University of Alberta

The influence of a community-based HIV/AIDS treatment project on HIV/AIDS knowledge, attitudes, and prevention practices in rural Uganda

by

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Dedication

I dedicate this thesis to the people who have loved and supported me most in life, my family. Without them, I would not be the person I am today.

Abstract

A community-based antiretroviral therapy (CBART) program has been operating in Rwimi sub-county in Western Uganda since 2005. The purpose of this study was to evaluate whether this CBART program led to increased knowledge and awareness of HIV and ART, improved attitudes towards people living with the disease, and improved HIV prevention practices in the broader community. Surveys and focus group discussions (FGDs) were carried out from September to December 2009 with 405 residents of Rwimi sub-county and 193 adult residents of a nearby sub-county without a CBART program. Logistic regression was used to describe associations with ART knowledge, HIV/AIDS-related attitudes, HIV testing, and condom use. Residents of Kisomoro had more positive results in all areas. However, in the multivariable models this was only statistically significant for HIV/AIDS-related attitudes. Findings from the FGDs confirmed that, overall, the CBART program did not appear to significantly increase HIV/AIDS knowledge, attitudes, and prevention practices.

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List of Abbreviations

95% CI	95% confidence interval
AIDS	Acquired immunodeficiency syndrome
ART	Antiretroviral therapy
CBART	Community-based antiretroviral therapy
FGD	Focus group discussion
GTZ	German government development agency
HAART	Highly active antiretroviral therapy
HIV	Human immunodeficiency virus
JCRC	Joint Clinical Research Centre
MSF	Médecins Sans Frontières
MTCT	Mother-to-child transmission
NAC	National AIDS Control
NGO	Non-governmental organization
OR	Odds ratio
PLWHAs	Persons living with HIV/AIDS
STIs	Sexually transmitted infections
TASO	The AIDS Support Organization
TB	Tuberculosis
UNAIDS	Joint United Nations Programme on HIV/AIDS

Note: The acronym HIV/AIDS is used when referring to the range of consequences of HIV infection: from the initial asymptomatic HIV infection through clinical AIDS.

Chapter 1: Introduction

Global HIV/AIDS epidemic

The biological consequences of acquired immunodeficiency syndrome (AIDS) are a debilitating and protracted illness more often than not leading to death. The resulting pressure on human and material resources is enormous and often occurs in the world's regions least equipped to deal with it. As of 2010, 33.5 million individuals worldwide were estimated to be living with human immunodeficiency virus (HIV), and 9 million were considered to require life-saving antiretroviral therapy (ART). Yet fewer than half of those in need have access to ART, considered the standard of care in the world's industrialized nations (1). In sub-Saharan Africa, where roughly 2/3 of those living with HIV/AIDS reside, the number of people requiring ART who receive it is less than 1/3 (1).

Uganda's response

One of the first countries to aggressively respond to HIV/AIDS was Uganda, a small land-locked country in East Africa. The first known AIDS case was reported there in 1982 (2). By the 1990's the country's HIV prevalence peaked, reaching 30% among the sexually active adult population in some urban areas. In 1986, the Ugandan Minister of Health was the first government in Africa to officially recognize the existence of HIV/AIDS during the World Health Assembly in Geneva. In the same year, the Ministry of Health launched the first National AIDS Control (NAC) Program, resulting in a well-documented decline of HIV infection rates in most parts of the country (3).

The NAC program piloted and implemented several interventions to avert the further spread of HIV. Specifically, the program initiated public education campaigns about the epidemic, promoted safer sexual behaviours–including abstinence, mutual faithfulness and condom use–and ensured safe blood transfusion practices in health facilities. Surveillance activities to monitor the magnitude and dynamics of HIV infection rates were also implemented (3). The interventions evolved over time as more knowledge about HIV/AIDS emerged.

The government realized that an effective response to HIV/AIDS must encompass branches of society and government outside of the health sector, and began to address individual and community barriers to improve prevention and care practices. Consequently, after the seemingly relentless spread of HIV infection in the late 1980's and early 1990's, the epidemic began to weaken. HIV prevalence rates steadily declined throughout the remainder of the 1990's, particularly in urban areas (3). As of 2010, the Uganda AIDS Commission estimated the national HIV prevalence ranged between 5% and 6% among the sexually active adult population (4).

AIDS is still an important health problem in Uganda. It is the leading cause of death among adults aged 15 to 49 years of age, and the fourth leading cause of death among children less than 5 years of age (5). In rural areas, where 85% of Uganda's population and the majority of AIDS patients live, the situation is especially severe. The health care infrastructure is weak, and the physician-to-population ratio is very low, at only 1 doctor per 25,000 Ugandans (6,7). As a result, the health facilities are overwhelmed. In some places, AIDS patients occupy 50% to 70% of the beds, and as many as 60% of tuberculosis (TB) patients are co-infected with AIDS (4). Another problem is that ART, which slows the progression of AIDS, is not provided equitably to all AIDS patients. The programs in place favour patients who live in, or have easy access to, urban centres where more physicians work. At the time of this study, only trained physicians were responsible for providing ART to AIDS patients. However, this practice was unsustainable in rural Uganda because of the low doctor-to-patient ratio in these areas (6,7). Consequently, in 2009, out of the estimated 500,000 persons living with advanced HIV infection in Uganda, roughly 250,000 were still in need of ART (4).

Kabarole District and the CBART program

Kabarole District is located in the southwest region of Uganda. It was originally part of the Toro Kingdom when Uganda gained independence from Britain in 1962 (8). Kingdoms were later abolished in 1967. The district is divided

into fourteen sub-counties, which are further divided into parishes and villages. As of 2005, the Kabarole District had a population of 359,180, with 90% of inhabitants residing in rural areas. The main language in the region is Rutooro, and most economic activities are centred on agriculture, with food crops, such as yams and bananas, and cash crops, such as tea and coffee, as primary staples (8).

Kabarole District has three hospitals located in the district capital of Fort Portal, which is located near the district centre as shown in Figure 1, one is run by the local government and two are run by non-governmental organizations (NGOs). The surrounding, more rural areas are served by health centres, which provide limited health services to the general public (9). There are three Health Centre IVs, which operate like mini-hospitals with a medical health officer and at least one other physician. All are government run. Twenty-three Health Centre IIIs and 31 Health Centre IIs serve the remaining populations. Health Centre IIIs can be found in every sub-county and are led by a senior clinical officer, with an outpatient clinic, maternity ward, and a laboratory (17 are run by government and 6 are run by NGOs). Health Centre IIs are run by a nurse and a midwife, with an outpatient clinic and necessary supplies to treat common diseases, such as malaria (20 are run by government, 7 by NGOs, and 4 by private organizations). In total, sixty health facilities serve residents of the Kabarole District.

Figure 1. Health Centres in the Kabarole District

In 2005, a community-based human HIV/AIDS antiretroviral therapy (CBART) program was established in Rwimi, a sub-county located in the southern region of the Kabarole District. The program was based out of the sub-county's Health Centre III, located in Rwimi Town Centre. The goal of this program was to provide highly active antiretroviral therapy (HAART) to individuals residing in the underserved rural areas of Rwimi in an effective and

sustainable manner, while minimizing the requirement for physician time and specialized laboratory services (10). In doing so, emphasis was placed on the roles of community members to deliver medications and provide support and companionship for patients residing outside the major treatment centres.

Since the introduction of the CBART project, the Health Centre III in Rwimi has had significant improvements in its infrastructure and training of health staff (11). Program volunteers have also been involved in promoting HIV/AIDS and ART education, and ensuring that AIDS patients are receiving appropriate medications on a regular basis. The volunteers also receive continuous supervision and monitoring by the head volunteer administrator. To date, 41 community volunteers have been established throughout the sub-county. In addition, since the program began to enrol patients in February of 2006, 191 clients have successfully initiated HAART in Rwimi (11). Of these, 185 were still receiving treatment as of 2008.

Proposed study

The CBART program has been engaging community volunteers and treatment associates to support ART monitoring and distribution since its inception in 2005. The purpose of this study was to evaluate whether the involvement of the community in this program led to increased knowledge and awareness of HIV and ART and led to improved HIV prevention practices in the broader population.

Chapter 2: Literature Review

A search was conducted in MEDLINE and PubMed databases using a combination of the terms "HIV," "antiretroviral therapy," "community-based," "knowledge," "attitudes," "behaviours," "prevention," and "sub-Saharan Africa." In total, 132 articles were found, 26 of which focused directly on whether improved availability of ART impacted both people receiving ART and the broader community.

Introduction

Since the early 2000's, programs centred in and around communities have been developed to improve access to ART for persons living with HIV/AIDS (PLWHAs). Several of these community-based responses have reported many benefits for both individuals receiving ART and the surrounding populations. They have gone on to positively influence voluntary HIV testing and risk behaviours, HIV/AIDS and ART-related knowledge, as well as attitudes towards PLWHAs. However, improved availability and accessibility of ART has also had unexpected drawbacks. Some groups have reported increases in risk behaviours as a result of improved availability of and access to ART. Additionally, new sources of stigma have emerged towards PLWHAs, including the belief that PLWHAs may go on to infect multiple new partners because of their improved health and extended lifespan.

The interplay between improved availability of ART for PLWHAs and its influence on knowledge, attitudes, and practices among local populations is a complex issue. Community-based programming in particular has had many benefits for patients involved in the programs, but broader, population-level benefits have been difficult to tease out.

Community-based responses

Less than fifteen years ago, opinions were divided as to the feasibility of providing ART in countries heavily affected by the HIV/AIDS epidemic, particularly in rural areas of sub-Saharan Africa, where the vast majority of

PLWHAs live (12). Some believed that the healthcare infrastructure in these regions would not be able to support treatment provision and expansion, and it would be difficult to maintain good adherence to the complicated regime of medications. This would lead to collapses in healthcare systems, and the possible emergence of new strains of drug-resistant HIV viruses, which would render the available methods of treatment useless (13,14). Others pointed out that there were already more cost-effective interventions available, such as improved access to condoms and education programs. Given the limited nature of HIV/AIDS funding at that time, some experts thought it was best to stick to prevention-centred activities, rather than invest in programs and activities that may worsen the already overwhelming HIV/AIDS epidemic (15).

In 2001, Farmer et al. became one of the first groups of researchers to show that, despite the reservations of many of the international community, the complicated regime of HAART could be implemented effectively in one of the poorest regions in the western hemisphere - the Central Plateau of Haiti. Despite deplorable health infrastructure in this HIV/AIDS-endemic area, only minor modifications to the treatment regime resulted in improved local capacity to treat those with advanced AIDS (14,16). Each of the 60 patients in the initial study were assigned to a community-health worker responsible for observing ingestion of medications, addressing patient and family concerns, and offering moral support (14). Reported side effects were rare and readily managed. All patients gained weight and improved functional capacity (14). When the program was expanded in 2003 to over 1,000 patients, both ART adherence and clinical outcomes were excellent. Viral load testing showed that nearly 90% of patients had undetectable viral loads one year after initiating ART (16).

According to Boulle et al., one of the first programs to demonstrate the feasibility of administering ART in southern Africa was the Khayelitsha program, set up in 2001 by Médecins Sans Frontières and the provincial government of the Western Cape, South Africa (12). Early outcomes from the Khayelitsha program helped to establish the importance of a patient-centred model and strong community activism for ART care. A study examining the outcomes of the

community-based ART program in Khayelitsha seven years after its inception found the program demonstrated substantial and durable clinical benefits for those enrolled (12). Of the 7,323 patients initiated on ART since 2001, over 80% had suppressed viral loads 5 years after initiating treatment (12).

The focus of attention is now shifting from feasibility to sustainability. In 2005, a CBART program was established in Rwimi, a sub-county of the Kabarole District in western Uganda, by a team of researchers from the University of Alberta in Edmonton, Canada, Makerere University in Kampala, Uganda, and the Kabarole Health District, Uganda. The goal of this program was to provide HAART to individuals in an effective and sustainable manner that takes maximum advantage of the available resources in the community (10). The program utilizes both treatment associates and community volunteers to provide support and companionship to patients outside of treatment centres and to deliver medications to the underserved rural AIDS patients. This has served to establish very high levels of treatment adherence, and thus very positive clinical outcomes, with 90% of patients still enrolled in the program having undetectable viral loads 6 months after initiation of treatment (17).

Now, nearly ten years after Farmer et al. became the first to successfully demonstrate that CBART programs were feasible, effective, and sustainable for treating PLWHAs, several CBART programs in rural and urban areas of sub-Saharan Africa have gone on to demonstrate excellent adherence and clinical outcomes (12,17-22).

Influence of improved access to ART

Throughout the 2000's, more and more members of the international HIV/AIDS community began hypothesizing what a stronger focus on AIDS treatment could accomplish, particularly in sub-Saharan Africa (14,23). In addition to the increasing number of flourishing CBART programs, other larger-scale ART success stories began to emerge. In 1996, Brazil guaranteed ART and treatment for opportunistic infections for all in need (24). In 2000, the Brazilian Minister of Health reported a lower than expected HIV incidence for that year, as

well as a significant decline in AIDS-related mortality. This was attributed to the policy of universal ART access put in place just four years earlier (25). Furthermore, some began to view treatment as a vehicle to increase voluntary counselling and testing, and helping to break the silence surrounding HIV/AIDS (14,23,24,26,27). As the 2000's came to a close, many individuals in the scientific community began to recognize the crucial role improved ART availability and accessibility played in the fight against HIV/AIDS.

Influence of improved access to ART on voluntary testing and risk behaviours

In mid-2004, the Ugandan government began to offer free ART to PLWHAs in need of treatment as part of a 5 year pilot program. It began with just 2,700 patients in the first year and by 2007 about 100,000 patients were enrolled in the program (28). By the end of 2009, 55% of the estimated 400,000 men and women in need of ART in Uganda were receiving treatment (4). Voluntary testing for HIV also increased over this time period. In 2005, only 4.5% of men and 5.0% of women of reproductive age had tested for HIV and received their results in the past twelve months (4). By 2009, this figure increased to roughly 20% of men and woman throughout the country (4). Condom use with last non-spousal partner also increased, from 39% in 2001 to 48% in 2005 among adult women (29). However, it decreased among adult men over this same time period from 61% to 54% (29).

To date, numerous studies have examined how ART availability has influenced risk behaviours among ART clients, but few have examined the influence it has on population-level voluntary testing and risk behaviours. In 2006, Bunnell et al. assessed changes in sexual behaviours and risk of HIV transmission six months after ART and prevention interventions were established in a rural area of eastern Uganda (30). Participants involved in the interventions were offered free ART, group education on ART, and home-based HIV testing and counselling for all participants' household members. Six months after enrolment, they found a 70% reduction in risky sexual practices, such as inconsistent condom use and unprotected sex, as well as a 98% reduction in the number of seroconversions in uninfected partners (30). This helped to provide

initial evidence that ART, in combination with education and prevention activities, can help reduce HIV transmission from ART clients (30).

Two years later, the same group analyzed sexual risk behaviours among Ugandan adults in a nation-wide survey (31). While ART expansion was occurring rapidly throughout Uganda, they tested 18,525 participants for HIV, of whom 1,092 tested positive. Only 21% of those who tested positive were already aware of their HIV status, and under 10% were aware of their partners' HIV status (31). Forty percent had a HIV-negative partner, but fewer than 30% had used a condom during their last sexual encounter (31). It appeared that, despite aggressive ART expansion, voluntary HIV testing and safe sexual risk behaviours among the general population were not common.

In 2010, Luganda et al. examined rates of voluntary HIV testing of household members of PLWHAs participating in either home or clinic-based ART programs in south eastern Uganda (32). Of the 7,184 household members involved in the study, those in the home-based component were more than ten times more likely to have undergone voluntary HIV testing than those in the clinic-based component (32). These results were in accordance with previous studies conducted throughout Uganda examining uptake of voluntary HIV testing when offered in home-based programs (33-36). In the presence of home-based ART programs, provision of voluntary HIV testing was well received and resulted in the detection of a large number of previously undiagnosed PLWHAs (32,33).

In studies examining risk behaviours in the general population, however, few have found strong evidence to show that voluntary HIV testing or risk behaviours improve in the context of increased access and availability of ART (4,29,37). In discussions with adults and youths, both in and out of school, in Kampala, Uganda, Atuyambe et al. found that increased availability of ART was undermining the traditional prevention approaches, including abstinence, being faithful, and condom use. The ABC strategy was spearheaded by Uganda's Ministry of Health in the mid-1980's (37). Only when prevention services were integrated with ART services were benefits to voluntary HIV testing and risk behaviours found.

Influence of improved access to ART on knowledge

Despite increased availability and accessibility of ART throughout Uganda, few studies have examined patients' levels of HIV/AIDS and ART knowledge. Even fewer have looked at knowledge levels among the general population. Consequently, the impact of improved ART availability on the public's knowledge is relatively unknown. In 2008, Opio et al. compared levels of HIV/AIDS knowledge reported by Ugandan national health surveys conducted in 2001 and 2005 (29). It is important to note that at the time this latter survey was conducted national access to free ART had only been in place for a few months and on a very limited basis, with only 2,700 PLWHAs enrolled in the program in the first year (28). However, this is the first (and only) Ugandan study comparing national HIV/AIDS knowledge figures over a multi-year period. When asked if condoms can prevent HIV infection, the proportion of women who answered correctly increased slightly over this period from 65% in 2001 to 68% in 2005. For men, the proportion of correct responses remained constant at 77% (29). Comprehensive knowledge of HIV/AIDS also changed slightly or remained constant over this time. In 2005, 28% of female respondents aged 15 to 49 were assessed as having comprehensive HIV/AIDS knowledge compared to 27% in 2001, and 36% of male respondents aged 15 to 49 in 2005 had comprehensive knowledge compared to 39% in 2001 (29). The Uganda Demographic Health Survey conducted in 2006 found that 28% of women and 36% of men aged 15 to 49 were categorized as having comprehensive knowledge on HIV/AIDS (4,38). These figures are nearly identical to the 2001 and 2005 statistics described by Opio et al., indicating there have been no major changes in HIV/AIDS knowledge at the national level despite increased provision of ART.

