longer survival times.

- Localized reductions in prevalence in specific regions and countries
- A general reduction in HIV associated deaths, due in part to recent scaling up of treatment access and availability of ARV therapy.
- A reduction in the number of annual new HIV infections globally

However, while great strides have been made in many areas, including involvement of the international community, increased research funding, development of care programs and improved access to treatment and care, many shortcomings are outstanding and the challenges remain enormous. Every day, over 6800 persons become infected with HIV and over 5700 persons die from AIDS, mostly due to inadequate access to prevention and treatment services. Sub-Saharan Africa remains most affected region globally, with AIDS being the leading cause of death across the continent<sup>vii</sup>.

### **HIV/AIDS in Uganda**

While the early 1980s found researchers around the globe racing to identify a mysterious and deadly disease that was infecting groups of homosexuals and hemophiliacs in the United States<sup>viii</sup>, HIV was already raging in sub-Saharan Africa. In 1982 the first two cases of a wasting disease, known locally as “slim,” (either as *silimu* or *mukenenya* in the local Luganda language) were reported in Uganda from Rakai District, which lies along the shores of Lake Victoria and borders Tanzania.<sup>ix</sup> In 1983, another seventeen cases had surfaced and the following year the disease was confirmed as AIDS by Dr. David Serwadda and his team from Mulago Hospital. To date all districts in Uganda have reported HIV/AIDS. Although the exact origin of HIV in Uganda is unknown, it has been widely speculated that the disease was brought by pillaging Tanzanian soldiers during the Ugandan-Tanzanian War in the late 1970s and that it was further spread by mobile communities of fishermen along the lake shores and inland along the highways by truck drivers moving cargo from Nairobi, Mombassa and Dar Es Salaam to Central and East Africa distribution points<sup>x</sup>. The first instances of HIV/AIDS in the Teso region occurred in the mid to late 1980s and it is widely believed that the virus was brought by Yoweri Museveni’s National Resistance Movement (NRM) soldiers, who were encamped in the area fighting with the Uganda People’s Army (UPA)<sup>xi</sup>.

In 1986, following over fifteen years of civil strife, Uganda's new head of state, President Museveni, responded to the alarming trends in HIV infection rates with a proactive commitment to prevention. He emphasized that fighting HIV/AIDS was a patriotic duty that required openness, communication and a multi-sector response. With this top-down encouragement, the Uganda AIDS Commission (UAC) was created to design a National Operational Plan, sponsor Task Forces and encourage the establishment of AIDS Control Programmes nationwide<sup>xii</sup>. In addition to governmental actions, the country so welcomed international aid that to date there are over 1,000 HIV/AIDS related NGOs operating across all districts of Uganda. Widespread public communications such as, "Zero-Grazing," "Love Carefully," the ABC campaign (Abstain from sex until marriage, Be faithful to one partner or use Condoms) and more recently, targeting young girls with the "Cross generational sex stops with you—say "no" to sugar daddies" message, scaling up of educational programs and advocacy for behavior change have all contributed to increasing HIV/AIDS awareness in Uganda<sup>xiii</sup>.

Uganda was the first country in sub-Saharan Africa to register a drop in adult national HIV prevalence and has gained considerable attention as a "success story" in the global battle against HIV/AIDS. However, despite reduction, the epidemic remains serious with national infection levels currently at 7.1%<sup>xiv</sup> and highest incidences reported among women (7.5% as opposed to 5% among men) and urban dwellers (10% compared to 5.7%<sup>xv</sup> rural). HIV prevalence in Uganda began to decrease in the early 1990s, alongside substantial evidence of behavior change for HIV prevention, however that trend appears to have stabilized and the current rates have stagnated in recent years. It is important to note that with a stable HIV incidence rate among a population growing as rapidly as the one in Uganda (which has a total fertility rate of 6.7<sup>xvi</sup>), there is an increasing number of people acquiring HIV every year and the epidemic is actually on the rise once again.

Several factors can be identified as "drivers" of the epidemic. Although there has been an increase in HIV awareness with more that 95% of the population having at least heard of the "slim" disease, comprehensive knowledge of disease prevention, transmission routes and treatment remains low at about 32% nationwide. In a series of national population based surveys conducted between 1995 and 2006, both men and

women have reported increased incidence of high-risk sex and although rates of condom use have gone up, only about 35% of women and 57% of men report condom use within the past twelve months, indicating a lack of progress in adoption of safer sexual behavior<sup>xvii</sup>. As ARV treatment is becoming more widespread and PLWHA are living longer, healthier lives, there is increase in HIV positives engaging in casual sex. Additionally, treatment-seeking behavior for STIs remains low and as the national prevalence rates of Syphilis, Gonorrhea and Chlamydia continue to rise, individuals are more vulnerable to acquiring the virus. Thus, with 136,000 new infections and 90,000 HIV related deaths annually, the AIDS epidemic remains a serious concern in Uganda demonstrating an urgent need to revive and adapt the original prevention efforts that first brought the epidemic under control<sup>xviii</sup>.

### **The AIDS Support Organization (TASO)**

Since its official organization in 1987, The AIDS Support Organization (TASO) has advocated against stigma and discrimination while pioneering a community-based approach for care of PLWHAs. During the first years of the epidemic, Dr. Neorine Kaleeba, a technician at Mulago Hospital, whose husband had become infected with HIV, along with fifteen affected others, began meeting informally in one another's homes to exchange new information on the disease, share experiences, provide mutual support or simply "share a meal together."<sup>xix</sup> Founded on the principle that people are unified by the common experience of HIV/AIDS, the group eventually came to be known as TASO. Today, TASO is the largest indigenous NGO providing HIV/AIDS services in Uganda and Africa, having supported over 150,000 clients. There are currently eleven TASO service centers in Uganda as well as thirteen "mini-TASOs," which serve those who fall outside of the regular centers' catchments areas<sup>xx</sup>. The philosophy of TASO is that people can live positively with AIDS and the organizations' mission is to help those affected by the disease to accept their diagnosis, seek prompt medical care, continue to live healthy, meaningful lives, prevent further HIV spread and continue with social activities. TASO works to fight stigma, promotes AIDS sensitization and offers counseling to those with HIV/AIDS and their families. The organization provides medical services and supports community-based efforts to respond to the epidemic<sup>xxi</sup>.

