RETENTION OF HIV POSITIVE PERSONS AT ANTIRETROVIRAL THERAPY CLINICS IN POST-CONFLICT NORTHERN UGANDA

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RETENTION OF HIV POSITIVE PERSONS AT ANTIRETROVIRAL THERAPY CLINICS IN POST-CONFLICT NORTHERN UGANDA

By

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DECLARATION

I declare that the mini-dissertation hereby submitted to the University of Limpopo, for the degree of Masters of Public Health has not previously been submitted by me for a degree at this or any other university; that it is my work in design and in execution, and that all material contained herein has been duly acknowledged.

A. Alyao Ocero (Dr) 15th May 2009

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Signature:

DEDICATION

I dedicate this work to people living with HIV in Northern Uganda and to that health worker that has persevered all manner of peril to remain tending to those in need.

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ABSTRACT

Retention of HIV Positive Persons at Antiretroviral Therapy Clinics in Post-Conflict Northern Uganda

- **Introduction**

Northern Uganda is experiencing a lull in a 20 year civil war that had led to the massive displacement of people from their homes. Majority of people living in internally displaced people's camps are now returning to their homes. The HIV scourge in the region has been fanned by the war, exposing the population to a higher prevalence of 8.4 % as compared to the HIV country average of 6.2%. Government in collaboration with other stakeholders is scaling up antiretroviral therapy in this resource limited, post-conflict setting through the decentralized health care delivery system. Factors that could influence long-term retention in such a setting are as yet poorly understood.

Methodology

This was a methodological retrospective review of 402 patient clinic cards, ART register and pharmacy records at regional referral hospital, district hospital and health centre IV. A quantitative approach was used to determine the retention rates for clients initiated on antiretroviral therapy at the three levels of care after 3, 6, 12, and 24 months. Predictors for loss to follow-up were derived from demographic and clinical characteristics captured in the clinic records.

- **Data management**

Data was summarized using frequency tables and bar graphs. Analysis was done using EPI-INFO and SPSS computer packages. Bivariate analysis was carried out to evaluate the association between the variables and loss to follow-up.

- **Results**

Overall 43.5% of patients were lost to follow-up from the ART programs. The district hospital retained most patients (73.1%), the regional referral hospital (53.7%) and health centre IV retained least (36.6%). Majority of patients were lost to follow-up after 3 completed months and least after 24 completed months. Patients accessing ART at the district hospital were five times more likely to remain in care (OR 0.21 95% CI 0.08, 0.50) and those at the regional hospital 2 times more likely (OR 0.48 95% CI 0.22, 1.07) as compared to those at the health centre. Loss to follow-up was 16 times more likely to occur in the bedridden functional status (OR16.3 95% CI2.0, 132.2) and three times more likely in the ambulant patient compared to those able to work. In this study age, sex, occupation, weight, WHO clinical stage and CD4 lymphocyte count were not predictive of retention on the ART program.

- **Conclusion**

Providing an accessible high quality ART service is feasible in the post-conflict region, as illustrated by the level of retention of patients at Kitgum District Hospital, through task shifting, training, and mentoring of lower cadre health workers. The collaboration of community based organizations to enhance the continuum of care at community level significantly improves retention of patient in the programme. There is need to relax the eligibility criteria and adopt strategies that will promote earlier access to VCT services so that appropriate care is initiated to patients before they are too weak.

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LIST OF ABBREVIATIONS AND ACRONYMS

AHC – Awach Health Centre IV

AIDS- Acquired Immunodeficiency Syndrome

ART – Antiretroviral therapy (The term is used interchangeably with HAART)

ARV's – Anti retrovirals

CBO – Community Based Organisation

CSO – Civil service organization

HAART - Highly Active Antiretroviral therapy (See ART above)

HIV- Human Immunodeficiency Virus

HMIS – Health Management Information System

ICAP – International Center for AIDS Care and Treatment

IDP – Internally Displaced People's camp

KDH – Kitgum District Hospital

LRA – Lord's Resistance Army

LRRH – Lira Regional Referral Hospital

MOH – Ministry of Health

NGO- Non-Governmental Organization

NUMAT- Northern Uganda Malaria AIDS Tuberculosis program

NNRTI – Non Nucleoside Reverse Transcriptase Inhibitor

NRTI – Nucleoside reverse transcriptase inhibitor

PEPFAR – Presidential Emergency Plan For AIDS Relief

UNAIDS – United Nations Joint Program on HIV/AIDS

WHO- World Health Organization

OPERATIONAL DEFINITIONS

Retention: refers to patients known to be alive and receiving antiretroviral therapy at a particular ART programme. In this study, retention was determined by a patient attending the last scheduled follow-up appointment.

Loss to follow-up: refers to a patient falling out of an ART programme for unknown reasons. In this study, loss to follow-up was determined if a patient failed to turn up for at least three consecutive months from his last scheduled appointment, and could not be traced.

Attrition: Refers to patients discontinuing attendance of an ART programme due to any reason, known or unknown.

CHAPTER I

BACKGROUND

Introduction

While health indicators in Uganda are steadily improving – the country is ranked 145 out of 177 on the United Nations Development Programme Human Development Index (WHO 2007). The humanitarian situation remains critical in Northern Uganda, a region that has been the arena of a 20-year old civil war that led to the death of thousands of people and the displacement of hundred of thousands more into Internally Displaced Peoples (IDP) camps (WHO, 2007,Ward, 2001). By 2005, the people displaced constituted eight percent of the total Ugandan population and 90% of the population of Northern Uganda. Over three quarters of the displaced families had no access to land for farming. For a population that mainly depended on subsistence farming, this meant dependency on handouts and donations to meet their basic needs (Rupesinghe, 1989).

The commencement of peace efforts in 2006 brokered by the Government of South Sudan brought a lull to the war allowing up to 2 million internally displaced people to leave the camps and return to their homes. However, the dissolution of the camps was likely to disrupt health care services that were developed around the camps by humanitarian agencies through the decades. This exposed the vulnerable population to renewed risks for disease and death (Becker, 2008). A recent United Nations assessment highlighted the need to rehabilitate, equip and re-construct health care and educational facilities in the returnee's villages. By the end of 2007, an estimated 900,000 people remained internally displaced because they recognized that they

would be faced with limited food supplies, health care services, water and sanitation at their places of origin (WHO, 2007). Those that opted to return home encountered a dilapidated "peace time" model of health care service delivery. The provision of medicines and supplies was erratic due to interruptions in transport and communication, and there were no health workers willing to take on jobs in these areas. Less than 30% of the returnee population lived within 5 km of a functional health facility. According to the district health officer for Gulu, one of the nine districts in the region, only half of the lower level health centres and none of the higher centres met the Ugandan ministry of health (MOH) staffing norms (WHO, 2007). This translated to over 70% vacant positions in the health units by 2006. This state of affairs is considered contributory to the unchecked spread of Human Immunodefiency Virus (HIV) in Northern Uganda. According to the national sero-prevalence and behavioral survey of 2005, the HIV prevalence rate of 8.2% was far above the Ugandan national average of 6.4 % (MOH, 2005).

In countries with limited resources like Uganda, the expanded availability of ART through funding from the President's Emergency Plan for AIDS Relief (PEPFAR), the Global Fund and other initiatives has made it possible to extend health care benefits to citizens living with HIV in Northern Uganda. Treatment access necessary to achieve the Emergency Plan goal of providing ART to two million individuals in 15 focus countries by 2008 has been made possible. But strategies that promote adherence on prescribed antiretroviral therapy for life have not been adequately addressed. It is known that adherence to ART is critical for optimal viral suppression and for a favourable clinical outcome. This, in other words, implies reduced morbidity and mortality and a lower the risk of ARV drug resistance (Weidle, 2006). The degree

of retention of patients on ART programs is a determinant of adherence. Patients must be actively attending and participating in an ART program if they are to receive their medication and have their clinical indicators monitored (Harrigan, 2005). However, in Uganda just like elsewhere, while the predictors and biological consequences of adherence to ART are well documented, information on patient retention on ART programs is still limited.

1.1 The Health Service Delivery System in Uganda

The Ugandan health service delivery system evolved into its present structure after elaborate changes that commenced in 1986, when power was decentralized from Central government to the regional, district governments and "grass root" administrative councils called Resistance Councils. The reform was promoted by government policy that was fronting for effective service delivery as enshrined in the new Ugandan Constitution of 1995. A Local Government Act which put into effect the provisions of that Constitution was passed in 1997, substantially devolving powers previously exercised by the central government to district local authorities. As a result Uganda has developed a health care delivery system where local authorities administer district hospitals, health centres II, III and IV and village health teams. The latter, as a grass root structure, is a functional equivalent of a health centre I. The system recognizes the Ministry of Health as an organ of Central Government that should provide mentoring and advisory services as opposed to direct implementation of health care services. Through this arrangement, only national referral, regional referral and teaching hospitals are directly administered by the health ministry since they provide critical specialist services, research, and training for health workers. The health ministry also plays a regulatory role providing guidance and technical support.

MOH provides certification for health care services so that the quality of care provided by both public and private health care institutions is standardized and maintained at an acceptable level.

In the decentralized health care system, the regional hospital supports about 2 million people in its service area. All the 5 regional referral hospitals are based in major towns of Uganda and employ a number of specialist doctors, nurses and clinical officers. District hospitals support about 100,000 people in the service area. The district hospital, often located within the vicinity of the district administration headquarters, is managed by the district local government that oversees all the administrative activities of the hospital ranging from human resource to financial management. The district hospital is run by general medical officers who provide both inpatient and ambulatory care for uncomplicated medical and surgical conditions. The health centre IV is based at the health sub district that covers a population of about 100,000. In Northern Uganda, this health facility is usually administered by a clinical officer who also manages common medical ailments and a few simple surgical emergencies. The health centre III is at parish level providing ambulatory care for a population of about 20,000. The health centre II supports a population of 10,000 while the village health team about 1,000 people within a village setting.

The ‘3 by 5’ campaign championed by the Joint United Nations Programme on HIV and AIDS (UNAIDS) motivated the scale up of antiretroviral therapy from ART clinics, only existent at Uganda’s national referral hospitals and at standalone HIV research centers, to the regional hospitals and to district hospitals a year later. By adoption of task shifting strategies the roll out of ART clinics to health centre IV was

also made possible. At this level, ART teams were often headed and managed by health care workers of lower cadre trained in HIV treatment, care and support.

Up to 200,000 people in Uganda have accessed antiretroviral drugs through these efforts. However, Northern Uganda is lagging behind the rest of the country, providing antiretroviral treatment to only 15% of all eligible persons, initiated onto treatment. This is mainly the result of conflict interfering with health care delivery. However, over the last two years since the lull in rebel activity a lot has been done to address this gap. With support from the donor community, the Ugandan government has accredited a number of new ART clinics, trained health care workers, refurbished and equipped a number of laboratories in the region. Improvement of HIV service utilization and the retention of patients in programme is a critical area that requires urgent focus if one is prolong antiretroviral drug efficacy and reduce on resource wastage. Strategies to address this include, improving the quality of care at the clinic and initiating activities that enhance patient follow-up and the continuum of care at community level.

1.2 Statement of the Problem

Northern Uganda has suffered the brunt of a 20 year-old insurgency pitching the rebel Lord's Resistance army (LRA) against the government of Uganda. During this conflict, there has been a breakdown in social services and infrastructure. The region has an HIV prevalence of 8.2%, far above the national average of 6.4% (MOH, 2005). Amongst the various forms of treatment, care and support provided to the HIV patient, antiretroviral therapy comes with a lot of responsibilities for the patient, care provider and the community as a whole to ensure that once the patient is initiated on antiretroviral drugs they are swallowed religiously for life. Long term adherence to

antiretroviral therapy and retention in an ART program is a prerequisite if the treatment is to work well, minimizing the possibilities of drug resistance. In this setting like else where efforts have concentrated mainly on facility based adherence monitoring while retention of patients in treatment programs, though recognized as a prerequisite for achieving any level of adherence, has received far less attention. Most large scale treatment providers have limited resources to track missing patients and therefore treat patient retention and loss to follow-up as a side issue focusing mainly on supporting adherence in patients that are retained (Rosen, 2007). The post-conflict setting of Northern Uganda has numerous peculiar challenges related to the patient and to the care provider that could influence retention of patients in ART programs. Patients who have no assurance of a daily meal, have to walk long distances to seek care, or are faced with stigmatization are unlikely to return for follow-up. Health providers that are overworked, poorly remunerated and motivated are likely to provide a less than satisfactory quality of service. Another key challenge in Northern Uganda that has influenced patient retention is the uneven distribution of HIV care services for the population. Donor agencies like USAID, Catholic Relief Agencies, European Community, Italian Relief Services and UNICEF amongst others have inadvertently supported selected health care establishments in the region probably motivated by political, security, logistical and historical considerations. Most of these health facilities are located in the more urbanized districts of Northern Uganda or where the missionaries set their foundations tens of years ago and are often inaccessible to majority of the sick due to stringent criteria used. As a consequence, while the supported health facilities provide relatively good care for selected populations, majority in the region make do with an inferior quality of care provided

by the government health care facilities. The government health facilities are well dispersed though out Northern Uganda but are plagued with an erratic supply of antiretroviral and opportunistic infection drugs, high health worker attrition, poor laboratory monitoring and an absence of community based follow-up. Loss to follow-up in these circumstances is contributed to by the uneven distribution of HIV services that leads patients to transfer out as they "shop" for better opportunities. As a consequence, patients that drop out of ART programs are sicker, expensive and difficult to manage. There is a risk of developing resistance to the relatively cheaper and conveniently used first-line regimens. Drug resistant HIV strains may quickly then spread to the general population.

High losses to follow-up from treatment programs therefore pose a challenge to program implementers and constitute an inefficient use of valuable and scarce resources. The issue of retention of patients in ART programs is of public health importance.

1.3 Justification for the Study

There are very few published studies about retention in ART programs in Uganda. On the hand, several studies have looked at how well patients stick to their day-to-day medication schedules. Adherence studies tend to address issues around those patients that have been retained in an ART programme. How long patients stay in treatment programs, and what they must do to prevent illness and death from AIDS, has received little attention. This review of medical records in health facilities at three levels of care will be the first of its kind in a post-conflict setting and in Northern Uganda in particular. The study will provide insight into the magnitude of patient retention in ART programmes, and help policy makers, donor agencies and program

implementers to identify challenges as well as windows of opportunity for improvement in the quality of care at the different levels of health care given the inherent limitations of each. Information generated will guide stakeholders in health care on how to strengthen the logistical systems and the continuum of care at the different levels of health care. The findings will also motivate development of care and treatment models that could improve HIV care retention rates in post-conflict situations.

With the coming of peace, people are going back to their homes, often remotely located. Most HIV patients will access ART at lower level government health care facilities that have been plagued with numerous constraints. USAID and the Government of Uganda are rolling out a project to provide technical and material support to these health facilities. In this regard, a preliminary assessment of the current state of ART programs at these health facilities using patient retention on ART as one measure of quality of care is justified. Scientific evidence already suggests that the site of ART delivery has a strong influence on treatment outcome as determined by virological response (Fielding, 2008).

1.4 Study Aim and Objectives

1.4.1 Aim

To assess the status of retention of patients initiated on antiretroviral therapy in post-conflict Northern Uganda and determine predictors for retention and loss to follow-up.

1.4.2 Objectives

The objectives of this study are:

a) To determine the two-year retention rate for clients started on antiretroviral therapy at HIV clinics at a regional referral hospital, district hospital and health centre IV in post-conflict Northern Uganda.

b) To determine the retention rates at 3, 6, 12, and 24 months following recruitment at the three levels of health care.

c) To identify, from the patient's demographic and clinical characteristics, predictors for retention and loss to follow-up from antiretroviral therapy in post-conflict Northern Uganda.

CHAPTER II

LITERATURE REVIEW

Introduction

Patients with the human immunodeficiency virus (HIV) infection require lifelong medical treatment, but many people do not remain in care. Poor retention in care predicts poor survival and puts a country's ART program at risk as resistance to antiretroviral regimens rapidly develops. In the developing world where there are limited options of antiretroviral regimens the emergence of resistance is a prelude to a reversal of gains of the recent years that has resulted in reduced mortality and morbidity due to HIV. Alongside adherence the retention of patients in ART programmes is gaining attention. However the criteria and time scales used for

establishing and describing retention in HIV programmes by various researchers are not yet standardized. There is now a call for consistency of this measure across the globe so that information sharing, planning and implementation of best practices become more applicable (Rosen 2007).

