

Emergency Planning for HIV Treatment Access in Conflict and Post-Conflict Settings

The Case of Northern Uganda



Internal Displacement Camp in Kitgum, Uganda.

U.S. Agency for International Development

Globally, 200 million people and 30 percent of sub-Saharan Africans live in a state of chronic, recurrent, or episodic emergency (World Health Organization [WHO] 2006). Emergencies include periods of unrest and displacement caused by political upheaval, predictable or unpredictable environmental events, and short- or long-term armed conflict. Regardless of duration, the impact of emergencies on fragile health care infrastructure in the developing world is often devastating, leaving people with acute injuries queuing for care provided by rescue organizations and those with chronic illness foregoing care entirely.

The paucity of functional health care infrastructure to manage chronic illness during emergencies is of utmost concern in sub-Saharan Africa, where approximately 22.5 million people are living with HIV and 10.6 million require treatment with antiretroviral therapy (ART; WHO 2010). Continuity of treatment for HIV is critical to the health of the individual, to prevent transmission of infection, and to ensure effectiveness of the ART regimen for the population as a whole.

Though providing care and treatment to people living with HIV (PLHIV) is challenging in these settings, WHO has published a consensus statement that states that emergencies should not impede a patient's access to HIV services and that the provision of care and treatment is "an inalienable human right and a public health necessity." Furthermore, emergency preparedness and contingency planning for HIV service provision must become a priority for national governments and

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international agencies both in official policy and in resource allocation, or universal access to care and treatment will never be achieved (WHO 2006, 1).

The United Nations has identified three stages of emergency that occur irrespective of cause: acute emergency, post-emergency, and reconstruction. Although settings where emergency events are unfolding often attract significant attention, there has been little focus on the post-emergency and reconstruction periods. These stages are characterized by resettlement and repatriation and may extend for years following the initial emergency event (U.N. High Commissioner for Refugees 2005). In the case of HIV care and treatment, contingency plans must include the inevitable need for long-term support in the post-emergency and reconstruction periods until treatment access is fully re-established.

The Crisis in Northern Uganda

Like many countries in sub-Saharan Africa, Uganda has faced a number of complex emergencies, from floods in the central region, to sporadic violence by armed nomadic tribes in the Karamoja region in the northeast, to frequent droughts leading to food insecurity and famine across the country. But none has been as long-lasting or destructive as the civil war in northern Uganda that began in the mid-1980s, peaked between 2002 and 2004, and finally quelled in 2006.

As violence became a recurrent theme in the lives of northern Ugandans, so did HIV. The most recent data suggest that HIV prevalence in northern Uganda is 8.2 percent, while nationwide prevalence is 6.7 percent (Mermin et al. 2008; Ugandan Ministry of Health 2009). Though the cause can be debated, disproportionately higher HIV prevalence is just one factor that differentiates this previously war-torn region from the rest of the country. Today, the

north remains a post-conflict region facing many challenges in HIV service provision, including ensuring access to treatment for transient, displaced populations.

This case study describes the challenges of HIV care and treatment in northern Uganda during both the conflict and post-conflict periods and highlights interventions such as those funded by the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) that have been successful in improving access to treatment. This case study also suggests clinical, policy, and programming recommendations to ensure continuous access to HIV care and treatment in the future.

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Armed Conflict in Northern Uganda

The civil war in northern Uganda was incited by religious fervor, ethnic tension, and the desire for political power. In 1986, the current president of Uganda, Yoweri Museveni, came to power by coup. Soon afterward, the Lord's Resistance Army (LRA), a self-defined spiritual movement seeking to overthrow the Ugandan government, began engaging in random, sporadic acts of violence in the north. For the next 20 years, the LRA raped, maimed, and kidnapped residents of the Acholi and Lango subregions (see map).