### **The Historical and Political Background of the Situation in the Teso Region<sup>xxii</sup>**

## **Cattle Raids**

Attacks on Katakwi district by Karimajong warriors have been traced back as far as 1954, though these early attacks were mostly restricted to the immediate border areas between Teso and Karamoja; damage to life and property was also minimal as these early raiders were armed only with hunting spears. The culture of cattle rustling has been a part of Karamoja life for centuries and with the introduction of the modern gun the frequency and severity of these attacks increased significantly and has drastically altered the relationship between Karimajong pastoralists and their Iteso neighbors. In the middle 1970s, the manufacture of arms began in Karamoja and a large arsenal was established in Moroto. When Idi Amin was overthrown in 1979, a group of warriors attacked the Moroto Barracks, where they were able to acquire modern weapons. The introduction of guns (high powered and automatic weapons such as AK47s in particular) prompted immediate, intensified inter-clan wars both within Karamoja and spilling over into Kenya and Sudan.

Today, the main livelihood throughout Amuria, Kaberamaido, Katakwi, Kumi and Soroti districts is subsistence farming, however in the past livestock keeping was not only a way of life, but also represented economic and social power. Both from interviews conducted within the Teso region and from articles published on the area's history, it is quite obvious that the people in this area look back on what used to be a prosperous period following independence<sup>xxiii</sup>. The wealth of the Teso elite consisted in the ownership of up to a couple hundred cows, while households regarded as the most poor had between thirty and fifty; bride prices were upwards of twenty-five cows, the people fed well on milk and beef, and were able to send their children to school with relative ease off the proceeds from livestock sales<sup>xxiv</sup>. Prior to 1986, Usuk County, which now forms Katakwi district, was considered to have the most highly educated people in all of Uganda. As a relic of these more affluent times, the Soroti Flying Academy, which was established as a joint East African Institution with the second longest runway in Uganda, still exists, but the relative prosperity of this area was truly shattered following the brutal regime of Idi Amin, the years of Museveni's war and subsequent armed conflict.

Since the early 1980s, the Iteso were finding themselves in increasingly serious confrontation with the Karimajong, leading to widespread cattle rustling, property theft, kidnapping, rape and murder. Despite these widespread atrocities, virtually no government action was taken and the Karimajong were even regarded as a factor to oppose the attacks the Holy Spirit Movement led by Alice Lakwena<sup>xxv</sup>, who came down from Acholi land through Teso in 1986. Further disturbances were experienced between 1987 and 1992, during which time the Iteso militia, known as the Uganda People's Army (UPA), rebelled against Museveni's NRM forces. These incidents helped to intensify the cattle raids as more illegal guns were accessed and the Karimajongs used this opportunity of widespread insecurity to expand their operations from Katakwi into Amuria, Kaberamaido, Kumi and Soroti districts<sup>xxvi</sup>. Throughout these areas there have been reported instances of warriors kidnapping people either to lead them to cows or to take them to carry stolen goods. Particularly gruesome details have also emerged, such as the practice of preventing abductees from escaping by passing a chord under their collarbones or through the skin in their wrists<sup>xxvii</sup>. Although specific figures on the numbers of incidents were not available, it has been reported that in Katakwi district between 2000 and 2002, over 4,000 cattle were stolen, 120 people were killed, property was looted or simply destroyed and people living in the camps were not even able to prepare food as cooking utensils were stolen by the warriors<sup>xxviii</sup>. Although peace talks have been initiated and there are periods of relative calm, these are punctuated by continued violent incidents. For example a peace agreement signed in Magoro Sub-county 1998 helped control the situation until 2000, when there were a series of raids culminating in a broad daylight massacre of seventeen IDPs in September of 2001. The government responded by drilling twelve water points throughout the area meant to facilitate deployment of forces, but warriors vandalized these points and the security had to be withdrawn. In 2003, a massacre twenty-one people occurred in Apeuro Aodot, more animals were raided and residents fled as far away as Busoga, Pallisa, Kumi and Soroti. Although there are continued efforts to broker a peace between the Karimajong and the Iteso, widespread disarmament programs have failed and raids are still common, though they are mostly confined to Katakwi district. To date there are almost 100,000 people living in camps and settlements due to incursions by Karimajong warriors<sup>xxix</sup>.

Development processes have been arrested in areas as harshly affected by long-term insecurity as Katakwi and Amuria districts. For example, schools are available, but are frequently interrupted by disturbance and many parents will not risk sending their children to school for fear they will be kidnapped or killed on the way by Karimajong warriors<sup>xxx</sup>. Health infrastructure is poorly developed in the district and to date there are no functional Health Center IIs in Katakwi district. The only available health facility is in Katakwi town, which is inaccessible to many due to high transportation costs, poor road quality and frequent flooding during the rainy season. The net result of these raids has been that the Teso people have not only lost their cattle for herding, but also for animal traction in crop production. This has led to further impoverishment and a completely depleted economic base. Due to the insecurity in the region, people have abandoned their villages and moved into spontaneous squatter camps (which were only formally recognized as IDP camps within the last three to four years<sup>xxxix</sup>) along the main Moroto road, leaving huge tracts of land along the Karamoja border virtually empty. This “no-man’s land” has provided large, unsupervised areas for Karimajong warriors and other thugs to camp out in, which has further compromised security and although the army has attempted to patrol the area, deep-seated government suspicion among locals has led to a general lack of cooperation<sup>xxxix</sup>. This past year the military established a new guard known as the Anti-Stock Theft Units (ASTUs) and trained recruits from both Teso and Karamoja hoping to create a more balanced security force and foster a sense of communal responsibility. The local response to this has been less than enthusiastic; many have expressed the view that the government is openly arming Karimajongs and have reported nightly cattle raids by people dressed in ASTU uniforms<sup>xxxiii</sup>.

### **The Lords Resistance Army (LRA)**

In June of 2003, the LRA attacked Teso through Obalanga sub-county in Amuria district (then a part of Soroti district). This insurgency generated another wave of displacement from all nine Amuria sub-counties. In Kaberamaido district five of the eight sub-counties experienced LRA hostilities, and in Soroti district, four of the fourteen sub-counties were affected<sup>xxxiv</sup>. The militants attempted to take control of Soroti town and enter a military barracks where there was a large store of arms. However, the UPDF engaged in a heavy gun battle on the border of town and were able to prevent the rebels



from entering. In addition to the presence of the national army, the Teso community mobilized their own militia force, known as the Arrow Boys, many of whom had served in the military under the Obote II government and had had military strategic training abroad<sup>xxxv</sup>. Additionally, these local fighters were familiar with the region's geography (much of which is swampy and difficult to navigate) and proved extremely effective in routing the militants from Teso. Periodic insurgences continued to disrupt the region until October of 2005<sup>xxxvi</sup>. The UPDF encountered considerable challenges in their confrontations with the LRA due to the swampy and marshy terrain. Ultimately, President Museveni sought support Rwandan troops, more accustomed to such environments, and reportedly better trained. However, while Ugandan soldiers had been able to listen to local people and heed the advice of who was a civilian and who was a militant, Rwandan soldiers, ignorant of the local language, indiscriminately killed whomever they came across, resulting in widespread civilian death and prompting an even deeper anger and distrust of the government among the Iteso people<sup>xxxvii</sup>.