2.1 Retention, attrition and Loss to Follow-up

While "retention" refers to the degree to which one remains in an ART program, "attrition" is a catch-all term that Rosen (2007) used to define all patients that did not turn up for their follow-up appointments. Attrition includes those have actually died as well as those that are alive but transferred to other centers or have interrupted antiretroviral medication due to a variety of reasons. Loss to follow-up then defines patients that have dropped out of an ART program and can not be traced. Patients lost to follow-up may be alive and have left or transferred out of a program, or may have died. However all these possible events remain unconfirmed for this group of patients. In Uganda, the AIDS Control Programme (ACP) defines three consecutive months of missed scheduled appointments as loss to follow-up. In this setting, attrition *almost* equates to "loss to follow-up" because mechanisms to establish death, transfer or interruption amongst the patients are non functional. This holds true especially in ART programs that lack capacity to trace and monitor patients outside the bounds of the clinic. Attempts at establishing actual causes of loss to follow-up by South African and Malawian investigators reported that a significant proportion of patients such were actually dead (Maskew 2007; Dalal, 2008; and Yu, 2007).

2.2 The Relationship between Retention and Adherence to ART

Since the first large-scale antiretroviral treatment (ART) programs for HIV/AIDS were launched in sub-Saharan Africa, much attention focused on patients' day-to-day

adherence to antiretroviral medications (Mills, 2006). Long-term retention of patients in treatment programs, a prerequisite for achieving any adherence at all, has received far less attention. Most large scale ART treatment providers in the third world have inadequate resources to track patients that stop returning for follow-up. As a consequence, patient retention and loss to follow-up become secondary as health care providers focus mainly on managing the quality of adherence in patients that actually return to the clinic (Rosen, 2007).

It was suggested by Oyugi (2007) that financial and logistical barriers affecting drug access lead to treatment interruption by preventing patients' return to the clinic for follow-up. These barriers in essence affect retention as much as they affect adherence because, while the latter defines the degree to which a patient takes his antiretroviral doses, retention addresses the processes that may interrupt access to the drugs. Indeed in many studies adherence and retention appear to share the same factors and predictors.

2.3 Retention Rates across sub-Saharan Africa

Studies across sub-Saharan Africa on retention in ART programs have come up with widely varying results on retention rates. As quoted earlier from a report by Rosen (2007), this may be a consequence of the criteria used. As an example, variations in the magnitude of loss to follow-up may result from variable capacities for patient tracing across different programmes. Additionally, variations in the quality of care offered at health facility level, as well as other health provider, client and socio-economical factors may have an impact on the retention rates. In a 3-year prospective study conducted in a community based ART program in South Africa the 12-month retention rate was 90.3% with a low mortality rate of 6.8%. This was an example of

an ART program with good retention and good treatment response. In this cohort, patients in an ART program were routinely traced once they missed an appointment by community-based counselors and linked to appropriate care (Bekker, 2006). The other extreme was a 2-year retention rate of 46% in a Ugandan ART program that offered HIV treatment at a fee. Patient follow-up was limited to the clinic since health workers lacked the capacity to trace and support patients back in the communities (Kabugo, 2005). A systemic review of sub-Saharan studies carried out between 2000 and 2007 reported retention and loss to follow-up rates as low as 60% after two years of treatment (Rosen 2007). As mentioned previously, many of these retention rates were derived using different criteria and time scales making comparison difficult.

2.4 Reasons for Attrition and Loss to Follow-up

Published studies elaborating on reasons leading to loss to follow-up are uncommon. However, in line with Oyugi's (2007) arguments, a number of barriers to good adherence are also the same factors that interrupt access to treatment at the ART programs. For instance, patient related factors like poor health, hunger or lack of disclosure to partner may lead a patient to miss scheduled doses but may also deter another from keeping a scheduled clinic appointment, eventually dropping out of care altogether. Smart (2007) in the *NAM HIV and AIDS treatment* bulletin quotes presenters at the 2007 HIV/AIDS implementers meeting in Kigali who stated that patients were dropping out of ART programs due to high travel costs, time spent traveling to the ART sites, lack of finances for travel and relocation and "patient choice". Researchers from South Africa attending the same conference, attributed loss to follow-up to non-disclosure and alcohol consumption, while another team from the

International Centre for AIDS Care and Treatment (ICAP), suggested that patient retention was also affected by myths about ART, competition with traditional medicine, lack of disclosure, lack of home-based support, and fears of loosing one's social standing.

However, death of a patient attending an ART programme is known to be the most consistent cause of attrition in Africa. According to the South African and Malawian studies quoted earlier, death was a major factor leading to poor retention in patients attending ART programme (Maskew, 2007; Dalal , 2008;Yu, 2007). In the systemic review of patient retention in sub-Saharan ART programmes between 2000 and 2007, (Rosen 2007) overall death in all the programmes was as high as 40% by the second year. Deliberations at the 2007 HIV Implementers meeting in Kigali (Smart 2007) also highlighted death as a major cause of loss to follow-up (42%). Death occurring in the earlier phases of antiretrovirals treatment probably results from opportunistic infections taking hold before the immune system has recovered, or conversely, as result of the immune reconstitution inflammatory syndrome.

In majority (58%) of defaulters however, the cause for attrition and therefore loss to follow-up is often undetermined because patients are not easily traced. Again the Kigali conference proceedings (Smart, 2007) describe 31 patients who had achieved undetectable viral loads and were subsequently lost to follow-up. This particular group of patients were probably alive and had transferred out to other clinics due to transport costs, or alternatively in search of better services. Yu et al (2007) described similar findings in a study tracing lost-to-follow-up patients in Malawi. It was determined other than the 50% of patients that had died, another 33% had transferred out to other units, and the rest had simply stopped ART.

2.5 Predictors of poor retention on ART programs

Like earlier mentioned, studies determining factors and predictors for poor retention are uncommon compared to those determining adherence. However, as more people stay longer on ART and more health facilities are accredited to provide ART, retention will become of greater importance. It is recognized that predictors for poor adherence are correlates of predictors for loss to follow-up. Predictors of poor retention can therefore be inferred from predictors of poor adherence in many of the studies carried out. A qualitative study carried out by Nam (2008) found that at community level, unresolved depression in a patient, substance abuse, lack of disclosure, inadequate support from social networks, and lack of a stable income were likely to be lead to poor adherence. Factors related to the health facility were also sited by Wolfe et al, (2006) namely distance and accessibility of the clinic, side effects of ART drug regimens and lack of empathy among the health care professionals.

A review article in The *Lancet*, noted that the health care level and the availability of other chronic medications for palliative care were critical determinants for adherence and retention in the ART program (Wakabi, 2008). Patients that were not provided Cotrimoxazole for prophylaxis alongside the ARV drugs, for example, were likely to transfer out. Other predictors of loss to follow-up and adherence include low pretreatment CD4 counts and a low baseline viral load of less than one log at 6 weeks (Fielding, 2008). Another investigator (Orrell, 2003) also established that amongst a group of indigent HIV infected Africans a younger age at initiation, and a lower mean CD4, were significantly associated with withdrawal from therapy within 48 weeks.

2.6 Retention in a post-conflict setting

The paradox of health of a population deteriorating after the end of conflict has been variously described. Reports from conflict zones in sub-Saharan Africa suggest that the post-conflict phase is characterized by a potentially disastrous confluence of factors including demobilization of combatants, the presence of peacekeeping forces, the return of potentially infected soldiers and refugees, high-risk behaviours and persistent economic and social debilitation. These factors, along with the concentration of populations into cities and urban areas, may further increase the risk to these populations of HIV infection (Becker, 2008). By 2005, health management information system (HMIS) data from Gulu District situated within the conflict stricken north of Uganda showed extremely high performance indicators in areas of infant immunization and management of childhood diseases because community mobilization, prevention and curative care was more easily addressed for populations living within the camps. According to Ellman (2003), "Health services in the settings of conflict are often concentrated around the camps and work well until the post-conflict period opens up the populations to great risk due to cross migration."

After conflict, the movement of people back to their homes disrupts the camp based health service delivery. With the return of relative peace to Northern Uganda the camps are closing down. Access to services on relocation back to their homes will be a challenge because of broken down infrastructure including health facilities, roads and bridges (Whyte, 2007). The lack of transport to health units and limited human resource and erratic supply of drugs to the health facilities people predisposes returnees that are on chronic HIV medication to therapeutic failure, opportunistic infections and death.

2.7 Retention in the Context of Decentralization

Wakabi (2008) states in a review article in *The Lancet* that, "In the decentralized system of health care, the level of care handling an ART programmes is a critical determinant of retention." This is corroborated by physicians from the international organization MSF working in Northern Uganda. In a recent edition of their newsletter (MSF, 2008) they decried the limitations of the decentralization process that is well underway in Uganda. Despite injection of donor funds to develop capacity of lower level health facilities to handle HIV care and management many patients still lacked access to appropriate services. There is inequity in care as the quality of HIV management varies greatly from one center to another. In poorly-functioning ART clinics, patients run the risk of receiving incomplete or interrupted treatment and are at a risk of developing drug resistance.

In Northern Uganda, government run health facilities that remained functional during the years of conflict were those situated in the towns where they were protected by the army. Lower health care units mainly situated in the more remote areas were in most cases abandoned and eventually looted and vandalized. Health workers were unwilling to work in such insecure environments. Those who ventured, often stayed for a short while before seeking employment else where. But yet on the other hand, health centres are better placed to improve access of care for rural communities that can not travel to the larger centers. These lower health units are better placed to adopt and implement primary health care strategies unlike the larger hospitals that provide more specialized clinical services. Government and civil service organizations can more easily support these lower health units with follow-up strategies to improve the

HIV services they provide. The disadvantage that these units run is the lack of professional expertise, laboratory monitoring, drugs and supplies to address complicated opportunistic conditions. In the Ugandan setting CD4 and viral load testing has been more accessible for patients visiting the regional hospital.

Indeed, successes in decentralized HIV care and treatment services have been recognized. A report by Bedelu et al (2007) describe successes by Medicins Sans Frontieres in implementing a decentralized HIV care model for a poor community with a high HIV prevalence (31%) at Lusikisiki sub-district, Eastern Cape, South Africa. These led to faster enrollment of patients into HIV treatment and better retention of the patients. This was made possible by providing integrated HIV care and treatment through decentralization to primary health care clinics, task shifting within the service, training and mentoring staff and creating a strong community linkage and support. A monthly newsletter by the International Centre for AIDS Care and Treatment Programmes (ICAP 2007) highlighted how the roll out of HIV care services through the decentralized health care system in Mozambique, South Africa and Tanzania improved the quality of care for the rural poor as they accessed antiretroviral therapy and other forms of support through the lower level units. Fundamental to the successes recognized was the patient's ability to adhere to treatment and remain in the programme.

2.8 Interventions that could improve Retention

Data analyzed from PEPFAR-supported programmes operating in eight countries (Smart 2007) showed that loss to follow-up in ART programmes supporting home-based care for their patients had significantly lower loss to follow up compared to ART programs that primarily offered facility-based adherence support. The

deductions were that ART programs were more effective if they supported people on ART as close as possible to their dwelling places (Smart, 2007). Despite the shortcomings, another worthwhile intervention is decentralization of HIV services to peripheral levels of health care with a greater reliance on nurses, and community health care workers through task shifting. Thirdly, people living with HIV/AIDS can be empowered and employed to work as members of a clinical care team. Fourth, formal partnerships with non-governmental organizations (NGOs), faith-based organizations (FBO's) and community-based organizations (CBOs) that are based in the communities that could provide additional support services for the patients is a vital contributor to the success of ART programmes (Weidle, 2006). A number of studies identifying hindrances to good adherence carried out before antiretroviral drugs were distributed free of charge recognized that poor adherence and loss to follow-up were associated with financial constraints in accessing medication. (Mills 2006, Byakiika-Tusiime 2005). In the setting of Northern Uganda these costs accrue from transportation to the clinics, purchase of expensive drugs to treat opportunistic infections and monitoring tests that are unavailable in the health centres, as well as and nutritional supplementation.

The access to antiretroviral drugs for every patient should be made as cheap as possible and free from hidden costs. These costs will certainly be lower if strategies are adopted that ensure better access to an HIV test, a CD4 test and those found eligible initiated earlier on antiretroviral drugs.

CHAPTER III

METHODOLOGY

Introduction

This chapter provides detail on this study's design, setting, sampling procedure and size estimation, selection criteria, data collection and analysis. Ethical considerations are also outlined as well as the timeline and budgets that guided the exercise.

3.1 Study design

The study was an observational retrospective review of health facility medical records through a probability sampling process. Each medical record selected was scrutinized retrospectively for follow-up information covering a period of two years from recruitment to determine retention and loss to follow-up (LTFU). This approach made it possible to determine and summate retention and LTFU for patients recruited at various times through out the ART clinics lifespan. This implied that this study's assumption was that health facility and health provider related factors influencing retention and follow-up at each ART clinic remained more or less unvarying throughout the clinic's existence. The study design also made it possible to analyze retention and loss to follow-up cascaded through 3, 6, 12, and 24 months from time of recruitment for each study patient.

3.2 Study Site:

A few months before this study commenced a collaborative agreement was signed between the Ministry of Health and a USAID funded NGO, Northern Uganda Malaria AIDS Tuberculosis Programme (NUMAT). The agreement stipulated the provision of

technical, material and financial support to HIV, TB and malaria services at 17 government-owned health facilities well dispersed throughout the nine districts of Northern Uganda. The 17 health facilities included one regional referral hospital, three district hospitals and 13 health centre IVs. Northern Uganda has one other government regional referral hospital that would not benefit from this USAID/NUMAT grant because its HIV and ART services were already supported by two other USAID funded agencies, The AIDS Support Organization (TASO) and Joint Clinical Research Council (JCRC). Northern Uganda also has four missionary funded hospitals and one NGO supported stand alone ART clinics. The missionary hospitals and the stand alone clinics have a proven, well documented record of pristine HIV treatment care and support that has been unevenly concentrated in only 3 out of the 9 districts.

The study was conducted at the ART clinics of three health facilities in the region; Lira regional referral hospital (LRRH) and Kitgum district hospital (KDH) and Awach health centre (AHC) IV. These are part of the 17 government owned health facilities dispersed throughout the 9 districts of Northern Uganda that were soon to benefit from the USAID/NUMAT support. Majority of patients accessing all forms of HIV care in the region were served at these 17 units (see section below).

LRRH is a 400 bed health facility situated 200 km *South* of KDH and 158km *South East* of AHC. LRRH is located in a major commercial town serving a semi urban population. Under the decentralized health care system, the regional hospital provides a range of diagnostic and specialist services. Its ART clinic is managed by a team that includes a physician, a pediatrician and a dermatology clinical officer as well as pediatric counselors. Patients here have better access to laboratory monitoring that

included free CD4 testing and viral load testing for a fee. The regional hospital is able to provide more specialized care for HIV opportunistic infections and complications.

On the other hand, KDH is a 200 bed hospital managed by a team of non specialized medical and clinical officers. The in-charge of the ART clinic at Kitgum is a clinical officer trained in HIV management. He heads a team of nurses, counselors and auxiliary staff who participate in tending to the patients. The laboratory only carries out slide tests for malaria, peripheral blood films and check hemoglobin levels. From November 2007 through USAID funded support, CD4 testing was offered free to the patients through a courier service. This involved a team of laboratory personnel visiting the hospital every fortnight, bleeding patients and ferrying samples to a specialized laboratory 100 kilometers away. The HIV patients at Kitgum hospital benefit from home based follow-up provided by a local non-governmental organization called *Meeting Point* located outside the health facility. Once patients are enrolled and provided ART at this health facility, they are referred to Meeting Point to access psychosocial support, nutritional support and other services. The World Food Programme (WFP) also provided cereals, cooking oil, sugar and powder milk to patients accessing care at KDH.

AHC situated in Awach subcounty is a remotely located rural 20 bed unit in Gulu district that till recently was surrounded by a big IDP camp and an army detach nearby. AHC is located 35 kilometres away from the regional town of Gulu that has four large ART clinics supported by various implementing agencies. By the time of the study, the civilian population around AHC was gradually leaving the camp. Up to 60% of the 20,000 original inhabitants of the IDP camps had returned to their homes. The unit is manned by a clinical officer who carries out simple surgical and medical

procedures. The ART team at this clinic is able to carry out referrals, counseling, basic clinical assessments and initiation of patients onto ART.

