

HIV/AIDS CARE IN RURAL UGANDA. PART 1.

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Abstract

HIV/AIDS therapies and healthcare were reviewed both from literature searches and by questioning healthcare workers, patients and family members in rural Uganda. Antiretroviral therapies are more easily accessed in some areas than others, we recommend greater access to second-line antiretroviral drugs for when patients become resistant to the first-line antiretroviral therapies. **Kalyesubula R, Schertz J. HIV/AIDS Care in Rural Uganda. Part 1. Med J Therapeut Africa. 2007;3:251-243.**

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Introduction

The impact of human immunodeficiency virus (HIV) infection and acquired immunodeficiency syndrome (AIDS) has expanded since 1981 when the Centers for Disease Control (CDC) first published their report describing 5 cases of *pneumocystis carinii* pneumonia in homosexual men in 1981.(1) At the end of the 20th century an estimated 36 million humans were living with HIV/AIDS worldwide, and close to 22 million deaths have been attributed to HIV/AIDS since 1981.(2)

Globally, 47 million humans are now believed to be infected with HIV, of which 25 million live in sub-Saharan Africa.(3) Approximately 2.8 million adults and children in this region acquired HIV in 2006, more than the combined total for all other regions of the world. In 2006, in sub-Saharan Africa, an estimated 2.1 million deaths resulted from HIV/AIDS, which comprised 72% of global HIV/AIDS deaths.

In 1982 health workers in the Rakai District in southwestern Uganda identified a new, fatal disease locally known as "slim", characterized by wasting, persistent fever and diarrhea, Figure 1.(4) Seventeen cases were identified the following year, with the burden of HIV/AIDS doubling every 6 months. By the early 1990s, HIV prevalence in Uganda was estimated at 31% among antenatal clinic patients who were tested, and at 15% for all adults. During this time, more than 50% of medical ward patients in Uganda's hospitals were infected with HIV, while in 1994, a Gulu District hospital in northern Uganda reported 67.7% of its medical ward patients were infected. In the same timeframe, in the southwest rural district of Rakai where HIV/AIDS was first identified in Uganda, 73.5% of adult deaths were due to HIV infection.

In 1987, President Yoweri Museveni established the National AIDS Control Program, the first of several intense government programs to address the epidemic. Ten years later, Uganda became the first African country and one of the first countries globally to report declining trends in HIV/AIDS.(5) By 2004, the national HIV prevalence had fallen to 6.4%, with 10.1% in urban locales and 5.7% in rural areas. However, we have found evidence suggesting that HIV/AIDS may be again be increasing in rural areas. In a study of 25 rural villages in southwest Uganda prevalence increased from 2000 to 2004, at 5.6% in men and 6.9% in women to 6.5% in men and 8.8% in women, respectively.(3) These findings are supported by the Uganda HIV/AIDS Sero-Behavioural Survey (UHSBS) that found a national prevalence of 6.4%, up from 6.0% in 2002.(9)

Over the last 20 years the Uganda Ministry of Health (MOH) in collaboration with the World Health Organization (WHO), the Joint United Nations Program on HIV/AIDS (UNAIDS), the President's Emergency Fund for AIDS Relief (PEPFAR) and other partners progressively established a comprehensive care program for HIV-infected humans. These services were initially available in the 2 national and 10 regional referral centers. Since 2003, programs in the prevention, care and management of HIV/AIDS have been launched throughout Uganda, and include supply of antiretroviral drugs. Comprehensive care for patients has 11 components: HIV counseling and testing; antiretroviral therapy; prevention and treatment of tuberculosis and other infections; cotrimoxazole prophylaxis for prevention of HIV-related infections; treatment of opportunistic infections; palliative care; family planning; good nutrition; social, spiritual, psychological and peer support; respect for human rights; and reduction of stigma associated with HIV/AIDS.

The infrastructure for providing comprehensive HIV/AIDS care is less advanced, particularly in the rural areas of the country due to chronic underdevelopment. This scenario is troubling because 90% of the population lives in the country, and access to health care is not available to at least half of households. According to the report by Okero et al, 1,600 physicians were available for over 20 million humans in 2003. Recent reports describe the successful implementation of antiretroviral therapy through a home-based care program and routine HIV counseling and testing for mother-to-child HIV transmission, our study addresses the issues of



Figure 1. Map of Uganda with districts and regions.(4)

additional documentation on how HIV/AIDS care and management challenges are being addressed in rural settings in Uganda. The objectives of our assessment were to

- 1)Review the challenges and lessons learned over the past 20 years regarding key HIV/AIDS issues in Uganda
- 2)Appraise the current status of HIV/AIDS management in several rural settings of Uganda
- 3)Identify primary deficits in care offered in rural locales requiring further study.

This article covers a)health resources and access to care; b) access to antiretroviral therapy; c) HIV diagnosis and monitoring.

Materials and methods

LITERATURE SEARCHES

The authors searched PubMed from 1984 to July 2007 using Medical Subject Headings: "HIV infections", "Acquired Immunodeficiency Syndrome", "HIV", "HIV long-term survivors", "Uganda", "rural population", "rural health services", "hospitals, rural", "rural health", "suburban health services", and "poverty areas". The terms searched in PubMed were repeated in Google or Lexus Nexus for reports from relief and government organizations, medical meetings, regional news sources.