### **Displacement and Humanitarian Intervention**

Displacement in Katakwi and Amuria districts stems from Karimajong cattle rustling and LRA incursions, while in Soroti and Kaberamaido it has almost exclusively been LRA driven<sup>xxxviii</sup>.

Based on 2005 UNOCHA estimates, at the height of the LRA insurgence in the Teso region there were approximately 140,000 IDPs in Katakwi district living in 82 camps and 136,000 people in Soroti (now divided into Soroti and Amuria districts), Kaberamaido and Kumi districts living in 22 camps. These figures are based on the numbers of those who were receiving relief assistance and do not take into account those displaced by Karimajong disturbances<sup>xxxix</sup>. The following charts display the numbers of displaced people in each district and show camp populations have decreased over the past four year. Although there has been a significant decline in IDP residents, these figures do not necessarily reflect resettlement. It is not uncommon to find IDPs who initially moved to camps near the main district roads to avoid Karimajong oppression, but then were forced to flee when the LRA insurgence began and moved perhaps once more when flooding ruined many camp settlements<sup>xl</sup>.

### Displaced Populations in Teso

District	2004 Displaced Population	Current Displaced Population (approx.)
Amuria	98,960	36,000
Kaberaido	107,560	3,000
Katakwi	69,373	42,000
Soroti	137,000	13,000

### Camp Population Movement Estimates March 2008<sup>xli</sup>

	Amuria	Katakwi
Number of camps	17	44
Camp population	25000	35000
Transit site	11000	7000
Village of origin	79000	22000

A brief assessment of the current situation is as follows. There has been extremely limited humanitarian assistance to these areas in the forms of seed and tool distribution, scholastic materials, shelter, child protection, psychosocial support, water and sanitation improvement. General food distribution was last done in October of 2004<sup>xlii</sup>. With scaling down of relief operations in Soroti and Kaberaido districts, humanitarian actors are now focusing mostly on Amuria district and giving less attention to Katakwi. In terms of district security, the LRA have not been reported in the area since October of 2005, however the Katakwi and Amuria districts continue to be disturbed by Karimajong raids. Large, uninhabited areas in both districts provide pockets of insecurity and heavily armed Karimajong warriors who continue to intimidate the local communities. In general, there has been very little recognition of the severity of these on-going conflicts, the government has give little aid, with most of the NGO support going either to Karamoja to address the poverty there, or to Gulu where the LRA conflict has been centered<sup>xliii</sup>.

### Floods

Unusually heavy rainfall from June to November of 2007 led to extensive flooding and water logging throughout Teso, which called for a major humanitarian response. Although these severe weather patterns caused widespread flooding, destroyed homes, made roads impassable and left ten people dead, it was not until second week of September, that any NGO aid was given and it was nearly October by the time the government of Uganda intervened, declaring the area a state of emergency<sup>xliv</sup>.

The flooding impacted a total of thirty districts in Teso with both long and short-term crises affecting all sectors. During the flooding, internal access became a major challenge as the road from Soroti to Kampala was cut and many more roads and bridges became impassable. A UNHAS helicopter was brought into Soroti town and the UPDF provided motorboats and airlifts to ferry some 10,000 cut-off students to schools so their could sit for their end of term exams. Submerged roads left thousands stranded, unable to access medical care. Thousands fled their collapsing, waterlogged homes and crowded into schools and churches, leaving behind spoiled foodstuffs and soggy fields. Food supplies ran low or were contaminated by overflowing latrines, prompting agencies to supply food aid to over 370,000 and medical teams struggled to in put controls that would counter the increased dysentery and diarrhea diseases that were reported. By early November, the heavy rains had stopped, only to be replaced by an intense fortnight of sun that left a layer of hard soil, paralyzing agricultural activities. An infestation of sweet potato worms and growth of snail colonies that cause slow wasting and ultimate death in cattle was reported in Soroti and Kumi, while all over Teso, farmers were reporting rotten crops and a ruined harvest. Much of the damage that occurred in this area was water logging in which water saturates the ground but is not necessarily visible on the surface. Thus, while the damage was widespread and severe, it was not attractive to reporters and NGOs, who according to Oinya Sam, the Soroti district disaster preparedness officer, “wanted only the most sensational situations.” Therefore little attention and relief has been paid to this area<sup>xlv</sup>.

Although the majority of the displaced were able to return home once the floods subsided, many who had moved from IDP camps to higher ground, simply began building more permanent homes at their new location, creating new camps or “transition sites,” as referred to by OCHA. While this practice has generally been supported by the

local governments as part of the natural closing of the camps, it has introduced a number of difficulties in assessing the numbers of IDPs, distributing aid and determining land ownership in the camps. Thus, while the absolute number of camp residents may have declined, this does not necessarily reflect a return to home villages but further displacement to temporary housing sites<sup>xlvi</sup>.

**Camp Population March 2008<sup>xlvii</sup>**

District	Population before flood	Population after flood
Amuria	41249	25435
Katakwi	61690	35168

Additionally, there is considerable potential for further flooding in this area. Over cultivation of the soil, cattle grazing and deforestation for firewood has led to a loose topsoil layer, widespread erosion<sup>xlviii</sup>.

**TASO Soroti**

In this context of long-term conflict, high levels of insecurity and large numbers of IDPs, the TASO center in Soroti was opened in 2004 as LRA insurgences began to die down in the area. Prior to the establishment of TASO in this area, there was no major HIV/AIDS support organization for the districts of Soroti, Kaberamaido, Kumi, Katakwi and Amuria, as well as some parts of Lira and Moroto districts. The branch was opened specifically to address the needs of HIV positives living in Teso, who have experienced long periods of civil strife and long-term internal displacement. While the center was originally operated from within the Soroti regional hospital, it is now located within its own building adjacent to the hospital complex. To date the center has registered over 11,000 clients (approximately 7,000 active) and enrolls around thirty more every week, though the demand for membership is much higher<sup>xlix</sup>.

**METHODS**

In order to fully examine the functioning of TASO Soroti, its outreach methods and how the needs of their clients who have been affected by the ongoing insecurity are addressed, a variety of research tactics were employed. Of all data gathering techniques, observations proved the most versatile and frequently employed. Many of these were acquired by directly participating in an activity, such as attending collaborative meetings

either among medical partners at the center or traveling to other districts to meet with local government representatives. Notes were taken both on the information exchanged as well as on the interactions between participants, then some assistance with report preparation was provided by the research, noting the information selected and the manner in which it was presented. Additionally, there were some opportunities to assist with a few basic duties such as helping the filing clerks, laboratory technicians and pharmaceutical staff. This afforded a view of the operations of these individual departments as well as the organization as a whole. In addition to direct participation, the researcher also accompanied TASO teams on a variety of projects outside the center, including weekly outreach clinics, home-based medical care and home counseling visits.