3.3 Study Population

The nine (9) districts have a total population of 2,900,000 million people with an estimated 250,000 people HIV positive representing an HIV prevalence of 8.2% for the region. The target population of the study was all HIV positive patients ever enrolled into the ART program in Northern Uganda. In this study the population of concern was the cumulative number of people that had ever assessed antiretroviral drugs, including those that had died, transferred out or defaulted treatment. By the time of the study up to 12,750 clients had at one point accessed antiretroviral drugs in Northern Uganda. Antiretroviral drugs were still accessed by 9,500 clients through all the ART clinics in the region while about 7,030 clients (74%) were currently accessing their antiretroviral drugs at the 17 government health facilities considered for this study.

For this study, LRRH was the only referral hospital amongst the 17 health facilities considered. It had a service area population of about 2,000,000 people. This included people from other regions outside the 9 districts of Northern Uganda. LRRH's HIV/ART clinic was opened in 2004 and by the time of study in August 2008 had 8,500 HIV positive people enrolled for chronic care, that is, opportunistic infection treatment, basic care and psychosocial support. At that time 3,858 eligible clients were enrolled onto ART at the unit. KDH with a service area of 500,000 has 3,500 HIV people enrolled for chronic care with 700 on ART. AHC, with a service area population of 100,000 people, was serving 230 people with chronic care and 75 on

ART. The three targeted sites therefore had a total population of 4,283 people (61% of all clients at the 17 sites) accessing ART.

The sampling frame included client records from 2004 at LRRH when its ART program commenced, from 2005 for the KDH and 2006 for AHC. Patients recruited onto the ART programs during the intervening period between 3 months before and prior to the commencement of study were not included. This was done to standardize the definition of "loss to follow-up" for all patients recruited into the study. We used the Ugandan Ministry of Health - World Health Organization adopted definition of loss of follow-up as consecutive missed scheduled appointments for three or more months.

3.4 Selection Criteria

Inclusion Criteria

- Government owned health facilities located in Northern Uganda selected to benefit from the USAID/NUMAT and Uganda Ministry of Health collaborative agreement.
- HIV positive patients registered and enrolled onto ART at least 3 months prior to commencement of the study.

Exclusion Criteria

- Patient clinic registration number selected but found to have incomplete clinic and pharmacy records.

3.5 Sample and Sampling Procedure

The sampling procedure was a two staged process: stratified sampling for selection of regional referral hospital, district hospital and health centre IV followed by Simple random sampling to select the study sample at each health facility.

3.5.1. Selection of facility for study

The 17 health facilities of Northern Uganda were grouped into 3 strata namely, regional referral hospital, district hospital and health centre IV. Due to logistical, financial reasons and time constraints this study selected one unit to represent each stratum. Each health facility selected for study was randomly selected out of each respective sampling frame. LRRH was the only "regional hospital" in its sampling frame and was selected by default. One out of four district hospitals was selected and one out of the 13 health centre IVs was selected by simple random sampling for each respective stratum. This was done by allotting a number to each sampling unit within a strata and randomly selecting out one district hospital and one health center IV.

3.5.2 Selection of the sample for study

Each 'element' for study was randomly selected from a sampling frame specific for each health facility until the required sample size was attained. To create the sampling frame, the researcher allotted a study number to represent each unique patient clinic identification number once arranged in an ascending numerical order. The serialized study numbers were then used to randomly select out the study sample using a computer generated list of sequential integers. Records not meeting the selection criteria were replaced by the next random number until sample size was attained. Slightly different methods had to be employed at each health facility to retrieve the records for the patients making up the sampling frame. As a routine, at the three ART clinics, an HIV patient that reported for chronic care (pre-antiretroviral management) was registered and allotted a unique clinic identification number. However, at KDH the patients initiated on antiretroviral therapy were again issued another ART specific identification number. The patient records for those on antiretroviral drugs were

henceforth filed separately. Patients that were confirmed dead or had transferred out had their files removed from the pool. For this study we collected all the files of those that had been initiated on ART, whether still attending the clinic, dead or lost to follow-up and compiled the patient record identification numbers in ascending order so as to constitute the sampling frame. At LRRH and AHC patients the initial pre-ART (chronic care) identification number was still used when a patient was found eligible and initiated on antiretroviral drugs. At LRRH and AHC, therefore the researcher had to identify and separate the records for patients on antiretroviral therapy from those on chronic care. Identification of these files was made possible by manual inspection of each patient file corroborated by the antiretroviral therapy register. At LRRH this process was made easier by the existence of an excel spread sheet that held record of the identification numbers of patients on antiretroviral drugs as well as patients on chronic care alone. These records then constituted the sampling frame.

3.5.3 Sample Size Estimation

A suitable sample size representing each health facility in the study was determined using the Kish – Leslie formula which considers a finite population as follows: -

$$N = Z^2pq/ d^2$$

Where n is the sample size, Z is the confidence interval, p is the proportion of patients retained in ART programs and q the proportion of patients lost to follow-up and d the margin of error for the 95% confidence interval. Results of a systematic review of sub Saharan Africa retention rates at ART programmes from 2000 to 2005 reported retention on ART of 60% and those lost to follow-up of 40% (Rosen, 2007).

Thus, $N = 1.96^2 \times 0.60 \times 0.40 / 0.05^2$

$$= 368.7936 \approx 400$$

In this study the optimum (disproportionate) allocation method was used so that there was greater representation of the smaller health facilities where the researcher anticipated more erratic, less standardized models of care with record keeping contributing to the variance. This would make it possible for the study to appropriately analyze the strengths and weaknesses across each stratum. Therefore from AHC all the 82 patient files identified were selected for study. At KDH 130 files were randomly selected and studied. At LRRH 190 files were randomly selected through this process. Making up a total sample size of 402 (See Appendix VI).

3.6 Data Collection

Data for this study was collected using a data collection tool (see below) developed by the researcher. It captured information from the HIV Comprehensive Care card (see Appendix III) corroborated with information from the ART register, laboratory and pharmacy records. The data collection tool extracted information that would determine whether a patient was lost to follow-up or still retained in the ART program. The tool would also determine the overall retention rates for each health facility cascaded at 3, 6, 12 and 24 months by establishing how long each patient remained in the programme from date of initiation of ART till attrition. The retention cascade times used allowed comparison of this study with previous ones that considered a similar time frame (Rosen, 2007). Data collection was preceded by a visit to the District health office and to the in charge of the health unit where permission to carry out the study was obtained on explaining the objectives and procedure for investigation. The data was collected by the researcher himself at the ART clinic in the afternoon of each clinic day from the clinic records. Information

extracted from the clinic records included, baseline socio-demographic information, type of ART regimen used, last pharmacy ART refill visit dates, referral and "transfer out" information. At the end of the exercise the data recording tool was checked for completeness and signed off.

3.6.1 The Data Collection Tool

The research instrument for this study is a collection tool derived to collect patient data primarily from the Ministry of Health/WHO HIV Comprehensive Care Card of each patient reviewed (see Appendix III). The information was corroborated with data from the ART Pharmacy Dispensing Log and Laboratory Records. The tool was divided into 6 major parts:

Coding Section A: Socio-Biographical Data

Part 1) Health facility Identification

Part 2) Socio-demographic data: age, sex, occupation, and physical address.

Coding Section B: Clinical Assessment Data

WHO Clinical stage, weight, functional status and opportunistic infections present.

Coding Section C: Laboratory Assessment

Initial CD4 Test, Follow-up CD4 Test,

Coding section D: ART Eligibility and Initiation

Date of first enrolment, date declared eligible, date of transfer, date of last ART refill.

Coding section E: ART Drug History

Record of antiretroviral type dispensed, dosage, refill dates and number of pills received from Month 0 to Month 24.

Coding Section F: Retention Status

3, 6, 12, 24 Months retention and retention status, i.e whether still retained in the program or lost to follow-up.

3.6.3 Instrument Validity

3.6.3.1 Content Validity

To ensure the content validity of the instrument the researcher consulted with the supervisor as well as experts at the Uganda AIDS Control Programme to validate the instrument in terms of relevancy, cover of the objectives and appropriateness of terminology used. The data collection tool was structured, standardized to ensure that the research question was addressed.

3.6.3.2 Internal Validity

The data collecting tool was pre tested at the HIV clinics of two non participating hospitals, Apac Hospital in Apac District and Pope John Paul's Missionary hospital in Oyam district. Both are districts in Northern Uganda. The tool was administered to collect information from 10 patient files at each unit as explained below.

3.6.4 Reliability

The instrument was checked for completeness at the end of data collection and information from the HIV comprehensive card was cross checked with that from the, ART register, Pharmacy Dispensing Log and the Laboratory register.

3.6.5 Bias

Error inherent in the sampling process due to selection bias was addressed by first performing a two-staged sampling process of strata sampling to select the site for

evaluation followed by random sampling to select the study sample from each site ensured that *every* individual at *every* site had a chance of being selected for the study. Second, the random sampling was carried out by use of computer generated random integers that represented the patient files to be selected for study.

3.6.6 Pre-Testing of Instrument

The researcher carried out a pilot study at two non-participating sites, namely Aber Hospital a 200-bed missionary hospital in Oyam District, one of the 9 districts of Northern Uganda and at Apac Hospital, a 150 bed government hospital whose ART clinic is managed by another USAID funded organization. The lists of patients on ART were compiled and at each site 10 files were selected randomly using computer generated sequential random integers. The time used to fill in the questionnaire, the data collection process and possible emerging problems were noted to plan and improve on the data-collection processes. It was recognized that the clinicians did not update the ART registers regularly and that the comprehensive ART card did not capture information on religion or education status and often patients would by pass the clinician to get refills and not have their records updated.

3.7 Data Management

Data that was compiled on a daily basis was filed labeled and stored securely for data entry. Data master sheets were formulated to cater for all variables of interest in a coded format. The data was entered into EPI INFO using a double entry method into two computers. Each variable was pre coded, with a code also provided for non response. Thus every questionnaire provided the same number of responses. The codes for non response were then later calculated as missing data. Back up copies were made of all the data. Cleaning of the data was first carried out visually and then

again electronically by running a frequency distribution for each variable, identifying and eliminating the input error identified.

3.8 Data Analysis

The data was then analyzed using Statistical Package for Social Scientists (SPSS) version 14. Data was summarized as follows: frequency tables to summarize patient specific socio-demographic information, including age, sex, occupation, and clinical information including immunological status (represented by WHO staging or CD4 level) and functional status at onset of ART. Histograms were used to depict the retention status with respect to health facility level, sex and age. Graphs displayed retention status at 3, 6, 12 and 24 months. Pie charts were used to display the spectrum of ART combinations in use. Exploratory data analysis using the bivariate method determined significant associations between loss to follow-up as a dependent variable, and the health facility level and functional status as independent variables. This then determined that further multivariate analysis was not required because only a pair of possible predictors were identified.

3.9 Ethical Considerations

The researcher sought permission and ethical clearance from the Medunsa Research and Ethics Committee. Written approval was also sought from the District Health Officers and the in-charges of the units before data collection at the health units could commence.

This study had no risks to the study subjects, but findings could inform processes for improving the retention of patients in ART programs in post-conflict settings. Confidentiality and integrity of all respondents was observed by use of unique identification numbers instead of names indicated on the data collection form. In

addition, all data records were kept in lockable filing cabinets for safety and confidentiality during data collection and analysis. During the records review medical files and registers were accessed by the researcher with the knowledge of clinic staff, reviewed in a secluded setting and returned with written acknowledgement of receipt given by the clinic staff.

The researcher ensured that he did not interfere with activities of the clinic by visiting the clinic outside working hours on weekdays and on the weekends.

CHAPTER IV

RESULTS

Introduction

This chapter presents a summary of relevant analysis carried out on data collected in this study. The results are a direct input into the objectives of this study. They are displayed in the form of frequency tables, histograms, a pie chart and the compilation of a bivariate analysis on socio-demographic and clinical characteristics of the study patients. A total of 522 patient records were randomly selected but 120 of these files were excluded due to incomplete records even after an attempt at corroboration with data from the pharmacy records. The records eventually used in the study included 190 patient records from LRRH 130 records for KDH and 82 patient records for AHC (See Appendix III). Only 85% of these client records had complete information. The rest had information corroborated from the ART, pre-ART and pharmacy records.

4.1 Baseline Characteristics

4.1.1 Characteristics of the study patients

Table 1 Baseline Characteristics of the Study Patients

Characteristic	Frequency	Percentage
Age (n = 402)		
Below 15	16	3.9
15-17	8	2.0
18-29	86	21.2
30-44	210	51.7
45 >	84	21.2
Sex (n = 396)		
Female	242	61.1
Male	154	38.9
Occupation (n=382)		
Student	28	7.3
Peasant Farmer	276	72.3
Unemployed	38	10.0
Employed skilled	40	10.5
Facility(n=402)		
Regional Hospital	190	47.2
District Hospital	130	32.3
Health Center	82	20.3

Majority of the patients were female (61.1%). The youngest patient was 11 years old and the oldest 65 years. The commonest age range was 30 – 44 years, with over 50% of patients falling into this category. The mean age was 35.92 years (S.E. 0.689, Variance 101.54). Only 5.9% of the patients studied were below 17 years of age. Majority of the patients in this study were peasant farmers. The rest of the occupations considered were represented in similar proportions of between 7 and 10 %; 6 times fewer than the peasant farmers represented in the study.

Table 2 Pre-treatment Clinical Characteristics of the Study Patients

Clinical Factors

Variable	Frequency	Percentage
Functional status (n=370)		
Working	298	80.6
Ambulatory	52	14.3
Bedridden	20	5.1
WHO Stage (n=352)		
Stage 1	52	14.7
Stage 2	92	26.6
Stage 3	174	49.5
Stage 4	34	9.2
Weight (n=326)		
</= 45kg	62	19.0
> 45kg	264	81.0
Pretreatment CD4 Count (n=262)		
1-100	102	39.0
101-200	89	34.0
201-350	43	16.3
> 350	28	10.6

Only 35% of all the study patients had a CD4 lymphocyte test done prior to initiation on antiretroviral drugs. 63.4% of the patients with a pretreatment CD4 were attending LRRH. Only 10% of the patients with a pretreatment CD4 lymphocyte count were attending AHC. Majority of patients (>70%) had a CD4 lymphocyte count less than 200 cells/ ul. 42% had a follow-up CD4 done with two-thirds of these patients attending the regional referral hospital. According to WHO clinical staging majority of patients (49.4%) were at stage III and a smaller proportion (9.7%) at stage IV. With regard to functional status, majority of the patients (80.6%) were working while those bedridden (5.1%) were fewer in number.

4.1.2 Patient Characteristics at the three health facilities

Table 3. Characteristics of the Study Patients in relation to Health Facility (% of n)*

Patient Characteristics	Regional Hospital		District Hospital		Health Centre	
Age *(n= 402)*						
Below 15	16	(4)	0	(0)	0	(0)
15-17	2	(0.5)	2	(0.5)	4	(1)
18-29	36	(9)	28	(7)	21	(5)
30-44	88	(22)	76	(19)	43	(11)
45 >	48	(12)	24	(6)	14	(4)
Total	190	(48)	130	(33)	82	(21)
Sex *(n= 396)*						
Female	105	(27)	85	(21)	52	(13)
Male	81	(21)	45	(11)	28	(7)
Total	186	(48)	130	(32)	80	(20)
CD4 Grouped*(n=262)*						
1-100	64	(32)	28	(9)	10	(4)
101-200	54	(20)	26	(8)	9	(3)
201-350	21	(7)	15	(5)	5	(2)
350 and Above	18	(6)	8	(3)	2	(1)
Total	157	(65)	77	(25)	26	(10)
Functional status *(n=370)*						
Working	126	(34)	114	(31)	57	(15)
Ambulatory	37	(10)	4	(1)	13	(3)
Bedridden	12	(3)	2	(1)	6	(2)
Total	175	(47)	120	(32)	75	(20)
Retention status *(n=400)*						
Retained	**102**	**(26)**	**95**	**(24)**	**30**	**(7)**
Loss to follow-up	**88**	**(22)**	**35**	**(9)**	**52**	**(13)**
Total	**190**	**(48)**	**130**	**(33)**	**82**	**(20)**

* Percentages in bracket are in relation to n for each variable.