INFORMAL INTERVIEWS AND DISCUSSION GROUPS

Between March and July 2007 one of us (RK) visited 4 rural treatment centers:

- 1)Nakaseke Hospital
- 2)Lifecare Center, both in Luwero District (central region)
- 3)Gulu Hospital in Gulu District (northwest region)
- 4)Kisubi Hospital in Entebbe District (southcentral

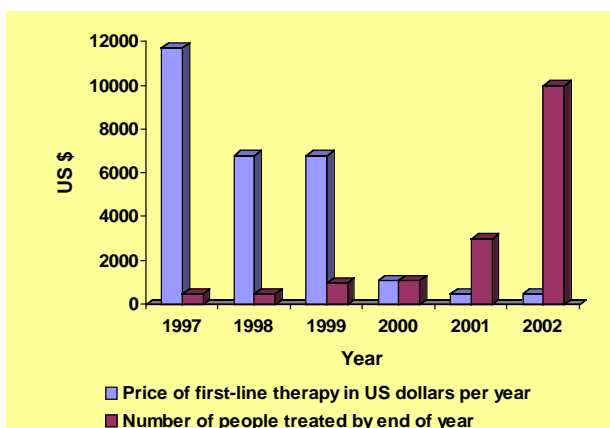


Figure 2. Trends in the cost of ARV drugs in Uganda overlaid with the number of people in therapy, 1997-2002.(15)

region).

Each facility gives care and treatment management to over 300 patients living with HIV/AIDS. We spoke informally with 8 physicians, 12 nurses, 8 counselors and 4 administrators from these healthcare facilities. Physicians, nurses, counselors and health visitors (health workers who make house-calls) at Nakaseke Hospital and Lifecare Center participated in 2 focus group discussions. Urban centers providing HIV/AIDS care in Kampala were visited, including the Infectious Disease Clinic (IDC), Joint Clinical Research Center (JCRC), Mildmay International Center and Mulago ISS Clinic. Topics on HIV/AIDS care and prevention were discussed (Appendix 1).

We consulted the Uganda Ministry of Health about the current national status of HIV/AIDS. We also gathered information from the Uganda AIDS Control Project (ACP), the JCRC, Infectious Disease Institute (IDI) and The AIDS Support Organization (TASO).

We consulted 2 traditional healers from the Luwero District for opinions on HIV/AIDS issues. They permitted us to report these findings (Appendix 2).

We collected data from focus group discussions and phone interviews with 4 non-governmental organizations: Association Françoise Xavier Bognoud (AFXB), Nakaseke Community Development Initiatives (NACODI), World Vision, Kasangombe and Integrated Community Efforts for AIDS (ICEA). We

- 1.HIV counseling and testing
- 2.AIDS care and treatment
- 3.Antiretroviral therapy
- 4.Prevention of perinatal HIV transmission
- 5.Control of sexually transmitted infections (STI)
- 6.Information, education, communication, and behavior change promotion
- 7.HIV/AIDS/STI surveillance, program monitoring and evaluation.

Table 1. Components of Ministry of Health's public health response to HIV/AIDS.(18)

LEVEL	ALL FACILITIES	POPULATION BASE / AREA	FUNCTION
HC II	1,469	5,000 Parish	Provide preventive, promotive and outpatient services
HC III	809	20,000 Sub-county	Offer preventive, promotive, outpatient curative, maternity and inpatient (IP) services
HC IV	154	100,000 County	Provide preventive, promotive, outpatient, curative inpatient services, emergency surgery, blood transfusion; supervise HC II & III facilities; centralized health trend data collection/analysis: disease surveillance
District general hospital		500,000 District	Laboratory, X-ray plus services offered at HV IV; research, training, consultation to community healthcare programs
Regional referral hospital		2,000,000 Region	Services offered at district hospital plus specialist services, including psychiatry, intensive care, dentistry, pathology, neurosurgery.
National referral hospitals		22,000,000 Nation	Services offered at regional hospital plus complicated tertiary care, comprehensive specialist services, teaching and research

Table 2. Government, private not-for-profit, and private for-profit health facilities and functions by population served in 2002.(20)

consulted 5 faith-based organizations: Catholic Relief Services Gulu, Islamic Medical Association of Uganda (IMAU), Uganda Catholic Medical Bureau, Church Human Services AIDS Prevention Program (CHUSA) and Nakaseke Redeemed Church for the civilian perspective, Appendix 2.

During routine clinical care in hospitals or in their homes, 30 patients discussed their thoughts about HIV/AIDS, Appendix 3. Patients were assured that their names and information were confidential.

