Knowledge and Attitudes towards HIV/AIDS and Associated Current Prevention Practices in the Era of Antiretroviral Therapy (ART) in Rwimi, Uganda

by

Nicole Naadu Lartey

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Department of Public Health Sciences

University of Alberta

Abstract

Background: The impact of the wide-spread availability of antiretroviral therapy (ART) on the sexual behaviour of the general population who are not on ART in African countries is understudied. Additionally, there are concerns of a return to risky behaviours by people on ART or increased opportunities for the general population to continue to engage in risky behaviours. The purpose of this study was to assess whether the fear of contracting HIV/AIDS had reduced in the era of ART and to describe the culture of HIV prevention among the general population in Rwimi sub-county, Kabarole District, Western Uganda.

Methods: A cross-sectional random cluster survey and a focused ethnography were conducted in Rwimi. We administered survey questions to 639 participants between June and August, 2013. We assessed whether the availability of ART has reduced the fear of HIV. In addition, we also assessed participants' knowledge of and attitudes towards HIV/AIDS and current prevention practices. Logistic regression was used to assess associations for the outcomes general fear and personal fear of HIV with demographic variables and some knowledge measures. We carried out four focus group discussions. Data was collected in the local language, Rutooro, audio-recorded and thereafter translated and transcribed into English and analysed using content analyses.

Results: The majority of participants felt that the availability of ART had reduced the fear of contracting HIV/AIDS in the community (89.4%; 95%confidence interval [CI]: 86.9–91.7%). No statistical difference was found for this outcome and any knowledge measures or demographics in logistic regression modelling. In contrast, few participants (22.4%; 95%CI: 17.7-25.6%) mentioned that their personal fear of the disease had reduced with the availability of ART. Participants who had at least a secondary level education had a lower odds (OR=0.29, p=0.022) of reporting a personal reduced fear; but those who were aware of the negative effects

of ART had a higher odds (OR= 1.72, p= 0.047) of reporting reduced personal fear of HIV/AIDS. Overall, the majority of participants (94.1%; 95%CI: 93.8-97.1%) were still fearful of contracting HIV/AIDS. Participants generally expressed a positive attitude toward HIV/AIDS prevention practices, but the mode of prevention practiced were influenced by factors such as policy, gender-based perceptions and trust in their relationships.

Conclusions: The fear of contracting HIV/AIDS still persists, although participants perceived other people as being less fearful than they were of the disease because of the availability of ART. Additionally, although the community is considerably knowledgeable about HIV/AIDS and the fear of HIV is still present, condom use as a prevention practice remains surprisingly low. There is the need to take into account socio-cultural influences such as gender-based perceptions; relationship dynamics such as power structure and trust; and socio-economic factors that play into HIV prevention in designing sustainable programs that encourage adherence to prevention practices.

Preface

This thesis is an original work by Nicole Naadu Lartey. The research project, of which this thesis is a part, received ethics approval from the University of Alberta Research Ethics Board, Project Name "Knowledge and Attitudes towards Prevention of HIV/AIDS and Associated Current Practices in the Era of Anti-Retroviral Therapy (ART): A Community Based Cross-sectional Study in Kabarole District, Uganda", No. Pro00038386, 5/29/2013.

Dedication

This thesis is dedicated to my wonderful family – Daniel Ofosu (my husband); Ernest & Anna (my parents) and Louis-Mark Lartey (my brother).

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List of Abbreviations

AIDS	Acquired Immune Deficiency Syndrome
AOR	Adjusted Odds Ratio
ART	Antiretroviral Therapy
ARV	Antiretrovirals
FGD	Focus Group Discussion
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immunodeficiency Virus
KAP	Knowledge, Attitude and Practice
LMIC	Low- and Middle- Income Countries
MDG	Millennium Development Goals
MSM	Men who have sex with men
NACP	National AIDS Control Program
OR	Odds Ratio
PT	Preventive Therapy
RA	Research Assistant
RCT	Routine Counselling and Testing
STI	Sexually Transmitted Infections
UN	United Nations
VCT	Voluntary Counselling and Testing
WHO	World Health Organisation

Note: For this study HAART, ART and ARV are used interchangeably.

Chapter 1: Introduction

Sub-Saharan Africa bears the highest burden of HIV infections and HIV/AIDS-related mortality in the world [1]. Of the 35 million people living with HIV at the end of 2013, 24.7 million lived in sub-Saharan Africa [2]. Additionally, sub-Saharan Africa accounted for 74% of all AIDS-related mortality in 2013 [2]. The human and economic costs of managing HIV/AIDS are of significant global and public health importance. HIV/AIDS increases the disease burden on countries and their healthcare systems, social support systems and families. In addition, it reduces the ability of those affected to reach their highest achievable levels of health and productivity, resulting in reduced economic productivity with adverse consequences for sustainable development. Consequently, there is increasing pressure on the governments of African nations and the international community to find ways of bringing HIV/AIDS under control.

The United Nations' Millennium Development Goals (MDG) initiative announced in 2000 was the first concerted effort to get global support to tackle the issue of HIV. Goal 6 of the MDG specifically requested the global community to combat HIV/AIDS and to aim for two targets: 1) to have halted by 2015 and begun to reverse the spread of HIV/AIDS; and 2) to achieve by 2010, universal access to treatment for HIV/AIDS for all those who need it [3]. In 2011, the United Nations made a political declaration on HIV/AIDS to intensify efforts to eliminate the problem. These global efforts yielded great health gains as indicated by the unprecedented declines in AIDS-related deaths and new HIV infections, as well as substantial financial commitment for HIV-related activities in low- and middle-income countries [4].

Improvements have been made in access to antiretroviral therapy (ART) in low- and middle-income countries (LMICs) [4]. By the end of December 2012, 9.5 million people in LMICs were receiving ARTs, which made up almost two-thirds of the targeted MDG goal of 15 million people accessing ARTs globally by 2015 [4, 5]. Access to ART results in considerable improvement in life expectancy and quality of life of persons living with HIV/AIDS [6, 7]. ARTs can help prevent people living with HIV from dying of AIDS prematurely, falling ill frequently as well as developing and transmitting tuberculosis and HIV [5]. Globally, 6.6 million HIV/AIDS-related deaths were averted because of ART in 1995-2012, of which 5.4 million was accounted for by developing countries [2]. In this study, the term "era of ART"

refers to the time period (2000 to date) in which ART has become more common in sub-Saharan Africa.

Uganda's Response to HIV/AIDS

Uganda is one of the countries in Sub Saharan Africa with long-standing HIV intervention programmes. Since 1986, Uganda has had a well organised and sustained response to the HIV challenge. Uganda's National AIDS Control Program (NACP) was set up in 1986 with the support of the World Health Organization (WHO), to respond to the HIV/AIDS threat [8]. The program lasted till 1995 and during that period a successful reversal in the HIV/AIDS epidemic was achieved. The nation addressed HIV/AIDS as a multi-sectoral challenge [8]. Thus, apart from tackling the natural dynamics of the epidemic, other aspects such as HIV/AIDS awareness education and campaigns to encourage positive sexual behaviour change were also engaged. Policies were developed to employ a concerted effort from individuals and various institutions across the nation to address the HIV/AIDS problem. The nation's efforts at controlling HIV/AIDS in the 1990s resulted in a significant decline in HIV prevalence rates [8].

Uganda's activities in relation to HIV/AIDS are now focused on prevention and dealing with challenges to sustaining access to lifelong treatment for infected persons [8]. In 2004, Uganda began to scale up access to free ART medication to people living with HIV [9]. By 2013, 69.4% of eligible people living with HIV in Uganda were receiving ART, based on treatment criteria of CD4+ cell counts <350 cells/mm^3 [9]. It has been shown that Ugandan patients receiving ART can experience a life expectancy similar to the national average of 55 years in the general population [8]. However, there is a concern that the availability of ART may cause a disinhibiting effect on sexual behaviour and could result in continued or relapse to risk behaviours among people living with HIV and their sexual partners [10-12]. This is because of the perceived reduced HIV transmission rate associated with ART usage as well as the knowledge that going on ART when infected makes the condition more manageable. Thus, people living with HIV who have the perception that HIV can be treated may also be more likely to be less adherent to prevention practices. Low adherence to ART combined with unsafe sexual practices could offset the reduced infectivity associated with ART usage and potentially result in the transmission of genetically resistant HIV viral strains [11, 13]. Studies in developed countries

have shown an increase in unprotected sex with the introduction of highly active antiretroviral therapy (HAART), especially among homosexual persons [14-16].

Recent trends in Uganda suggest an increase in HIV prevalence. Among adults aged 15-49 years, the prevalence increased from 6.1% in 2002 to 6.4% in 2004/05 to 7.3% in 2011 [8, 9, 17]. New infections were diagnosed in over 100,000 people each year of which 76% were due to sexual transmission and 22% from mother-to-child transmission [18]. Statistics from Uganda indicate that most of the risky sexual practices, including having multiple sexual partners occur within age groups ranging from 15 – 49 years [9]. In addition, the 2013 UNAIDS global report cited Uganda as one of the countries in which recent evidence indicates a significant increase in multiple sexual partners and a decline in condom use [4].

Rationale

The availability and accessibility of effective treatment through ART has raised concerns about the associated potential for risky behaviour among people living with HIV and their sexual partners [10-12]. Some studies conducted in other parts of sub-Saharan Africa suggest an association between ART availability and sexual risk behaviour among people living with HIV [11, 14, 19]. However, there are very few studies on the response of uninfected persons to HIV in the era of ART. Uninfected person may respond differently to HIV-infected persons in terms of risk behaviour in the era of ART [15]. Apart from controlling the effects of HIV/AIDS among people living with the disease, the world aims at reducing its spread and eventually eradicating it. Therefore, studies on the changing HIV prevention practices of uninfected persons will be useful in this regard.

Epidemiological studies can readily examine whether people living with HIV who are on ART engage in risky sexual behaviours or whether a population is adhering to prevention practices [20]. However, qualitative data can bring context and meaning for such quantitative findings. A combination of quantitative and qualitative studies as used in this research can provide useful information on the culture of HIV prevention in the era of ART among the general population who are not on ART. This would help in strengthening public health campaigns against HIV transmission in sub-Saharan Africa.

The overall purpose of this research was to assess whether the fear of HIV/AIDS had reduced in the era of ART among the general population who are not on ART in Rwimi sub-county, in Western Uganda. The specific objectives were:

1. To determine whether participants believe that the availability of ART has reduced the fear of HIV/AIDS in the community.
2. To determine whether the availability of ART has reduced the participants' personal fear of contracting HIV/AIDS.
3. To determine if there is still the fear of contracting HIV/AIDS.

In addition, we assessed the community's knowledge and attitudes towards HIV/AIDS and ART and their current HIV prevention practices.

Chapter 2: Literature Review

Impact of Antiretroviral Therapy (ART)

Access to ART in resource-limited settings has improved because of the increase in international commitment to providing therapy, the reduction in ART drug prices and the introduction of generic forms of ART [21]. As a result, more people living with HIV/AIDS have benefited from the positive impact of ART – reduction in viral loads to undetectable levels, reduced risk of transmission of the virus, significant reduction in the incidence of HIV-related opportunistic infections, and improved survival and quality of life of people living with HIV/AIDS [21, 22]. Concurrent with the introduction of ART in sub-Saharan Africa, new HIV infections have gone down by 33% over the past decade, and AIDS mortality has declined by 32% since its peak in 2005 [23]. Presently, Africa is leading the world in expanding access to antiretroviral therapy [4].

Concerns have been raised about the possibility of an increase in risky sexual behaviour since ART became available. According to Crepaz et al. [24], apart from the beneficial clinical effects, these treatment advances may also have unintended effects on sexual behaviour. Such undesirable changes in sexual behaviour have been associated with "treatment optimism" – the belief that ART mitigates the risk and consequences of HIV infection [22, 25].

For this literature review, the help of a librarian was sought to conduct searches for studies examining associations between the availability of ART and knowledge and attitudes to HIV and HIV prevention practice. Searches were conducted in MEDLINE, PubMed and the Google scholar databases using a combination of the terms "HIV", "AIDS", "ART", "antiretroviral therapy", "behaviour", "knowledge", "attitude" and "sub-Saharan Africa". Ninety-five quantitative studies across the world were found through the search. Based on the titles and abstracts 27 studies which were conducted in sub-Saharan Africa were identified. After reading through these studies, sixteen quantitative studies were found that related well to the research topic. These studies were of prospective cohort (Table 2.1) and cross-sectional (Table 2.2) study designs. These included studies from Côte d'Ivoire, Kenya, Mozambique, South Africa and Uganda. Within the context of ART, a variety of the studies assessed ART knowledge, attitudes/beliefs and sexual behaviour/prevention practices. This was a general literature review

to assess the gaps in the available literature. Therefore formal assessment on the methodological quality of the studies was not conducted.

Prospective Cohort Studies

There were 10 prospective cohort studies assessing changes in risky behaviours Nine of the prospective cohort studies were conducted among people living with HIV/AIDS [6, 11, 14, 20, 28, 29, 30, 31, 33] and only one was conducted among HIV negative persons [27] (Table 2.1). Of the studies conducted among people living with HIV/AIDS, seven found no associations between ART use and increased risky sexual behaviours [6, 11, 20, 28, 30, 31, 33] while two found an association [14, 29]. Due to the common trends in these seven studies, only two are described in this section. The remainder are summarized in Table 2.2. In the study by Luchters et al. [11], pre-ART data was compared with data while on ART. They collected information on participants' heterosexual and homosexual contacts with regular, non-regular, and commercial partners; condom use; disclosure of HIV status to partners and knowledge of their partner's HIV status; and history of sexually transmitted infection (STI). Over 75% of the sexually active participants reported having had unprotected sex in the 12 months prior to ART, however at the 12-month follow-up visit, there was a reduction to about 62.6% in the number of participants who had had unprotected sex. After adjusting for gender and stigma, unsafe sex was 0.59 times less likely after 12 months on ART than before ART initiation (95% confidence interval [CI] = 0.37–0.94; p = 0.026). Hence the study found no evidence supporting increased risky sexual behaviour among the participants 1 year after the initiation of ART.

In the study by Wandera et al. [33], they assessed clinical and sexual behaviour at enrolment and semi-annually for 3 years after ART initiation among 559 HIV-infected, ART-naïve individuals initiating ART at an HIV clinic. The strength of this particular study compared to the other studies was its long period of follow-up. The results showed that overall, there was a reduction in unprotected sex over time; however, women reported unprotected sex more often than men before and after initiation of ART. This raised issues of low awareness of partners' HIV status among married individuals. Although the researchers suggested that counsellors encourage patients to share their HIV status with their partners, they mentioned that this had to be balanced

with the risk of violence following disclosure, particularly for women. Additionally, they found that being a woman, being unmarried, having lower household income, reporting unprotected sex at the time of ART initiation, having no children, and believing that ART reduced the risk of HIV transmission were independently associated with higher prevalence of unprotected sex at follow-up in the adjusted analysis.

Two studies found an association between ART use and increased risky sexual behaviours [14, 29]. The study by Diabate et al. [14] was aimed at determining whether ART is related to risk taking among the participants (312 untreated and 303-ART initiating patients). Measures on sexual practices, particularly unprotected sex at enrolment for ART and 6 months after ART enrolment were assessed. The results showed an increase in unprotected sex among patients on ART (from 20.4% to 30.1%, $p<0.0001$) and stability in sexual behaviour trends among untreated patients. This led to the conclusion that ART appeared to be associated with sexual risk taking. The increase in risk taking among patients on ART was initially limited to participants with steady sexual partners. Thus, the researchers hypothesized that if the positive outcomes from being on ART became more evident and stable with time, treated patients could start seeking unprotected sex with casual or serodiscordant partners. They felt this was supported by the fact that nearly half of their treated patients reported their last sexual partner was HIV negative or of unknown status. Their conclusions are suggestive of the effect of treatment optimism – the belief that ART mitigates the risk and consequences of HIV infection, on people on ART.

The study by Pearson et al. [29] assessed sexual behaviours of participants (277 HIV positive patients) before ART initiation and 12-months after ART initiation. Data was collected on behaviours such as number of sexual partners, condom use, concurrent relationships, disclosure of HIV status, alcohol use; and partners' serostatus. The results showed that compared to before ART initiation, there was an increased proportion of participants who were sexually active and increased proportion of participants with HIV-negative or unknown serostatus partner 12 months after the initiation of ART. The one study conducted among HIV negative persons [27] found no association between ART availability and sexual behaviour.

Cross-sectional Studies

A summary of the six cross-sectional studies, assessing associations between ART availability and knowledge, attitudes and practices is shown in Table 2.2. Two of the studies assessed participants' knowledge on HIV/AIDS and ART [19, 25]. While the Smith et al. [19] study was conducted among the general population, the Nachega [25] study was conducted among people living with HIV. Both studies found that the participants were knowledgeable about ART; knowledge scores about HIV including the cause, mode of transmission, and progression of disease were high. In the first study [19], about 98% of the participants mentioned that ART prolongs life however, 23% of the participants agreed to the statement that "HIV/AIDS can be cured with ART". In the second study [25], 49% of the participants mentioned that ART is a cure for HIV. This belief was found to be associated with a low level of education ($p < 0.001$).