In Kabarole District, a region in western Uganda with slightly higher ART coverage (60%) than the national average of 54%, special efforts have been made to increase access to ART (4,39). The capital city of Fort Portal is home to a centre of excellence in HIV/AIDS research, one of only seven in the country (40). In 2009, Kipp et al. examined public knowledge of HIV/AIDS and ART in the

Kabarole District. They sampled individuals randomly from the general population and asked them a series of questions pertaining to HIV transmission, testing history, and condom use. After interviewing 370 participants, they found that 70% were scored as having sufficient HIV/AIDS and ART knowledge, which compared well to other studies examining HIV/AIDS and ART knowledge among individuals on ART (39). The authors concluded that, overall, there were good levels of HIV/AIDS and ART knowledge in Kabarole, which was a direct result of the district's ART and education efforts (39). Unfortunately, there is no previous data on knowledge in the district, so it is not possible to compare results from this study with previous studies to establish a trend in HIV/AIDS and ART knowledge levels.

In 2003, the World Health Organization released a report stating that increased availability of ART in Khayelitsha had demonstrated that community-based, universal treatment is important for prevention because it can fuel education activities led by PLWHAs, help drive down HIV/AIDS-related stigma, and promote openness (22). A 2008 South African study (41) went on to examine the public's knowledge of HIV/AIDS and ART in Khayelitsha. Boulle et al. surveyed 1,576 members of the general public in Khayelitsha on HIV/AIDS and ART knowledge and HIV/AIDS openness. They found that the majority of respondents were able to cite at least one mode of HIV transmission, and almost half of the female respondents identified mother-to-child transmission (MTCT). Surprisingly, only one quarter of respondents stated that they had heard of ART. They also found that more than 80% of respondents discussed HIV/AIDS with their friends, more than 70% discussed HIV/AIDS with their partner, and more than 50% discussed HIV/AIDS with their relatives. In addition to listing whom they openly spoke to about HIV/AIDS, willingness of respondents to answer questions on sexual practices, history, and condom use also served to strengthen the evidence of a general openness about HIV/AIDS among participants.

Although respondents reported low levels of ART knowledge, the majority of participants had at least some knowledge of HIV/AIDS and were quite open about HIV/AIDS with their friends and families. However, these findings

only serve to further ascertain that the relationship between greater treatment availability and population-level benefits is nearly impossible to unravel.

Influence of improved access to ART on stigma

Several recently published studies (37,42,43) have challenged the assumption that improved ART provision will lead to a reduction in stigma. Two years after the introduction of free ART in a hospital in northern Tanzania, Roura et al. (43) talked to a sample of community leaders, ART clients, and health care workers using in-depth interviews and focus group discussions. They reported that with improved access to ART, new sources of stigma had emerged. Community leaders expressed persistent blaming attitudes towards individuals receiving ART, including the belief that as ART users regained their health, they would be more likely to engage in sexual risk behaviours and spread the disease to the uninfected.

Ezekiel et al. (42) examined perceptions towards ART patients in a series of focus group discussions with adolescents and young adults in a nearby rural district of northern Tanzania. Similar to Roura et al.'s findings, Ezekiel et al. found that the young people displayed a mix of positive and negative attitudes towards ART and the individuals receiving ART. The primary concern was that ART was creating the false impression among young people that HIV/AIDS could be cured, consequently leading to high-risk sexual practices. ART also made it increasingly difficult to differentiate between HIV-positive and HIV-negative individuals since ART enabled HIV-positive persons to return to good health, thus restoring their sexual desires and making them sexually attractive to other people. Consequently, persons on ART were considered to be "deliberate transmitters" of the HIV virus, although, there was disagreement among participants whether the label of "deliberate transmitter" could be applied to some or all HIV-infected individuals.

Atuyambe et al. (37) also examined the effects of enhanced access to ART on community perceptions in Kampala, Uganda. They also found that the majority of individuals interviewed, irrespective of their education level, believed that increased access to ART would enhance the spread of HIV by increasing the

frequency of unsafe sexual behaviour. Participants believed the availability of ART could lead to false confidence of protection from disease among uninfected individuals, especially if they were sure of their ability to purchase drugs for life.

On a more positive note, participants in two studies (37,42) noted that PLWHAs no longer had to succumb to the opportunistic infections associated with AIDS, such as herpes zoster and thrush. Their immediate recovery allowed them to not only return to work and care for their families, but also helped to prolong their life (42). Some participants even hoped that a complete cure for HIV/AIDS would soon be discovered (37). In addition, clients on ART experienced a positive change in stigma among themselves. They reported a reduction in negative attitudes among themselves and a growing openness with fellow ART clients (43). Several other studies (44-47) have also described a connection between improved ART access and a reduction in stigma.

In 2006, Abadía-Barrero and Castro (44) examined how Brazilian children and adolescents between the ages of one and fifteen who were living with HIV/AIDS experienced stigma in São Paulo, Brazil. What they found was that improved access to ART led to a reduction in stigma in three key ways. First, it transformed HIV/AIDS from a fatal disease into one that is chronic and manageable. Second, it ensured their right to treatment. Third, it redressed inequalities that impeded them from having access to appropriate health services. By improving access to ART, these children and adolescents living with HIV/AIDS had improved access to essential health services, which helped reduce the level of stigma they experienced in their day-to-day lives.

Castro and Farmer (45) published similar findings reported by adult patients undergoing ART in rural Haiti. The authors reported that improved availability of ART has transformed AIDS into an illness that is largely invisible to the average observer. Additionally, by integrating PLWHAs into the workforce of the community-based health program responsible for administering ART in the area, the program enabled PLWHAs to earn regular wages and take care of their families. This allowed them to return to their normal social roles within their communities. Also, many who witnessed the improved health status of PLWHAs

receiving treatment became interested in voluntary HIV testing and counselling. According to Castro and Farmer, taken together, these overlapping processes have contributed to lessening the impact of HIV/AIDS-related stigma in the local area (45).

There is a complex interplay between increased availability of ART and its influence on stigma. Findings from several studies (44,45,47) suggest that universal access to ART will play a critical role in the reduction of HIV/AIDS-related stigma in sub-Saharan Africa. Others (37,42,43) do not report that ART provision reduces stigma. These counterbalancing trends may help to explain the slow increase in uptake of voluntary HIV testing throughout sub-Saharan Africa despite increased availability of ART (1,43).

Overall

A concerted focus is now being made to better understand the interplay between HIV/AIDS prevention and treatment efforts in order to maximize the potential of ART to contribute to patient, family, and population-level HIV prevention benefits (48). In the 2010 Joint United Nations Programme on HIV/AIDS (UNAIDS) report (48) on the global HIV/AIDS epidemic, it was recognized that broader family and population-level benefits will only be realized in regions where ART reaches everyone in need and where PLWHAs are able to positively contribute to the local HIV prevention framework (48). Treatment should no longer be thought of as the "magic bullet" to bring the HIV/AIDS epidemic to a halt, but rather an essential element of HIV prevention programs (48). Not until strong prevention and treatment responses are built in tandem will broader populations be able to benefit from improved access to ART in a way that, hopefully, starts to impede local HIV/AIDS epidemics.

Most of the studies described here examine the influence of large-scale ART programming on the general population, as opposed to community-based ART programming. This is because literature on population-level impacts of CBART programs in sub-Saharan Africa is still limited. The findings presented in

this study help to expand on current efforts to better understand how CBART programming influences prevention.

Purpose of study

The purpose of this study was to assess whether a community-based HAART program influenced knowledge, attitudes and behaviours related to HIV/AIDS in the general community. This involved a comparison of residents of Rwimi sub-county, which has a community-based ART program, and of the nearby Kisomoro sub-county where residents have no local access to an ART program.

Research questions

Specifically, this study aimed to answer the following questions:

1. What knowledge, attitudes and behaviours do residents of Rwimi sub-county, Kabarole District have and/or exhibit surrounding HIV/AIDS and ART?
2. How do the findings obtained in (1.) compare with those obtained from residents of Kisomoro, a similar resource-poor sub-county in Kabarole District without a formal ART program?
3. What are the community's knowledge of and attitudes towards the community-based ART program in Rwimi, Uganda?

Overall significance

The results of this study can be applied to future initiatives and generate hypotheses for further research into similar community-based treatment programs.

Chapter 3: Methods

Study design

This was a mixed-methods study consisting of both quantitative and qualitative components. Participants were recruited from two resource-poor sub-counties within the Kabarole District of Uganda: one with an established CBART program and one with no local access to an ART program. Data pertaining to the quantitative component of the study was collected by structured questionnaires to quantify levels of knowledge surrounding HIV/AIDS and HAART, the attitudes of community members towards these topics, and common preventive behaviours. The findings obtained from each group were compared to assess the influence of a community-based AIDS treatment program on knowledge, attitudes, and practices in the general community. Following this, focus group discussions were held with community members and local health care workers to gather qualitative insights on key findings generated from responses to the questionnaires, and to assess the community's knowledge of and attitudes towards the community-based program.

Ethics

Study approval

Approval for this study was obtained from the University of Alberta's Health Research Ethics Board – Panel B. Approval of the study was also obtained from Uganda's National Council for Science and Technology in Kampala, Uganda and the District Health Officer in Kabarole District, Uganda.

Privacy and anonymity

Each participant was assigned a four-digit subject number to ensure privacy during the course of data collection. This was used in place of participant names on all study documents, with the exception of the subject number assignment sheet and consent forms. Access to confidential data was restricted to the principal investigator and field research staff. All original study documents were stored in the CBART program office in Fort Portal, Uganda and will be destroyed five years after the time of data collection.

Informed Consent

Informed consent was obtained from all study participants. Information sheets (Appendices I to IV) and consent forms (Appendix V) were given to participants and contained information about the project, including the purpose, procedure, benefits, risks, confidentiality, freedom to withdraw at anytime, and investigators' names and contact information. All documents were available in Rutooro and English and were assessed for clarity and cultural appropriateness within the context of western Uganda. Participants were asked to sign the consent form to indicate that they understood the information given and that they agreed to participate. If participants were illiterate, they had the information sheets and consent forms read to them by a research assistant, and were asked to place a thumbprint in a designated area on the consent forms to indicate they understood the documents and agreed to participate.

Possible harms

As this research addressed culturally sensitive topics, tension and emotional distress might have occurred during participation. Therefore, participants were reminded that they could withdraw from an interview or focus group discussion at any point in time. All feasible measures were taken during the study to protect the participants' confidentiality and avoid harm. These included but were not limited to: discreet methods of participant recruitment, the selection of private, neutral interview locations, and using numbers in the place of names to protect confidentiality. If any adverse events occurred as a result of participation in the study, the principal investigator, project supervisor, and research team were available to provide support to participants.

Study population

The study was conducted in the Rwimi and Kisomoro sub-counties of the Kabarole District of western Uganda. This district had a population of 359,180 people in 2005 (8). Of these individuals, 179,079 (49.9%) were female, and

318,575 (88.7%) resided in rural settings (8). Rwimi sub-county is comprised of four parishes: Kadindimo, Kaina, Kakooga and Rwimi Town Centre, each consisting of several villages (49). Kisomoro sub-county also has four parishes: Kicuucu, Kisomoro, Lyamabwa and Rubona (49). The populations of the two sub-counties, stratified by parish, are shown in Table 1.

Table 1. Populations of Rwimi and Kisomoro sub-counties in 2005

Sub-county	Parish	Households	Population			Average household size
			Male	Female	Total	
Rwimi		**5,338**	**12,389**	**12,610**	**24,999**	**4.7**
	Kadindimo	1,248	2,766	2,937	5,703	4.6
	Kaina	881	2,189	2,149	4,338	4.9
	Kakooga	839	1,887	1,980	3,867	4.6
	Rwimi Town Centre	2,370	5,547	5,544	11,091	4.7
Kisomoro		**6,167**	**14,816**	**15,831**	**30,647**	**5.0**
	Kicuucu	1,450	3,483	3,777	7,260	5.0
	Kisomoro	1,546	3,751	4,063	7,814	5.1
	Lyamabwa	1,382	3,298	3,503	6,801	4.9
	Rubona	1,789	4,284	4,488	8,772	4.9

The population of Kisomoro sub-county is slightly higher than Rwimi sub-county, at 24,999 and 30,647 respectively, with both sub-counties consisting of roughly 50% men and 50% women. According to the last Uganda Demographic and Health Survey conducted in 2006, in rural areas of Uganda mean household size is typically 5.1 persons (50). This is only slightly higher than the average household sizes in Rwimi and Kisomoro sub-counties, at 4.7 and 5.0 persons per household respectively.

Quantitative study

Sample size considerations

Limited data was available on HIV testing practices in Kabarole District. The most recent numbers showed that in 2005 19.6% of individuals surveyed in the district had ever tested for HIV (39). In addition, it was thought the presence of a community-based HAART program at least doubles the proportion of individuals testing for HIV. This estimate was considered to be appropriate since numerous studies exhibited substantial increases in HIV testing once ART is made locally available (18-21,51). Consequently, the proportion of individuals who had ever tested for HIV in Rwimi sub-county was presumed to be approximately 40%, or double the proportion tested throughout Kabarole District. A recruitment ratio of roughly 2:1 allowed for a more in-depth sub-analysis of the findings obtained from residents of Rwimi sub-county.

To enable the study to achieve a power of 80% with a significance level of 0.05, a design effect of 3.0, and a 2:1 recruitment ratio, a sample size of 600 participants was required, given an attrition rate of 5% or less (52). Participants in the study were recruited using two-stage cluster sampling of villages within each sub-county. To achieve the required sample sizes, 27 villages were randomly selected as recruitment sites from Rwimi sub-county, and 13 villages were randomly selected from Kisomoro sub-county using the random number generator function in Microsoft Excel 2007. Within each village 15 contiguous households were chosen, radiating out from a randomly selected starting point. For the purposes of this study, the next household was defined as the one whose front door is closest to the one previously visited (53). If no one was present in the chosen home, or there was a natural obstacle that prevents access, such as a river or a fence, then the next closest household was selected. One eligible participant was recruited from each household.

Eligibility

Individuals 18 to 49 years of age were eligible to participate in this study. If more than one eligible person was present in a household, then one participant

was randomly selected from the available household members (39). Households with individuals directly involved with the community-based HAART program in Rwimi, such as patients, treatment associates, and community volunteers were not eligible to participate in the study. This is because residents of these households would have intensive exposure to the community-based ART project and one might expect that their HIV/AIDS-related knowledge, attitudes and behaviours would have changed more than the general population.

Instrument

The survey questions were derived from a previously validated questionnaire examining knowledge and attitudes regarding HIV/AIDS and ART in the general population of the Kabarole District (39). Permission to us the survey for this study was granted by Project Manager Arif Alibhai. In addition, literature on community views regarding HIV/AIDS and ART in the context of the availability of ART was reviewed and incorporated into the final survey instrument. The survey instrument (Appendix VI) consisted of 48 questions on demographic characteristics, socioeconomic indicators, knowledge surrounding HIV/AIDS and ART, attitudes towards these topics, and common preventive behaviours. Twenty-four questions were taken from the previously validated survey (39), and 24 questions were added. Several open-ended questions were purposively incorporated into the survey to collect data deemed unsuitable for closed-ended questions due to the broad spectrum of potential responses, such as the respondent's occupation or reasons for not obtaining a HIV test.

The questionnaire was assessed for language reliability through multiple translations. They were first translated from English into Rutooro, and then translated back to English by a different research assistant (54). The two English documents were compared to ensure accuracy, and any inconsistencies found were adjusted accordingly. Test-retest reliability of the questionnaire was also assessed by randomly selecting 8 participants to complete the same survey 10 days after their initial survey was completed. Percent agreement between the two interview periods for these 8 interviewees was 92%.

Before the final questionnaires were given to community members, pilot survey instruments were administered to ten persons not connected with the study in order to assess whether the sequence of questions and terminology employed was appropriate. After the pilot surveys were completed, wording of some questions and/or coding categories were altered to improve the clarity and coherence of the survey instruments.

Data collection

Data collection took place from September to December 2009 in Rwimi and Kisomoro sub-counties. Upon arriving in each village, a research assistant fluent in Rutooro sought out the Local Council 1 Chairman (village leader). The research assistant introduced himself or herself to the Chairman, explained the purpose of the study, and presented a letter from the Kabarole District Health Officer, Dr. Okech Ojony Joa, supporting the study. The Chairman provided verbal consent for the research assistant to proceed with data collection in the village.

The surveys were administered by trained research assistants during face-to-face interviews, and took approximately 30 to 45 minutes to complete. Informed consent was sought from all participants prior to the interview. Interviewers informed respondents of the study's purpose, and communicated that they did not have to answer any of the questions they did not want to and they could stop the interview at any time (55). The interviewer then sought consent to proceed with the survey. A written information letter outlining the purpose, benefits, risks, and confidential nature of the interviews was provided or read. The participant gave consent by either signing or producing a thumbprint on the consent form prior to commencing the interview. All interviews were conducted in Rutooro, and all responses were recorded in English on the questionnaires. Interviews were considered complete once respondents had answered all of the questions, or when respondents decided to terminate the interview, whichever came first.

At the end of each interviewing day, the principal investigator reviewed all surveys, and the research assistant who conducted the interview clarified any discrepancies or unclear language.

Data analysis

The information gathered by the surveys was entered into a Microsoft Access 2007 database, and reviewed on a separate occasion to ensure accuracy. Data entry for closed-ended questions proceeded according to the codes specified for each question, while information derived from open-ended questions were broadly categorized and coded into Microsoft Excel 2007 to permit analysis of these questions.