By 2006, through military action and negotiations led by the Ugandan Government, the LRA signed the Cessation of Hostilities Act, and peace was restored to the region. However, by the time the violence subsided, tens of thousands of people had been killed and more than 60,000 children had



Map of Uganda.

been forced to become child soldiers, laborers, and “wives” for the LRA. Moreover, at the height of the conflict, more than 1.8 million people—80 percent of the population of northern Uganda—had been displaced. Some fled to urban centers in the south, but most were forced to live in camps for internally displaced persons (IDPs).

Life in Internal Displacement Camps

As violence escalated throughout the north, the national government began to institute policies to provide safer living conditions for inhabitants of the region. Under the Protected Villages Policy, people living in affected areas were forced to leave their homes and move to IDP camps in each district. To provide continuous access to health care for residents, these camps were established around existing health centers, such as clinics or hospitals. At the height of the conflict, each IDP camp was home to between 2,000 to, in the largest camp in Pabo, Amuru District, as many as 60,000 individuals. Each family lived in a small hut separated from their neighbors by approximately five feet (see photo of IDP camp in Kitgum). To protect camp residents from

LRA assaults, armed guards patrolled the perimeter, and curfews were imposed.

Conditions in the IDP camps have invariably been described as deplorable. Violence was rampant. In a WHO survey of three district camps, more than 4,000 people were killed and 1,300 were abducted in one year (WHO 2005). Though rapes were reported, no data were aggregated. Few residents were employed and, with little to occupy their time, alcohol abuse was rampant. Poor sanitation and close living conditions led to frequent outbreaks of cholera and other communicable diseases. Overall mortality rates were higher than in the rest of Uganda (WHO 2005).

Though living conditions were suboptimal, there were abundant services provided by nongovernmental organizations (NGOs). Because northern Uganda was in a state of emergency, international relief organizations provided funding, supplies, and staff to support service provision. Daily food rations were distributed, and schools were opened within the camps. Health care was also provided. Most health care workers fled to cities, leaving NGO volunteers to serve as temporary clinic and hospital staff.

HIV Service Provision in Internally Displaced Person Camps

The spread of HIV in Uganda has disproportionately affected the northern subregions, with higher prevalence in the north than the average nationwide. Mermin and colleagues (2008) have noted that the risk of HIV in north central Uganda was three times higher than in central Uganda, including the capital city of Kampala.

Despite the dire need for HIV services and the presence of NGOs, HIV services in the IDP camps were severely limited. In most of the camps, the only

HIV service offered to residents was information, education, and communication focused on ABC strategies (*abstinence, be faithful, and use condoms*) and prevention of sexually transmitted infections. Condoms were available in a number of camps, although stockouts were frequent. HIV testing and counseling services for adults and children were primarily available at higher-level clinics and hospitals located in or near camps. Lower-level clinics that may have been more accessible to camp residents rarely provided HIV testing (International Organization for Migration [IOM] 2006).

Treatment for opportunistic infections (OIs)—primarily co-trimoxazole and tuberculosis treatment—was available at most health facilities irrespective of level. However, the limited availability of HIV testing, laboratory services, and radiology limited the ability to diagnose and treat specific OIs.

To prevent mother-to-child transmission of HIV, nevirapine or zidovudine was available free of charge at 38 percent of higher-level clinics and hospitals (see Figure 1). HIV-positive women were encouraged to give birth there as opposed to giving birth at home or at lower-level clinics. However, in many cases that was not feasible, and maternal morbidity and mortality were disproportionately high.

ART became available at some higher-level clinics and hospitals located near IDP camps in late 2005.

Figure 1. Percentage of Health Facilities in Northern Ugandan IDP Camps Offering HIV Services (IOM 2006)

HIV service	IDP health facilities offering these services (%)
Adult HIV testing	44%
Pediatric HIV testing	27%
Treatment for opportunistic infections	97%
Prevention of mother-to-child transmission services (ART for prophylaxis)	38%

Barriers to offering and accessing ART included lack of staff training and limited drug supply. During periods of LRA insurgency, travel to health care facilities was difficult, which sometimes disrupted the supply chain for ART and HIV commodities (Ario 2010). Because drug supplies were limited, sites offering ART were quickly overwhelmed with patients, and waiting lists were common (IOM 2006). However, health care workers who provided care and treatment to adult patients at that time believe that on average clinical outcomes were optimized because adherence to care and treatment was high. Patients were easy to track because they lived nearby, and home visits within the camp provided ongoing care (Onok 2010).