In line with the disproportionate sampling methods opted for, participants in the study were in a ratio of 1: 1.3: 2.3 for the AHC, KDH and LRRH respectively.

AHC

AHC had the smallest representation in the study. Majority of the records accessed in this study indicated addresses within the camps around the health centre. Most of the patients (65%) were female and most patients (52%) fell within the 30 – 44 year age range. Adolescents, 15 – 17 years initiated onto ART at the health centre IV were proportionately higher than those at other units. A proportion of the records (23%) belonged to soldiers and their spouses attending the ART program from a nearby army detach (not in table). Only 2 of all the soldiers recruited into the programme at AHC were still in the program after 2 years. Only 26 out of the 82 patients (31.7%) had a pretreatment CD4 lymphocyte count. The functional status of the patients indicated that majority of the patients were recruited while still able to work (75%).

KDH

This unit served a wider geographical area providing antiretroviral's to 700 patients registered in the programme. 22 patients in the KDH records came from neighboring districts as well as from across the border with Sudan. Many of the records accessed (74.3%) were for patients registered recently, between 2007 and 2008 partly as a result of cession of recruitment at the ART program at the nearby St Josephs Missionary Hospital. The district hospital's ART team was managed by a clinical officer and many of the clinical duties had been shifted to other lower cadre of staff. There were more women (65%) than men on antiretrovirals at this health unit. 25 % of all pretreatment CD4 lymphocyte tests were derived from KDH. The tests however suggested that more patients initiated on to antiretrovirals had a CD4 level of 100

cell/ul or less, followed by those with a CD4 level of between 101 and 200 cells/ul. In contrast to the low pre-treatment CD4 lymphocyte counts most patients at KDH were recruited when still able to work (95%). This was a figure much higher than that derived from the other two facilities.

LRRH

Majority (190) of the patients in this study were registered and receiving antiretrovirals at this unit. Comparatively more study patients in this setting were formally employed (31.9%) or were students (18.6%), but peasant farmers (40.8%) were also represented (Information compiled but not displayed). Like all the other sites most patients (45.8% at this facility) belonged to the age group 30-44 years. Unlike the other units however, only LRRH had 16 children included in this study that were aged less than 15 years. Compared to the other units, LRRH had a better representation of the male gender (44%) in the study group. Most men in this study had some form of education (73 %) and a significant number of these men (43%) were formally employed (not in table). Majority of the patients were recruited with CD4 levels less than 200 cell/ul (78%). By functional status 72% of the patients were working by the time of initiation onto therapy.

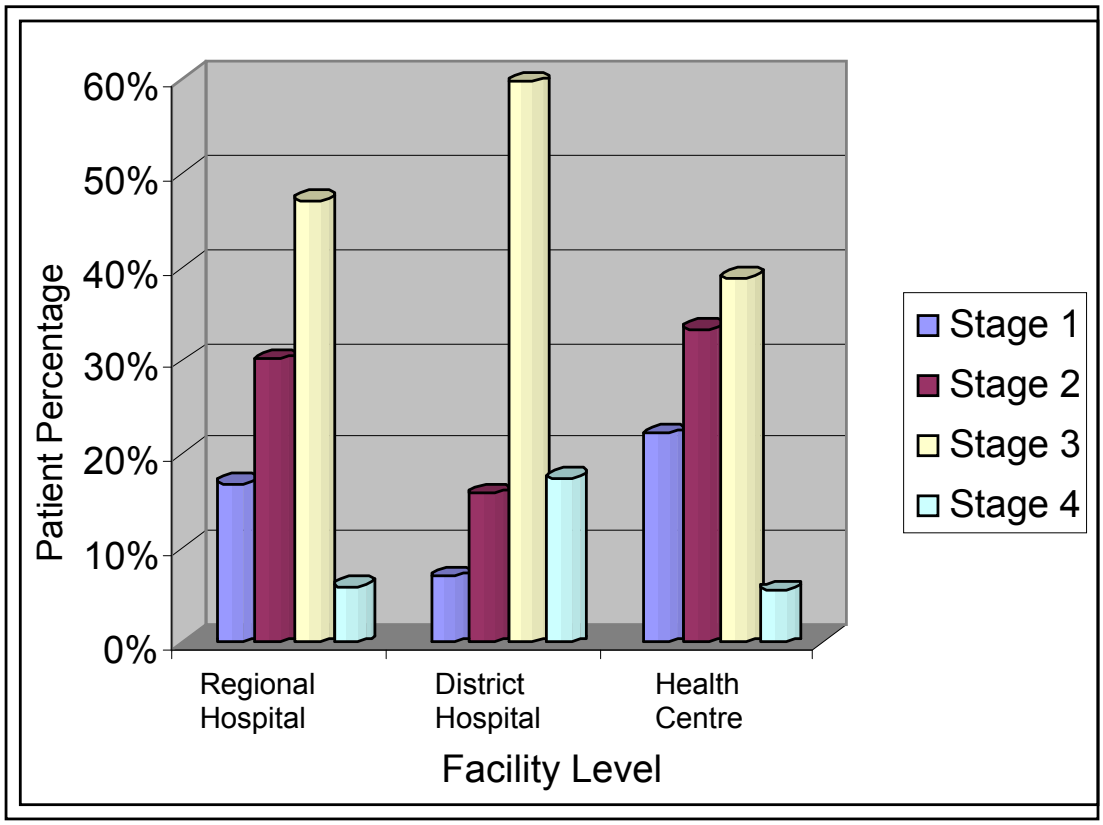


Figure 1: Pretreatment WHO clinical staging for Patients at the facilities

Majority of the patients (68%) in this study were initiated onto ART on the basis of a physical evaluation using WHO clinical staging. Only 35% of all patients in the study had a CD4 lymphocyte count before commencing treatment. Figure 1 illustrates that majority of patients initiated onto ART when in clinical stage III followed by patients in clinical stage II. Patients with severe HIV disease in WHO stage IV had the smallest representation at LRRH and AHC. At KDH after stage III most of the patients initiated onto antiretrovirals had stage IV disease.

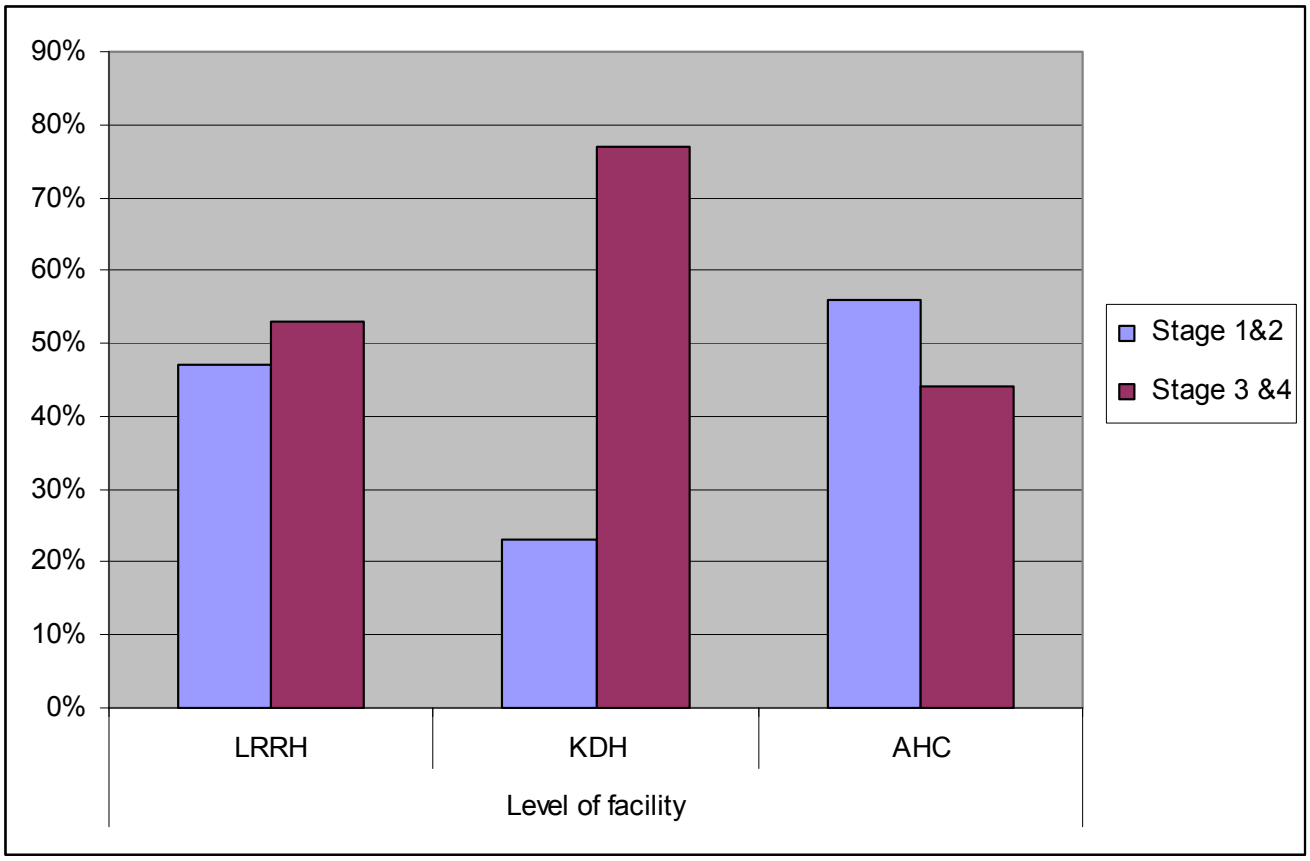
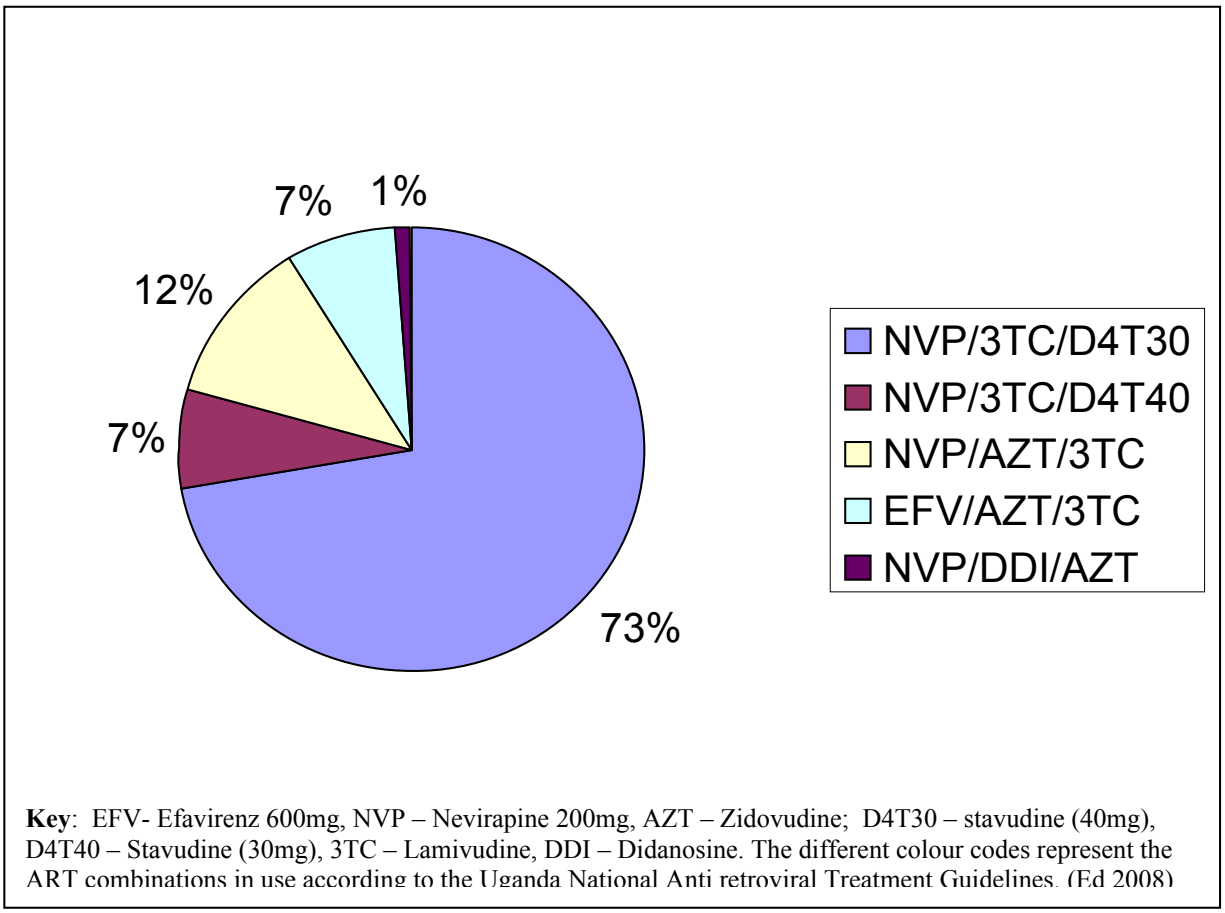


Figure 2: Pre treatment Immunological status by WHO clinical staging at the Health facilities

The Uganda National guidelines on antiretroviral therapy recommend that patients should be initiated at WHO clinical Stage III and IV. In this study a number of patients initiated at the respective facilities had clinical stage noted as stage I and II. Patients with WHO clinical stages I or II for LRRH (47%), KDH (23%), and AHC (56%) respectively were also initiated onto ART. At the regional hospital almost equal numbers of patients initiated on ART were in stage I and II as well as in stage III and IV (see figure 2). In the district hospital one third of patients were initiated at WHO clinical stage I and II while at the health centre more patients initiated onto ART were in clinical stage I and II.



Key: EFV- Efavirenz 600mg, NVP – Nevirapine 200mg, AZT – Zidovudine; D4T30 – stavudine (40mg), D4T40 – Stavudine (30mg), 3TC – Lamivudine, DDI – Didanosine. The different colour codes represent the ART combinations in use according to the Uganda National Anti retroviral Treatment Guidelines. (Ed 2008)

Figure 3: ART regimens used in the health facilities

All the health units used a fixed dose combination of NVP/3TC/D4T30 provided by the ministry of health as the first line option. Separate formulations of the same combination were used during the first two weeks of ART initiation at the regional hospital to allow the "lead in" process of initiating the patient onto treatment. . Another popular combination for first line treatment according to figure 3 is NVP/AZT/3TC (Cream colored legend). This observation reflects a pronouncement by the Ugandan Ministry of Health 4 months ago instructing the withdrawal of *stavudine* containing combinations in favour of the zidovudine containing ones given the formers frequently occurring adverse side effects. Only one patient , a transfer in from a research clinic was on Didanosine (DDI) at the regional hospital as first line combination. None of the patients studied was on a second line regimen.

4.2 Retention and Loss to follow-up in this study

4.2.1 Overall Retention and Loss to Follow-up

Analysis of valid patient data from the clinic records alone provided a total of 179 patients retained in the program as opposed to 223 lost follow-up. This spelt a lower retention rate of 51.4% for this study. However, the overall retention rate described below was obtained after the patient personal records were additionally triangulated with the clinic registers as well as Pharmacy records. Many of the personal files were not routinely updated by the ART clinic team.