Data analysis was undertaken using descriptive, univariate, and multivariable methods using STATA 11. A $p<0.05$ was considered for statistical significance. The two-stage survey design was controlled for using STATA's "survey" features. These features take into account the number selected versus available sampling units at each level of sampling to account for different sample pools at each level. In order to adjust two-stage design effect, the sampling weights were assigned to each household to get representative estimates using the following formula:

$$w_{ij} = (n_{\text{villages in } i}/n_{\text{villages selected in } i})*(n_{\text{households in } j(i)}/n_{\text{households selected in } j(i)})$$

Where:

w_{ij}	=	Sampling weight assigned to each household
$n_{\text{villages in } i}$	=	Total number of villages in i^{th} sub-county
$n_{\text{villages selected in } i}$	=	Number of villages selected from i^{th} sub-county
$n_{\text{households in } j(i)}$	=	Total number of households in j^{th} village of i^{th} sub-county
$n_{\text{households selected in } j(i)}$	=	Number of households selected from j^{th} village in i^{th} sub-county

The total number of households per village, $n_{households\ in\ j(i)}$, was estimated for each sub-county. These figures were calculated by dividing the known number of households in each sub-county (as shown in Table 1) by the known number of villages in each sub-county. For example, $n_{households\ in\ j(i)}$ for Rwimi sub-county = 5,338/35 = 153. The same estimate was then used for all villages in the sub-county.

Descriptive statistics for residents of Rwimi and Kisomoro sub-counties were used to summarize the characteristics of the study population. Univariate analyses were used to compare questionnaire response frequencies between residents of the two sub-counties using chi-square test. Univariate logistic regression modelling was used to examine relationships between sociodemographic, knowledge, attitudes, and behaviour variables. Results from both the univariate analyses and univariate logistic regression were used to determine which variables would be included in multivariable modelling. Any sociodemographic indicators found to have a $p \leq 0.2$ in the univariate logistic regression models were initially included in the multivariable models.

Representative variables for knowledge, negative attitudes, HIV testing, and condom use were selected as dependent variables for multivariable models and independent variables were selected based on results from both univariate analyses and univariate logistic regression modelling. If more than one variable met these criteria, then the variable deemed to have better representation of the category was selected by the principal investigator. The chosen dependent variables for each category are shown in Table 2.

Table 2. Representative variables for knowledge, attitudes, and behaviour categories

Category	Representative variable
Knowledge	Have you heard about ART?
HIV/AIDS-related attitudes	Should people with HIV/AIDS be given equal opportunity to work?
Testing for HIV	Have you ever tested for HIV?
Condom use	Did you use a condom the last time you had sex?

Four multivariable logistic regression models describing knowledge, HIV/AIDS-related attitudes, HIV testing, and condom use were developed using backwards elimination procedures. Initially, all pre-selected sociodemographic variables were included in the model. After each step, the variable with the highest p-value was removed, one at a time. These steps were repeated until all variables remaining in the model had a $p \leq 0.05$ or were deemed to have an association with the independent variable according to current literature.

Potential confounding and interaction terms were assessed in each model. Confounding was measured by examining the change in regression coefficients (ß). Typically, if the addition of a potential confounder changed ß for any variable by more than 15%, it is considered a confounder. The equation for this assessment can be written as:

$$(ß_{\text{with confounder}} - ß_{\text{without confounder}})/(ß_{\text{with confounder}})*100$$

While some potential confounders did in fact change ß more than the typical cut-off of 15%, no confounders were considered to be significantly associated with the outcome of any model upon further examination.

Finally, potential interactions were assessed in each model. This was accomplished by adding each interaction term of interest to the corresponding model one at a time. Any interaction term significantly associated with the model's outcome ($p<0.05$) was added to the multivariable model. All significant interaction terms were added to the model and the interaction term with the highest p-value was then removed. This would be repeated until only one interaction term remained in the model. Multiple interaction terms were not kept

in the models in order to simplify the interpretation of the interaction. At this point, the model was considered to be complete.

Qualitative study

Sample

During the quantitative data collection phase, it was discovered that HIV testing rates were much higher than expected in Kisomoro sub-county (the comparison sub-county). The questionnaire did not provide enough detail to help explain why this was observed. Therefore, in addition to the four planned focus groups in Rwimi, four additional focus groups were undertaken in Kisomoro.

The original four focus groups planned for Rwimi sub-county were to be held with: a) male participants (x2); and b) female participants (x2). However, the composition of the focus groups was also modified so that in each sub-county focus groups were held with: a) males who had tested for HIV; b) males who had not tested for HIV; c) females who had tested for HIV; and d) females who had not tested for HIV. This was done to better understand what may have influenced the uptake of HIV testing in each sub-county.

Community members were recruited to the focus groups from those that had completed the survey. Participants were informed that they were selected for a particular focus group because they had been identified as someone who had tested or not tested for HIV and that other similar individuals would be in their group.

Two focus group discussions with local health care workers were also added, one in Rwimi and one in Kisomoro. The purpose of these focus groups was to better understand what other health services or interventions were in place that may have influenced the uptake of HIV testing. All clinical officers, nurses, counsellors, and health assistants from the Health Centre III clinic in each community were asked to participate. These focus group discussions were carried out in English by the principal investigator.

Instruments

Guiding questions for the focus group discussions with community members and health care workers were developed to further examine key findings generated from responses to the quantitative component of the study (Appendices VII to VIII). Comments and themes frequently mentioned by respondents in the open-ended survey questions were incorporated into the discussion to provide an opportunity to clarify information obtained from the surveys. The discussions also served to examine the community's knowledge of and attitudes towards the community-based ART program in Rwimi, Uganda. A funnel-type method was used to develop questions, beginning with general questions and eventually leading to a more specific discussion in order to achieve a balance between obtaining data to answer the research questions and allowing the respondents to introduce new, but relevant, topics (56).

The guiding questions were checked for language reliability through a back translation process similar to that used for the survey instruments (54). They were first translated from English into Rutooro, and then translated back to English by a different research assistant. The two English documents were compared to ensure accuracy and identify any inconsistencies.

Data collection

Focus group discussions with community members were co-facilitated by the primary investigator and research assistants fluent in Rutooro. They were recorded using a digital recording device and backup audiotape recorders for later transcription. Key messages were translated into English throughout the session so that the principal investigator was able to follow the course of the discussion and add any additional questions as needed. At the beginning of each discussion participants were informed of the need for confidentiality and respectful conduct towards other participants and were reminded that group discussions were being audio taped. Researchers and participants then introduced themselves by stating their name and providing background information about themselves. Questions posed by the participants at any point in the discussion were addressed. Each

focus group discussion took approximately 45 to 90 minutes to complete. Probing was used to encourage participants to elaborate on specific statements made and to achieve a suitable depth of understanding. At the end of each group discussion, participants were thanked for their contributions to the discussion and notified that they could contact the principal investigator or the research assistants at any time for further information. As remuneration for participants' travel and time, sodas and snacks were offered at the conclusion of the discussion, and a reasonable transportation reimbursement was provided (approximately 5,000 Uganda shillings or $2.90).

Focus group discussions with local health care staff were conducted in English and recorded using a digital recording device. The principal investigator both led and transcribed the discussions. Each discussion took approximately 20 to 30 minutes to complete. For the focus group discussion held in the Rwimi Health Centre, a note taker was also present. As with the focus group discussions with community members, at the end health care staff were thanked for their time and reminded they could contact the principal investigator at any time for additional information.

Data analysis

Since the focus group discussions with community members were carried out in Rutooro, transcriptions of the audio recordings were completed in English and reviewed by another research assistant not involved in the original translation. Any inconsistencies found were adjusted accordingly. Once the focus group discussions were transcribed, an overall reading and surface analysis of the transcripts was done to review the data and identify general themes and possible subthemes. Following this initial reading, themes and subthemes were assigned a code. Statements or thoughts within a statement were assigned a particular theme or subtheme, with up to two themes and/or subthemes per statement. The coded statements were divided up according to the theme of the answer, group, and gender responses to each question (57).

Chapter 4: Quantitative Study Results

Sociodemographic characteristics

Table 3. Sociodemographic characteristics of 18 to 49 year old residents of Rwimi and Kisomoro sub-counties, Uganda, 2009

	n (%)	%[†]		
Variable	Total (n=598)	Rwimi (n=405)	Kisomoro (n=193)	p-value[‡]
Housing				0.627
Permanent	74 (12.4)	11.9	13.8	
Semi-permanent/ temporary	521 (87.6)	88.1	86.2	
Number of people living in household				0.652
0-4	283 (47.3)	48.4	45.0	
5-9	264 (44.2)	43.7	45.2	
≥10	51 (8.5)	7.9	9.9	
Number of people living in household under 18 years of age				0.741
0-2	311 (52.0)	52.8	50.2	
3-5	223 (37.3)	37.0	37.9	
≥6	64 (10.7)	10.1	11.9	
Sex				0.289
Male	302 (50.5)	52.4	46.5	
Female	296 (49.5)	47.7	53.6	
Age				0.184
18-29	313 (52.3)	54.8	47.2	
30-39	181 (30.3)	28.2	34.7	
40-49	104 (17.4)	17.0	18.2	
Marital status				0.004
Single/divorced/ widowed	146 (24.5)	19.5	34.8	
Married/ living with partner	451 (75.5)	80.5	65.2	
Religion				0.832
Catholic	320 (53.6)	54.2	52.3	
Protestant	180 (30.2)	30.2	30.0	
Other	97 (16.3)	15.6	17.7	
Occupation				<0.001
Professional	20 (3.4)	2.8	4.7	
Non-professional	150 (25.7)	19.8	38.2	
Farmer	364 (62.4)	68.1	50.6	
Other	49 (8.4)	9.4	6.5	
Education				0.094
None	72 (12.0)	14.1	7.8	

Primary	389 (65.1)	62.5	70.3
Secondary or higher	137 (22.9)	23.5	21.9

†Results weighted for cluster sampling design
‡Pearson chi-squared

Overall, sociodemographic characteristics of respondents from Rwimi and Kisomoro sub-counties were fairly similar. There was a slight difference between the proportions of male and female respondents between the two sub-counties. In Rwimi, 52.4% of the 405 respondents were male. While in Kisomoro 46.5% of the 193 respondents were male. This difference was not statistically significant (p=0.289). In both sub-counties, the majority of participants fell within the youngest age category of 18 to 29 years of age, at 54.8% and 47.2% respectively. For the middle age group of 30 to 39 years of age, 28.2% and 34.7% of respondents from Rwimi and Kisomoro respectively fell within this age group. The eldest age group, which consisted of those 40 to 49 years of age, had the smallest proportion of participants at 17.0% and 18.2% for Rwimi and Kisomoro respectively. These differences were not statistically significant (p=0.184).

In Rwimi sub-county, 11.9% of respondents resided in permanent homes. This was quite similar to responses from Kisomoro residents, at 13.8%. The remaining proportion of respondents, 88.1% in Rwimi and 86.2% in Kisomoro, resided in either semi-permanent or temporary houses. Overall, there was no significant difference in housing between the two sub-counties (p=0.627). The distribution in the number of people living in a respondent's household was also quite similar between the two sub-counties. In Rwimi, 0-4, 5-9, and 10 or more people living in their households were 48.4%, 43.7%, and 7.9%, while in Kisomoro were 45.0%, 45.2%, and 9.9%, respectively. These differences were not statistically significant (p=0.652). Similar to the number of people living in the household, the distribution in the number of people living in household under 18 years of age was comparable between the two sub-counties. In Rwimi, 0-2, 3-5, and 6 or more minors living in their households were 52.8%, 37.0%, and 10.1%, and -in Kisomoro were 50.2%, 37.9%, and 11.9%, respectively. These differences were not statistically significant (p=0.741)

There was quite a large difference in the proportions of individuals who identified themselves as married or living with partner and those who identified as single, divorced, or widowed between Rwimi and Kisomoro. Only 19.5% of respondents in Rwimi were single, divorced, or widowed, while 34.8% of respondents in Kisomoro fell within this category. Conversely, 80.5% of respondents in Rwimi sub-county and 65.2% of respondents in Kisomoro sub-county identified themselves as either married or living with a partner. This difference was statistically significant ($p=0.004$). As for religious affiliations, in both Rwimi and Kisomoro sub-counties slightly over half of the respondents identified themselves as Catholic, at 54.2% and 52.3% respectively. The proportion of individuals who identified themselves as Protestant was also similar, at 30.2% and 30.0% for Rwimi and Kisomoro respectively. Lastly, 15.6% of respondents from Rwimi and 17.7% of respondents from Kisomoro fell within the category of other (primarily Muslim or Seventh-day Adventist). These differences were not statistically significant ($p=0.832$).

Only 2.8% of respondents in Rwimi sub-county and 4.7% of respondents in Kisomoro were professionally employed (primarily nurses or teachers), while 19.8% and 38.2% were non-professionally employed (primarily self-employed) in Rwimi and Kisomoro respectively. The majority of respondents in both sub-counties were subsistence farmers, at 68.1% in Rwimi and 50.6% in Kisomoro. The category of other was comprised of primarily students or housewives. Slightly fewer than ten percent (9.4%) of respondents from Rwimi and 6.5% of respondents from Kisomoro fell within this latter category. These differences were statistically significant ($p<0.001$). As for highest reported level of education, 14.1% of survey respondents from Rwimi and 7.8% of survey respondents from Kisomoro never attended school, 62.5% and 70.3% in Rwimi and Kisomoro respectively attended primary school, and 23.5% and 21.9% in Rwimi and Kisomoro respectively attended secondary school or higher. None of these differences were statistically significant ($p=0.094$)

Univariate analysis

HIV/AIDS knowledge

Table 4. HIV/AIDS knowledge in 18 to 49 year old residents of Rwimi and Kisomoro sub-counties, Uganda, 2009

	%[†]		
Variable	**Rwimi (n=405)**	**Kisomoro (n=193)**	**p-value**
Have you ever heard of HIV/AIDS?	99.8	100	0.272
What are the main symptoms of HIV/AIDS?[‡]			
Skin rash/infection	75.8	82.4	0.107
Weight loss	42.5	39.9	0.605
Cough	34.1	37.4	0.370
Fever/malaria	27.4	32.7	0.142
Diarrhoea	26.9	21.1	0.222
How can HIV/AIDS be spread?[‡]			
Unprotected sex	97.0	98.4	0.293
Blood contact	63.0	66.7	0.481
MTCT	12.1	4.1	0.004
Can a healthy-looking person be infected with HIV/AIDS? (Yes)	92.1	99.0	<0.001
How can a person avoid getting HIV/AIDS?[‡]			
Use condoms	65.2	76.0	0.024
Abstinence	54.8	59.8	0.316
Be faithful	40.0	26.0	0.004
Avoid blood contact	25.2	30.1	0.286

[†]Results weighted for cluster sampling design

[‡]Responses are independent from each other and given by at least 15% of respondents from either sub-county

Overall, HIV/AIDS knowledge in respondents from both Rwimi and Kisomoro sub-counties appeared to be good. Virtually all survey respondents had heard of HIV/AIDS before participating in the research study (99.8% in Rwimi and 100% in Kisomoro). Skin rash/infection was the most commonly cited symptom of AIDS in both Rwimi sub-county and Kisomoro sub-county at 75.8% and 82.4% respectively. The next most commonly cited symptoms of AIDS infection were weight loss (42.5% in Rwimi and 39.9% in Kisomoro), cough (34.1% in Rwimi and 37.4% in Kisomoro), fever/malaria (27.4% in Rwimi and 32.7% in Kisomoro), and diarrhoea (26.9% in Rwimi and 21.1% in Kisomoro).

The majority of survey respondents listed unprotected sex as a mode of HIV transmission (97.0% for Rwimi and 98.4% in Kisomoro. Blood contact was

the second most common mode of HIV transmission given (63.0% in Rwimi and 66.7% in Kisomoro). MTCT was only cited by 12.1% of respondents in Rwimi and 4.1% of respondents in Kisomoro. This finding was further partitioned by sex to see if more women than men were citing MTCT as a mode of HIV transmission in each sub-county. It was found that 8.0% of men and 16.6% of women in Rwimi identified MTCT as a mode of transmission, while only 4.4% of men and 3.9% of women in Kisomoro identified MTCT.

Nearly all respondents from both Rwimi sub-county (92.1%) and Kisomoro sub-county (99.0%) correctly answered "Can a healthy-looking person be infected with HIV/AIDS?" The most commonly cited way to avoid getting HIV was to use condoms (65.2% in Rwimi and 76.0% in Kisomoro). Slightly over half of the respondents in each sub-county identified abstinence as a way to avoid getting HIV, at 54.8% and 59.8% for Rwimi and Kisomoro respectively. The next most commonly cited ways to avoid getting HIV were being faithful (40.0% in Rwimi and 26.0% in Kisomoro), and avoiding blood contact (25.2% in Rwimi and 30.1% in Kisomoro).

When the suggested methods to avoid getting HIV were analyzed by marital status, rather than sub-county, it was found that single, widowed, or divorced individuals more often cited condoms as a way to prevent acquiring HIV (83.8%) compared to individuals who were married or living with a partner (66.4%). This difference was statistically significant ($p=0.001$). A similar finding was found for those who cited being faithful as a way to prevent getting HIV. Individuals who were married or living with a partner more often cited faithfulness as a way to prevent getting HIV (37.7%) while only 18.1% of individuals who identified themselves as single, divorced, or widowed cited faithfulness ($p<0.001$). There were no statistical differences between marital statuses for those who identified abstinence or avoiding blood contact as methods to prevent acquiring HIV.

