University of Alberta

TB, HIV, and TB/HIV co-infection: Community Knowledge and Stigma in Western Uganda

by

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Abstract

The threat of Tuberculosis(TB) cannot be considered in isolation from the HIV/AIDS epidemic. This study assessed knowledge and stigma surrounding TB and HIV co-infection in Kabarole district, Uganda. This cross-sectional mixed methods study used a multi stage survey design (n=360) and focus groups discussions.

Mean knowledge scores were 58% for HIV, 33% for TB and 48% for TB/HIV. Percentage classified as having high stigma were 26% for HIV, 47% for TB, and 21% for co-infection. Education predicted higher HIV knowledge, co-infection knowledge, and lower TB stigma. TB knowledge was predicted by rural residence, and age ≥45years. Those who had an HIV+ friend had lower HIV stigma. Respondents believed that TB was transmitted by sharing cups, smoking, and that TB was not curable. Fear of TB is driven by the assumption that "TB means HIV".

TB knowledge is low and stigma is high, TB awareness campaigns should be a priority.

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List of abbreviations

ABC	Abstinace, Be faithful, Condoms (HIV prevention strategy\0
AIDS	Acquired Immune deficiency syndrome
ART	antiretroviral therapy
ARVs	antiretrovirals
CI	Confidence interval
DOTS	directly observed therapy, short course
GTZ	German development corporation
HIV	Human immunodeficiency virus
MDR	Multi drug resistant
OR	Odds ratio
PLWHA	People living with HIV/AIDS
SD	Standard deviation
TB	tuberculosis
WHO	World Health Organisation

Chapter 1: Introduction

Background

In 2010, there were 8.8 million new tuberculosis (TB) cases and 1.4 million deaths from TB worldwide. In Africa, 44% of TB patients were infected with the Human Immunodeficiency virus HIV (1). HIV infection is a significant risk factor for TB for several reasons: HIV infection increases the risk of reactivation of latent TB infection; the yearly risk of reactivation in co-infected individuals can exceed 10%, whereas the lifetime risk in non-HIV infected individuals is 10-20%, and re-infection after cure is also common (2, 3). In addition, HIV infection also increases the risk of rapid TB progression and death following primary infection or reactivation (4). Diagnosis of TB in HIV patients is complicated since HIV patients are more likely to present with non-typical and extra-pulmonary TB (5). Despite all this, TB is both treatable and preventable in HIV positive individuals.

According to the most recent national survey, Uganda had an HIV prevalence of 6% in 2004 in the general population, a significant decline since the peak of the epidemic in the early 1990s (6). This rapid decline is attributed to effective prevention messaging and political commitment. As a result, knowledge about HIV has been shown to be relatively high in Uganda which has facilitated recent roll out of antiretroviral therapy (ART)(7).

Although TB control has been slowly improving in Uganda in recent years, TB still constitutes a major challenge (1). In 2010, TB incidence in Uganda was estimated at 209/100 000 population per year, or 70 000 new TB cases. 54% of new TB cases (with known HIV status) were in HIV positive individuals. TB prevalence is estimated at 193/100 000 (1). Mortality rates (in 2007) from TB are high at 93/100 000. The mortality proportion attributable to TB/HIV co-infection is even more. Out of 29 000 deaths per year from TB, 55% are in HIV positive individuals (8). While this biological and epidemiological interconnectedness of TB and HIV has been increasingly taken into account in health systems and disease control programs, very little discussion has focused on the community perceptions of TB and HIV co-infection and the implications of community discourse on TB control (9). Previous work in Kabarole district in western Uganda found the TB system largely non-functional (10). In 2009-2010, , the cure rate (those who had a smear negative result at end of treatment) of reported new smear positive cases was 14.7%, treatment completion rate was 59.9%, and official default rate was 12.2% (11).

HIV and TBs are overarching public health issues both globally and in Uganda. However, in-depth knowledge of how the local people understand the interaction between TB and HIV is currently not available for health care providers in most parts of Uganda. Community knowledge and beliefs about disease and health have significant impact on health seeking behaviour and

treatment outcomes. Perceived knowledge on the causes of TB has been found to influence transmission of the disease, and certain beliefs may result in failure to recognize symptoms and thus delay diagnosis (12). It has also been highlighted that health care workers are often not aware of the knowledge and beliefs of the communities they serve, which can negatively affect health care provision (13). When explanatory models of individuals are conflicting with those of healthcare providers, there is a lack of congruence in beliefs and practices leading to poorer patient adherence to recommendations and management of illness thereby resulting in poorer patient outcomes (14). Perceptions around disease and ill health, not just of patients but of family, friends, and general community members, have been identified as important factors influencing health seeking behaviour (15). Evaluating local knowledge and perceptions relating to TB and HIV infection will allow district health providers to tailor services and health messaging to the specific needs of the patients, and will provide new insights into program planning.

Both people living with HIV/AIDS and TB are severely stigmatised. HIV stigma arises from its association with socially unacceptable sexual behaviour (16). Stigma prevents the delivery of effective social and medical care (including treatment), in addition to increasing the number of HIV infections through ongoing transmission (16). People are less likely to be tested for HIV because of stigmatisation and therefore the effectiveness of testing programs are reduced. For example, in KwaZulu-Natal, South Africa, stigma was identified as the primary cause of poor uptake of voluntary HIV counselling and testing (17). Stigma also reduces the likelihood that individuals will seek care after diagnosis, and results in the negative treatment of people living with HIV/AIDS by family and community members (16).

The stigma associated with tuberculosis has been recognised as a major global cause of the limitations of the World Health Organisation's directly observed therapy DOTS strategy for TB control (18). The major cause of stigma associated with TB has been identified as the fear of infection; this is also mitigated by the physical frailty of TB patients, perceived causes and spread of TB, commonly held misconceptions, isolation practices within the health care setting, judgement and blaming of TB patients, past experiences with TB, and an association between TB and poverty (19). Stigma contributes to delays in diagnosis and poor treatment adherence, which both negatively impact TB control (20).

The association between HIV and TB may result in a multiplicative effect on stigma. This is in part due to signs and symptoms shared by both diseases such as extreme weight loss, and because of awareness that the two diseases are linked (19). HIV stigma and fears about being labelled as HIV positive may deter TB patients from seeking care because of the belief that someone with TB also has HIV (21). Stigma against TB because of its association with HIV was found to

be a common reason for TB treatment default in KwaZulu-Natal, South Africa (17).

Literature Review

Literature review was completed with the assistance of a health sciences librarian at the University of Alberta. Databases searched included Global Health, Medline, Psychinfo, Web of Science, and Academic search complete. Search headings and title searches used were knowledge level/ knowledge/ health behaviour/ attitudes/ social stigma/ prejudice/ perception/ awareness/ care seeking/ health seeking/ understandings/ conceptualisations. These results were geographically limited using the subject headings Africa south of the sahara/ east Africa/ Africa/ Anglophone Africa/ Uganda. Finally, the search was narrowed to include only articles relating to tuberculosis and HIV or AIDS. Grey literature from the World Health Organisation and the Ugandan Ministry of Health was also included. Two hundred and seventy articles were found. After duplicates (of the same article from different databases) were removed, titles were screened for relevance and abstracts reviewed, 64 relevant articles were found, 19 of which related directly to our topic.

Despite the importance of understanding community knowledge, relatively few studies (10 studies to our knowledge) have investigated knowledge of TB and TB/HIV co-infection in Sub-Saharan Africa. A study in Tanzania conducted focus groups to assess knowledge attitudes and practices around TB and treatment. The study found low knowledge of TB, frequent self treatment, and friends and family being the main source of information about TB (12). In a South African community survey, respondents believed that TB was caused by having sex after spontaneous abortion, or caused by environmental pollution, smoking, or drinking. These beliefs influenced presentation to health services and adherence (13). In Eastern Cape Province, South Africa, a mixed methods study found that the most important risk factor for TB was considered to be drinking and smoking. Moral and biomedical understandings of TB risk were intertwined in this community (22). In an Ethiopian survey, exposure to cold air was the main perceived cause of TB and the study found that knowledge of TB was higher in literate individuals (23). A qualitative study in Rwanda found a wide variety of understandings of causes of cough, that cough is mainly treated with herbal medicines, and only very severe symptoms seek medical care. In the study TB was consistently confused with HIV infection by respondents (24). Another qualitative study amongst the Turkana tribe in Kenya found a strong understanding of the conceptual link between TB and HIV. TB and HIV were attributed to the same causes of drinking alcohol and sexual intercourse (25).

There is a wide variety of different understandings around TB and HIV infection in different regions, thus it is critical to have locally relevant

information for health messaging and services. In Uganda, only one study to date has investigated local knowledge about TB. This was a qualitative study in eastern Uganda and found that respondents held multiple TB aetiologies including sharing utensils, heavy labour, smoking, bewitchment, and a belief that TB is inherited. There was also a strong assumption of HIV co-infection in TB patients (26). As it was shown in the South African studies discussed above, there can be a major variation in TB knowledge even within one country. In western Uganda, knowledge about HIV and ART has been found to be remarkably high (7). In a study investigating the role of family support for TB patients in western Uganda, incidental finding was that local knowledge about TB was limited (10). No studies to date have comprehensively evaluated how the local people view and understand the relationship between HIV and TB in western Uganda.

A plethora of studies have been conducted assessing and measuring HIV/AIDS stigma in a variety of contexts. A 2009 literature review discussed 65 papers on HIV stigma in Sub-Saharan Africa and found that HIV stigma continues to be highly present and rooted in local beliefs, religion, and gender. This review recommended more qualitative studies in Sub-Saharan Africa to better understand the social constructs of HIV stigma (16). A systematic review of the literature on TB stigma found that fear of infection is the most common cause of TB stigma, and that TB stigma has serious socioeconomic consequences, increases TB diagnostic delay and treatment non-compliance. This review found that qualitative methods were commonly used to investigate TB stigma and recommended more quantitative assessments in different populations (27). Another review highlighted the scarcity of quantitative TB stigma assessments and recommended additional studies assessing TB stigma in diverse contexts in order to make stigma a priority in TB care (20). Macq et al. remark on the scarcity of studies assessing TB stigma compared to other health conditions; stigma is the centre of global strategies to fight AIDS but is not present in international TB priorities (20). That said, in settings with a high prevalence of HIV, assessing TB stigma alone will be insufficient- the interaction and combination of the double sigma around TB and HIV must be understood as TB/HIV co-infection stigma. One qualitative study in Zambia explored the interconnectedness of TB and HIV for people and found that visible signs of TB become triggers for TB-HIV stigma. They identified three key causes of TB-HIV stigma: judgement blame and shame; fear of contagion; and public health practices, for example separate waiting areas for TB patients at the clinic (9). No other studies have directly investigated TB/HIV stigma in Sub-Saharan Africa.

Stigma varies greatly from country to country, and it is important for health policy makers to understand the local context. Very little work has been done investigating stigma around TB or TB/HIV co-infection in Uganda. There has been some recent evidence suggests that HIV stigma may be decreasing with the

wider availability of antiretroviral drugs, but that stigma is still significant especially within the health care system (28). TB stigma has not been extensively evaluated in Uganda, but evidence suggests it is high and has a major impact on TB control (10). One study suggested that ineffectiveness of TB control in Uganda may be in part due to the stigma associated with HIV infection (29). (29)

Justification of the problem

HIV and TB are overarching public health issues both globally and in Uganda; however, in-depth knowledge of how the local people understand the interaction between TB and HIV is currently not available for health care providers in most parts of Uganda. This study will help to understand the community's understanding and perceptions of TB/HIV co-infection. The new knowledge will help to understand how the local people conceptualise the relationship between TB and HIV, and how stigma affects decision-making of patients and family members. Evaluating local knowledge, attitudes and perceptions relating to TB and HIV will allow the district health providers to tailor services to the specific needs of the patients, and will provide new insights into program planning and implementation. The results will help in the development of programs aiming to reduce the stigma associated with TB/HIV co-infection. This study has the potential to create improvement in TB and HIV services in western Uganda.

Research Objectives

This study investigated local knowledge, attitudes, and perceptions of the relationship between HIV and TB in western Uganda. The extent of knowledge about co-infection and the interaction between TB and HIV in the general population was assessed. The extent and interaction between HIV stigma and TB stigma was also explored. Findings will help inform district TB and HIV services to the specific needs of the community.

The main research objectives of this study were:

(1) To assess knowledge, attitudes, and perceptions about TB/HIV co-infection amongst the general population in western Uganda;

(2) To identify specific misconceptions and beliefs that may influence utilization of TB and HIV services and adherence to treatment

(3) To examine current levels of TB, HIV, and TB/HIV co-infection stigma and the extent to which HIV stigma may have contributed to a possibly increased stigma towards TB and vice versa

Ethical considerations

This study received ethics approval from the Human Research Ethics Board, Health panel at the University of Alberta. It also received approval from the Makerere School of Public Health Internal Review Board, the Uganda National

Council for Science and Technology, and from the Uganda Office of the President. Informed consent was obtained from all participants.

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 information (age, gender) was utilized in documents. The issue of privacy and confidentiality was discussed with participants when obtaining informed consent. During focus groups, the issue of privacy and confidentiality was also brought up and all participants were asked to keep information discussed private. The information letter for focus group participants reminded them "...In the focus group discussions, complete confidentiality cannot be guaranteed. All participants will be reminded that the names of volunteers and what is discussed are to remain confidential. If there is something you would not like to discuss or have known, please do not feel any pressure to share it with the group..." In addition, all research assistants were required to sign a confidentiality agreement.

Language barriers and illiteracy affecting informed consent: Not all participants were fluent in English; therefore all information and consent forms were available in both Rutooro (the local language) and English. A research assistant fluent in both languages provided information and was available to answer questions. Participants that were illiterate and unable to sign the consent form indicated their consent through a thumbprint.

Coercion: Many study participants lived in poverty, and so in order to minimize the possibility of coercion but still acknowledge the participant's contribution to the study, participants were offered a small thank you gift. They were given a bar of soap (approximately $0.30 value) for their time at the end of the interview without being informed about the gift before deciding to participate.

Setting

The study was conducted in the Republic of Uganda in East Africa. Uganda has a population of 30,900,000 (2005 estimate) with a median age of 15. The western district of Kabarole had a 2002 census population of 359,180 and a population growth rate of 3%; the 2010 population estimate is 455,000. Most people in Kabarole live in rural areas or the one major centre, Fort Portal. The district's economy is mainly agriculture. The main language is Rutoroo and English is taught in schools; the literacy rate is 49% (30). The district health services include 47 health units with 75% of the population being less than 5 kilometres away from a unit (30). The rural district of Kabarole in western Uganda has been chosen as the site for this research because of the long lasting relationship between the University of Alberta's School of Public Health and the district health department in Kabarole. As such, the department has an excellent relationship with the district Health Officers. In addition to a larger scale long

term department wide project ongoing at this site, more than 30 MSc and PhD students from the University of Alberta have successfully completed thesis projects in this area on important health topics such as HIV, family planning, Tuberculosis and others. This international partnership has had a overall positive impact on the health services in the area; the students have investigated key issues identified by the local communities and have generated information used to improve local health services. The existing relationship with the District Health services allows effective dissemination and knowledge transfer of research findings. In this way research can have a direct impact on health services in the district. Stakeholders for this project included the district health services, community members, health care providers, the University of Alberta's School of Public Health, and the researcher. All these parties identified TB/HIV co-infection as a priority and supported this work throughout the research process.

Overview of chapter 2: TB in the era of HIV/AIDS: community knowledge of HIV, TB, and TB/HIV co-infection in western Uganda

Background: Tuberculosis (TB) is treatable regardless of HIV status; however Uganda continues to incur 29,000 TB deaths annually, 55% in HIV positive individuals. The purpose of this study was to assess knowledge about TB and HIV co-infection in the general population in western Uganda and to examine common knowledge gaps and misconceptions.

Methods: We implemented a multi stage survey design to randomly select 360 participants from one district in western Uganda. Weighted summary knowledge scores for TB, HIV and co-infection were calculated and multiple linear regression (with knowledge score as the dependant variable) was used to determine significant predictors. Six focus group discussions were conducted to inform survey findings.

Results: Mean HIV knowledge score was 58% (SD 12%), mean TB knowledge was 33% (SD 15%) and mean TB/HIV knowledge was 48% (SD 20%). Multivariate regression models included age, sex, marital status, education, residence, and having a friend with HIV/TB. Higher education was a significant ($p<0.05$) predictor for HIV knowledge (coefficient=0.9, 95%CI: 0.3-1.6) and for co-infection knowledge (coefficient=8.6, 95%CI: 3.1-14.2). TB knowledge was predicted by rural residence (coefficient=-6.27, 95%CI: -11.7 to -0.8), and age ≥45years (coefficient=7.45, 95%CI (0.3-14.6)).