SUMMARIES OF FINDINGS AND RECOMMENDATIONS FOR FOLLOW-UP

The Ministry of Health identified 7 components to the public health HIV/AIDS response in their 2005-6 report, Table 1.(18) Findings from discussions and interviews with the 4 groups (hospitals, traditional healers, FBOs and NGOs, and patients) were summarized according to the relevant MOH components and source of information. Tables 2 to 5 are sum-

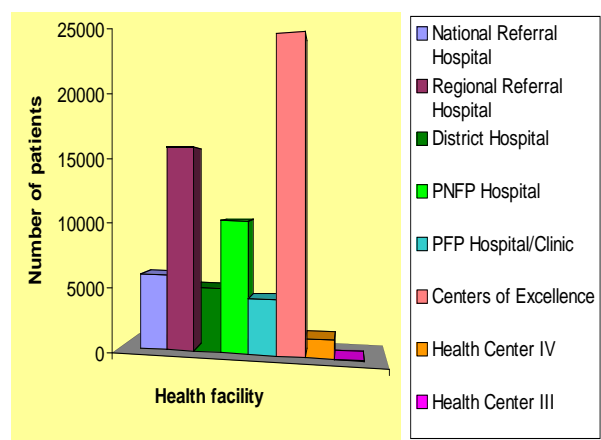


Figure 3. Distribution of patients on antiretroviral therapy per type of health facility.(38)

maries, corresponding to the 4 groups interviewed.

Results

HEALTH RESOURCES AND ACCESS TO CARE

HISTORY & LITERATURE OVERVIEW

In 1986, 5 years after the first cases of HIV/AIDS were reported, the Ministry of Health established the National AIDS Control Program, and launched a

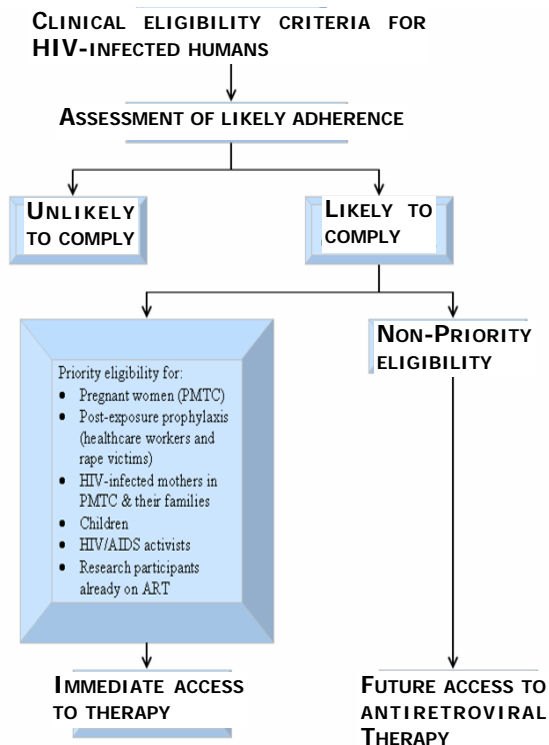


Figure 4. Eligibility criteria for antiretroviral treatment.(35)

Service	Urban Hospital/Healthcare Facility				Rural Hospital/Healthcare Facility			
	IDC	JCRC	Mildmay	Mulago	Lifecare	Gulu	Kisubi	Urban Hospital/Healthcare Facility
HIV counselling and testing	Usually receive already tested patients but repeat tests	Usually receive already tested patients but repeat tests	Cares for both adults and children	Pioneered the RCT program	Primarily offer community outreach, liaising with FBOs and NGOs	VCT offered at hospital and through community outreach	VCT offered at hospital and through community outreach	Sends out patients to other centers after managing acute problems
AIDS care and treatment	VL access only for special cases eg drug switching	Very comprehensive OI treatment	+Comprehensive OI treatment	+Comprehensive OI treatment	*Limited OI treatment	+Comprehensive OI treatment	*Limited OI treatment	CD4 offered
Anti-retroviral therapy	Research centre with increased access due to research trials and PEPFAR funds	Research centre with increased access	Research centre with increased access	Research centre with increased access	No ART Refers patients to other centers	1st line ART regimens	1st line ART regimens	VL not offered

Table 3. Status of relevant MOH national response components in select rural and urban hospitals or healthcare facilities

VCT = voluntary counseling and testing; RCT = routine counseling and testing; PCR = polymerase chain reaction; FBOs = faith based organizations; NGOs = non-governmental organizations; VL = viral load; OI = opportunistic infections; ART = antiretroviral therapy

*Limited OI treatment = treatment of few OI such as pneumocystic pneumonia and diarrheal diseases

+Comprehensive OI treatment = treatment of most OI diagnosed except those requiring admission as in the case of Mildmay (does not admit patients though it has the capacity to diagnose)

Very comprehensive OI treatment = treatment of all OI diagnosed.

nationwide response that gradually included other relevant sectors coordinated by the Uganda AIDS Commission. The objectives of these national initiatives were to introduce "new policies, expanded partnerships, increased institutional capacity for care and research, public health education for behavior change, strengthened sexually transmitted disease (STD) management, improved blood transfusion services, care and support services for humans with HIV/AIDS, and a surveillance system to monitor the epidemic." (5)

Today, 13 government programs and perhaps 2,000 NGOs and FBOs are active in national HIV/AIDS control plans. Components of the Ministry of Health's public health response to HIV/AIDS are given in Table 1. (19)