Table 4: Overall Retention status for the study

Retention Status	***n***	**%**
Retained	227	**56.5**
Loss to follow-up	173	**43.5**
Missing Data	*2*	*0.5*

For the patients *ever* recruited to the ART programs across all the three units the two year retention rate was 56.5 % while the rest were lost to follow-up (see table 4). Overall more patients were retained in the ART programs two years after enrolment. However when broken down to specific health facilities the retention rate AHC actually lost more patients than it retained (figure 4 below)

4.2.2 Retention and Loss to Follow-up at the three health facilities

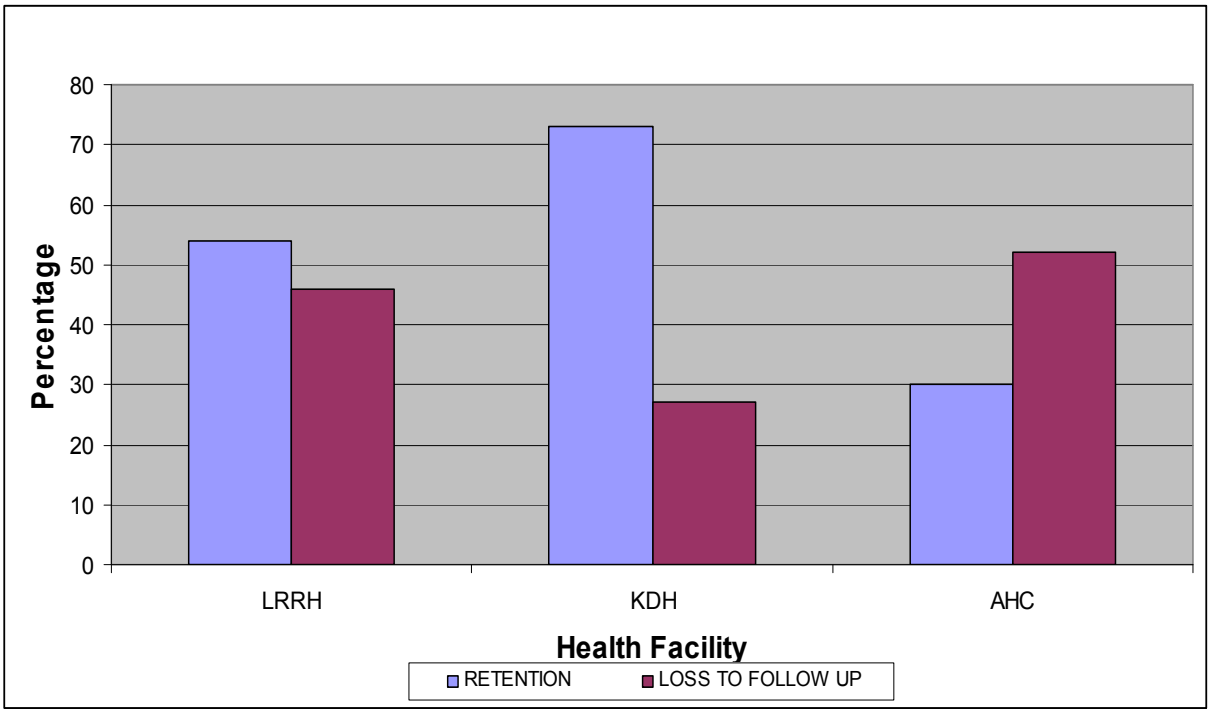
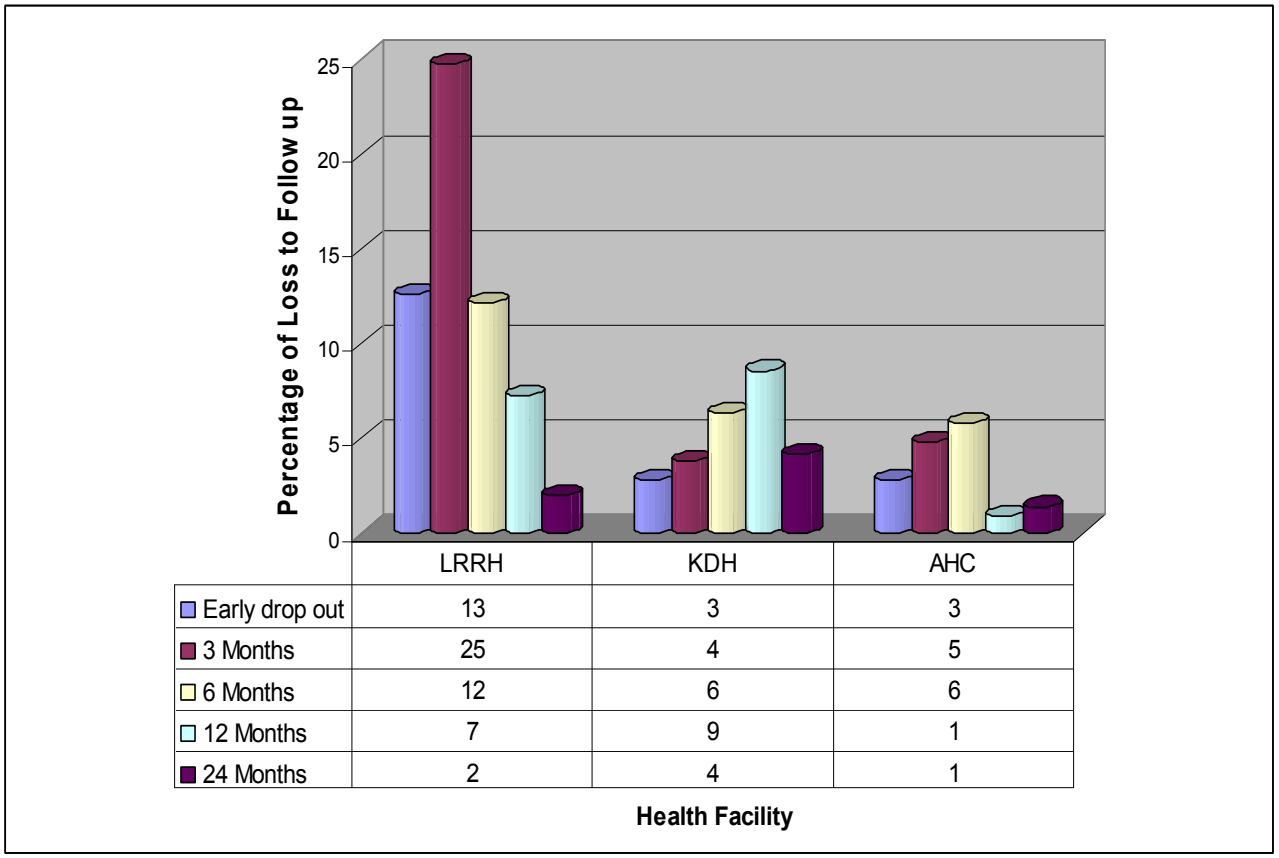


Figure 4: Retention and Loss to follow-up at the health facilities.

Further analysis of the overall two year retention indicated that KDH had the highest two year retention rate of 73.1 % with only 26.9 % lost from the ART programme. LRRH had a 53.7 % two year retention rate for patients enrolled for antiretrovirals and lost 46.3 % of patients. AHC had a dismal two year retention rate of 36.6 % for patients at the site with loss to follow-up of 63.4 % of all patients enrolled for antiretroviral therapy.

4.2.3 Retention Rates and Loss to Follow-up at 3, 6, 12 and 24 Months



	LRRH	KDH	AHC
Early drop out	13	3	3
3 Months	25	4	5
6 Months	12	6	6
12 Months	7	9	1
24 Months	2	4	1

Figure 5: Loss to follow-up cascade at 3, 6, 12 and 24 months at the health Facilities (Percentage of n = 402)

Enrollment of patients on to the ART programs and subsequent follow-up across the three sites was cascaded over 3, 6, 12 and 24 months to evaluate when LTFU was more likely to occur. 175 patients overall were lost to follow-up in this study by the 24th month in care. 59% of all lost to follow-up were from LRRH, 26% from KDH and 16% from AHC. Additionally, in this study 19 % actually never returned for follow-up or dropped out during the intervening period before completing three months. In accordance with the definitions used in this study LTFU was confirmed when a patient did not return for three consecutive months. After this period, most of the patients lost to follow-up at LRRH (25% of 175) left the ART programs after completing 3 months in care. At KDH most patients lost to follow-up (9%) left after

completing 12 months in care. At AHC the loss to follow-up (6%) occurred mainly after 6 completed months in care. A small number of patients did stop coming even after reaching the 2 year mark. KDH had a bigger representation within this category while LRRH had the lowest. LTFU in this last category was confirmed if the patients were not returning for follow-up for 3 consecutive months after this, i.e. at the 27th month.

4.3 Predictors of Loss to follow-up in the Study Patients

In this study, multivariable analysis was not carried out given that only two independent variables showed significant association with retention status at bivariate analysis. These were health facility (table 5) and functional status (see table 6).

Table 5: Loss To Follow-up In Relation To Socio-Demographic Characteristics

Variable	Number	# proportion lost to follow	Unadjusted odds ratio	95% CI	p-value
Facility					
Regional Hospital	91	42(46.2)	0.48	0.22-1.07	0.074**
District Hospital	60	16(26.7)	0.21	0.08-0.50	<0.001***
*Health Center	36	23(63.9)	1.00		
Age Group					
*<=29	51	26(51.0)	1.00		
30-44	100	38(38.0)	0.59	0.30-1.17	0.128
>45	42	19(45.2)	0.79	0.35-1.80	0.582
Occupation					
Farmer	123	58(47.2)	1.53	0.56-4.15	0.403
Unemployed	30	12(40.0)	1.14	0.35-3.74	0.825
Employed skilled	19	7(36.8)	1.00		
Sex					
Female	114	47(41.2)	0.80	0.45-1.44	0.461
*Male	75	35(46.7)	1.00		

***reference category; ** Significant at 10%; ***Significant at 5%**

Loss to follow-up at AHC was taken as reference point to testing the null hypothesis. An HIV patient accessing antiretrovirals at KDH was 5 times *less* likely to drop out of the program compared to those assessing care at AHC (p-0.001; 95% CI). Meanwhile a patient assessing care at LRRH was two times less likely to drop out of the programme but this was not statistically significant at 5% level of significance..

In this study, there were no statistical association between age group, occupation or sex (gender) and the retention status in the ART programme (table 5).

Table 6: Loss To Follow-up In Relation To Clinical Characteristics

Variable	Number	# proportion lost to follow	Unadjusted odds ratio	95% CI	p-value
weight					
*<=45kg	62	24(38.7)	1.00		
>45kg	238	98(41.2)	1.11	0.49-2.49	0.803
Pre-treatment WHO					
*Stage 1	44	22(50.0)	1.00		
Stage 2	92	42(45.7)	0.84	0.30-2.32	0.737
Stage 3	172	74(43.0)	0.76	0.30-1.93	0.557
Stage 4	34	14(41.2)	0.70	0.20-2.51	0.584
Pre-CD4 count					
*1-100	88	50(56.8)	1.00		
101-200	42	38(46.3)	0.66	0.28-1.54	0.335
201-350	23	24(57.1)	1.01	0.35-2.90	0.980
>350	24	8(33.3)	0.38	0.10-1.45	0.157
Functional status					
*Working	298	106(35.6)	1.00		
Ambulatory	50	30(60.0)	2.72	1.14-6.45	0.024***
Bedridden	20	18(90.0)	16.3	2.01-132.2	0.009***

***reference category; ** Significant at 10%; ***Significant at 5%**

Bivariate analysis to evaluate any association between clinical characteristics in the study patients and loss to follow-up was undertaken. Functional status at the time of initiation, amongst the study patients, was significantly associated with loss to follow-up in this population. Table 6 indicates that relative to the working patient, the bedridden patient was up to 16 times more likely to fall out of the program by the end of 2 years (OR 16.3 95% CI 2.01,132.3). On the other hand the ambulating patient in comparison with the working patient was approximately 3 times more likely to leave the programme. (OR2.72 95%CI 1.14,6.45). The statistical inferences stated above conversely showed that the working patient was as much as 16 times more likely to remain in the ART programme and this was significant statistically (p-0.009 CI 95%) Tests to establish association between WHO clinical stage and the pre-CD4 count and LTFU failed to show any significance in this study.

CHAPTER V

DISCUSSION, CONCLUSION, RECOMMENDATION

Introduction

The chapter discusses the results provided by this study and makes scientific deduction and conclusions based on this information. The evidence provided is correlated with the existing body of knowledge to ensure scientific plausibility. It is upon this that recommendations have also been made.

5.1 Discussion

5.1.1 Baseline Characteristics

Socio-demographic Characteristics

At all the three health facilities majority of patients studied were female. This mirrored findings of major studies all over sub-Saharan Africa (Karcher, 2007; Sow, 2007). This however contrasted with the findings of studies carried out in the western world where HIV was predominantly an affliction of the male gender affecting men that have sex with men. (Giordano, 2007) This study highlighted the observation that female patients with HIV more willingly sought HIV related services. (Dalal, 2008). In this setting women had an extra entry point into the ART program through the PMTCT program (Creek TL 2007) probably explaining their disproportionate number as compared to the males. These findings were also consistent with UNAIDS estimates of age specific HIV prevalence and access to combination antiretroviral therapy in Uganda (UNAIDS 2003). It was noteworthy however that at the regional hospital the gender difference was smaller as more men accessed care. The male preference to seek HIV care services at the regional hospital probably reflects the fear

that men have of being stigmatized and ostracized by their communities. According to the study a more affluent, literate and urbanized community was accessing care at the regional hospital. By inference the men assessing care at the regional hospital had knowledge and therefore greater motivation to assess appropriate HIV related services. This study however indicated that there was no statistically significant difference in the influence of gender on the retention of patients on ART programmes. This observation is supported by findings of a South African study by Dalal (2008) and another meta-analysis by Brinkhof et al (2008). One could assume that the better health seeking behaviour exhibited by the women did not translate into better retention practices because women in this setting lacked both financial and decision making independence to ensure strict compliance to requirements. The absence of an advantage in retention for the female is also epidemiologically explained thus; in a mature HIV epidemic like Uganda's, the female HIV related mortality is characteristically higher than that for the males unlike what happens in younger epidemics else where (Ngom 2003). In this study's setting where causes of failed appointment are not routinely determined, death in a patient often translates to loss to follow-up.

Age

Majority of this study population were within the 30 to 40 year age range with a median of 35.92 years. This pattern was maintained across all the three health facilities studied. This observation was similar to that reported in other studies. A median enrolment age of 36.4 years was reported in a similar population of HIV patients in a South African study by Dalal and others (2008). Similarly an age range and median age of 30.2 – 41.3 and 34.8 years respectively was described at a five year

ART program in Botswana (Bussman 2008). In Northern Uganda like elsewhere in the world most breadwinners and heads of families fall within this group. These are people more likely to have a stable income and more able to meet expenses involved in keeping up with clinic appointments. Children were inadequately represented in this study making any analysis of their age characteristic inappropriate. It was expected that a more mature age group would stick to appointments and adhere better to medication favouring retention of the group. However the study did not show any statistical evidence as such. Age as a poor predictor of adherence and retention was corroborated by both bivariate and multivariate logistic regression analyses carried out in a Tanzanian investigation by Ramadhani (2007).

Immune Status

In all the health facilities studied, majority of the patients initiated on ART were of WHO clinical stage III and IV disease (59.1%). This was mirrored findings in a Tanzanian study by Johannessen and others (2008). However in *this* study the immunological pre treatment status measured by the CD4 lymphocyte count or by WHO clinical staging was not predictive of loss to follow-up. This was supported by the study by Orrell (2003) who recognized that limited options for care in that study setting forced patients to remain adherent to the only programme available. In much of Northern Uganda this situation was similar. Nevertheless inadequate training and poor data recording practices may have contributed to the large number of patients in this study initiated on treatment but yet with records indicating WHO clinical stage I and II. This may have contributed to the lack of association between severe HIV disease and LTFU in this study. During the war many of the health workers that had received formal training in HIV clinical management had left the health facilities for

better opportunities elsewhere. Even those that stayed on were overworked and poorly motivated. The consequence was less care assess and prepare patients for their lifelong treatment. Indeed at the regional hospital and health centre a lower CD4 lymphocyte counts, a more adverse functional status and a lower weight were in the same patient record that indicated a WHO clinical stage I or II. In addition information collected about pre-existing opportunistic infections did not correlate well with the reported WHO clinical stages. At KDH the participation of people living with HIV/AIDS (PHAs) in some basic none technical clinic activities saved the health worker some time to attend to the patients better. Again an active civil society organizations supporting the facility at community level, educating and encouraging the community to test for HIV and seek care was probably paying off as healthier people sought care earlier.

In this study finding up to 74.1% of patients with a CD4 level of below or equal to 200 cells /ul was consistent with reports by Lawn et al (2005). The researcher observed that African patients tend to seek help when significantly ill and immunocompromised leading to reduced survival outcomes. This was also in keeping with the suggestions that late initiation onto ART common in sub-Saharan results from poor access to VCT, infrequent measurement of CD4 cell counts, delayed referral and stringent guidelines like the one just updated in Uganda. (Dalal, 2008; UNATG, 2008)

The CD4 lymphocyte count test is generally recognized as an established predictor of morbidity, mortality and loss to follow-up in patients on ART (Egger, 2002). However in this study the CD4 count was not predictive of retention or loss to follow-up. At LRRH the CD4 testing was available at a fee. Those that could afford the test

could presumably also afford better nutrition, better care for opportunistic infections and were more knowledgeable and motivated to stay on in the programme. LRRH as a regional referral unit was also providing specialized care to patients with lower CD4 lymphocyte count and keeping then retained.