The study by Smith et al. [19] assessed ART-related attitudes/beliefs in relation to practices among the general population. They found that attitudes about ART were significantly associated with certain high risk sexual behaviours. Specifically, the researchers found that among women, an attitude that ''HIV is more controllable now that ART is available'' was associated with sex with a non-spousal partner (Adjusted Odds Ratio (AOR) =1.42, $p<0.05$). They also found that the belief that ART cures HIV was associated with increased odds of exchanging gifts or money for sex among men 25-29 years (AOR = 3.92, $p<0.05$), and a decreased odds of reporting condom use at last sexual encounter among men 15-24 years (AOR = 0.30, $p<0.05$).

Comparisons of sexual behaviour between participants on ART and ART-naïve participants were made by four cross-sectional studies [12, 21, 26, 32]. They all found no associations between ART use and sexual behaviour. Two of these studies are discussed in this section and the remainder are summarized in Table 2.1. The study by Sarna et al. [32] examined sexual risk behaviour, specifically unprotected sex among people on ART compared with people on preventive therapy (PT). Overall, they found that the use of ART was not associated with risky sexual behaviour. Their results showed that participants receiving PT were more likely to report two or more sexual partners (13% vs.1%; $p = 0.006$). Participants receiving PT reported more unprotected sex with regular partners (odds ratio (OR) = 3.9; 95% confidence interval [CI]: 1.8–8.4) and also more sexually transmitted infections (STI) symptoms (OR= 1.7; 95% CI: 1.0–2.8). The researchers suggested that the emphasis on adherence during the ART counselling session at

the time of initiating ART as well as differences in perception of the seriousness of their illness could account for the difference in sexual behaviour among the two groups.

The association between ART use and sexual behaviour among people on ART compared with HIV positive persons not on ART in the 6 months prior to enrolment into the study was assessed in the Bateganya et al. [21] study. Overall, they found that use of ART was not associated with risky sexual behaviour. Their results showed that being on ART was not associated with a significantly higher likelihood of being sexually active (adjusted odds ratio (AOR) = 2.0, 95% confidence interval [CI], 0.3–9.9). Respondents on ART were more likely to report consistent condom use with their spouses than were ART-naïve respondents (OR= 2.82 95% CI 1.74–4.6). Additionally, respondents on ART were more likely than ART-naïve respondents to have disclosed their HIV status to their spouses (OR= 1.57 95% CI 1.07–2.30).

Summary

The prospective cohort studies investigated changes in sexual behaviours pre-ART and during ART use, and also between ART-naïve persons and persons on ART. The majority of the studies found no associations between ART use and increased risky sexual behaviours [6, 11, 20, 28, 30, 31, 33]. Only two of the studies conducted among people living with HIV/AIDS found an association between ART use and increased risky sexual behaviours [14, 29]. Only one of the prospective studies was conducted among non-HIV positive persons [27] and found no association between ART availability and sexual behaviour. Most of the prospective cohort studies assessed sexual behaviour prospectively from 6 months up to a year after the initiation of ART Three of the prospective cohort studies followed up the participants longitudinally beyond 12 months [6, 27, 33] years and found no association between ART use and risky sexual behaviour. The majority of the cross-sectional studies [12, 21, 26, 32] also assessed sexual behaviour with the availability of ART among people living with HIV/AIDS. All of these studies found not association between ART use and risky sexual behaviour. Only one study assessed sexual behaviour among the general population with the availability of ART [19] and found an association between some ART-related attitudes and sexual behaviour. Reduced risky sexual behaviours as described in the studies, mainly involved decrease in the number of sexual contacts, change in types of risky sexual contacts and increase in condom use. The observation of no association between ART and risky sexual behaviour among people living with HIV/AIDS

could probably be as a result of effective counselling received from health workers or persons with symptomatic disease experiencing a decline in sexual desire as a result of the adverse effects of ART, as suggested by Luchters et al. [11]. In addition, issues related to stigma in some of these communities as well as the stressfulness of living with HIV/AIDS may play a role in dissuading people living with HIV/AIDS from risky sexual behaviour.

Another important aspect of studies on ART to be considered is the effect of the availability of ART on people who are not HIV positive. Among the studies were two that assessed the relationship between ART-related beliefs and attitudes, and sexual behaviour among HIV negative persons [19, 27]. The study by Smith et al. [19], a population-based cross-sectional study, showed an increase in risky sexual behaviour, particularly among women while the study by Bechange et al. [27], a prospective study, showed a decrease in risky sexual behaviour after a 2-year follow up. The latter targeted non HIV-infected non-spousal household members of ART patients receiving home-based AIDS care.

Studies from other LMIC have also shown similar trends of no association between ART use and risky sexual behaviour, as was found in sub-Saharan Africa. In a study conducted in Taiwan, sexual behaviours and practices of HIV positive persons were examined [34]. These included frequency and pattern of condom use, sexual orientation and number of sexual partners. The researchers also included physical examinations and laboratory tests in their measures and proposed that HIV-positive persons who subsequently developed sexually transmitted infections (STIs) were likely to practice risky sexual behaviours, and could potentially transmit HIV to others. Their study showed that ART was associated with lower acquisition of STIs in the HIV-positive population and also there was no evidence to support the association of ART with risky sexual behaviour among HIV-positive persons. In a second study conducted in India, sexual behaviour over a three-month period was assessed, and they also found no association between ART use and unprotected sex [35]. In Thailand, a study assessing sexual risk behaviour and CD4 levels among HIV positive persons receiving ART also showed similar results; no association was found between risk behaviours and CD4 levels [36].

Most of the findings from LMIC on risky sexual behaviour in the era of ART appeared to be in contrast to the view being put forth as a result of studies conducted in developed countries, particularly among men who have sex with men [38-42]. Some of the studies from LMIC showed predictors of unprotected sex among people living with HIV to be alcohol use, desire for children, trust in the partner and sexual sensation, rather than the availability of ART [35, 37]. These studies suggest that the focus should not only be on sexual behaviours of people on ART, but also on the effect of ART-related attitudes and beliefs on the sexual behaviour of the general population. Most of the information on ART is directed towards people who have tested HIV positive, since they would be starting treatment. The rest of the population may not be receiving such direct information and may have to rely on other sources, whose credibility may be unknown. Attitudes and beliefs about ART influence the sexual behaviour of both people living with HIV/AIDS as well as the rest of the population [19]. Wrong beliefs and attitudes towards ARTs may put people at risk of contracting HIV and will subsequently contribute to an increase in HIV/AIDS prevalence in sub-Saharan Africa. Only two studies [19, 27] conducted in sub-Saharan Africa have tried to examine the relationship between sexual behaviour and ART-related beliefs among HIV-negative persons. Since the world desires to halt the spread of HIV, there is the need to know if ART availability has an impact on the fear of HIV/AIDS and sexual behaviour among the general population. Therefore more studies conducted among the general population would be useful in this regard.

Table 2.1 Summary of literature review of prospective cohort studies on ART-related knowledge, attitudes, beliefs and practices in sub-Saharan Africa.

Reference	Country	Study Design	Sample	Measures	Outcome
Eisele TP et al.(2009)	South Africa	Prospective cohort	1,280 participants (people on ART vs ART- naïve)	Sexual behaviour of patients on ART vs ART-naïve patients.	Significant decrease in unprotected sex among the patients on ART.
Apondi R et al.(2011)	Uganda	Prospective	928 adults in a home-based AIDS program (pre-ART and after start of ART)	Sexual behaviours and HIV plasma viral load at start of the study and at 6 months interval for 3 years	Risky sexual behaviour and estimated risk of HIV transmission remained lower than baseline levels.
Bechange S et al.(2010)	Uganda	Prospective	455 HIV-uninfected non-spousal household members of patients on ART	Sexual behaviour, HIV risk perceptions, AIDS-related anxiety, and perception that AIDS is curable at baseline, 6, 12 and	Decrease in risky sexual behaviour from 29% at baseline to 15% at 24-months.

				24 months.	
Bunnel R et al.(2006)	Uganda	Prospective	926 HIV positive adults	Sexual behaviours and HIV plasma viral load at baseline and follow-up (6 months later).	70% reduction in risky sexual behaviour after 6 months.
Diabaté S et al.(2008)	Côte d'Ivoire	Prospective	312 ART- naïve vs 303 patients on ART	Sexual practices at enrolment into the study and 6 months post enrolment.	Use of ART was associated with sexual risk taking
Luchters S et al.(2008)	Kenya	Prospective	234 adults on ART in two groups: 1)modified directly observed therapy (m-DOT) 2)standard care)	Pre-ART vs Post-ART sexual behaviour.	No evidence of increased risky sexual behaviour among people receiving ART 12months after start of treatment.
Pearson CR et	Mozambique	Prospective	277 HIV positive	Sexual behaviours before and 12-	Compared to before ART initiation,

al.(2011)			patients	months after ART initiation	increases were seen 12 months after ART in the proportion of participants who were sexually active and in the proportion of participants with HIV-negative or unknown serostatus partners.
Peltzer K et al.(2010)	South Africa	Prospective	735 HAART initiating adults	Sexual behaviour at enrolment into the study, and at 6 and 12 months after initiation of HAART	No evidence of increased risky sexual behaviours over time was found, from before commencing on HAART, to 6 and 12 months on HAART.

Venkatesh KK et al.(2010)	South Africa	Prospective	1544 HIV-positive men and 4719 HIV-positive women	Assessment of sexual behaviour at 6 months intervals after initiation of HAART.	Sexual risk behaviour significantly decreased following HAART initiation.
Wandera B et al.(2011)	Uganda	Prospective	559 HIV-infected, HAART-naïve individuals initiating HAART at an HIV clinic	Clinical and sexual behaviour at enrolment and semi-annually for 3 years after HAART initiation.	Sexual risk behaviour reduced over time.

Table 2.2 Summary of literature review of cross-sectional studies on ART-related knowledge, attitudes, beliefs and practices in sub-Saharan Africa.

Reference	Country	Study Design	Sample	Measures	Outcome
Andia I et al.(2009)	Uganda	Cross-sectional	484 HIV-positive women (on ART vs ART naïve)	Association between ART use and sexual behaviour/prevention practices.	Use of ART was not associated with risky sexual behaviour.
Bateganya M et al. (2005)	Uganda	Cross-sectional	723 HIV-positive adults (on ART vs ART naïve)	Sexual behaviour in the 6 months prior to enrolment into the study.	Use of ART was not associated with risky sexual behaviour in the 6 months prior to enrolment into the study.
Moatti JP et al. (2003)	Côte d'Ivoire	Cross-sectional	164 people on ART vs 547 ART naïve	Sexual behaviour of the 2 groups in the 6 months prior to enrolment into the study	Use of ART not associated with risky sexual behaviours.
Nachega, JB (2005)	South Africa	Cross-sectional	105 HIV positive clinic patients	Assessment of knowledge and attitudes/beliefs about HIV/AIDS and ART.	Participants showed good knowledge on causes of HIV/AIDS; modes of transmission; and importance of adherence to ART. The belief that ART can cure HIV was associated with a low level of

					education.
Sarna A et al. (2008)	Kenya	Cross-sectional	179 people on ART vs. 143 on preventive therapy (PT)	Sexual behaviour of patients on ART vs. Preventive therapy	Use of ART not associated with risky sexual behaviour.
Smith RM et al. (2011)	Kenya	Cross-sectional	1655 participants from the general population	Knowledge, attitudes/beliefs and related sexual behaviours.	Participants showed good knowledge on ART. Attitudes about ART ("HIV is more controllable with the availability of ART") were associated with high risk sexual behaviour particularly among women

Chapter 3: Methods

Study Design

Two studies were conducted to meet our research objectives – a quantitative study and a qualitative study. The quantitative aspect of this study was a cross-sectional random cluster survey and the qualitative study was a focused ethnography in which data was generated through focus group discussions (FGDs).

Setting

The study was carried out in Rwimi sub-county, Kabarole District, Western Uganda. The total population of Uganda is about 37.6 million [43]. Kabarole is one of the 111 districts in the country. It is a predominantly rural district with a population of about 455,000 [44], with Fort Portal as the district capital. It has a land area of 1,818 km^2. Kabarole has two rural counties and one semi-urban municipality. The rural counties are further divided into 11 sub-counties. The Kabarole District health services consist of three hospitals, all in Fort Portal, and 60 government health units. Seventy-five percent (75%) of the population live within 5 km of a health unit. The main language in the district is Rutooro, and most economic activities in the district are centred on agriculture. Rwimi sub-county comprises of 40 villages with an estimated population of 25,000 and is served by a Health Centre III health unit [44].

Ethics

Ethical approval for the study was provided by the Uganda National Council for Science and Technology, Makerere University School of Public Health Institutional Review Board and University of Alberta Research Ethics Board. Only participants who gave their written or thumb-print informed consent were recruited for the study.

Ethical considerations

Several ethical considerations were noted in this research project. They are outlined below, along with the strategies for appropriate management:

Maintaining privacy and confidentiality: Names or any other personal identifying information (address, physical description) were not used, instead participants were

assigned a code and only necessary personal information (age, gender) were used in related documents. Only the researcher, the research team, and the researcher's supervisors could have access to participant's names and the associated codes. The issue of privacy and confidentiality was discussed with participants when obtaining informed consent. During the focus group discussions, issues on privacy and confidentiality were also brought up and participants were urged to keep information discussed private; although this could not always be guaranteed, it was encouraged. In addition, all research assistants (RAs) were required to sign a confidentiality agreement.

Language barrier and illiteracy affecting informed consent: Not all participants were fluent in English; therefore all information and consent forms were available in Rutooro. Research assistants fluent in both languages provided the information and were available to answer questions. Participants who were illiterate and unable to sign the consent forms indicated their consent through a thumbprint.

Coercion: In order to minimize coercion due to the incentives given for participation, but still acknowledge the participant's contribution to the study, participants were offered a small thank you gift (half a bar of soap – USD 0.36) for their time at the end of the interview. This was done without them being informed about the gift prior to their decision to participate.

Potential to identify individuals that are upset or distressed: Since participants were to be asked to discuss their ideas on knowledge, attitudes and practices towards HIV prevention, experienced and well-trained research assistants were employed. These research assistants had experience with these types of interviews and so they were able to provide comfort to participants in the course of the discussions when distressing situations arose. Research assistants could refer participants requiring further assistance to a trained field staff member or to the clinical officer in charge of the Rwimi Health Centre III.

Quantitative Methodology

Study Population

Thirty-two villages in Rwimi were selected for the study, based on ease of accessibility to the Rwimi Health Centre III. Study participants were recruited from these villages.

Individuals 18 to 49 years of age were eligible to participate in this study. Participants were excluded if they were on ART however the HIV status of eligible participants was not determined. Participants were also excluded if they did not speak Rutooro or English and did not live in Rwimi.

Sample Size

The quantitative study was a prevalence study. Thus in determining the sample size from a total population of 25,000 (in Rwimi sub-county), the most conservative prevalence of 50% was considered (i.e. most conservative response for sample size requirements for knowledge, attitude or practice); and a design factor of 2.0 (which doubles the sample and takes into account the cluster study design). As a result, a sample size of 600 was determined which would result in a confidence interval of 5.6% (i.e. the largest confidence intervals) [45]. Thus, from the 32 selected villages, 20 households in each village in 31 villages and 19 households in one village were systematically sampled radiating from the determined focal point of the village. One participant was recruited per household giving a total sample of 639. The number of households in each village was obtained from the Local Council 1 Chairman (village leader). In each household, a Kish grid was used to select one eligible participant in each household out of all the eligible members present in the household at the time of recruitment. This involved making a list of all eligible members of the household noting demographics such as age, sex and profession in table as shown in Appendix 4. Based on the number of eligible participants present, several crossed pieces and only one ticked piece of paper were presented for a random draw. The participant who drew the ticked piece of paper was selected for the interview. If he/she declined, the randomization was conducted again to select another participant.

Recruitment

Eligible participants from each household were approached by trained research assistants with an information letter and consent form which had been assessed for cultural appropriateness and clarity (Appendix 1) to ask if they would be willing to participate in the research study. Participants were asked to undertake an interview and potentially a focus group discussion. The research assistants described the purpose of the research, potential risks and benefits, confidentiality, freedom to withdraw at any time, and contact information for the researcher; furthermore, time was given for potential participants to consider participation and to ask questions. Persons who were willing to participate signed or provided a thumb-print on the consent form.

Participants received half a bar of soap in compensation for the time spent participating in the study. This level of compensation had previously been used for similar research projects and was based on recommendations from local Ugandan researchers in the area (Kabarole Research and Resource Centre staff and Mountains of the Moon University faculty).

Data Collection

Survey data collection took place from June to August 2013 in Rwimi. Research assistants fluent in both Rutoroo and English administered the surveys. Before entry into the villages, the researcher and members of her team first met with the Kabarole District Health Officer and explained the work they were about to embark on. In each village, the research assistants sought out the Local Council 1 Chairman (village leader) and introduced themselves. The Chairman provided verbal consent for the research assistants to proceed with data collection in the village.

