



**THE UNIVERSITY OF ZAMBIA,
SCHOOL OF MEDICINE.**

**Barriers to Accessing HIV Care and Treatment Services by
TB patients who are co-Infected with HIV in Lusaka District
Clinics**

BY

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A dissertation submitted to the University of Zambia in partial fulfilment of the requirement for
the Masters Degree in Public Health (MPH).

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DECLARATION

This dissertation is the original work of Loyce Munthali. It has been prepared in accordance with the guidelines for MPH dissertation of the University of Zambia. It has not been submitted elsewhere for a degree at this university or any other university.

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Dedication

I dedicate this dissertation to my three daughters Tiwonge, Nsamwa and Wizado. Hope you ladies will persevere in your education as I, your mother, has.

Acknowledgements

I would like to acknowledge Center for Infectious Disease Research in Zambia (CIDRZ) for supporting this research study, my supervisors Prof. Seter Siziya, Dr Stewart Reid, Mr. Oliver Mweemba, and the late Dr Gavin Silwamba. This study would not have been what it is without two special ladies who drilled me through the whole process, Jennie Harris and Stephanie Topp. Lastly, I would like to thank my dearest husband, James for all the support rendered during my period of study.

Acronyms

ART	Antiretroviral Therapy
CIDRZ	Centre of Infectious Disease Research in Zambia
DCT	Diagnostic Counseling and Testing
HIV	Human Immunodeficiency Syndrome
KI	Key Informant
LDHMT	Lusaka District Health Management Team
MOH	Ministry of Health
NTBLCP	National Tuberculosis and Leprosy Control Programme
TB	Tuberculosis
UNAIDS	The Joint United Nations Programme on HIV/AIDS
VCT	Voluntary Counseling and Testing
WHO	World Health Organization
ZEBS	Zambia Exclusive Breastfeeding Study

OPERATIONAL DEFINITION OF TERMS

Stigma	: A mark or sign of disgrace (MoH, 2006)
Diagnostic Counselling and Testing	: A tool to diagnose HIV in TB patients and refer them to ART Clinics
Self Stigma	: Patients with TB recognise the possibility of having HIV and therefore, do not want to accept their status.
Discrimination	: Patients who are known to have TB/HIV are kept away from their peers or refused employment
Community Based Providers	: Community people with no special qualification in health who help give health education advice to people in their communities. They can give out some medications like anti-malarial tablets and pain killers. They are also used as family planning distributors for non-invasive methods like issuing out condoms and oral contraceptives. They provide support to TB/HIV patients and are called Treatment Supporters.
Health Facility Based Providers	: These include all health Care providers at the health facility. They give out medications to all patients as well as moral support to those in need.
TB /HIV Co Infection	: A patient who has both diseases, TB and HIV at the same time

LIST OF TABLES and FIGURES

- Table 1** What do TB patients and people in the community think about having both TB and HIV at the same time?
- Table 2** What do TB patients and people in the community think about offering HIV testing at TB corner?
- Table 3** What are the reasons that TB patients with HIV do not enroll at ART clinics?
- Figure 1** Trends of TB and HIV in Zambia, 1980 - 2003
- Figure 2** Sample size and sex of respondents.

ABSTRACT

The objective of the study was to identify barriers to accessing HIV services by TB patients who are co-infected with HIV in Lusaka District clinics. CIDRZ program monitoring data shows that 30% of TB patients refuse HIV testing and that 45% of HIV-positive TB patients identified through DCT do not enrol in HIV care (Harris et al., 2007).

This was a cross-sectional qualitative study using free listing and interview guides. The first part of the study involved 32 TB patients who attended a TB clinic. The criteria for selection included: those who refused DCT, those who accepted DCT but tested HIV negative, those who accepted DCT and tested HIV positive and were referred as well as those who refused referral to an ART clinic. The data was collected using free-listing technique which entails that the patient lists all the possible responses and gives a small description to each of those responses. The study further collected information from 31 key informants using an unstructured interview guide. These informants were selected by the respondents in during the free listing exercise. The study was conducted in 8 Lusaka Urban District Clinics and analysed using thematic analysis.

Both free listing and key informants' questions were based on people's understanding of causes of TB/HIV co-infection and how these can be reduced. The respondents associated TB/HIV co-infection to a lot of issues, notably prostitution and poor diet. They emphasized the need for provision of more information on TB/HIV to patients as a way of the spread of these diseases.

The study revealed that lack of confidentiality was seen as a barrier for most respondents. Many people do not access TB/HIV services because of fear of lack of confidentiality on the part of the health workers which is associated with stigma and discrimination by the general public. Suggestions to curb this vice included calling for Government to merge the services for both TB and HIV patients. Taking of TB/HIV treatment at the same time is seen as a 'good thing' by the general community but there is need to sensitize the people affected on its importance. Many people avoid taking drugs for these diseases at the same time because they believe the drugs are 'too strong to be taken together' and can 'kill a patient'.

The results of this survey have helped identify community perceptions that contribute to the under-utilization of HIV services by TB patients who are co-infected with HIV in Lusaka

District clinics. The hypothesis generated from this study is that underutilization of TB/HIV co-treatment services is associated to the barriers identified in this study.

1. INTRODUCTION

1.1 Background

Human Immunodeficiency Virus (HIV) in sub-Saharan Africa is causing an increase in the incidence of tuberculosis (TB) with 75% of incident TB cases occurring in HIV-infected individuals (WHO Report, 2005). The integration of TB and HIV services in Lusaka District is currently being scaled-up to increase the number of TB/HIV co-infected individuals receiving optimal care for *both* diseases. Sentinel site data has confirmed that approximately 70% of TB patients receiving care in Lusaka District are also HIV-infected, and 80% of these patients meet the eligibility criteria for immediate antiretroviral therapy (ART) (Centre for Infectious Disease Research in Zambia (CIDRZ), Unpublished Data).