ART knowledge

Table 5. ART knowledge in 18 to 49 year old residents of Rwimi and Kisomoro sub-counties, Uganda, 2009

	%[†]		
Variable	**Rwimi (n=405)**	**Kisomoro (n=193)**	**p-value**
Can HIV/AIDS be cured? (Yes)	12.6	6.7	0.027
Have you heard about ART? (Yes)	93.6	97.4	0.058
If yes, what can ART do?[‡]			
Improve health	38.5	50.8	0.032
Reduce viral load	34.3	27.8	0.290
Increase lifespan	33.0	26.6	0.124
Do you know someone on ART? (Yes)	72.6	83.0	0.074
Do you know where to get ART? (Yes)	88.6	95.4	0.040
If yes, where can you get ART?			
Health centres	89.4	91.8	0.480
Hospitals	44.9	57.2	0.110
Volunteers	12.0	0	<0.001
How long should a person take ART? (Lifetime)	49.0	74.2	<0.001
Can people on ART still infect others? (Yes)	89.4	91.1	0.473
If yes, how can they prevent infecting others?[‡]			
Use condoms	67.9	76.3	0.095
Abstinence	69.3	62.0	0.091
Be faithful	21.1	4.0	<0.001
Avoid blood contact	17.5	15.3	0.571
Are you aware of the following HIV/AIDS treatment programs?			
JCRC	19.5	50.2	<0.001
TASO	18.5	3.6	<0.001
CBART	27.7	2.6	<0.001

[†]Results weighted for cluster sampling design
[‡]Responses are independent from each other and given by at least 15% of respondents from either sub-county

Most respondents correctly answered 'no' to the question "Can HIV/AIDS be cured?" (72.4% in Rwimi and 79.2% in Kisomoro). In Rwimi, 12.6% incorrectly answered "yes," while the remaining 15% responded they were "unsure." In Kisomoro, 6.7% incorrectly answered "yes," and the remaining 14.1% were "unsure." The majority of respondents had heard about ART before the research study (93.6% in Rwimi and 97.4% in Kisomoro). When asked "What

can ART do?" 38.5% of respondents in Rwimi and 50.8% of respondents in Kisomoro answered improve health. Reduced viral load was the second most cited response (34.3% in Rwimi and 27.8% in Kisomoro) followed by increased lifespan (33.0% in Rwimi and 26.6% in Kisomoro).

Many respondents in both sub-counties knew someone on ART (72.6% in Rwimi and 83.0% in Kisomoro). Nearly all knew where to get ART (88.6% in Rwimi and 95.4% in Kisomoro), with health centres being the most commonly cited location in both sub-counties. Only half (49.0%) of respondents from Rwimi sub-county correctly answered "How long should a person take ART?" while 74.2% of respondents from Kisomoro were able to correctly answer this question. However, when asked "Can people on ART still infect others?" most respondents from both sub-counties knew the correct answer (89.4% in Rwimi and 91.1% in Kisomoro). The most commonly cited way for individuals on ART to prevent infecting others was to use condoms (67.9% in Rwimi and 76.3% in Kisomoro). Abstinence was also commonly cited by 69.3% of respondents in Rwimi and 62.0% of respondents in Kisomoro, followed by being faithful (21.1% in Rwimi and 4.0% in Kisomoro).

When methods to prevent infecting others while on ART were analyzed by marital status, rather than sub-county, it was found that single, widowed, or divorced individuals more often cited condoms as a way to prevent spreading HIV (82.2%) compared to individuals who were married or living with a partner (68.5%). This difference was statistically significant ($p=0.008$). There were no statistical differences between marital statuses for those who identified abstinence, being faithful, or avoiding blood contact as ways someone on ART can prevent spreading HIV.

Slightly over one-quarter (27.7%) of the respondents in Rwimi were aware of the CBART program running in their community, while only 2.6% of respondents in Kisomoro were aware of the program. Respondents more commonly cited other AIDS treatment programs running at the district or national level, such as the AIDS Support Organization (TASO) and the Joint Clinical Research Centre (JCRC).

HIV/AIDS-related attitudes

Table 6. HIV/AIDS-related attitudes in 18 to 49 year old residents of Rwimi and Kisomoro sub-counties, Uganda, 2009

	%[†]		
Variable	**Rwimi (n=405)**	**Kisomoro (n=193)**	**p-value**
Are people with HIV/AIDS dirty? (Yes)	17.4	3.2	0.001
Are people with HIV/AIDS cursed? (Yes)	14.9	5.2	0.005
Should people with HIV/AIDS be ashamed? (Yes)	25.4	12.4	0.003
Do you believe a person with HIV/AIDS must have done something wrong and deserves to be punished? (Yes)	13.1	3.6	0.005
Should people with HIV/AIDS be isolated? (Yes)	16.3	6.2	0.004
Are you willing to be casual friends with someone with HIV/AIDS? (Yes)	86.4	96.9	<0.001
Should people with HIV/AIDS be given equal opportunity to work like others? (Yes)	79.0	89.1	0.013

[†]Results weighted for cluster sampling design

Overall, respondents from Rwimi sub-county had a higher degree of negative HIV/AIDS-related attitudes compared to respondents from Kisomoro sub-county. Seven different questions pertaining to HIV/AIDS-related attitudes were asked, and for all seven questions respondents from Kisomoro sub-county reported lower frequencies of negative attitudes compared to respondents from Rwimi sub-county. All of these differences were statistically significant (Table 6).

Ever tested for HIV?

Table 7. Ever tested for HIV in 18 to 49 year old residents of Rwimi and Kisomoro sub-counties, Uganda, 2009

	%[†]		
Variable	**Rwimi (n=405)**	**Kisomoro (n=193)**	**p-value**
Do you know where to go for HIV/AIDS testing? (Yes)	96.5	99.0	0.082
If yes, where can you go?			
Health centres	89.8	89.0	0.826
Hospitals	55.5	64.7	0.140
Have you ever tested for HIV/AIDS? (Yes)	47.7	57.0	0.092
If yes, why did you test?[‡]			
To know my status	73.6	69.0	0.456
I was pregnant	22.3	21.1	0.820
I was in poor health	2.1	9.1	0.008
If yes, did you receive your test results? (Yes)	78.8	90.8	0.115
If no, why did you not test?[‡]			
No reason to	59.4	38.7	0.006
I plan to test	19.3	32.4	0.014
I fear to test	6.6	21.8	0.007
I have no time to test	2.8	16.7	<0.001

[†]Results weighted for cluster sampling design
[‡]Responses are independent from each other and given by at least 15% of respondents from either sub-county

Slightly under half of respondents from Rwimi sub-county had ever tested for HIV (47.7%), while slightly over half of respondents from Kisomoro sub-county had ever tested (57.0%). This difference was not statistically significant (p=0.092). When those who had ever tested were asked if they received their results, 78.8% of respondents in Rwimi and 90.8% of respondents in Kisomoro answered they had. The most commonly cited reason for ever testing for HIV in both sub-counties was simply to know their status (73.6% in Rwimi and 69.0% in Kisomoro). This was followed by being pregnant (22.3% in Rwimi and 21.1% in Kisomoro) and being in poor health (2.1% in Rwimi and 9.1% in Kisomoro). When respondents who had not yet tested for HIV were asked why, 59.4% of those in Rwimi and 38.7% of those in Kisomoro cited having no reason to. 19.3%

of respondents from Rwimi and 32.4% of respondents from Kisomoro were planning to go for the test at some point.

Condom use during last sexual encounter & male circumcision

Table 8. Condom use during last sexual encounter & male circumcision in 18 to 49 year old residents of Rwimi and Kisomoro sub-counties, Uganda, 2009

	%[†]		
Variable	**Rwimi (n=405)**	**Kisomoro (n=193)**	**p-value**
Do you know where to get condoms? (Yes)	90.9	99.0	<0.001
If yes, where can you get condoms?			
Hospital/clinic	92.7	72.8	<0.001
Shop	65.5	77.2	0.057
Pharmacy/drug shop	39.4	7.3	<0.001
Did you use a condom the last time you had sex? (Yes)	22.5	33.6	0.020
If yes, why did you use a condom?[‡]			
Protecting against HIV/AIDS	81.3[*]	69.1[*]	0.080
Protecting against STIs	14.3[*]	18.5[*]	0.483
Family planning method	6.6[*]	24.7[*]	0.001
If no, why did you not use a condom?[‡]			
In a relationship	43.0	13.2	<0.001
I trust my partner	26.4	27.3	0.875
Partner did not want	8.0	18.9	0.005
Did you ever want to but not use a condom? (Yes)	16.5	16.5	0.995
If yes, why?[‡]			
My partner refused	34.3[*]	62.5[*]	0.008
It was not available	34.3[*]	21.7[*]	0.207
Do you know male circumcision may lower the risk of HIV/AIDS transmission? (Yes)	72.8	82.0	0.050
Would you consider circumcision to lower your risk of HIV transmission? (Yes; men only)	70.3	84.6	0.020

[†]Results weighted for cluster sampling design
[‡]Responses are independent from each other and given by at least 15% of respondents from either sub-county
[*]Proportion not weighted and not adjusted for cluster as primary sampling unit

The majority of respondents from Rwimi and Kisomoro sub-counties knew where to get condoms from at 90.9% and 99.0% respectively. The most

cited place to get condoms was a hospital or clinic (92.7% in Rwimi and 72.8% in Kisomoro). Other commonly listed locations to get condoms were shops (65.5% in Rwimi and 77.2% in Kisomoro) and pharmacies/drug shops (39.4% in Rwimi and 7.3% in Kisomoro).

More respondents living in Kisomoro sub-county had used a condom the last time they had sex compared to respondents from Rwimi sub-county (22.5% in Rwimi and 33.6% in Kisomoro). This difference was statistically significant (p=0.020). When condom use during last sexual encounter was analyzed by marital status, rather than sub-county, it was found that 40.4% of single, widowed, or divorced individuals used a condom the last time they had sex, while only 23.9% of respondents who were either married or living with a partner reported using a condom the last time they had sex. This difference was also statistically significant (p=0.001). When condom use was analyzed by sex, 32.9% of male respondents and 24.0% of female respondents had used a condom during their last sexual encounter (p=0.031). Lastly, when condom use during last sexual encounter was analyzed by ever having tested for HIV, it was found that a higher proportion of individuals who had tested used a condom (59.2% compared to 50.2%). However, this was not statistically significant (p=0.129).

For respondents who used a condom during their last sexual encounter, most cited protecting against HIV (81.3% in Rwimi and 69.1% in Kisomoro) and protecting against sexually transmitted infections (STIs) (14.3% in Rwimi and 18.5%) as reasons why a condom was used. Unfortunately, only 6.6% of respondents in Rwimi reported using a condom as a family planning method, while 24.7% of respondents in Kisomoro reported using a condom as a family planning method. For respondents who did not use a condom during their last sexual encounter, most cited being in a relationship (43.0% in Rwimi and 13.2% in Kisomoro) and trusting their partner (26.4% in Rwimi and 27.3% in Kisomoro) as reasons why a condom was not used. The same proportion of respondents in Rwimi and Kisomoro had ever wanted to but could not use a condom during a sexual encounter (16.5%). When asked why, 34.3% of respondents from Rwimi and 62.5% of respondents from Kisomoro reported it was because their partner at

the time refused. The second most reported reason for not being able to use a condom was because a condom was not available at the time (34.3% in Rwimi and 21.7% in Kisomoro).

A high proportion of respondents from Rwimi and Kisomoro sub-counties reported that they knew that male circumcision could lower the risk of HIV/AIDS transmission, 72.8% in Rwimi and 82.0% in Kisomoro (p=0.050). When male participants were asked if they would consider circumcision to lower their risk of HIV transmission, 70.3% in Rwimi and 84.6% of men in Kisomoro responded that they would (p=0.020).

Logistic regression

ART knowledge – Have you heard about ART?

Table 9. Odds ratios and 95% confidence intervals from logistic regression for association with ART knowledge in 18 to 49 year olds in Rwimi and Kisomoro sub-counties, Uganda, 2009

	Univariate analysis		Multivariable analysis	
Variable	**OR (95% CI)†**	**p-value**	**OR (95% CI)†**	**p-value**
Sub-county				
Rwimi	1.00		1.00	
Kisomoro	2.61 (0.93-7.29)	0.067	2.31 (0.75-7.08)	0.138
Sex				
Male	1.00		1.00	
Female	0.76 (0.34-1.67)	0.481	0.89 (0.40-1.97)	0.776
Age				
18-29	1.00		1.00	
30-39	1.20 (0.53-2.70)	0.660	1.50 (0.67-3.40)	0.317
40-49	4.27 (0.97-18.73)	0.054	5.72 (1.40-23.32)	0.016
Marital status				
Single/divorced/ widowed	1.00			
Married/living with partner	0.62 (0.23-1.68)	0.339		
Occupation				
Professional	1.00			
Non-professional	1.15 (0.11-11.99)	0.907		
Farmer	0.61 (0.07-4.92)	0.632		
Other	0.36 (0.04-3.49)	0.368		
Education				
None	1.00		1.00	

Primary	3.15 (1.31-7.60)	0.012	3.48 (1.48-8.17)	0.005
Secondary or higher	4.45 (1.18-16.73)	0.028	5.47 (1.59-18.75)	0.008

†Weighted odds ratio (OR) adjusted for cluster as primary sampling unit; 95% confidence interval (95% CI)

In univariate logistic regression modelling, only sub-county of residence and highest level of education attained met the inclusion criteria for the multivariable model ($p \leq 0.20$). Sex and age were included in the multivariable modelling because they likely have a significant clinical association with ART knowledge. Marital status and occupation were also included in the model, but were not found to be statistically significant in the multivariable model and were subsequently dropped.

The final multiple logistic regression model demonstrated only one significant association with having knowledge of ART. It was with education. The higher a respondent's level of education, the more likely he or she had knowledge of ART. Individuals whose highest level of education was primary school were 3.5 times more likely to have heard of ART compared to individuals who never attended school (OR 3.48, p=0.005). This association was even stronger for individuals who attended secondary school or higher (OR 5.47, p=0.008). Sub-county of residence, sex, and age of respondent were not found to be significantly associated with having knowledge of ART in the final model.

HIV/AIDS-related attitudes – Should people with HIVAIDS be given equal opportunity to work?

Table 10. Odds ratios and 95% confidence intervals from logistic regression for association with HIV/AIDS-related attitudes in 18 to 49 year olds in Rwimi and Kisomoro sub-counties, Uganda, 2009

	Univariate analysis		Multivariable analysis	
Variable	**OR (95% CI)†**	**p-value**	**OR (95% CI)†**	**p-value**
Sub-county				
Rwimi	1.00		1.00	
Kisomoro	2.18 (1.18-4.03)	0.015	2.06 (1.12-3.80)	0.021
Sex				
Male	1.00		1.00	
Female	2.12 (1.34-3.36)	0.002	2.31 (1.40-3.83)	0.002
Age				
18-29	1.00		1.00	
30-39	1.28 (0.78-2.10)	0.313	1.33 (0.77-2.29)	0.303
40-49	1.38 (0.72-2.65)	0.324	1.46 (0.73-2.92)	0.281
Marital status				
Single/divorced/ widowed	1.00			
Married/living with partner	0.57 (0.34-0.97)	0.038		
Occupation				
Professional	1.00			
Non-professional	0.91 (0.21-4.07)	0.903		
Farmer	0.49 (0.10-2.37)	0.365		
Other	1.09 (0.15-7.87)	0.928		
Education				
None	1.00		1.00	
Primary	0.95 (0.48-1.90)	0.881	1.05 (0.47-2.34)	0.908
Secondary or higher	2.07 (0.86-4.94)	0.100	2.62 (0.92-7.48)	0.071
Have you heard about ART?				
No	1.00		1.00	
Yes	2.78 (1.14-6.80)	0.026	2.43 (1.00-5.89)	0.050

†Weighted odds ratio (OR) adjusted for cluster as primary sampling unit; 95% confidence interval (95% CI)

In univariate logistic regression modelling, sub-county of residence, sex, marital status, occupation, education, and having knowledge of ART met the inclusion criteria for the multivariable model ($p \leq 0.20$). Age was included in the multivariable modelling because it likely has a significant clinical association

with HIV/AIDS-related attitudes. Marital status and occupation were not found to be statistically significant in the multivariable model and were subsequently dropped.

The final multiple logistic regression model demonstrated several significant associations with HIV/AIDS-related attitudes. Individuals who resided in Kisomoro sub-county were 2.1 times more likely to demonstrate low levels of negative HIV/AIDS-related attitudes compared to individuals who resided in Rwimi sub-county (OR 2.06, p=0.021). It is important to note that odds ratio reported here for positive HIV/AIDS-related attitudes is an overestimation of the actual risk ratio for positive HIV/AIDS-related attitudes in the population. The odds ration always overestimates the risk ratio if prevalence of an outcome is high, and in our study the percentage of positive HIV/AIDS-related attitudes was high in both sub-counties. Women were also more likely to demonstrate lower levels of negative attitudes compared to men (OR 2.31, p=0.002). Having heard of ART had was significant with expressing lower levels of negative attitudes (OR 2.43, p=0.050). Respondents whose highest level of education was secondary school or higher were more likely to express positive HIV/AIDS-related attitudes compared to individuals who never attended school (OR 2.62, p=0.071). However, this association was not statistically significant. Age of respondent was not found to be significantly associated with negative HIV/AIDS-related attitudes in the final model.

Ever tested for HIV?