Survey questions were derived from similar studies on knowledge, attitude and practices conducted in Uganda and Kenya [19, 44]. Additional questions were included to assess whether the availability of ART has reduced the fear of contracting HIV. A question on reduced personal fear of HIV/AIDS with the availability of ART was later included in the survey when we realized that participants were answering the question on reduced fear of

HIV/AIDS with the availability of ART impersonally. Therefore, 219 of 639 participants did not get to answer this question. The questionnaire (Appendix 4) consisted of sections on (1) participant's demographic background; (2) knowledge on HIV/AIDS; (3) attitudes towards HIV/AIDS and ART; and (4) current HIV/AIDS prevention practices. Some open-ended questions were purposely incorporated into the survey to capture fuller and broader ideas, especially around perceptions and attitudes. Responses were directly recorded on the questionnaire at the time of the interview. Interviews were considered complete once participants had answered all of the questions, or when participants decided to terminate the interview; whichever came first.

All the materials for the study were translated into Rutooro and back-translated by a second translator into English to ensure accuracy. Validity of the study instruments were evaluated through key informants input and assessment and through pilot testing. A clinical officer and a program manager were asked to assess the surveys for face validity. Before the final survey was administered, the survey was pre-tested in the adjoining Kibiito sub-county in order to assess if the sequence of questions and terminology employed was appropriate. After the pre-test was completed, some questions were rephrased, additional questions were added and some coding categories were altered to improve the clarity and coherence of the survey.

Data management and Analysis

Data entered for closed-ended questions were analyzed according to the codes specified for each question. Information derived from open-ended questions were translated into English, broadly categorized and then coded. The information gathered by the surveys was entered into an Epi Info 7 database using the self-defined boundaries in Epi Info to ensure that only valid codes could be entered.

Data analysis was undertaken using descriptive, univariate and multivariable methods using Stata 12. For statistical significance, $b < 0.05$ was considered. The results were weighted for the cluster sampling design using Stata's "survey" features. These features take into account the number selected versus the available sampling units at each level of sampling

to account for different sample pools at each level. In order to adjust for the design effect, the sampling weights were assigned to each household to get representative estimates using the following formula:

w_n = (nhomes/nhomes_selected)*(npersons)

Where:

w_n	=	Sampling weight assigned to each household
nhomes	=	Number of households in a village
nhomes_selected	=	Number of households selected from that village
npersons	=	Number of eligible person in a household

The number of households per village was recorded during the visits to the villages for data collection and entered into the Epi Info 7 database.

Descriptive statistics were used to summarize the characteristics of the study population. Frequencies for responses to all the questions were assembled. Multivariable logistic regression models were developed with dependent variables: 1) Do you think the fear of HIV has reduced now that ART is available? 2) Are you less fearful of HIV now that ART is available? Univariate logistic regression analyses were used to examine relationships between demographic variables and knowledge measures, and the dependent variables on fear of HIV with the availability of ART. These were used to select independent variables to consider for the multivariable logistic regression models.

Any indicators found to have $p \leq 0.25$ in the univariate logistic regression models were initially included in the multivariable models. In addition, the variables “sex” and “age” were selected as predictors for each model based on their biological importance. For each of the models, only variables of biological importance and statistical significance ($p<0.05$) were kept in the main effects models. Next, each model was assessed for confounding by putting each variable that was not included in the main effects model individually into the model. A change of at least 15% between the odds ratios of the original variables in the

main effects model and the corresponding variables in the new model was assessed to determine confounding between the variables, i.e. [(new OR- old OR)/new OR]*100%. If there was confounding, the final model was presented with the confounding variables. The models were tested for meaningful interactions where there was no confounding. A final model with interaction was presented if there was interaction. In the absence of confounding or interaction, the main effects model was presented as the final multivariable model.

Qualitative Methodology

Research Paradigm

Qualitative research is "primarily naturalistic, interpretive and inductive" [46, p.11]. It occurs in a natural setting where the researcher, as an instrument of data generation, works inductively to make sense of the meaning people attach to their experiences or a particular phenomenon. Its purpose is to describe, explain and understand the phenomena being researched [47]. It is from this background that the following qualitative study was designed.

Researcher's Position

Clarifying the researcher's position from the onset of qualitative research enhances the quality of the research results [48]. By this, the researcher becomes more aware of their potential biases and beliefs that may impact on the way they approach the study. It also helps define the way that an individual's position in the social hierarchy compared to other groups potentially "limits or broadens" one's understanding of others [47]. This study was approached from a constructivist's perspective. Thus the researcher acknowledges that her personal background influences the research and positions herself in the study in a way that acknowledges how her background shapes her interpretations. In this study, the researcher locates herself outside the culture in which the research was conducted. Although she was born on the same continent and is of the same race as the participants, she is from a different country and is not part of the culture she was exploring. Therefore, there is a sense

of detachment and this is presumed to reduce bias. However, being of a similar race helped the participants adjust well to her presence in the community. The researcher understands that without empathy and sympathetic introspection derived from personal encounters, human behaviour will not be fully understood and that there is a middle ground between becoming too involved (clouding judgement) and remaining too distant (reducing understanding) [47]. The researcher reflected on her own assumptions and beliefs, and those of the participants in the study.

Rigor

Rigor is an important aspect of qualitative research, as it ensures that findings are presented in an appropriate manner. In qualitative inquiry, internal validity is concerned with whether the conclusions come from the actual data; generalizability results from a purposeful sampling of participants in order to capture a range of experiences with the phenomenon; and reliability comes though as repetition or duplication within the data set [46]. Although various terms exist for concepts of rigor in qualitative inquiry the concepts are consistent [46]. For this research project the following strategies were put in place to ensure rigor:

- The local language (Rutooro) was used to enable participants express their thoughts freely.
- The focus group discussions were carried out by persons who had training and experience with facilitating focus group discussions.
- Transcripts were checked for accuracy by comparing sections that were transcribed and translated by a second research assistant.
- The researcher continuously verified data through discussion with colleagues, supervisors and other research team members to ensure accurate interpretation of the data.
- The researcher ensured methodological coherence through continual review of methodology, data collection strategies, sampling and analysis
- The researcher maintained a journal as a record of personal biases and assumptions in order to provide context and background for analysis

Study Design

The study was a focused ethnography, which explored the culture of HIV prevention based on the specific research question on fear of HIV and attitudes towards HIV prevention in Rwimi in the era of ART. A focused ethnography is a form of ethnography that is "led by a specific research question, is conducted within a particular context or organization among a small group of people to inform decision-making and is more time limited" [46, p.39]. This study was aimed at answering the research question, "What are the Rwimi community's views on and experiences with the fear of contracting HIV/AIDS and what are their attitudes towards HIV prevention in the era of ART?" Since the study's objectives were directed towards specific areas in the big picture of HIV/AIDS in the community, a focused ethnography was best suited for this study rather than a general ethnography.

The qualitative data generation period was in August 2013. Data were generated through focus group discussions (FGDs) conducted in Rwimi, among the community members who had participated in the quantitative study. Based on the definition for focused ethnography as described by Mayan [46], FGDs were deemed to be the most suitable data generation strategy for this study because they provide interactive forums for participants to share their views and to listen to and reflect on other participants' views. This kind of interaction was needed in order to bring understanding to the culture of HIV/AIDS prevention among the community.

Recruitment

We used previous relationships established by other researchers to gain entry into the community. Participants were purposefully sampled from the respondents to the previously administered survey based on their survey response to perceived risk of contracting HIV. Four FGDs were conducted with the following groups: a) males with a self-declared low risk of HIV; b) females with a self-declared low risk of HIV; c) males with a self-declared high risk of HIV; and d) females with a self-declared high risk of HIV. There were between six to seven participants in each of the four FGDs, totalling 26 participants.

Procedures for Focus Group Discussions

Each FGD lasted approximately 60 to 75 minutes and was moderated by a research assistant who was fluent in the local language. A second research assistant assisted in note-taking. A FGD guide was used. The topics were designed based on the research objectives of exploring the fear of HIV/AIDS and current HIV prevention practices among the general population. We selected questions based on the key areas of knowledge, attitude and practices we wanted to explore and in addition we used the findings from the quantitative survey results to refine the topic guide. The guide was checked with the research assistants, by translating into the local language and then back-translating into English to ensure accuracy of translation, during the FGDs. Participants were encouraged to express their own views even if they differed from the views of other participants.

The FGDs were tape-recorded and transcribed and translated into English by the research assistant who moderated the FGD. All participation was voluntary. Privacy and confidentiality were encouraged and maintained as much as possible. Informed consent for participants' involvement, including audio-taping of the interviews were obtained. Participants received 10,000 Ugandan shillings ($3.66 USD) in compensation for their transportation expenses. Refreshments were also made available to participants at the end of the FGDs.

Data Analysis

Following each focus group discussion, data generated were translated and transcribed as soon as possible by the research assistants who facilitated the focus group discussion. We did not have the full transcripts prior to some of the FGDs, so I had to rely on discussions with RAs and analysis of field notes after each FGD to identify patterns and emerging themes to help inform subsequent FGDs. To ensure the accuracy of transcription, sections of the data were translated and transcribed by an independent RA and compared with the original transcripts.

Latent content analysis as described by Mayan [49] was used for analyzing the qualitative data generated in the study. This involves identifying, coding and categorizing the primary patterns in the data. Thus the meanings of specific passages within the data are examined

and appropriate codes or categories for these passages are determined rather than just tallying the number of times specific words are used. Therefore, latent content analysis allows the "coding of the participant's intent within context" [49, p.94]. In this study, the results were organized by the primary researcher using Microsoft Word 2010 and coded with Atlas.ti7 (ATLAS.ti7 Student Semester License). Analysis began with a preliminary read through of the data through which ideas and concepts expressed by the participants were identified and labeled [49]. The final stage of the analysis involved the integration of the categories and themes into a theoretical framework for understanding the concepts from the perspectives of the participants [48, 49]. Excerpts from the interview transcripts were integrated to illustrate concepts clearly and to give evidence to support each theme, as well as the overall research findings.

Field notes and memos were also analyzed to help identify important issues related to the research objectives, and to highlight any disagreements between participant statements and observed practices. The major themes related to the culture of HIV prevention in the era of ART were chosen according to the patterns that emerged from the FGDs.

Data Storage

All participants in both studies were given a coded number as their identification, which was used during data collection and transcription. Names and personal identifying information were excluded from all reports, presentations and documents resulting from this study. A master list of participant names and the corresponding codes were kept by the principal investigator and would not be revealed to anyone other than the research supervisor. Any data files that are stored electronically were password protected. No identifiable data left Uganda. The informed consent forms and subject number assignment sheet remained in Uganda. The research documentation and hard copies of the data was stored in a locked cabinet in the Community-based ART Project Research Office in Fort Portal.

Chapter 4: Manuscript 1

Has the Availability of Antiretroviral Therapy Reduced the Fear of Contracting HIV/AIDS in Kabarole District, Uganda?

ABSTRACT

Background: The impact of the wide-spread availability of antiretroviral therapy (ART) on the sexual behaviour of the general population who are not on ART in African countries is understudied. We assessed knowledge and attitudes towards HIV/AIDS and current prevention practices; and whether the availability of ART has reduced the fear of contracting HIV and reduces prevention practices among the general population in Rwimi, Uganda.

Methods: Between June and August 2013, we conducted a cross-sectional random cluster survey of 639 participants in Rwimi, Kabarole District of Uganda. We assessed whether the availability of ART has reduced fear of contracting HIV. In addition, we also assessed participants' knowledge on HIV/AIDS; attitudes towards prevention and current prevention practices. Logistic regression was used to assess associations for the outcomes general fear and personal fear of HIV with demographic variables and some knowledge measures.

Results: The majority of participants felt that the availability of ART had reduced the fear of contracting HIV/AIDS in the community (89.4%; 95% confidence interval [CI]: 86.9-91.7%). Of these, 86.8% (95% CI: 82.1-91.1%) of male participants and 90.8% (95% CI: 88.0-93.6%) of female participants reported a perceived reduced fear of HIV in the community. No statistical difference was found for this outcome and any knowledge measures or demographics in the logistic regression model. In contrast, few participants (22.4%; 95%CI: 17.7-25.6%) mentioned that their personal fear of the disease had reduced with the availability of ART. Of these, were 24.4% (95% CI: 17.4-30.7%) male and 21.2% (95% CI: 15.2-25.1%) were female. Participants who had at least a secondary level education had a lower odds (OR=0.29, p=0.022) of reporting a personal reduced fear; but those who were aware of the negative effects of ART had a higher odds (OR= 1.72, p=

0.047) of reporting reduced personal fear of HIV/AIDS. Overall, the majority of participants (94.1%; 95%CI: 93.8-97.1%) were still fearful of contracting HIV/AIDS (males: 94.2%; 95%CI: 91.2-97.3%; females: 96.1%; 95%CI: 94.3-98.0%).

Conclusion: The fear of contracting HIV/AIDS still persists, although participants perceived other people as being less fearful of the disease because of the availability of ART. Additionally, although the community is considerably knowledgeable about HIV/AIDS and the fear of HIV is still present, condom use as a prevention practice remains surprisingly low.

Key Words: Africa, antiretroviral therapy, attitudes, knowledge, prevention, Uganda

Introduction

Access to antiretroviral therapy (ART) potentially yields great health gains – declines in new HIV infections and AIDS-related deaths; improvement in life expectancy and quality of life of people living with HIV/AIDS [5, 6]. By the end of December 2012, 9.5 million people in low- and middle- income countries (LMICs) were receiving ART and more than 7.5 million of them were from the WHO African region [4, 5]. In this study, the term "era of ART" refers to this time period in which ART has become more common in sub-Saharan Africa.

However, there is concern about the availability of ART causing a disinhibiting effect on sexual behaviour and resulting in continued or relapse to risk behaviours among people living with HIV and their sexual partners [10-12]. Low adherence to ART combined with unsafe sexual practices could offset the reduced infectivity associated with ART usage and potentially result in the transmission of genetically resistant HIV viral strains [11, 13]. Studies in developed countries have shown an increase in unprotected sex with the introduction of (ART), especially among homosexual persons [14-16]. Some studies conducted in other parts of sub-Saharan Africa suggest an association between ART availability and sexual risk behaviour among people living with HIV [14, 19, 29]. Such studies among the general population who are not on ART are limited. I found one such study that showed that attitudes about ART were associated with high risk sexual behaviour particularly among women [19].

Uganda is one of the countries in sub-Saharan Africa with long-standing HIV intervention programmes. The nation's efforts at controlling HIV/AIDS in the 1990s resulted in a significant decline in HIV prevalence rates [8]. In recent years, Uganda's activities in relation to HIV/AIDS are focused on prevention and dealing with challenges to sustaining access to lifelong treatments infected persons [8]. In 2004, Uganda began to scale-up access to free ART medication to people living with HIV [9]. By 2013, 69.4% of eligible people living with HIV in Uganda were receiving ART, based on the treatment criteria of CD4<350 cells/mm^3 [9]. It has been shown that Ugandan patients receiving ART can

experience a life expectancy similar to the national average of 55 years in the general population [8]. In recent years, HIV prevalence trends in Uganda indicated an increasing prevalence. Among adults aged 15-49 years, the prevalence increased from 6.1% in 2002 to 6.4% in 2004/05 to 7.3% in 2011 [8, 9, 17]. In 2013, new infections were diagnosed in 140,908 people of which 76% were due to sexual transmission and 22% from mother-to-child transmission [18]. Most of the risky sexual practices such as having multiple sexual partners occur within age groups ranging from 15- 49 years [9]. In addition, the 2013 UNAIDS global report cited Uganda as one of the countries in which recent evidence indicated a significant increase in multiple sexual partners and a decline in condom use [4]. This has generated a growing interest in the association between access to ART and increase in HIV-related risky sexual behaviours.

To better understand these associations, we undertook a study to assess the knowledge and attitudes towards HIV/AIDS and current prevention practices of people who were not on ART in a community in rural Uganda, and whether the availability of ART has reduced the fear of contracting HIV.

Methods

Study Participants

A cross-sectional random cluster survey design was used for this study. Between June to August 2013, 639 participants were enrolled from 32 villages in Rwimi sub-county which were selected based on the ease of accessibility of these villages to the Rwimi Health Centre III. We systematically sampled 20 households each in 31 villages and 19 households in one village radiating from the determined focal point of the village. In each household, one individual aged between 18 to 49 years was randomly selected to participate in the survey. Participants were excluded if they were on ART; however, the HIV status of eligible participants was not determined. Participants were also excluded if they did not speak Rutooro or English and did not live in Rwimi. The Uganda National Council of Science and Technology and the Institutional Review Boards of Makerere University, Uganda and University of Alberta, Canada approved the study.

Measurements

Survey questions were derived from similar studies on knowledge, attitude and practices conducted in Uganda and Kenya [19, 44]. Additional questions were included to assess whether the availability of ART has reduced the fear of contracting HIV. A question on reduced personal fear of HIV/AIDS with the availability of ART was later included in the survey when we realised that participants were answering the question on reduced fear of HIV/AIDS with the availability of ART impersonally. Therefore, 219 of the 639 participants did not get to answer this question. The questionnaire consisted of sections on (1) participant's demographic background; (2) knowledge on HIV/AIDS; (3) attitudes towards HIV/AIDS and ART; and (4) current HIV/AIDS prevention practices. Some open-ended questions were purposely incorporated into the survey to capture fuller and broader ideas, especially around perceptions and attitudes.