Uganda's healthcare services are primarily provided by national referral, regional referral, and district/rural hospitals that are government facilities, as well as non-government hospitals and health centers serving parishes, sub-counties, and sub-districts. Currently, the Ministry of Health reports 2,536 health units across the country, which is likely an underestimation because many are not registered with the Ministry of Health. (20) Most lack adequate supplies and clinical equipment, a reality that is relatively unchanged since the turn of this century. (21)

According to the 2000 Health Inventory, 42% of Uganda's 5,152 parishes had one or more health-care facility. (22) A 1997 assessment concluded that in the country where 86% of the population lived, 36% of the qualified staff needed was available. (23) In 2003, 57% of health workers were qualified and most of them served in hospitals or urban areas; thus, unqualified health personnel served the vast majority of Ugandans. (22)

By the end of 2005, 68% of approved posts were filled with trained health personnel. (24) The current physician to patient ratio in Uganda is estimated at 1:24,700 while the nurse to patient ratio is 1:5,000. (25) In contrast, Cuba had an estimated physician patient ratio of 1:167 and the USA ratio was 1:358 between 1990 and 2003. (26)

The healthcare situation is worse for HIV/AIDS patients who are chronically sick and have to compete with other patients for health services. A study of 903 humans by the Uganda AIDS Commission (UAC) in the 56 districts of Uganda confirmed that service coverage across all activities was inconsistent. (27) Rural areas were underserved, while urban areas had high concentrations of health services. In 2004 the average distance to government facilities where humans sought first treatment was 5.2km in rural areas, and almost 20% of the population traveled more than 5km to a health facility. (28) According to the African Regional Health Report published in 2006, 33% of those needing HIV/AIDS treatment in Uganda were receiving it. (29) Lack of transportation is especially problematic for patients

who are switched to second-line antiretroviral therapies that may not be available locally, since these patients will need to travel for monthly supplies for the rest of their lives. This leads to non-adherence and subsequently drug resistance. (30)

In order to address such complexities, several strategies have been implemented; some are clinic-specific, while others are government or non-government initiatives. Rural clinics assign specific days of the week when HIV/AIDS patients are seen. In addition clinical officers (similar to physicians' assistants or nurse practitioners in the United States) and, in some cases, nurses have been trained to take on the role of physicians in HIV/AIDS care. As a result, patients with disease complications have greater access to the physicians. For example, nurses and clinical officers at Nakaseke Hospital have monthly appointments with newly diagnosed patients without opportunistic infections and with those on antiretroviral treatment for more than 6 months who have kept all their appointments and have demonstrated good treatment compliance. Every 3 months, or when an urgent need arises, these patients are seen by physicians. When HIV/AIDS is treated like any other chronic disease, integrating care within existing health services is an important means of minimizing stigma and discrimination. Furthermore integration of HIV/AIDS clinics maximizes use of the available minimal resources (especially healthcare personnel), particularly in rural, resource-poor settings.

Using a slightly different approach, AIDS Healthcare Foundation, through their Uganda CARES organization, has graduated at least 2 classes of lay humans in their HIV Medic program. (31) Working as treatment extenders under the direct supervision of physicians, the medics provide care to HIV/AIDS patients who are stabilized on treatment. Another program, Integrated Management of Adult and Adolescent Illness of Uganda's National AIDS Program, has trained more than 1,400 health workers in HIV/AIDS care. (27) Utilizing simplified guidelines and training materials, lay and community workers administer some elements of care previously provided by nurses, while nurses take on select responsibilities typically handled by physicians. This approach has been successfully applied in Botswana and other African nations.

To ensure continuity of care, collaboration between rural and urban treatment centers has been a priority of the government of Uganda and other funding partners. Rural clinics can refer patients too complex for them to Centers of Expertise, such as the Mildmay International Center, the JCRC, the IDI, Uganda Virus Research Institute, and Reach Out Mbuya. Many centers have access to second line drugs for HIV treatment and also have higher capacity to do more advanced testing. Other organizations like The AIDS Support Organization have assumed key roles in counseling and provision of home-based

	Rural Hospital/Healthcare Facility Nakaseke Hospital, Lifecare Center and Kisubi Hospital (n=30)
Service	Patient Perspective
HIV counselling and testing	80% (n = 24/30) interviewed expressed a preference for home vs hospital-based testing Long distances to health facilities, lack of privacy and at times shortage of test kits were reasons cited for not visiting testing facilities. All patients (n = 30/30) preferred rapid kit tests because of same-day availability of results. Disclosure and discordance were very difficult issues to deal with especially if the woman tested first Best handled if testing done as a couple
AIDS care and treatment	All patients (n = 30/30) were receiving free co-trimoxazole prophylaxis from healthcare units Patients from Nakaseke Lifecare (NLC) (n = 10, 33%) had to buy fluconazole from there or other hospitals Tuberculosis treatment was free of charge to all participants but those from NLC had to travel for x-rays and most other diagnostic investigations X-ray was available for 5,000-10,000Shs (USD4-7) at two hospitals Cost was unaffordable for most patients Clinicians primarily available only once weekly If patient fell sick on day when clinician was not available, healthcare workers would have difficulty accessing patient's files and patient would have to line up in long queues
Antiretroviral therapy	Eleven patients (36.7%) interviewed were on ARVs with 9 on 1st line ARVs and 2 on 2nd line ARVs One patient on 2nd line ARV got monthly treatment from IDI in Kampala Second patient on 2nd line ARV defaulted on treatment because of lack of funds for transport to collect drugs from Mulago Hospital None of the 3 centers visited had ART for children but those from Nakaseke Hospital would be referred to Kasana Health Center which is a TREAT centers started by JCRC Patients required to pay for first CD4 measurement Patients on ARVs reported tremendous improvement in health and well being Patients requested nutritional support to accompany the medications especially when very sick.