Table 11. Odds ratios and 95% confidence intervals from logistic regression for association with ever tested for HIV in 18 to 49 year olds in Rwimi and Kisomoro sub-counties, Uganda, 2009

	Univariate analysis		Multivariable analysis	
Variable	**OR (95% CI)†**	**p-value**	**OR (95% CI)†**	**p-value**
Sub-county				
Rwimi	1.00		1.00	
Kisomoro	1.46 (0.93-2.26)	0.093	1.29 (0.80-2.09)	0.293
Sex				
Male	1.00		1.00	
Female	4.78 (3.25-7.02)	<0.001	5.50 (3.51-8.63)	<0.001
Age				
18-29	1.00		1.00	
30-39	1.06 (0.65-1.73)	0.802	0.81 (0.45-1.46)	0.467
40-49	0.79 (0.46-1.35)	0.376	0.69 (0.34-1.39)	0.294
Marital status				
Single/divorced/ widowed	1.00			
Married/living with partner	0.91 (0.60-1.39)	0.663		
Occupation				
Professional	1.00			
Non-professional	0.52 (0.17-1.61)	0.245		
Farmer	0.43 (0.14-1.30)	0.131		
Other	1.01 (0.33-3.06)	0.991		
Education				
None	1.00		1.00	
Primary	0.76 (0.44-1.31)	0.316	0.98 (0.58-1.65)	0.924
Secondary or higher	1.25 (0.69-2.28)	0.456	1.88 (0.93-3.78)	0.076
Have you heard about ART?				
No	1.00		1.00	
Yes	2.38 (1.06-5.33)	0.036	2.95 (1.38-6.29)	0.006
Should people with HIV/AIDS be given equal opportunity to work?				
No	1.00			
Yes	1.59 (1.00-2.53)	0.049		
Did you use a condom the last time you had sex?				
No	1.00		1.00	
Yes	1.44 (0.89-2.34)	0.130	1.03 (0.57-1.84)	0.929
Age & condom use during last sexual encounter				

18-29 & yes	1.00	
30-39 & yes	3.98 (1.51-10.5)	0.006
40-49 & yes	3.01 (0.76-11.9)	0.113

†Weighted odds ratio (OR) adjusted for cluster as primary sampling unit; 95% confidence interval (95% CI)

In univariate logistic regression modelling, sub-county of residence, sex, occupation, education, having knowledge of ART, expressing positive HIV/AIDS-related attitudes, and using a condom during last sexual encounter met the inclusion criteria for the multivariable model ($p \leq 0.20$). Age was included in the multivariable modelling because it likely has a significant clinical association with ever tested for HIV. Marital status, occupation, and expressing positive attitudes were not found to be statistically significant in the multivariable model and were subsequently dropped.

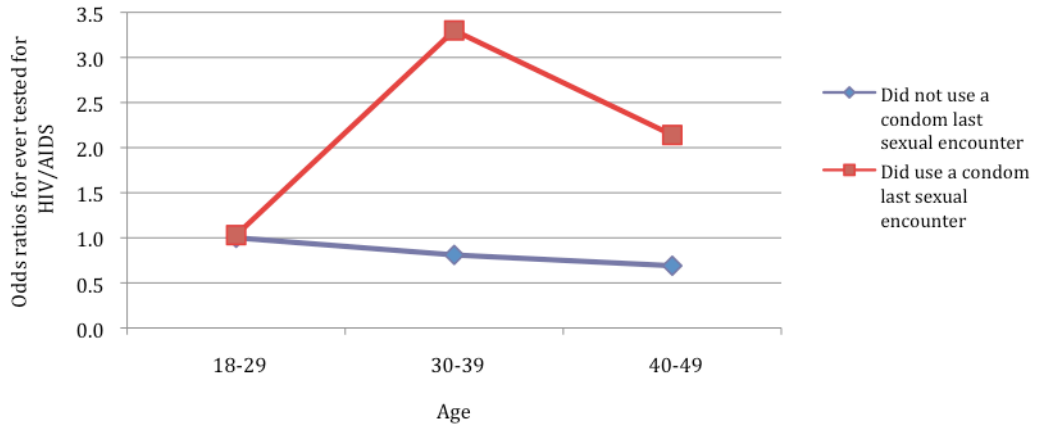
The final multiple logistic regression model demonstrated several significant associations with ever tested for HIV. Women were 5.5 times more likely to have ever tested for HIV compared to men (OR 5.50, $p<0.001$). Individuals with knowledge of ART were also more likely to have ever tested for HIV/AIDS (OR 2.95, $p=0.006$). Respondents whose highest level of education was secondary school or higher were more likely to have ever tested for HIV compared to individuals who never attended school (OR 1.88, $p=0.076$). However, this association was not statistically significant.

The interaction between age and using a condom during last sexual encounter was statistically significant in the final multivariable model. Compared to individuals who were between 18-29 years of age and had used a condom during their last sexual encounter, individuals who were between the ages of 30-39 and had using a condom during their last sexual encounter were 4 times more likely to have ever tested for HIV (OR 3.98, $p=0.006$). While individuals who were between the ages of 40-49 and had used a condom during their last sexual encounter were still 3 times more likely to have ever tested for HIV (OR 3.01, $p=0.113$). However, this last association was not statistically significant.

Table 12. Odds ratios for ever tested for HIV (based on Table 11 – multivariable logistic regression model) for different age groups and using a condom last sexual encounter

		OR		
		Age		
		18-29	30-39	40-49
Did you use a condom the last time you had sex?	No	1.00	0.81	0.69
	Yes	1.03	3.30	2.14

Figure 2. Odds ratios for ever tested for HIV



For individuals who did not use a condom during their last sexual encounter, the odds of ever testing for HIV decreased slightly with age (Table 12 and Figure 1). Individuals who did not use a condom during their last sexual encounter and between the ages of 18-29 had an OR of 1.00 (reference group), while individuals between the ages of 30-39 had an OR of 0.81 and those between the ages of 40-49 had an OR of 0.69.

For individuals who did use a condom during their last sexual encounter, the odds of ever testing for HIV fluctuated with age (compared to the reference group, who did not use a condom during their last sexual encounter and 18-29 years of age). Those who were between the ages of 18-29 had an OR of 1.03. This increased to an OR of 3.30 for those who were between the ages of 30-39, and then slightly decreased to 2.14 for those who were between the ages of 40-49.

Condom use during last sexual encounter

Table 13. Odds ratios and 95% confidence intervals from logistic regression for association with condom use during last sexual encounter in 18 to 49 year olds in Rwimi and Kisomoro sub-counties, Uganda, 2009

	Univariate analysis		Multivariable analysis	
Variable	**OR (95% CI)†**	**p-value**	**OR (95% CI)†**	**p-value**
Sub-county				
Rwimi	1.00		1.00	
Kisomoro	1.59 (1.02-2.50)	0.042	1.45 (0.91-2.31)	0.113
Sex				
Male	1.00		1.00	
Female	0.73 (0.50-1.07)	0.106	0.58 (0.37-0.92)	0.023
Age				
18-29	1.00		1.00	
30-39	0.71 (0.41-1.26)	0.234	0.32 (0.14-0.72)	0.007
40-49	0.57 (0.33-0.98)	0.043	0.19 (0.06-0.65)	0.009
Marital status				
Single/divorced/ widowed	1.00		1.00	
Married/living with partner	0.42 (0.27-0.65)	<0.001	0.57 (0.35-0.91)	0.021
Occupation				
Professional	1.00		1.00	
Non-professional	0.80 (0.30-2.13)	0.650	0.69 (0.27-1.78)	0.433
Farmer	0.33 (0.13-0.87)	0.027	0.38 (0.16-0.93)	0.034
Other	0.38 (0.12-1.16)	0.088	0.43 (0.15-1.24)	0.115
Education				
None	1.00			
Primary	1.09 (0.56-2.14)	0.790		
Secondary or higher	1.74 (0.81-3.70)	0.149		
Have you heard about ART?				
No	1.00			
Yes	1.04 (0.43-2.49)	0.936		
Should people with HIV/AIDS be given equal opportunity to work?				
No	1.00		1.00	
Yes	1.86 (1.11-3.12)	0.020	1.62 (1.00-2.63)	0.052
Have you ever tested for HIV/AIDS?				
No	1.00		1.00	
Yes	1.41 (0.89-2.24)	0.134	0.98 (0.57-1.69)	0.945
Age & ever tested for HIV/AIDS				

18-29 & yes	1.00	
30-39 & yes	3.54 (1.22-10.3)	0.022
40-49 & yes	3.73 (0.87-16.0)	0.075

†Weighted odds ratio (OR) adjusted for cluster as primary sampling unit; 95% confidence interval (95% CI)

In univariate logistic regression modelling, sub-county of residence, sex, age, marital status, occupation, education, expressing positive HIV/AIDS-related attitudes, and ever testing for HIV met the inclusion criteria for the multivariable model ($p \leq 0.20$). Having knowledge of ART was also included in the multivariable modelling to further examine its association with condom use during last sexual encounter. Subsequently, education and ever hearing of ART were not found to be statistically significant in the multivariable model and were subsequently dropped.

The final multiple logistic regression model demonstrated several significant associations with condom use during last sexual encounter. Women were 42% less likely to have used a condom during their last sexual encounter compared to men (OR 0.58, p=0.023). Individuals who were 30-39 years of age were 68% less likely to have used a condom during their last sexual encounter compared to those 18-29 years of age (OR 0.32, p=0.007). Those 40-49 years of age were even less likely to have used a condom (OR 0.19, p=0.009). People who were either married or living with a partner were 43% less likely to have used a condom during their last sexual encounter compared to those who were single, widowed, or divorced (OR 0.57, p=0.021).

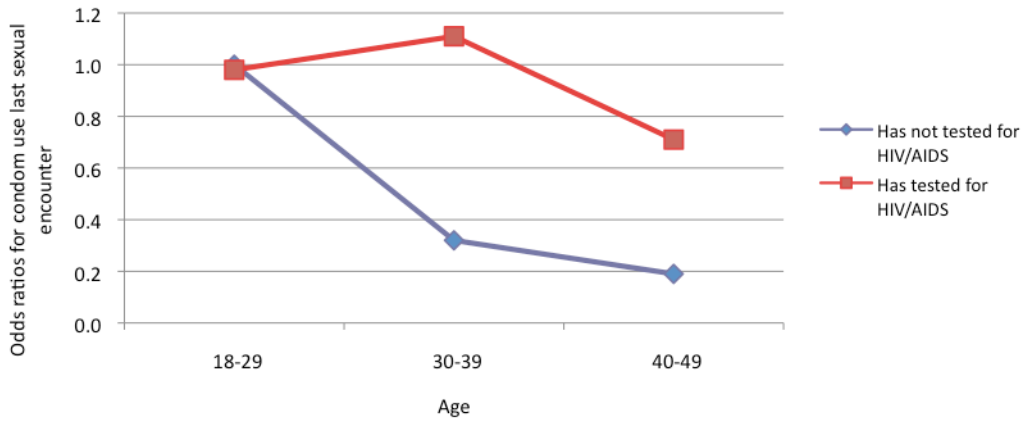
Compared to those who had a professional occupation, farmers were 62% less likely to have used a condom during their last sexual encounter (OR 0.38, p=0.034). Individuals with non-professional occupations and other occupations (primarily students and housewives) were also less likely to have used a condom compared to professionals. However, these associations were not significant. Demonstrating low levels of negative HIV/AIDS-related attitudes was borderline significant with condom use during last sexual encounter (OR 1.62, p=0.052). Sub-county of residence was not found to be significantly associated with condom use during last sexual encounter in the final model.

The interaction between age and ever tested for HIV was statistically significant in the final multivariable model. Compared to individuals who were between 18-29 years of age and had tested for HIV, individuals who were between the ages of 30-39 and had tested for HIV were 3.5 times more likely to have used a condom during their last sexual encounter (OR 3.54, p=0.022). Individuals who were between the ages of 40-49 and had tested for HIV were also more likely to used a condom during their last sexual encounter (OR 3.73, p=0.075). However, this last association was not statistically significant.

Table 14. Odds ratios for condom use during last sexual encounter (based on Table 13 – multivariable logistic regression model) for different age groups and ever tested for HIV

		OR		
		Age		
		18-29	30-39	40-49
Have you ever tested for HIV/AIDS?	No	1.00	0.32	0.19
	Yes	0.98	1.11	0.71

Figure 3. Odds ratios for condom use during last sexual encounter



For individuals who have not tested for HIV, the odds of having used a condom during their last sexual encounter decreased with age (Table 14 and Figure 2). Individuals who had never been tested for HIV and between the ages of

18-29 had an OR of 1.00 (reference group), while individuals between the ages of 30-39 had an OR of 0.32 and those between the ages of 40-49 had an OR of 0.19.

For individuals who had tested for HIV, the odds of using a condom during their last sexual encounter fluctuated slightly with age (compared to the reference group, who never been tested for HIV and 18-29 years of age). Those who were between the ages of 18-29 had an OR of 0.98. This increased to an OR of 1.11 for those who were between the ages of 30-39, and then slightly decreased to 0.71 for those who were between the ages of 40-49.

Chapter 5: Qualitative Study Results

During the data collection phase, it was discovered that HIV-testing rates were much higher than expected in Kisomoro sub-county (the comparison sub-county). The questionnaire did not provide enough detail to help explain why this was observed. Therefore, in addition to the four planned focus groups in Rwimi, four additional focus groups were undertaken in Kisomoro. In each sub-county, the focus groups were comprised of: a) males who had tested for HIV; b) males who had not tested for HIV; c) females who had tested for HIV; and d) females who had not tested for HIV. There were between five to fifteen participants in each of the eight focus groups, totalling sixty-five participants (Table 15).

Table 15. Number of participants in focus groups with community members

	Sub-county	
Focus group participants	**Rwimi**	**Kisomoro**
Men who have tested for HIV	8	6
Men who have not tested for HIV	15	5
Women who have tested for HIV	8	8
Women who have not tested for HIV	9	6

Two focus group discussions were also added with local health care workers, one in Rwimi and one in Kisomoro. The purpose of these groups was to better understand what other health services or interventions were in place that may have influenced the uptake of HIV/AIDS testing. Four health care workers attended the session in Rwimi sub-county, while three health care workers attended the session in Kisomoro.

Several themes and subthemes were identified in the focus group data. The themes provided context for key findings generated from responses to the questionnaires, and highlighted the complex interplay between knowledge, attitudes, prevention practices, and access to HIV/AIDS programming. In addition, several subthemes demonstrated the benefits and shortfalls of existing efforts.

Focus group discussions – Community members

Testing for HIV

Several barriers and enablers to testing for HIV were given by discussion participants. Fear and stigma were commonly cited barriers to HIV testing. Participants feared that a positive diagnosis might affect their lives. Few had the resources to support themselves and their family members if they became too ill to work. For many, to know your status was associated with the possibility of knowing your death. Some simply preferred not to know:

> You find nowadays others fearing to go for HIV check-up because they might have lost their parents due to HIV/AIDS scourge, and maybe their family members died of AIDS. So, they say, "If I happen to test and know my HIV status, I may also die." - Rwimi, woman who had not tested

Several women voiced concern that their spouses might divorce them if they were diagnosed with HIV. One woman stated "We fear testing because if you're found positive and you tell your husband, he divorces you" (Rwimi, woman who had tested). Male participants on the other hand did not report the same level of concern. They agreed that some husbands were likely to leave their HIV-positive wives, but not vice versa. For women who already had few resources to support themselves, an HIV-positive diagnosis would be devastating for both themselves and their children if their husbands chose to leave them. Others worried their peers would learn of their status and refuse to have anything to do with them:

> [People] wouldn't wish to associate with infected people, not even touching their hands because they consider HIV victims as a curse in the community. So people feel ashamed to go for HIV testing and be told they're positive. - Rwimi, man who had not tested.

Even if their status didn't become public knowledge, being recognized at the health centre could "become the headline story of the day" (Kisomoro – woman who had tested). The ensuing gossip was too much for some to face.

Another major barrier to HIV testing was a lack of adequate access to testing and treatment services. Health centres were typically situated far away

from the villages and could only be accessed by dirt roads over rough terrain. Most focus group discussion participants were not able to sacrifice a day of work to travel to the health centre. The amount of time and money that would be lost to the trip was considered too valuable:

> In our village, we still have many people who haven't tested for HIV just because health units are far away from our village… You find all health units situated far away from the village, and some people find difficulties in accessing the health unit for HIV testing. - Kisomoro, woman who had not tested.

Others who were able to make the journey to the health centre were still discouraged by the lack of available ART. Several participants reported that the health facilities often had periods of ART shortages. "When you visit the hospital where you're supposed to get treatment from, health workers tell you that drugs are out of stock" (Kisomoro, man who had tested). Some stated that the health centre staff "dispense to specific individuals" (Rwimi, man who had not tested), depending on the availability of the drugs. This was compounded by the fact that in previous years ART supplies were more reliable. One participant reported, "In the past, HIV programs used to supply HIV drugs to people in the village. It's now past two years and they no longer bring drugs to patients. That's why most people refuse to be tested" (Rwimi, man who had not tested).

Focus group participants spoke on numerous occasions of the benefits of local education and sensitization activities. These pursuits helped other community members better understand the importance of HIV testing and make the crucial decision to travel to the health centre and request a test:

> At every function which takes place in the village there's always awareness raising about HIV/AIDS, and they educate us how to protect ourselves from HIV/AIDS. This helps people to be firm and test. - Rwimi, woman who had not tested

Many also reported a great need for more education and sensitization activities in their villages, so that more people would develop an interest in HIV testing. Even relatively minor activities influenced some to go and test:

> In our villages, we've not yet had a chance of people coming to sensitize us in the community, so that they can get interest in HIV testing. Few people decide to go for check-up without being told, and when [the note taker] visited our village, some of us were encouraged and made up our minds. Then decided that whoever wanted to test for HIV was free to go and test. - Kisomoro, woman who had not tested.

Another factor that enabled people to test for HIV was having known someone else who had taken the test. In knowing someone else who had tested, family members and friends saw the benefits of testing first hand, and they got "Courage to go and test and live normally like [the person who had tested]" (Rwimi, woman who had not tested). One male participant decided to test after his wife tested and encouraged him to do the same. He even went on to persuade his colleagues to go and test:

> "[My wife] got a chance of testing for HIV. When she came back to home, she showed me her results. After listening to her explanation, I was encouraged to go with her for check-up… I then picked interest in sensitizing my fellow boda-boda cyclists at [X] Stage to go for HIV testing and know their status. - Kisomoro, man who had tested

Focus group discussion participants also reported people that were given confidence to test after seeing the health of their peers on ART improve:

> In our village, people go for HIV testing because they see their friends who were badly off looking good after getting HIV treatment from the health unit. So they get courage to go for treatment in order to live healthy as their friends. - Rwimi, man who had not tested.