All the materials for the study were translated into Rutooro and back translated by a second translator into English to ensure accuracy. Validity of the study instruments were assessed through key informants input and pre-testing. Trained local research assistants administered

the questions in Rutooro but recorded the answers in English. After the survey, the information gathered was entered into an Epi Info 7 database and checked for completeness and accuracy. Data entered for close-ended questions were analyzed according to the codes specified for each question. Information derived from open-ended questions were translated into English, broadly categorized and then coded.

Analysis

Data analysis was undertaken using descriptive, univariate and multivariable methods using Stata 12. For statistical significance, $b < 0.05$ was considered. Descriptive statistics were used to summarize the characteristics of the study population and to describe measures of knowledge, attitudes and practices. Representative measures for ART-related attitudes ("Do you think the fear of HIV has reduced now that ART is available?" and "Are you less fearful of HIV now that ART is available?") were selected as dependent variables for multiple logistic regression models. The demographic variables and some knowledge measures were used as independent variables. Results from the univariate logistic regression were used to determine which demographic variables to include in each multivariable model. Variables found to have $p \leq 0.25$ in the univariate logistic regression models were initially included in the multivariable models. In addition, the variables "sex" and "age" were selected as predictors for each model based on their biological importance. For each of the models, only variables of biological importance and statistical significance ($p<0.05$) were kept in the main effects models. Next, each model was assessed for confounding by including each variable that was not included in the main effects model individually into the model. A change of at least 15% between the odds ratios of the original variables in the main effects model and the corresponding variables in the new model was assessed to determine confounding between the variables, i.e. [(new OR- old OR)/new OR]*100%. If there was confounding, the final model was presented with the confounding variables. The models were tested for interactions where there was no confounding. The interaction terms considered were those suggested by literature and those that seemed meaning to consider based on the data. A final model with interaction was presented if there was interaction. In the absence of confounding or interaction, the main effects model was presented as the final multivariable model.

Results

Background Information

Six hundred and thirty-nine (639) participants were selected from 32 villages, comprising 4,849 households in Rwimi. Of the 639 study participants, there were more females (64.9%) than males (35.1%) (Table 4.1). The majority of participants (57.1%) were young adults (18-29 years). Most participants were married (67.0%) and subsistence farming was the most common occupation (70.7%). Few (26.6%) had gone beyond primary school education. Overall, when asked in an open-ended question, participants exhibited good knowledge on how HIV is spread through unprotected sex (98.9%) and contact with infected blood (85.1%); and methods of HIV prevention through condom use (74.5%). Knowledge about ART was also widespread among participants (100%) and ART was highly valued among participants because of its ability to improve health and quality of life of people living with HIV/AIDS. The majority of participants (91.6%) knew that ART is a lifelong treatment. However, less than half of the participants (48.9%) were aware of any negative effects of ART.

Table 4.1 Background Information on 18-49 year old residents of Rwimi, Kabarole District, Uganda, 2013

Demographics		HIV/AIDS Knowledge		ART knowledge	
Variable	%	Variable	**%** †	Variable	**%**†
Gender		**How can HIV/AIDS be spread?** ††		**Have you heard about ART? (Yes)**	100
Male	35.1	Unprotected Sex	98.9	**What are ART used for?** ††	
Female	64.9	Blood Contact	85.1	Improve health	25.9
Age in years (mean ± SD)		Mother-to-Child	14.7	Reduces virus in body	66.6
Male	29.4 ± **8.14**	Unlikely answer	0.6	Prolong life	19.4
Female	28.9 ± **8.13**	**How can a person avoid getting HIV/AIDS?** ††		**Can ART restore a person to how they were before they had HIV?**	
Age category		Abstinence	53.4	Yes	85.8
18-29	57.1	Be faithful	47.3	No	13.7
30-39	29.6	Condom use	74.5	No idea	0.5
40-49	13.3	Avoid blood contact	60.0	**If no, why not?** ††	
Marital Status		Unlikely answer	0.3	ART is not a cure	49.9
Married/cohabiting	67.0			HIV/AIDS is irreversible	36.3
Single	25.8			ART worsens the condition	14.7
Divorced/widowed	7.2			**If yes, why?** ††	
Religion				Improves health	81.5

Catholic	46.6
Non-Catholic Christians*	46.0
Muslim	7.0
Other**	0.3
Education	
None	11.1
Primary	62.3
≥Secondary	26.6
Occupation	
Farmer	70.7
Non-professional	21.6
Professional***	7.7

Controls opportunistic infections	2.2
Prolongs life	2.6
Other † † †	13.7
How long should a person take ART? (For life)	91.6
Are you aware of any negative effects of ARTs on those who take them? (Yes)	48.9
If yes, what are they? † †	
Undesirable changes in appearance	100.0
Weakness	16.1

*Includes Protestants, Pentecostals and Seventh Day Adventists

** Cult

*** Includes students

† Results weighted for cluster sampling design

† † Answers are not mutually exclusive

† † † It depends on how the person's body reacts to the drugs

Fear of HIV/AIDS in the Era of Highly Active Antiretroviral Therapy

The majority of participants felt that the availability of ART had reduced the fear of contracting HIV/AIDS in the community (89.4%; 95%CI: 86.9-91.7%). Of these, 86.8% (95%CI: 82.1-91.1%) of male participants and 90.8% (95%CI: 88.0-93.6%) of female participants reported a perceived reduced fear of HIV in the community. Few participants (22.4%; 95%CI: 17.7-25.6%) mentioned that their personal fear of the disease had reduced with the availability of ART. Of these, were 24.4% (95%CI: 17.4-30.7%) male and 21.2% (95%CI: 15.2-25.1%) were female. Overall, the majority of participants (94.1%, CI: 93.8-97.1%; males: 94.2%; 95%CI: 91.2-97.3%; females: 96.1%; 95%CI: 94.3-98.0%) were still fearful of contracting HIV/AIDS (Table4.2).

Table 3.2 Fear of HIV/AIDS among 18 to 49 year old residents of Rwimi, Kabarole District, Uganda, 2013.

Variable	%*
Do you think the availability of ART has reduced the fear of HIV?	
Yes	89.4
No	10.6
If yes, why do you think so?**	
Prolongs life	79.5
Improves health	25.1
If no, why not?**	
ART does not cure HIV/AIDS	92.9
Fear of taking ART for life	7.5
Are you (personally) less fearful of HIV/AIDS now that ART is available?***	
Yes	22.4
No	77.6
If yes, why?**	
ART prolongs life and improves health	99.0
Prevents dying badly	1.0

If no, why not?**	
ART does not cure HIV/AIDS	88.9
HIV/AIDS is a terrible disease	9.3
Fear of ART	10.7
Are you scared of getting HIV?	
Yes	94.1
No	5.9
If yes, why?**	
HIV/AIDS has no cure	31.1
HIV/AIDS is deadly	78.1
HIV/AIDS is a terrible disease	24.2
Fear of ART	6.9
If no, why not?**	
HIV/AIDS is just like any other disease	71.2
ART is available to mediate the effect of the disease	54.8

*Results weighted for cluster sampling design

**Answers are not mutually exclusive

*** Missing values excluded

Factors associated with the fear of contracting HIV/AIDS

In the survey, the majority of participants felt that the availability of ART had reduced the fear of contracting HIV/AIDS in the community. No statistical difference was found for this outcome and any knowledge measures or demographics in the logistic regression model (Table 4.3). In contrast, the majority of participants mentioned that their personal fear of the disease had reduced with the availability of ART. Participants who had at least a secondary level education had a lower odds (OR=0.29, p=0.022) of reporting a personal reduced fear; but those who were aware of the negative effects of ART had a higher odds (OR= 1.72, p= 0.047) of reporting reduced personal fear of HIV/AIDS with the availability of ART (Table 4.4).

Table 4.3 Odds ratios (OR) and 95% confidence intervals (CI) of reduced fear of HIV (in the community) among 18 to 49 year olds in Rwimi, Kabarole District, Uganda, 2013.

	Univariate Analysis*		Multivariable analysis*	
Variable	**OR (95% CI)**	**p-value**	**OR (95% CI)**	**p-value**
Sex				
Male	1.00			
Female	1.51 (0.82-2.77)	0.184	1.69 (0.91-3.14)	0.098
Age				
18-29	1.00			
30-39	0.95 (0.50-1.82)	0.882	1.03 (0.51-2.09)	0.934
40-49	1.44 (0.57-3.67)	0.444	1.65 (0.62-4.38)	0.318
Marital Status				
Married/cohabiting	1.00			
Single	0.73 (0.36-1.46)	0.370		
Divorced/widowed	1.39 (0.38-5.14)	0.622		
Education**				
None	1.00			
Primary	1.63 (0.63-4.19)	0.309	1.96 (0.75-5.12)	0.171
≥Secondary	1.56 (0.58-4.21)	0.379	2.00 (0.67-6.01)	0.216
Religion				
Catholic	1.00			
Non-Catholic Christians	1.55 (0.82-2.93)	0.181		
Muslim	1.12 (0.41-3.06)	0.831		
Occupation				
Farmer	1.00			
Non-professional	1.04 (0.53-2.06)	0.910		
Professional	0.65 (0.25-1.69)	0.379		
ART can restore a				

person to how they were before they had HIV		
No	1.00	
Yes	0.56 (0.23-1.38)	0.211
Aware of negative effects of ARTs on those who take them		
No	1.00	
Yes	0.98 (0.54 –1.78)	0.942

Variables which attained the inclusion criteria for the multivariable model (p<0.25) but which were eventually neither statistically significant nor biologically important were: "religion" and "Can ART restore a person to how they were before they had HIV?"

**Results weighted for cluster sampling design*

** Education was confounding for sex and age hence model with confounding was presented

Table 4.4 Odds ratios (OR) and 95% confidence intervals (CI) of reduced personal fear of HIV among 18 to 49 year olds in Rwimi, Kabarole District, Uganda, 2013.

	Univariate Analysis*		**Multivariable analysis***	
Variable	**OR (95% CI)**	**p-value**	**OR (95% CI)**	**p-value**
Sex				
Male	1.00			
Female	0.83 (0.49-1.41)	0.491	0.68 (0.39-1.21)	0.189
Age				
18-29	1.00			
30-39	0.68 (0.36-1.30)	0.245	0.67 (0.34-1.31)	0.240
40-49	1.20 (0.59-2.43)	0.620	0.89 (0.41-1.94)	0.777
Marital Status				
Married/cohabiting	1.00			
Single	0.93 (0.52-1.68)	0.818		
Divorced/widowed	1.04 (0.39-2.76)	0.941		
Education				
None	1.00			

Primary	1.13 (0.52-2.42)	0.760	0.99 (0.43-2.24)	0.974
≥Secondary	0.40 (0.16-1.03)	0.057	0.29 (0.10-0.84)	0.022
Religion				
Catholic	1.00			
Non-Catholic Christians	0.97 (0.56-1.67)	0.907		
Muslim	1.01 (0.31-3.28)	0.981		
Occupation				
Farmer	1.00			
Non-professional	0.51 (0.25-1.02)	0.059		
Professional	0.73 (0.25-2.16)	0.568		
ART can restore a person to how they were before they had HIV				
No	1.00			
Yes	0.68 (0.29-1.59)	0.379		
Aware of negative effects of ARVs on those who take them				
No	1.00			
Yes	1.60 (0.94-2.71)	0.081	1.72 (1.00-2.95)	0.047

Variables which attained the inclusion criteria for the multivariable model ($p<0.25$) but which were eventually neither statistically significant nor biologically important was: "Occupation?"

*Results weighted for cluster sampling design

Current Attitudes and HIV/AIDS-prevention practices

Out of all the males who participated in the study, 71.7% of them had tested for HIV and 88.8% out of all the female participants had tested for HIV (Table 4.5). Most participants said they would inform their partners (87.3%) if they were HIV positive and would like to be informed (97.7%) if their partner was HIV positive. The majority (95.0%) mentioned that their sexual practices would change if their partner was HIV positive. Participants were evenly split with

regard to whether or not they felt they were at risk of contracting HIV (At risk: 50.2% versus not at risk: 49.7%). "Distrustfulness of partner" (69.8%) made participants feel at risk while "fidelity" (60.2%) and "Condom use" (39.8%) made them feel safe. Most participants (80.6%) had been sexually active in the past 6 months. "Faithfulness to partner" (71.3%) was the most common prevention practice among participants. Condoms had been used by only 25.3% of the sexually active participants during their last sexual encounter.

Table 4.5 Current Attitudes and HIV/AIDS-prevention practices among 18 to 49 year old residents of Rwimi, Kabarole District, Uganda, 2013

Variable	%*
Tested for HIV	83.1
Males who had tested for HIV	71.1
Females who had tested for HIV	88.8
If yes, why?	
To know my status	100.0
If no, why not?**	
Confident of being HIV negative	55.2
Fear of results	26.6
No Reason	48.7
Do you know your HIV status?	
Yes	77.8
No	22.2
Would you want to be informed, if your partner were HIV positive?	

Yes	97.7
No	2.3
If yes, why?**	
To protect self	84.4
To plan for the future	13.6
To support partner to start treatment	32.8
To build trust	2.0
If no, why not?	
To prevent conflict	100
Would your sexual practices change if you found out your partner was HIV positive?	
Yes	95.0
No	4.3
Not sure	0.7
If yes, how?**	
Use Protection	71.5
Abstinence	9.1
Separation	30.6
Reduced Sex	2.2
Would you inform your partner if you were HIV positive?	
Yes	87.3

No	12.7
If yes, why?**	
To know each other's status	85.9
To prevent conflict	14.1
If no, why not?	
Fear of partner's response to the situation	100.0
Do you think you are at risk of getting HIV?	
Yes	50.2
No	49.7
Don't know	0.1
If yes, what makes you think so?**	
Distrustful of partner	69.8
Lifestyle	19.2
Inconsistent use of condoms	10.2
Uncertainty of life	9.6
If no, what makes you think so?**	
Fidelity in relationship	60.2
Consistency in prevention practices	39.8
Have you been sexually active in the past 6 months? (Yes) ****	80.6
What have you been doing to protect yourself from getting HIV/AIDS?**	

Abstinence	3.4
Fidelity	71.3
Condom use	28.6
Avoiding blood contact	6.7
Regular testing with partner	2.8
Nothing	7.7
Did you use a condom the last time you had sexual intercourse?	
Yes	25.3
No	74.7
If yes, why?**	
To prevent pregnancy	33.1
For protection	85.0
If no, why not?**	
No need for condoms	34.8
We trust each other	30.7
Partner refused to use condom	27.0
Condom unavailable at the time	4.9
Did you ever want to use a condom but did not use it?	
Yes	7.4
No	92.0
No answer	0.6

If yes, why?**	
Condom unavailable at the time	27.0
Partner refused to use condom	59.5
Other***	16.2

*Results weighted for cluster sampling design

**Answers are not mutually exclusive

***Did not know how to use condoms, allergy/pain from using condoms, fear of condom breaking.

****Only participants who answered "yes" to this question went on to answer the subsequent questions in this section.

Discussion

The main purpose of this study was to assess whether the fear of contracting HIV/AIDS had reduced with the availability of ART and to describe knowledge and attitudes towards HIV/AIDS and current HIV/AIDS prevention practices of the general population who are not on ART in Rwimi. Overall, the results showed that the fear of HIV/AIDS still persists, although participants perceived other people as being less fearful of the disease than they themselves were because of the availability of ART.

A comparison of some of the results was made with a previous study by Aplin [44] conducted in 2009 in the same area, Rwimi, Kabarole District, Uganda, and among a similar population. The comparison revealed an improvement in knowledge and attitudes towards HIV/AIDS between 2009 and 2013. More participants reported having tested for HIV in 2013 (83.1%) than in 2009 (47.7%). Additionally, 71.7% of all male respondents in 2013 had tested for HIV, while only 30% of the male respondents in 2009 had tested for HIV (Laura Aplin, personal communication, December 2, 2014). Among the women, 88.8% of all the female respondents in 2013 had tested for HIV compared with 67% of the female respondents in 2009 (Laura Aplin, personal communication, December 2, 2014). For women, this improvement in testing could be attributed to change in Uganda's HIV testing policy to routine counselling and testing during antenatal care visits in 2006 [50]. For men, the increased rates of testing could reflect their reported fear of HIV infection. A study conducted in South Africa on the attitude of men to HIV voluntary counselling and testing showed that increased concerns about health issues could account for improved testing among men [51]. All participants in the 2013 study had heard of ART and more of them knew where to access ART from and how long to take it for, than did those in 2009 (93.6%). However, with regard to practices, there was not much change in reported use of condoms. In both 2009 and 2013, approximately a quarter of the participants reported condom use at last sexual encounter. Fewer participants in 2013 than in 2009 (7.4% versus 16.5%) reported ever wanting to use a condom but not using it. This question measured lifetime prevalence. We were therefore surprised to find the large difference in the responses between the two studies as the majority of patients in the 2013 study would have been eligible to participate in the 2009 study (i.e. patients 18-45 in 2009 would still be have been eligible for the 2013 study). However, it may have been because participants in our study had been asked earlier on if they had been sexually active in the past six months. Hence they may have responded with reference to the past

six months instead of over their lifetime. The Aplin [44] study did not ask about sexual activity in the past six months.