In 2004, the Zambian Ministry of Health (MOH) introduced ART in government health centres. At this time, there was a huge demand for HIV services. Because of the huge demand and need for rapid scale-up, ART clinics were established separately from existing health centre services. As a result, ART clinics became a vertical system within each health facility. As a result, TB patients did not automatically access ART services; likewise, ART patients were not being screened for TB. Therefore, the problem of not receiving the best care persisted and many patients were lost to follow-up. Reid et al have noted that encouraging TB patients to learn their HIV status and integrating services is essential to improving clinical outcomes of co-infected patients (Reid et al, 2006).

In 2005, the Zambian MOH and the Lusaka District Health Management Team (LDHMT) declared that prevention and identification of HIV infection a priority for TB control programs. National policies requiring reporting of HIV data for TB patients were implemented in 2006. In partnership with the LDHMT, CIDRZ began providing technical and financial assistance to implement HIV testing of TB patients and referral to ART Clinics. As of September 2007, CIDRZ-supported TB/HIV integration activities had been introduced and implemented in fourteen Lusaka District clinics. Staffs in these clinics were identified and trained in the rationale for service integration as well as TB/HIV epidemiology and clinical care issues for co-infected patients.

As part of TB/HIV integration, Diagnostic Counselling and Testing (DCT) was introduced as a tool to diagnose HIV in TB patients and refer them to ART Clinics. As part of a new triage system, all TB patients are requested to undergo DCT during TB treatment. If the patient accepts testing, a rapid HIV test is performed. For patients found to be HIV positive, blood is sent to the laboratory for CD4 count and an appointment is scheduled at the ART clinic. Performing an immediate or “reflex” CD4 count expedites both enrolment at the ART clinic and the decision to start ART. Recent data confirms that DCT is an effective way to identify and refer TB/HIV co-infected patients to HIV care. Initial findings show high rates of HIV testing (70% accepted) and seropositive results (73% of those tested) with 83% of HIV-positive patients being eligible for anti-retroviral therapy according to national guidelines (Harris et al, 2007). The high testing uptake, high percentage of positive results and clinical status of co-infected patients demonstrated a need for DCT as standard part of TB care (Reid et al, 2006).

During 2009, CIDRZ expanded its TB/HIV integration activities to all Lusaka District Clinics’ TB corners and into provincial care centres in Lusaka, Western and Southern provinces of Zambia in order to increase the number of co-infected patients receiving optimal management of both their TB and HIV infections.

1.2 Statement of the problem

CIDRZ program monitoring data shows that 30% of TB patients refuse HIV testing and that 45% of HIV-positive TB patients identified through DCT do not enrol in HIV care (Harris et al, 2007). A qualitative study is needed to better understand why so many TB patients do not accept HIV services and how integration programs can be modified to address this.

1.3 Justification of the study

This study has provided qualitative patient data needed to improve current TB/HIV integration programs. As part of the study analysis, the investigator also identified strengths and weaknesses

of the TB/HIV integration program and have made recommendations for improvements to CIDRZ and the Lusaka DHMT. It is hoped that once programming is improved, greater numbers of TB patients testing for HIV and enrolling into ART care will be achieved.

The study was also expected to provide baseline data on the impact of social, cultural and programmatic issues on the uptake of HIV services among TB patients. Research findings of this study will be communicated to the TB/HIV integration program implementers who will be able to modify their programs and/or design interventions to address these issues.

The data generated from this study will be published in thesis form, journal articles and presented at scientific conferences.

2. LITERATURE REVIEW

The two leading causes of infectious-disease associated mortality worldwide are tuberculosis (TB) and human immunodeficiency virus (HIV) disease (Friedland et al, 2007). These two diseases have been closely associated ever since HIV/AIDS was discovered. This association is regarded as dangerous as it affects “all aspects of each disease, from pathogenesis and the epidemiologic profile; to clinical presentation, treatment, and prevention; to larger issues of social, economic and political consequences” (Friedland et al, 2007). The Zambian Ministry of Health Guidelines (Zambian Ministry Of Health TB-HIV Integration Guidelines, 2006) note that:

- TB is a leading cause of illness and death among people living with HIV/AIDS
- TB in combination with HIV infection has a higher risk of mortality than infection with TB alone
- HIV increases the risk of progression from latent TB infection to active disease
- Adverse drug reactions to anti-TB medication are common in HIV-infected TB patients
- Smear-negative pulmonary TB and extrapulmonary TB are more common in HIV-infected TB patients.

TB has a long natural history with cases being reported as early as the 19th century. Conversely, recognised cases of HIV emerged only 25 years ago. Despite this, anecdotal evidence shows that community awareness of HIV in Zambia is much greater (Lusaka District Nursing Staff, 2007, unpublished). The use of radio, billboards, posters and street theatre by HIV programs around Zambia has helped to educate people about HIV causes, symptoms and treatment. Knowledge about TB, however, remains comparatively limited and available information often focuses on its link to HIV (Lusaka District Nursing Staff, 2007, Unpublished).

According to Bond (2006), little work has been done to understand the importance of the relationship between TB and HIV in developing good public health interventions. In particular, little work has been done to understand the way TB/HIV co-infection may create or contribute to stigma. Yet in many places awareness of HIV and TB is still quite low and stigma is a barrier to people openly discussing these two diseases. This may be related to the fact that they are often referred to as “twins” or “sisters”, reflecting the impression that having TB is a sign that you are HIV-positive and vice-versa (The Union, Feb, 2007). This deters patients from seeking help in a timely manner (The Union, Feb, 2007).

Evidently, with the continued increase in the disease burden of TB and HIV, collaborative activities should be established if these two diseases are to be controlled (Onyebujoh et al, 2007). The new Stop TB Strategy and Plan was launched in 2006 (Raviglione and Uplekar, 2007). Its aim is to expand implementation of collaborative activities with the aim of achieving universal access (The WHO Stop TB Strategic Plan 2006). The plan hopes, depending on its financial capabilities, to capture 29 million TB patients who will receive counselling and testing for HIV and at least 3 million of these will commence ART (The WHO Stop TB Strategic Plan, 2006). Two hundred and ten million HIV infected people will also be screened for TB (The WHO Stop TB Strategic Plan, 2006) indicating the high priority being placed on addressing TB and HIV together amongst high-level world health officials.