Improved access to testing to testing and treatment services also helped encourage friends and neighbours to test for HIV:

> People can only access HIV testing services easily if we get volunteers to come to our villages and test from there. It would be so easy for most people because there's a time when people visited our village shortly and many people were eager and tested for HIV. - Kisomoro, woman who had tested

Condom use

Condom use was another practice participants cited numerous barriers to. Several focus group participants reported the lack of concern some people exhibited towards preventing HIV transmission, especially when it came to condom use. With AIDS now being thought of as a chronic condition, rather than a lethal disease, some failed to recognize the seriousness of actions which put both themselves and others at risk. "There are some individuals who say that, 'After all, HIV/AIDS treatment services are available. I am not scared of death'" (Rwimi, man who had tested). Others perceived they could die at any time from a number of causes, so why should they be concerned about HIV:

> Some people fear getting AIDS, while others don't mind being infected. They say, "How long will I live? Will they get timber out of me? Whether I am positive or not, I will die at any one time." - Rwimi, man who had tested

Female participants reported their partner's lack of willingness to use a condom, even if their partners were engaging in unsafe sex with other people:

> Some men refuse to use condoms after reaching a mutual understanding with their wives or prostitutes to protect. But in the end, they refuse to keep their promise and force women to have unprotected sex. - Kisomoro, woman who had not tested.

Most women didn't have a choice to use a condom when their husbands wanted to have unprotected sex with them. Their husbands' word was what they had to abide by, whether they agreed with him or not.

Despite the reported barriers to condom use among residents of Rwimi and Kisomoro sub-counties, focus group participants also spoke of numerous enablers. As with testing for HIV, education and sensitization activities were mentioned most often. Local funeral services were a popular venue for these activities. "When someone dies in the village, mourners always advise people to protect themselves against HIV/AIDS" (Rwimi, man who had tested). This in turn helped community members to "[Adopt] preventive behaviours at a fast rate" (Rwimi, man who had tested).

Knowing others who had either died of AIDS or initiated ART also helped motivate people to adopt prevention practices and protect themselves from HIV/AIDS:

> After hearing and knowing that there's an outbreak of HIV/AIDS, then we started seeing our village mates dying of HIV/AIDS, getting serious signs and symptoms. Most of us started fearing… Many people developed fear and started protecting themselves against HIV/AIDS, even if some people are having many partners nowadays. - Rwimi, man who had tested

Increased availability and accessibility of condoms, combined with education and sensitization activities, helped to encourage people as well:

> People in villages protected themselves against HIV/AIDS so much because volunteers giving our ARVs were given condoms also to supply in villages. And they used to advise us that, "If you have a sexual partner, you must use a condom. When he/she refuses to protect, you leave playing sex." - Rwimi, man who had tested

Participants reported increasing availability of condoms was not enough. People needed to be better educated to enable them to make more informed and safer choices.

HIV/AIDS and ART knowledge

Participants listed many shortfalls in HIV/AIDS and ART knowledge among community members. However, they also shared several benefits and sources. During discussions, the importance of education and sensitization activities for improving HIV/AIDS knowledge was brought up repeatedly. One of the biggest shortfalls reported by participants was that not enough education and sensitization activities were currently taking place, especially by PLWHAs. Those that did happen often targeted individuals living and working in urban areas. By failing to "Start from the common people deep in the village… [existing programs] deny rural people the chance of being educated also" (Rwimi, man who had not tested). Participants also cited many sources of misinformation, which helped to incite rumours that the government was intentionally withholding ART from those suffering from AIDS:

> They heard that ARVs have decreased in number and patients who used to get ARVs for a lifetime will never get them again… patients will take them for 6 months and they die… There are rumours circulating around that the government wants all positive people to die. - Rwimi, woman who had tested

Higher levels of HIV/AIDS knowledge helped improve people's attitudes towards HIV/AIDS and those living with the disease. Participants reported some people were too fearful to learn their status. It was easier for them not to know than it was to deal with the consequences of having the infection. When discussing how some couples were not willing to test for HIV together, one woman reported, "Such cases can cease to exist if there's thorough sensitization in the villages and people stop fearing" (Kisomoro, woman who had tested). Another participant went on to say that, "If they were educated, they wouldn't be having stigma. Fear has led to the increment of HIV/AIDS among people" (Kisomoro, woman who had tested). Participants also recognized the benefits of increased efforts by health care workers to educate community members. These had helped to "influence people's knowledge, which changed people's thoughts" (Kisomoro, man who had not tested).

Education and sensitization activities also went on to increase uptake of prevention practices, particularly testing for HIV and condom use:

> We were sensitized about HIV/AIDS in our villages, and we involved ourselves in testing for HIV/AIDS to know our status. After testing and knowing our status, we started getting ARVs, so education programs on HIV/AIDS helped us so much in villages. - Rwimi, man who had tested

> Most of them use condoms whenever having sexual intercourse, so that they can prevent themselves from getting HIV/AIDS. This is so because sensitization programs have been taking place, plus radio programs, which teach people preventative measures against HIV/AIDS. - Rwimi, man who had tested

Other focus group participants spoke of improved ART adherence as a result of improved HIV/AIDS and ART knowledge. "Those who are knowledgeable after

being sensitized put more effort into taking ARVs" (Kisomoro, woman who had tested).

Participants listed many sources of HIV/AIDS and ART knowledge, including: education and sensitization activities, PLWHAs, friends, family, and radio programs. Radio programs were particularly informative:

> I think it's because of the awareness taking place on the radio, advising people, and when people visit a health unit they're advised to test for HIV and know their status. That's why most people are interested in HIV testing. - Kisomoro, women who had tested

Individuals who acquired HIV/AIDS-related knowledge then went on to share it with their friends and family members.

> We get information from radios then other people get knowledge from their fellow friends, neighbours who discuss about AIDS. People are aware, unlike in the past. – Rwimi, woman who had not tested

Participants also reported that gossip and misinformation were shared in the same manner, and often the two were difficult to separate.

Attitudes to HIV/AIDS

Particularly in focus group discussions with male participants, the notion that AIDS is a chronic disease rather than a death sentence was brought up repeatedly. People were no longer able to recognize someone living with AIDS. PLWHAs could die without anyone knowing they were ever infected with the HIV virus. As a result, the seriousness of the illness was greatly reduced in some people's minds. One man reported, "People nowadays consider AIDS as an accident… They think its malaria or an accident you get when walking on the road. It's like being hit by a speeding car" (Kisomoro, man who had tested). This had serious consequences for youth who "See their friends dying of malaria when, in actual sense, it's AIDS which has killed them" (Kisomoro, man who had not tested). These youth were part of new generation that did not have first-hand experience dealing with the health consequences of untreated AIDS.

Others recognized the seriousness of HIV/AIDS, but regardless went on to infect their sexual partners. One participant from Rwimi sub-county reported this was a widespread problem in his community:

> Another common problem occurring in villages is that someone may have sexual intercourse with a person and that person dies later of HIV… And the partner suspects him/herself of being infected with HIV/AIDS, yet he/she has never gone for HIV testing to confirm his/her status. Such culprits are always tempted to sleep with other people without any protection because they suspect themselves to be positive. - Rwimi, man who had tested

Another participant from Kisomoro described an even more heinous scenario:

> Some people refuse to wear condoms deliberately because they want others to be infected too. They sleep with different people without using condoms. Most of them want to spread the virus all over the universe. - Kisomoro, man who had tested

These attitudes were having a detrimental impact on the struggle against HIV/AIDS in their communities; participants were becoming increasingly frustrated.

HIV/AIDS programming

Many shortfalls and benefits to existing HIV/AIDS programming efforts were cited by discussion participants. There was an overwhelming recommendation from focus group participants that more HIV/AIDS programs were needed in rural and remote villages. Numerous individuals reported that no such activities were currently available in their communities. One woman shared, "We don't get testing services or discussion about HIV/AIDS in our villages… so that people can test. Such services aren't there" (Kisomoro, woman who had tested). When participants from Rwimi were asked about the CBART program that had been running in their communities since 2005, respondents replied they were only partially aware of the existence of the program and that no education or awareness of HIV/AIDS was provided by the program. To the participants, the solution was simple. Bring more HIV/AIDS-related activities and services to remote villages to give people a chance to access them:

> Sensitization and testing services shouldn't be carried out at health units only, but health workers should select days and make outreach visits to different villages. Mainly testing people for HIV/AIDS. With that done, many people can get interest in testing. - Kisomoro, man who had tested

> When services are accessed easily, many people can get interest in testing. We also need more education or sensitization programs in our villages, plus AIDS victims to give testimonies, which encourage people to go for HIV check-up after seeing HIV victims looking healthy. - Kisomoro, woman who had not tested

> I don't know much about them, I'm ignorant. That's why I still insist on education/sensitization programs to be extended in our villages. Because I might hear it from my neighbour, but saying or gathering us at the health unit for a counselling session as a community, such that people who are ignorant can learn more and get a clue of AIDS is, no way, I've never heard of that calling. - Kisomoro, woman who had tested

Furthermore, programs and services needed to put more effort into giving clear, straightforward, and detailed messages to the general public.

> There are some groups which visit different villages to sensitize people, but they don't discuss HIV in details. They instead give them a brief clue of HIV. - Kisomoro, woman who had tested

Individuals who lived in villages where HIV/AIDS programs were running, or had run in the past, spoke of numerous benefits. One man from Kisomoro sub-county reported, "HIV programs brought change among the community, and most people adopted preventive measures like using condoms" (Kisomoro, man who had tested). Another conveyed, "HIV programs have helped people to have open minds, and everyone is aware not to mistreat HIV patients" (Kisomoro, man who had not tested). Above all, local HIV/AIDS programming had many benefits, particularly in remote villages where services are difficult to access.

Focus group discussions - Local health care staff

Two additional focus group discussions were held with local health care workers: one in Rwimi sub-county and one in Kisomoro sub-county. The purpose of these discussions was to better understand what other health services or interventions were offered that may have influenced the uptake of HIV testing in each sub-county.

Education and sensitization activities

Health care staff reported numerous sensitization activities taking place in both sub-counties. In Kisomoro, the district health office ran "many programs on HIV/AIDS awareness." Nurses at the local health centre held seminars to "give teachers knowledge so that they can sensitize their students/pupils about the information." They also participated in church and community events to sensitize the audience about important health issues. The seminars and public appearances did not always focus on HIV/AIDS, but rather provided an overview of pertinent health issues in the region, such as malaria, TB, and diarrheal diseases. As a result of these prevention-based activities, staff in Kisomoro agreed that:

> There is a change… in all: condom use, testing rates, coming to be tested, and those who are on ARVs. In the past stigma was actually great… but it is decreasing with time… because we have some people here who come and they give testimonies… so that others also learn from them.

In Rwimi, the local health centre staff reported that the German government development agency (also known as GTZ) used to carry out sensitization activities in the communities. The activities were "mainly focusing on prevention, especially PMTCT." At the time, GTZ did not provide ART. Instead, it gave "information to people, and they [were] providing them with condoms." It wasn't until 2005, "when [the community-based ART] project came here… [that] more sensitization," was done, and "people starting coming for testing and eventually ARVs." As more and more people in the surrounding villages began to hear about the project and its activities, they would gradually "get information from maybe one person to another, maybe through meetings,

maybe going to the villages." The health care staff in Rwimi were attempting to "balance prevention and treatment" activities with those involved in the CBART program by educating patients' treatment partners. Additionally, staff at the health centre attempted to sensitize women coming for antenatal services so that they also had an opportunity to be educated. They would also "carry out outreach," and other "health education" activities.

Health care staff in Rwimi however also reported that the health centre would sometimes have "stock outs." When this occurred, they would ask people to "first go back then come back another day." Unfortunately, they "could not motivate [everyone] to come back." The government had also recently "stopped paying for all clients' CD4 testing. Consequently, "some people [were] tested, when they [were] told to go back and [bring] that money to come and pay for CD4, some don't come back." According to the local staff, these shortages and cutbacks were having a damaging impact on progress made by GTZ and the CBART program in the sub-county.

Community-based programming

Besides the activities carried out by health centre staff and the CBART program, no other widespread HIV/AIDS programming was taking place in Rwimi sub-county. However, in Kisomoro, Kisomoro Parish had a volunteer-based health program running throughout its villages:

> There's a group selected from the community… it's on the village level. They are village health workers… They go for twenty-five homes in that village. Then another village... they select another two for twenty-fives homes/households. So they were selected by… the village, the village people selected them to help in that awareness of HIV, family planning, malaria… and hygiene areas and others.

The village health workers were initially trained by a non-governmental organization (NGO), with support by the district health office. Unfortunately, the NGO had withdrawn from the region earlier in the year of data collection, 2009. At that point, it wasn't clear what effect this would have on the program.

Possible explanations for quantitative differences

When asked why Kisomoro residents had higher HIV testing, lower stigma, and more condom use compared to residents of Rwimi sub-county, a health care worker in Kisomoro responded:

> Rwimi, it also goes with maybe the tribe in that they are traditional… But when you come, like here in Kisomoro… they know that after getting that awareness in testing, I'll have this service and I'll become better and I will continue with my work. But, like in the other area they say, 'Even if I die, some other people will keep on.'"

Another possible explanation provided by a health worker in Kisomoro was:

> The relationship between poverty and HIV… A person in town… their surviving is very hard. And people in Kisomoro are having their portions on hand, and they are better off… [A] person in a town, it is mandatory that he has to survive by hook or crook.

When health care workers in Rwimi sub-county were asked about the same differences, no one was quite sure what the cause or causes might be.

Chapter 6: Discussion

Comparison of Rwimi and Kisomoro

The first two aims of this study were to: 1) assess levels of knowledge surrounding HIV/AIDS and HAART, attitudes towards these topics, and common preventive behaviours among residents of Rwimi sub-county, and 2) compare the findings obtained in Rwimi with those from residents of Kisomoro, a similar nearby resource-poor sub-county without an ART program. By providing data on these trends, this study helps to complement and expand on previous research examining the influence of increased availability and accessibility of ART through community-based programming.

Sociodemographic characteristics

Univariate analyses found that overall sociodemographic characteristics of respondents from Rwimi and Kisomoro were fairly similar. The only statistically significant sociodemographic differences between respondents from the two sub-counties were marital status and occupation. Almost twice the proportion of respondents from Kisomoro, 35%, identified themselves as single, divorced, or widowed compared to respondents from Rwimi, at 20%. The majority of respondents from Rwimi, 68%, identified themselves as subsistence farmers, while only 51% of respondents from Kisomoro identified themselves this way. It is possible that these sociodemographic differences may have contributed to other statistical differences found between the two sub-counties. Respondents from Kisomoro sub-county might be more financially secure compared to respondents from Rwimi since less have to harvest their own food to sustain themselves and their families. A higher and more stable income would enable respondents from Kisomoro to access better health services, which would likely lead to higher levels of knowledge and better uptake of prevention practices. These figures compared moderately well to the national figures provided in the last national demographic and health survey completed in 2006. (38).

Knowledge

A moderate proportion, 28%, of respondents from Rwimi identified the CBART program as a HIV/AIDS treatment program in the region. Only 20% identified other nation-wide programs, such as JCRC and TASO. In Kisomoro, the majority of respondents only identified national programs. Another 12% of respondents in Rwimi identified volunteers associated with the program as a source of ART. No respondents from Kisomoro identified program volunteers as a source of ART.

In the last national survey assessing HIV/AIDS and STI knowledge, completed in 2006, knowledge levels were deemed to be "high and widespread" throughout the country (38). When HIV/AIDS and ART knowledge among respondents from Rwimi and Kisomoro sub-counties was assessed using univariate analyses, knowledge levels appeared to be good overall. The majority of respondents were able to correctly answer basic questions assessing different aspects of HIV/AIDS and ART knowledge, such as "What are the main symptoms of HIV/AIDS," "How can HIV/AIDS be spread," and "Can people on ART still infect others?" However, a few questions exemplified higher levels of knowledge among participants from Kisomoro sub-county. The question that illustrated the starkest difference between respondents from Rwimi and Kisomoro was, "How long should a person take ART?" Only half of the respondents from Rwimi were able to correctly answer the question, compared to three-quarters of respondents from Kisomoro.

Despite most respondents having at least good level of HIV/AIDS and ART knowledge, respondents from Kisomoro were more likely to have higher levels of knowledge compared to respondents from Rwimi.

HIV/AIDS-related attitudes

Seven questions were used to assess HIV/AIDS-related attitudes towards PLWHAs on the survey. For all seven questions, respondents from Kisomoro sub-county were more likely to report positive attitudes compared to respondents from Rwimi sub-county. All differences were statistically significant. On average, 17%

of respondents from Rwimi expressed negative attitudes towards PLWHAs, while only 6% of respondents from Kisomoro expressed negative attitudes. In addition to being more likely to have higher level of HIV/AIDS and ART knowledge, participants from Kisomoro sub-county were also more likely to have lower levels of negative attitudes towards PLWHAs.

Prevention practices

Differences in responses to questions assessing prevention practices were less apparent than they were for HIV/AIDS-related knowledge and attitudes. A higher proportion of respondents from Kisomoro sub-county reported having ever tested for HIV, 48% in Rwimi and 57% in Kisomoro, but this difference was not statistically significant. These proportions of participants who had tested were considerably higher than the district-wide estimate of 19% reported by Kipp et al. in 2005 (39). When responses were stratified by gender, considerably more females had tested in Rwimi and Kisomoro sub-counties compared to males. In Rwimi, only 30% of male respondents had tested compared to 67% of women. In Kisomoro, 38% of males had tested compared to 74% of women. These figures were notably higher than the national estimates of 25% for women and 21% for men (38). It is important to note that the higher levels of testing in women were likely due to the introduction of routine counselling and antenatal HIV testing for all pregnant women throughout Kabarole District in 2008 (58). The national figures date back to 2006 (38).