However, despite the versatility of these observations, certain constraints existed especially during medical treatment, counseling sessions, home care and home visits, and in any context that involved client-care provider interaction. In almost every client setting, the challenges of language and communication were present. These manifested themselves in several ways. Primarily, as the researcher was not competent in the dominant local languages of Ateso, Kumam and Luganda, all data gathering relied heavily on the translations of the present TASO staff member. Frequently, a series of miscommunications would arise between the student and the translator, such that it is possible that the researcher's own questions were not being asked in the manner intended and frustration at times arose as it appeared that the staff were jumping into answer questions before letting the local people give their responses. It is also quite possible that the counselors and medical staff did not translate everything that was either asked or replied as perhaps it was felt that some of the information relayed was either insignificant or too personal for discussion in a mixed-gender, foreign group. It is also possible that due to the heavy volume of work, some translations were truncated in the interests of saving time. Thus, the information that was finally relayed may have been either inaccurate or incomplete. Additionally, in some observational settings, such as medical consultations, home care or home visits, it was not always appropriate to take notes due to the personal nature of the information disclosed and out of respect for the clients' confidentiality.

In addition to direct observation, a series of interviews were conducted. The researcher primarily targeted TASO staff as key informants who could provide information not only on the organization but also on the social and cultural history of the area. Major informants on the operation of TASO services included Alutia Sam, the projects manager, and Ajuu Ambrose, a clinician and the assistant ART team leader, both of whom are among the oldest employees at TASO Soroti. Others included members of the medical department such as physicians and medical field officers, as well as counselors and several administrators. In an attempt to gather more information on the history and politics of the Teso region, a number of interviews were conducted with local government officials in Soroti, Amuria and Katakwi districts. Further information was provided both in interview form and in prepared reports by UNOCHA, which has established an office in Soroti and whose chief information officer agreed to be interviewed. Individual interviews with clients were also conducted. Typically, the student was able to ask a series of questions in the context of a counseling session. Prior to the start of a session, the counselor would seek permission from the client for the researcher to be present, take notes and ask questions. When this was granted, the session would commence with the counselor intermittently translating and at the end, time would be left for research questions to be put to the client. Although some information was undoubtedly lost in translation, this proved to be an extremely effective way to hear clients' perspectives on their challenges in seeking care. During the session, a rapport was established between the client, counselor and student observer, which generally left clients very open to discussing their particular situation and also gave the student a context from which to begin questioning. The names of the clients have been withheld for purposes of confidentiality.

A series of focus group discussions were also conducted during the practicum period. Any focus group that occurred with TASO staff, it was a purely an informal gathering of members, usually at the end of a clinic day either at the center or some outreach location. Although lacking a formal questionnaire, these informal discussion groups promoted a relaxed conversational environment in which many were able to share information on the operations of the organization, as well as factors that are driving the epidemic forward in this area. Two focus groups were held with clients. Both were

situations in which clients had been assembled for some related TASO activities during which the researcher had been present. Following the program, permission was then sought to ask the clients a series of questions regarding their experiences with TASO and their continued challenges in seeking care. The first group was assembled at a health center in Orungo, located in the northern part of Amuria district, and had come together to retrieve their monthly supply of drugs and speak with the medical field officer. Although the context provided a good opportunity to observe fieldwork, many were loathe to answering questions. This could be attributed to the medical nature of the field officer's visit and the clients may not have seen a point in addressing issues more pertinent to a counseling session. Also, the field officer and translator were men, while the group gathered consisted entirely of women, this may have caused some women to feel uncomfortable in sharing personal details of their home and relationship situations, especially to a foreign student. The second group discussion was held in the context of a counseling session, which followed essentially the same format as the counselor-led interviews described previously.

A significant source of background information on public health in general in Uganda was addressed during a series of lectures at the Makerere School of Public Health. Several lecturers were able to provide pertinent information especially on HIV/AIDS in Uganda.

The researcher was also able to review a series of internal reports at TASO detailing both past and current activities. This provided insight into a variety of areas including what projects the organization has been involved in, who the local partners are, what problems have been reported to the organization by the communities and then how this information is presented. In addition, an ongoing review of literature provided information on the history and progress of the epidemic and contributed to the historical perspective. This method proved to be limited as there is very little available information on the history of the Teso region, the specifics of the epidemic there and how to implement HIV/AIDS care in a situation as complex as the one faced by TASO Soroti. Thus, much of the published information was found to be either out of date or irrelevant.

Of all the data gathering techniques, the one that contributed the least amount of useful information was attendance at the 5<sup>th</sup> National AIDS Conference at the Speke

Resort Munyonyo in Kampala. The conference is an annual scientific forum that has been set up to discuss national responses to the epidemic and to recommend future actions in the areas of research, policy and program implementation. The program outlined three major tracks of lectures and presentations at the conference: basic research, policy and program, and counseling. The researcher's intention was to attend lectures that focused on prevention training, community responses, care and treatment options, social support, and impact mitigation. In particular, any lecturer who addressed issues of outreach treatment programs and how they are adjusted during times of complex emergencies, that person could be identified as a possible key informant interviewee. Unfortunately, such topic was not addressed. Although the conference shed light on a variety of important HIV/AIDS related issues such as current research topics and policy formation, and raised innumerable questions on the ethical nature of resource allocation to HIV/AIDS support programs, there was virtually no pertinent information on the issue of this report. Perhaps the most troubling aspect to note from the conference was the stark disparity between the well-appointed organizers and attendees of the conference in Munyonyo and the dire poverty of HIV/AIDS infected clients at the village level.

## **JUSTIFICATION**

The steady prevalence of HIV/AIDS and the increasing number of HIV infected individuals in Uganda are strong indicators that there is a continued need to adapt and develop education, prevention, treatment and care implementation strategies nationwide.

Unfortunately, there is a very high probability that health care providers will continue to face the challenge of HIV/AIDS care in settings of complex emergencies. As political tensions continue to grow in the great lakes region and the possibility of sporadic, ethnic-based violence increases, East African nations will continue to be confronted with issues of displaced peoples. Soroti is an appropriate case study because it is located in an area that has experienced both long-term ethnic conflict in the form of Karimajong-Iteso struggles, as well as rebel groups engaging in local guerilla warfare, such as both the presence of the UPA and recent LRA violence.