2.1 Global TB/HIV Co-infection burden

The number of people living with HIV infection has increased to 39.5 million in 2006 from 37.5 million in 2003 (The joint United Nations Programme on HIV/AIDS (UNAIDS)). Approximately one-third of this population is co-infected with TB (Thom, 2007). At the same time, one third of

the world's population is infected with latent *Mycobacterium tuberculosis* (WHO, 2007). Latent TB can be reactivated if an individual has immuno-suppression which can, for example, be due to HIV infection (Corbett et al, 2003). The greatest burden of latent TB, 46%, is found in South-east Asia, 32% in Western Pacific region, 31% in Africa and 27% in Eastern Mediterranean region (Corbett et al, 2003). In America and Europe, the figures are lower at 15% and 14% respectively. Latent TB affects about 30% of the global population (WHO, 2006) and approximately 1.7 million deaths are due to TB every year (WHO, 2006; Corbett et al, 2003).

The WHO estimates that only 14% of HIV-positive tuberculosis cases were identified through testing for HIV in 2005 (WHO, 2007). Worldwide, TB is a leading cause of HIV-related deaths, with one third of AIDS deaths being due to TB. The rate of co-infection in western countries is, however, levelling off. By the end of 2007, WHO goals are to reach 70% TB case detection rate, 85% TB cure rate and a 100% DCT access rate for all TB patients (WHO, 2007).

The resurgence of TB worldwide, in parallel to the spread of the HIV, has led to a growing public health response focusing on the integration of TB and HIV programmes (The WHO Stop TB Strategic Plan, 2006). The increasingly wider availability of anti-retroviral (ARV) drugs has underscored the importance of the integration, with TB diagnosis being an excellent entry point for voluntary, counselling and testing (VCT) and referral to comprehensive HIV services, including ARVs, for those TB patients living with HIV (WHO TB/HIV Integration Guidelines, 2006). However, numerous challenges exist, including how to time the initiation of ART in patients with TB and HIV coinfection (Onyebujoh et al, 2007).

2.2 Regional Perspective

While globally it is estimated that 11% of new adult TB cases are HIV infected, in Sub-Saharan Africa this figure rises to 38%. However, estimates rise to 65% in Kwazulu Natal, South Africa (Fourie, 2001) and 75% in countries such as Malawi and Zimbabwe (Fujiwara et al, 2005).

As ARVs have become increasingly available and affordable in many low-income countries, their use has necessitated training of health care providers in the management of HIV-infection and its associated opportunistic infections. Availability of ARVs has also increased the demand for HIV counselling and testing and encouraged the incorporation of HIV testing into routine clinical practices (WHO, Health Worker Shortage and the response to AIDS, 2006). Despite Africa being labelled the region that has been slowest to start collaborative activities for TB and HIV, a number of countries are now making some progress (Nunn et al, 2007). In 2005, for example, Malawi indicated that one-third of all TB patients requiring treatment for HIV infection were receiving this treatment (WHO Report, 2004). In 2004, Rwanda tested 48% of the TB patients for HIV, and 48% were HIV positive (Programme National Intégré de la Lutte contre la Tuberculose, Annual Report, 2005). In Tanzania, the health centres in Iringa reported that more than half of the TB patients who accepted VCT were HIV positive and were commenced on treatment in 2005 (WHO, Current Status of Global TB/HIV Activities, 2005). Kenya also recorded that 37% all the TB patients tested for HIV and 57% of these were HIV positive. Some TB patients were even commenced ART (Nunn et al, 2007).

Africa faces challenges just like the rest of the world in its efforts to integrate TB/HIV activities. People's willingness to go for HIV testing is often linked to the presence of other health or life problems (Thio, 2007). It is common for patients to report that they would consider testing for HIV once they are employed or once TB treatment is complete (Gebrekristos et al, 2005). Ironically, being diagnosed with TB is also reported to lead patients to think about HIV testing (Nuwaha, 2002).

Despite these challenges, a number of African countries have introduced and started scaling up integration of TB and HIV services as a way of improving entry and access to care for the two

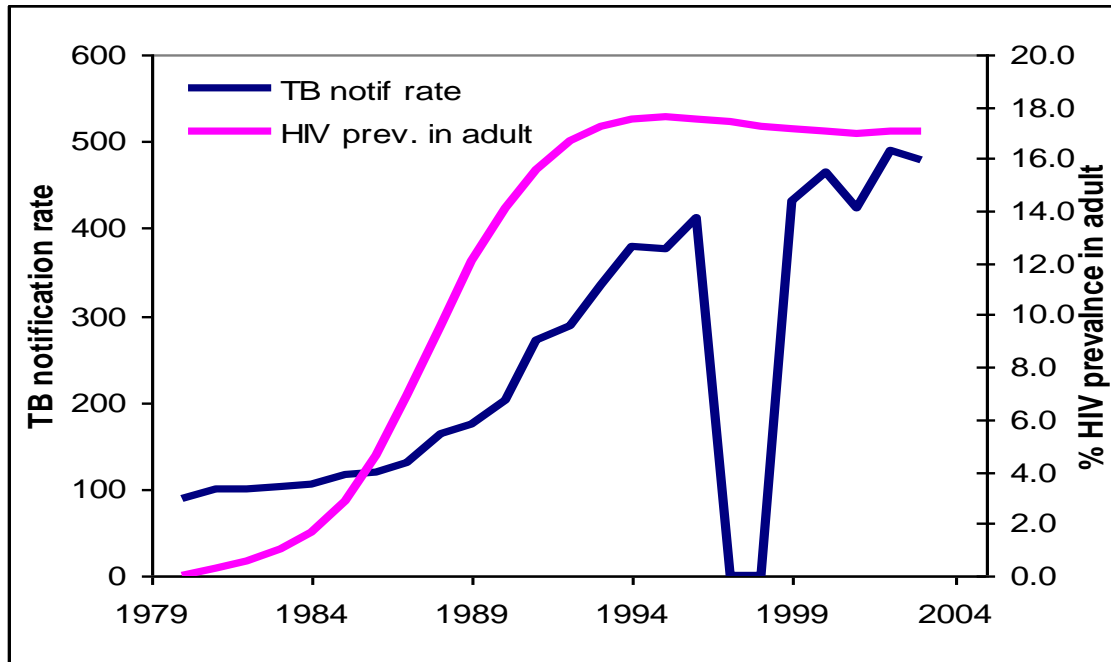
diseases. Unfortunately, insufficient political will and financial, human and institutional resources at the country level in many sub-Saharan settings continues to play a big role in hindering the progress of the collaborative programmes (Nunn et al, 2007). In Zambia, the MOH faces financial limitations to integrating TB/HIV services but there has been strong political will since 2005. To address this financial need several NGOs, including the Centre for Infectious Diseases in Zambia (CIDRZ), are collaborating with the MOH to integrate TB and HIV services.