Patients who wanted to start treatment but were unable to do so at camp facilities were forced to travel outside of the camp to obtain treatment. Though there is no documentation of such incidents, the risk of abduction and violent attack by the LRA was high (Oloya 2010).

Pediatric HIV treatment was largely unavailable. Few service providers within the camps offered ART to children during the period of conflict. However, ART for children was offered at larger hospitals and higher-level clinics. Health care workers providing HIV care to children in 2005 note that, though the programs were small, quality of care was high. Follow-up was conducted optimally and up to 95 percent of children benefited from long-term retention (Atim 2010).

Internally Displaced and HIV-Positive Persons

There are no estimates of the number of HIV-positive individuals who were displaced and lived in IDP camps during the period of conflict. However, some HIV-positive individuals who spent years struggling to access care and treatment in

the camps became advocates and leaders in the PLHIV community. Many expressed the belief that stigma was pervasive and that overt rejection was a commonplace occurrence.

In addition to medical care and treatment, psychological support was identified as an unmet need for HIV-positive IDP camp residents, but few health facilities provided these services. Peer-led support groups were formed in the larger camps, but gatherings were not well attended for fear of public disclosure and resultant stigma from other camp residents (HIV-positive patient 2010). A few PLHIV were trained in human rights and stigma reduction (IOM 2006).

Though camp life presented numerous challenges for PLHIV, the proximity of health care services (even though many were suboptimal and did not offer ART) was advantageous. According to Jimmy Oloya, an HIV-positive individual who agreed to be interviewed, “At least then everyone knew where to go to get services.” As mentioned previously, follow-up of patients was feasible because huts were close together and patient residence was documented at the local clinics.

Post-Conflict and Resettlement

With the signing of the Cessation of Hostilities Agreement, relative peace was restored to northern Uganda in 2006. As the violence subsided, the Ugandan Government announced that IDP camp residents would be asked to voluntarily return to their home communities. In 2007, supply shipments to IDP camps decreased significantly, and many NGOs began to close their camp operations. By the end of 2009, 1.4 million of the 1.8 million IDPs had either returned home or established alternative residences outside of the camps. Alternative residences included “transit sites,” which are camp-like residences established by former camp residents

PLHIV Speak Out on Stigma in IDP Camps

The biggest problem for people living with HIV in the camps was stigma. People were congested, one on top of another. Once you disclosed to even one person, everyone would know. No one would want to share the latrines with you.

—Raphael Ocholo

Rejection was also a problem. People thought we were going to die and were useless.

—Molly Ajoy

Other people did not want us to participate in activities like income generation offered by the NGOs. They would tell us to go away.

—Anonymous

who had no home to return to. However, some could not travel even to those sites. By the end of 2010, an estimated 182,000 people remained in either transit sites or former IDP camps. Most of these individuals are elderly, disabled, or living with HIV (Internal Displacement Monitoring Centre [IDMC] 2010).

While returning to their communities is the ultimate goal for IDPs, many in northern Uganda have returned to find shells of their former villages. The pace of return has significantly outpaced the rebuilding effort. Homes need to be rebuilt, and lives need to be re-established. In most instances, basic services are poor or completely lacking. School buildings are dilapidated, and few teachers are available. In many districts, clean water is not yet available. Health facilities are unstaffed and in disrepair. Inadequate health care infrastructure and

poor sanitation have led to outbreaks of hepatitis E and the re-emergence of polio in several districts (IDMC 2010).