The situation further complicated by recent flooding and is therefore a reasonable case study for examining an area that has experienced both political and natural disasters



and has a large displaced population. Additionally, due to global warming and widespread changing weather patterns, there is significant likelihood of future flooding, both in this area and elsewhere in the region, and it is important that what has been learned from the experience of managing HIV/AIDS care during periods of natural disaster be made available to protect vulnerable populations against future emergencies<sup>1</sup>.

Understanding what interventions have been used in this area, their successes and failures is an important lesson, not only for the people of this region but for all who reside in what are either current or post conflict zones. Questions regarding how HIV/AIDS will be addressed in future conflict and disaster settings should provide useful information for developing treatment strategies.

## **FINDINGS and DISCUSSION**

### **TASO: A description of the organization and the roles assumed during the practicum period**

#### TASO Soroti Activities

All TASO centers are organized according to the same general structure. There are three main departments: medical, counseling and projects. The activities of each department at most TASO centers are as follows:

MEDICAL	COUNSELING	PROJECTS
<ul style="list-style-type: none"> <li>● Nursing care</li> <li>● Home care</li> <li>● Management of OI</li> <li>● Dispensing</li> <li>● Use of ARVs and ART</li> <li>● Outreach clinics</li> <li>● Triage</li> <li>● Health Talks</li> <li>● Community training</li> <li>● Laboratory activities</li> <li>● Aromatherapy</li> <li>● Prophylaxis</li> <li>● TB management</li> <li>● HBHCT</li> </ul>	<ul style="list-style-type: none"> <li>● Counseling sessions</li> <li>● Child counseling</li> <li>● Centre counseling</li> <li>● Outreach</li> <li>● Home visits</li> <li>● Issues on ART</li> <li>● Community support supervision</li> <li>● Sensitization and education</li> <li>● Community training</li> <li>● Health talks</li> <li>● Day center</li> <li>● Support supervision in counseling</li> </ul>	<ul style="list-style-type: none"> <li>● Nutrition (current programs include WFP distribution)</li> <li>● Child support (apprenticeship, formal education)</li> <li>● IGAs</li> <li>● Memory book writing</li> <li>● Support visits to schools and families</li> <li>● Advocacy</li> <li>● Monitoring and Evaluation</li> </ul>

<ul style="list-style-type: none"> <li>• Monitoring and Evaluation</li> </ul>	<ul style="list-style-type: none"> <li>• Registration and record keeping</li> </ul>	
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TASO Soroti has four major outreaches: Acowa, the largest IDP camp in Amuria district, Katakwi, Kumi and Serere, which attracts clients from the landing site areas around Lake Kyoga in Soroti District. (It should be noted that the Soroti District areas around the lake are inhabited mostly by fishermen and those associated with the fishing business. This tends to be a mobile population, characterized by risky recreational behaviors such as heavy drinking and forming relationships with many sexual partners. Hence, HIV rates in these areas are also significant, however as the focus of this project was more directed more towards the IDP populations, this region was not as thoroughly investigated.) Each Monday the entire clinic is packed up and moved to a location at least seventy-five kilometers away from the center so that those who are challenged to find transportation have an opportunity to seek treatment. At these outreach clinics, all TASO services are offered, including testing and counseling, medical care, individual and group counseling, aromatherapy and massage for pain management, family planning and general health talks, drug dispensing and a limited number of laboratory services. TASO is the only HIV/AIDS support organization in the area that provides such a wide array of services, though there are many smaller local groups that do testing and offer some basic counseling.

A major part of TASO Soroti operation is in outreach activities including the following: home visits (which consist of a medical field officer and counselor traveling to provide bedside treatment, HBHCT of other family members and general support), home care (which involves a single counselor visiting a home), Community Drug Distribution Points (CDDP) (in which a field officer delivers drugs to a group in a remote location), educational presentations (the researcher was able to attend sensitization meetings both at a local primary school and at the Soroti prisons) and drama group performances for local communities.

Unfortunately, due to direct participation in volunteer activities, interaction with clients during general clinics held at the center was kept to a minimum. General clinic days at the center are Tuesdays and Thursdays, with an ARV specific clinic held on Wednesday. Clients gather at the center for appointments with counselors and medical

officers, they receive drug supplies for either one or two month, some are given aromatherapy or massage for pain management and some client support groups meet. New clients are given pre-HIV test counseling appointments, tested to confirm their status and then provided with follow up counseling. The center has also recently constructed a child play center, where clients who are children can come wait for their sessions in a friendly and relaxed environment with specially donated toys and activities.

It should be noted that while funding and partnership building remains a challenge for supporting the many TASO activities, a wide array of contributors are involved with the program, including the following:

- Action AID Uganda
- AIDS Information Centre (AIC)
- Celtel
- Centers for Disease Control (CDC)
- DANIDA
- DFID
- Elton John Foundation
- European Union
- Global Fund
- Government of Uganda
- Irish Aid
- JICA
- Johnson & Johnson
- PEPFAR
- Rockefeller Foundation
- SIDA
- SIPAA
- UNICEF
- USAID
- World in Need
- World of Hope

Funding partners and contributors specific to TASO Soroti:

- District leadership in Teso
- Leadership at community level
- World Food Programme (WFP)
- ACDI/VOCA
- PSI
- Local health units
- Food and agricultural organizations
- Friends of TASO (German sponsor group)

#### Responsibilities at TASO Soroti

In addition to observations of TASO activities both at the center and in the field, this practicum period allowed the researcher to directly become involved with the organization's work by participating in a variety of activities. The most common task was providing some basic administrative support such as preparing reports. This included attending meetings among TASO staff and with external groups such as other NGOs, medical officers from the regional hospital and local government officials. For

example, during the time spent at TASO Soroti, a new program for community involvement was being designed and launched. The Community Initiative Program (CIP) involves designating and training interested community members to act as local surveillance officers in terms of checking up on clients in a specific area and reporting their status or health problems to the local AIDS focal person at the district level. During the design of this project, the researcher was able to assist with the preparation of reports on staff training, location selection and meetings with district government leaders who would be involved. The researcher was able to hear directly from camp managers on their specific challenges of HIV/AIDS care in a population of IDPs. Many expressed great frustration at the general lack of care and disinterest of NGOs in working within Teso. According to an LCV representative in Kapelebyong, “the NGOs [that came following LRA disturbances] are moving away, they have what they have come for... Sometimes NGOs come once and never come back, we then hear that they are working somewhere there [northern Uganda].” Another project involved data collection on the needs of potential outreach locations. The researcher was able to accompany medical and project officers to meetings with leaders of IDP camps in Kapelebyong, Obalanga and Oditel, which are very far from Soroti and the even the nearest out reach point in Acowa. (It should be noted that to reach these camps in a land cruiser was an entire days journey. The majority of TASO clients travel on foot, bicycle, taxi or truck bed. If a journey consumes the entire day, they are also faced with greater expenses of finding overnight accommodations near the center. These expenses are preventing many from even seeking testing). The visits provided opportunities to hear directly from leaders about the challenges of HIV/AIDS care for camp residents and the lack of government and NGO support. Leaders noted bitterly that one organization had come in briefly over a year ago, done a series of VCT, identified over five hundred HIV positives in the Obalanga area and then left without providing any further treatment.