2.3 National Perspective

In Zambia, records indicate that there are high rates of TB/HIV co-infection suggesting that prevention and identification of HIV infection must be a priority in TB control programs. In 2006, for example, the Zambian Ministry of Health reported that 50 - 70% of TB patients were co-infected with HIV (MoH, 2006). While the incidence of TB among the HIV infected patients is unknown in Zambia, anecdotal evidence indicates that it is high. Likewise, TB prevention and care must also be a priority in the HIV programs (MoH, 2006).

Figure 1 shows the steady increase in TB notification rates in Zambia from 1979 with a drastic decline around the 1997-98 period. This could be attributed to a number of reasons which includes lack of records for the period in question. After 1998, the steady increase continues. In contrast, however, there has been a drastic increase in HIV prevalence rates over the 20 year period from 1979 with a peak around the 1991 – 95 period (MOH, 2006). It is for this reason that the Government Republic of Zambia, through Ministry of Health and all stakeholders started looking at programs that could address the HIV pandemic. Needless to say that the TB/HIV coinfection problem was left out. This resulted in vertical programs for TB and HIV.

Fig. 1: Trends of TB and HIV in Zambia, 1980 - 2003



Source: MOH, 2006.

In order to ensure collaboration of TB and HIV services, diagnosis, care and treatment must be coordinated at all levels (Friedland et al, 2007). In many settings in Zambia, however, these services remain separate and substandard. Recognising this, the Zambian Ministry of Health introduced the TB/HIV Integration Guidelines in 2006 based on WHO recommendations that were adapted to the local setting.

Based on the guidelines in 2006, the Centre for Infectious Disease Research in Zambia (CIDRZ) embarked on implementing integration of TB/HIV activities in Lusaka’s urban clinics as well as clinics in Lusaka rural, Southern, Eastern and Western provinces. This is hoped to spread to all the provincial capitals in Zambia by the end of 2008.

Planned research by CIDRZ, in collaboration with the MOH, will also look at the rates of TB among HIV-infected patients in order to better understand the link between these two diseases in Zambia (CIDRZ TB Team, 2007, Unpublished).

The need to better understand TB/HIV coinfection in Zambia, and improve access to both services and information is supported by anecdotal evidence which shows that many Zambians

are now associating TB with HIV, assuming that diagnoses with TB is synonymous with having HIV. Themes to be explored should include lack of awareness and knowledge among patients about available services and the relationship between TB and HIV. In addition, stigma about TB and HIV in the community and the importance of patient confidentiality must be explored. To ensure the health system is adequately prepared to provide integrated care to patients, training for TB and HIV care providers that foster collaboration should be a priority (Reid et al, 2006).

3.0 RESEARCH OBJECTIVES AND DESIGN

3.1 General Objective: To identify and examine the barriers to accessing HIV care and treatment services by TB patients who are co-infected with HIV in Lusaka District clinics.

3.2 Specific Objectives:

1. To identify socio-cultural, environmental and programmatic factors having positive and negative effects on DCT uptake and enrolment into HIV care.
2. To generate hypotheses for potential integration activities for further exploration.
3. To summarize patient and investigator recommendations and communicate them to TB/HIV integration program implementers at the LDHMT and CIDRZ.

3.3 Study design

This was a cross-sectional study conducted in two phases. Data were collected using two qualitative methods. Free Listing interviews with TB/HIV patients in phase 1 and with key community members in phase 2.

4.0 STUDY POPULATION

For this study, a pseudo-representative method was used. The sample size for free listing interviews thus incorporated 32 patients from 8 Lusaka District clinics that have implemented the TB/HIV integration program for six (6) months or more. Only patients who consented to being included in the study were enrolled. Sample selection and interviewing were done between 08.00 hrs in the morning and 12.00hrs every day in each of the 8 clinics. This choice of time was due to the preference of most TB patients to come to the clinic in the morning. This exercise stretched from 1 or 2 days per clinic depending on how long it took to recruit the patients who fit in the inclusion criteria. Data collection for free listing and key informant participants took 15 days in total. The participants who fulfilled the selection criteria were subjected to a consent

process. A witness signed for those who were unable to read. If participants agreed, they were asked basic demographic information including their sex and age. All this was done in the presence of a witness. The clinics included in this study were Chipata Clinic, with a catchment population of 107, 107, Kabwata – 61, 170, Matero Main – 70, 219, George – 100, 487, Chawama – 89, 282, Chilenje – 75, 405, Makeni – 28, 979, and Ng’ombe – 31, 871 (LDHMT HMIS, 2009). The socio-economic status of the catchment areas for these clinics is generally low to middle income, with the majority very poor. Staffing in the clinics is also not very good. These clinics are Government clinics, and as such, the carter for a large catchment population and the few health workers that serve these populations are always overworked. In most of the clinics, only one health workers, usually a nurse was allocated to the TB Corner. The nurse is usually assisted by lay TB Supporters from each clinic’s surrounding community.

4.1 Participant Withdrawal

Participants were allowed to voluntarily withdraw from the interview or withdraw their responses for any reason at any time.