Focus group participants mentioned various beliefs in the aetiology of TB including sharing cups, alcohol consumption, smoking, air pollution, and HIV. Respondents discussed three different types of TB, and believed that "TB in HIV positive patients" and "inherited TB" were not curable. When asked about symptoms, respondents viewed TB and HIV symptoms as interchangeable.

Conclusion: TB knowledge is low. Priority should be placed on educational messages about the curability of TB regardless of HIV status. We recommend that youth and urban residents be targeted at district level with specific health information related to TB and HIV co-infection.

Overview of chapter 3: HIV, TB, and TB/HIV co-infection: exploring community stigma in western Uganda

Background: The threat of Tuberculosis (TB) in Uganda cannot be considered in isolation from the HIV/AIDS epidemic. Stigma contributes to delays in seeking treatment and poor adherence for both TB and HIV patients. This study aimed to explore stigma about TB and HIV co-infection in order to improve health services and messaging.

Methods: This was a cross-sectional mixed methods study. A survey was administered to 360 individuals, randomly selected from one district in western Uganda. Participants were classified as low/high stigma based on weighted scores built from survey questions. Logistic regression was used to determine significant predictors for high stigma. Six focus groups were conducted to inform survey findings; themes were developed using content analysis.

Results: Percentage classified as having high stigma was 26% for HIV, 47% for TB, and 21% for co-infection. Multivariate logistic regression models included age, sex, marital status, education, residence, and having a friend with HIV/TB. Those who had an HIV+ friend were less likely to have high HIV stigma (OR: 0.41, 95%CI: 0.23-0.72). Those with secondary education or more were half as likely to have high stigma (OR: 0.50, 95% CI: 0.27-0.91).

"Normalisation" of HIV has contributed to reduced HIV stigma, but villagers still report rumours and "finger-pointing" at HIV patients. There is a strong fear of being recognised at the HIV clinic. TB stigma causes patients to remain silent because of TB being associated with carelessness and immoral behaviours (such as drinking and smoking), as well as segregation of them and their families. Fear of TB is driven by the assumption that "TB means HIV".

Conclusion: Declining HIV stigma is encouraging but more effort needs to be made to improve confidentiality at health centres to reduce fear of being recognised as HIV positive at clinics. TB stigma is high and is likely affecting care seeking behaviour; TB awareness campaigns should be a priority. These should emphasise that TB is a disease on its own, separate from HIV infection.

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Chapter 2: TB in the era of HIV/AIDS: community knowledge of HIV, TB, and TB/HIV co-infection in western Uganda

Introduction

In high HIV prevalence settings, tuberculosis (TB) and HIV/AIDS cannot be considered in isolation from each other. TB is the leading cause of death in HIV positive people, and HIV infection is a significant risk factor for TB (1-4). HIV infection increases the risk of rapid TB progression, and complicates diagnosis since HIV patients are more likely to present with non-typical and extra-pulmonary TB (5, 6). Despite all this, TB is treatable in HIV positive individuals.

According to the most recent national survey, Uganda had a national general population HIV prevalence of 6% in 2004 (7), (8). Although TB control has been slowly improving in Uganda in recent years, TB still constitutes a major challenge. In 2010, TB incidence in Uganda was estimated at 209/100 000 population per year. Fifty four percent of new TB cases (with known HIV status) were in HIV positive individuals (9). Mortality rates (in 2007) from TB are high at 93/100 000. In Kabarole district in western Uganda, of reported new smear positive cases, the cure rate (those who had a smear negative result at end of treatment) was 14.7%, treatment completion rate was 59.9%, and default rate was 12.2% (10).

While this biological and epidemiological interconnectedness of TB and HIV has been increasingly taken into account in health systems and disease control programs, very little discussion has focused on the community perceptions of TB and HIV co-infection and the implications of community discourse on TB control (11).

HIV and TB are overarching public health issues both globally and in Uganda. However, in-depth knowledge of how the local people understand the interaction between TB and HIV is currently not available for health care providers in most parts of Uganda. Community knowledge and beliefs about disease and health have significant impact on health seeking behaviour and treatment outcomes. Perceived knowledge on the causes of TB has been found to influence transmission of the disease, and certain beliefs may result in failure to recognize symptoms and thus delay diagnosis (12). It has also been highlighted that health care workers are often not aware of the knowledge and beliefs of the communities they serve, which can negatively affect health care provision (13). When explanatory models of individuals are conflicting with those of healthcare providers, there is a lack of congruence in beliefs and practices leading to poorer patient adherence to recommendations and management of

illness thereby resulting in poorer patient outcomes (14). Perceptions around disease and ill health, not just of patients but of family, friends, and general community members, have been identified as important factors influencing health seeking behaviour (15). Evaluating local knowledge and perceptions relating to TB and HIV infection will allow district health providers to tailor services and health messaging to the specific needs of the patients, and will provide new insights into program planning.

Despite the importance of understanding community knowledge, relatively few studies have investigated knowledge of TB and TB/HIV co-infection in Sub-Saharan Africa. A study in Tanzania conducted focus group discussions to assess knowledge attitudes and practices around TB and treatment. The study found low knowledge of TB, frequent self treatment, and friends and family being the main source of information about TB (12). In a South African community survey, respondents believed that TB was caused by having sex after spontaneous abortion, or caused by environmental pollution, smoking, or drinking. These beliefs influenced presentation to health services and adherence (13). In Eastern Cape Province, South Africa, a mixed methods study found that the most important risk factor for TB was considered to be drinking and smoking. Moral and biomedical understandings of TB risk were intertwined in this community (16). In an Ethiopian survey, exposure to cold air was main perceived cause of TB and the study found that knowledge of TB was higher in literate individuals (17). A qualitative study in Rwanda found a wide variety of understandings of causes of cough, that cough is mainly treated with herbal medicines, and only very severe symptoms seek medical care. In the study TB was consistently confused with HIV infection by respondents (18). Another qualitative study amongst the Turkana tribe in Kenya found a strong understanding of the conceptual link between TB and HIV. TB and HIV were attributed to the same causes of drinking alcohol and sexual intercourse (19).

This overview of the literature highlights the wide variety of different understandings around TB and HIV infection in different regions, thus it is critical to have locally relevant information for health messaging and services. In Uganda, only one study to date has investigated local knowledge about TB. This was a qualitative study in eastern Uganda and found that respondents held multiple TB aetiologies including sharing utensils, heavy labour, smoking, bewitchment, and hereditary transmission. There was also a strong assumption of HIV co-infection in TB patients (20). As we saw in the South African studies discussed above, there can be a major variation in TB knowledge even within country. In western Uganda, knowledge about HIV and ART(Antiretroviral therapy) has been found to be remarkably high (21). In a study investigating the role of family support for TB patients in western Uganda, the incidental finding was that local knowledge about TB was limited (22). No studies to date have

comprehensively evaluated how the local people view and understand the relationship between HIV and TB in western Uganda.

This study explored local knowledge about HIV, TB, and TB/HIV co-infection in western Uganda in a community sample, and aimed to identify specific misconceptions and beliefs that may be influencing utilization of TB and HIV services and adherence to treatment.

Methods

Setting

This study was conducted in the Republic of Uganda in East Africa. Uganda has a population of 30,900,000 (2005 estimate) with a median age of 15 years. The western district of Kabarole had a population estimate of 455 000 in 2010. Most people in Kabarole live in rural areas or the one major centre, Fort Portal. The district's economy is mainly agriculture. The main language is Rutoroo and English is taught in district schools; the literacy rate is 49% (23).

Study design

This was a cross-sectional sequential mixed methods study. The study population was a random sample of the general population of Kabarole district in western Uganda. Inclusion criteria were the ability to speak Rutooro (the local language) or English, and being over 18 years of age. HIV status and history of TB were not asked, therefore this sample neither excludes nor purposefully includes HIV or TB patients. Participants were selected using four levels of sampling. Of 10 sub-counties in Kabarole district (after two were eliminated because of logistic limitations), six sub-counties were randomly selected. In each sub-county, three parishes were randomly selected (number of parishes in each sub-county ranged from three to five). One village was randomly chosen from each parish (total number of villages in each parish ranged from three to 18). Twenty individuals from different households were randomly selected from each village, by four research assistants, starting in the center of the village and proceeding outwards in a four different directions.

Six focus group discussions were conducted. Focus group participants were sampled from three of the six sub-counties (chosen because of availability of meeting facilities). Participants were selected from villages that were not sampled in the survey.

This study received ethical approval from the University of Alberta Human Research Ethics board, Health panel (Canada), the Makerere University School of Public Health's Internal Review Board in (Uganda), and the Uganda National Council for Science and Technology. Participants were given information and a detailed explanation of the study by a trained research

assistant in the local language. Informed consent was provided by signature or thumbprint of the consent form.

Demographic information was gathered about age, gender, employment, education, type of house (concrete vs. mud walled), and marital status. Questionnaire items covered knowledge about HIV transmission, symptoms, prevention, and treatment; TB transmission, symptoms, and treatment; and questions about the association between TB and HIV. The questionnaire was developed in collaboration with local partners to ensure appropriateness and comprehensiveness of the questions in the local context. The questionnaire was translated into the local language and the translation was verified for accuracy by four separate collaborators fluent in both languages. The survey was administered by trained research assistants (fluent in the local language) who interviewed the participants.

The survey tool was pilot tested in two phases. The initial tool was administered to 10 randomly selected individuals from a sub-county not selected for data collection. Some small adjustments were made, and then it was administered to 10 more people to finalize the instrument. Test-retest was completed to ensure reliability of the survey tool. Ten respondents were located one week after completing the survey and asked to participate for a second time. The agreement in responses (for all questions) was 86%.

Focus group topics were developed after most of the surveys had been completed and preliminary data analysis using the first 180 participants had been conducted. Focus group questions aimed to add a richer understanding of key issues, and explore further topics not included in the survey that had emerged during data collection (for example topics that respondents had wanted to discuss and provide information but that were not on the survey). These topics guides were developed in partnership with the four local research assistants conducting the surveys. Six focus group discussions were conducted, three with women only and three with men only. Separating the genders was expected to help the women feel comfortable speaking freely, and designed to facilitate discussion of gender specific themes around the topics. Focus groups were co-facilitated by the principal investigator and a research assistant fluent in the local language. A second research assistant took concurrent notes in English as the discussion progressed. Research assistants were of the same gender as participants for each focus group. Focus group discussions were audio-recorded. Focus group discussions were conducted in a separate quiet area outside of rural clinics (two discussions each at two separate clinics), and in the conference room of the district health department (two discussions). Discussions lasted 40 minutes to one and a half hours.

Focus groups discussions were transcribed and translated. A sample of transcripts was translated by a second translator and the two English versions

compared to ensure accuracy. Transcripts were analyzed inductively using latent content analysis to identify, code, and categorize the primary patterns in the data. Themes were developed from these categories. Results were presented and discussed with key informants during a return trip to the study area to confirm and validate themes.

Rigour of the qualitative portion of this study was ensured through several strategies. A subsample of transcripts was re-coded by the same researcher, and a sub-set were also coded by an independent researcher to ensure inter-rater reliability (agreement in coding tree was established) and to contribute to the trustworthiness of the study. The primary researcher travelled to the study site again in October and November 2011 to present and discuss the results (member checking) with key informants and stakeholders in the district health department of Kabarole. These in depth discussions with local informants contributed to the trustworthiness of the findings.

Quantitative data management and analysis

Survey data was entered into a Microsoft Access database. Ten percent of entered surveys were thoroughly crosschecked, the remainder checked for completeness and out of range values. Open ended questions were coded thematically. Summary scores were developed by weighting and combining multiple questionnaire items as described in Table 2-1. Certain responses that indicated incorrect and potentially detrimental information were assigned negative weights. Summary scores were then standardized on a percentage scale for comparability.

Table 2- 1: Summary Score weights

Summary Score	Questionnaire Item	Response	Response weight
HIV knowledge (possible range: -3 to 17)	How can someone get HIV?	Sex	3
		Blood	2
		Mother to Child transmission	2
		Sharing sharp instruments	1
	Is it possible for a healthy-looking person to have HIV?	Yes	1
		No, unsure	0
	What are the things a person can do to avoid getting HIV?	Abstinence	2
		Be faithful	2
		Condoms	2
		Avoid sharp instruments	1
	Is it possible for HIV to be completely cured?	No	1
		Yes, Unsure	-3
TB knowledge (possible range: -2 to 14)	How can someone get TB?	Airborne	3
		Near patient	1
		Other responses	0
	Is it possible for TB to be completely cured?	Yes	2
		No	0
	If yes, how?	Antibiotic pills	1
		Other	-2
	What are the main symptoms of TB?	Cough	1
		Weight loss	2
		Coughing blood	2
		Fever/ night sweats	2
TB/HIV association (possible range: 0 to 13)	Does having TB mean a person is HIV positive?	Yes, unsure	0
		No	2
	How many TB patients have HIV?	Most, half, some	1
		All, none, unsure	0
	Can TB be cured in someone who has HIV?	Yes	3
		No, unsure	0
	What are the main signs or symptoms of HIV?	TB	1
		Other responses	0
	How can someone get TB?	HIV/AIDS	1
		Other responses	0
	Are there any other diseases	TB	3

	that HIV positive people are more likely to get than healthy people?	Other responses	0
	What type of person is likely to get TB?	HIV positive people Other responses	2 0
	Are there any other diseases that someone with TB is likely to have?	HIV Other responses	3 0
	Do you know of any diseases that are likely to make someone vulnerable to get TB?	HIV Other responses	3 0

Stata10 was used for data analysis. Multistage survey design was controlled for using STATA's "survey" features. These features take into account the number selected versus available sampling units at each level of sampling to account for different sample pools at each level.

The basic formula for this adjustment was:
(nsubcounties/nsubcountiesselectedper district) *(nparishes/nparishesselectedpersubcounty)* (nvillages/nvillagesselecetedperparish) * (npeoplepervillage/npeoppleselectedpervillage).

Where:
nsubcounties: number of sub-counties in Kabarole district
nsubcountiesselectedperdistrict: number of sub-counties selected in the district(6)
nparishes: number of parishes in each sub-county
nparishesselectedpersubcounty: number of parishes selected from each sub-county (3)
nvillages: number of villages in each parish
nvillagesselectedperparish: number of villages selected from each parish (1)
npeoplepervillage: estimated population of each village
npeopleselectedpervillage: number of people selected from each village (20)

Descriptive statistics were used to summarize each questionnaire item. Bivariate student t-test analysis was used to compare summary scores. Purposeful multiple linear regression was used to model predictors of summary scores for HIV knowledge, TB knowledge, and TB/HIV co-infection knowledge. Outcome knowledge score variables were approximately normally distributed. A $p<0.05$ was considered for statistical significance. All analyses were adjusted for the multistage survey design using survey estimation techniques in STATA (24).

Results

Demographics

Of 360 survey respondents, 50.7% (n=182) were female, mean age was 33 years (median 29, range 18-84). Other demographic information for the survey can be found in Table 2-2. Three women only focus group discussions contained a total of 30 women, and three men only focus groups included a total of 31 men. Male participants in the focus groups were slightly older (mean 34, median 28, range 18-78) than female participants (mean 30, median 26, range 18-58). Two focus groups were conducted in an urban area (one male, one female). Urban participants were younger (mean 26, median 25, range 18-64) than rural participants (mean 36, median 31, range (18-78). Demographic description by individual focus group can be found in table 2-3.

Table 2- 2: Demographic characteristics of survey subjects

Variable		n	(%)
Age in years			
	18-24	116	32.2
	25-44	174	48.3
	>=45	70	19.4
Sex			
	Male	177	49.3
	Female	182	50.7
Type of House			
	Permanent	46	12.9
	Semi-permanent	312	87.2
Education level			
	None or Primary	238	66.3
	Some Secondary or higher	121	33.7
Marital status			
	Single	140	38.9
	Living with partner or ever married	220	61.1
Residence			
	Urban	60	16.7
	Rural	300	83.3
Occupation*			
	Farmer/Peasant	167	46.5
	Small business	85	23.7
	Student	25	7.0
	Professional/public sector	22	6.1
	Skilled trades	20	5.6
	Unskilled labour	16	4.5
	Driver/boda boda	6	1.7
	Unemployed/ambiguous	18	5.0

*Note that occupation was not used in regression analysis because of difficulty combining categories.