In addition to observations, the organization required a number of typed reports as well as the compilation of several PowerPoint presentations and Excel spreadsheets, which occupied the majority of practicum time.

A variety of other activities were also available. There was ample opportunity to assist the filing clerks and learn how the center’s database of clients was managed, how

files are retrieved, removed for outreach, passed through a data entry point and returned to their permanent location. The system appeared hugely inefficient with many employees working on managing these large paper files, which are bulky and tend to decay with age, causing many of the clients' forms to fall out and be lost. The student was also allowed to participate in some basic laboratory staff and was given the opportunity to learn from the head technician. Activities in this department included drawing blood samples, preparing and reading HIV tests, recording lab data and learning looking at sputum samples collected for TB follow-up tests. Frequently when accompanying the staff on outreaches, there was need for more volunteers to work in the pharmacy counting drugs, packaging, labeling and dispensing to clients. Similarly, on food distribution outreaches, activities included identifying and recording names and signatures of eligible recipients, forming receiving groups and distributing food. Lastly, opportunities to directly participate in counseling sessions were presented. Due to expressed interest and the need to carry out some client interviews the researcher was invited to participate in a number of both individual and group-based, English language, counseling sessions during outreach clinics.

### Challenges to Care: Perspectives from Staff and Clients

Throughout this practicum period, a number of key factors that are contributing to the epidemic in this area were identified based on a series of interviews and focus group discussions with TASO staff and clients. Some information was also furnished by interviews with staff members from UNOCHA/UNHCR and local district officers.

It is important to note that many of the cultural norms, which dictate the treatment of women, encourage multiple sexual partners within relationships that do not traditionally foster open communication regarding sexual health or HIV/AIDS. Throughout the Teso region, the practices of polygamy, wife sharing and widow inheritance are common. The tradition of wife sharing implies that any man from the husband's family or extended clan is allowed sexual privileges with the woman, who may be referred to by the family as "our wife." Men who have contributed to the bride price, which in Teso is cows or occasionally goats, are also allowed these rights. Wife inheritance is the term for when a man dies, his wife is then passed on or "inherited" by his brothers or other clan members.

The consequences of refusing to participate in such traditions are serious. During an informal interview with Ayoo Proscovia, who is both a counselor and client of TASO, she related her personal experience with the difficulties of such practices as an HIV positive:

*When my husband died there was a struggle between my brothers-in-law to inherit me, but I refused. This annoyed them very much and I was sent packing very fast and very abruptly. I left home with nothing, not even my own dresses, not even a thing for the children. I carried not even a single cup or a plate, saucepan or blanket. I started by renting someone's kitchen in town for 10,000/= per month, sleeping under soot and with a lot of stress. I used to cry a lot. I grew very thin and weak as I was left helpless...*

In addition to the risk of contracting HIV/AIDS by having so many sexual partners, women who are inherited or passed around families are frequently left to look after the many children that their husbands produce. This puts an enormous burden on women, who traditionally are responsible for the majority of household work, childcare and support. As the resources of these women are stretched ever thinner, they are less able to travel to health centers to seek testing, counseling and medical care either for themselves or for their children. This was the perspective of countless TASO clients who spoke on the main challenges to seeking HIV/AIDS care for themselves and their dependents.

According to interviews with camp residents and TASO counselors, income-generating activities (IGAs) in the camps are few and as women are finding themselves responsible for increasingly large numbers of children, the pressure to find income to support the family increases. Camp IGAs tend to be limited to activities such as casual labor (i.e. digging in gardens, shelling groundnuts, etc.) boda-boda driving (available to men), petty trades such as making mandazi or firewood, and prostitution. While not a first choice, it is understandable how a woman with multiple dependants who is earning less than a thousand shillings per day for digging would accept to have sex with a man who offered three thousand. Confined to the camps due to continued insecurities and with few activities to pass the time, the culture of drinking local brew has grown. (Millet brew or *ajon* is a common throughout Teso and it is typically prepared by women and enjoyed by groups of men. Preparing the brew is another common employment for

women, who are frequently pressured for sex by their clients.) This is the situation according to a series of interviews with female TASO clients at the Obuku, which is located camp just outside of Soroti town. With frequent casual sex either because of polygamous traditions or as an IGA, many camp residents have many sexual partners and are at an elevated risk for contracting HIV. Additionally, due to their low economic status residents are often not in a position to test their status or seek treatment if they are positive. The net result is that there is high incidence of HIV/AIDS within the camp populations and few resources available for testing and medical support without TASO outreach services. To combat the spread of the disease in this situation not only there a need for increased awareness of the risks from multiple sexual partners, but there is also a demand for sustainable livelihood activities and more IGAs so that women are not forced to turn to sex for money. While stigma and discrimination are lessening with heightened knowledge of HIV/AIDS, there is still a huge reluctance especially among men to seek treatment or disclose their status. This is resulting in self-stigma, denial and HIV positive men continuing to infect women and drive up the epidemic in this area, according to a series of interviews with members of the counseling department.

Another challenging component of HIV/AIDS care is the poor general health of those who are living in impoverished and congested circumstances in IDP camps. These camps, many of which were built as temporary settlements over thirty years ago, have gradually grown as continued insecurity has caused increased displacement. Thus, the camps have formed without any organizational plans and are generally characterized by groups of small, highly congested, single family dwellings and a few common latrines that serve the entire camp<sup>li</sup>. Under the best of circumstances, this crowded lifestyle tends to make people more vulnerable to airborne, communicable diseases, such as tuberculosis, and the poor sanitation tends to lead filthy latrines, which overflow frequently into gardens or common water supplies. This puts camp residents at further risk of contracting diarrhea diseases, intestinal worms, malaria and even cholera. The flooding of last fall intensified this situation, producing greater incidences of malaria and diarrhea diseases. Such circumstances are specifically challenging to HIV/AIDS care. As PLWHA are vulnerable even with ARV therapy, such unsanitary conditions promote

the risk of opportunistic infections and make the goals of healthy living and continuing to work even more challenging.