HIV-Positive Individuals Return Home

For HIV-positive individuals, the return home presented additional concerns. Where would treatment be available? Would health care workers be available to provide care? How far would the treatment site be from home? How would one travel there? According to PLHIV who lived in the camps, formal referrals to health care facilities were not offered, and there was no coordinated system to identify treatment sites for patients to access once home; according to one person living with HIV, “It was up to the patient to find their way to health care.” Despite the expectation that there would be delays in accessing treatment, patients were reportedly not given additional medications because of limited supply and lack of buffer stock. Patients were not counseled about how to stop medications safely in case the next month’s supply was delayed. In addition, most did not leave the camps with official medical records that could be helpful when they attempted to access care at distant sites (Makumbi 2010). “When there is war, the health system breaks down and people who have diseases like HIV really suffer. When war ends and there is nothing left, our trials are just beginning,” said Oloya.

These fears were warranted. For those who left the camps in 2008 and 2009, treatment availability was extremely limited in outlying villages. The lower-level health facilities nearest to the villages did not have the capacity to manage HIV treatment. Those that offered treatment experienced frequent stockouts of ART and OI prophylaxis and treatment. PLHIV were forced to travel and incur transportation costs to access services. The health care facilities in the camps were still operational; as one person living

with HIV put it, “Some traveled back to the clinics in the camp or just stayed there [in the IDP camps] because there was nothing at home.” Loss to follow-up was difficult to assess during this period, but HIV program managers interviewed believed that it was extremely high (Makumbi 2010).

As mentioned previously, minimal support services existed for HIV-positive individuals in the IDP camps. Psychosocial support became even more limited as people dispersed. Health care providers who treated patients at outlying clinics described mental health services as a need second only to HIV treatment for HIV-positive IDPs. In addition, the lack of basic services, food shortages, risk of malnutrition, and lack of clean water in the home villages may have had a greater impact on those living with HIV.

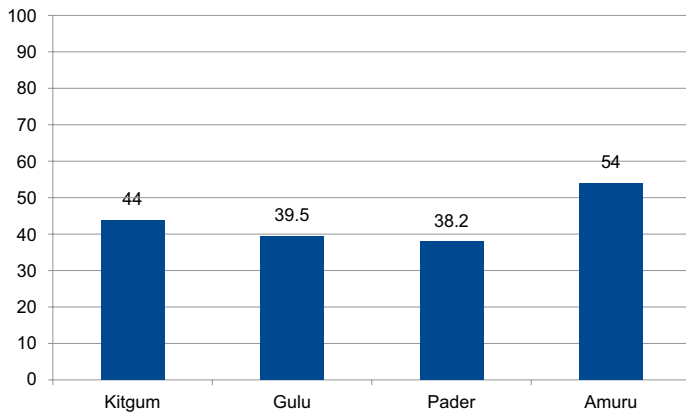
Though many were ostracized in the camps, there was some semblance of community among those who were HIV-positive: “Camp life was a culture for us and probably for others too. But for us we knew the pain of stigma together. It was difficult to exist and cope outside of the camps,” said Oloya.

Human Resource Challenges

During the period of conflict, many health care workers fled to towns or larger cities in southern Uganda; few were left to staff the health care facilities in the home villages. Though peace had been restored and no LRA activity was reported after 2006, many did not want to return to northern Uganda. The police force has not been fully restored. Housing, if available, is still suboptimal, and general amenities are lacking. According to a study of human resources for health in northern Uganda, most districts are facing a critical shortage of staff (see Figure 2).

Lack of training in HIV care and treatment is an ongoing issue. Programs such as the successful

Figure 2. Percent of Positions Filled at Health Centers in Four Districts in Northern Uganda in 2008 (Kyobutungi 2008)



Northern Uganda Malaria, AIDS & Tuberculosis Programme (NUMAT; see following Programmatic Interventions section) are funded by the U.S. President's Emergency Plan for AIDS Relief, through the U.S. Agency for International Development, in part to recruit health care workers and expand training for nurses, clinical officers, and doctors in the region. However, in Uganda, health care workers are often transferred from one location to another. Too often, patients at sites where trained staff have been transferred do not reap the benefits of new HIV treatment knowledge (Makumbi 2010).