Table 2- 3: Demographic description of focus groups

Focus group	Gender	Location	Number of participants	Age		
				Mean	Median	Range
1	Male	Fort Portal	11	30	25	(19-64)
2	Female	Fort Portal	11	23	24	(18-28)
3	Male	Bukuuku	9	33	23	(18-70)
4	Female	Bukuuku	11	33	30	(19-52)
5	Male	Kibiito	11	40	38	(22-78)
6	Female	Kibiito	8	36	36	(18-58)

HIV knowledge

Respondents were asked multiple questions about their HIV knowledge. Three hundred fifty seven people (99.7%) knew that a healthy looking person can have HIV. When asked to list the main signs or symptoms of HIV (respondents could list as many as they wanted), the most frequently mentioned symptoms were skin rash (n=241, 66.9%), weight loss (n=128, 35.6%), diarrhoea (n=121, 33.6%), cough (n=108, 30.0%), boils (n=105, 29.2%), herpes (n=95, 26.4%), and weakness (n=69, 19.2%). Three hundred and fifty people (97.2%) mentioned sexual transmission when asked how someone can get HIV. Other responses were sharing sharp instruments (n=146, 40.6%), blood transfer (n=68, 18.9%), mother to child transmission (n=49, 13.6%) and having many partners (n=34, 9.4%). In order to assess knowledge of HIV prevention, respondents were asked “What are the things a person can do to avoid getting HIV?” Three hundred and twelve people mentioned condoms (86.7%), 230 mentioned abstinence (63.9%), and 166 mentioned ‘be faithful’ (46.1%). Other responses were to avoid sharp instruments (n=42 11.7%), and to go for testing or check-up (n=16, 4.4%). Three hundred and forty people (94.7%) knew that HIV cannot be completely cured. Two hundred and fifty nine people (71.9%) had a friend who had told them they were HIV positive.

Mean HIV knowledge summary score was 58 out of a possible 100 (SD 12, range 18-100). Univariate regression analysis showed that older age (>=45years) and having ever been married were significantly related to lower HIV knowledge. Having a secondary education and living in an urban centre were significantly related to higher knowledge (Table 2-4). In a multivariate model containing age, education, sex, marital status, place of residence and having an HIV positive friend, having a secondary education or higher was the only significant predictor for HIV knowledge (table 2-4).

Table 2- 4: Univariate and multivariate linear regression analysis of HIV knowledge score

		Univariate analysis		Multivariate analysis	
Variable		**Slope (95%CI)**	**p**	**Slope (95%CI)**	**p**
Age	18-24	1.0		1.0	
	25-44	-1.02 (-4.74, 2.69)	0.510	0.91 (-3.08, 4.91)	0.582
	>=45	-6.03(-11.77,-0.30)	0.043	-2.86 (-8.80,3.07)	0.270
Education	Primary or less	1.0		1.0	
	Secondary or higher	6.61 (3.15, 10.08)	0.004	0.94 (0.27,1.62)	0.016
House**	Mud walled	1.0		-	
	Concrete walled	0.43 (-4.92, 5.77)	0.846	-	
Sex	Male	1.0		1.0	
	Female	0.85 (-3.15, 4.84)	0.609	1.19 (-2.77, 5.14)	0.475
Marital status	Single	1.0		1.0	
	Ever married	-3.68 (-6.83, -0.54)	0.030	-1.87 (-5.05,1.31)	0.192
Residence	Rural	1.0		1.0	
	Urban	4.22 (0.50, 7.95)	0.033	2.00 (-1.75, 5.75)	0.229
Has an HIV positive friend	No	1.0		1.0	
	Yes	-2.62 (-6.90, 1.66)	0.176	-2.48 (-6.48,1.51)	0.171

**Not included in model because of collinearity

TB knowledge

Despite 98.9% of respondents having heard of TB (n=354), overall TB knowledge was limited. Three hundred forty three participants (95.3%) mentioned correctly that cough is one of the main signs and symptoms of TB, but of the other two classic TB symptoms only 91 people (25.3%) mentioned weight loss, and only 10 people mentioned anything that could be interpreted as "night sweats" (responses included fever, sweating, evening fevers, evening sweats, and evening malaria). When asked how someone can get TB, 49 people (13.7%) mentioned that it was an airborne disease, and 62 people said that you can get it from being near a patient (17.3%). The most common form of transmission mentioned was through saliva, usually by sharing cups (n=263, 73.3%). Fifty eight people (16.2%) mentioned that someone could get TB from smoking and/or drinking, 35 people (9.8%) stated that TB was hereditary, 35 (9.8%) mentioned other ways of getting TB (for example from uncooked milk or meat, from working in factories, through sex, from hard labour), and 21 (5.9%) were unsure how TB is transmitted. Two hundred eighty nine people (80.5%) knew that TB can be cured, with 37 (10.3%) saying they did not know, and 33 (9.2%) stating that TB cannot be cured. Of those that knew TB can be cured, 98.6% knew it was cured by pills/tablets, with only four people saying that TB is

cured by traditional medicine or spiritual healing. Seventy five percent of respondents (n=270) knew someone who had had TB.

Mean TB knowledge summary score was 34 out of 100 (SD 15, range 0-79). Mean TB knowledge was significantly lower than HIV knowledge with a difference in means of 24 (p<0.0001). Linear regression analysis of age, education, type of house, sex, marital status, place of residence, and knowing someone who has had TB were analyzed in the model. For both univariate and multivariate regression, older age (>=45years) was associated with higher TB knowledge, and urban residence was associated with lower TB knowledge. (Table 2-5)

Table 2- 5: Univariate and multivariate linear regression analysis of TB knowledge score

		Univariate analysis		Multivariate analysis	
Variable		slope (95%CI)	p	slope (95%CI)	p
Age	18-24	1.0		1.0	
	25-44	1.33 (-4.47, 7.12)	0.582	1.88 (-3.43, 7.19)	0.404
	>=45	6.76 (0.27, 13.26)	0.044	7.45 (0.30, 14.60)	0.044
Education	Primary or less	1.0		1.0	
	Secondary or higher	1.08 (-3.63, 5.80)	0.580	3.07 (-2.03, 8.18)	0.183
House**	Mud walled	1.0		-	
	Concrete walled	-1.75 (-7.69, 4.18)	0.482	-	
Sex	Male	1.0		1.0	
	Female	-0.43 (-6.34, 5.51)	0.859	-0.31 (-6.08,5.45)	0.894
Marital status	Single	1.0		1.0	
	Ever married	1.17 (-5.27,7.62)	0.660	-0.49 (-6.77, 5.79)	0.850
Residence	Rural	1.0		1.0	
	Urban	-6.02 (-11.37, -0.68)	0.034	-6.27 (-11.73,-0.81)	0.032
Has a friend who has had TB	No	1.0		1.0	
	Yes	1.04 (-4.59,6.67)	0.654	0.63 (-4.47, 5.74)	0.762

**Not included in model because of collinearity

Focus group participants discussed general population knowledge about TB, different types of TB symptoms and transmission. Respondents reported a general lack of knowledge about TB amongst their village mates. A lack of awareness was linked to delays in seeking treatment because people do not recognize the symptoms of TB. When asked why people were dying of TB despite treatment being available, one respondent stated: "*For me I think our people lack information. You find someone coughing without knowing that it's TB." (urban male)* There is a significant perception that TB isn't curable. Participants mentioned either directly that TB doesn't have a cure, or that their fellow

villagers believed that TB has no cure. One respondent stated: *"The government announced that there is no complete cure for TB, that one we know." (rural male)* Distinctions were also made between types of TB that are curable, for example "inherited" TB can't be cured, or TB that has progressed very far. It is also believed that TB cannot be cured in HIV patients. One explanation given was because HIV destroys all the white blood cells so even with the help of strong drugs the body cannot fight TB.

Focus group participants believed that there were three different types of TB. The first was "regular TB" or TB on its own. This type of TB can develop in HIV negative individuals if they contract it from an infected person. This type was considered by some respondents to be the only type that is contagious. The second type is TB which is related to HIV infection. One respondent indicated that this type of TB can only be transmitted to other HIV positive people:

> *"Now I used to hear most people saying, [that when] a person is suffering from HIV/AIDS that's when he/she gets TB, but when he gets that TB [it] will not spread to others who are not infected with HIV/AIDS." (urban male)*

The third type of TB discussed by participants was TB which is inherited. This type of TB runs in a family lineage and they believed that it cannot be cured.

TB transmission

People believe that TB is transmitted through saliva by sharing utensils, cups, plates, and food stuffs. For example, one respondent noted that;

> *"When a TB patient spits and another comes close to it [he/she] gets TB. Then sharing things like cups, forks you also get it." (urban female)*

The idea of TB being transmitted though sharing cups is especially mentioned in the context of sharing cups when drinking alcohol. The situation of passing around a common cup at a local bar is associated with TB transmission. For example, as one respondent stated, *"TB spreads easily to those people who drink local booze because they share straws among themselves." (rural male).* In addition to alcohol, smoking is also understood as a way that TB is transmitted. The relationship is explained by respondents in a variety of ways. Both alcohol and cigarettes are thought to damage the lungs as explained by one respondent: "*This TB comes in due to your lungs being destroyed because of too much intake of alcohol and smoking on daily basis." (rural male)* There also seems to be a dose response understanding of smoking and TB- those who smoke a lot are most likely to get TB. *"TB [comes] when you smoke too much, immediately from the bed right away [you] start smoking cigarettes." (rural male)*
Some participants demonstrated a high level of understanding about TB transmission, as one respondent explained:

> *"Someone can get it through air, it's an airborne disease, when a TB patient goes to the community and coughs and the germs spread through*

air being coughed or sneezed out thus infecting other people." (rural female)

Other respondents mentioned that *"staying close to the patient while coughing his/her air can cause it easily" (urban female)* and "*you may get it when staying with a person, through sleeping together in the same house." (urban female)*

TB was also associated with being an environmental air pollutant. TB can be contracted from smoky fires in local houses that don't have good chimneys and where the kitchen and bedrooms are together.

"Most especially we have kitchens in the same house where people sleep, so the smoke is too much. [The] lungs develop something like feathers which causes that person to cough, cough and cough." (urban male)

Also, *"people who work mostly in industries and factories are vulnerable" (urban male)* to TB because of inhaling chemicals and dust.

There was also an understanding of TB being inherited from one's parent though blood, that it runs in a family, as one respondent explained: "*some diseases we inherit from the blood of our parents like TB, that TB can be inherited" (rural male)*

Interestingly, there was some understanding of transmission of bovine TB from unpasteurized milk, according to one respondent *"it would come […] from animals; from milk which was not well prepared in the past years" (rural male)* and another respondent mentioned that his "*lungs were affected because of eating raw cow ghee." (urban male)*

This understanding of TB coming from animals to is not limited to milk products; one respondent describes how animal fur causes TB:

"TB comes from sleeping with animals in the same house. In the past – even these days -people have a tendency of sleeping with animals in their rooms – for instance a goat can rub itself against the wall and some hair is rubbed off from its skin. When people breathe in the animals' hair, someone can begin coughing there and then. The continuous breathing in of the animals' hair can lead one to suffer from TB disease." (rural male)

Another respondent agreed and added on to this idea:

"The issue of sleeping with animals in the same house. Like what he said that a goat can rub itself against the wall and the hair gets off its skin --- and so on. But the hair can even drop in the drinking cup and when they pour water or even tea in the cup and you just drink unnoticeably – then from there the TB disease manifests." (rural male)

TB symptoms

People are generally aware of cough as the main symptom of TB. However, TB is associated with a very serious set of symptoms including very severe and prolonged cough, often associated with coughing up or vomiting

blood. Less severe symptoms are assumed to be a "normal cough", and so people don't seek medical attention. As one participant explained:

> *"Yes, asthma and other things, regular coughs. I see that the reason leading to many people dying of TB [is that] they assume it's a normal cough yet it's TB." (rural female)*

People assume it is a "normal cough" until it gets very serious and then they think about TB. A "normal cough" can also develop into TB after a certain time without treatment or improvement. Abnormal weight loss is also understood as a symptom of TB, but not independently of cough. One respondent stated:

> *"It's hard to tell that someone has TB, you can only realize when the person starts getting signs like chronic cough, abnormal loss of weight that's when you can say "eehh that person is infected with TB"."(rural female)*

There was almost no mention of night sweats (only person to mention it was a nurse) and no discussion of having weight loss/ night sweats without the cough.

TB prevention

A wide variety of strategies for preventing TB were mentioned. The respondents believed that an important preventative measure was to avoid sharing cups/utensils/ and food with TB patients. As one participant suggested:

> *"Everyone should get his/her own cup and there should be cups for visitors because you may not know what the visitor is suffering from" (rural male)*

Another common preventative measurement that was mentioned was to avoid contact with TB patients, for example by not sharing a bed with a TB patient, by isolating and avoiding TB patients, and by avoiding overcrowded places. A participant mentioned:

> *"To avoid getting TB [one should] avoid congested places like where they show football. You may find people in homes, three of them sleeping in one bed: that one we should avoid it" (rural male).*

The importance of not sharing a bed or food with children was also mentioned:

> *"They found him with TB, we would make sure we avoided getting in touch with his utensils or giving his leftovers to children, we ended up not getting infected with TB." (rural female)*

Respondents also explained preventive measures involving sputum- there was a strong belief that TB is transmitted by the sputum, and so sputum should be covered, handled with gloves, and disposed of properly at a distance by burying it or pouring down the pit latrine. As one respondent described:

> *"You can prevent yourself from getting TB by covering the patients' tin where he/she spits sputum and throwing it far away from home like in the pit latrine to prevent its spread. You're not supposed to wash it." (rural female)*

Prevention measures were also tied to behavioural judgments surrounding TB and smoking, as one participant stated "*the way of avoiding TB is to stop smoking cigarettes, sharing [cigarettes] with TB patients." (urban male).*
Some notable preventive measure mentioned were to prevent HIV infection because it goes hand in hand with TB, to make sure TB patients get treated early and adhere to their treatment and to ensure that houses are well ventilated. As one respondent noted:

> *"A TB patient is required to live in a well-ventilated house containing windows and ventilators. You shouldn't be congested in a home where there's a TB patient."(rural female)*

Preventive measures that indicated a clear lack of knowledge about TB transmission were also mentioned. One participant stated:

> *"For me I see TB is caused by cold weather like moving on the motor bikes when it's very cold, so these people get heavy jackets to cover their body to avoid that coldness entering their lungs. That is how we should prevent TB." (urban male)*

Another respondent explained:

> *"You endeavour to avoid that patient, you avoid the patient's urine, and his/her basin. Even when washing clothes for him/her, you shouldn't mix them with your clothes."(rural female)*

Other participants described workplace safety measures to avoid TB:

> *"To prevent getting TB, if [someone] is working in the factory for example they should use face masks and some other things to be put in ears to avoid air pollution (rural male)*

TB/HIV knowledge

Several different open ended questions were embedded throughout the survey to elucidate the perceived association between HIV and TB. When asked if they knew of any diseases that are likely to make someone vulnerable to get TB the most common response was that they did not know (n=191, 53.1%), but 132 people (36.7%) mentioned HIV/AIDS. In response to being asked if there are any other diseases that someone with TB is likely to have, 123 people (34.2%) mentioned HIV/AIDS, and the next most common response was malaria (n=84, 23.3%). A very wide range of answers were provided when asked if there are any other diseases that someone with HIV is more likely to get, but the most frequent response was TB (n=119, 33.1%), followed closely by STDs (n=116, 32.2%).

Forty three people (11.9%) answered that having TB means a person is HIV positive, and 28 people (7.8%) did not know. When asked what proportion of TB patients are HIV positive, 80 people (22.3%) selected all or most, 273 people (76.3%) said half or some, and only one person said none. Forty four people

(12.2%) said that TB cannot be cured in HIV positive patients, and 55 (15.3%) were unsure if TB could be cured in HIV positive patients.

Mean TB/HIV knowledge summary score was 48 out of 100 (SD 20, range 0-100). This was statistically lower than HIV knowledge by 10 points (p<0.0001) and higher than TB knowledge by 14 points (p<0.0001). Univariate regression analysis showed that having a secondary education and living in a permanent house with concrete walls were both significantly related to higher TB/HIV knowledge. In a multivariate model containing age, education, sex, marital status, place of residence, and having a friend who has had both TB and HIV, (type of house was removed because of collinearity) having a secondary education or higher was the only significant predictor for TB/HIV knowledge (table 2-6).