5.0 STUDY PROCEDURES

Qualitative methods have been identified as useful for examining concepts and issues on which little previous research has been done (Bolton, et al, 2004). Particular strengths of qualitative methods include:

- Their ability to describe contextual factors that connect sensitive topics (Murray et al, 2006).
- They seek to understand how people perceive most problems in the community and ‘how they will receive and respond to an intervention’ especially in resource constrained places (Bolton et al, 2004).
- They help to save time and resources as interventions identified in one community can be used in another community since they are community based (Bolton et al, 2004).
- Interventions identified in this manner focus on ‘the perceived cause(s) of a problem, who tends to be affected by the problem and how it can be avoided’ (Bolton et al, 2004).
- Qualitative research helps in identifying interventions that will suit a community or group of people in certain settings. People may not accept an intervention if they think they cannot be affected by it or if it can be avoided by other means (Bolton et al, 2004).

The particular qualitative methods that were used in this study were free listing and key informant interviews, and have shown to be especially useful in identifying and examining local perceptions and behaviours of sensitive issues (Bolton et al, 2004).

In contrast, well designed quantitative studies and surveys rely on sound information regarding individual and community perceptions in order to develop and deliver appropriate questions or interventions (Bolton et al, 2004). In this case, that information does not exist, making a quantitative study unfeasible. This study thus returns to first principles, seeing to collect and analyze data which will form the basis for *future* quantitative studies by clarifying patient, clinic staff and community perceptions about TB and HIV services in Lusaka, and dealing more appropriately with cultural differences and sensitive topics. Given the objectives of this study

and the highly sensitive nature of the issues being examined, we believe that a qualitative approach is the most appropriate for this study.

5.1 Free Listing

This method was used to learn what current and former TB patients think are the social, economic, logistical and cultural issues surrounding TB/HIV co-infection as well as acceptance of HIV care and treatment. Bernard, (2002) describes free listing as a simple but powerful technique in which informants are asked to “list all the X you know about” or to inquire “what kinds of X are there?”

Free listing was used to find out and identify where to concentrate our effort in the key informants’ interviews. Patients were not asked for personal motivations regarding these issues; rather patients were asked to comment on community and TB patients’ perceptions and approaches to these issues.

The interviewers used in this study were already trained in interviewing methods. Therefore, initial 2-day training in qualitative methods was held at which 16 interviewers were re-trained in free listing methods and were trained to ask TB patients the following questions:

1. “What do TB patients and the community think about having both TB and HIV at the same time?”
2. “What do TB patients and people in the community think about offering HIV counseling and testing at TB corner?”
3. “What are the reasons that TB patients with HIV do not enroll in HIV care and treatment clinics?”

Bolton (2004) points out that in free listing interviews, questions are stated broadly to encourage a wide variety of responses, which should be recorded in the order in which they are mentioned. These questions were designed to elicit all of the reasons that women and men identify in their

community. When the respondent confirmed that they had mentioned all applicable issues/reasons, the interviewer would return to the top of the list and ask the participant if there was a person in the community who was knowledgeable about that issue. These people were used as the key informants in the next phase. Free List interviewees were asked to mention people who have both positive and negative views on issues of co-infection and co-treatment as key informants. Interviewers worked in teams of two. All interviews were completed in the language chosen by the informant, (primarily Nyanja and Bemba). These were translated into English by the interviewers immediately after the interview.

5.1.1. Free-listing Selection

Four patients attending the TB clinic were purposively and conveniently selected at each of the above mentioned clinics. The four patients corresponded to the following categories:

- TB patients who have refused DCT
- TB patients who accept DCT and test HIV negative
- TB patients who test HIV positive but have not enrolled in ART care
- TB patients who tested HIV positive and enrolled at the ART clinic.

When the interviewers arrived at a clinic, they presented a list of the four categories of the TB patients to the TB nurse, and the first patient eligible in any category was offered the chance to participate. If the patient refused, the nurse would continue to screen for eligible candidates in any category until one patient provided informed consent. The TB nurse was asked to recruit two males and two females TB patients. When that patient had provided informed consent, the TB nurse would subsequently recruit patients from the remaining three categories and so on. While the interviews were in progress, the TB nurse would only recruit one patient. That patient would only have to wait at most for 45 minutes.

5.1.2 Free listing interviews

These interviews were conducted by local men and women with prior interview training and experience through the Zambia Exclusive Breastfeeding Study (ZEBS), a study run by Boston

University, USA. The interviewers were all re-trained prior to these interviews. They obtained consent from patients prior to commencement of the interview. Only those patients willing and offering to be interviewed were interviewed. The interviewers worked in teams of two; one person who interviewed, while the other wrote responses. Responses were recorded and summarized. The interviews were conducted until 32 patients (4 patients at each of 8 clinics) are interviewed.

5.1.3 Interviewer Duties

Introduced study objectives and goals

Obtained informed consent for study participation from each participant

Explained his/her role and that of the recorder

Explained confidentiality, that individual participation and responses would not be discussed outside the interview; no identifiers were recorded

Posed questions defined in the free listing interview guide.

Asked respondents for a person knowledgeable about each response given (key informant)

Worked with recorder to translate responses into English immediately following the interview.

5.1.4 Recorder Duties

Recorded that consent has been obtained to participant in the free listing interview

Recorded the date, time and location of the session

Recorded demographic information of all participants (sex, age)

Recorded verbatim responses to free list questions in interview language

Recorded names and locations of each key informant given

Worked with interviewer to translate responses into English immediately following the interview.

5.2 Key Informant Interviews

Following the free listing exercise, the interviewers were provided with 1-day training on key informant interviewing techniques. Key informants identified during the free listing were interviewed on themes that emerged from the free lists and were selected for further exploration. The purpose of the key informant interviews was to provide additional information about selected themes. Simple open-ended key informant interview scripts were developed based upon the themes that emerged as most common and relevant in the free-listing exercise.