ART regimen

This study was carried out in a resource limited setting that was benefiting from a scale up of antiretroviral therapy initiated by UNAIDS under the 3 by 5 HIV/AIDS initiative of 2003. The public health based approach of antiretroviral therapy promoted WHO was used in this setting. A limited number of preselected antiretroviral combinations supported by simplified treatment guidelines and tools were promoted to enable task shifting and the rapid roll out of treatment to the lowest levels of care. Weiser et al (2002) alluded to an association between loss to follow-up and the type of ART drug regimens used. In other studies, the formulation used, the dosing frequency reduced from three to two times a day all showed an effect on adherence and retention. (Cheevers, 2000; Saag, 2000) In this study an analysis carried out to investigate such a relationship did not show any relationship. At the time of the study majority of the patients (73%) were on a *stavudine* based fixed dose combination as first line therapy. Because most of the patients were on the same antiretroviral combination the association between antiretroviral regimen and retention or loss to follow-up could not be easily ascertained. However the regimen used was a twice daily single tablet. From previous study this was a good predictor for strong adherence and retention. (Orrell 2003)

5.1.2 Retention Status

In this study the overall 2 year retention rate (56.7%) was similar to that described in a systemic review of patient retention in ART programs in sub Saharan Africa (60%) (Rosen, 2007). The findings also tallied with that of Bedelu (2007) that showed lower health facilities quite effective in managing patients satisfactorily once task shifting, mentoring and community support for the patients was made an integral part of the scale up of HIV care. This was effectively demonstrated in this study by the operations of KDH where PHA groups and civil society organizations were actively collaborating with the health facility with a view to enhancing the continuum of care beyond the health facility.

Retention at Kitgum District Hospital in comparison with a Centre of Excellence

An abstract about an ART program at a Catholic Relief Society supported missionary hospital in the same setting of Northern Uganda described a retention rate of 81% for patients on ART (Rigon, 2006). This was largely attributable to a robust community based follow-up component offered to patients accessing treatment at that unit. The missionary hospital collaborated with a faith based organization; the Good Samaritans of Comboni that offered home based support services for patients' resident within a 40km radius from the hospital. In addition for initiation onto ART at the missionary hospital patients were taken through rigorous screening for potential factors that could hamper drug adherence. The elaborate process was then crowned with a number of therapeutic counseling sessions. In that setting patients considered terminally ill or resident outside the 40 kilometre radius were often provided palliative care and referred to units nearer their homes. By implication, the population was highly

selected and retention in the program was bound to be high. In this study KDH nonetheless stood up to that rank by incorporating PHA peer groups into its clinic activities and making use of community based organizations to follow-up clients initiated onto care. In this study, the involvement of Meeting Point, a local community based organizations and provision of food supplementation by the World Food programme led to the remarkable 2 year retention rate of 73.3%.

Retention at Lira Regional Referral Hospital and Awach Health center IV

Another Ugandan study reports out of another missionary hospital based in the Ugandan capital city, Kampala. Here patients were not routinely followed up into the community (Kabugo 2006). The unit had a showed a dismal patient retention rate of 48% .In this study, LRRH and AHC community based support for the patients on ART was non existent. At AHC only 36.1% were retained with a majority, over two thirds lost to follow-up. The population accessing services at AHC was skewed towards the more indigent and sickly; the population was made up of people less able to afford travel and user fee expenses involved in accessing care at one of the large missionary hospitals situated at *Gulu*, a town less than 30 km away (this includes the one that compares with KDH). These patients were bound to suffer loss to follow-up due to high mortality or transfer to the larger centers once they got the opportunity. Another contributor to the large fall out was the large itinerant population being served that included soldiers and internally displaced people that were gradually leaving the camps in the health facility's service area for their homes.

Loss to Follow-up

Loss to follow-up in this study within two years was high (43.3%) but was still consistent with findings of Rosen (2008) who reported up to 40% of patients from a

systematic review of 33 different studies as either lost to follow-up or dead. This however contrasted with findings of the ART-LINC Collaboration that analyzed 18 HIV cohorts across the developing world and reported a 15% loss to follow-up in the first year (Braitstein, 2006). Possible reasons leading to loss to follow-up in this study included financial constraints limiting repeated travel to the unit, myths about ART, competition with traditional medicine, lack of disclosure, lack of home based support, and fears of loosing one's social standing. This factors have also been mentioned by Nam (2008) and others. The successes observed at KDH clearly demonstrated the need for the community follow-up to address many of these hindrances.

Loss to follow-up and Death

Death as a contributor to attrition is notably underestimated in several programs because of inadequate tracing of patients (Bisson, 2008). In studies carried out all over Africa where tracing has been possible death has been consistently shown to be a major cause of loss to follow-up (Rosen 2007). In the sub-Saharan setting where stringent guidelines, stigma and inaccessible VCT services contributes to late initiation of patients on ART, mortality is a bigger contributor to attrition when compared to the developed world (Braitstein P 2006; Johannessen 2008). In this study, mortality could not be determined from record review. A few patient files at the study sites had inscriptions or markings to indicate demise but the practice was not consistent and could not contribute useful statistical information. Patient tracing and community monitoring was non existent and notification of death was not institutionalized. Most of the patients and their treatment supporters did not have telephone contacts and the movement of populations from the camps back to their places of origin especially this year made given addresses incorrect.

The *Retention Cascade*

In this study retention was further analyzed to establish when patients were likely to drop out of the programs after initiating ART. The reducing trend in loss to follow-up observed from the third month up to the twenty forth completed month corroborated reports by Bisson et al (2008) and Dalal RP et al (2008) demonstrating that up to 60% of loss to follow-up and death occurs within the first 42 days after initiation of antiretrovirals. The meta-analysis by Rosen (2007) also showed a similar downward trend in all the studies considered.

This trend only held true for LRRH and AHC on analysis of the respective health facilities in the study. At KDH significant early survival after initiation for many patients was occurring as a result of concerted efforts at appropriate care by both the health care workers and the community volunteers. The early survival in this setting also gave opportunity for factors influencing loss to follow-up later on to emerge. These factors include transfer out in search of new points of care that may have additional packages, for instance, financial and legal support. Patients that are now healthy after months of treatment become inpatient waiting in the long queue outside the clinician's door. Patients eventually avoid the long wait and simply visit the pharmacy for the antiretroviral drug refills. This contributes to incomplete updating of patient clinic records giving a wrong impression getting lost to follow-up.

5.1.3 Predictors of Loss to follow-up

Enrolment at the AHC ART programme and to a lesser degree, enrolment at LRRH was likely to lead to loss to follow-up. A small poorly facilitated remote facility like AHC was likely to loose significant number of patients. At the time of the study the civilian population of Northern Uganda was highly mobile and this was reflected by

what was happening at AHC. The larger referral hospital presented the other extreme of the spectrum. There was a heavy patient load attended to by doctors including some specialists. Laboratory support and the management of opportunistic infections were more wholesome in this setting. However care for the HIV patient was impersonal and strictly hospital based. The result was a less than satisfactory retention on the ART programme. In this study the client cards, pharmacy and laboratory record provided a limited number of variables that nevertheless provided useful statistical inference on possible predictors of poor retention. A qualitative study carried out by Nam (2008) suggested that at community level, a lack of stable income and inadequate support from social networks was likely to lead to loss to follow-up. Indeed the relative success of the district hospital in this study resulted from the continuum of care being addressed through collaboration between the hospital and community based organizations. Inadequate social support in this investigation was not statistically tested but was inferred from the significant difference in loss to follow-up at KDH and at LRRH and AHC where formal approaches to community support was virtually none existent.

The second predictor noted in this study was functional status prior to initiation. A book by Berger and others (2006) asserts that patients with an extremely low immunological status, the functional status becomes more accurate in predicting death. In this study though death was not verifiable in most patients lost to follow-up from the three facilities, it was recognized as one major cause for patients failing to return for care.

This study differed from many by findings that clinical characteristics namely CD4 lymphocyte count, WHO clinical staging and weight were not predictive of loss to

follow-up. Orrell (2003), De Beaudrap (2008) and many other authors allude to this association. As mentioned previously incorrect recording of the parameters by the clinicians may have contributed to our findings. On the other hand given that this was a desperately poor population the weight and BMI therefore of the healthier HIV infected individuals was not different from that of the very ill.

5. 2 Limitations

Improper Records

Data was collected from HIV comprehensive care cards, pharmacy records and clinic registers that in most occasions were inadequately or improperly filled. For example majority of patients clinically assessed and categorized into WHO clinical stage IV had no corresponding records alluding to existent AIDS defining conditions. This was a common finding at LRRH and AHC. Again at LRRH and KDH a number of patients that were declared lost to follow-up on the grounds of no updates to their clinic records were actually doing well and regularly picked their refills from the pharmacy. Despite this KDH was making attempts to maintain complete.

Health Facility Related Factors

It is possible that at the different health facilities other factors that we were not able to analyze for instance distance from the clinic and attitude of the health workers had some relationship with loss to follow-up.

Mortality

The reasons that led to follow-up could not be ascertained in this study. Therefore factors that may have contributed to death, transfer out of the patients, discontinuation of treatment were considered together. This was a key limitation of the study. Indeed, South African studies by Bisson (2008), Maskew (2007) and Dalal (2008)

demonstrated that survival estimates derived from loss to follow-up clinic records as opposed to patient tracing were notoriously inaccurate. At KDH where there was strong community support and at LRRH were a number of patients or treatment supporters had mobile phones some form of patients tracing had being developed. Anecdotal information from the tracing indicated that more than half of the patients were lost to follow-up had probably died (Unpublished data). AHC had a highly itinerant population especially during this post-conflict period. As stated previously people were returning to their homes from the camps and the soldiers were gradually being transferred out of the military detaches that guarded the camps. It was therefore hard to establish death as well as other causes of attrition in this study.

Follow-up of Calendar Cohorts

In this record review retention and loss to follow-up was not retrospectively followed for each periodical cohort so as to establish retention status with respect to calendar period. This made it impossible to demonstrate any changes in the trend of loss to follow-up relative to point in time or events at the health facilities.

CD4 Monitoring

CD4 monitoring was not yet universal in this setting. Only a minor proportion of patients had CD4 test before being initiating treatment. CD4 cell testing was mainly available in the regional hospital where a system of ferrying blood samples to a stand alone laboratory every week at a fee was ongoing. Therefore in this study it impossible to verify the actual relationship between retention and the CD4 cell lymphocyte count recognized as an independent predictor of immunological status.

Education Status

The health related literacy was expected to differ amongst the different communities we studied, with probably more educated people accessing care at the regional hospital. Unfortunately in *this* study the correlation between retention and literacy could not be determined because the patient/client cards did not capture information on education status. However the retention rate for LRRH was comparable with that for the study by Kabugo et al (2006) mentioned above that was carried out at a missionary hospital based at the capital city Kampala where a more educated, affluent community was assessing care.

5.3 Conclusion

This study was carried out in Northern Uganda a region of Africa just recovering from a 20 year old civil conflict and was now facing the movement of over 90% of the civilian population back to their homes. The HIV scourge in the region was fanned by the war, exposing the population to a higher prevalence of 8.4 % as compared to the HIV country average of 6.2%. The scale up of antiretroviral therapy in this resource limited post-conflict setting has numerous poorly understood challenges that could influence long-term retention on ART and increase the risk of developing resistance to the relatively cheaper and less toxic first-line regimens currently in use. Few studies about retention in ART programs in Uganda let alone Northern Uganda had so far been carried out. This methodological review of medical records was able to highlight a number of predictors and factors influencing retention that could motivate the development of strategies that could improve retention on antiretroviral therapy at the three levels of care in post-conflict Northern Uganda.

Retention

The study demonstrated a 2 year retention rate of 56.7% that was similar to findings else where in sub-Saharan Africa. It was recognized that in these health facilities studied death of clients that were initiated onto ART was not known. The most impressive 2 year retention rate was at achieved at the district hospital, KDH followed by the larger regional referral hospital and least at the health centre IV. The district hospital was collaborating with local CBOs to provide community based follow-up for patients initiated onto ART and the patients were receiving supplementary food stuff from the World Food Program (WFP). The regional hospital and the health centre IV had no such arrangements for following up and supporting their clients once

initiated onto ART. Findings at KDH illustrate that through task shifting, participation of PHA groups and collaboration with civil society organizations; it is possible to provide high quality care for HIV patients.

Periodic Retention

The period that patients remained on follow-up after initiation on ART was further analyzed at 3, 6, 12, and 24 completed months. There was a significantly larger loss to follow-up of patients after completing three months of treatment with a reducing trend there after. A sizable number of patients initiated onto ART never complete 3 months in the program. Many in this category dropped out of care before returning for follow-up. There are factors that lead to earlier loss to follow-up that may include death, immune reconstitution inflammatory syndrome, as well as psychosocial issues like lack of disclosure to spouse and social stigma. This however was not established in this study.

Predictors of Loss to Follow-up

In this study loss to follow-up from the ART program was the adverse outcome. Predictors were identified that were significantly associated with loss to follow-up. The strongest predictor was the pre treatment functional status where bedridden patients were most likely to be lost to follow-up followed by ambulant patients. Patients that were able to work were likely to be retained in the program. The health facility where one was accessing ART from was also found to be a critical predictor for loss to follow-up. Patients assessing care at the health centre IV were highly likely to fall out of programme followed by those at the regional referral hospital.

5.4 Recommendations

1. Entry points into HIV care including HIV counseling and testing should be enhanced and broadened so that more people can access care earlier before they are weak and bedridden. Promotion of voluntary counseling and testing, home based HIV testing and provider initiated HIV testing; encouraging partner disclosure, and focusing more on the vulnerable persons in society that would include women, children, adolescents and the underprivileged of society will enhance the enrollment of those in need.
2. Collaboration with CSOs and PHA groups should be institutionalized so that all levels of care make use of these entities to ensure the continuum of care for the HIV patient. This study shows that where decentralization exists, coordination and networking amongst HIV/AIDS organizations if promoted as a good practice can support the scale up of the HIV/AIDS response even in difficult circumstances.
3. The government should develop strategies to build capacity of health workers equip and strengthen HIV care in the lower level health facilities. This should be coupled with encouragement of patients to decongest the regional hospital ART clinic leaving it to attend to patients that require specialized care.
4. Uniform methods of identification for patients on ART across the country should be adapted to aid formal transfer of patients and tracing of those that are lost to follow-up.
5. Health workers should be supported to appreciate the importance of properly recorded information. They need to own the data management process and understand how correct information can motivate measures to improve services.

For as long as they perceive data capturing as a burden and fulfilling the requirements of a third party the attitude will remain.

6. The updated National ART treatment guidelines recommends for initiation of patients onto ART at a higher CD4 level of 250 cells/ul. This is a positive step towards improving earlier and wider assess to ART treatment. However there is still need to increase eligibility criteria to about 350 cells/ul and make CD4 testing more available for all ART programs if patients are to benefit early and avoid attrition due to immune reconstitution syndrome, toxicities and death as a result of late initiation on antiretroviral drugs.
7. There is need to enhance Health literacy in this population living in the post-conflict area where formal education has been disrupted for the last 20 years.
8. Studies should be carried out to establish whether factors affecting adherence are synonymous with those influencing retention. It is recognized that adherence is studied in highly selective populations that are still retained in an ART program. It would be important to establish whether low adherence in a population of patients would affect factors and predictors of attrition.

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APPENDICES

***Appendix I* : MEDUNSA Research and Ethics Committee Clearance Certificate**

UNIVERSITY OF LIMPOPO

Medunsa Campus

MEDUNSA RESEARCH & ETHICS COMMITTEE

CLEARANCE CERTIFICATE

P O Medunsa
Medunsa
0204
SOUTH AFRICA

Tel: 012 - 521 4000
Fax: 012 - 560 0086

MEETING: 08/2008

PROJECT NUMBER: MREC/PH/192/2008: PG.

PROJECT :

Title:	Retention of HIV positive persons at Antiretroviral Therapy Clinics in Post-Conflict Northern Uganda
Researcher:	Dr A Alyao-Ocero
Supervisor:	Prof S Pengpid
Department:	Health System Management and Policy
School:	Public Health
Degree:	Masters in Public Health

DECISION OF THE COMMITTEE:

MREC approved the project.