Table 2- 6: Univariate and multivariate linear regression analysis of TB/HIV knowledge score

		Univariate analysis		Multivariate analysis	
Variable		Slope (95%CI)	p	slope (95%CI)	p
Age	18-24	1.0		1.0	
	25-44	2.48 (-5.34, 10.30)	0.452	2.70 (-5.01, 10.42)	0.409
	>=45	2.56 (-4.43, 9.55)	0.390	3.94 (-3.34, 11.2)	
Education	Primary or less	1.0		1.0	
	Secondary or higher	8.03 (2.88,13.18)	**0.010**	8.64 (3.12, 14.16)	**0.010**
House**	Mud walled	1.0		-	
	Concrete walled	-6.18 (-12.10, -0.27)	**0.043**	-	
Sex	Male	1.0		1.0	
	female	-1.93 (-7.60, 3.72)	0.418	-0.79 (-6.14, 4.55)	0.719
Marital status	Single	1.0		1.0	
	Ever married	0.96 (-4.72, 6.64)	0.681	1.29 (-4.32, 6.90)	0.580
Residence	Rural	1.0		1.0	
	Urban	2.54 (-5.76, 10.83)	0.468	-0.45 (-8.34, 7.44)	0.890
Knows someone w HIV/TB	No	1.0		1.0	
	Yes	-4.11 (-10.90, 2.67)	0.180	-4.08(-10.83, 2.66)	0.180

**Not included in model because of collinearity

Focus group participants understood the association between TB and HIV in a wide variety of ways. Respondents seemed to have a good understanding of TB as an opportunistic infection that happens when HIV patients are immune-compromised. This is explained as HIV patients being weak, HIV patients having low immunity, or having weak blood cells. One respondent explained:

"he may be suffering from HIV and AIDS disease makes him weak, and again he comes and meets the person with TB and when TB comes [it] finds his immunity is low [so] there it affects him also." (rural male)

Respondents understood that TB and HIV can develop separately and each is a disease on its own. One participant explained:

"Not all HIV patients get infected with TB; TB comes like any other disease. It's not a must that when you are infected with HIV, you have TB. TB is a disease on its own. You find when someone has lived with HIV for a long time and due to his/her low immunity he/she gets TB in the due course, [but] not all HIV patients have TB." (rural female)

However, a strong theme emerged of TB developing only in HIV patients. Respondents stated that all or most people have both diseases simultaneously, and that someone with TB must also be infected with HIV. One participant stated: *"Me according to my understanding, I think TB and HIV, when you have TB you also have HIV."(rural male)* Another respondent had a similar understanding: *"According to me, as I know when someone is suffering from TB she/he must have AIDS."(urban female)* As a result, TB patients are assumed to also be HIV positive.

"Most times people associate HIV/AIDS with TB, when you have TB that means you're HIV positive. In most cases when you see someone suffering from TB you suspect him/her to be having HIV." (urban female)

One of the reasons the association between TB and HIV is so strong is the perceived similarity of symptoms. Growing thin, 'slippery' hair, loss of appetite, skin rash, sweats, fever every evening, cough, and swollen legs were all stated as symptoms common to both diseases, and cough and weight loss were considered guaranteed signs of both diseases. People understood that because the symptoms were the same, the diseases were interrelated. One respondent noted: *"Yes, when most people see TB patients they assume they're HIV positive because the signs and symptoms are the same." (rural female)* Cough, or any other sign of sickness, is thought to be associated with AIDS. The awareness around AIDS is so strong that it has become the default assumption for any illness, as one respondent explained:

"When someone coughs they say he has Silimu [AIDS]– the same applies to TB, when one cough they still say he has Silimu. All fingers are pointed at Silimu, even when you loose hair and it turns yellow, they say it is Silimu." (rural male)

Because of similar symptoms TB patients are afraid to go for testing since they think they will be diagnosed with HIV.

Respondents also expressed an understanding that HIV/AIDS develops into TB. One participant thought that if you have AIDS and do not take drugs it

can develop into TB: *"The first disease is HIV/AIDS, it also develops into TB." (rural male)* Another participant expressed a similar opinion:

> *"Sometimes it's due to a prolonged cough [when you] don't give it proper medication you can end up getting TB. [Or] you can be having AIDS, you know that you have it [but] then when you don't give it medication you end up getting TB." (urban female)*

Another participant agreed:

> *"But the problem which is with the AIDS disease is that when it enters a persons' body, whether you like it or not, it causes TB. Therefore there is a need for more research as to why AIDS brings about TB and yet when you have TB you don't get AIDS."(rural male)*

Another pathway that was brought up in the discussion was that if an HIV positive person smokes and drinks then they will get TB.

> *"You may find someone with HIV and at the same time smoking cigarettes and alcohol these things also cause TB." (rural male)*

One respondent also remarked on the role that AIDS has played in the resurgence of TB which is otherwise treatable and preventable:

> *"AIDS has brought back TB to stay in the community."(rural male)*

Discussion

HIV knowledge

HIV knowledge (mean score 58 out of 100) was lower than in earlier studies. Previous work in Kabarole district found that knowledge about HIV and antiretroviral treatment was high, although direct comparisons cannot be made since different methods and questionnaire was used(Kipp 2009). This could possibly be related to recent focus on ART treatment, which may be taking some focus away from preventative education. It has been previously shown in this area that ART treatment has had a some negative effects on other primary health care services, (25) so it may be that some aspect of HIV education have suffered as well. However, knowledge about sexual transmission of HIV was high in this study, with 97% of respondents mentioning sexual transmission when asked how someone can get HIV; this finding is similar to a study conducted in Ethiopia where all respondents knew that HIV was transmitted sexually (26). Knowledge about mother to child transmission however was low in our sample, with only 14% of respondents mentioning it as a way someone can get HIV. This is lower than a study in Ethiopia that found that over half of respondents didn't know that HIV could be transmitted from mother to child (17). Although the open ended nature of this question may have contributed to this low response, it is a point that merits further investigation and intervention as knowledge about prevention of mother to child transmission has been shown to be important in the general population, not just pregnant mothers (27). Results show fair knowledge of the "ABCs" of HIV prevention, with 64% of respondents mentioning abstinence, 46% saying "be faithful", and 87% mentioning condoms as a way to prevent HIV. This would indicate that the Ugandan approach of ABC prevention has been effective. Multivariate regression analysis results found educational attainment to be the single significant predictor. This is not surprising, as education has been linked to health knowledge in countless studies around the world, and previously in Kabarole district (21). The lack of other predictors of HIV knowledge indicates a fairly uniform distribution of knowledge across the population.

TB knowledge

Mean TB knowledge summary score of 33% is low and demonstrates an overall lack of knowledge about TB. This is the first time TB knowledge has been assessed in this region, and this result was unexpectedly low. Although 95% of respondents mentioned cough as a symptom, very few were able to identify weight loss or night sweats. This is similar to other studies finding that cough is the major symptom identified, with a variety of other symptoms identified occasionally (12, 20). This has serious implications for care seeking in extra-pulmonary TB (which is increasingly common in high HIV prevalent settings) when cough is not part of the presentation. In addition, TB is associated with a very severe set of symptoms and is distinguished from "normal cough". This has

major implications for treatment seeking behaviour, and explains in part why many TB cases delay presenting to health services until a very advanced stage of disease. This study found a wide variety of understandings about TB transmission. While 31% of respondents knew TB could be transmitted through air or being near a TB patient, an overwhelming majority of respondents thought that TB was transmitted through sharing cups and utensils. This consistency of misinformation is perplexing. Similar results have been found elsewhere in Uganda, but sharing cups does not emerge as a major way that people understand TB transmission in other sub Saharan countries (12, 13, 20, 28). It is interesting that this belief is so consistent in Uganda but not described elsewhere. Whether this belief stems from health care worker messages, or just from confusing TB with other diseases, it is not necessarily harmful. Proper hygiene and not sharing cups and utensils is a good preventative health practice in general, so although it is stemming from misconceptions about TB, focussing on this aspect of TB knowledge may detract from more critical and useful messages around chronic untreated cough as a source of TB risk. Also important is the understanding that TB is an untreatable hereditary disease. This was mentioned by 10% of survey respondents, and the theme emerged in each focus group discussion. This has also been described elsewhere in Uganda and in Tanzania (12, 20). This should be targeted since conceptualising TB as a hereditary disease has the potential to negatively affect decisions to seek care, and also will increase stigma towards families of TB patients. Understandings of TB prevention vary widely, including not sharing cups, avoiding public places, not smoking and drinking, and complicated measures to dispose of sputum. While these preventative procedures do have some epidemiological support, the WHO's TB control strategy holds effective treatment of infectious cases as the main pillar of prevention, and as such community ideas about prevention are not of top priority (9).

One of the most significant findings is that 20% of respondents did not know that TB can be cured. Focus group participants confirmed that many people believe that TB cannot be cured, or that certain types of TB cannot be cured (TB that is inherited for example). This has serious implications; if people do not believe that their illness can be treated they will not seek care. This finding is different from other studies in Uganda, Tanzania, and Rwanda that found that people universally understood that TB was curable, at least in HIV negative patients (12, 18, 20).

Multivariate regression models for TB knowledge found that older age, and rural residence predicted higher TB knowledge. This is a surprising result, and opposite to expected. As other studies exploring community knowledge around TB have been entirely qualitative, it is difficult to compare these findings (12, 18, 20). However, one survey in Ethiopia found that literacy predicted better knowledge around TB cause, transmission, and prevention (17). It is also

critical to note that we found predictors of TB that are very different from the predictors of HIV and TB/HIV co-infection knowledge (higher educational attainment). These findings can be explained in part by a major focus on TB in the study area during the 1970s and early 1980s. These programs focussed on TB education in rural areas, and as such, individuals who were old enough during that period to absorb that information were positively impacted. Since the start of the HIV epidemic, the Ugandan government has focussed resources and political commitment towards combating HIV. While this has been successful, (reducing the HIV prevalence from 18% in 1992 to the 6% current national average), TB programming has been neglected. TB education efforts have declined, and with this lack of focus it is not surprising that TB knowledge amongst youth is low. Another study in Kabarole district found that primary health care services (which would include TB education) had deteriorated following the roll-out of ART(25). This also may help to explain lower TB knowledge amongst urban residents where ART services were first offered. It may also be that there have been small programmatic interventions targeting rural residents out of a perceived lack of knowledge in that demographic.

TB/HIV knowledge

This is the first time TB/HIV knowledge has been directly assessed in Uganda to our knowledge. Multiple questionnaire items attempted to evaluate the perceived association between TB and HIV; “what makes someone vulnerable to get TB?”, “are there any other diseases that someone with TB is likely to have?”, and “are there other diseases that someone with HIV is likely to get?” 68% of respondents associated TB and HIV in at least one of these questions, indicating a high level of awareness of a link between TB and HIV. Qualitative data also support this, with a very high level of awareness that TB is related to HIV. This relationship is considered by many to be obligatory: 12% of respondents said that having TB means that a person must be HIV positive (and 8% were unsure), and 22% of people thought that all or most of TB patients were HIV positive. This came across even more strongly in the qualitative data, with many respondents reporting that it was a must that TB patients had HIV. This is consistent with findings from other studies; most discussants believed having TB was synonymous with having HIV/AIDS, and it was a common perception that all TB patients are HIV positive (12, 20). This may detrimentally affect TB treatment if HIV negative individuals believe they cannot get TB and so don’t seek care. There was also confusion in both the survey and focus groups about the difference between TB and HIV symptoms, with many symptoms viewed as interchangeable. This is consistent with other studies in Tanzania, Zambia, and Rwanda (11, 12, 18). This perception also contributes to solidifying the perceived association between TB and HIV, and may contribute to delays in seeking TB treatment if symptoms are thought to be due to HIV.

There is a strong misperception around treatment of co-infected patients; 28% of people did not know that TB can be cured in HIV patients. This theme also emerged in the focus groups, with participants discussing different types of TB and reporting that the type of TB that HIV patients get is not curable. This finding is consistent with other studies where TB is believed not to be curable if the patient also has HIV (11, 12, 20). As with TB alone, if the general population doesn't think that TB is curable in HIV patients, they will not seek care if they are HIV positive (or will not encourage their HIV positive friends to seek treatment), accepting the perceived fatality of the condition.

The mean summary percentage score for TB/HIV co-infection knowledge (48 out of 100) is closer to the score for HIV knowledge (58) than the mean TB knowledge score (34). In addition, multivariate regression analysis found that, like HIV knowledge, the single significant predictor for higher TB/HIV co-infection knowledge is having a secondary education or higher. The lack of other predictors indicates that low knowledge is fairly widespread and any intervention should target the general community and not specific demographic groups. It appears that HIV knowledge is influencing co-infection knowledge. Although initially surprising that TB/HIV co-infection knowledge is so much higher than knowledge about TB alone, this is explained by the major focus on HIV education in Uganda. Any educational campaigns addressing TB are likely to be encompassed within HIV interventions, thus knowledge around TB in the context of HIV (and the association between the two diseases) is much more frequently addressed than TB alone. TB programming alone is neglected and only messages around TB as a opportunistic infection in HIV patients are disseminated. Within the clinical setting a very admirable effort is made to screen HIV patients for TB by asking HIV patients about cough smptoms lasting 2 weeks or more, and WHO staging charts (with TB listed as a symptom of HIV in clinical stages three and four) are prominently displayed in clinics. All of this contributes to increasing awareness about the association between TB and HIV, but doesn't help to improve knowledge around TB alone or its treatability.

Limitations

This study has several limitations. The questionnaire used was developed by the study team with significant local input, but a previously validated questionnaire was not used. This study investigated two separate diseases and the interaction between them, so existing measurement instruments were not available. The survey developed for this study showed to be reliable through test-retest. Multiple local key informants had input in the survey development and felt that the questions measured the concepts accurately. During analysis, responses were weighted to form summary scores. Although based on professional knowledge and understanding of the data, this weighting was nonetheless subjective and constitutes a limitation. Several other studies have used a similar method of summary scores and scales to evaluate TB or HIV

knowledge (17, 21), but it is more common to use descriptive statistics of individual questionnaire items and model "key questions" (28). The summary scores used in this study attempted to give a more robust assessment of overall knowledge, and were designed to be comparable between HIV, TB, and TB/HIV co-infection where individual questions would not have been.

In order to get a rich and descriptive understanding of the types of knowledge this population has, many questions were open ended, allowing multiple responses for each question which may have limited the conclusions drawn from some questions. Previous studies have used mainly close ended questions (16), which may limit the depth and range of responses. Because this was an exploratory study, open ended questions helped to elucidate unexpected responses.

While the multistage cluster sampling technique used gives a good representation of the district, it is important to note that two sub-counties located high in the mountains were not included in the sampling pool for logistical reasons. Thus results cannot be generalized to the most remote areas of the district. Results may not be representative of other districts in Uganda, where educational messaging and district priorities may be different. In addition, because participants were recruited during on weekdays during the day, there may be an under-representation of individuals employed in the formal sector since they would not have been home during the day.

Qualitative data was limited by the delays required to transcribe and translate the discussions from Rutooro to English. As such, it was not possible within the time limits of field work to analyze this data iteratively before conducting subsequent discussions.

Conclusions and recommendations

HIV knowledge is higher than TB knowledge and it appears that Uganda's focus on HIV education has been effective. Excellent knowledge around condom use is encouraging. Gaps still exist in general population knowledge of mother to child transmission; this is an important area for future targeted messaging. HIV educational campaigns should be continued, preferably targeting those with little or no formal education.

TB knowledge is low overall and demonstrates a significant neglect of TB in country priorities. Lack of knowledge around non-cough symptoms is a problem given the high proportion of extra-pulmonary TB in this region. Most importantly, educational messaging around the curability of TB is needed. The unexpectedly lower knowledge of TB in youth and in urban populations should be addressed though targeted educational campaigns.

TB/HIV co-infection knowledge is higher than expected and seems to be driven by HIV educational campaigns. The strong perceived association between TB and HIV may have negative effects on treatment seeking and may be increasing stigma towards TB patients. Educational messages focusing on the curability of TB in HIV patients are recommended, and all interventions should target those with low educational status.

This study demonstrates gaps and misconceptions that may be contributing to delays in care-seeking for TB and poor TB outcomes in the region. The confusion between TB and HIV symptoms and the understanding that TB is only in HIV patients may be deterring HIV negative individuals from seeking care. TB is associated with a very severe set of symptoms -which may be resulting in late presentation to health services, and the reliance on cough as the main symptoms of TB is likely contributing to low case finding for extra-pulmonary TB. Most importantly, the perception that TB cannot be cured must be addressed to encourage people to seek care if they suspect TB.

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Chapter 3: HIV, TB, and TB/HIV co-infection: exploring community stigma in western Uganda

Introduction

Both HIV and Tuberculosis are major public health problems in Uganda. According to the most recent national survey, Uganda had a national general population HIV prevalence of 6% in 2004 (1). In 2010, TB incidence in Uganda was estimated at 209/100 000 population per year. Mortality rates (in 2007) from TB are high at 93/100 000. The biological and epidemiological interconnectedness of TB and HIV cannot be ignored; 54% of new TB cases (with known HIV status) were in HIV positive individuals (2).