Key informant interviews entail questions seeking an expansion or more detailed information on themes that were listed in the free-listing exercise. Questions usually begin with phrases such as “tell me more about.....” (Murray, 2006). For example, "Tell me more about the fear of taking TB and HIV drugs together". The topics were guided by the responses of the participants during the free-listing phase, reflecting the concerns of the study participants. We did not discuss topics that the participants did not feel comfortable with or that put them at risk, either socially or psychologically, beyond that normally present when discussing these issues. We informed participants that the information they provided was confidential and that they were free to discuss only on those themes that he/she felt comfortable with.

Key informants were local people referenced by free list respondents and said to be knowledgeable about at least one of the issues being explored. Both activities in Phase 1 and Phase 2 took a period of two weeks.

These interviews were conducted by the same interviewers as conducted the free-list interviews. After free-listing responses were analyzed, themes were chosen for further exploration, for example “tell me more about the fear of taking TB and HIV drugs together”. The key informants

associated with these topics were probed for explanations of the responses given during free listing interviews. Interviews were conducted by teams of two; an interviewer and a recorder.

5.2.1. Key Informant Selection

Sample size for key informants comprised of 30 individuals who were identified during the free listing interviews. These were people identified as being knowledgeable about the issues raised in response to free list questions. This was a purposive (snow balling) sample derived from information obtained from the free listing interviews. Key informant interviews are a technique used in public health research to investigate issues where there is little previous information (Murray, 2006). For both free listing and key informant interviews, only adults aged 18 – 60 years of age were interviewed.

The information generated from these two phases of interviews is not intended to be generalized to the TB/HIV population. It is intended to provide a body of knowledge which will assist in the development of better TB/HIV co-infection interventions and integrations, as well as providing baseline information for future quantitative research. The sample size in this study is thus determined for convenience purposes, taking into account the number of interviews that we could reasonably conduct and analyze with the time and resources available.

5.2.2 Interviewer Duties

Introduced study objectives and goals

Obtained informed consent for study participation from each participant

Explained his/her role and that of the recorder

Explained confidentiality, that individual participation and responses would not be discussed outside the interview; no identifiers were recorded on the interview scripts

Posed questions defined in the key informant interview guide.

Worked with recorder to translate responses into English immediately following the interview.

5.2.3 Recorder Duties

Recorded consent to participant in the key informants' interview

Recorded the date, time and location of the session

Recorded demographic information of all participants (sex, age)

Recorded comments to questions posed in the key informant interview guide.

Worked with interviewer to translate responses to English immediately following interview.

5.3 Inclusion Criteria

Phase 1, Free-listing: Group A: Male and female adult TB patients aged between 18 and 60 years attending the TB clinic at one of the health centres included in the study. These patients fitted in the categories mentioned above.

Phase 2, Key Informant interviews: Inclusion criteria for key informant interviews were identification by a participant in the free-listing exercise. These were local men and women in the health centre or surrounding community. Bernard (2002) suggests that experts (key informants) can be used for collecting cultural data as contrasted with data about individuals.

5.4 Exclusion Criteria

Phase 1, Free-listing: Any one *not* attending the TB clinic at one of the health centres included in the study. Of those who attend, patients under age 18, those who do not fit in the categories mentioned above and those who come while the interviewers are busy were excluded.

Phase 2, Key Informant interviews: Key informants identified during free listing for issues which did not need further exploration were excluded. Of those identified, those which we could not locate were excluded.

5.5 Recruitment Process

Phase 1: Free listing: Clinic staff asked patients during their regularly scheduled appointment if they would be willing to speak to an interviewer for a few minutes. The recruitment script read as follows:

Clinic staff will say the following to TB clinic clients during their regularly scheduled visit:

“There are some interviewers here working with CIDRZ and the Lusaka District Health Management Board who would like to speak to patients about the TB and HIV services offered at this clinic. They want to get patients’ perspective in order to improve the services offered here. Before they ask you any questions, they will explain what the interview is about and you can decide whether you want to participate in the interview. Would you be willing to meet the interviewers and learn more about why they’re here?”

If they agreed, the patient was directed to a private room where the interviewer explained the study and obtained consent from each participant.

Phase 2: Key informants: Key informants were identified by participants in the free listing activity who also provided a location where the informant could be found. Interviewers phoned the key informant or went to the provided location, explained the study, and obtained consent for participation.

6. STATISTICAL CONSIDERATIONS

6.1 Review of study design

This was a cross-sectional study of self-reported opinions, intentions and behavior by TB patients and key informants from the clinics and surrounding communities. Data was collected using qualitative methods. Systematic sampling was used for all parts of the study.

6.2 Sample Size Determination

Phase 1, Free-listing: Four patients from TB clinic at each of 8 Lusaka District clinics that have implemented DCT in the TB Corner were interviewed. This provided a total of 32 patients. In order to pick the study sample, the first TB patient of either sex the TB nurse saw in any of the four categories were interviewed. Thereafter, the first TB patient in any of the remaining three

categories willing to provide informed consent was interviewed. This process continued until a TB patient from each category had been interviewed. The nurse ensured that two of the patients were female and two were male. In this way, every TB patient was given an equal opportunity to participate in the study. The selected TB patients were only entered into the study if they fulfilled the selection criteria. This helped eliminate some selection bias.

Phase 2, Key informant interviews: - Thirty individuals who were identified during the free-listing as being knowledgeable about the issues raised in response to the free list questions. Each interview was summarized and assessed by the interviewers as well as the investigating team. Interviewers were instructed to probe potentially related topics and were coached to return until the respondent stated they had exhausted all the problems.

6.3 Data Collection

6.3.1 Free Listing and Key Informant Interviews

Data were collected and were translated into English by the interviewers immediately after the interviews.

6.4 Data Analysis

Qualitative data analysis was done thematically. The problems and their descriptions identified during the free listing and key informant's interviews were manually compiled into a single, consolidated database. Analysis was then conducted, assessing whether these issues were currently accounted for in the CIDRZ implementation model. The purpose of the analysis was to identify common concerns and/or barriers to HIV care for TB patients; and to assess whether those concerns had been addressed by the TB CIDRZ Team. It is hoped that the implementers will further investigate and modify their interventions as a way of improving the TB/HIV integration program.