DATE: 07 October 2008

RESEARCH & PARTNERSHIP
2008 -10- 07
MEDUNSA CAMPUS

PROF GA OGUNBANJO
CHAIRPERSON MREC

Note:

i) **Should any departure be contemplated from the research procedure as approved, the researcher(s) must re-submit the protocol to the committee.**

ii) **The budget for the research will be considered separately from the protocol.**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES.

African Excellence - Global Leadership

Appendix II: Proposed Workplan for the Research Study

Activities by Month	***Aug***	***Sept***	***Nov***	***Dec***	***Jan***	***Feb***
Proposal Devt & Review	*X*	*X*				
Proposal validation	*X*					
Apply for MPEC approvals	*X*					
Secure necessary District Health Officers approval (MOH, sites)	*X*	*X*				
Implementation preparation						
Pre-testing tools		*X*				
Data collection and analysis						
Collect data		*X*				
Enter data			*X*	*X*		
Analyze data			*X*	*X*	*X*	
Writing Final report				*X*	*X*	
Dissemination					*X*	*X*

Appendix III: Estimated Budget For The Study

S/No	*ITEM/ACTIVITY*	*Quantity*	*Unit Cost/rate US$*	*No. of days*	*Total US$*
1	*Printing and Photocopying*	*7*	*5*	*1*	*35*
2	*Printing and Binding of Study Report*	*4*	*10*	*1*	*40*
3	*Transport*	*1*	*30*	*15*	*450*
	TOTAL				*$525*

Unique # ☐☐☐☐☐☐☐ **HIV CARE/ART CARD** ____

District _____ Health unit_____ District clinician/team_____

Name_____ Pt clinic #_____

Sex: M ☐ F ☐ Age_____ DOB_____ Marital status_____

Address_____

Telephone (whose):_____

Prior ART:
- ☐ Transfer in with records
- ☐ Earlier ARV but not a transfer in
- ☐ PMTCT only
- ☐ None

Care entry point:
- ☐ PMTCT
- ☐ Medical
- ☐ Under5
- ☐ TB
- ☐ STI

(Outpatient)

- ☐ Private/Co
- ☐ Inpatient
- ☐ IDU
- ☐ Add
- ☐ Sex

(Outreach)

- ☐ Self-refer
- ☐ CBO
- ☐ Other:

Treatment supporter/med pick-up if ill:_____

Address_____

Telephone (whose):_____

Home-based care provided by:_____

Names of family members and partners	Age	HIV +/-	HIV care Y/N	Unique no.

Drug allergies

ART treatment interruptions

Stop Lost (circle)	Date	Why	Date if Restart:
Stop Lost			
Stop Lost			
Stop Lost			
Stop Lost			
Stop Lost			
Stop Lost			

Date

_____ Confirmed HIV+ test Where_____ HIV 1 2 Ab / PCR *(if < 18 mo)*

_____ Enrolled in HIV care

COHORT:

ARV therapy

_____ Medically eligible Clinical stage____

Why eligible: ☐Clinical only ☐CD4%_____ ☐TLC_____

_____ Medically eligible *and* ready for ART

_____ Transferred in from_____ART started_____

_____ **Start ART 1st-line initial regimen:**_____

At start ART: Weight _____ Function_____ Clinical stage_____

Substitute within 1st-line:

1st-line

_____ New regimen_____ Why_____

_____ New regimen_____ Why_____

Switch to 2nd-line (or substitute within 2nd-line):

2nd-line

_____ New regimen_____ Why_____

_____ New regimen_____ Why_____

_____ New regimen_____ Why_____

_____ **Dead**

_____ **Transferred out** To where:_____

Why STOP codes:
1. Toxicity/side effects
2. Pregnancy
3. Treatment failure
4. Poor adherence
5. Illness, hospitalization
6. Drugs out of stock
7. Patient lacks finances
8. Other patient decision
9. Planned Rx interruption
10. Other

Why SUBSTITUTE or SWITCH codes:
1. Toxicity/side effects
2. Pregnancy
3. Risk of pregnancy
4. Due to new TB
5. New drug available
6. Drug out of stock
7. Other reason (specify)

Reasons for SWITCH to 2nd-line regimen only:
8. Clinical treatment failure
9. Immunologic failure
10. Virologic failure

Unique # ☐☐☐☐☐☐☐ **HIV CARE/ART CARD** **Name**_____

Date Check if scheduled. Write in alternate pick-up if ill	Follow-up date	Duration in months since first starting ART/ since starting current regimen	Wt	If Pregnant EDD? PMTCT? FP/no FP If FP write method(s) **If child write height**	Function Work Amb Bed	WHO clinical stage	TB status	Potential SIDE EFFECTS	New OI, Other PROBLEMS	Cotri-moxazole		Other meds dispensed	**ARV drugs**		CD4	Hgb, RPR, TLC, other lab	Refer or consult or link/ provide If hospitalized, # of days
										Adhere	Dose		Adhere/ Why	Regimen/ Dose dispensed			
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Pregnancy/family planning status if woman is of childbearing age:
P = Pregnant
If pregnant, give estimated due date (EDD) and write PMTCT if referred to PMTCT
FP= Not pregnant and on family planning
If using FP, note methods (note: more than 1 method may be recorded)
No FP = Not pregnant and not using FP

Codes for TB status (check on each visit):
No signs = no signs or symptoms of TB
TB refer = TB suspected and referred for evaluation
INH = currently on INH prophylaxis (IPT)
TB Rx = currently on TB treatment. Record TB card #
Sputums = TB suspected and sputum sample sent or record results

Codes for potential side effects or other problems:
Nausea
Diarrhoea
Fatigue
Headache
BN burning/numb/tingling
Rash
Anaemia
ABdominal pain
Jaundice
FAT changes
CNS: dizzy, anxiety, nightmare, depression

Codes for new OI or other problems:
Zoster
Pneumonia
DEmentia/**Enceph**
Thrush–oral/vaginal
FEVER
COUGH
DB difficult breathing
IRIS Immune reconstitution inflammatory syndrome
Weight loss
UD urethral discharge
PID pelvic inflammatory disease
GUD genital ulcer disease
Ulcers–mouth or other_____

Codes for why poor/ fair adherence:
1 Toxicity/side effects
2 Share with others
3 Forgot
4 Felt better
5 Too ill
6 Stigma, disclosure or privacy issues
7 Drug stock out—dispensary
8 Patient lost/ran out of pills
9 Delivery/travel problems
10 Inability to pay
11 Alcohol
12 Depression
13 Other_____

Codes for ART adherence. Estimate adherence for twice daily ART using the table below:

Adherence	%	Missed doses per month
G(good)	≥ 95%	≤ 3 doses
F(fair)	85-94%	4-8 doses
P(poor)	< 85%	≥ 9 doses

Follow-up education, support and preparation for ARV therapy

		Date/comments	Date/comments	Date/comments
Educate on basics, prevention, disclosure	Basic HIV education, transmission			
	Prevention: abstinence, safer sex, condoms			
	Prevention: household precautions, what is safe			
	Post-test counselling: implications of results			
	Positive living			
	Testing partners			
	Disclosure			
	To whom disclosed (list)			
	Family/living situation			
	Shared confidentiality			
	Reproductive choices, prevention MTCT			
	Child's blood test			
Progression, Rx	Progression of disease			
	Available treatment/prophylaxis			
	Follow-up appointments, clinical team			
	CTX, INH prophylaxis			
ART preparation.....initiation.....support, monitor...	ART -- educate on essentials (locally adapted)			
	Why complete adherence needed			
	Adherence preparation, indicate visits			
	Indicate when READY for ART: DATE/result Clinical team discussion			
	Explain dose, when to take			
	What can occur, how to manage side effects			
	What to do if one forgets dose			
	What to do when travelling			
	Adherence plan (schedule, aids, explain diary)			
	Treatment supporter preparation			
	Which doses, why missed			
	ARV support group			
Home-based care, support	How to contact clinic			
	Symptom management/palliative care at home			
	Caregiver booklet			
	Home-based care -- specify			
	Support groups			
	Community support			

Appendix V – The Levels of Care in Decentralized Health Service Delivery

Table I. The national standard for the following levels of health care

i	Ministry of health and other national level institutions
ii	National referral hospitals - entire population – 27000000
iii	Regional referral hospital – regional population – 2000000
iv	District health services - District Level population – 500000
v	General district hospital (district level – 500000 population)
vi	Health centre IV – sub country level 100000)
vii	Health centre III – parish level – 20000
viii	Health centre II - sub parish level - 10000
ix	Health centre I - up to 1000 people.

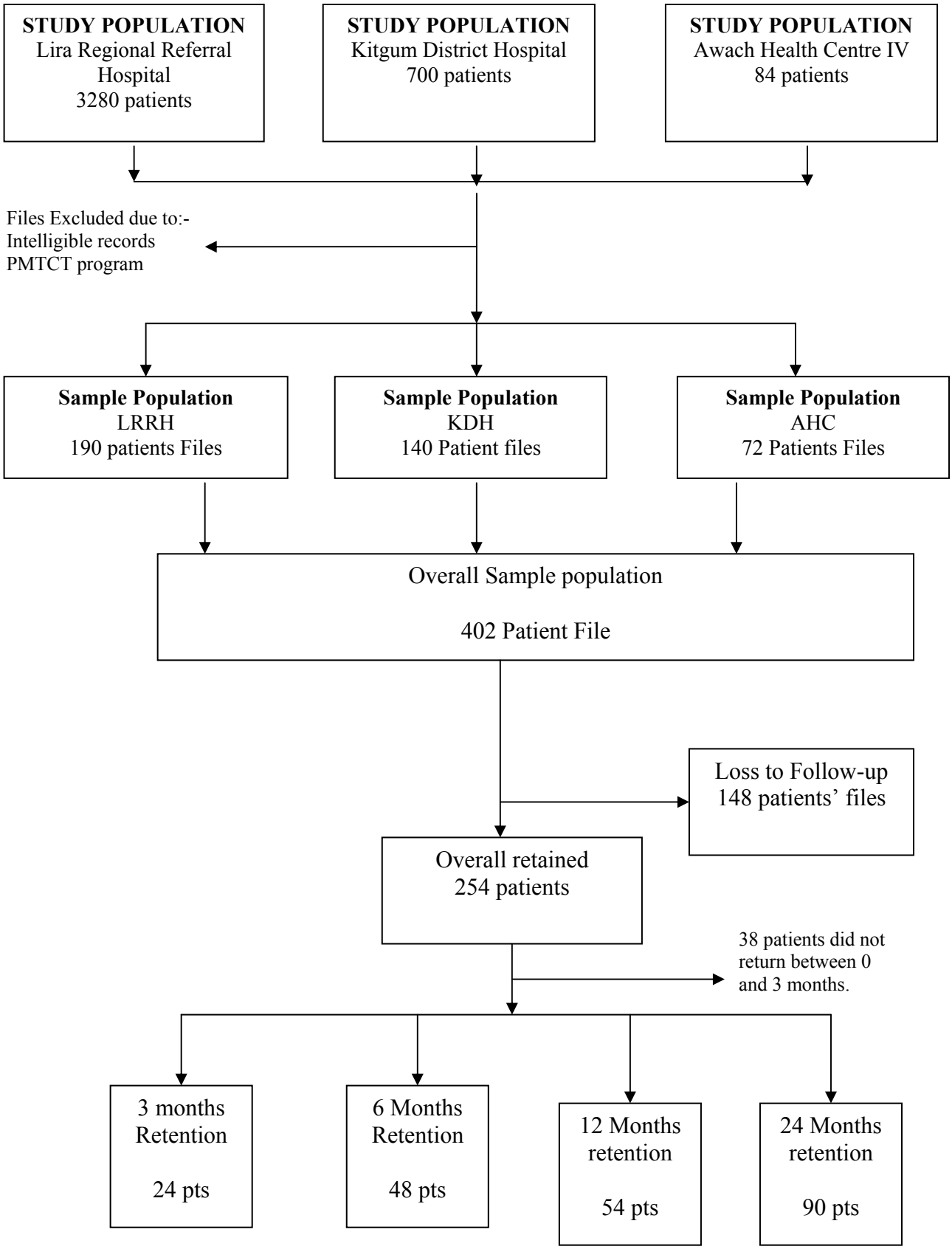
Table II. Roles of the decentralized system in HIV care in Northern Uganda

Regional Hospital	Managed by a team of provide Specialist care – including in patient care and OI management. CD4 lymphocyte testing
District Hospital	Managed by team of medical officers. Support supervision to health units in the district, medical and surgical in patient and outpatient care. Psychosocial support, In patient TB services.
Health Centre Four	Often sub county based, manned by a Medical officer (doctor). Carry out emergency surgical and medical care. Carry out referrals, Counseling, Psychosocial Support. Provide assessments and initiate patients on ART. Supervise TB services in the sub county.
Health Centre Three	Carry out follow-up for PHA on HAART, Provide check ups, out patient care, on going counseling and psychosocial support. Identify problems and making referrals
Health Centre Two	Carries out follow-up providing co trimoxazole and other support services
Health Centre One	Village level health service delivery support by Village health teams, Home visitors and community based Organizations. Carry out motivation for PHAs, Therapeutic counseling, Community based directly observed therapy, linkages with CBCs for social and material support

Appendix VI – The WHO Clinical Classification for HIV

CODES	WHO Stage I indicator condition	CODE	WHO Stage IV
WS 11	Asymptomatic HIV infection	WS41	Candidiasis, bronchi, trachea, or lungs
WS12	Persistent lymphadenopathy	WS42	Candidiasis, eosophageal
WS13	Acute retroviral infection	WS43	Carcinoma, invasive cervical
	WHO Stage II	WS44	Cryptococcosis, extrapulmonary
WS21	Unintentional weight loss(<10%)	WS45	Cryptosporidiosis, with diarrhoea (>1 month duration)
WS22	Minor mucocutaneous manifestations	WS46	Cytomegalovirus disease
WS23	Herpes Zoster infection	WS47	Cytomegalovirus retinitis(with loss of vision)
WS24	Recurrent upper respiratory infections	WS48	Herpes simplex (mucocutaneous > 1 month, or any visceral disease
		WS49	Histoplasmosis, disseminated or extrapulmonary
	WHO Stage III	WS410	HIV encephalopathy
WS31	Unintentional weight loss (>10%)	WS411	HIV wasting syndrome
WS32	Chronic diarrhoea (>1month)	WS412	Isosporiasis, with diarrhoea (> 1/12)
WS33	Prolonged fever (> 1 month)	WS413	Kaposi's sarcoma
WS34	Oral candidiasis	WS414	Lymphoma
WS35	Oral hairy leukoplakia	WS415	Mycobacterium avium complex or M. kansasii, disseminated or extrapulmonary
WS36	Severe bacterial infections	WS416	Mycobacterium, of other species or unidentified species, disseminated or extrapulmonary
WS37	M. tuberculosis, pulmonary (within previous year)	WS417	M. tuberculosis, dessiminated or extrapulmonary
WS38	Vulvovaginal candidiasis (> 1 month, or poorly responsive to treatment).	WS418	Pnuemocyctis carinii pnuemonia
		WS419	Progressive multifocal leukoencephalopathy
		WS420	Salmonella septicaemia (non – typhoid)
		WS421	Toxoplasmosis of brain
		WS422	Coccidoidomycosis, disseminated or extrapulmonary
WS39	Other: specify		

Appendix VII – Flow Chart of Study Procedure



Appendix VIII- Data Collection Tool

__ __ __ __ __ __
Patient Study Number

No.	Questions and Filters	Coding Category	Skip To	Answer
1.	Name of health facility	[codes to be listed]		
2.	Level of health facility	Regional Hospital 01 District Hospital 02 Health Centre 03		

NO.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP TO	ANSWER
3.	Data Collecting Tool Identification Number	Clinical records 01 Laboratory register 02 Pharmacy logbook 03		
4.	Site Identification Number	[Codes to be listed]		
5.	Interviewer code	[Codes to be listed]		
6.	Data collection date	[__ __ | __ __ | __ __] DD MM YY		
7.	Patient unique ID number	……		
8.	Patient Age	15 – 17 years 01 18 – 29 years 02 30 – 44 years 03 45 (and above) years 04		
9.	Patient Sex	Female 01 Male 02		
10.	Patient Occupation	Student Peasant Farmer Unemployed Employed		
11.	Home Village, Parish, Sub Country District	…… …… …… ……..		
12.	Start time of data collection	__ __ : __ __ [Hour: minute]		
NO.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP TO	ANSWER
13.	Record date of last clinic visit	[__ __ | __ __ | __ __] DD MM YY Not recorded 09		
14.	Record patient weight at ART treatment initiation.	[__ __ __] kg Not recorded 09		