Table 4. Status of relevant MOH national response components from perspective of patients interviewed from 3 rural hospitals.

care. Most of the previously mentioned centers have branches in rural areas where they continue to provide care for patients. For example, TASO has several branches throughout the country, and the JCRC, through the Timetable for Regional Expansion of Antiretroviral Therapy program, has expanded to several districts in the country with the aim of improving care and bringing services nearer to the PLWAs.(32) In total, from 1999 to 2006 JCRC was supporting 46 centers throughout Uganda with a total of 52,199 patients, including 4,960 children.

Research institutions within Uganda additionally care for and treat humans with HIV/AIDS, these institutions have international partners and are funded internationally. The Uganda Virus Research Institute manages the Rakai Project and collaborates with the United States Centers for Disease Control. Other institutions are the Academic Alliance for AIDS Care and Prevention in Africa; Makerere University; Uganda Medical Research Council Program on AIDS; the JCRC; Mulago, Nsambya, and Mengo Hospitals; and the Mildmay International Center. HIV/AIDS interventions undertaken by private industry have thus far been limited.(11)

SUMMARY OF INTERVIEWS AND DISCUSSION

As stated in the National Strategic Framework for HIV/AIDS Activities in Uganda, by the year 2005/6, 80% of HIV-positive humans were to have access to HIV/AIDS care. However, few comprehend this need as intensely as those on the frontlines: humans who require healthcare and the workers who treat them, such as a physician from Entebbe who stated, "We now have over 150 patients on antiretroviral drugs. We could actually get more patients started but our facility cannot handle more patients, so we follow up only on the ones we have."

Table 3 compares the status of the relevant MOH public health response components in the hospitals and healthcare facilities visited, both rural and urban.

Table 4 reports the opinions of patients and PLWAs regarding whatever components are applicable. Robert to update.

AREAS FOR FOCUS AND FOLLOW-UP

Based on the findings described by current reports, both published and observed, we make these recommendations:

- 1) Increase rural access to care, including antiretroviral therapy for children, so more patients can benefit from treatment that would otherwise be unavailable to them. Use of existing adult treatment centers may be a means for extending care to children.
- 2) Increase the number of rural healthcare facilities and train healthcare workers to integrate HIV and tuberculosis care in their services.
- 3) Evaluate the costs and benefits of offering incentives to healthcare workers in rural health facilities to ensure equitable distribution of medical services throughout Uganda.

Access to antiretroviral therapy

HISTORY & LITERATURE OVERVIEW

In the past decade, Uganda has expanded HIV/AIDS care and support services and access to antiretroviral therapy. The Drug Access Initiative (DAI), a UNAIDS program, was launched in 1997 to generate appropriate healthcare transformation with the goal of increasing access to HIV/AIDS care including antiretroviral therapy.(15) In cooperation with DAI, the National Advisory Board in the MOH directed the

Antiretroviral drug	Urban access	Rural access
Abacavir	Yes	Some centers
Delarviridine	Yes	No
Didanosine	Yes	No
Efavirenz	Yes	Yes
Hydroxyurea	N/A	N/A
Indinavir	Some centers	No
Lamivudine	Yes	Yes
Lopinavir + ritonavir	Some centers	No
Nelfinavir	Some centers	No
Nevirapine	Yes	Yes
Ritonavir	Some centers	No
Saquinavir soft gel	Some centers	No
Saquinavir hard gel	Some centers	No
Stavudine	Yes	Yes
Stavudine + lamivudine + nevirapine	Yes	Yes
Tenofovir	Some centers	No
Tenofovir+ Emtricitabine	Some centers, research trials	Only in research trials.
Zalcitabine	Some centers	No
Zidovudine	Yes	Yes
Zidovudine + lamivudine	Some centers	Some centers
Zidovudine + lamivudine + abacavir	Some centers	No

Table 5. Antiretroviral drugs and access to them.

project's introduction and implemented a more comprehensive HIV/AIDS medical care program, including a plan for expanding antiretroviral drug access throughout Uganda. By the end of 2000, when the DAI concluded, 5 accredited HIV/AIDS treatment centers had been established in Kampala, and 1,000 patients were taking antiretroviral drugs.