Furthermore, the free listing and key informants' interviews provided baseline information for the creation of future survey by CIDRZ.

Phase 1: Analysis of free listing responses was done by the local interviewers with guidance from the principal investigator and advisors from Boston University who had developed this technique. Murray (2007) points out that the free list responses should be consolidated into one large list, which should later be divided into larger "lumped" subcategories. The research team examined the list to determine major themes for follow-up with key informants' interviews.

Phase 2: Key informant interviews were analyzed in the same way free list interviews were analyzed. According to Murray (2007), key informants were asked to speak about the themes identified during the free listing interviews in greater detail as well as give descriptions of the situations where these happen. The themes which were discussed were decided upon based on the frequency of responses during the free listing interviews, as well as areas that were more feasible to be addressed by the TB/HIV integration programs. Once completed, key informants' responses were categorized and analyzed for data revealing new or untried interventions, as well

as ways to overcome existing barriers to TB/HIV integration. No qualitative data management program was used.

7.0 HUMAN SUBJECTS CONSIDERATIONS

7.1 Ethical considerations

This protocol and the associated forms contained in Appendices was reviewed and approved by the University of Zambia Research Ethics Committee (REC) and the University of Alabama Institutional Review Board (IRB) with respect to scientific content and compliance with applicable research and human subjects' regulations.

7.2 Informed Consent

Informed consent was obtained from each of the free listing and key informant interviewees. Informed consent descriptions described the purpose of the study, the procedures, and risks and benefits of participation in accordance with all applicable local and US regulations. Participants were given the opportunity to ask questions until they fully understood the study before they indicated their informed consent. They were told that they could request more information or have further questions answered at any time.

7.3 Risks

This study did not involve any risks to participants. Participants were not being forced to answer any question. They had the right to refuse to participate in the study or seek any clarification whenever necessary. Refusal to participate, participation in or withdrawal from the study did not affect patients' access to care or quality of care or treatment.

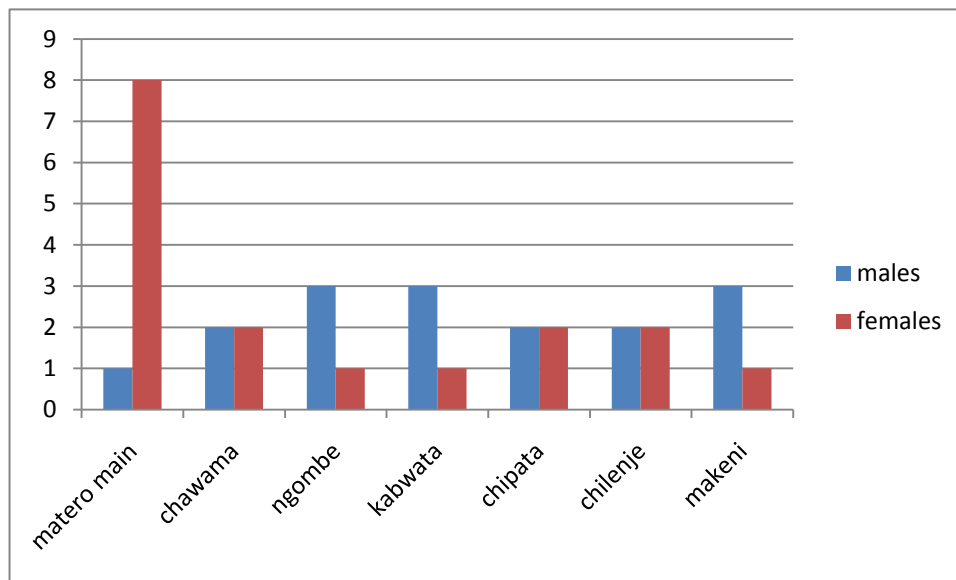
Participants were assured of confidentiality, therefore, they were informed that they were under no obligation to answer questions that made them uncomfortable and were free to withdraw from the interview at any point. The only individual information used was the names provided during Free Listing interviews of potential Key Informants. These names were not being linked to the participants who provided them. The information collected through interviews was stored in a

locked room with access to the researcher and her team only. Only the research team had access to raw data. Information used in reports or subsequent publications will not be attributable to individual participants.

8.0 PRESENTATION OF STUDY FINDINGS

8.1 Free Listing Interviews

Fig 2. Sample Size and Sex Distribution of respondents.



Demographic Profile of Respondents

All respondents interviewed in the free listing exercise were adults aged between 18 and 60 years old. They comprised a relatively low to medium income community. In Matero Main clinic, almost all respondents interviewed were women (Fig 2). This was attributed to the fact that in this community, most men sought private health services because of the stigma attached to the TB illness. Women, on the other hand, had no choice but to seek public health services because they could not afford the private alternative.

Free list data was reviewed by the investigative team together with the interviewers and a total of 88 unique responses to the question “What do TB patients and the community think about having both TB and HIV at the same time” were identified amongst the responses given. Similar responses were collapsed into 9 summary categories determined by the research team. (Table 1).

Eighty seven responses were given concerning what TB patients and people in the community thought about offering HIV testing at TB corner. These were collapsed into 10 summary categories (Table 2). One hundred and ten reasons were given as to why TB patients with HIV do not enroll at ART clinics and 14 categories were formulated. Twenty four of the 88 responses were identified as reasons of what TB patients and people in the community thought about

having TB and HIV at the same time (Table 1). Of these stigma/discrimination occurred most frequently (75 %). The other 9 categories were also associated with stigma in one form or the other. Fifty percent of the respondents stated that people in the community viewed having both TB and HIV as a death sentence while 38% of the respondents stated that having both HIV and TB would lead to self stigma and depression.

Table 1; What do TB patients and people in the community think about having both TB and HIV at the same time?