Another subject touched upon in every interview with both TASO clients and staff is that of nutrition. Due to the congested living conditions within the camps, few IDPs are able to meaningfully cultivate. Some have tried to go back to their original homes but continued insecurity, land disputes and lack of infrastructure away from the camps have discouraged many from returning. Without growing food or having enough income to buy, many TASO clients are faced with continued malnutrition in the camps. Additionally, the last year's floods ruined the region's entire harvest, with the result that food is scarce in the fields and imported products from Mbale or Kampala are expensive. One client who is trying to support himself, his wife, mother and ten children reported:

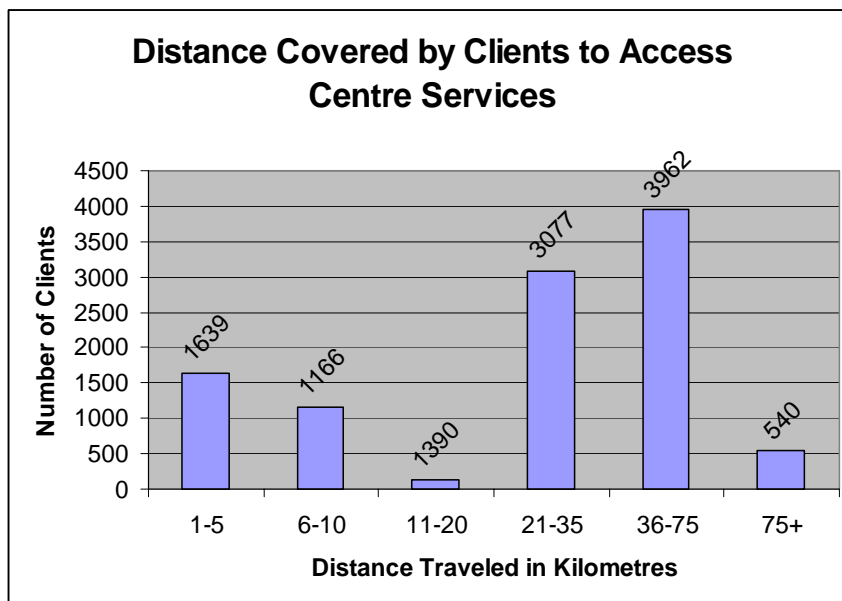
*We are in a food crisis... there is no food ...we are only eating mangos and don't know what we will do when the season is finished...*

For HIV/AIDS clients, access to reliable food sources is especially crucial. Not only are these individuals at higher risk for OIs, but for those who are enrolled in ART these drugs must be taken with food or severe side effects are experienced (such as debilitating nausea and weakness).

Major challenges faced by clients in this area are distance and accessibility. During every interview with clients and with staff the issues of finding and paying for transport were addressed. One issue that affects access is that of road quality. Due to the heavy conflicts that have plagued this area many of the roads, especially in the northern parts of Amuria and Katakwi districts, have been damaged by landmines and continued insecurity in the region (as well as lack of government initiative) has prevented road improvement or construction. Additionally, the recent floods have caused widespread road damages, including bridge destruction, road flooding, increased rutting and pothole formation and general worsening such that avenues become impassable even in comparatively light storms. This creates a number of challenges to delivery of HIV/AIDS care: during floods, clients are cut off from service centers, such that they are not able to access medical care or renew their drugs. For clients taking ARVs this is especially worrisome as these are medications that must be taken every day or the virus can develop treatment resistance. During last year's floods, thousands of TASO clients



found themselves cut off from the center and outreach points. Although a helicopter was ultimately made available so that some drugs could be delivered, a number of clients died and there was net backlog of follow up work, drug effectiveness re-evaluation and distribution. Today, the damaged roads make traveling to clients' homes for home care even more difficult and clients whose only form of transportation is on bicycle are challenged to reach service points. Additionally, many clients, who are traveling from remote areas, especially in Amuria and Katakwi districts, report that not only is finding a vehicle to and from service points difficult, but that the costs are prohibitively high. For example, camp leaders in Kapelebyong and Obalanga, when requesting closer outreach clinics, pointed out that transport to Acowa or Soroti is at least five thousand shillings, which many residents do not even make in a month. The following graph shows the distance traveled by TASO clients to access the service center.



From this graph it is clear that the issues of distance and accessibility represent major challenges for the majority of TASO Soroti clients and that there is an urgent need to reach out to clients in these remote areas.

Another characteristic of the client population in this region is the general attitude toward life and health. Due to the persistent conflict in this area, displacement to camps and loss both of property as well as culture, many camp residents feel resigned to suffering and even to death. Loss of tradition, inability to school children and

consequential lowering of the educational standard has produced widespread despair and apathy towards life. According to Oinya Sam, the Soroti district disaster preparedness officer, “the dignity of our people has been drastically eroded.” Atako Agnes Apedu, a client representative and a former resident of an unspecified camp in northern Amuria district, “the life I experienced from the camp was the worst life... people just went there accepting to die.” This general discouragement and fatalistic attitude towards life make counseling HIV/AIDS clients even more challenging in this context. Both Ajuu Ambrose, a managing clinician, and Olinga Charles, a senior counselor, reported that they frequently have clients who just give up and go on hunger strikes or disappear into the swamps, never to be heard from again. Mr. Olinga also stated that many people have already experienced so much suffering and general insecurity, they tend to lead risky lives such as turning to heavy drink or frequent casual sex.

After all of these challenges (especially regarding the most recent flooding disaster) had been identified through interviews and discussion not only with clients, but also with TASO staff and local government officials, the question was raised of, “if all of these issues are known, why is there not an action plan should another emergency arise?” According to representatives from the Soroti office of UNOCHA and UNHCR, the disaster situation of the recent floods had been fully analyzed and strategies were have been set up specifically to address health issues for the next time the area floods. Apparently a workshop had been held with local government and NGO representatives, a report had been generated and a series of plans formed. However, despite these well-laid plans, they do not seem to be easily converted from on-paper agreements to relief actions. During the fourth week of the practicum another major storm occurred. As winds knocked down power lines, collapsed trees and de-roofed homes, rains flooded streets and ruined food stores across the Teso region. Nearly a hundred thousand people were affected by loss of property, foodstuffs, power and crops. Five people were killed either by drowning or in storm related accidents. Yet apart from the immediate area, there was no national coverage or government recognition and NGO aid was minimal. Mr. Oinya reported that after several days the Red Cross was “expressing interest” in assisting those whose food supplies had been ruined and were either squeezing into relatives’ houses or sleeping in local schools. Finally, several relief packages were re-directed from

recipients in a Katakwi IDP camp and sent to flood victims, however the majority of the delivery seemed to consist of children's slippers, which were of little use to people whose crops had been ruined for the second consecutive harvest season. As HIV/AIDS affected clients are faced with further malnutrition, standing water, which serves as a breeding ground for malaria carrying mosquitoes, cold and damp houses, they are at greater risk of compromised health, opportunistic infections, tuberculosis and difficulty taking their ARV therapy. Thus, while there has been widespread research on disaster management and extensive material is available on specifically how to manage HIV/AIDS in an emergency setting, this area represents a huge gap between research and implementation. According to counselor Olinga Charles, "we do not have the resources to prepare for disasters, today we have flooding tomorrow we have dry weather. We are just going along with what we have, we can do no more..."