People living with both HIV/AIDS and TB are significantly stigmatised. Stigma prevents the delivery of effective social and medical care (including treatment), in addition to increasing the number of HIV infections through ongoing transmission (3). Because of stigmatisation, people are less likely to be tested for HIV, therefore reducing the effectiveness of testing programs. For example, in KwaZulu-Natal, South Africa, stigma was identified as the primary cause of poor uptake of voluntary HIV counselling and testing (4). Stigma also reduces the likelihood that individuals will seek care after diagnosis, and results in the negative treatment of people living with HIV/AIDS by family and community members (3). The stigma associated with tuberculosis has been recognised as a major global cause of the limitations of the World Health Organisation's DOTS strategy for TB control (5). Stigma contributes to delays in diagnosis and poor treatment adherence, which both negatively impact TB control (6).

A plethora of studies have been conducted assessing and measuring HIV/AIDS stigma in a variety of contexts. A 2009 literature review discussed 65 papers on HIV stigma in Sub-Saharan Africa and found that HIV stigma continues to be highly present and rooted in local beliefs, religion, and gender(3). A systematic review of the literature on TB stigma found that TB stigma has serious socioeconomic consequences, increases TB diagnostic delay and treatment non-compliance. Macq et al. remark on the scarcity of studies assessing TB stigma compared to other health conditions; stigma is the centre of global strategies to fight AIDS but is not present in international TB priorities (6). That said, in settings with a high prevalence of HIV, assessing TB stigma alone will be insufficient- the interaction and combination of the double stigma around TB and HIV must be understood as well as stigma associated with TB/HIV co-infection.

One qualitative study in Zambia explored the interconnectedness of TB and HIV for people and found that visible signs of TB become triggers for TB/HIV stigma (7). No other studies have directly investigated TB/HIV stigma in Sub-Saharan Africa.

Stigma varies greatly from country to country, and it is important for health policy makers to understand the local context. Very little work has been done investigating stigma around TB or TB/HIV co-infection in Uganda. There has been some recent evidence suggests that HIV stigma may be decreasing in part due to wider availability of antiretroviral drugs, but that stigma is still significant especially within the health care system (8). TB stigma has not been extensively evaluated in Uganda, but evidence suggests it is high and has a major impact on TB control (9). One study suggested that ineffectiveness of TB control in Uganda may be in part due to the stigma associated with HIV infection (10).

This study aimed to investigate, using both quantitative and qualitative assessments, HIV, TB, and TB/HIV co-infection stigma in the general population of western Uganda.

Methods

Setting

This study was conducted in the Republic of Uganda in East Africa. Uganda has a population of 30,900,000 (2005 estimate) with a median age of 15 years. The western district of Kabarole had a population estimate of 455 000 in 2010. Most people in Kabarole live in rural areas or the one major centre, Fort Portal. The district's economy is mainly agriculture. The main language is Rutoroo and English is taught in district schools; the literacy rate is 49% (11). There is an equivalent word for "stigma" in Rutooro, and the concept is well understood and frequently used. The data was collected between September and December 2010.

Study design

This is a cross-sectional sequential mixed methods study. The study population was a random sample of the general population of Kabarole district in western Uganda. Inclusion criteria were the ability to speak Rutooro (the local language) or English, and being over 18 years of age. HIV status and history of TB were not asked, therefore this sample neither excludes nor purposefully includes HIV or TB patients. Participants were selected using four levels of sampling. Of 10 sub-counties in Kabarole district (after two were eliminated because of logistic limitations), six sub-counties were randomly selected. In each sub-county, three parishes were randomly selected (number of parishes in each sub-county ranged from three to five). One village was randomly chosen from each parish (total number of villages in each parish ranged from three to 18). Twenty individuals

from different households were randomly selected from each village, by four research assistants, starting in the center of the village and proceeding outwards in a four different directions.

Six focus group discussions were conducted. Focus group participants were sampled from three of the six sub-counties (chosen because of availability of meeting facilities). Participants were selected from villages that were not part of the survey sample.

This study received ethical approval from the University of Alberta Human Research Ethics board, Health panel B (Canada), the Makerere University School of Public Health's Internal Review Board (Uganda), and the Uganda National Council for Science and Technology. Participants were given information and a detailed explanation of the study by a trained research assistant in the local language. Informed consent was provided by signature or thumbprint of the consent form.

The questionnaire was developed by the study team, as no suitable standard questionnaire was found to assess HIV, TB, and TB/HIV co-infection stigma. TB and co-infection questions were added following the same model as the HIV questions. Demographic information was gathered about age, gender, employment, education, type of house (concrete vs. mud walled), and marital status. The questionnaire items attempted to asses stigma through both direct close ended measures (for example "Do HIV patients deserve to get it?"), and through indirect open ended questions (for example "What type of person is likely to get TB?") from which stigmatizing responses were coded. The questionnaire was developed in collaboration with local partners to ensure appropriateness and comprehensiveness of the questions in the local context. Questionnaire was translated into the local language, and the translation was verified for accuracy by four separate collaborators fluent in both languages. The survey was administered by trained research assistants (fluent in the local language) who interviewed the participants.

The survey tool was pilot tested in two phases. The initial tool was administered to 10 randomly selected individuals from a sub-county not selected for data collection. Some small adjustments were made, and then it was administered to 10 more people to finalize the instrument. Test-retest was completed to ensure reliability of the survey tool. One day of surveys was randomly selected and ten respondents who had completed the survey that day were located one week later and asked to participate for a second time. The agreement in responses was 86% for all questions.

Focus group topics were developed after most of the surveys had been completed and preliminary data analysis using the first 180 participants had been conducted. Focus group questions aimed to add a richer understanding of

key issues, and explore further topics not included in the survey that had emerged during data collection (for example topics that respondents had wanted to discuss and provide information but that were not on the survey). These topics guides were developed in partnership with the four local research assistants conducting the surveys. Six focus group discussions were conducted, three with women only and three with men only. Separating the genders was expected to help the women feel comfortable speaking freely, and in order to facilitate discussion of gender specific themes around the topics. Focus groups were co-facilitated by the principal investigator and a research assistant fluent in the local language. A second research assistant took concurrent notes in English as the discussion progressed. Research assistants were of the same gender as participants for each focus group. Focus group discussions were audio-recorded. Focus group discussions were conducted in a separate quiet area outside of rural clinics (two discussions each at two separate clinics), and in the conference room of the district health department (two discussions). Discussions lasted between 40 minutes and one and a half hours.

Rigour of the qualitative portion of this study was ensured through several strategies. A subsample of transcripts was re-coded by the same researcher, and a sub-set was also coded by an independent researcher to ensure inter-rater reliability (agreement in coding tree development was high) and to contribute to the trustworthiness of the study. The primary researcher travelled to the study site again in October and November 2011 to present and discuss the results (member checking) with key informants and stakeholders in the district health department of Kabarole. These in depth discussions with local informants contributed to the trust worthiness of the findings.

Focus groups discussions were transcribed and translated. A sample of transcripts was translated by a second translator and the two English versions compared to ensure accuracy. Transcripts were analyzed inductively using latent content analysis to identify, code, and categorize the primary patterns in the data. Themes were developed from these categories. Results were presented and discussed with key informants during a return trip to the study area to confirm and validate themes.

Quantitative data management and analysis

Survey data was entered into a Microsoft Access database. Ten percent of entered surveys were thoroughly crosschecked, the remainder checked for completeness and out of range values. Open ended questions were coded thematically.

Summary scores were developed by weighting and combining multiple questionnaire items as described in Table 3-1. Scores were then dichotomised into none/low stigma (scores from zero to two) and medium/high stigma (scores of three or higher). Cut off scores were determined by the study team based on

professional experience and an understanding of the data and issues. These methods has been previously used for evaluating stigma in multiple studies: a systematic review of HIV/AIDS stigma intervention evaluations, nine of 19 studies evaluated used multi item scale in which a summary or mean score was calculated (12).

Table 3- 1: Summary score weights

Score	Questionnaire Item	Response	Response weight
HIV stigma Low (or no) stigma: 0-2 Medium/High stigma: 3-10	Do HIV patients deserve to get it?	Yes	3
		Unsure	1
		No	0
	Should HIV patients be ashamed?	Yes	3
		Unsure	1
		No	0
	Would you buy something in the market from someone who had HIV?	No	3
		Unsure	2
		Yes	0
	Would you visit someone in their home if you knew they had HIV?	No	2
		Yes	0
	Would you share a home with someone who has HIV?	No, Unsure	1
		Yes	0
	Would you tell your friends and family if you were HIV positive?	No	2
		Unsure	1
		Yes	0
	What type of person is likely to get HIV? (open ended)	Prostitutes, those with many partners, the negligent ones	2
		Sexually active people, with STDs, who have unprotected sex	1
		Other responses	0
TB stigma Low (or no) stigma: 0-2 Medium/High stigma: 3-12	Do TB patients deserve to get it?	Yes	3
		Unsure	1
		No	0
	Should TB patients be ashamed?	Yes	3
		Unsure	1
		No	0
	Would you buy something in the market from someone who had TB?	No	3
			2
		Unsure	
		Yes	0
	Would you visit someone in their home if you knew they had TB?	No	2
		Yes	0
	Would you share a home with someone who has TB?	No, Unsure	1
		Yes	0
	Would you tell your friends and family if you had TB?	No	2
		Unsure	1
		Yes	0
	What type of person is likely to get TB? (open ended)	Smokers, drunkards	2
		Other responses	0
TB/HIV co-infection stigma Low (or no) stigma: 0-2	Do HIV patients deserve to get TB?	Yes	3
		Unsure	1
		No	0
	Should patients with TB and HIV be ashamed?	Yes	3
		Unsure	1
		No	0
	Would you buy something in the market from	No	3

Medium/High stigma: 3-10	someone who had TB and HIV?	Unsure	2
		Yes	0
	Would you visit someone in their home if you knew they had TB and HIV?	No	2
		Yes	0
	Would you share a home with someone who has TB and HIV?	No, Unsure	1
		Yes	0
	Would you tell your friends and family if you had TB and HIV?	No	2
		Unsure	1
		Yes	0
	Note: no open ended questions were asked to indirectly assess TB/HIV stigma		

Stata10 was used for data analysis. Multistage survey design was controlled for using STATA's "survey" features. These features take into account the number selected versus available sampling units at each level of sampling to account for different sample pools at each level.

The basic formula for this adjustment was:
(nsubcounties/nsubcountiesselectedper district) *(nparishes/nparishesselectedpersubcounty)* (nvillages/nvillagesselecetedperparish) * (npeoplepervillage/npeoppleselectedpervillage).

Where:
nsubcounties: number of sub-counties in Kabarole district
nsubcountiesselectedperdistrict: number of sub-counties selected in the district(6)
nparishes: number of parishes in each sub-county
nparishesselectedpersubcounty: number of parishes selected from each sub-county (3)
nvillages: number of villages in each parish
nvillagesselectedperparish: number of villages selected from each parish (1)
npeoplepervillage: estimated population of each village
npeopleselectedpervillage: number of people selected from each village (20)

Descriptive statistics were used to summarize each questionnaire item. Bivariate student t-test analysis was used to compare HIV and TB summary scores. Because of slightly different questions included in the TB/HIV co-infection stigma score, this score is not directly comparable to scores for HIV and TB stigma. Multivariate logistic regression was used to model predictors of dichotomized (none/low versus medium/high) scores for HIV stigma, TB stigma, and TB/HIV co-infection stigma. A $p<0.05$ was considered for statistical significance. All analyses were adjusted for the multistage survey design using the survey estimation techniques in STATA (13).

Results

Demographics

Of 360 survey respondents, 50.7% (n=182) were female, mean age was 33 years (median 29 years, range 18-84 years). Other demographic information for the survey can be found in Table 3-2. Three women only focus group discussions constituted of a total of 30 women, and three men only focus groups included a total of 31 men. Male participants were slightly older (mean 34 years, median 28 years, range 18-78 years) than female participants (mean 30 years, median 26 years, range 18-58 years). Two focus groups were conducted in an urban area (one male, one female). Urban participants were younger (mean 26 years, median 25 years, range 18-64 years) than rural participants (mean 36 years, median 31 years, range 18-78 years). Demographic description by individual focus group can be found in table 3-3.

Table 3- 2: Demographic characteristics

Variable		n	(%)
Age in years			
	18-24	116	32.2
	25-44	174	48.3
	>=45	70	19.4
Sex			
	Male	177	49.3
	Female	182	50.7
Type of House			
	Permanent	46	12.9
	Semi-permanent	312	87.2
Education level			
	None or Primary	238	66.3
	Some Secondary or higher	121	33.7
Marital status			
	Single	140	38.9
	Living with partner or ever married	220	61.1
Residence			
	Urban	60	16.7
	Rural	300	83.3
Occupation*			
	Farmer/Peasant	167	46.5
	Small business	85	23.7
	Student	25	7.0
	Professional/public sector	22	6.1
	Skilled trades	20	5.7
	Unskilled labour	16	4.5
	Driver/boda boda	6	1.7
	Unemployed/ambiguous	18	5.0

*Note that occupation was not used in regression analysis because of difficulty combining categories.

Table 3- 3: Demographic description of focus group participants

Focus group	Gender	Location	Number of participants	Age in years		
				Mean	Median	Range
1	Male	Fort Portal	11	30	25	(19-64)
2	Female	Fort Portal	11	23	24	(18-28)
3	Male	Bukuuku	9	33	23	(18-70)
4	Female	Bukuuku	11	33	30	(19-52)
5	Male	Kibiito	11	40	38	(22-78)
6	Female	Kibiito	8	36	36	(18-58)

HIV stigma

A variety of direct and indirect questions were asked to assess stigmatising attitudes around HIV in the community. Ninety five percent (n=340) of respondents stated that HIV patients did not deserve to get the disease, the most common reason cited was because HIV is acquired unknowingly (44.6% of respondents, n=157), and that no one wishes to get it (29.0%, n=102). Ninety six percent (n=342) said that HIV patients should not be ashamed, with the most common reason being that they needed treatment (40.7%, n=143). Respondents were also asked whether they felt that nurses treated HIV patients the same as other patients: 5.3% were unsure, 17.1% said that nurses do not treat HIV patients the same, and 77.6% of respondents said yes they do treat them the same. Respondents were asked what type of person is likely to get HIV as an open ended question (multiple responses were allowed). The most common response was “prostitutes” (24.4%, n=88), followed by “anyone” (21.9%, n=79), and then “those who have many partners” (19.4%, n=70). Ninety five percent (n=341) of respondents said that they would buy something from the market from someone who has HIV. Ninety eight percent (n=353) reported that they would visit a friend or neighbour who you know had HIV. Ninety seven percent (n=349) said they would share a home with someone who had HIV. When asked if they would tell their family and friends their status if they were HIV positive, 96.4% (n=345) said they would. Two hundred and fifty nine people (71.9%) had a friend who had told them they were HIV positive.

Distribution of HIV stigma scores are described in table 3-4. Stigma scores were dichotomised into none/low stigma versus medium/high stigma. Twenty six percent (n=93) of respondents had higher HIV stigma. Univariate logistic regression showed that having a friend who has disclosed that they are HIV

positive was the only significant predictor (table 3-5). This remained the only significant predictor in a multivariate logistic model containing age, sex, education, marital status, and place of residence. Those who have had a friend or family member tell them they have HIV have an odds ratio of 0.38 of having stigma compared to those who have not had a friend or family member tell them they have HIV.

Table 3- 4: HIV stigma score distribution

	Score	HIV stigma
None	0	27.8% (n=100)
Low stigma	1-2	46.4% (n=167)
Medium	3-4	18.6% (n=67)
High stigma	5-10	7.2% (n=26)

Table 3- 5: Univariate and multivariate logistic regression of HIV stigma

		Univariate analysis		Multivariate analysis	
Variable		Odds ratio (95% CI)	p	Odds ratio (95% CI)	p
Age	18-24	1.0		1.0	
	25-44	0.88 (0.42-1.83)	0.678	0.91 (0.46-1.78)	0.731
	>=45	0.74 (0.31-1.76)	0.418	0.79 (0.32-1.98)	0.539
Education	Primary or less	1.0		1.0	
	Secondary or higher	1.12 (0.50-2.51)	0.722	1.17 (0.49-2.82)	0.663
House**	Mud walled	1.0		-	
	Concrete walled	2.10 (0.57-7.73)	0.202	-	
Sex	Male	1.0		1.0	
	female	1.50 (0.73-3.09)	0.211	1.52 (0.69-3.33)	0.230
Marital status	Single	1.0		1.0	
	Ever married	1.14 (0.49-2.69)	0.702	1.39 (0.21-0.68)	0.387
Residence	Rural	1.0		1.0	
	Urban	0.95 (0.46-1.98)	0.860	1.18 (0.486-2.87)	0.650
Has an HIVpositive friend	No	1.0		1.0	
	Yes	0.38 (0.22-0.67)	**0.008**	0.38 (0.21-0.68)	**0.008**

**Not included in model because of collinearity

Focus group discussants held a variety of opinions around HIV stigma in their communities, some believed stigma was no longer an issue, but others felt stigma was still a significant problem.