In our study, the majority of participants mentioned no need for condoms and refusal of partner to use condoms as reasons why they did not use condoms at the last sexual encounter. Only 4.9% mentioned that condoms were unavailable at the time. Therefore, the very low use of condoms could not be as a result of unavailability of condoms in the community. Although faithfulness to partner was mentioned as a more common prevention practice (71.3%), there was no guarantee that the other partner is also being faithful. There was also a possibility of social desirability bias in the response on faithfulness to partner since the majority of participants were married. Additionally, the majority participants (98.9%) mentioned unprotected sex as a method by which HIV/AIDS is contracted but there had not been much change in the proportion of participants who use condoms. Consequently, the low use of condoms is a cause for concern. According to the Ugandan 2011 AIDS Indicator Survey "nearly 3 in 4 women and 80% of men age 15-49 know that HIV can be prevented by using condoms and by limiting sexual intercourse to one uninfected partner." Yet only 16% of women and 15% of men who had multiple sexual partners in the past 12 months reported using a condom at their last sexual encounter [17]. This is less than the proportion of participants in our study. Since the Rwimi community has had a lot HIV/AIDS-related programs it could probably have influenced the use of condoms in the area, hence the higher proportion of reported condom use among our study participants. In addition, the 2013 UNAIDS global report cite Uganda as one of the countries in which recent evidence indicated a significant increase in multiple sexual partners and a decline in condom use [4]. This raises concerns about knowledge translation and practice; as well as perceptions surrounding condom use among the general population. Some studies investigating condom use have shown that the decision to use condoms is influenced by factors such as perception of condoms, infidelity, issues of trust/mistrust in the relationship and level of education [52, 53].

Although the majority of our study participants were of low education levels they showed good knowledge about ART. This is suggestive of the widespread knowledge on ART in the area. Studies conducted in sub-Saharan Africa within the past 10 years among people living with HIV and among the general population have shown similar results of overall good knowledge of

HIV/AIDS and ART [19, 25]. The outcome of the question on reduced personal fear showed that on a personal level, most of the participants were not less fearful of HIV/AIDS even though they knew that ART was available. This matched the overall expression of being scared of contracting HIV/AIDS which was answered by all participants. Thus, even with the availability of ART the fear of HIV/AIDS persists for most people although they perceived others as being less fearful of the disease. The multiple logistic regression model on personal reduced fear of HIV/AIDS with the availability of ART had some statistically significant outcomes. The results showed that participants who had at least a secondary level education had a lower odds of reporting a personal reduced fear. Lower education levels are associated with misconceptions about ART [25] and education level influences decisions to use HIV prevention methods such as condom [52, 53]. Thus, the participants with a higher level of education were probably better informed about the HIV/AIDS and ART and hence less likely to experience a disinhibiting effect of the availability of ART and so their fear still persisted. The results also showed that participants who were aware of the negative effects of ART had a higher odds of reporting reduced personal fear of HIV/AIDS with the availability of ART. This was a surprising finding and we do not have a ready explanation for it. However, it could probably be that those who knew about the side effects of ART probably also knew people on ART and had seen the improved health of these individuals, despite the side effects. Therefore, in considering the bigger picture of HIV/AIDS these participants felt the benefits of ART outweighed its negative effects hence their position of reporting a reduced personal fear of the disease. This result did not imply that their fear of the disease was eliminated.

There were no statistical differences for the outcome of perceived reduced fear of HIV/AIDS in the community with regard to the knowledge measures and demographic variables such as age, sex, marital status, etc. in the multiple logistic regression. This suggests that a similar proportion of persons from different subgroups had similar perceptions of reduced fear of contracting HIV/AIDS. Studies from Uganda have shown that in the 1990s, when Ugandans were made to fear HIV/AIDS and feel personally at risk of dying from the disease, it resulted in crucial behaviour changes such as promoting fidelity and discouraging multiple and concurrent sexual partnerships [54, 55]. Thus a personal sense of fear and risk of the disease as indicated by most of our participants could suggest less inclination towards practices that put them at risk of contracting the disease. In a qualitative study exploring the need to reemphasize behaviour

change for HIV prevention in Uganda, participants believed that "Ugandans now seem less afraid of becoming infected with HIV, at least in part because ART is available" [55]. The authors also suggested that the diminished fear may be having a disinhibiting effect on sexual behaviour. Although we did not find other quantitative studies directly assessing whether the fear of HIV/AIDS had reduced in the era of ART, there were some studies on associations between ART-related beliefs/attitudes, and sexual behaviour among HIV negative persons [19, 27]. The study by Smith [19], a cross-sectional study, showed that ART-related beliefs/attitudes were associated with risky sexual behaviour. In that study, they found that 20% of men and 29% of women believed that ART was a cure for HIV. This belief was found to be associated with younger age of sexual debut among women; and increased likelihood of exchanging sex for gifts and decreased likelihood of condom use at last sexual encounter among men. On the other hand, a prospective cohort study by Bechange et al. [27], targeting HIV-uninfected non-spousal household members of ART patients receiving home-based AIDS care showed a decrease in risky sexual behaviour after a 2-year follow-up.

The outcome of this study adds to the limited studies available that assess knowledge, attitude and behaviour amongst the general population in the era of ART. It also sheds light on the influence of ART on attitudes and prevention practices. Such information is imperative for planning sustainable programs to encourage adherence to HIV/AIDS prevention practices, particularly in high prevalence areas. This study utilized a probability-based sampling methodology to evaluate the knowledge, attitude and practices among the general population in Rwimi. This is a strength compared with other studies which only target high risk groups or those receiving ART through convenience sampling methods, since the outcomes of our study are more reflective of the community. The many open-ended questions included in the data collection made room for collecting responses that may otherwise have been missed by the structured responses utilised in such cross-sectional studies. Limitations of our study include the possibility of social desirability bias in some participants' responses. Because of confidentiality issues, we did not exclude HIV positive persons not on ART from the study. The responses of an unknown number of HIV positive persons not on ART might have been different from those of HIV negative participants. Study participants were randomly selected at the household level from household members who met the eligibility criteria and were present at the time of the interview. This probably accounts for the higher proportion of females in the study since male

participants were more likely to be working outside the home during the daytime. The males participating in the study may also have been different from those not available to participate thus introducing a potential selection bias for male participants. The data are therefore likely to be more representative of the female than the male population in Rwimi. As we did not collect data on how many household participants initially selected for the study declined to participate in the study we cannot comment on whether additional selection bias was introduced for both male and female participants. Power calculations for the logistic regression analyses were not done apriori since there was not enough information on the key component of fear of HIV/AIDS. In the post hoc power calculation based on the results in Table 4.3 with 412 females and 224 males; 90.8% and 86.6% (OR=1.5) perceived reduced fear of HIV/AIDS in the community for females compared to males and level of significance of 5%, the power was 31%. Similarly, based on Table 4.4 with 258 females and 162 males; 20.2% and 24.1% (OR=0.83) reduced personal fear of HIV/AIDS for females compared to males, the power was 12%. Our study lacked power to identify predictors of these dependent variables.

The cross-sectional design of this study, does not allow for assessments on changes in sexual practices over time with the availability of ART. Although this study does not provide definitive evidence that reduced fear of HIV/AIDS with the availability of ART is associated with risky sexual behaviour, the findings support the need for further longitudinal research.

Conclusion

The fear of contracting HIV/AIDS still persists, although participants perceived other people as being less fearful of the disease because of the availability of ART. Additionally, although the community is considerably knowledgeable about HIV/AIDS and the fear of HIV is still present, condom use as a prevention practice remains surprisingly low. HIV/AIDS prevention programs in Uganda should focus on promoting the translation of knowledge into practice to affect behaviour change. Furthermore, studies on HIV prevention practices, particularly with regard to condom use among the general population are needed.

Chapter 5: Manuscript 2

Fear of HIV/AIDS and attitudes towards HIV prevention in the era of antiretroviral therapy – a qualitative study in Rwimi, Kabarole District, Uganda

ABSTRACT

Background: The impact of the wide-spread availability of antiretroviral therapy (ART) on the sexual behaviour of the general population who are not on ART in African countries is understudied. This study explores the community's views on, and experiences with the fear of contracting HIV/AIDS and attitudes towards HIV prevention in the era of ART.

Methods: This was a focused ethnography conducted in August 2013, in Rwimi, Kabarole District, Western Uganda. We carried out four focus group discussion with sexually active persons in the community who were not on ART. Data was collected in the local language, Rutooro, audio-recorded and thereafter translated and transcribed into English and analysed using content analyses.

Results: Fear of HIV is reduced because of the availability of ART. However, concern about HIV remains due to factors such as stigma, the increased prevalence of people living with HIV and worries about the challenges of being on ART. Participants generally expressed a positive attitude toward HIV/AIDS prevention practices, although these practices were highly influenced by factors such as policy, gender-based perceptions and trust in relationships.

Conclusion: Though the fear of HIV/AIDS has reduced because of the availability of ART, fear still remains high enough to encourage people to continue to try to prevent infection. There is still the need to scale up sustainable programs that encourage adherence to prevention practices with a consideration for how socio-cultural influences such as gender roles and trust expectations play into HIV prevention.

Introduction

Sub-Saharan Africa bears the highest burden of HIV infections and HIV/AIDS related mortality in the world [1]. Of the 35 million people living with HIV at the end of 2013, 24.7 million lived in sub-Saharan Africa [2]. Additionally, sub-Saharan Africa accounted for 74% of all AIDS-related mortality in 2013 [2].The human and economic costs of managing HIV/AIDS are of significant global and public health importance. HIV/AIDS increases the disease burden on countries and their healthcare systems, social support systems and families. In addition, it reduces the ability of those affected to reach their highest achievable levels of health and productivity; resulting in reduced economic productivity with adverse consequences for sustainable development. Consequently, there is increasing pressure on the governments of African nations and the international community to find ways of bringing HIV/AIDS under control.

Considerable improvements have been made in access to ART in low- and middle- income countries (LMICs) [4]. By the end of December 2012, 9.5 million people in LMICs were receiving ARTs, which made up almost two-thirds of the targeted MDG goal of 15 million people accessing ARTs globally by 2015 [4, 5]. Access to ART has resulted in considerable improvements in life expectancy and quality of life of persons living with HIV/AIDS [6, 7]. ARTs can help prevent people living with HIV from dying of AIDS prematurely, falling ill frequently as well as developing and transmitting tuberculosis and HIV [5]. In this study, the term “era of ART” refers to this time period in which ART has become more common in sub-Saharan Africa.

Uganda is one of the countries in Sub Saharan Africa with long-standing HIV intervention programmes. Since 1986, Uganda has had a well organised and sustained response to the HIV challenge. Uganda’s National AIDS Control Program (NACP) was set up in 1986 with the support of the WHO, to respond to the HIV/AIDS threat [8]. The program lasted till 1995 and during that period a successful reversal in the HIV/AIDS epidemic was achieved. The nation addressed HIV/AIDS as a multi-sectoral challenge [8]. Thus, apart from tackling the natural dynamics of the epidemic, other aspects such as HIV/AIDS awareness education and campaigns to encourage positive sexual behaviour change were also engaged. Policies were developed to employ a concerted effort from individuals and various institutions across the nation to address

the HIV/AIDS problem. The nation's efforts at controlling the problem of HIV/AIDS in the 1990s resulted in a significant decline in HIV prevalence rates [8]. In addition to efforts to encourage HIV prevention, Uganda's activities now focus on dealing with challenges to sustaining access to lifelong treatments for the infected persons [8]. In 2004, Uganda scaled up access to free ART medication [9]. By 2013, 69.4% of eligible people living with HIV in Uganda were receiving ART, based on the treatment criteria of CD4<350 cells/mm^3 [9]. Patients receiving ART can potentially experience a similar life expectancy to the national average of 55 years in the general population [8].].

Recent trends in Uganda suggest an increase in HIV prevalence. Among adults aged 15-49 years, the prevalence increased from 6.1% in 2002 to 6.4% in 2004/05 to 7.3% in 2011 [8, 9, 17]. New infections were diagnosed in over 100,000 people each year of which 76% were due to sexual transmission and 22% from mother-to-child transmission [18]. Most of the risky sexual practices, including having multiple sexual partners occurred within age groups ranging from 15-49 years [9]. In addition, the 2013 UNAIDS global report cited Uganda as one of the countries in which recent evidence indicated a significant increase in multiple sexual partners and a decline in condom use [4].

The availability and accessibility of effective treatment through antiretroviral therapy (ART) has raised concerns about the associated potential for risky behaviour among people living with HIV and their sexual partners [10-12]. Some studies conducted in parts of sub-Saharan Africa suggest an association between ART availability and sexual risk behaviour among people living with HIV [11, 14, 19]. However, studies conducted on the response of uninfected persons to the threat of HIV in the era of ART are very few. HIV-infected persons and uninfected persons may respond differently in terms of sexual risk in the era of ART [15]. Apart from controlling the effects of HIV/AIDS among people living with the disease, the world aims at reducing its spread and eventually eradicating it. Thus, studies on the HIV prevention practices of uninfected persons will be useful in this regard. Epidemiological studies can readily examine whether people living with HIV who are on ART engage in sexual risk behaviours or whether a population is adhering to prevention practices [20]. However, qualitative data are also needed to bring deeper meaning for such quantitative findings. Our overall objective was to determine whether the fear of contracting HIV/AIDS had reduced with the availability ART, and we used

both quantitative and qualitative methods for this purpose. Thus, this qualitative component was employed to provide the needed context and meaning for the fear of HIV/AIDS and current HIV prevention practices among the general population in Rwimi.

Methodology

Study Design

A focused ethnography is "led by a specific research question, is conducted within a particular context or organization among a small group of people to inform decision-making and is more time limited" [46, p.11]. Our study was a focused ethnography, which explored the culture of HIV prevention based on the specific research question on fear of HIV and attitudes towards HIV prevention in Rwimi in the era of ART.

The qualitative data generation period was in August 2013. Data was generated through four focus group discussions (FGDs) with community members who had participated in an earlier survey on HIV-related knowledge, attitudes and prevention practices in the era of ART. The FGDs provided the needed interactive forum for participants to share their views and to listen to and reflect on other participants' views.

Study Site

The study was carried out in Rwimi sub-county, Kabarole District, Western Uganda. The main language in the district is Rutooro, and most economic activities in the district are centred on agriculture. Rwimi comprises 40 villages, with an estimated population of 25,000 and it is served by a Health Centre III health unit [44]. Routine HIV testing is carried out for all pregnant women who attend antenatal services at the Health Centre III in addition to an HIV/AIDS treatment program.

Recruitment

We used previously established relationships with the community by other researchers to gain entry into the community for this study. Participants were purposefully sampled from the respondents to the previously administered survey based on their survey response to perceived risk of contracting HIV. Four FGDs were conducted with the following groups: a) males with a self-declared low risk of HIV; b) females with a self-declared low risk of HIV; c) males with a

self-declared high risk of HIV; and d) females with a self-declared high risk of HIV. There were between six to seven participants in each of the four FGDs, totalling 26 participants.

Procedures for focus group discussions

Each FGD lasted approximately 60 to 75 minutes and was moderated by a research assistant who was fluent in the local language. A second research assistant assisted in note-taking. A FGD guide which had been checked with the research assistants, by translating into the local language and then back-translating into English to ensure accuracy of translation, was used during the FGDs. Participants were encouraged to express their own views even if they differed from the views of other participants.

The FGDs were tape-recorded and transcribed and translated into English by the research assistant who moderated the FGD. All participation was voluntary. Privacy and confidentiality were encouraged and maintained as much as possible. Informed consent for participants' involvement, including audio-taping of the interviews were obtained. Participants received 10,000 Ugandan shillings ($3.66 USD) in compensation for their transportation expenses. Refreshments were also made available to participants at the end of the FGDs.

Data Analyses

Latent content analysis as described by Mayan [46] was used for analyzing the qualitative data generated in the study. This involves identifying, coding and categorizing the primary patterns in the data. Thus the meanings of specific passages within the data are examined and appropriate codes or categories for these passages are determined rather than just tallying the number of times specific words are used. Therefore, latent content analysis allows the "coding of the participant's intent within context" [49, p.94]. The results were organized by the primary researcher using Microsoft Word 2010 and coded with Atlas.ti7 (ATLAS.ti7 Student Semester License). Analysis began with a preliminary read through of the data by which ideas and concepts expressed by the participants were identified and labeled [49]. The final stage of the analysis involved the integration of the categories and themes into a theoretical framework for understanding the concepts from the perspectives of the participants [48, 49]. Excerpts from the interview transcripts were integrated to illustrate concepts clearly and to give evidence to support each theme, as well as the overall research findings.

Field notes and memos were also analyzed to help identify important issues related to the research objectives, and to highlight any disagreements between participant statements and observed practices. The major themes related to the culture of HIV prevention in the era of ART were chosen according to the patterns that emerged from the FGDs.

Rigor

Rigor is an important aspect of qualitative research, as it ensures that findings are presented in an appropriate manner. To ensure rigor, the local language was used to enable participants express their thoughts freely. The data was continuously verified though discussion with colleagues, supervisors and other research team members to ensure that data was reliable and valid. Transcripts were checked for accuracy by comparing sections that were transcribed and translated by a second research assistant. A journal was maintained as a record of personal biases and assumptions in order to provide context and background for analysis.