Following reorganization of the advisory board, the National Committee on Access to Antiretroviral Therapy was formed. In 5 months the Committee had developed 7 proposals, including a national policy for antiretroviral therapy, implementation guidelines for antiretroviral therapy, and costing of the country's antiretroviral therapy program.(15) Expansion of antiretroviral access was to be undertaken in a systematic way consisting of 4 stages. In phase I, regional referral hospitals were qualified by December 2003. By the end of 2004, phase II was completed, with district hospitals equipped to provide antiretroviral drugs. Rollout to healthcare centers IV was to be completed by December 2006, and phase IV was to follow with expansion to lower level facilities and the local community.(15) Each center had to fulfill criteria for accreditation including:

- 1)Adequate staffing of trained personnel who are physicians, counselors, pharmacists, laboratory technicians, nurses
- 2)Functioning laboratories for basic tests
- 3)Antiretroviral drug procurement and safe storage facilities
- 4)Availability of counseling and support services for patients
- 5)Health management information system (HMIS) for record keeping.(34)

The primary purpose for the national guidelines was to provide a consistent, systematic framework for expansion of antiretroviral access that was to be carried out in 4 stages. In phase I, regional referral hospitals were qualified by December 2003. By December 2004, phase II was completed, with district hospitals equipped to provide antiretrovirals. Rollout to healthcare centers IV was to be completed by December 2006, and phase IV was to follow

with expansion to lower level facilities and the local community.(15) Each center had to fulfill criteria for accreditation including

- 1)Adequate staffing of trained personnel including physicians, nurses, counselors, laboratory technicians, pharmacists
- 2)Functioning laboratories for basic tests
- 3)Antiretroviral drug procurement and safe storage facilities
- 4)Availability of counseling and support services for patients
- 5)Health management information system (HMIS) for record keeping.

In 2003, the MOH drafted national eligibility criteria for antiretroviral therapy since broad availability of antiretroviral therapy had not been realized, Figure 4. Once clinical eligibility was established, patients were assessed for likelihood of adherence to therapy and then prioritized according to their health status. All HIV-positive patients are considered eligible for antiretroviral if they meet the clinical criteria and other patient-specific factors (see detailed discussion in HIV Diagnosis and Monitoring). The government, in collaboration with other funding agencies, supplies most antiretroviral treatment for HIV/AIDS patients. Faith Based Organizations (FBOs), Community Based Organizations (CBOs) and Non-Governmental Organizations (NGOs) sometimes meet the additional costs of treatment above and beyond the capacity of the government.

The MOH guidelines for first-line antiretroviral therapy for adults and adolescents with no prior antiretroviral exposure or initiation more than 3 months previously but immediately stopped, consists of a 3-drug combination of zidovudine-lamivudine plus nevirapine or efavirenz; or stavudine-lamivudine plus nevirapine or efavirenz.(36) Nevirapine is to be given to pregnant women or women for whom contraception cannot be assured. In patients requiring ART plus tuberculosis therapies containing rifampicin, efavirenz is to be given.(36) If first-line therapy fails, second line therapy should be initiated according to the recommendations in Table 6.

In 2000, a partnership between the United Nations and 5 pharmaceutical companies, known as the Accelerating Access Initiative, resulted in price reductions of antiretroviral drugs. The AIA program, coupled with the Joint Clinical Research Center's importation of low-cost generic drugs, brought first-line generic antiretroviral therapy to Uganda for USD480 per year, Figure 2. By 2004 the national program rolled out a free antiretroviral program to reach the projected 200,000 humans needing treatment. Currently, 19 antiretroviral medications are available in Uganda, more in urban than in rural areas, Table 5. The 5 categories of drugs are nucleoside reverse transcriptase inhibitors, nucleotide reverse transcriptase inhibitors, non-nucleotide reverse transcriptase inhibitors, fusion inhibitors, protease inhibitors.

By April 2007, staff from 268 health facilities estimated 101,000 patients nationwide were on antiretroviral therapies, Figure 3.(37,38)

Summary: Interviews and discussions

Access to antiretroviral therapy is increasing in Uganda, both in urban and rural areas. Nonetheless, limitations to broader use remain, partly due to inadequate drug supply but more frequently due to lack of accessible, accredited health-care facilities.

During a home-visit, a patient in Nakaseke District shared her dilemma: "I have been on antiretroviral drugs for 3 years now. My doctor said that the drugs I am taking are causing me to have difficulty breathing and are also making my face thin. He has stopped all my drugs and has told me to go to Mulago in Kampala where I can get better drugs because Triomune is all he had. The problem is that I don't have transportation to and fro, which costs 8000 Uganda shillings (USD5). I think I am going to die but who will take care of my 13 year old daughter who is also living with HIV?"

Table 3 reviews the status of the relevant MOH public health response components in the hospitals and healthcare facilities visited, both rural and urban. Table 4 reports the opinions of patients and PLWAs regarding these same components.

AREAS FOR FOCUS AND FOLLOW-UP

Based on the findings described by current reports, both published and observed, we recommend for focus and follow-up in Uganda:

- 1) Provide second-line antiretroviral therapies to district hospitals to increase access to antiretroviral therapies since many patients have been on first-line antiretroviral drugs for an extended time.
- 2) Increase the number of healthcare facilities in rural areas and train healthcare workers to integrate HIV and tuberculosis care in their services.
- 3) Evaluate the costs and benefits of offering incentives to healthcare workers in rural health facilities to ensure equitable distribution of medical services throughout Uganda.