Decline of stigma

Some respondents felt that stigma had reduced in their community. HIV has become a very common disease, and some respondents felt that because so many people are affected, patients are no longer stigmatized. "*Some people don't have stigma because almost everyone in the community is on HIV drugs and people are aware of it [HIV]." (rural female)* Another respondent repeated a common saying: "*I can't laugh at an HIV positive person, he/she is neither the first person to be infected with HIV nor the last." (rural female)* HIV has been normalized as a regular disease, as one respondent pointed out: *"People no longer have stigma because HIV/AIDS is like any other disease such as malaria." (rural female)*

One of the major drivers of stigma reduction seems to be access to antiretroviral drugs. Treatment is readily available and because the dramatic effects of ART on patients are well known, people understand the benefits of coming forward for testing and treatment. One respondent outlines the benefits of disclosing one's status:

> *"If you disclose [your HIV status], maybe you can get treatment and help from your family members. If you keep it to yourself, you may incur difficulties in the future. People are no longer ashamed of HIV, I can disclose my HIV status to anyone." (rural female)*

Drugs have reduced the fear surrounding HIV and so it is no longer considered an immediate death sentence by communities.

> *"The community is no longer ashamed of HIV. If I am tested positive, I can go for my drugs freely and take them openly when everyone is watching me." (rural female)*

In addition, people seem to have internalized the HIV campaigns promoting "living positively" with HIV, as one respondent mentioned:

> "*Most people are interested in HIV testing and they don't have stigma. If tested positive they are started on drugs, most of them have learnt how to live positively: they no longer fear." (rural female)*

Respondents were all very aware of the concept of stigma, and would freely use the term. However, there seems to be an interesting twist of the concept by some respondents: some people seemed to focus on the individual level stigma experienced by patients as a sort of negative character flaw that must be overcome. This seemed to frame stigma as the patient's fault. As one respondent stated: *"If you get stigma and fail to take drugs you end up dying." (rural female, 21)* and another participant echoed this idea:

> *"If you get stigma, you won't be helping yourself in any way. You must visit the hospital and get drugs so that your life span is extended." (rural female)*

Some respondents agreed that stigma was decreasing in their communities, but perceived a negative consequence of reduced stigma to be a decline in motivation to prevent HIV transmission. Respondents discussed the lack of fear and stigma having resulted in people not using condoms to prevent themselves from being infected. This was especially thought to be true amongst the youth, as one respondent outlined:

> "*But when you meet the youth, they tell you that they fear to become pregnant [more] than they fear Silimu [AIDS]. They say that as long as the drugs for AIDS are now available, even if they get HIV/AIDS, they will go to the hospital and get the drugs. People have developed a tendency of not fearing to catch HIV/AIDS as long as they know that the drugs are now available. The old people still fear to catch AIDS, but for the youth that fear is no longer there." (rural male)*

Stigma is still an issue

Many focus group discussants felt that stigma was still an ongoing concern in their communities. Conversations around stigma show that it is still a problem and were almost always phrased in third person recounts of what other people think and do. One exception was a comment by a woman who stated that "*HIV is a shameful disease." (rural female)*

Much of the discussion around stigma focused on accessing health services. Respondents felt that stigma was a barrier for many people to get tested and go for treatment. One participant explained:

> "*There's stigma in villages. […] There are people who refuse to go for treatment completely, they say "where did I contract AIDS from, I don't have it." They stay in villages till they die. Even if you try to convince him/her to go hospital he/she won't accept, instead he/she hates you more. This is because they have stigma." (rural female)*

Another woman recounted a similar situation:

> *"People have stigma even [in our village] there's a widow whose husband died of AIDS, but when they advised her to go for check up at the health unit, she refused. She fears being known that she is HIV positive." (rural female)*

People are scared that if they are seen at the hospital, their village mates will know they have HIV, as one respondent outlined:

> *"That's how it is, people still have stigma. HIV victims don't disclose their status, they even fear going for drugs in hospitals and [getting blood drawn for tests]. They say "How will the community perceive it? Maybe they will think I am HIV positive." He/she stays in the village yet he/she is HIV positive but ignorant." (rural female)*

This fear of being seen at the local clinic leads some patients to seek services far away from their village so they won't be recognized. One woman describes patients who travel from the next district three hours away to seek care:

"And now due to stigma we heard that people from Kasese come for check up in Fort Portal because they don't know him/her [there]. That shows someone has stigma." (urban female)

Another woman had a similar story of patients travelling up to five hours through the mountains instead of seeking care in their own district:

"There is still a lot of stigma because you find a person traveling all the way from Bundibugyo to Buhinga referral [hospital] just for a check-up of AIDS. He doesn't want people from home to know [that he had AIDS], so he comes here where they don't know him." (urban female)

This also results in patients seeking lower standard of care because they feel the likelihood of being recognized in the main hospitals is too high:

"Yes most people have stigma, they fear to go for check up in the hospital. They say that there are people [at the hospital] who know him/her: "They know me I will not go and test from there." He will look [instead] for a hospital where he wants [far away], or he may go to small clinics." (urban female)

Reluctance to seek medical help stems from an expectation of being mistreated by village mates and friends.

"Stigma is there in the villages. You may find someone with HIV, signs are seen but he refuses to go to hospital and check to know his status. Many people in the village are talking about him and finger-point at him "that one is sick!" That's why most people fear to go and test." (rural male)

Focus group respondents reported that there is still segregation and ostracism towards HIV patients. Respondents felt that some people would visit an HIV patient, but others would avoid going near them. One participant reflected that *"even nowadays when you tell someone that you are suffering from Silimu [AIDS], they will never come back to your house." (rural male)* Another respondent had a similar view:

"Most people fear HIV/AIDS. Some think when they are infected with it their friends and relatives will segregate them. They fail to disclose their status when [they are] tested positive wanting to be considered as someone negative." (rural female)

TB stigma

The same questions assessing stigma that were asked about HIV infection were also asked in relation to TB. Ninety three percent (n=334) of respondents stated that TB patients did not deserve to get the disease, the most common reason cited was because TB is acquired unknowingly (49.4% of respondents, n=178). Ninety four percent (n=340) said that TB patients should not be ashamed, with the most common reason being that they needed treatment (42.5%, n=153). Respondents were also asked whether they felt that nurses

treated TB patients the same as other patients: 6.7% (n=24) were unsure, 16.1% (n=58) said that nurses do not treat TB patients the same, and 75.3% (n=271) of respondents said yes they do treat them the same. Respondents were asked what type of person is likely to get TB as an open ended question (multiple responses were allowed). The most common response was “smokers” (59.4%, n=214), followed by “drunkards” (38.3%, n=138), and then “anyone” (14.4%, n=52). Eighty six percent (n=311) of respondents said that they would buy something from the market from someone who has TB, however of these 10.9% qualified their response, for example by saying they would only buy packaged goods like soap, but not food. Ninety five percent (n=341) reported that they would visit a friend or neighbour who they knew had TB, and 94.7% (n=340) said they would share a home with someone who had TB, but 6.1% of these qualified this by stating only if it was a close family member. When asked if they would tell their family and friends their status if they had TB, 97.8% (n=352) said they would. Seventy five percent of respondents (n=270) knew someone who had had TB.

TB stigma score distribution is described in table 3-6. Forty seven percent (n=170) of respondents were classified as having medium/high TB stigma. This was significantly higher than the 25.8% of respondents that had medium/high HIV stigma ($p< 0.0001$). In the univariate analysis having a secondary education or higher was the only significant predictor of TB stigma, and remained the only significant predictor in a multiple logistic regression model containing age, sex, marital status, place of residence, and knowing someone with TB (*Table 3-7*). Those who had a secondary education or higher were half as likely to have medium/high TB stigma as those who had only primary education or less (OR 0.53).

Table 3- 6: TB stigma score distribution

	Score	TB stigma
None	0	24.4% (n=88)
Low stigma	1-2	28.3% (n=102)
Medium	3-4	32.2% (n=116)
High stigma	5-12	15.0% (n=54)

Table 3- 7: Univariate and multivariate logistic regression analysis of TB stigma

		Univariate analysis		Multivariate analysis	
Variable		Odds ratio (95% CI)	P	Odds ratio (95% CI)	p
Age	18-24	1.0		1.0	
	25-44	0.79 (0.40-1.54)	0.402	0.86 (0.39-1.91)	0.653
	>=45	1.65 (0.72-3.76)	0.178	1.66 (0.65-4.27)	0.227
Education	Primary or less	1.0		1.0	
	Secondary or higher	0.50 (0.28-0.91)	**0.031**	0.53 (0.29-0.97)	**0.043**
House**	Mud walled	1.0		-	
	Concrete walled	1.90 (0.71-5.01)	0.153	-	
Sex	Male	1.0		1.0	
	female	1.35 (0.86-2.11)	0.149	1.24 (0.75-2.03)	0.319
Marital status	Single	1.0		1.0	
	Ever married	0.92 (0.54-1.57)	0.708	0.82 (0.46-1.45)	0.415
Residence	Rural	1.0		1.0	
	Urban	0.60 (0.31-1.17)	0.107	0.77 (0.37-1.57)	0.386
Knows someone with TB	No	1.0		1.0	
	Yes	0.65 (0.30-1.42)	0.217	0.62 (0.28-1.38)	0.188

**Not included in model because of collinearity

Focus group participants discussed the causes, manifestations, and current situation around TB stigma. Respondents held differing views on the extent and importance of TB stigma; many believed it was a major problem for TB patients, others believed that TB patients were treated well in the communities and that stigma was not an issue.

Factors contributing to TB stigma

Stigma around TB stems in part from a fear of infection that leads people to avoid TB patients. As one participant explains:

> *"People fear TB very much because TB kills quickly and if TB is not treated early […]then it kills you, and everyone starts running away from you. Our people fear TB very much." (rural male)*

Unlike for HIV, respondents were willing to personally state that they would not visit a TB patient. *"Me, I can't go there to tell you the truth. I can't go there." (rural female)* Another woman had a similar view, and offered an explanation as to why she would not visit:

> *"Me, I can't go there because if you happen to go there you need to talk and comfort that patient, in the process of doing so he/she may cough and you will get infected with TB." (rural female)*

This fear of infection leads to isolation and ostracism of TB patients. One woman shared a personal story of her experience with a TB patient:

> *"In our village we've been having a TB patient, […] we used to avoid visiting the patient, he was our grandfather, we used to fear visiting him at his home. When we took him food, if he was still asleep in his bedroom we would serve food on the table then call him and run away. He just finds food on the table not knowing who brought it there." (rural female)*

Another aspect contributing to stigma is the association between TB patients and certain negative attributes. Participants consistently associated TB with smoking and drinking ("immoral behavior") but also referred to TB patients as being dirty:

> *"If that person is clean I could visit him/her. But if I hear that those people are unhygienic I would avoid going there." (rural female)*

When asked what difficulties or problems TB patients might face in getting treatment, one man responded (and was echoed by others in the group*) "They don't have any difficulty except they are lazy." (urban male)*

TB is understood by many to be a hereditary disease, passed from parents to children and running in families. As a result, certain families are thought to be "TB families" and people do not want to marry in to those families. The stigma surrounding TB therefore affects not just the patient, but also the entire family:

> *"Nobody wants to admit that he/she is sick so that it brings blame to him or to his family, they instead keep the disease a secret." (rural male)*

In addition, TB stigma doesn't end when the patient is cured. Because it is considered to be hereditary, otherwise healthy family members are stigmatized:

> *"There were about three patients but the good chance they went and got treatment and got cured now they live with family members nicely but when the children cough people move a distance they fear them." (urban male)*

Focus group participants felt that the stigma surrounding TB caused many TB patients to remain silent about their disease.

> *"Most people have TB stigma and they can't disclose their status to anyone, […] they fear talking to their friends about it." (rural female)*

This also translates in relational issues within couples, if the man refuses to test, a woman may have to take her TB treatment in secret out of fear of her husband finding out:

> "*When [a person] starts taking TB drugs, she may not tell village mates[…], she can't even disclose it to her spouse. I've heard of that instance, she feared telling her husband that she was started on drugs. Some women keep it to themselves."(rural female)*

Respondents understood that remaining silent about TB could have negative consequences and lead to ongoing transmission.

> *"So much TB stigma exists in villages. When you get cough, you can't tell your friend, even if that cough is persistent and treated in all the hospitals but you aren't getting cured. You keep it to yourself, when you are found with TB you can't disclose it instead you remain silent and infect other people." (rural female)*

In addition to remaining silent about their condition, the stigma experienced by some TB patients results in them not seeking treatment.

> *"TB disease, it depends on the stigma because some people refuse, they stay in the village and they refuse to be given treatment." (rural female)*

Another respondent echoed this, highlighting the point that stigma leads to patients not presenting at hospitals for treatment:

> *"Some people have stigma and don't want it to be known that they are suffering from TB. Because of stigma they fear going to hospitals for treatment." (rural female)*

TB stigma is not a major issue

While many respondents discussed TB stigma and factors around it, some respondents disagreed and felt that TB stigma was not a big problem. Some of the respondents that felt that there wasn't much stigma around TB felt that this was because the disease wasn't as common as HIV.

> *"TB is not very common and very few are suffering from it, so I don't know if people still have stigma, but they don't fear TB as they do fear HIV." (urban female)*

Another reason offered was that because TB is curable, the stigma associated with fatal diseases wasn't there.

> *"With TB, people have less stigma [compared to AIDS] because he/she knows that if he/she starts medication it may be cured." (urban female)*

Respondents professed a certain amount of compassion for TB patients when discussing stigma and isolation. They discussed the importance of visiting patients and not isolating them. One woman described how she would help a TB patient:

> *"I can stay with the TB patient and nurse her. If she is your friend, you give her money for maintenance like 10000 shillings [$4]." (rural female)*

Another respondent mentioned other types of support:

> *"You can visit that person, you can help with house work. Can you leave that person to suffer because he/she has TB? If you isolate the patient and run away from him/her who will offer help when he/she is in need? You shouldn't isolate him/her so much." (rural female)*

Other participants felt that it was their duty to visit and give the patient advice and counseling. Some thought that it was important to visit to tell the patient

not to smoke or drink alcohol, and not to share utensils. Others mentioned the importance of encouraging the patient to take their tablets.

> "*I can visit the TB patient, except I wouldn't spend a lot of time with him, and I wouldn't come close to him. But I can visit him and speak nicely to him, I encourage him to take drugs and I give him hope that he may be cured and everything will be okay." (urban female)*

An interesting reflection by one respondent was that so long as TB patients didn't hide their disease and take "preventive measures", her village mates didn't stigmatize.

> "*No, they used not to isolate him because everyone in the village knew he had TB. He was aware of his status and he used to move with his own utensils. We used to like him because he wasn't hiding the disease, he would say "no, don't give me food from your plates just serve me on a banana leaf that's where I will eat from". (rural female)*

TB/HIV co-infection stigma

The same questions assessing stigma that were asked about HIV infection and TB were also asked in relation to TB/HIV co-infection. Eighty one percent of respondents (n=289) stated that HIV patients did not deserve to get TB. Ninety two percent (n=330) said that co-infected patients should not be ashamed, with the most common reason being that they needed treatment (37.5%, n=135). Respondents were also asked whether they felt that nurses treated co-infected patients the same as other patients: 5.3% (n=19) were unsure, 18.4% (n=66) said that nurses do not treat TB/HIV co-infected patients the same, and 76.3% (n=273) of respondents said yes they do treat them the same. Eighty eight percent (n=317) of respondents said that they would buy something from the market from someone who has both TB and HIV. Ninety six percent (n=346) reported that they would visit a friend or neighbour who they knew had both TB and HIV. Ninety four percent (n=340) said they would share a home with someone who had TB and HIV. When asked if they would tell their family and friends their status if they had TB and HIV, 97.2% (n=349) said they would. Sixty eight percent of respondents (n=243) knew someone who had had TB and HIV. Respondents were asked if they thought most people fear TB or HIV more: 72.2% (n=260) answered HIV, 10.8% (n=39) answered TB, 10.8% (n=39) answered "both", and 5.8% (n=21) answered "neither". When asked if they thought TB stigma was worse because of HIV, 71.4% (n=257) said yes, 18.6% (n=67) said no, and 10.0% (n=36) were unsure.