Ethics

Ethical approval for the study was provided by the Uganda National Council for Science and Technology, Makerere University School of Public Health Institutional Review Board and University of Alberta Research Ethics Board. Participants who gave their informed consent were recruited for the study.

Results

I identified a number of themes related to the study questions around the fear of HIV/AIDS and attitudes towards HIV prevention in Rwimi.

ART are not perfect but they are successful

During the discussions, participants talked about their beliefs about ART. All of the participants knew of ART and some had had experiences with family members who were on ART. Overall, they believed that ART was successful in treating HIV although it did not cure the disease. Descriptions given by participants about ART included "improves health", "prolongs life", "helps you plan for the future" and "reduces the worry and stress of HIV". Older participants who were around during the 1980s had seen how people who contracted HIV suffered and died. With the availability of ART, the difference in the HIV/AIDS situation when people were on ART was evident to them:

"… I know that the drugs are successful. There are some people who are our friends and HIV positive. They have spent 20 years on ARTs, besides they have proved to us that all their plans have been accomplished. Those who hadn't built houses have now built, due to …the help of ARTs. HIV patients no longer get signs/symptoms as how they used to get them in the 1980's when HIV was prevalent." – (Self-declared low risk male)

The limitations of ART were also discussed. Adjusting to ART can also be hard on the body, because of the strength of the medication. Participants identified the need to improve nutrition as a way to help the body function well under the influence of ART. Additionally, participants mentioned that inconsistency in taking the drugs could adversely affect the person on ART:

"If you don't follow medical instructions, you may get problems with ARTs… The moment you get infected with HIV, you need to be strong-hearted and take good care of yourself so that the drugs are effective in your body. If you miss taking drugs at a specific time … you might fall sick and get problems in your life. That's my opinion" – (Self-declared low risk male)

There were diverse views on the availability of ART. Some participants were not worried about ART stock-outs in the future:

"…I don't think ARTs will run out of stock because the whole world has people infected with HIV according to research. That's why we are [sure] that ARTs will be available all the time. If it was in Uganda only, then we would doubt and think ARTs will run out of stock." – (Self-declared low risk male)

"…the government will not give up on us, they see that the moment they stop supplying ARTs the whole nation would perish. ARTs will continue coming." – (Self-declared high risk female)

On the other hand, some participants felt that there was no guarantee that ART would not run out in future. The government was seen to play an important role in determining whether or not ART would run out:

"At times they announce on radios that HIV drugs have reduced… There are HIV patients who stay for [about] four days without taking ARTs because they're out of stock. You cannot guarantee that ARTs will continue in existence; People working with the Ministry supplying ARTs know better." – (Self-declared high risk male)

"The government might give up on us because … they advised us to stop being immoral because of HIV prevalence but we don't want to stop. With that the government might get fed up and say, "…Government money has all been spent on ARTs and people." They [will] give up on us and we [will] suffer." – (Self-declared high risk female)

Availability of ART does not completely erase the fear of HIV/AIDS

The majority of participants mentioned that the availability of ART had reduced their fear of HIV/AIDS. This was because ART mitigates the effect of the disease:

"I personally don't fear HIV so much, after all ARTs are available." – (Self-declared low risk male)

"Yes, I am [less fearful] because I know I can live for 30 – 40 years with it [ART]." – (Self-declared low risk male)

"I personally, I fear HIV but I am less fearful because in the past before drugs … they [people] would be recognized from HIV signs, those signs were so bad, they used to have diarrhoea so much and the care-takers were fed up with such patient but these days they are no longer there.

Yes, there's fear but it's not as much as how it used to be in the past." – (Self-declared low risk female)

However, there still remained an overall fear of contracting the disease:

"I fear HIV because it's an incurable disease, it cannot be treated for you to get healed. Ok, even if you take ARTs, it is no cure. Drugs just treat it." – (Self-declared high risk male)

"I do fear HIV. I fear infecting others [if I get infected] because it's a dangerous disease despite the availability of ARTs." – (Self-declared low risk male)

For the majority of participants, even with ART available, there was still some degree of fear of contracting the disease. Additionally, not everyone was comfortable with the idea of taking ART for life or facing the side effects of the drugs:

"I am so much aware that ARTs are available but I fear HIV… because I have a problem of taking tablets. What scares me the most is when you start ARTs, you have to take them till death." – (Self-declared high risk female)

Some participants were concerned that the ability of ART to make HIV positive persons look healthy and normal like any other person was contributing to the spread of the disease:

"This is so, because it's difficult to recognize someone on drugs. The person looks good and healthy, you end up having sex with that person, and then later on you hear that you are HIV positive." – (Self-declared low risk female)

"Most people don't fear HIV because of the availability of drugs. They say that, 'Let me have unprotected sex, after all drugs are available. If I get infected with HIV, I will buy Septrin [cotrimoxazole] and take [it].'" – (Self-declared low risk female)

Fear of the social stigma attached to being HIV positive still persisted in the minds of people. Some participants reported still being fearful of the disease because they felt that being on ART was an inconvenience. There was also concern about the stigma of being recognised as HIV positive, which was evident when one was seen to be on ART:

"Now, there are some of us who are always on the move – business men; it will inconvenience us to carry ARTs all the time. Everywhere you go, you would have to carry ARVs, yet you fear a person seeing you taking them; that is why I fear HIV." – (Self-declared high risk male)

In addition, there was still fear of disclosing an HIV positive status to one's partner. Participants attributed the spread of HIV to failure to disclose one's HIV positive status to one's partner:
"What is causing the spread of HIV is that one of the couples goes for HIV testing alone and after being tested positive they start taking drugs privately without partner's knowledge. The one who hasn't tested to know his HIV status will go outside and have sex with another woman, yet he is infected. Finally he infects another person unknowingly…This has led to the spread of HIV because they don't want to disclose their HIV status to their partners." – (Self-declared low risk female)

"Women fear breaking the news to their husbands that they are HIV positive." – (Self-declared low risk female)

Attitudes towards HIV Prevention

Gender-based perceptions of socially accepted sexual behaviour

Participants discussed their prevention practices – abstinence, being faithful, using condoms and testing for HIV:

"…I avoid having extra marital affairs. You stick to your husband but you need to find time and test with your spouse. You won't know his HIV status, you might be faithful to him yet he has multiple sexual partners." – (Self-declared low risk female)

"I do have a girlfriend at the moment but I have told her to go for HIV testing first before we do anything. With that, we are still abstaining from sex. She is still at school, when she comes for holidays, we shall go for testing." – (Self-declared high risk male)

"I also use condoms for fear of getting HIV" – (Self-declared high risk male)

Being faithful and condom use were the most common prevention practices mentioned. There were differences in perceptions of socially accepted sexual behaviour for men and women.

Women mentioned practicing abstinence before marriage and being faithful in marriage as a prevention method:

"I was abstaining from sex in the past as a way of preventing myself against HIV before they engaged me---- laughs--- after getting married I decided to be faithful to my husband up to now." – (Self-declared high risk female)

Women perceived being unfaithful in their marriage as a taboo so were not open to discussing it but most men on the other hand were indifferent. This was evident in how freely they spoke about such affairs, suggesting it was a normal way of life:

"That's why I told you, us business men we cannot manage to keep travelling with our wives. You may move from here to Kampala and you spend there a whole month. You cannot spend a full month without having sex. It's not possible!! It might not be possible because men are sexually active." – (Self-declared high risk of HIV male)

"Right now, how I am protecting myself, I always use a condom when I am cheating on my wife, that's what I use." – (Self-declared low risk of HIV male)

"I spend 2 to 3 months without going back home. I have to be with condoms, even if my wife finds them in the car or motorcycle, she cannot remove them. I have to explain to her that those are my protectors...Why quarrel? Instead of having unprotected sex, I would rather have my condoms with me because I won't be with her all the time…. Extra marital affairs have many challenges but we need to protect ourselves." – (Self-declared low risk of HIV male)

There were also a few men who mentioned being faithful to their wives:
"Me, I protect myself with my wife. I have one faithful sexual partner." *– (Self-declared low risk of HIV male)*

Condom use between married couples was not popular; it was seen as a sign of trust in the relationship not to use condoms:
When i was still at my husband's home, i wasn't using it [condoms]. Now that i am no longer there, if i want to have sex, i use a condom. – (Self-declared low risk female).

Thus, the married men used condoms mainly during extra-marital affairs:
"For instance, us who are married, it's a shame to have children out of wedlock and bring them to my home yet I won't be helping their mothers. My mission ends after having sex with that woman nothing else. If you are at home with your official wife, you may not use condoms, but when you go outside you must protect yourself." – (Self-declared low risk male)

Unmarried men also used condoms but it was usually with women who were not their regular partners. Condom use among men was also popular if students were involved in the affair. They were usually concerned about disrupting the girl's education:

"You may meet a school-going girl and you don't want to spoil her future, you want her to continue as a student; there you use condoms for those going to school." – (Self-declared low-risk male)

Among the women, there were other uses for condoms such as for birth control. Condom use was also mentioned among married women if they had spouses who travelled away from home frequently and whose fidelity they were unsure of:

"I am protecting myself as a woman when my man is out of the home for a month. When he returns we first use a condom then go for checkup the following day—he already knows that." – (Self-declared high risk female)

The discussions revealed several factors that could potentially influence how participants would respond to a partner who was HIV positive. These included the presence of children, perceived socio-economic status, and personal beliefs about marriage. For the majority of women, divorce was the last resort to be considered if their partner contracted HIV. They were willing to stay with their partner to preserve their family. They proposed that they would encourage their partner to get on ART and also to use condoms during sex. In a rural setting such as Rwimi, there is a lot of security for women within the confines of marriage, since most women were not empowered to support themselves and their children. If the couple had children, it was a greater motivator for the woman to remain with the man:

"If I find husband positive and I negative, we [will] live together. It depends on what you agree upon. I tell him to start using condoms so that we raise our children. He would also be seeing it, [because] if he infects me with HIV and we both die at once, who will take care of the children?" – (Self-declared high risk female)

"I [will] stay *with him. I can't leave him if he is positive and I negative. We [will] sit and talk over it and if he wants, he is free to go anywhere he wishes to go, but as for me, I can't leave my home. If he dies, I will stay behind and look after our children. Instead of leaving our children to suffer when we die of HIV." – (Self-declared low risk female)*

There were three women who mentioned that they would divorce their spouses if the men were HIV positive. One mentioned divorcing him because she would not be able to come to terms with him being HIV positive while she was negative. One other mentioned that if she did not divorce him, then she would seek a separation but allow him to seek other women if he so desired. The third mentioned that she would divorce him but care for him if he got critically ill: *"If the man [is HIV positive], ok, I can divorce him and go back to my home then leave getting married. If I happen to see that the man is critically ill…I can go back to nurse him." – (Self-declared low risk female)*

The men were divided along even lines in their response to the HIV situation. Some felt that divorce or separation from the HIV positive partner was the right choice for them. Of these some mentioned that they would still care for the woman although they were divorced or separated, particularly if they had children together. The presence of children in the relationship modified the terms of separation:

"The truth is if I found my wife positive and I negative, the most important thing is that I can't chase her away. I can take good care of her and her children then leave the home. I leave her at home as I am taking good care of her from outside my home." – (Self-declared low risk male)

Among men who mentioned that they would stay with their partner, a lot of them mentioned that it was for the sake of the children. They also planned to use condoms in such a situation. The desire for children also influenced their decisions. One man mentioned that although he would

still stay with his wife and use condoms with her, he would get another woman on the side to have children with:

"I leave her at home as we discussed so she takes care of the children. If I am to get another woman who is HIV negative we test, we go to hospital and test then get counseling on how to protect ourselves. I would be having two wives. The first wife stays in her home. I can't chase her away and I would be using condoms to avoid getting HIV." – (Self-declared low risk male)

Personal beliefs about marriage also influenced people's response to a partner who was found to be HIV positive:

"If the woman is HIV positive, it's not like I have caught her committing adultery. Such things happen where you might get her with another man and you chase her away from your home. But that the disease which has come, I won't know where she got it from but she's infected and I am not." – (Self-declared low risk male)

"Now, according to me if I find my wife infected with HIV and I am negative, I devote myself to taking care of her because we passed through difficulties, good times together and the time we've spent living together as a discordant couple, I wouldn't be knowing how God planned for it. I stay with my wife except I start using condoms." – (Self-declared low risk male)

HIV Testing more common with women than men

Barriers and enablers to testing for HIV were brought out during the discussion. Several participants mentioned that they got tested just to know their status. As a protective measure, some participants ensured that their partners tested for HIV before they started a serious relationship with them. Some women expressed frustration with convincing their male partners to get tested for HIV/AIDS. The availability of ART was not a popular motivator for testing. Testing was more common among the women than the men, particularly because of routine counselling and testing during antenatal services:

"Me I tested with a reason, by then I was expecting. I was like, 'If I am tested positive at least I will save my children by delivering safely from hospital.'" – (Self-declared high risk female)

"…what encouraged me to test is the time when I was pregnant and I fell sick, I decided to go for check-up to find out my HIV status. If I test positive at least my child will be delivered negative, that's what encouraged me to go for HIV testing." – (Self-declared high risk female)

Only two female participants mentioned that they were fearful of getting tested for HIV. In addition to routine testing, experiences with long illnesses or a partner who had contracted HIV/AIDS usually pushed people to get tested:
"What forced me to test…? I saw that I was falling sick so often. I had recurring fever. I was like maybe I have HIV, let me go and test and if I am tested positive, I treat it early before it kills me." – (Self-declared high risk female)

Among men, distrust for their partner, insecurities about their own sexual behaviours and experiences with a partner diagnosed with HIV were enablers for testing. There were several male participants who mentioned that they did not see any need to get tested for HIV. Some were waiting to see signs that they might be sick before getting tested for HIV. Some men also used the HIV status of their partners as a measure for their HIV status:

"Now me, I have never been tested for HIV. Except my wife was expecting and they tested her for HIV. She was found negative. … She was again tested for the second time. She tested negative. By seeing her results, I knew that my HIV status was negative too." – (Self-declared, high risk male)

Recommendations for HIV/AIDS prevention

Participants discussed recommendations to promote HIV/AIDS prevention. They raised the issue of the need to improve knowledge on HIV/AIDS. It was suggested that the government should put more effort into outreaches to the villages for HIV/AIDS education. Making HIV/AIDS a part of the school curriculum was also suggested and in addition, religious groups could also put in more effort to educate their members:

"We have different groups and churches… Let's call it spreading the gospel of HIV. Pastors should take the responsibility of sensitizing their Christians about prevention measures." - (Self-declared low risk male)

Measures to improve access to HIV/AIDS services were also discussed, it was suggested that HIV/AIDS testing and counselling services should be brought within easy access of the villages. Rwimi has forty villages which are served by one major health centre. Some of the villages are located in the mountains and access to the health centre can be challenging, particularly during the rainy season. Thus participants suggested counselling and testing services should be brought within easy access of the villages. Worship centres were suggested as a good site for counselling and testing services:

"They [the government] should extend HIV sensitization to worship centers." – (Self-declared high risk male)

One participant mentioned that he found such discussions as they had had in the focus group discussion helpful in encouraging people to get tested:

"…what I want the government to [do] …send help in villages by bringing sensitization programs in the community as how you have called us here. This will encourage people who don't want to test for HIV to do so. I personally now, the time I have spent in this discussion; I feel I have the courage to test for HIV, I no longer fear to be tested." – (Self-declared high risk male)

Male participants also suggested some strategies to encourage people, particularly other males, to get tested for HIV. In the past the Rwimi Health Centre III tried to get women to bring their partners along with them for HIV testing when they came for antenatal services but it is no longer being practiced. The participants felt that it should be a prerequisite for men to also get tested along with their pregnant partners during antenatal services:

"To help us the men too, it should be a law for us to test for HIV. Expectant mothers should be tested together with their husbands. That policy might help men to test."– (Self-declared low risk male)

It was also suggested that trickery be used to get men to go for HIV testing:

"If they use that system disguising HIV as Bilharzia very many people would test for HIV in the village. Since most people fear testing for HIV, if you tell them they're being tested for another disease, they'll accept. In case they are positive, you give them drugs, by the time they realize that those drugs are for HIV, it would be too late" – (Self-declared high risk male)