HIV diagnosis and testing

HISTORY & LITERATURE OVERVIEW

HIV testing is the first step in preventing HIV/AIDS and accessing life-lengthening treatment.

Early in 2002, 3 institutions in Uganda provided HIV/AIDS reference laboratory services: the Uganda Virus Research Institute, the JCRC, and Makerere University-Johns Hopkins University Research Collaboration Core Laboratory. Additionally, in 2003, more than 20 fee-for-service testing sites were reported in all key sites through the AIDS

Information Center.(15) In total, 43 HIV testing and counseling facilities were operational in 2003, clearly inadequate for serving the population. The 2004 to 2005 national sero-behavioral survey reported that 15% of Ugandans were aware of their HIV status, while 22% of women and 20% of men did not know where they could be tested.(9) However, a recent publication noted an increase in the number of testing sites, to 460 by August 2006, and an estimated 3 million Ugandans have accessed testing or counseling.(41,42)

Initially patients had to pay for testing, and when ELISA assay technology was the only test used, patients had to wait up to 3 weeks for the results.(43)

In resource-limited settings, reuse of test membranes are a cost-effective possibility for extending testing to more patients. Acaye et al evaluated the performance of reusing test membranes which had been used previously for negative tests for the detection of HIV antibodies (HIVCHEK 1 + 2, Ortho Diagnostic Systems, Paris, France). The sensitivity and specificity of the reusing strategy compared with a HIV determination obtained by using new HIVCHECK 1 + 2 tests were 89.1% and 100%, respectively. For ethical reasons, the reuse strategy was abandoned.(44)

Although voluntary counseling and testing (VCT) has been the primary HCT model, with facilities in 51 of 56 districts in 2006, other approaches such as RCT and home-based testing have been instituted in an attempt to increase access to care.(45) VCT is initiated by the client and is typically obtained through outreach services or stand-alone programs. Home-based HCT is another version of VCT except that the service is provided in the home. In the RTC model, the healthcare provider initiates the discussion about HIV/AIDS testing and counseling, offering the services as part of routine healthcare. Mandatory testing and counseling is required if organ or blood donation is involved or in cases of rape or assault. Even with variations in HCT delivery the simplified protocol has 5 steps: (1) initial contact; (2) pre-test session; (3) HIV testing; (4) post-test session; and (5) referral and follow-up.(42)

UNAIDS/WHO recommends that RCT become the norm for curative healthcare centers "if the benefits of ART and prevention of opportunistic infections are to reach all the people that need them."(46) In theory, RCT represents an intervention opportunity with previously untested individuals who seek emergency treatment or who are inpatients, since it has been suspected that many are HIV-infected.(47) Furthermore, offering HIV testing as part of the overall workup to determine the cause of the presenting illness precludes the potential stigmatization that a patient might experience if seen at a testing clinic. Patients have the opportunity to opt out, but according to one study, 5% declined the opportunity to test.(46)

To better understand HIV testing practices at an urban hospital, Wayenze and colleagues interviewed medical inpatients at Mulago Hospital in Kampala, the largest public hospital in Uganda.(47) The interviews were conducted with 395 patients on the day of discharge. During their hospital stay 28% of patients stated that they were asked to test for HIV. Of these, 72 agreed to test, 52 received results, 33 were HIV-positive and another 5 patients (1.3%) said they were tested at their own request. The authors concluded that the foremost barrier to testing was the lack of having the opportunity to test.

In a recent report, patient acceptance of RCT in Mulago Hospital's medical emergency unit was described by Nakanjako et al.(46) Of 233 patients enrolled in the study, 83% were not aware of their HIV status, although 171 had visited a health facility in the prior 6 months. Of eligible patients, 95% accepted the opportunity to test. Altogether 43% were HIV-positive, and all but one received the results within 30 minutes of testing. Interestingly, patients accepted testing because it cost nothing and because they wanted to know the cause of their current illness. The authors concluded that RCT was acceptable to patients visiting the emergency unit at Mulago Hospital, and therefore, RCT should become standard policy.

In Uganda, HIV sero-status is assessed in adults using antibody or antigen tests. The Uganda National Policy Guidelines for HIV Counseling and Testing recommend use of 2 rapid specimen antibody kits, employing either the parallel or the serial method, Figure 5.(42) Results are typically available in 10 to 20 minutes so counseling and treatment can be offered immediately thereafter. HIV testing in

ARV drug	Urban	Rural
Abacavir	Yes	Some centers
Delavirdine	Yes	No
Didanosine	Yes	No
Efavirenz	Yes	Yes
Hydroxyurea	N/A	N/A
Indinavir	Some centers	No
Lamivudine	Yes	Yes
Lopinavir + ritonavir	Some centers	No
Nelfinavir	Some centers	No
Nevirapine	Yes	Yes
Ritonavir	Some centers	No
Saquinavir soft gel	Some centers	No
Saquinavir hard gel	Some centers	No
Stavudine	Yes	Yes
Stavudine+lamivudine	Yes	Yes
+nevirapine		
Zalcitabine	Some centers	No
Zidovudine	Yes	Yes
Zidovudine+lamivudine	Some centers	Some centers
Zidovudine+lamivudine	Some centers	No
+abacavir		