TB/HIV stigma score distribution is described in table 3-8. Twenty one percent (n=64) of respondents were classified as having medium/high TB/HIV co-infection stigma. Univariate analysis found place of residence to be border line significant as a predictor for TB/HIV co-infection stigma: urban residents were

less likely to have medium or high HIV/TB stigma than rural residents. However, in the multivariate logistic regression model containing age, education, sex, marital status, place of residence, and knowing someone with TB and HIV, no significant predictors were found. (Table 3-9)

Table 3- 8: TB/HIV stigma score distribution

	Score	TB/HIV stigma
None	0	67.2% (n=242)
Low stigma	1-2	12.2% (n=44)
Medium	3-4	13.6% (n=49)
High stigma	5-10	6.9% (n=25)

Table 3- 9: Univariate and multivariate logistic regression analysis of TB/HIV stigma score

		Univariate analysis		Multivariate analysis	
Variable		**Odds ratio (95% CI)**	**P**	**Odds ratio (95% CI)**	**p**
Age	18-24	1.0		1.0	
	25-44	0.84 (0.39-1.79)	0.585	0.79 (0.37-1.69)	0.457
	>=45	1.02 (0.44-2.37)	0.945	0.91 (0.36-2.34)	0.825
Education	Primary or less	1.0		1.0	
	Secondary or higher	0.50 (0.20-1.22)	0.101	0.52 (0.21-1.27)	0.119
House**	Mud walled	1.0		-	
	Concrete walled	2.23 (0.61-8.15)	0.172	-	
Sex	Male	1.0		1.0	
	female	0.97 (0.41-2.29)	0.928	0.85 (0.33-2.17)	0.667
Marital status	Single	1.0		1.0	
	Ever married	0.95 (0.39-2.34)	0.896	0.83 (0.29-2.36)	0.669
Residence	Rural	1.0		1.0	
	Urban	0.40 (0.15-1.07)	**0.062**	0.51 (0.17-1.48)	0.163
Knows someone with TB and HIV	No	1.0		1.0	
	Yes	1.42 (0.78-2.59)	0.191	1.33 (0.70-2.54)	0.308

**Not included in model because of collinearity

One major clear and consistent theme emerged through the focus group discussions around TB/HIV co-infection stigma. Because of the strong association between the two diseases, people fear being tested or diagnosed with TB because they assume it means that they are also HIV positive. *"Yes, there's TB stigma in villages because if I am diagnosed with TB, I will think that I have HIV too. Its true there's much TB stigma." (rural female)*

When asked if people fear to test for TB because it is one of the signs of AIDS, one young woman had the following response:

> "*Yes because he knows when he goes [to the clinic] and they find out that he is HIV positive, also TB will be there. He thereby fears to go [to the clinic] and stays in the village and ends up dying, even spreading more the disease because he has feared to go to the hospital. He starts raping children and old people, he wants to spread it to the village then at the end he dies as a result of that." (urban female)*

The fear and stigma of TB seems to be driven by the associated fear of HIV, as illustrated by the following quotes:

"TB patients fear going for check up thinking that they will be tested HIV positive. They refuse to visit hospitals and keep it to themselves. You advise them saying "please go for check up if you are found with TB, health workers can give you TB drugs," but they just look at you" (rural female)

"There's TB stigma in the community because when a TB patient goes to hospital two tests must be conducted and when they are found HIV positive they get so scared." (rural female)

"People fear TB very much because it has signs. When you are suffering from it you start coughing, they may say "that so and so has HIV." They take TB to be HIV, they don't take it to be TB." (rural male)

Discussion

HIV stigma

Two conflicting themes emerged surrounding HIV stigma. 1) That HIV stigma is declining because of normalisation and availability of treatment, and 2) that HIV stigma is still a major barrier to seeking health services.

Seventy five percent of respondents were classified as having a low HIV stigma score. This is encouraging and suggests that political commitment and focus on stigma reduction have been having an effect in Kabarole district. Individual questionnaire items that directly asked about stigmatising views (ex. Do HIV patients deserve to get it?) had very low rates of stigmatising responses, usually less than 5%. Another encouraging aspect was that 72% of respondents had had a friend or family member disclose that they were HIV positive. This personal experience with HIV patients was the single significant predictor of lower HIV stigma. This is different from other studies which have found literacy, socioeconomic status and gender to be important factors predicting HIV stigma (14). This indicates that stigma reduction campaigns focussing on disclosing your status and "living positively" with HIV have been effective. Focus group discussants supported these views, feeling that because HIV was so common now, it was considered a "normal" disease and the stigma was less. This seems logical, that as the number of HIV cases has increased, stigma has reduced since it is considered a disease like any other. They also felt that stigma was reduced because of the availability of treatment. One worrisome theme that emerged during the focus group discussions was that stigma reduction was having a negative effect on prevention; because people no longer fear HIV infection they are not protecting themselves. This is thought to be especially amongst the youth.

Conversely, some of the indirect questions on the survey captured unexpected aspects of stigma. When asked what type of person was likely to get HIV, the most common response was "prostitutes" (24%), and many people answered "those who have many partners" (19%). This indicates there is still a strong association between HIV infection and promiscuity and "immoral" choices. Although this is accurate epidemiologically, the moral judgment associated shouldn't be ignored. The most prominent theme that emerged from the focus group discussions around HIV stigma was that stigma is still a major barrier to accessing health services. There is a consistent fear of being recognised at the clinic. Similarly, a study in South Africa found that the fear of being seen at the HIV clinic overrode the potential benefits of treatment (15). This fear is probably exacerbated by health clinics' model of having designated days for HIV patients. This procedure of separating out HIV patients on one or two designated clinic days instead of having them integrated into the normal clinic hours may be more efficient for the staff, but it makes it very easy to identify which patients are HIV patients. The health care system should develop infrastructure that allows higher confidentiality. Integrating TB and HIV services into routing care (instead of having vertical segregated programming) would be helpful. The fear of being recognised at the clinic results in many patients travelling far distances to attend a clinic where they are less likely to run into someone they know. Distance to health centres has been shown to be a major barrier to ART (antiretroviral therapy) adherence, and so this self-imposed distance caused by stigma will likewise have negative effects on adherence. The fear of being seen at clinics and identified as HIV positive stems from a fear of negative treatment by other villagers. Focus group discussants felt that friends and neighbours spread rumours and "finger-pointed" at HIV patients, and that HIV positive individuals were still segregated. Respondents also felt that stigma was worse for men, and for the rich and educated.

TB stigma

To our knowledge, this is the first attempt to quantify TB stigma in Uganda. This information will be useful for the district health department in Kabarole, and could serve as a baseline for future intervention evaluations. TB stigma was much higher than HIV stigma, with 47% of respondents classified as having medium/high TB stigma (versus 25% medium/high HIV stigma). This result is similar to a study in Ethiopia that found that 56% of people had high prejudice towards TB patients, but only 24% had high prejudice towards HIV patients (14). However, several international studies have found the opposite to be true, that HIV stigma is more significant than TB stigma (16-20). The open ended question asking what type of people were likely to get TB was especially telling: fifty nine percent of people said "smokers", and 38% said "drunkards". It is worrisome that TB is so strongly associated with behaviours perceived in this setting to be immoral. Although smoking is an established risk factor for TB, the moralistic judgements surrounding smoking in this context are contributing to

stigma. This strong association between TB and smoking and drinking has previously been reported in South Africa, and smoking has been linked with TB elsewhere in Uganda (21, 22).

The only significant predictor of lower TB stigma was higher education. Literacy was also found to be a significant predictor of lower prejudice in Ethiopia (14). The lack of other predictors indicates that TB stigma is widespread across the general community and any intervention would be best to have a general approach and community-wide target.

The qualitative inquiry provided some insight into what is driving the higher stigma around TB in this population. Focus group participants felt that TB stigma came mostly from a fear of infection. This is similar to another qualitative study in Uganda that found that TB patients were feared and discriminated against because of a fear of airborne infection (22). Other studies in Ghana and Zambia have also found that one of the main causes of TB stigma was fear of infection (7, 23). Stigma also stemmed from a perception of TB patients having negative attributes such as dirtiness or laziness. A study in Zambia found that TB patients were considered careless and to blame for their infection because of their own social transgressions (7). Participants perceived several serious consequences of TB stigma. Because people believe that TB is a hereditary disease, TB stigma affects not just the patient but also his or her whole family. Long after the patient has been cured (or died), the family is considered to be a "TB family" to be avoided. Likely the most serious consequence of stigma was also one of the strongest themes: TB patients remain silent about their condition. This results in major problems for TB control, as patients will not seek treatment, or will delay seeking treatment until their disease becomes very advanced, thus continuing disease transmission in the community. For those that do seek treatment, lack of disclosure will make it difficult to adhere to the full course of antibiotics. A study in South Africa found that stigma was the most common problem that patients face in accessing and adhering to treatment (24).

TB/HIV co-infection stigma

Close ended stigma questions showed similar answers for co-infection as for HIV, and slightly lower stigma than for TB alone. No open ended questions were used to elucidate co-infection stigma, which is part of the reason co-infection stigma was found to be lower than HIV or TB stigma alone, since for HIV and TB alone the open ended question of "What type of person is likely to get (HIV or TB)?" was one of the major indicators of stigma. It is also likely that a certain compassion and empathy was evoked when participants were asked about someone with two different diseases. Nevertheless, results for co-infection stigma were unexpected; our hypothesis was that effects of stigma around HIV and TB would be multiplicative. It is very surprising that co-infection

knowledge is lower than for TB alone. One possible explanation would be that TB is considered part of HIV anyway, and so when asked about co-infection people feel the same way about those patients as they do about HIV patients. This "masking" of TB stigma within HIV merits further investigation.

No significant predictors were found for co-infection stigma in the multivariate models. However, the lower odds ratios (although non-significant) were found for higher education and urban residence. This suggests that individuals with secondary education or higher may have lower TB/HIV stigma, and that those living in urban areas may have lower TB/HIV stigma. The analysis of this study component does not have enough power to determine whether effects are true.

Seventy one percent of people thought that TB stigma was worse because of HIV. This key question was echoed strongly in the qualitative assessments. One clear and consistent theme emerged from the focus group discussions: people fear being tested for or diagnosed with TB because they assume that TB means they are HIV positive. This has been previously reported amongst TB patients in Uganda: 46% felt that their neighbours thought they had HIV because of TB (10). This assumption that TB patients must have HIV has also been observed in Ethiopia, Rwanda, and Zambia (7, 14, 19, 25). One of the main causes of TB stigma in Ghana was found to be its association with HIV/AIDS (23). This is in part due to similar signs and symptoms in both diseases such as extreme weight loss, and the awareness that the two diseases are linked (23). This association may be contributing to low case finding rates in Kabarole district, and poor adherence of patients. HIV stigma and fears about being labelled as HIV positive have been shown previously to deter TB patients from seeking care (26). In addition, stigma associated with TB and its association with HIV was found to be a common reason for TB treatment default in KwaZulu-Natal, South Africa (4).

Health system policies do nothing to discourage this belief since it is standard procedure for all TB patients to be (very strongly) encouraged to get tested for HIV. In addition, because of the low priority set on TB education, the only information and messaging that people receive about TB is within HIV messaging. It is therefore not surprising that TB is so inseparable from HIV infection in people's understandings. In South Africa, stigma associated with TB had decreased when a cure was found, but became re-stigmatised as a marker of AIDS (21). Bond et al. also highlight the importance of addressing TB/HIV stigma in order to improve treatment seeking and adherence (7).

Limitations

This study has several limitations. The questionnaire used was developed by the study team with significant local input, but a previously validated questionnaire was not used. This study investigated two separate diseases and the interaction between them, so existing stigma measurement instruments were not available. Several instruments evaluating HIV/AIDS stigma have been developed: in systematic review of 14 studies, only one tool was used in Africa and the results were unpublished. The majority of instruments used in the United States (27) and so are not easily applicable to the Ugandan context. Previous assessments of TB stigma have been mostly qualitative. A systematic review of TB stigma literature recommended that an assessment tool be developed and validated for use in varied cultural contexts (28) but no such instrument is available as of yet. During analysis, responses were weighted to form summary scores and cut points were chosen to dichotomise between no/low and medium/high stigma. Although done in partnership based on professional experience and an understanding of the issues and data, this weighting was nonetheless subjective and constitutes a limitation. This was mitigated in several ways. The survey developed for this study showed to be reliable through test-retest. Multiple local key informants had input in the survey development and felt that the questions measured the concepts accurately. Triangulation with qualitative results also validated the results. Finally, results were presented to the district health department in Kabarole on a return trip to Uganda which further validated the finding through member-checking.

While the multistage cluster sampling technique used gives a good representation of the district, it is important to note that two sub-counties located high in the mountains were not included in the sampling pool for logistical reasons. Thus results cannot be generalized to the most remote areas of the district. Results may not be representative of other districts in Uganda, where educational messaging and district priorities may be different. In addition, because participants were recruited during on weekdays during the day, there may be an under-representation of individuals employed in the formal sector since they would not have been home during the day.

Qualitative data was limited by the delays required to transcribe and translate the discussions from Rutooro to English. As such, it was not possible within the time limits of field work to analyze this data iteratively before conducting subsequent discussions.

It is possible that social desirability bias played a role in the low levels of stigma observed in the survey results. Many of the questions were close ended (yes/no), and it may be that respondents were aware of what the “correct” non-stigmatising answer was supposed to be. The open ended question around what type of person is likely to get HIV indicates that there is slightly more stigma in this population than indicated by the close ended questions. The language used

during the focus groups also give some clues; when discussing non- stigmatising views respondents often used first person statements and spoke about what they have done or would do, but when speaking about stigmatising behaviours respondents invariably used third person statements to discuss what other people thought and did.

Conclusions and Recommendations

Low levels of HIV stigma and a perceived decline are encouraging. It appears that an increasing number of HIV cases have resulted in a "normalisation" of the disease. In addition, campaigns around "living positively" with HIV appear to have been effective. We recommend that these efforts be continued. There is still a strong fear of being seen at the clinic and identified as HIV positive. More effort needs to be put into maintaining patient confidentiality. Integrating HIV services into regular clinic care, instead of having segregated days for ART clinics, would help to reduce the likelihood of patients' HIV status being identified.

TB stigma is high. More commitment and focus on TB stigma reduction is required. Educational campaigns addressing some of the key myths perpetuating stigma, such as "drunkards" being the ones to get TB, should be attempted. The misconception that TB is a hereditary disease needs to be addressed. In addition, campaigns around "living positively" with TB, with an emphasis on the curability of TB, would help patients to be open and seek treatment early.

Awareness needs to be raised about TB being a disease on its own, separate from HIV. Any educational messages around TB should also include the key message that TB can affect HIV negative individuals as well.

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Chapter 4: Conclusions and Recommendations

Conclusions

HIV infection:

This study found lower HIV knowledge than previously reported in the region, but still high overall with good knowledge about sexual transmission and condom use. HIV knowledge was significantly higher than TB knowledge in this sample. HIV stigma was found to be low overall, and focus group participants felt that HIV stigma was declining. This is attributed both to the availability of treatment, and to a high HIV prevalence in the area resulting in "normalization" of the disease.

There are still some key areas of lower HIV knowledge and persisting HIV stigma. Very few people mentioned mother to child transmission as a way to become infected with HIV. Knowledge of mother to child transmission has been shown to be important in the general population, not just in pregnant mothers, and so addressing this gap in knowledge will be important in reducing new infant infections. HIV stigma, although perceived to be declining, is still a barrier to treatment. The fear of being seen at the clinic by friends or neighbours (and so then labelled as HIV positive) is a major deterrent for seeking health services. This results in many people travelling long distances to visit clinics outside of their area. This is a result of the low priority placed on confidentiality at clinics. Designated ART clinic days mean that anyone seen at the clinic that day is known to be HIV positive. Health services need to be re-structured with patient confidentiality as a priority. These changes could be done easily without requiring additional funds.

One worrisome finding from the focus group discussions was that with the growing availability of ART, the fear of HIV is decreasing, and with it the motivation to prevent infection. Participants felt that people, especially youth, were no longer protecting themselves from contracting HIV because treatment is readily available. Efforts to promote the importance of HIV prevention should not be relaxed as treatment becomes the focus of the district HIV program.

Tuberculosis:

Overall, TB knowledge was low and stigma was high. This is indicative of the neglect that TB programs have faced in recent years. One of the significant predictors of higher TB knowledge was older age (≥45 years), which suggests that previously functional TB educational programs have not been sustained since the onset of the HIV epidemic. To our knowledge, no current programs address TB knowledge or stigma specifically in Kabarole district. Current

messaging around TB is only within HIV programming where TB is listed as a symptom of HIV, which explains why TB/HIV co-infection knowledge was found to be higher than knowledge of TB alone.

We found several misconceptions which have the potential to negatively influence TB care. The first, and likely the most important, is that many people believe that TB is not curable. Some people think that TB is not curable in any type of person, others distinguish between HIV positive and negative individuals and believe that TB cannot be cured in HIV patients. Some believe that TB cannot be cured if it is "inherited" from family members. Regardless of the specific details of the misconception, the belief that TB is incurable will certainly have serious effects on case finding and health seeking behaviour. If people don't believe they can be treated, they will not seek health services. This should be the main message in future TB awareness campaigns.