As for condom knowledge and use, a higher proportion of respondents from Kisomoro, 99%, knew where to get condoms compared to respondents from Rwimi sub-county, at 91%. They were also more likely to have used a condom the last time they had sex, at 34%, compared to 23% for respondents from Rwimi. When condom use was stratified by sex, 24% of women and 32% of men had used a condom during their last sexual encounter. Again, these figures were considerably higher than the national figures captured in the 2004/2005 Uganda HIV Sero-Behavioural Survey, 9% in women and 16% in men (4).

Overall

The results of the univariate (unadjusted) analyses showed that throughout the survey, respondents from Kisomoro consistently had higher levels of HIV/AIDS and ART knowledge, lower levels of negative attitudes, and better uptake of prevention practices compared to respondents from Rwimi.

Predictors of knowledge, attitudes, and practices

Univariate logistic regression modelling was used to examine relationships between sociodemographic, knowledge, attitudes, and behaviour variables. Results from both the univariate analyses and univariate logistic regression were used to generate four multivariable models describing knowledge, HIV/AIDS-related attitudes, HIV/AIDS testing, and condom use. These models were developed in order to better understand how the aforementioned outcomes of interest were influenced among study participants.

Knowledge

The final multiple logistic regression model for knowledge only demonstrated one significant association, with education level. Individuals with at least a primary school level education were more likely to have heard of ART compared to individuals who never attended school. This association was even stronger in individuals who attended secondary school or higher. Interestingly, sub-county of residence was not significantly associated with having heard of ART.

This is in accordance with a study carried out by Kipp et al. in 2005 examining public knowledge towards HIV/AIDS and ART in the Kabarole District in 2005 (39). Using multivariable analysis, they found that education level was the only variable associated with knowledge. Other variables of interest, such as age, gender, and occupation, were not associated with higher levels of knowledge.

HIV/AIDS-related attitudes

The final multiple logistic regression model for HIV/AIDS-related attitudes included several significant associations, including sub-county of residence. Individuals residing in Kisomoro sub-county were more likely to demonstrate positive HIV/AIDS-related attitudes compared to individuals who resided in Rwimi sub-county. Gender was also significantly associated with the outcome. Women were twice as likely to express lower levels of negative attitudes towards PLWHAs compared to men. These findings are in contrast to national figures on acceptance of PLWHAs across the country. In the national survey, nearly 40% of men expressed positive attitudes towards PLWHAs, while only one in four women did (38). As with HIV testing, these differences were likely the result of the introduction of routine counselling and testing services for all pregnant women seeking antenatal services in Kabarole District since 2008, two years after the national statistics were collected (58).

Ever tested for HIV?

The final multiple logistic regression model for ever testing for HIV/AIDS demonstrated two significant associations. Women were 5.5 times more likely to have ever tested compared to men. Once again, this was likely due to the introduction of routine counselling and testing for all pregnant women in the district. Having knowledge of ART, which was represented by the variable "ever heard of ART," meant an individual was 3 times more likely to have ever tested for HIV. Interestingly, sub-county of residence was not significantly associated with ever testing for HIV in the multivariable model.

These findings are in agreement with those from study carried out by Boulle et al. in 2008 examining HIV risk perceptions and behaviours in the context of ART (41). The authors found multiple associations with voluntary HIV testing among 14 to 49 years old men and women in Khayelitsha, South Africa, including age, employment status, and various knowledge indicators. Their models were stratified by gender, but univariate analysis showed that testing among women was considerably higher than men for all age groups.

The interaction between age and using a condom during last sexual encounter was statistically significant in the final multivariable model. For individuals who did not use a condom during their last sexual encounter, the odds of ever having tested for HIV/AIDS decreased slightly with age. For those that did use a condom, the odds of ever testing for HIV/AIDS fluctuated with age, increasing for individuals between the ages of 30-39 and decreasing slightly for those between the ages of 40-49. It is unclear why testing for HIV fluctuated between age groups among those who did use a condom during their last sexual encounter. Typically, those in younger age categories are more likely to have tested for HIV (38,41). It was surprising that among those who had used a condom, respondents 18-29 were the least likely to have tested. Perhaps they thought there was no need to obtain a HIV test if they were using condoms during their sexual encounters.

Condom use during last sexual encounter

The final multiple logistic regression model for condom use during last sexual encounter also demonstrated several significant associations. Again, gender was significantly associated with the outcome. Women were less likely to have used a condom compared to men. Respondents 30-39 and 40-49 were increasingly less likely to have used a condom during their last sexual encounter compared to respondents 18-29 years of age. Marital status was also significantly associated. Those married or living with a partner were half as likely to have used a condom compared to individuals who were single, widowed, or divorced. Interestingly, sub-county of residence was not significantly associated with condom use during last sexual encounter.

As with ever having tested for HIV, these findings are in accordance with those in Boulle's 2008 study examining risk behaviours in Khayelitsha, South Africa (41). Age, type of relationship, and various knowledge indicators were significantly associated with condom use during last sexual contact in multivariable analysis. Their model also demonstrated no direct association with ever having tested for HIV and condom use. These findings are in disagreement

with other studies that have suggested an association between the two factors (59,60). The model for condom use during last sexual encounter was stratified by gender, but univariate analysis showed that men were more likely to have used a condom in any last sexual contact compared to women. The finding that men were more likely than women to have used a condom is common throughout the literature and national reports documenting condom use in Uganda (4,38,61-64). This is often the result of an imbalance of power in sexual relationships between men and women, which limits a woman's ability to negotiate condom use.

The interaction between age and ever testing for HIV/AIDS was statistically significant in the final multivariable model. For individuals who have not tested for HIV/AIDS, the odds of having used a condom during their last sexual encounter decreased considerably with age. For those who had tested for HIV/AIDS, the odds of using a condom during their last sexual encounter fluctuated slightly with age. Respondents 18-29 years of age were just as likely to have used a condom during their last sexual encounter, regardless of ever having tested for HIV. This changed considerably for respondents 30-39 years of age. Participants in this age group who had tested for HIV were over 3 times more likely to have used a condom compared to those had not tested. This difference became less drastic for respondents 40-49 years of age. This interaction might explain why some studies found associations between testing for HIV and condom use, while others have not.

Overall

After adjusting for other variables, the indicator for HIV/AIDS-related attitudes was the only one with a statistically significant difference between residents of Rwimi and Kisomoro sub-counties.

Influence of prevention and treatment efforts

The third aim of this study was to examine the community's knowledge of and attitudes towards the community-based ART program in Rwimi sub-county. This was to be accomplished by carrying out a series of focus groups with

residents of Rwimi. However, during the data collection phase it was discovered that HIV testing rates were much higher than expected in Kisomoro sub-county. The questionnaire did not provide enough detail to help explain why this was observed. As a result, the focus group discussions were redesigned. The discussion guides were altered to focus more on what factors influenced knowledge, attitudes, and prevention practices, with a particular focus on HIV testing. Discussions with participants from Kisomoro sub-county and health care workers from Rwimi and Kisomoro sub-counties were also added to help better understand why HIV testing was much higher in Kisomoro than originally expected.

Community members

During focus group discussions participants described factors that enabled members of their communities to benefit from existing prevention and treatment efforts. These included, knowing someone who has tested for HIV/AIDS and/or was currently on ART, education and sensitization activities, especially by PLWHAs, and improved access to testing and treatment services. Numerous focus group discussion participants also voiced their concern about the need for more local efforts, particularly in remote communities where services were extremely limited or non-existent. The policy favouring centralization did not allow residents of these remote communities to access the same quality of preventative and educational services available to individuals living in more urban areas. Consequently, many barriers were still in place that prevented individuals from improving their knowledge surrounding HIV/AIDS and HAART, their attitudes towards these topics, and uptake of preventative practices.

When participants from Rwimi were asked about the long-running CBART program in their communities, respondents replied they were only partially aware of the existence of the program. A few had heard some people were receiving treatment in their homes, but not everyone who needed treatment was provided it. Furthermore, respondents also reported that no education or awareness of HIV/AIDS was provided by the program. Therefore, it is unlikely

the CBART provided quantifiable benefits on local knowledge, prevention practices, and HIV/AIDS-related attitudes beyond the patients receiving ART. This was in stark opposition to the findings of a study undertaken in Rwimi a year earlier that showed the CBART program was both well known and well-received by program patients and local community members (65). It is unclear why this study had such different findings.

Participants also discussed how additional HIV/AIDS programming would help to increase HIV/AIDS-related knowledge, which in turn would help to decrease fear and improve attitudes surrounding the disease, increase uptake of HIV-testing, increase update of prevention practices, and increase adherence to ART. These benefits align with those described in a reported released by the World Health Organization in 2003 (22). The report stated that increased availability of ART in Khayelitsha, South Africa had demonstrated that community-based, universal treatment is important for prevention because it can fuel education activities led by PLWHAs, help drive down HIV/AIDS-related stigma, and promote openness. Thus, additional programming would not only help those in immediate need of services, such as those requiring ART, but would also benefit other community members. More individuals would have the opportunity to learn about HIV/AIDS and ART, and have better access to resources to prevent themselves from acquiring the infection or deal with existing infections.

When asked how future CBART initiatives might be better able to influence the broader community, participants responded they should make more deliberate efforts to provide HIV/AIDS education and sensitization, fuelled by PLWHAs, bring HIV testing and counselling services to remote villages, and provide clear messages that emphasize the importance and benefits of services offered by the CBART program. Unless more programs adopt these efforts, it is unlikely they will have much impact on improving knowledge, attitudes, and prevention practices in the general population.

Local health care staff

When health care workers from Rwimi and Kisomoro sub-counties were asked about possible reasons for these differences, each group had considerably different responses. Health care workers from Rwimi were not able to pinpoint a possible reason for the observed differences. Rather they focussed on continued efforts by themselves and their colleagues to promote local education and sensitization activities in the surrounding villages. However, they acknowledged they could not compete with recent cutbacks and rampant rumours circulating about possible ART shortages. Some community members were simply not willing to take the risk of learning their HIV/AIDS status and starting ART only to be later told that their medications were no longer available.

Alternatively, health care workers in Kisomoro sub-county suggested possible factors that might have contributed to better uptake in their region. Individuals in Kisomoro were generally more financially secure than individuals in Rwimi and more concerned about health issues facing the region. Additionally, health care workers in Kisomoro spoke of community-based initiatives that may have contributed to the differences captured in the survey, including a volunteer-based program running throughout one of its parishes. The program was not focussed only on HIV/AIDS, but all health issues of importance to local residents. Its success, demonstrated by its continued support by community members and volunteers, was an example of greater capacity to address health issues in the region. This might be a least a partial explanation of why survey respondents from Kisomoro sub-county consistently demonstrated higher levels of HIV/AIDS and ART knowledge, better attitudes, and higher uptake of prevention practices compared to respondents from Rwimi.

Overall

The findings from the focus group discussions corresponded quite well to the findings from the quantitative component of the study. Participants discussed what factors influenced knowledge, attitudes, and prevention practices in their

communities and how future programs can have a greater impact. The overall tone from participants both in Rwimi and Kisomoro was quite similar.

Future studies

A study examining past and current prevention and treatment activities in the regions, including strengths and weaknesses identified by community members, would also provide valuable insight on what elements should be included in HIV/AIDS activities, both prevention and treatment focussed. This would serve as a more thorough assessment of what activities have taken place or are taking place than this study was able to capture.

This study was not equipped to assess the impact of the routine testing and counselling policy introduced in 2008 for all pregnant women seeking antenatal services. It is likely this policy had a considerable impact on district-wide knowledge levels, positive attitudes towards PLWHA, and uptake of preventive behaviours, particularly HIV testing. A comparison of these factors at the district level before and after 2008 would provide important insight on the influence of this policy on knowledge, attitudes, and behaviours.

Study strengths

The use of a comparison region without an active CBART program to assess the impact of CBART programs on community-wide knowledge, attitudes, and prevention practices was a strength of this study. To date, few studies assessing the impact of CBART programs on the general population have done this.

A mixed methods design allowed this study to provide a detailed assessment of knowledge, attitudes, and prevention practices in Rwimi and Kisomoro sub-counties. The survey instruments allowed for quantifiable descriptions of indicators for knowledge, attitudes, and behaviours, and the focus group discussions enabled the study to further explore differences observed between the two sub-counties. In doing so, questions and gaps were addressed that each element on their own would have left unanswered.

Participants in this study were selected using random cluster sampling. This allowed participants to be selected randomly from pre-selected clusters at the village and household levels in each sub-county, rather than sampling from all villages in the two sub-counties as would be required for simple random sampling.

Study weaknesses

The cross sectional nature of the study design was a weakness. It did not allow for a thorough evaluation of the change in knowledge, HIV/AIDS-related attitudes, and prevention practice indicators before and after the initiation of the CBART program.

There was a lack of comparative data on other interventions which might have influenced HIV/AIDS-related knowledge, attitudes, and prevention practices. The study design did not allow for assessment of other interventions that may have led to the differences found in this study.

The sample size used in this study was based on the assumption that HIV testing among residents in Rwimi sub-county would be 20% higher compared to residents of Kisomoro. As a result of this, the study lacked the power to detect differences less than 20%.

Dissemination activities

This study has been presented in both oral and poster format at several conferences, including the Canadian Conference on Global Health (Ottawa, 2012), AIDS 2010 (Vienna), and INSIGHTS: A focus on public health research at the University of Alberta (Edmonton, 2010). Results from this study will be disseminated to residents of Rwimi and Kisomoro sub-counties later this year.

Chapter 7: Conclusions and Recommendations

It is difficult to conclude if any of the differences that were found between Rwimi and Kisomoro sub-counties, or between Rwimi sub-county and available national statistics, were the result of the CBART program. It is likely that other policies, such as routine testing and counselling for all women seeking antenatal services introduced in Kabarole District in 2008, also influenced knowledge, attitudes, and prevention practices in the regions. Without thorough evaluations of past and current programming and policies in the two sub-counties, it is not possible to tease apart the impact of the CBART program.

Overall, the presence of the CBART program in Rwimi sub-county was not associated with greater levels of knowledge, attitudes, and prevention practices in the surrounding populations. Despite a CBART program running in their sub-county since 2005, residents of Rwimi consistently scored lower than the comparison sub-county for knowledge of ART services and the percentage of individuals who tested for HIV, had a higher percentage still engaging in unprotected sex, and had a higher degree of negative attitudes in the community compared to residents of Kisomoro, a similar resource-poor sub-county without a formal CBART program.

In retrospect, it was unlikely that a comparatively small CBART program with fewer than 200 HAART recipients that did not include any explicit components of engaging the general community around HIV/AIDS knowledge, attitudes, and prevention practices would have much influence on a scattered rural population of nearly 25,000. This was substantiated by study participants stating they were only partially aware of the CBART program.

One may speculate that the better levels of HIV/AIDS knowledge, attitudes, and prevention practices measured in Kisomoro sub-county may be related to a number of factors, including a closer proximity to centralized services in the district capital of Fort Portal and greater outreach activities by local health care workers. However, we do not have data to confirm these speculations.

Recommendations

Discussion participants strongly emphasized the recommendations given below as ways to help ensure that future CBART initiatives are better able to influence the broader population.

Future CBART initiatives can better influence the broader community by:

- Making deliberate efforts to provide HIV/AIDS education and sensitization, fuelled by PLWHAs
- Providing clear messages that emphasize the importance and benefits or services offered by the CBART program
- Bringing HIV testing and counselling services to villages

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Appendices

UNIVERSITY OF ALBERTA

Appendix I: Information Letter – General Population Survey

Project Title: Does the availability of antiretroviral therapy impact HIV/AIDS knowledge, attitudes and prevention practices in rural Uganda?

Principal investigator:
Laura Aplin, Principal Investigator
Master of Science Student, Global Health
Department of Public Health Sciences
School of Public Health
University of Alberta, Edmonton, AB

Supervisor:
Dr. L Duncan Saunders, Supervisor
Professor and Chair
Department of Public Health Sciences
School of Public Health
University of Alberta, Edmonton, AB

Dear Sir or Madame:
You are being asked to participate in a research project examining knowledge, attitudes and behaviours surrounding HIV/AIDS. This study is being done by the University of Alberta with the support of the Kabarole District Health Department and Makerere University in Kampala.

Purpose of the study:
This study aims to evaluate whether a community-based AIDS treatment program in a rural setting influences HIV knowledge and HIV prevention practices in the general community.

Procedure:
If you decide to participate, a trained interviewer will ask you a series of questions regarding HIV/AIDS. This will take 30 to 45 minutes and can be done in either Rutooro or English. You can choose to have the interview take place inside your home or at another location of your choice. If you need some help selecting an alternative location, the interviewer will assist you. You may also be offered an

opportunity to take part in a group discussion about 4 to 8 weeks after your interview. You can choose to participate in the interview but decline to participate in the group discussion.

Possible benefits:
There are no direct benefits from participating in this study. However, your answers may help to guide the development and implementation of future community-based AIDS treatment programs.

Possible harms:
There are no expected harms from participating in this study. If you do not feel comfortable with any of the questions, you can chose not to answer the question or stop participating in the study at any point in time.

Confidentiality and voluntary participation:
Information that you provide during the interview will be completely confidential. During the study, surveys will be kept in a secure area. After the study, the information will be kept for at least five years in a secure area at the University of Alberta in Edmonton, Canada. However, your name and any identifying information will be removed from it.

Freedom to withdraw:
If you agree to participate in the study, you may choose to leave at any point in time by informing the researcher without having to provide a reason.

For more information on the study:
If you have any concerns about this study or would like more information, please contact the principal investigator at aplin@ualberta.ca or at mobile 0784426789 or Mr. Tom Rubaale at the Health Department in Fort Portal 0777912866.

Your consent and legal rights:
Your signature or thumbprint on the consent form means that you understand the information in this letter. It also means you agree to participate in the study.