Post-Emergency Resource Decline

Recovery and resettlement needs for all northern Ugandans are significant. The transition from an emergency lasting greater than 20 years to redevelopment is inherently complex. A large influx of funding and international support is necessary to support development and rehabilitation in the north. Unfortunately, resources previously provided by international agencies have decreased by more than 50 percent since the conflict began (IDMC 2010). Various bilateral and multinational organizations, including the United Nations, the World Bank, and the

African Development Bank, have committed support. However, it is uniformly agreed that the Government of Uganda must take the lead in these efforts.

In regards to HIV program scale-up in northern Uganda, program managers commented that funding for HIV services has been severely limited. Globally, funding levels have not risen enough to adequately meet the need. This has led to decreased treatment initiation at the site level (Makumbi 2010). In the north, resource limitation has been more difficult to manage because the needs are greater. In some areas, health care infrastructure needs to be completely rebuilt.

Policy and HIV in Northern Uganda

Several policy initiatives have been created in Uganda to provide guidance during conflict and post-conflict periods. Uganda is one of the few African nations to establish a policy framework to address internal displacement. Ratified in 2004, the policy framework provides protection to IDPs and outlines a human rights approach to internal displacement and resettlement. Although health care is discussed in this document, there is no mention of access to HIV services.

An IDP Resettlement Plan was developed in 2005. This plan sets forth a step-by-step approach to preparing IDPs for return to their villages and rebuilding infrastructure, including police

When there is war, the health system breaks down and people who have diseases like HIV really suffer. When war ends and there is nothing left, our trials are just beginning.

***—Jimmy Oloya,
living with HIV in northern Uganda***

departments, prisons, schools, and health care facilities. But it is unclear whether any aspect of that plan has been implemented.

The Peace, Recovery and Development Plan (PRDP) for northern Uganda was developed in 2007, but formal implementation was delayed for two years due to funding deficits. Its primary goal is to reduce disparities in development between the north and the south. International aid agencies have donated U.S.\$600 million to this effort. As is the case with the IDP policy and the IDP Resettlement Plan, HIV is largely overlooked in the PRDP.

Successful Programmatic Interventions

A number of program interventions have been successful at increasing access to care during the conflict and post-conflict periods in northern Uganda.

Northern Uganda Malaria, AIDS & Tuberculosis Programme: Funded by PEPFAR, NUMAT has provided comprehensive HIV services in the region since 2006. NUMAT's primary goals are to increase access to and uptake of high-quality HIV, tuberculosis, and malaria treatment services. A focal point of the program during IDP resettlement was assisting with re-establishment of health care infrastructure in home communities. Since its inception, NUMAT has been dedicated to training health care workers in HIV care and treatment, providing site mentorship, recruiting health care workers, improving laboratory services, and decreasing stockouts of key commodities. There are currently more than 7,100 adults and children accessing NUMAT-supported treatment, the majority of whom are former IDPs.

A critical component of NUMAT's access strategy is the involvement of PLHIV. In 2006, NUMAT

collaborated with the International HIV/AIDS Alliance to train more than 100 HIV-positive volunteers as Network Support Agents (NSAs). Using a mobile approach, NSAs help link PLHIV with facility-based care and treatment services, work to improve health literacy, advocate for stigma reduction, promote adherence to both care and treatment, and lead support groups throughout their assigned communities. Their efforts have led to over 35,000 referrals to a variety of HIV services, including, as of 2008, HIV treatment.