Table 6. Antiretroviral drugs available in select urban and rural communities in Uganda

infants requires a slightly different initial approach because the majority (approximately 90%) of HIV-positive children acquire the virus in utero.(36) Antibody tests like ELISA are only useful after 18 months when the children are producing their own antibodies; before then they have maternal-derived HIV antibodies. Accordingly, HIV polymerase chain reaction (PCR) and protein 24 (p24) antigen tests are used to detect viral presence and diagnose HIV infection during infancy. By the time most infected infants are 3 months old, definitive HIV diagnosis is possible and virtually in all by the age of 6 months using PCR. PCR testing is generally available at national referral, regional referral, and district general hospitals, while the degree of immunosuppression via CD4+ T cells evaluation is available at the regional referral hospitals and several other facilities like the Mildmay International Center.(15)

Healthcare providers may additionally diagnose HIV from symptoms and a thorough clinical evaluation.(36) This is a common approach in resource-limited settings where ELISA or rapid testing is not available. The World Health Organization (WHO) HIV staging guidelines are frequently used to evaluate

- 1)Determination of immunosuppression when CD4 T cells are absent
- 2)The clinical progression of HIV/AIDS
- 3)When to initiate ARVs.

The WHO stages range from 1 to 4 and represent disease progression from HIV infection to advanced HIV/AIDS.(36) When the WHO HIV clinical staging criteria are used to determine eligibility for antiretroviral therapy, they are often used in conjunction with CD4 cell counts or total lymphocyte counts (TLC).

Most rural and urban centers have adopted the national guidelines for initiation and management of antiretroviral depending on their HIV testing and diagnostic capacities. However, since comprehensive laboratory services are not available in rural areas, the total lymphocyte count (TLC) is used as a surrogate marker for CD4 counts.(36) HIV-related symptoms meeting WHO HIV stage III or IV clinical criteria and a TLC of 1200/mm3 or below may be used to determine eligibility for antiretroviral treatment.

As an example, Masaka Hospital in Masaka District uses the following criteria for ARV eligibility:

- CD4 count of less than 200 cells/L (where available) or absolute lymphocyte counts of <1200/dL
- WHO stage III and IV
- Patient living in or around the hospital or clinic
- Strict adherence to schedule demonstrated by keeping appointments and, where applicable, adherence to other drugs like co-trimoxazole and anti-tuberculosis treatment

The national guidelines for antiretroviral therapy

include laboratory guidelines for monitoring drug toxicities and response to therapy.

SUMMARY OF INTERVIEWS AND DISCUSSION

Table 3 reviews the status of the relevant MOH public health response components in the hospitals and healthcare facilities visited, both rural and urban. Table 4 reports the opinions of patients and humans living with HIV/AIDS regarding these same components.

Areas for focus and follow-up:

Based on the findings described by current reports, both published and observed, the following recommendations should be considered for focus and follow-up:

Stakeholders should consider providing RCT rather than VCT to at-risk populations within the confines of their communities. This will lead to earlier detection of HIV infection, thereby improving care and prevention.

Community involvement in HIV/AIDS activities needs to be a priority of policy makers, as CBOS, NGOS, and FBOs have limited capacity to do this work.

Conclusions

Over the past 25 years, Uganda has made tremendous strides in the fight against the HIV/AIDS pandemic. However, considerable resources are needed to ensure that the rural communities have broad access to available healthcare services.

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Appendices

APPENDIX 1

Topics discussed with hospitals and healthcare facilities caring for HIV/AIDS patients

1.HIV/AIDS testing capabilities (on-site vs referral only, types of tests)

2.Number of HIV/AIDS patients currently managing and percent of those on antiretroviral treatment

3.Types of HIV/AIDS support activities offered (counseling, support groups, community outreach)

4.Services for PMTC and OI offered

5.Surveillance and monitoring of HIV/AIDS incidence, prevalence, antiretroviral treatment

6.Challenges faced by hospitals and healthcare facilities regarding HIV/AIDS

APPENDIX 2

Topics discussed with traditional healers

1.Identifying humans with HIV/AIDS (signs and symptoms)

2.Treatment(s) offered for humans with HIV/AIDS

3.Collaboration with local HIV/AIDS organizations

4.Challenges faced by traditional healers regarding HIV/AIDS

APPENDIX 3

Topics discussed with faith-based organizations and non-governmental organizations

1.Programs offered on HIV/AIDS prevention, care, and support

2.Key communication objectives regarding HIV/AIDS

3.Assessment of program and communication effectiveness

4.Challenges faced by organizations regarding HIV/AIDS

APPENDIX 4

Topics discussed with humans living with AIDS

1.Effectiveness of HIV/AIDS prevention strategies

2.Time since HIV/AIDS diagnosis

3.Access to HIV/AIDS medical care and support in local community with antiretroviral treatment, counseling, and support groups.

4.Types of services utilized at care centers in local community with antiretroviral treatment, counseling, and support groups.

5.Personal role in prevention and care of HIV/AIDS

6.Challenges faced as a person living with HIV/AIDS