Please keep these pages in case you need them in the future.

UNIVERSITY OF ALBERTA

Appendix II: Information Letter for Focus Group Discussion Participants who have Tested

Project Title: Does the availability of antiretroviral therapy impact HIV/AIDS knowledge, attitudes and prevention practices in rural Uganda?

Principal investigator:
Laura Aplin, Principal Investigator
Master of Science Student, Global Health
Department of Public Health Sciences
School of Public Health
University of Alberta, Edmonton, AB

Supervisor:
Dr. L Duncan Saunders, Supervisor
Professor and Chair
Department of Public Health Sciences
School of Public Health
University of Alberta, Edmonton, AB

Dear Sir or Madame:
You are being asked to participate in a research project examining knowledge, attitudes and behaviours surrounding HIV/AIDS. This study is being done by the University of Alberta with the support of the Kabarole District Health Department.

Purpose of the study:
This study aims to evaluate whether a community-based HIV/AIDS treatment program in a rural setting influences HIV knowledge and HIV prevention practices in the general community. Specifically, we would like to explore factors in your community that may have prompted individuals in the community to be tested for HIV.

Procedure: If you decide to participate in the focus group discussion, a trained interviewer will ask you a series of questions relating to the attitudes of the community towards testing, the availability of and access to testing and other factors that may contribute to the motivation of individuals to be tested for HIV. The discussion will last 45 to 90 minutes and will take place in a convenient location at either Rwimi Health Centre or Kisomoro Health Centre. The

discussion will be conducted in English and will be audio taped. If you do not wish to participate, please inform the interviewer.

Possible benefits:
There are no direct benefits to you from participating in this study. However, your answers may help to guide the development and implementation of future community-based HIV/AIDS treatment programs.

Possible harms:
There are no expected harms from participating in this study. If you do not feel comfortable with any of the questions, you can chose not to answer the question or stop participating in the study at any point in time.

Confidentiality and voluntary participation:
In the focus group discussions, complete confidentiality cannot be guaranteed. All participants will be reminded that the names of volunteers and what is discussed are to remain confidential. If there is something you would not like to discuss or have knows, please do not feel any pressure to share it with the group. During the study, information provided from the discussions will be kept in a secure area. After the study, the information will be kept for at least five years in a secure area at the University of Alberta in Edmonton, Canada as well as in the University's project office in Fort Portal. However, your name and any identifying information will be removed from it.

Freedom to withdraw:
If you agree to participate in the study, you may choose to leave at any point in time by informing the researcher without having to provide a reason.

For more information on the study:
If you have any concerns about this study or would like more information, please contact the principal investigator at aplin@ualberta.ca or at mobile 0784426789 or Mr. Tom Rubaale at the Health Department in Fort Portal at 0777912866.

Your consent and legal rights:
Your signature or thumbprint on the consent form means that you understand the information in this letter. It also means you agree to participate in the study.

Please keep these pages in case you need them in the future.

UNIVERSITY OF ALBERTA

Appendix III: Information Letter for Focus Group Discussion Participants who have Not Tested

Project Title: Does the availability of antiretroviral therapy impact HIV/AIDS knowledge, attitudes and prevention practices in rural Uganda?

Principal investigator:
Laura Aplin, Principal Investigator
Master of Science Student, Global Health
Department of Public Health Sciences
School of Public Health
University of Alberta, Edmonton, AB

Supervisor:
Dr. L Duncan Saunders, Supervisor
Professor and Chair
Department of Public Health Sciences
School of Public Health
University of Alberta, Edmonton, AB

Dear Sir or Madame:
You are being asked to participate in a research project examining knowledge, attitudes and behaviours surrounding HIV/AIDS. This study is being done by the University of Alberta with the support of the Kabarole District Health Department.

Purpose of the study:
This study aims to evaluate whether a community-based HIV/AIDS treatment program in a rural setting influences HIV knowledge and HIV prevention practices in the general community. Specifically, we would like to explore factors in your community that may have prompted individuals in the community to be tested for HIV.

Procedure: If you decide to participate in the focus group discussion, a trained interviewer will ask you a series of questions relating to the attitudes of the community towards testing, the availability of and access to testing and other factors that may contribute to the motivation of individuals to be tested for HIV. The discussion will last 45 to 90 minutes and will take place in a convenient location at either Rwimi Health Centre or Kisomoro Health Centre. The

discussion will be conducted in English and will be audio taped. If you do not wish to participate, please inform the interviewer.

Possible benefits:
There are no direct benefits to you from participating in this study. However, your answers may help to guide the development and implementation of future community-based HIV/AIDS treatment programs.

Possible harms:
There are no expected harms from participating in this study. If you do not feel comfortable with any of the questions, you can chose not to answer the question or stop participating in the study at any point in time.

Confidentiality and voluntary participation:
In the focus group discussions, complete confidentiality cannot be guaranteed. All participants will be reminded that the names of volunteers and what is discussed are to remain confidential. If there is something you would not like to discuss or have knows, please do not feel any pressure to share it with the group. During the study, information provided from the discussions will be kept in a secure area. After the study, the information will be kept for at least five years in a secure area at the University of Alberta in Edmonton, Canada as well as in the University's project office in Fort Portal. However, your name and any identifying information will be removed from it.

Freedom to withdraw:
If you agree to participate in the study, you may choose to leave at any point in time by informing the researcher without having to provide a reason.

For more information on the study:
If you have any concerns about this study or would like more information, please contact the principal investigator at aplin@ualberta.ca or at mobile 0784426789 or Mr. Tom Rubaale at the Health Department in Fort Portal at 0777912866.

Your consent and legal rights:
Your signature or thumbprint on the consent form means that you understand the information in this letter. It also means you agree to participate in the study.

Please keep these pages in case you need them in the future.

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Appendix IV: Information Letter for Health Care Workers

Project Title: Does the availability of antiretroviral therapy impact HIV/AIDS knowledge, attitudes and prevention practices in rural Uganda?

Principal investigator:
Laura Aplin, Principal Investigator
Master of Science Student, Global Health
Department of Public Health Sciences
School of Public Health
University of Alberta, Edmonton, AB

Supervisor:
Dr. L Duncan Saunders, Supervisor
Professor and Chair
Department of Public Health Sciences
School of Public Health
University of Alberta, Edmonton, AB

Dear Sir or Madame:
You are being asked to participate in a research project examining knowledge, attitudes and behaviours surrounding HIV/AIDS. This study is being done by the University of Alberta with the support of the Kabarole District Health Department.

Purpose of the study:
This study aims to evaluate whether a community-based HIV/AIDS treatment program in a rural setting influences HIV knowledge and HIV prevention practices in the general community. Specifically, we would like to explore factors in your community that may have prompted individuals in the community to be tested for HIV.

Procedure: If you decide to participate in the small group discussion, a trained interviewer will ask you a series of questions relating to the attitudes of the community towards testing, the availability of and access to testing and other factors that may contribute to the motivation of individuals to be tested for HIV. The discussion will last 30 to 45 minutes and will take place in a convenient location at either Rwimi Health Centre or Kisomoro Health Centre. The

discussion will be conducted in English and will be audio taped. If you do not wish to participate, please inform the interviewer.

Possible benefits:
There are no direct benefits to you from participating in this study. However, your answers may help to guide the development and implementation of future community-based HIV/AIDS treatment programs.

Possible harms:
There are no expected harms from participating in this study. If you do not feel comfortable with any of the questions, you can chose not to answer the question or stop participating in the study at any point in time.

Confidentiality and voluntary participation:
In the small group discussions, complete confidentiality cannot be guaranteed. All participants will be reminded that the names of volunteers and what is discussed are to remain confidential. If there is something you would not like to discuss or have knows, please do not feel any pressure to share it with the group. During the study, information provided from the discussions will be kept in a secure area. After the study, the information will be kept for at least five years in a secure area at the University of Alberta in Edmonton, Canada as well as in the University's project office in Fort Portal. However, your name and any identifying information will be removed from it.

Freedom to withdraw:
If you agree to participate in the study, you may choose to leave at any point in time by informing the researcher without having to provide a reason.

For more information on the study:
If you have any concerns about this study or would like more information, please contact the principal investigator at aplin@ualberta.ca or at mobile 0784426789 or Mr. Tom Rubaale at the Health Department in Fort Portal at 0777912866.

Your consent and legal rights:
Your signature on the consent form means that you understand the information in this letter. It also means you agree to participate in the study.

Please keep these pages in case you need them in the future.

Appendix V: Consent Form

Title of Project:
Does the availability of antiretroviral therapy impact HIV/AIDS knowledge, attitudes and prevention practices in rural Uganda?

Part 1: Research information

Name of principal investigator: Laura Aplin
Affiliation: University of Alberta
Contact information: 0784426789

Name of supervisor: Dr. L Duncan Saunders
Affiliation: University of Alberta
Contact information: +17804926814

Part 2: Consent of Participant

	Yes	No
Do you understand you have been asked to participate in a study?		
Have you read and received a copy of the information sheet?		
Do you know the risks and benefits of participating in the study?		
Have you been able to ask questions and discuss the study?		
Do you know that you can withdraw anytime without an explanation? You have the right to refuse to participate.		
Do you understand confidentiality?		
Do you know who has access to your personal information?		

Part 3: Confirmation of Eligibility

	Yes	No
Is the participant between the ages of 18 and 49?		
Is the participant, or anyone living in the household, directly involved with the community-based HAART program in Rwimi?		

Part 4: Signatures

The study was explained by: _____ Date: _____

I agree to take part in this study:

Signature or thumbprint of participant: _____

Date: _____

Printed name: _____

Thumbprint

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of interviewer: _____

The appropriate information sheet must be attached to this consent form and a copy given to the research subject.

Appendix VI: General Population Survey

KNOWLEDGE, ATTITUDES AND BEHAVIOURS

SURVEY

About HIV/AIDS and ARVs

General population

RESPONDENT I.D. NUMBER _____

DIVISION/SUB-COUNTY _____

PARISH _____

VILLAGE/ZONE/LC1 _____

INTERVIEWER NAME _____

COMPLETION TIME **START TIME** _____ **END TIME** _____

DATE _____

COMPLETED ON VISIT: **1st** _____ **2nd** _____

Demographics

No.	Questions and filters	Coding Categories	Comments
1	What type of house does the respondent live in? **(Researcher's observation)**	Permanent (concrete) .....1 Semi-permanent (mud/wattle, iron roof) ...2 Temporary (grass thatched, grass or mud walls) 3	
2	Sex of the respondent	Male .....1 Female 2	
3	How old are you? When were you born?	_____ ..... / ……. / …… DD / MM / YY	
4	How many people are living in your household?	_____	
5	How many people living in your household are under 18 years of age?	_____	

No.	Questions and filters	Coding Categories	Comments
6	What is your marital status?	Single .....1 Married, living with a partner .....2 Not married, living with a partner .....3 Divorced .....4 Widowed 5	
7	What is your religious affiliation?	Catholic .....1 Protestant .....2 Muslim .....3 Other .....4 Specify _____	
8	What is your occupation?	_____	
9	Have you ever attended school?	Yes .....1 No 2	**If no, go to Q 11**
10	If yes, what is your highest level of education?	Primary .....1 Level _____ Secondary .....2 Level _____ Post secondary - technical .....3 Post secondary - college .....4 Post secondary - university .....5 Other .....6 Specify _____	

HIV/AIDS knowledge

No.	Questions and filters	Coding Categories	Comments
11	Have you ever heard of an illness called AIDS (Silimu)?	Yes ..... 1 No 2	
12	What are the main symptoms of AIDS?	_____ _____ _____ _____ _____ _____	

No.	Questions and filters	Coding Categories	Comments
13	What are the ways through which HIV may be spread that you know?	_____ _____ _____ _____ _____ _____ _____ _____	
14	Is it possible for a healthy looking person to be infected with HIV?	Yes ..... 1 No ..... 2 Do not know 88	
15	What are the things a person can do to avoid getting HIV?	_____ _____ _____ _____ _____ _____ _____ _____	

ART knowledge

No.	Questions and filters	Coding Categories	Comments
16	Is it possible for AIDS to be completely cured?	Yes..... 1 No ..... 2 Do not know 88	**If no, go to Q 18**
17	If yes, how?	Antiretroviral drugs..... 1 Traditional medicine..... 2 Spiritual healing ..... 3 Other..... 4 Specify _____	
18	Have you heard about ARVs (antiretrovirals)?	Yes..... 1 No 2	**If no, go to Q 20**

No.	Questions and filters	Coding Categories	Comments
19	If yes, what can they do?	_____ _____ _____ _____ _____ _____ _____	
20	Do you know somebody who receives these drugs (antiretroviral drugs?	Yes..... 1 No 2	
21	Do you know where to obtain drugs to treat HIV /AIDS (antiretrovirals)?	Yes ..... 1 No 2	**If no, go to Q 23**
22	If yes, where can they be obtained?	_____ _____ _____	
23	For how long should a person take ARVs?	_____ _____ _____	
24	Are people taking ARVs still able to infect others?	Yes..... 1 No ..... 2 Do not know..... 88	**If no, go to Q 26**
25	If yes, what should they do to keep from infecting others?	_____ _____ _____ _____	

HIV/AIDS-related attitudes

No.	Questions and filters	Coding Categories	Comments
26	Are people who have AIDS dirty?	Yes..... 1 No 2	
27	Are people who have AIDS cursed?	Yes..... 1 No 2	
28	Should people who have AIDS be ashamed?	Yes..... 1 No 2	

No.	Questions and filters	Coding Categories	Comments
29	Do you think a person with AIDS must have done something wrong and deserves to be punished?	Yes..... 1 No 2	
30	Do you think people who have AIDS should be isolated?	Yes..... 1 No 2	
31	Are you willing to be casual friends with someone who has AIDS?	Yes..... 1 No 2	
32	Should people with AIDS be given equal opportunity to work like others?	Yes .....1 No 2	

Testing, condom use and male circumcision

No.	Questions and Filters	Coding Categories	Comments
33	Do you know where one can go for HIV testing?	Yes ..... 1 No 2	**If no, go to Q 35**
34	If yes, where can one go for HIV testing?	_____	
35	Have you ever been tested for HIV?	Yes ..... 1 No ..... 2 Refuse to answer..... 3	**If yes, go to Q 36** **If no, go to Q 37**
36	If yes, why, when and did you receive the results?	_____ _____ _____	
37	If no, why not?	_____ _____ _____	
38	Do you know where to obtain condoms?	Yes ..... 1 No ..... 2 Refuse to answer..... 3	**If no, go to Q 40**
39	If yes, where can condoms be obtained? **(circle all that apply)**	Partner ..... 1 Shop ..... 2 Pharmacy/drug shop..... 3 Hospital / clinic ..... 4 Family planning centre ..... 5 Bar/ hotel ..... 6 Other ..... 7 Specify _____	
40	Did you use a condom the last time you had sexual intercourse?	Yes ..... 1 No ..... 2 Refuse to answer..... 3	**If yes, go to Q 41** **If no, go to Q 42**

41	If yes, why?	_____ _____ _____ _____ _____ _____	
42	If no, why not?	_____ _____ _____ _____ _____	
43	Did you ever want to but did not use a condom?	Yes ..... 1 No ..... 2 Refuse to answer..... 3	**If no go to Q 45**
44	If so, why?	_____ _____	
45	Do you know male circumcision may lower the risk of HIV transmission?	Yes ..... 1 No ..... 2 Refuse to answer..... 3	
46	Would you consider circumcision to lower your risk of HIV transmission?	Yes ..... 1 No ..... 2 Refuse to answer..... 3	**This Q applies to male respondents only**

ART programs

No.	Questions and Filters	Coding Categories	Comments
47	Are you aware of AIDS treatment programs in Kabarole District?	Yes ..... 1 No 2	**If no, stop survey**
48	If yes, what programs do you know about?	JCRC ..... 1 TASO ..... 2 Community-based project in Rwimi ..... 3 Other.....4 Specify _____	

Thank you for participating in this survey. Your responses are very important to us.

Appendix VII: Discussion Guide for Community Members

1. In the past five years, do you think there has been a change in HIV/AIDS knowledge in your communities?

    a. What has contributed to this change in knowledge?

2. How accessible is HIV testing in your communities?

    a. What factors in your community may have prompted individuals to be tested for HIV?

    b. What factors are still preventing individuals from testing for HIV?

3. Have you heard of the community-based HIV/AIDS treatment program, or any other HIV/AIDS treatment programs, operating in the sub-county?

    a. If so, how did you hear about them?

    b. If so, what do you think about them?

4. How have these programs influenced HIV/AIDS knowledge in your communities?

5. How have these programs influenced preventative behaviours in your communities?

6. How have these programs influenced HIV/AIDS-related stigma?

7. Is there anything else you would like to discuss regarding the community-based treatment program?

8. Would you like to add anything to any previously discussed questions?

9. Are there any topics that we have not covered in this session that you would like to discuss?

Appendix VIII: Discussion Guide for Local Health Care Staff

1. Please tell me a little about the history of HIV/AIDS in the sub-county.

2. What types of HIV/AIDS interventions have taken place in the sub-county?

3. How well did the general population receive these interventions?

4. How have these interventions influenced HIV/AIDS knowledge throughout the sub-county?

    a. What else has influenced HIV/AIDS knowledge?

5. How have these interventions influenced preventative behaviours throughout the sub-county?

    a. What else has influenced preventative behaviours?

6. How have these interventions influenced HIV/AIDS-related stigma throughout the sub-county?

    a. What else has influenced stigma?

7. What are the main factors prompting individuals to be tested for HIV?

    a. In the past year, testing rates for women have increased dramatically. Why are men still not testing?

    b. What other factors are preventing individuals from testing for HIV?

8. What factors do you think may have contributed to the results of the comparison between Rwimi and Kisomoro Sub-Counties?

9. Would you like to add anything to any previously discussed questions?

10. Are there any topics that we have not covered in this session that you would like to discuss?