The AIDS Support Organization (TASO):

TASO began working in northern Uganda in 2005. Its initial mission was to provide HIV counseling and peer-led social support to IDP camp residents in Gulu. It also worked to reduce stigma against PLHIV, a challenging task in camp settings. Once resettlement began in 2006, TASO shifted its focus to helping PLHIV access care in their home communities and tracing patients who left the camps to link them to treatment in their home communities. TASO now also provides home-based HIV testing and counseling as well as treatment adherence counseling.

Recommendations

Based on findings from this case study and suggestions from key informants, the following recommendations support continuous access to HIV care and treatment during both the conflict period (IDP camp) and the post-conflict period (resettlement).

During the conflict:

- **Create a referral plan for PLHIV to nearby treatment facilities:** Patients should be provided with a copy of their records, which should include their current ART regimen and any recent laboratory results. A list of nearby clinics offering

ART should also be provided in case patients need to urgently flee from their home village and cannot make it to a camp where ART is provided.

- *Provide patients with an extra supply of ART:* Patients should be given an additional one-month supply of ART in case they cannot get to referral sites or if travel to IDP camps is extended.
- *Provide ongoing access to HIV services within the camp:* HIV services, including ART, should be available to all in the camp who need them. Patients should not be required to travel outside of the camp and risk danger to access necessary health care. Trained health care staff must be present in camp facilities, and buffer stock of ART should be available in case of disrupted drug supply.
- *Establish support groups for PLHIV:* Few support mechanisms were available in northern Ugandan IDP camps. Formal support group structures through organizations such as TASO or groups such as NSAs help decrease stigma and address psychosocial issues.
- *Introduce campaigns to decrease stigma and discrimination:* Sensitization campaigns using media and increasing widespread HIV education should be initiated in the camps in situations of long-term displacement.
- *Prioritize the needs of PLHIV:* IDP policies should ensure that the needs of PLHIV receive priority, particularly in high-prevalence settings.
- *Institute a patient referral and follow-up plan:* Patients should be referred to specific clinics in their home villages. Instituting a tracking system with unique identification numbers would be helpful to determine loss to follow-up during resettlement.
- *Educate and prepare patients for treatment interruptions and new clinics:* Provide additional drug supplies to cover the period during which the patient will be traveling home or trying to re-establish care. As noted previously, patients should be provided with a personal copy of their clinical records that details their regimen and any recent laboratory results so that transition to new treatment sites can be easily facilitated.
- *Make buffer stocks of antiretrovirals and treatment for OIs available:* Having buffer stock available is important during both the conflict and post-conflict period because the transport of drugs may be limited by violence and/or destruction of roadways.
- *Provide incentives to health care workers to work in less desirable areas:* Incentives may increase their willingness to return to staff health facilities.
- *Provide mental health services training:* All patients will benefit if health care workers stationed in conflict and post-conflict settings can offer mental health services.
- *Include HIV care and treatment in resettlement plans:* Plans must include budgets and funding so that contingency initiatives can actually be implemented.

During the post-conflict period:

- *Prioritize building HIV care and treatment capacity at health facilities in the home villages:* This ensures that HIV care and treatment are available before resettlement begins.

Planning for Future Conflicts

The 20-year-long armed conflict in northern Uganda was a tragedy. Although peace has finally arrived, much remains to be done to restore basic

services, particularly health care infrastructure. For PLHIV, these basic services include continuous access to ART, which is critical both to the health of the individual and to the community at large. Contingency planning must include strategies to ensure ongoing access to treatment during the acute phase of the emergency and throughout the post-emergency resettlement period until access to care and treatment are newly established or restored. These plans must be well funded to avoid implementation delays.

Emergencies of this kind are inevitable. In the case of Uganda, it is quite possible that the events similar to those leading to the war will recur. Though the LRA was driven out of Uganda, LRA activities have continued in neighboring Sudan, the Democratic Republic of Congo, and the Central African Republic. For Ugandans, particularly those living in the north, planning ahead and allocating resources to emergency preparedness in the case of recurrence is prudent. For those living with HIV, it is imperative. ■

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