## **CONCLUSIONS**

Though time spent in the Teso region was relatively brief it was obvious that the entire area has suffered from gross neglect on the part the government and NGO projects. The people of these districts have suffered from ongoing conflict and massive displacement for almost forty years and as AIDS continues to plague the area, development processes and welfare improvements are slow. Health and development partners need to recognize the needs of northeastern Uganda and contribute to infrastructure improvement and HIV/AIDS needs specific to this area.

From this practicum period with TASO Soroti, the overall impression gained from observing the work carried out is that many are benefiting greatly from the services offered, but that the challenges are overwhelming. There is a huge demand for services: at every outreach clinic at least a hundred new people come to register, but the center can only enroll thirty each week. The seventy that are turned away may go back to their communities, presumably to fall sick and continue to infect others. These are the people who have voluntarily come for services, there is also an unknown number of affected individuals who either do not know their status or due to stigma and discrimination are not coming for treatment. There are huge volume of existing clients who need follow up care or visit, there is an increased demand for sustainable livelihood activities, especially

among those living in the IDP camps and trying to return to their homes. Transportation and accessibility remain huge issues for many clients. Many coming from remote areas are challenged to find money and transportation either to the center or to the closest outreach point. The poor conditions of the road network cut clients off from services during periods of flooding, the inadequate health facilities places an even greater burden on the already exhausted TASO medical staff and though other AIDS support partners exist in the area, there is a general lack of cooperation and collaboration between similar interest groups. The net result is that TASO staff and resources are at a breaking point; continued outreach and expansion of services is desperately needed, but the funds and personnel simply are not available.

Lastly, the ultimate conclusion that can be drawn from this whole experience is that there is something terribly wrong with the way HIV/AIDS funding is addressed in Uganda and indeed in the whole world. In Uganda over 100 million USD are spent annually on combating HIV/AIDS, the majority of which comes from PEPFAR and the global fund, though many other parties also make substantial contributions (such as the 5<sup>th</sup> Annual AIDS conference, which attracted over a thousand delegate each of whom paid an entrance fee of fifty and a hundred dollars). And yet despite huge funding and the articulation of widespread concern for the HIV affected in Uganda, treatment and care are simply not reaching those with the greatest needs. It was painful to note the luxurious environments of funding offices and research centers in Kampala and the abrupt departure from such to visiting HIV positive women in the IDP comps of northern Amuria and Katakwi districts, where they are shelling baskets of groundnuts for just 500/= per day trying to provide for their children and find enough food to offset the debilitating effects of ARV therapy. There needs to be a huge review of the distribution processes of AIDS funding such that the resources that are allocated actually reach the people of Uganda who are still living hard lives, made even harder in the face of HIV/AIDS.

## **RECOMMENDATIONS**

During the limited time spent at TASO Soroti, a number of inefficiencies were noted. Though the researcher only participated in volunteer activities for a few weeks

and therefore presumably does not fully understand the complex function of the entire organization, it seems that some improvement in these areas could save time, resources and effort that would allow more clients to be better served.

One area that appeared highly inefficient was that of report preparation. There seemed to be a huge emphasis on preparing handwritten reports, typing them and creating related PowerPoint presentations. For a staff that is largely computer illiterate, lacks typing skills and does not fully know these programs, the execution of these activities consumes enormous amounts of time for many members and is frustrating and exhausting. Simply from the point of view of an observer, I would recommend that there be serious review of report requirements and establish which truly require typed format and presentation software. The same information can be just as readily disseminated by copying a neatly hand written document or presenting using flipcharts and chalkboard. If the organization still insists upon electronic documents, it would be a good use of resources to invest in a professional typist or secretary who could take charge of report preparation or alternatively, the organization could provide some computer training courses for its staff.

In addition, an area that could be improved upon is that of the filing system and database of client information. The center has over 11,000 registered clients, each of whom has a file of medical and counseling forms stored in a floppy, plastic binder. These files are stored in floor to ceiling shelves, which are located in a crowded room. The files are so packed and their floppy shape causes the rows of binders to fold over sideways making storage and removal difficult tasks. The binders themselves are also not durable with the result that client documents frequently fall out and the files are bent or torn. Currently there are a total of two filing clerks and three volunteers who work on moving the files from the center to outreach and back. From the perspective of an observer, this whole system seems highly inefficient. It appears that reorganizing the system with more neat and durable binders or at least putting more dividers into the shelves would make filing a less arduous task that would require fewer workers.

Another activity that would benefit from better organization is that preparing for outreach activities. Every Monday when the staff would gather to set out for an outreach clinic and invariably experienced delays due to uncertainties of assigned staff, waiting to

pack files and drugs and general time mismanagement. Once at the outreach site, frustrations were frequently expressed due to missing files, drug shortages or inability to locate drugs from the large box they were packed in. It appeared that each of these departments could benefit from the adoption of some basic organizing strategies, such as providing dividers or containers within the drug box so that similar drugs could be packed together and more easily accessed, the employment of checklists for files or necessary medical items and the appointment of an official time keeper could make the entire process run more smoothly and efficiently.

Lastly, it was noted that widespread frustration was encountered during home visits and care when staff members were trying to locate clients. When new clients joint TASO they are interviewed about how to access their homes, however the given directions are frequently inadequate or misleading, which result in a huge amount of time given to trying to access them. Perhaps this system could be improved if the clients were given space on the mapping form to draw a diagram of how to access their homes, pointing out pertinent landmarks. Additionally, many of the clients either have their own mobile telephones or have access to the use of one. Perhaps a small amount of funding could be designated for home care and home visit related airtime to that staff could call clients or neighbors before heading to the field to make sure the person was actually available. During this observational period, it appeared that staff would frequently arrive at clients' homes only to discover the person was not around, had gone to hospital or in some cases had even died. Thus a huge amount of time was used both in locating the homes and in visiting places where clients were not even accessible.

As stated above, it is not possible for a brief observational period to afford complete understanding of the organization and its constraints, but it appeared that each of these areas could be slightly improved upon, each of which would make better use of the already exhausted resources.

## APPENDIX

QuickTime™ and a  
TIFF (LZW) decompressor  
are needed to see this picture.















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## NOTES

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