15.	Record patient weight at last clinic visit.	[__ __ __] kg Not recorded 09		
16.	Record patient's functional status at last clinic visit.	Working 01 Ambulatory 02 Bedridden 03 Not recorded 09		
17.	Record patient's WHO stage at ART treatment initiation.	Stage 1 01 Stage 2 02 Stage 3 03 Stage 4 04 Not recorded 09		
18.	Record patient's WHO stage at last clinic visit.	Stage 1 01 Stage 2 02 Stage 3 03 Stage 4 04 Not recorded 09		
19.	Was patient receiving CTX prophylaxis at the last clinic visit?	No 00 Yes 01 Not recorded 09		
20.	Was patient on active TB treatment, or no treatment at all at last clinic visit?	On active TB treatment 01 Not on treatment at all 02		
21.	Has patient been a transfer in through PMTCT?	No 00 Yes 01 Not applicable (if male)		
22.	Was patient ever pregnant while on ART treatment?	No 00 Yes 01 Not applicable (if male)		
23.	Was patient pregnant at last clinic visit?	No 00 Yes 01 Not applicable (if male) 444 Not recorded 09		

NO.	QUESTIONS AND FILTERS	CODING CATEGORY						
24.	Record whether there was an active disease 1) before ART initiation (date before Q21), during ART treatment, and 3) at the last clinic visit (date Q36). Circle 01 for 'yes' and 02 for 'no'. Circle 09 for 'not recorded'. Step 1: a) Find ART initiation date (Q23): [__ __| __ __| __ __] DD MM YY b) Find last clinic visit date (Q36): [__ __| __ __| __ __] DD MM YY Step 2: Record active disease before ART initiation (Step 1-a). Step 3: Record active disease during ART treatment. This is any active disease occurring between ART initiation date (Step 1-a) and last clinic visit date (Step 1-b). Step 4: Record active disease at last clinic visit (Step 1-b).	**Stage Defining Condition**	**Before ART initiation**		**During ART treatment**		**At last clinic visit**	
			Yes	**No**	**Yes**	**No**	**Yes**	**No**
		a) Chronic diarrhoea > 1 month	01	00	01	00	01	00
		b) Oral candidiasis	01	00	01	00	01	00
		c) Pulmonary tuberculosis	01	00	01	00	01	00
		d) Several bacterial infections	01	00	01	00	01	00
		e) Unexplained prolonged fever > 1 month	01	00	01	00	01	00
		f) Weight loss greater of equal to 10%	01	00	01	00	01	00
		g) Candidiasis of oesophagus trachea/ bronchi	01	00	01	00	01	00
		h) Cryptococcosis, extrapulmonary	01	00	01	00	01	00
		i) Crytosporidiosis with diarrhoea > 1 month	01	00	01	00	01	00
		j) Cytomegalovirus disease	01	00	01	00	01	00
		k) Extrapulmonary tuberculosis	01	00	01	00	01	00
		l) Herpes simplex infection, mucocutaneous/ visceral	01	00	01	00	01	00
		m) HIV encephalopathy	01	00	01	00	01	00
		n) Kaposi's sarcoma	01	00	01	00	01	00
		o) Lymphoma	01	00	01	00	01	00
		p) Non-typhoid Salmonella septicaemia	01	00	01	00	01	00
		q) Pneumocystis carinii pneumonia	01	00	01	00	01	00
		r) Toxoplasmosis of the brain	01	00	01	00	01	00
		s) Wasting syndrome	01	00	01	00	01	00
		t) Disseminated mycosis	01	00	01	00	01	00
		u) Not recorded	09	09	09			

NO.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP TO	ANSWER
1.	Pre-treatment CD4 count.	[__ __ __ __] Not recorded 09	→ Q54 → Q55	
2.	Date of pre-treatment CD4 count	[__ __ | __ __ | __ __] DD MM YY Not recorded 09		
3.	Most recent CD4 count	[__ __ __ __] Not recorded 09	→ Q56 → Q57	
4.	Date of most recent CD4 count	[__ __ | __ __ | __ __] DD MM YY Not recorded 09		
5.	Lowest ever CD4 count	[__ __ __ __] Not recorded 09	→ Q58 → Q59	
6.	Date of lowest ever CD4 count	[__ __ | __ __ | __ __] DD MM YY Not recorded 09		
7.	Date First enrolled in the HIV clinic.	[__ __ | __ __ | __ __] DD MM YY Not recorded 09		
8.	Date Found Eligible for ART.	[__ __ | __ __ | __ __] DD MM YY Not recorded 09		
9.	Date Transferred in already on ART	[__ __ | __ __ | __ __] DD MM YY Not recorded 09		

10.	Date First ART dispensed.	[__ __ | __ __ | __ __] DD MM YY Not recorded 09		
11.	Date of last refill of the current ART dispensed.	[__ __ | __ __ | __ __] DD MM YY Not recorded 09		
12.	Record date of last prescription/ refill (ART)	[__ __ | __ __ | __ __] DD MM YY Not recorded 09		

NO.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP TO	ANSWER	
13.	Record start date of FIRST ART treatment prescribed at this facility. Use Code in ART KEY below to indicate combination used	[__ __ | __ __ | __ __] DD MM YY Not recorded 09			
14.	Record start date of Second ART treatment prescribed at this facility. Use Code in ART KEY below to indicate combination used	[__ __ | __ __ | __ __] DD MM YY Not recorded 09			
15.	Record start date of Third ART treatment prescribed at this facility. Use Code in ART KEY below to indicate combination used	[__ __ | __ __ | __ __] DD MM YY Not recorded 09			
ART KEY	Record the ART prescribed at the facility: First look for fixed dose combinations (FDC). FDC are a combination of drugs in one pill/ tablet/ capsule. - Triple combination means there are three drugs in one pill, such as "D4T(3), 3TC, NVP". - Double combination means there are two drugs in one pill, such as	**DRUG NAME** **Triple combination: three drugs combined in one pill** a) d4T (30), 3TC, NVP b) d4T(40), 3TC, NVP c) AZT (ZDV), 3TC, NVP d) TDF, FTC, EFV			

	"Combivir" (AZT/3TC). Find and circle the correct FDC. If a FDC is not available, circle each single antiretroviral drug in regimen. If antiretroviral is not listed in the table, record the name of the drug under x) Others (Specify).	e) AZT (ZDV), 3TC, ABC **Double combination: two drugs combined in one pill (including boosted PIs)** f) AZT (ZDV), 3TC g) TDF, FTC h) LPV, RTV **Single antiretroviral drug** i) AZT (Zidovudine/ ZDV) j) ddI (Didanosine) k) d4T (Stavudine) l) 3TC (Lamivudine) m) ABC (Abacavir) n) NVP (Nevirapine) o) EFV (Efavirenz) p) IDV (Indinavir) q) NFV (Nelfinavir) r) SQV (Saquinavir) s) RTV (Ritonavir) t) FTC (Emtricitabine) u) TDF (Tenofovir) v) Others? (Specify) _____			
16.	Record stop date of first ART.	[___ | ___ | ___]			

		DD MM YY Not recorded 09		

NO.	QUESTIONS AND FILTERS	CODING CATEGORY	Date	ANSWER
17.	What was the reason for discontinuation of First ART regimen? Record start date of First ART treatment prescribed at this facility.	Starting TB treatment 01 Adverse reactions (see list) 02 Treatment failure clinical 03 Treatment failure immunological 04 Poor adherence 05 Patient decision 06 Pregnancy 07 End of PMTCT 08 Stock out 09 Other, specify _____ N.B. Adverse reactions include: nausea/ vomiting, diarrhea, headache, fever, rash, peripheral neuropathy, hepatitis, jaundice, dementia, anemia, pancreatitis, CNS adverse event, other adverse event	[__ __ | __ __ | __ __] DD MM YY Not recorded 09	
18.	What was the reason for discontinuation of Second ART regimen? Record start date of Second ART treatment prescribed at this facility.		[__ __ | __ __ | __ __] DD MM YY Not recorded 09	
19.	What was the reason for discontinuation of Third ART regimen? Record start date of Third ART treatment prescribed at this facility.		[__ __ | __ __ | __ __] DD MM YY Not recorded 09	

Record ARV, dosage, refill visit dates and the number of pills dispensed for each refill from Month "0" to Months "24".

20.	Record date: [__ __| __ __ | __ __] DD MM YY Not recorded 09		ARV drug name	ARV dosage (mg)	# of pills dispensed	# of pills returned
		1				
		2				
		3				
21.	Record date: [__ __| __ __ | __ __] DD MM YY		ARV drug name	ARV dosage (mg)	# of pills dispensed	# of pills returned
		1				

	Not recorded 09	2				
		3				
22.	Record date: [__ __| __ __ | __ __] DD MM YY Not recorded 09		ARV drug name	ARV dosage (mg)	# of pills dispensed	# of pills returned
		1				
		2				
		3				
23.	Record date: [__ __| __ __ | __ __] DD MM YY Not recorded 09		ARV drug name	ARV dosage (mg)	# of pills dispensed	# of pills returned
		1				
		2				
		3				
24.	Record date: [__ __| __ __ | __ __] DD MM YY Not recorded 09		ARV drug name	ARV dosage (mg)	# of pills dispensed	# of pills returned
		1				
		2				
		3				
25.	Record date: [__ __| __ __ | __ __] DD MM YY Not recorded 09		ARV drug name	ARV dosage (mg)	# of pills dispensed	# of pills returned
		1				
		2				
		3				
26.	Record date: [__ __| __ __ | __ __] DD MM YY Not recorded 09		ARV drug name	ARV dosage (mg)	# of pills dispensed	# of pills returned
		1				
		2				
		3				
27.	Record date: [__ __| __ __ | __ __] DD MM YY Not recorded 09		ARV drug name	ARV dosage (mg)	# of pills dispensed	# of pills returned
		1				
		2				
		3				

28.	Record date: [__ __| __ __ | __ __] DD MM YY Not recorded 09		ARV drug name	ARV dosage (mg)	# of pills dispensed	# of pills returned
		1				
		2				
		3				
29.	Record date: [__ __| __ __ | __ __] DD MM YY Not recorded 09		ARV drug name	ARV dosage (mg)	# of pills dispensed	# of pills returned
		1				
		2				
		3				
30.	Record date: [__ __| __ __ | __ __] DD MM YY Not recorded 09		ARV drug name	ARV dosage (mg)	# of pills dispensed	# of pills returned
		1				
		2				
		3				
31.	Record date: [__ __| __ __ | __ __] DD MM YY Not recorded 09		ARV drug name	ARV dosage (mg)	# of pills dispensed	# of pills returned
		1				
		2				
		3				
32.	Record date: [__ __| __ __ | __ __] DD MM YY Not recorded 09		ARV drug name	ARV dosage (mg)	# of pills dispensed	# of pills returned
		1				
		2				
		3				
33.	Record date: [__ __| __ __ | __ __] DD MM YY Not recorded 09		ARV drug name	ARV dosage (mg)	# of pills dispensed	# of pills returned
		1				
		2				
		3				
34.	Record date: [__ __| __ __ | __ __]		ARV drug name	ARV dosage (mg)	# of pills dispensed	# of pills returned

	DD MM YY Not recorded 09	1					
		2					
		3					
35.	Record date: [__ __| __ __ | __ __] DD MM YY Not recorded 09		ARV drug name	ARV dosage (mg)	# of pills dispensed	# of pills returned	
		1					
		2					
		3					
36.	Record date: [__ __| __ __ | __ __] DD MM YY Not recorded 09		ARV drug name	ARV dosage (mg)	# of pills dispensed	# of pills returned	
		1					
		2					
		3					
37.	Record date: [__ __| __ __ | __ __] DD MM YY Not recorded 09		ARV drug name	ARV dosage (mg)	# of pills dispensed	# of pills returned	
		1					
		2					
		3					
38.	Record date: [__ __| __ __ | __ __] DD MM YY Not recorded 09		ARV drug name	ARV dosage (mg)	# of pills dispensed	# of pills returned	
		1					
		2					
		3					
39.	Record date: [__ __| __ __ | __ __] DD MM YY Not recorded 09		ARV drug name	ARV dosage (mg)	# of pills dispensed	# of pills returned	
		1					
		2					
		3					
40.	Record date: [__ __| __ __ | __ __] DD MM YY Not recorded 09		ARV drug name	ARV dosage (mg)	# of pills dispensed	# of pills returned	
		1					
		2					

		3				
41.	Record date: [__ __| __ __ | __ __] DD MM YY Not recorded 09		ARV drug name	ARV dosage (mg)	# of pills dispensed	# of pills returned
		1				
		2				
		3				
42.	End time of data collection	__ __ : __ __ [Hour: minute]				
No.	**QUESTIONS AND FILTERS**	**CODING CATEGORY**			**SKIP TO**	**ANSWER**
43.	Cumulative No of Months of return for follow-up	1 - 01 2 - 02 3 - 03 4 - 04 5 - 05	6 - 06 7 - 07 8 - 08 9 – 09 10 - 10	11 – 11 12 - 12 13 - 13 14 - 14 15 - 15	16 - 16 17 - 17 18 - 18 19 - 19 20 - 20	21 - 21 22 – 22 23 – 23 24 - 24
44.	No of months consecutively not returning for follow-up till date of record review	None 01 One months 02 Two months 03 Three month 04				
45.	Retention Status	Retained in the ART program 01 Lost to Follow-up 02			→ Q 33	
46.	Details of Retention Status	3 months retention 01 6 months retention 02 12 months retention 03 24 months retention 04 Overall retention 05				

Data Management Form

RETENTION OF HIV POSITIVE PERSONS AT 3 ANTIRETROVIRAL THERAPY CLINICS IN POST-CONFLICT NORTHERN UGANDA

NO.	QUESTION AND FILTERS	CODING CATEGORY	SKIP TO
1.	Form 1 Clinical Record/ Laboratory Result	Completed 01 Partially completed 02 Other (specify) 03	
2.	Form 2 Pharmacy Logbook Result	Completed 01 Partially completed 02 Other (specify) 03	
3.	Checked by Researcher	Signature_____ [__ __| __ __| __ __] DD MM YY	→ Ready for data entry

Appendix IX: Letter of Introduction

To: (1) The District Health Officer
: (2) The Superintendent in Charge of the Health Facility

My name is Andrew Alyao Ocero. I am a Final Year, Masters Student at the National School of Public Health, Medunsa, University of Limpopo, Republic of South Africa. I am carrying out a study to establish how long HIV positive people that are started on ART in health units in Northern Uganda continue attending the clinic. The study will also help us to determine what are reasons make some people leave the ART clinic and why some people stay on. We also as much as possible wish to find out what has happened to the people that stopped coming for their ARV drugs. This study will be a record review of HIV positive adults enrolled into ART clinics your health facility

Since you have been selected to participate in the study the following will be requested for:

Access to the ART and Pre-ART Registers.
Patient comprehensive care cards and clinic files.
Pharmacy records
Laboratory records

Risks Of the Study:

There is no potential risk. No physical contact shall be made with the patients.
The review shall be carried out aware from your area of activity.

Benefits

You will receive the results of the study which will provide information on the retention and follow-up rates of patients on the ART program in your health facility.
The review process will help you to know how well your records are kept.

Confidentiality and Security of records:

The patient records shall be reviewed in a isolated area to ensure confidentiality.
Patient numbers and not names shall be used in the review process.

The records shall be retrieved and used in bits. All the records picked by the researcher and returned will be signed for.

If you have any problem or queries relating to this study, you may state them at any time during the course of the study.

You are free to contact Andrew Alyao Ocero, the researcher, at P.O. Box 281, Lira or Phone, Andrew on 0772-456-915.

STATEMENT OF CONSENT

I am the in charge of this health facility/ in charge of the ART clinic.

The purpose and nature of this study has been explained to me and I fully understand this information.

I wish to know the results of the survey.

…….. ……. ……

Name of in charge/DHO Signature. Date

…….. …….. ……

Name of the Clinic in charge. Signature Date

…….. ……. ……..

Name of Researcher. Signature Date