Discussion

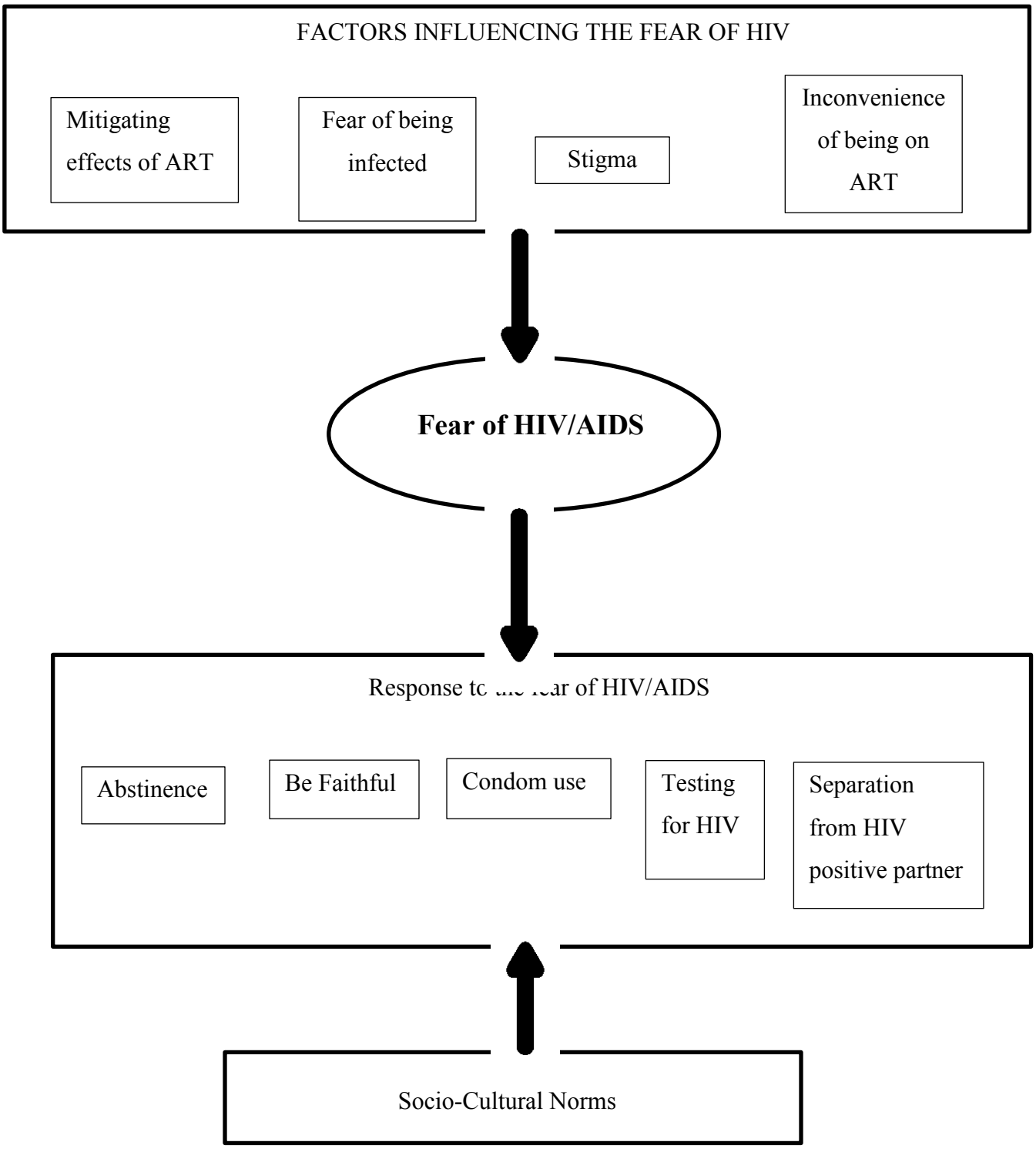

Figure 5.1: Theoretical Framework for Fear of HIV/AIDS in the era of ART in Rwimi

Factors influencing the fear of HIV/AIDS in the era of ART

Our main interest was in the mitigating effects of ART on the fear of HIV/AIDS. Consistent use of ART has been shown to improve health and prolong the life of HIV positive persons. As a result, susceptibility to optimistic diseases and painful early death can potentially be reduced because of the availability of treatment. A study by Green et al. [55] found that participants believed that "Ugandans now seem less afraid of becoming infected with HIV, at least in part because ART is available." They further suggested that the diminished fear could have a disinhibiting effect on sexual behaviour. In our study, the majority of participants expressed that their fear of HIV/AIDS had reduced to some extent because of the availability of ART. However, we realized that there were various factors beyond ART that shaped how fearful participants were of the disease and how they responded to this fear (Figure 1). Understanding these factors give us a clearer context to how participants perceived fear and the extent to which the fear was reduced.

Though participants felt that ART had reduced their fear, there were other factors that led them to continue to fear HIV infection. One of these was a concern that the availability of ART would lead to an increased spread of HIV. ART would increase life spans, and thus increase prevalence, which would increase the pool of HIV positive persons from whom one could potentially contract the disease from. Such persons would also look healthy and would not show signs of the opportunistic infections and debilitating effects of the disease which would normally deter people from considering them as sexual partners. Other studies have indicated a similar concern among participants that enhanced access to ART would increase risky sexual behaviour and HIV transmission, particularly because ART would make it difficult to differentiate between HIV-positive and HIV negative persons [55, 56].

Another factor emerging from the focus group discussions was the fear participants had of the stigma associated with being HIV positive. They felt that this may deter people living with HIV from disclosing their status to potential sexual partners. The 2013 Ugandan stigma index reported experiences of both external and internal stigma [9]. Of the participants surveyed, the forms of external stigma reported were gossip (60.5%), verbal harassment (35.9%) and sexual rejection (21.5%). The forms of internal stigma commonly experienced included self-blame (36.8.5), low self-esteem (35.4%), shame (30.6%), guilt (28.8%) and blaming others (25.2%).

Thus, the worry of the stigma associated with being HIV positive made people still fearful of the disease.

A third factor contributing to the fear of HIV was the inconvenience of being on ART. The requirements of taking ART for life, the consequences of inconsistency in taking the drugs and the nutritional demands required for persons on ART was a stress people did not want to deal with. According to literature, missing doses of ART increases the risk that the drugs will stop working [57]. Additionally there are some side effects to ART that tend to worsen over time such as lipodystropy (fat redistribution) and neuropathy (nerve damage) [57].

In sum, the fear of the immediate clinical debilitating effects of HIV/AIDS had reduced for most people however the overall unpleasantness of the disease condition and the associated social consequences made people still fearful of contracting HIV/AIDS. Some studies have shown that in the 1990s, when Ugandans were made to fear HIV/AIDS and feel personally at risk of dying from the disease, it resulted in crucial behaviour changes such as promoting fidelity and discouraging multiple and concurrent sexual partnerships [54, 55]. Thus a sense of fear of HIV/AIDS as shown among our participants would suggest a conscientious effort on their part to engage in behaviours and practices that reduce the risk of contracting the disease.

Socio-cultural norms and the response to the fear of HIV

Our study explored the prevention practices of participants in order to better understand how fear manifested itself in prevention behaviours. We also examined the factors that influenced these behaviours. The participants focused on five main prevention practices – abstinence, being faithful to the partner, using condoms, being tested for HIV and separating from an HIV-positive partner. I discovered that these practices were governed by fear, but highly influenced by policies and certain socio-cultural norms such as gender expectations, expectations of trust, and family responsibilities.

Amongst women, the routine counselling and testing policy at antenatal services made it a norm for pregnant women to test for HIV to prevent mother-to-child HIV transmission [50]. The majority of the female participants expressed that they had tested because they were pregnant. Although the policy was not directly associated with the individual's fear of HIV, it still formed

part of the norms that influenced response to the fear of HIV, especially for pregnant women who were unsure of the extra-marital practices of their partners.

The study showed that trust in relationships had a big influence on condom use. Trust in marriage seemed obligatory and couples were therefore not expected to use condoms. However, this could lead to underuse of condoms for HIV infection and an increased potential for the spread of HIV in cases of undisclosed infidelity. The unfaithful partner could easily infect their spouse if they had contracted HIV from another source. Prevention practices were also complicated by the fear of the social stigma associated with disclosing one's HIV positive status and the fear of destabilizing the family unit which was expressed by participants in the study. Some research has shown that HIV-infected men found it more difficult than HIV-infected women to disclose their status directly to their partners and they preferred to use a mediator in such situations [59]. A similar sentiment of unwillingness to disrupt the family harmony even in an atmosphere of mistrust between the couple was expressed by participants in the study by Larsson et al. [50].

Gender perceptions on roles and expectations in the relationship backed by the power structure of marriages also influenced prevention practices. In the study by Larsson et al. [50], it was expressed that, "men's portrayed tendency to deceive their wives was supported by the power structure of marriages in which men are decision-makers and have the power over their wives' actions." The 2011 Ugandan AIDS Indicator Survey showed that the proportion of men (15-49 years) who had two or more sexual partners in the past 12 months was more than six times higher than the proportion of women with two or more sexual partners (19% versus 3%). For most of the families in the rural community of Rwimi, men were the breadwinners therefore women tended to depend on them whether or not they were faithful. Our study showed that while some men perceived their unfaithfulness in relationship as part of their natural male inclination, women on the other hand perceived abstinence and faithfulness as a normal expectation of themselves. Women were therefore compelled to remain with men who were unfaithful because of the security offered by the marriage – financial, social, emotional, physical, et cetera as well as because of the children in the marriage.

I found that the response to the fear of HIV/AIDS in the era of ART did not lead to people deliberately pursuing prevention practices. Rather, people continued to engage in practices and

behaviours that seem normal or logical to them and were consistent with socio-cultural norms in their society. On a theoretical level, this study supports previous research that has pointed out how socio-cultural norms can constitute barriers to behaviours that promote health [58]. Social structures, cultural norms and gender-influenced perspectives stand in complex relationships to one another and influence health outcomes for men and women differently [55]. Thus, in addition to the suggestions by participants for improved knowledge on HIV/AIDS and enhanced access to associated HIV/AIDS services, I recommend that the socio-cultural determinants of health such as gender-based perceptions, relationship dynamics such as power structure and trust, and socio-economic factors be taken into account in designing HIV-related public health programs.

Conclusion

People in Rwimi are still fearful of contracting HIV/AIDS although the fear the disease is slightly reduced for some because of the availability of ART. However the response to the fear in terms of the mode of prevention practices being used is influenced by some socio-cultural factors. Considering these socio-cultural determinants of health such as gender-based perceptions; relationship dynamics such as power structure and trust; and socio-economic factors in designing sustainable programs that encourage adherence to prevention practices will go a long way toward curbing the incidences of new cases while improving the health outcomes of people already living with HIV/AIDS.

Chapter 6: General Discussion & Conclusions

Discussion

The overall purpose of this study was to assess whether the fear of contracting HIV/AIDS had reduced in the era of ART and to describe the culture of HIV/AIDS prevention among the general population in Rwimi sub-county, Kabarole District, Western Uganda. We used both quantitative and qualitative methods to answer the research question. The results from our quantitative study showed in Rwimi, the fear of contracting HIV/AIDS still persists, although participants perceived other people as being less fearful of the disease because of the availability of ART. On a personal level, most of the participants were still fearful of HIV/AIDS even though they knew that ART was available. This matched the overall expression of being scared of contracting HIV/AIDS which was answered by all participants. Thus, although ART is available, the fear of HIV/AIDS persists for most people. The multiple logistic regression model on personal fear of HIV/AIDS with the availability of ART had some statistically significant outcomes. The results showed that participants who had at least a secondary level education had a lower odds of reporting a personal reduced fear. Lower education levels are associated with misconceptions about ART [25] and education level influences decisions to use HIV prevention methods such as condom [52, 53]. Thus, the participants with a higher level of education were probably better informed about the HIV/AIDS and ART and hence less likely to experience a disinhibiting effect of the availability of ART and so their fear still persisted. The results also showed that participants who were aware of the negative effects of ART had a higher of reporting reduced personal fear of HIV/AIDS with the availability of ART. This was a surprising finding and a ready explanation could not be derived for it. However, it could probably be that those who knew about the side effects of ART probably also knew people on ART and had seen the improved health of these individuals, despite the side effects. Therefore, in considering the bigger picture of HIV/AIDS these participants felt the benefits of ART outweighed its negative effects hence their position of reporting a reduced personal fear of the disease. However, this result did not imply that their fear of the disease was eliminated. Studies from Uganda have shown that in the 1990s, when Ugandans were made to fear HIV/AIDS and feel personally at risk of dying from the disease, it resulted in crucial behaviour changes such as promoting fidelity and discouraging multiple and concurrent sexual partnerships [54,55]. In a qualitative study

exploring the need to reemphasize behaviour change for HIV prevention in Uganda, participants believed that "Ugandans now seem less afraid of becoming infected with HIV, at least in part because ART is available" [55]. The authors also suggested that the diminished fear may be having a disinhibiting effect on sexual behaviour.

Although we did not find other quantitative studies directly assessing whether the fear of HIV/AIDS had reduced in the era of ART, I found some studies conducted in sub-Saharan Africa assessing the knowledge, attitude/beliefs and practices of people living with HIV/AIDS (PLWHA). The majority of these studies found no association between ART use and risky sexual behaviour [6, 11, 12, 20, 21, 26-28, 30-33]. This observation could probably be attributed to effective counselling received by PLWHA from health workers or persons with symptomatic disease experiencing a decline in sexual desire as a result of the adverse effects of ART [11]. These studies suggest that the focus of HIV prevention should not only be on sexual behaviours of people on ART, but also on the effect of ART-related attitudes/beliefs on the sexual behaviour of the general population. Most of the information on ART is directed towards PLWHA, since they would be starting treatment. The rest of the population may not be receiving such direct information and may have to rely on other sources, whose credibility may be unknown. Attitudes and beliefs about ART influence the sexual behaviour of both people living with HIV/AIDS as well as the rest of the population [19]. Wrong beliefs and attitudes towards ARTs may put people at risk of contracting HIV and will subsequently contribute to an increase in HIV/AIDS prevalence in sub-Saharan Africa.

In assessing current prevention practices, our quantitative study showed that participants were knowledgeable about prevention practices. However, I found that there was low use of condoms in the community. A comparison of the prevention practices with a previous study by Aplin [44] conducted in 2009 in the same area, Rwimi, Kabarole District, Uganda, and among a similar population showed an improvement in knowledge and attitudes towards HIV/AIDS between 2009 and 2013. However, there was not much difference in the use of condoms. In both 2009 and 2013, approximately a quarter of the participants reported condom use at last sexual encounter. According to the Ugandan 2011 AIDS Indicator Survey "nearly 3 in 4 women and 80% of men age 15-49 know that HIV can be prevented by using condoms and by limiting

sexual intercourse to one uninfected partner." Yet only 16% of women and 15% of men who had multiple sexual partners in the past 12 months reported using a condom at their last sexual encounter (Uganda Ministry of Health and ICF International. 2012). In addition, the 2013 UNAIDS global report cited Uganda as one of the countries in which recent evidence indicated a significant increase in multiple sexual partners and a decline in condom use [5]. This raises concerns about knowledge translation and practice; as well as perceptions surrounding condom use among the general population. Some studies investigating condom use have shown that the decision to use condoms is influenced by factors such as perception of condoms, infidelity, issues of trust/mistrust in the relationship and level of education [52, 53].

Our qualitative study provided some context to the fear of HIV/AIDS in Rwimi. We realized that there were various factors beyond ART that shaped how fearful participants were of the disease and how they responded to this fear (Figure 1). Understanding these factors give us a clearer context to how participants perceived fear and the extent to which the fear was reduced. One of the factors was the concern that the availability of ART would lead to an increased spread of HIV. This contributed to the sense of increased personal risk of the disease for participants. Other studies have indicated a similar concern among participants that enhanced access to ART would increase risky sexual behaviour and HIV transmission, particularly because ART would make it difficult to differentiate between HIV-positive and HIV negative persons [55, 56]. Another factor emerging from the focus group discussions was the fear participants had of the stigma associated with being HIV positive. They felt that this may deter people living with HIV from disclosing their status to potential sexual partners. Thus, the worry of the stigma associated with being HIV positive made people still fearful of the disease. A third factor contributing to the fear of HIV was the inconvenience of being on ART. The requirements of taking ART for life, the consequences of inconsistency in taking the drugs and the nutritional demands required for persons on ART was a stress people did not want to deal with. According to literature, missing doses of ART increases the risk that the drugs will stop working [57]. Additionally there are some side effects to ART that tend to worsen over time such as lipodystropy (fat redistribution) and neuropathy (nerve damage) [57]. In sum, the fear of contracting HIV/AIDS has reduced because of the relief offered by ART; however, the fear of living with a chronic and infectious disease that reduces quality of life and increases the risk of dying still persists.

The qualitative study results also provided context to the culture of HIV prevention in Rwimi. In the FGDs the participants focused on five main prevention practices – abstinence, being faithful to the partner, using condoms, being tested for HIV and separating from an HIV-positive partner. I discovered that these practices were governed by fear, but highly influenced by policies and certain socio-cultural norms such as gender expectations, expectations of trust, and family responsibilities. Overall, I found that the response to the fear of HIV in the era of ART did not lead to people deliberately pursuing prevention practices. Rather, people continued to engage in practices and behaviours that seem normal or logical to them and were consistent with socio-cultural norms in their society.