The second misconception that must be addressed is the concept of "inherited TB". While this may be stemming from a partial understanding of latent TB infection, the effects may contribute to increased stigma and are detrimental to health seeking behaviour. Family members of TB patients face stigmatisation and lifelong labelling, even after the patient has been cured.

Third, general understandings of TB symptoms are limited. Most people know that cough is a symptom of TB, but very few people recognise weight loss or night sweats and fever as TB symptoms. This is problematic in a high HIV prevalence context since extra-pulmonary TB (without cough symptoms) is more common in HIV patients. This study also found that TB is associated with a very serious set of symptoms, and minor symptoms are assumed to be a "normal cough" for which health services are not sought.

Finally, there are many misconceptions around TB transmission including sharing cups, smoking, drinking. One of the major drivers of TB stigma is the fear of infection. Directly addressing these misconceptions and informing people that TB is airborne may not be the best strategy since it could increase stigma and fear of infection. Instead the main message should be that TB patients are no longer infectious after two weeks of treatment. This message would have the dual role of reducing stigma around TB patients, and encouraging patients to seek treatment early instead of remaining silent at home.

Co-infection with HIV and Tuberculosis:

Surprisingly, we found higher co-infection knowledge than TB alone, and lower co-infection stigma than either TB or HIV alone. This is contrary to our expectation that TB/HIV co-infection would not be well understood in the general population, and that HIV and TB stigma would have a multiplicative effect. The higher co-infection knowledge compared to TB knowledge can be

explained by the fact that HIV education is a major priority, and some TB education (about TB as a symptom of AIDS) has been included in HIV messages. Although not designed to target co-infection specifically, these campaigns have provided more information than has been available about TB alone. This also explains the strong and consistent perceived association between TB and HIV. Many people assume that TB patients must automatically be HIV positive also. The finding that co-infection stigma is lower is more difficult to explain. It may be that respondent felt a heightened sense of sympathy for patients with both diseases when asked stigma questions about co-infected people. As a result of these findings, we do not recommend educational interventions around TB/HIV co-infection, instead we recommend that campaigns be designed around TB as a disease on its own.

Recommendations

We make the following recommendations based on our study results:

Health services:

- **Improve patient confidentiality at health clinics**.
- **Increase integration of HIV and TB health services into regular health care services.**

There is still a strong fear of being seen at the clinic and identified as HIV positive. Integrating HIV services into regular clinic care, instead of having segregated days for ART clinics, would help to reduce the likelihood of patients' HIV status being identified.

Recommendations for educational campaigns:

- **Continue HIV campaigns around "living positively" with HIV**.
- **Emphasise mother to child transmission of HIV.**

Having a friend or family member disclose that they are HIV positive was found to be the single significant predictor of lower HIV stigma, so campaigns that encourage status disclosure should be continued. Knowledge of mother to child transmission of HIV was low, and is important in the general population to prevent infant infections.

- **More commitment to TB education and awareness is needed**.
- **Target youth and urban populations.**

- Key messages for TB awareness campaigns should be:
    - **TB can be cured**.
    - **TB can be cured even in HIV positive patients.**
    - **It is very important to seek treatment for TB early.**
    - **TB does not mean HIV: HIV negative people can get TB too.**
    - **Weight loss and night sweats are symptoms of TB, not only cough.**
    - **TB patients are not contagious after two weeks on treatment.**
    - **Everybody can be infected with TB.**
    - **TB is not hereditary.**

<u>Recommendations for future research:</u>

- How do community level beliefs translate into delays in patients seeking care?
- More research is needed understanding TB stigma and its effects on TB control.
- There is a need for programmatic and intervention research evaluating strategies to improve TB knowledge and reduce stigma. This will allow development of effective strategies to decrease health seeking delays.
- Follow-up study on stigma to investigate trends, using the scores in this study as baseline

Appendix A: Survey instrument

HIV and Tuberculosis Co-infection: Knowledge, Attitudes, and Practices in Rural Western Uganda

Demographics

No.	Questions and filters	Coding Categories	Comments
1	What type of house does the respondent live in? **(Researcher's observation)**	1- Permanent (concrete) 2- Semi-permanent (mud/wattle, iron roof) 3- Temporary (grass thatched, grass or mud walls)	
2	Sex of the respondent	1- Male 2- Female	
3	How old are you?	_____ 18-24 25-34 35-44 45-54 55-64 >65	
4	What is your marital status?	1- Single 2- Married, living with a partner 3- Not married, living with a partner 4- Divorced/ Separated 5- Widowed	
5	Have you ever attended school?	1- Yes 2- No	

No.	Questions and filters	Coding Categories	Comments
6	If yes, what is your highest level of education?	1- Primary Level_____ 2- Some Secondary Level _____ 3- O level 4- A level 5- Tertiary 6- University 7- Other Specify _____	
7	What is your occupation?	_____	

HIV/AIDS knowledge

No.	Questions and filters	Coding Categories	Comments
8	What are the main signs or symptoms of AIDS?		
9	How can someone get HIV?		
10	Is it possible for a healthy looking person to have HIV?	1- Yes 2- No 77- Do not know	
11	What are the things a person can do to avoid getting HIV?		

No.	Questions and filters	Coding Categories	Comments
12	Is it possible for HIV to be completely cured?	1- Yes 2- No 77- Do not know	
13	If yes, how?	1- Antiretroviral drugs 2- Traditional medicine 3- Spiritual healing 4- Other_____	
14	Are there any other illnesses that HIV positive people are more likely to get than healthy people?		
15	Have any of your friends or neighbours told you they have HIV?	1- Yes 2- No 77- Do not know	
16	If Yes, how is he/she doing?	1- well 2- sick 3- died	

HIV/AIDS-related stigma

No.	Questions and filters	Coding Categories	Comments

No.	Questions and filters	Coding Categories	Comments
17	Do you think nurses and health care workers treat people with HIV the same way they treat others?	1- Yes 2- No 77- Do not know	
18	What type of person is likely to get HIV?	_____	
19	Do you think people with HIV deserve to get it?	1- Yes 2- No 77- Do not know	
20	Why or why not?		
21	Should people who have HIV be ashamed?	1- Yes 2- No 77- Do not know	
22	Why or why not?		
23	Would you buy things at the market from someone who you know has HIV?	1- Yes 2- No 77- Do not know	
24	If you knew your friend or neighbour had HIV would you visit them in their home?	1- Yes 2- No 77- Do not know	
25	Would you be willing to share a home with somebody who has HIV?	1- Yes 2- No 77- Do not know	

No.	Questions and filters	Coding Categories	Comments
26	Would you be willing to tell your family and friends if you were HIV positive?	1- Yes 2- No 77- Do not know	

TB knowledge

No.	Questions and filters	Coding Categories	Comments
27	Have you ever heard of an illness called tuberculosis or TB?	1- Yes 2- No 77- Do not know	
28	What are the main symptoms of TB?		
29	How can someone get TB?		
30	Is it possible for TB to be completely cured?	1- Yes 2- No 77- Do not know	
31	If yes, how?	1- Antibiotic drugs/ pills 2- Traditional medicine 3- Spiritual healing 4- Other_____	
32	Are there any other diseases that someone with TB is more likely to have?		
33	Are some people more likely to get TB than others?	1- Yes 2- No 77- Do not know	

No.	Questions and filters	Coding Categories	Comments
34	If yes, Who?	_____	
35	Do you know anybody who has ever had TB?	1- Yes 2- No 77- Do not know	
36	If Yes, how is he/she doing?	1- Cured 2- Still sick 3- Died 4- Other _____	

TB stigma questions

No.	Questions and filters	Coding Categories	Comments
37	Do you think nurses and health care workers treat people with TB the same way they treat others?	1- Yes 2- No 77- Do not know	
38	What type of person is likely to get TB?	_____	
39	Do you think people with TB deserve to get it?	1- Yes 2- No 77- Do not know	
40	Why or why not?		
41	Should people who have TB be	1- Yes	

No.	Questions and filters	Coding Categories	Comments
	ashamed?	2- No 77- Do not know	
42	Why or why not?		
43	Would you buy things at the market from someone who has TB?	1- Yes 2- No 77- Do not know	
44	If your friend had TB would you visit them in their home?	1- Yes 2- No 77- Do not know	
45	Would you be willing to share a home with someone who has TB?	1- Yes 2- No 77- Do not know	
46	Would you be willing to tell your family and friends if you had TB?	1- Yes 2- No 77- Do not know	

TB/HIV knowledge questions

47	Do you know of any diseases that are likely to make someone vulnerable to get TB?	_____	
48	Does having TB mean a person is HIV positive?	1- Yes 2- No 77- Do not know	

49	How many TB patients have HIV?	1- All 2- Most 3- Half 4- Some 5- none	
50	Can TB be cured in someone who has HIV?	1- Yes 2- No 77- Do not know	
51	Do you know any HIV positive person who has had TB?	1- Yes 2- No 77- Do not know	
52	If Yes, how is he/she doing?	1- TB Cured, doing well 2- Still sick from TB 3- TB cured, still sickly from HIV 5- Died 6- Other _____	

TB/HIV stigma questions

No.	**Questions and filters**	**Coding Categories**	**Comments**
53	Do you think nurses and health care workers treat people with both HIV and TB the same way they treat others?	1- Yes 2- No 77- Do not know	
54	What type of person is likely to get both HIV and TB?	_____ _____	

No.	Questions and filters	Coding Categories	Comments
55	Do you think people with HIV deserve to get TB?	1- Yes 2- No 77- Do not know	
56	Why or Why not?		
57	Should people who have both TB and HIV be ashamed?	1- Yes 2- No 77- Do not know	
58	Why or Why not?		
59	Would you buy things at the market from someone who you know has both HIV and TB?	1- Yes 2- No 77- Do not know	
60	If your friend had both TB and HIV would you visit them in their home?	1- Yes 2- No 77- Do not know	
61	Would you be willing to share a home with someone who has both TB and HIV?	1- Yes 2- No 77- Do not know	

62	Would you be willing to tell your family and friends if you had both HIV and TB?	1- Yes 2- No 77- Do not know	
63	Do you think TB stigma has been made worse because of HIV?	1- Yes 2- No 77- Do not know	
64	Do you think people fear TB or HIV more?		

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

Appendix B: Focus group discussion guide

Introduction: Re-explain the process, informed consent, voluntary participation, confidentiality. Explain recordings and why they are important.

Norms: Put up hand, open discussion, everyone is encouraged to participate but no one is forced. Please turn off cell phones, minimise back and forth in and out of room.

What do you know about Tuberculosis?

-Are there different types of TB? What are they?

-How does someone get TB, is this different for the different types of TB?

-How does someone get cured? Is it possible to cure all types of TB?

How serious is TB?

-Do many people die from it or does everyone get cured easily?

-Does this depend on the type of TB?

How can you prevent TB?

- What types of preventive measures can be used?

Where did you learn about TB? (Media, Health centres, friends)
Is this the same place you learnt about HIV?

What type of person is likely to get TB?

-What behaviours make someone vulnerable?

What other diseases are related to TB? How are they related?

What is the relationship between Tb and HIV?

Do you know anyone who has ever had TB?

- How were they treated in your community?
- How did you know they had TB? Did they tell you or did you just guess because of coughing?

If anyone in your community had TB would you visit them in their home?

-What about if someone asked you to visit their friend (who you didn't know)?

-If someone in your church had TB, how would people treat them?

If you had HIV would you tell your family? Friends? Neighbours?
What about if you had TB- would you tell your family? Friends? Neighbours?

Do you think there is much stigma around HIV in your community?
Is there more or less stigma around TB?
Do you think that HIV has made TB stigma worse?

- Do people fear getting tested for TB because of it being a sign of HIV?
- Do people assume that if someone has TB, they also are HIV positive?

Do health care workers treat people with HIV the same as they treat other patients?

- Do they treat them better or worse?
- Does it depend on the health centre?
- What sort of behaviour do health care workers have towards HIV patients?
- How are AIDS patients treated in hospitals?

Do health care workers treat people with TB the same as they treat other patients?

- Do they treat them better or worse?
- Does it depend on the health centre?
- What sort of behaviour do health care workers have towards TB patients?
- How are TB patients treated in Hospitals?

Are there barriers to treatment for TB patients?

TB is curable but many people still die from it. Why do you think this is? What are the biggest problems for TB patients?

How do you think these problems could be solved? What are some ways to reduce the stigma? How do you think we could improve treatment success?

Appendix C: Information letter and consent form

HIV and Tuberculosis Co-infection:Knowledge, Attitudes, and Practices in Rural Western Uganda

Information Letter- General population

My name is Ashley Wynne and I am a graduate student in Public Health at the University of Alberta in Canada. I am working in Fort Portal to over the next several months to learn more about HIV and tuberculosis in your community. You are being asked to participate in a study that will look at how people in Kabarole understand HIV and tuberculosis.

Purpose: The purpose of the study is to have a better understanding about how people in Kabarole think about HIV, tuberculosis, and the relationship between the two diseases. This information is important to improve TB and HIV treatment and prevention programs so that fewer people will get sick from these diseases.

Procedure: A trained interviewer will ask you questions from a questionnaire. The questions will be about your knowledge of TB and HIV, and experiences you may have had with people who have had these diseases. The questions will be asked in Rutoroo, and answering the questions from the questionnaire will take about 30 minutes. The interview can take place at your home or somewhere that you choose. You may also be asked to participate in a group discussion. You can take part in the questionnaire without participating in the group discussion. Not all people will be asked to participate in the group discussion since once we have enough participants recruitment will close. The group discussion will last for 1 hour. It will take place at a clinic or community meeting place near your village and any travel costs will be paid. The group discussion will be audio- taped.

Benefits: At the end of the questionnaire, the interviewer will ask you if you have any questions about the study or about HIV or tuberculosis. If the interviewer cannot answer the question, he or she will refer you to someone else who can answer your question. The information from this study will help the Kabarole Health Department improve tuberculosis and HIV services for your community. This will mean that many people in Kabarole and Uganda could benefit from this study. You may also learn more about TB and HIV by participating in this study which could benefit you and your family.

Possible harms: Some of the questions about HIV and TB may make you uncomfortable. We will make every effort to avoid this possibility. We do not want you to feel any pressure to share information with us. If you feel badly while you are participating, please remember you can leave at any time or refuse to answer any questions and you will not be affected in any way.

Confidentiality and volunteer participation: All records will be kept private. None of your answers will have your name on it. The questionnaires and the information from the group discussions will be kept in a secure area. We will report to the Kabarole Health Department and the Ministry of Health in Kampala what we learn from this study. We will not tell them what any individual said. We will tell them only about the comments of the whole group of participants in

general. We will never use your name. Nobody will know the response came from you. In the focus group discussions, complete confidentiality cannot be guaranteed. All participants will be reminded that the names of volunteers and what is discussed are to remain confidential. If there is something you would not like to discuss or have knows, please do not feel any pressure to share it with the group.

You are not required to participate in this study. You do not have to answer any questions that you don't want to answer. You can also leave the study at any time, without worrying about anything bad will happen.

For more information: If you have any concerns about the study or would like more information, please contact me at 0788 461313 or by email at wynne@ualberta.ca. You can also contact Mr. Tom Rubale at the District Health department in Fort Portal.

Your Consent: Your signature means that you understand the information in this letter. It also means that you agree to participate in this study.

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

Initials participant:

Initials Interviewer:

Date:

Appendix D: Consent form

HIV and Tuberculosis Co-infection:
Knowledge, Attitudes, and Perceptions in Rural Western Uganda

Principle Investigator: Ashley Wynne, School of Public Health, University of Alberta, Canada.
wynne@ualberta.ca Mobile: 0788 461313
Supervisor: Dr. Walter Kipp, School of Public health, University of Alberta, Canada.
walter.kipp@ualberta.ca

Consent of Participant

Please circle YES or No for the following questions:

Do you understand that you have been asked to participate in a research study?	YES	NO
Have you read and received a copy of the attached information letter?	YES	NO
Do you understand the benefits and risks involved in taking part in this study?	YES	NO
Have you had adequate opportunity to ask questions and discuss the study and your participation?	YES	NO
Do you understand that you are free to withdraw from the study at any time, without having to give a reason and without facing any consequences? You do not have to give a reason. This will not affect the future health of you or your family.	YES	NO
Has the issue of confidentiality been explained to you?	YES	NO
Do you understand who will have access to the information you provide?	YES	NO
Do you agree to participate in this study?	YES	NO

This study was explained by: _____
Participant Name (print): _____
Signature or thumbprint of participant: _____
Date/Time: _____
Witness (print name): _____
Witness Signature or thumbprint: _____
Date/Time: _____
I believe that the person signing this form understands what is involved in this study and voluntarily agrees to participate.
Signature of investigator or designee: _____
Date/Time of consent: _____