The results of this study add to the limited studies available that assess trends in knowledge, attitude and behaviour among the general population in the era of ART. It also sheds light on the influence of ART on attitudes and prevention practices. Such information is imperative to planning sustainable programs to encourage adherence to HIV/AIDS prevention practices, particularly in high prevalence areas. The use of both a quantitative study and a qualitative study to answer our research question was a strength of our study. It enabled us to provide context, meaning and interpretation to our quantitative findings and thus, a clearer picture of the fear of HIV/AIDS and culture of prevention in Rwimi. Limitations of our study include the possibility of social desirability bias in some participants' responses. The later addition of the question on reduced personal fear could have potentially introduced bias if the missing respondents were demographically different from the other respondents. Additionally, the non-exclusion of HIV positive persons may have introduced some response bias in the study from likely HIV positive persons who participated. The under-representation of males and unknown number of participants who may have declined to participate in the study may also have potentially introduced some selection bias. As indicated earlier, the power of the study for both multiple logistic regression models was low. The cross-sectional study design of the quantitative did not allow for assessments on changes in sexual practices over time with the availability of ART. Although this study does not provide definitive evidence that reduced fear of HIV/AIDS with the availability of ART is associated with risky sexual behaviour, the findings support the need for further longitudinal research.

Conclusion

The fear of contracting HIV/AIDS still persists, although participants perceived other people as being less fearful of the disease because of the availability of ART. Additionally, although the community is considerably knowledgeable about HIV/AIDS and the fear of HIV is still present, condom use as a prevention practice remains surprisingly low. The response to the fear of HIV/AIDS in terms of the mode of prevention practices being used is influenced by some socio-cultural factors. Considering these socio-cultural determinants of health such as gender-based perceptions; relationship dynamics such as power structure and trust; and socio-economic factors in designing sustainable programs that encourage adherence to prevention practices will go a long way toward curbing the incidences of new cases while improving the health outcomes of people already living with HIV/AIDS.

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Appendices

Appendix 1: Consolidated information letter and consent form (English)

Makerere University
School of Public Health

UNIVERSITY OF ALBERTA

Consent form for Individual Interview

Title of Research Study: Knowledge and Attitudes towards Prevention of HIV/AIDS and Associated Current Practices in the Era of Antiretroviral Therapy (ART): A Community based Cross-sectional Study in Kabarole District, Uganda.

Principal Investigator: Nicole Naadu Lartey, University of Alberta, Canada (lartey@ualberta.ca)

Supervisor Dr. L. Duncan Saunders, University of Alberta, Canada (duncan.saunders@ualberta.ca)

Uganda Researcher: Professor Joseph Konde-Lule, Makerere University, Tel: 0772-418451

Local Project Manager: Mr. Tom Rubaale, Fort Portal, Uganda, Tel: 0777-912866

Makerere University School of Public Health IRB Chair: Dr John Ssempebwa, Tel 0794-944404

Study Purpose: The purpose of this study is to evaluate knowledge, attitudes and prevention practices around HIV/AIDS in rural Uganda in the era of antiretroviral treatment (ART) availability. We hope that the findings will help in strengthening public health campaigns on HIV/AIDS.

Procedure: If you decide to participate, a trained interviewer will ask you a series of questions regarding HIV/AIDS. This will take about 30-40 minutes and will be conducted in Rutooro. 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 asked to take part in a group discussion about 8 weeks after your interview. You can choose to participate in today's interview but decline to participate in the group discussion.

Benefits: There are no direct benefits from participating in this study. However, your answers can help in strengthening public health campaigns on HIV/AIDS.

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: To make sure your answers are kept confidential, we will:

1. Ensure that your name will not be shared by us at any time, to anyone.
2. The research team will be required to sign a document stating that they will keep all information confidential.
3. Any reports published as a result of this study will not identify anyone by name.
4. The information provided, including the audio recordings, will be kept in a safe place for at least five years after the study is done. It will be kept in a locked cabinet in the offices of Mr. Tom Rubaale in Fort Portal.

Freedom to withdraw: You do not have to participate in this study if you do not wish to. You can withdraw from the study at any time.

Contact: If you have any questions or concerns, you may contact Professor Joseph Konde-Lule at Makerere University at telephone 0414-545002 or Tom Rubaale, Project Manager in Fort Portal at 0777-912866. Concerns or questions about participant rights regarding this study can be forwarded to theMakerere University School of Public Health IRB Chair: Dr John Ssempebwa, Tel 0794-944404.

To be completed by the research participant:	**Yes**	**No**
Do you understand that you have been asked to be in a research study?	☐	☐
Was the study explained to you directly or through a document that you could read?	☐	☐
Do you understand the benefits and risks involved in taking part in this research study?	☐	☐
Have you had an opportunity to ask questions and discuss this study?	☐	☐
Do you understand that you are free to withdraw from the study at any time without having to give a reason?	☐	☐
Has the issue of confidentiality been explained to you?	☐	☐
Who explained this study to you? _____		

I agree to take part in this study: YES ☐ NO ☐

Signature (or thumbprint) of Research Participant:

_____

Printed Name of Participant:

_____

Date:_____

Signature (or thumbprint) of Witness (if available):

_____

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

Signature of Investigator or Designee: _____ Date: _____

A COPY OF THIS DOCUMENT IS TO BE GIVEN TO THE RESEARCH SUBJECT

Appendix 2: Consolidated information letter and consent form (English)

Makerere University
School of Public Health

UNIVERSITY OF ALBERTA

Consent Form for Focus Group Discussion

Title of Research Study: Knowledge and Attitudes towards Prevention of HIV/AIDS and Associated Current Practices in the Era of Antiretroviral Therapy (ART): A Community based Cross-sectional Study in Kabarole District, Uganda.

Principal Investigator: Nicole Naadu Lartey, University of Alberta, Canada (lartey@ualberta.ca)

Supervisor Dr. L. Duncan Saunders, University of Alberta, Canada (duncan.saunders@ualberta.ca)

Uganda Researcher: Professor Joseph Konde-Lule, Makerere University. Tel: 0772-418451

Local Project Manager: Mr. Tom Rubaale, Fort Portal, Uganda. Tel: 0777-912866

Makerere University School of Public Health IRB Chair: Dr John Ssempebwa, Tel 0794-944404

Study Purpose: The purpose of this study is to evaluate knowledge, attitudes and prevention practices around HIV/AIDS in rural Uganda in the era of antiretroviral treatment (ART) availability. We hope that the findings will help in strengthening public health campaigns on HIV/AIDS.

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 prevention of HIV, your perspectives on ART availability and use, and perceived barriers to HIV prevention. The discussion will last about 45 to 90 minutes and will take place in a convenient location at the

Rwimi Health Centre III. The discussion will be conducted in Rutooro and will be audio taped. If you do not wish to participate, please inform the interviewer.

Benefits: There are no direct benefits from participating in this study. However, your answers may help in strengthening public health campaigns on HIV/AIDS.

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: To make sure your answers are kept confidential, we will:

1. Ensure that your name will not be shared by us at any time, to anyone.
2. The research team will be required to sign a document stating that they will keep all information confidential.
3. Any reports published as a result of this study will not identify anyone by name.
4. The information provided, including the audio recordings, will be kept in a safe place for at least five years after the study is done. It will be kept in a locked cabinet in the offices of Mr. Tom Rubaale in Fort Portal.

Freedom to withdraw: You do not have to participate in this study if you do not wish to. You can withdraw from the study at any time.

Contact: If you have any questions or concerns, you may contact Professor Joseph Konde-Lule at Makerere University at telephone 0414-545002 or Tom Rubaale, Project Manager in Fort Portal at 0777-912866. Concerns or questions about participant rights regarding this study can be forwarded to the Makerere University School of Public Health IRB Chair: Dr John Ssempebwa, Tel 0794-944404.

To be completed by the research participant:	**Yes**	**No**
Do you understand that you have been asked to be in a research study?	☐	☐
Was the study explained to you directly or through a document that you could read?	☐	☐

Do you understand the benefits and risks involved in taking part in this research study?	☐	☐
Have you had an opportunity to ask questions and discuss this study?	☐	☐
Do you understand that you are free to withdraw from the study at any time without having to give a reason?	☐	☐
Has the issue of confidentiality been explained to you?	☐	☐
Who explained this study to you? _____		

I agree to take part in this study: YES ☐ NO ☐

Signature (or thumbprint) of Research Participant:

_____

Printed Name of Participant:

_____

Date: _____

Signature (or thumbprint) of Witness (if available):

_____

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

Signature of Investigator or Designee: _____ Date: _____

A COPY OF THIS DOCUMENT IS TO BE GIVEN TO THE RESEARCH SUBJECT

Appendix 3: Confidentiality Agreement

RESEARCH ASSISTANT CONFIDENTIALITY AGREEMENT

COMMUNITY BASED ARV PROJECT

KABAROLE DISTRICT, UGANDA

In consideration of my employment to work on the Community-Based ARV Project:

1. I agree to keep all information concerning the project, including all information collected by me for this project confidential.

2. I will collect, access, use, destroy or disclose confidential information only within the scope of my official position and normal responsibilities.

3. I will not remove any confidential information from the designated project offices without permission from my supervisor.

4. I will not create any false record as part of my duties under the project.

5. At the end of my employment, I will continue to treat all information of the project as confidential and I will immediately return all documents and/or materials belonging to the project.

I understand that failing to comply with the above requirements may result in disciplinary action including loss privileges, or termination of my employment.

I acknowledge that the terms of this Confidentiality Agreement will survive the expiry of my employment with the project, and that the project reserves the right to seek prosecution of an individual committing an infraction of the terms of this Agreement, regardless of the individual's present status of employment.

Signed: _____ Date: _____

Name: _____

(First, & Last Name)

For Project Manager:

Appendix 4: General Population Survey

Participant ID: ……

KNOWLEDGE, ATTITUDES AND PRACTICES SURVEY

DATE: …….

DIVISION/SUB-COUNTY: …….....

PARISH: ……

VILLAGE/ZONE/LC1: …….

INTERVIEWER'S NAME: ……..

COMPLETION TIME: START TIME ……... END TIME: …….

A. HOUSEHOLD MEMBERS FORM

Now we would like some information about the people (18-49yrs) who usually live in your household or who are staying with you.

NO.	INITIALS OF PERSON	SEX	RESIDENCE	AGE	OCCUPATIO N	ELIGIBILIT Y
	Please give the initials of the persons (18-49yrs) who	Is [INITIA LS] male or	Does [INITIALS] usually live here?	How old is [INITIAL S]? (age in	What is the primary occupation of [INITIALS]?	Circle line number if [INITIALS] is aged 18-49

	usually live in your household	female?				years at last birthday)		and is currently present in the house
	A	B		C		D	E	F
01.		M	F	YES	NO			01
02.		1	2	1	2			02
03.		1	2	1	2			03
04.		1	2	1	2			04
05.		1	2	1	2			05
06.		1	2	1	2			06
07.		1	2	1	2			07
08.		1	2	1	2			08
09.		1	2	1	2			09
10.		1	2	1	2			10

DEMOGRAPHICS

No.	Questions and Filters	Coding Categories	Comments
1	Sex	• Male …….. • Female……	

2	How old are you? When were you born?	_____ ..... / ……. / …… DD / MM / YYYY	
3	Marital Status	• Married: • (Cohabiting) Living with a partner……. • Single…… • Divorced……..... • Widow/Widower….....	
4	If married, are you living with your partner?	• No • Yes	
5	What is your religious affiliation?	• Catholic..... • Protestant..... • Muslim..... • Other..... *Specify* _____	
6	What is your occupation?	……..	
7	What else do you do for		

	income?	……..	
8	Have you ever attended school?	• Yes…… • No……	If no, go to Q10
9	What is your highest level of education?	……..	

KNOWLEDGE ON HIV/AIDS AND PREVENTION

No.	**Questions and Filters**	**Coding Categories**	**Comments**
10	What happens to someone who contracts HIV/AIDS?	…….. …….. …….	
11	How does HIV/AIDS spread from one person	……..	

	to the other?	…….. ……	
12	What can one do to avoid getting HIV? (Probe)	…….. …….. ……	

ARV KNOWLEDGE

No.	Questions and Filters	Coding Categories	Comments
13	Have you heard about ARVs (antiretrovirals)?	• Yes..... • No.....	If no, go to Q26
14	What are ARVs used for?	……..	

		…… …….	
15	Can ARVs restore a person to how they were before they had HIV? (i.e. be able to work? Look healthy?)	…….. ……. ……..	
16	How long should a person be on ARVs?	……..	
17	Are you aware of any negative effects of ARVs on those who take them?	• No……. • Yes……	If no, go to Q19
18	If yes, what are they?	……... ……... ……...	

19	Do you know anyone who takes these drugs (Antiretrovirals)?	• Yes..... • No.....	
20	Do you know where people can get drugs to treat HIV /AIDS (Antiretrovirals)?	• Yes..... • No.....	If no, go to Q22
21	If yes, where can they be obtained?	…….. …… ……	
22	Where did you get this knowledge on ARVs from?	……	

HIV/AIDS-Related Attitudes

No.	Questions and Filters	Coding Categories	Comments
23	Do you think the availability of ARVs has reduced the fear of	• Yes…… • No…….	

	HIV?		
24	If yes, why do you think so?	…… …… ……	
25	If no, why not?	…… …… ……	
26	Would you want to be informed, if your partner were HIV positive?	• Yes…….. • No……	
27	If yes, why?	…… ……	

		…….	
28	If no, why not?	…… …… …….	
29	Would your sexual practices change if you found out your partner was HIV positive?	• Yes…….. • No……	
30	If yes, how and why?	…… …… ……	
31	If no, why not?	……	

		…… ……	
32	If you were HIV positive, would you tell your partner?	• Yes…… • No…….	
33	If yes, why?	…… …… ……	
34	If no, why not?	…… …… ……	
35	Are you scared of getting HIV?	• Yes…….. • No……	

36	If yes, why?	…… …… ……	
37	If no, why not?	…… …… ……	
38	Do you think you are at risk of getting HIV?	• Yes……. • No……..	
39	If yes, what makes you think so?	…… …… ……	

40	If no, what makes you think so?	…… …… ……	
41	Are you less fearful of contracting HIV now that ARV is available?	• Yes……. • No……..	
42	If yes, why?	…… …… ……	
43	If no, why not?	…… …… ……	

PREVENTION PRACTICES

No.	Questions and	Coding Categories	Comments

	Filters		
41	Have you ever been tested for HIV?	• Yes…… • No…….	
42	If yes, why?	…… …… ……	
43	If no, why not?	…… …… ……	
44	Do you know your HIV status?	• Yes..... • No.....	
45	Have you been sexually active in the past 6 months?	• Yes..... • No.....	If no, go to end
46	What have you been doing to protect		

	yourself from getting HIV/AIDS?	…… …… ……	
47	Did you use a condom the last time you had sexual intercourse?	• Yes..... • No..... • Refuse to answer.....	
48	If yes, why?	…… …… ……	
49	If no, why not?	…… …… ……	
50	Did you ever want to use a condom but did not use it?	• Yes…….. • No……...	

		• Refuse to answer……..	
51	If yes, why?	…… …… ……	

Thank you very much for your time. We may get in touch with you later.

Appendix 5: Guiding Questions for Qualitative Study

ARVs - Beliefs, Effectiveness

I would like to start by asking you what you know about ARVs:

- Who knows about ARVs?
- Could you tell us what ARVs do?
- **Based on what you've probably seen or heard, how successful or effective are they in doing what they are supposed to do? Can you explain your answer?**
- **Do you think there are problems with the ARVs? What about negative side effects of ARVs? How about problems because people have to take these for life? How big a problem are these issues? Can you describe these problems to me?**

Availability of ARVs and Fear /Risk of contracting HIV

Let's move on to discussing what you think about the fear of contracting HIV now that ARVs are available:

- Now that ARVs are available, do you fear getting infected with HIV or infecting others with HIV? Please explain.
- **Is your fear of getting HIV/AIDS the same or less than it was before ARVs were available? What makes you more/less fearful?**
- Are there concerns about ARVs running out when people need them (stock-outs)?

Perceived barriers to HIV/AIDS prevention

I'd like to now talk about changes in attitudes and behaviours as a result of ARV treatment being available:

- Have you tested for HIV?
- **Did the availability of treatment for HIV (ARVs) influence your decision to get tested or are you more willing to test for HIV because of ARVs? Why or why not?**
- Before ARVs were available were you doing anything to protect yourself from HIV? If yes, what were you doing?
- Now that ARVs are available has it changed your practices towards prevention of HIV in anyway? How? Or why not?

Recommendations

Finally, I would like to ask you how the government/district can improve on prevention practices:

- Do you think that more needs to be done to raise awareness of prevention of HIV in Rwimi?
    - What types of things do you think need to be done? How effective do you think these things will be?

Appendix 6: Table A: Comparison of Knowledge, Attitudes and HIV/AIDS-prevention practices in 2009 and 2013 among 18 to 49 year old residents of Rwimi, Kabarole District, Uganda.

	2009 † (n=405)	2013 (n=639)
Variable	**%***	**%***
Have you ever been tested for HIV? (Yes)	47.7	83.1
Men ††	30.0	71.7
Women †††	67.0	88.8
Have you heard about ART? (Yes)	93.6	100.0
Do you know where to get ART? (Yes)	72.6	97.9
How long should a person take ART? (Lifetime)	49.0	91.6
Did you use a condom the last time you had sexual intercourse? (Yes)	22.5	25.3
Did you ever want to use a condom but did not use it? (Yes)	16.5	7.4

*Results weighted for cluster sampling design

† Aplin [44]

† † Percentage of men who tested out of all male participants

† † Percentage of women who tested out of all female participants