Themes that emerged about perceptions of patients with TB/HIV co-infection	Reporting Number	Percentage
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Stigma/Discrimination: Made to feel as an outcaste	24	75
Death Sentence	17	53
Depression/self-denial/self-stigma	16	50
Misconception/Lack of knowledge	12	37.5
Prostitution/sleeping around/misbehaving: Diseases comes as a result of prostitution	6	18.9
High Pill burden: Taking too many pills at once	5	15.6
Accepting treatment: Good to know one can be treated for both diseases at the same time	4	12
Fear of dying either from the diseases or the pills	3	7
Weakness/illness: Too ill to get better even with treatment	3	9

Reasons given as to what TB patients and people in the community thought about offering HIV testing at TB corner are listed in table 2. Most popular response of the 13 responses was welcome idea (103%). 65.5% sited ignorance of this service and self stigma/self denial was at 43.7%.

Table 2; What do TB patients and people in the community think about offering HIV testing at TB corner?

Themes that emerged explaining why patients do not accept HIV testing in TB clinics	Reporting Number	Percentage
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Offering HIV testing in TB clinic was a welcome idea	33	104
lack of patient knowledge /ignorance	21	66
patient fear	18	56
Patient Self stigma/self denial	14	44
Lack of patient Confidentiality	10	31
Patient unwillingness to Accept treatment	6	19
Shyness: self stigma	4	12
Discouragement: Because they will die anyway	3	9
Depression: Loss of income, family, friends	2	6
High Pill burden/ not accepting treatment	2	6
Stigma/discrimination: Out caste	2	6
Lack of food: unable to provide adequate food for self due to loss of income	1	3
Other	1	3

Fourteen of the 110 responses were summarized as issues concerning the reasons why TB patients with HIV do not enroll at ART clinics in Table 3. Of these self stigma/self denial and ignorance, 81% and 68.7% respectively, topped the list. While other respondents stated the issue of pill burden as one of the reasons why clients did not enroll in the ART. Thirty three responses welcomed the idea of co-treatment. The percentage stretch to 104 because of the possibility of having more than one response per respondent.

Table 3; What are the reasons that TB patients with HIV do not enroll at ART clinics?

Problem description	Reporting Number	Percentage
Self-denial/Self-stigma	26	81
Lack of Knowledge/Ignorance	22	69
High Pill burden	16	50
Fear of dying	14	44
Side effects of the many drugs one has to take at once	14	31
Death sentence	10	31
Lack of Confidentiality	9	28
Shyness: self stigma	9	28
Stigma/Discrimination	7	22
Time spent at ART clinic: patients felt that long waiting times were disincentive to ART enrollment	6	19
Lack of food: unable to provide adequate food for self due to loss of income	5	16
Others	2	6

8.2 Key Informants' Interviews

Thirty interviews were conducted, comprising 2 community-based volunteers and 2 clinic-based volunteers at 6 clinics while in one clinic, interviewers could only interview two clinic based and one community based volunteer. In one clinic a respondent was aged 17 years old, and therefore did not meet the inclusion criterion. A list of key informants was generated by participants in the free-listing exercise, and final participants were selected by the study team on the basis that they were knowledgeable on the reported TB/HIV co-infection issues and were also key members in the local community who were referenced to by the free listing respondents. They included teachers of local schools surrounding a designated Health Centre, Chairpersons of the NHC, nurses, as well as TB corner nurses in the selected clinics and other members of the community.

Key Informants' interviews were conducted to try to expand on the responses obtained from the free listing interviews as well as obtain other responses not mentioned in the free listing exercise. They focused on TB/HIV Co-infection issues identified during the free listing interviews and they were open-ended questions such as "Tell me more about ..." (a TB/HIV response that was listed in the free listing exercise). Below are responses from the key informants' questions.

The responses to common misunderstandings and misconceptions around TB/HIV co infection and co treatment included;

- They say you were misbehaving (prostitution)
- Some say you had an abortion or slept with someone who had an abortion
- Some say the illness is from God
- You become sexually active when you are taking both TB and HIV drugs.

In response to the question “In what ways can we reduce these misunderstanding“, the key informants stated the following:

- Provision of more information on TB/HIV
- Encouraging people to be tested for HIV
- Food supplements

When asked in what ways, if at all, has the acceptance of HIV testing changed since DCT began at TB corner, the responses were as follows;

- Most people are nowadays accepting to have the HIV test and open files at the ART corners than before
- The health talks every morning have also helped as people listen to different topics
- People are encouraged to join support groups.
- It’s now easier for a TB person to start treatment for HIV

Responses to “In what ways can confidentiality about TB and HIV co-infection be improved” included;

- People are maintaining confidentiality. This is because even when we meet these people we do not greet them for fear that we may have recognize them
- Confidentiality is there
- Government should build a place which is hidden.
- Join support groups
- People should be invited to different workshops.

Responses to “How would you describe the acceptance of HIV testing and treatment among TB patients?” included;

- People must first go for HIV testing.

- Some people have to consult their spouses.
- There is more stigma at ART clinics than at TB clinic.
- It has not been accepted as once a person is given a yellow slip and they are booked for an appointment they go for good.
- Some run away
- Improve sensitization and improve knowledge through sensitization

Responses to “How can we make the treating of both TB and HIV at the same time more acceptable (taking both ARVs and TB medicines at the same time)?” were as follows;

- No shortage of medicines.
- Sending peer educators door to door to sensitize people,
- Building centers in the communities

Responses to “How does self stigma or denial affect people’s acceptance of testing and treatment?” included;

- Lack of adequate information
- Some refuse because of traditional beliefs.
- There is a lot denial especially common among couples
- Drugs are too strong to take at the same time.
- People do not go to the clinics
- People fear especially women to have VCT as they fear losing husbands.
- People fear dying
- They think they will not get better as both diseases are dangerous.
- Some people start ART and then stop along the way

Responses to “What are some of the reasons that people think TB/HIV co infection means they will die?” included;

- Both diseases are too powerful
- Drugs to these diseases are too strong
- HIV drugs are not easily accessible
- Some patients want to complete TB treatment before they can take HIV treatment and by then it may be too late for them

Responses to “What are the common misunderstandings and issues of ignorance around TB/HIV?” included;

- All those that have TB have HIV
- TB is very infectious that is why you find a special TB corner
- People take their relatives to the witchdoctor and there they don't find any cure
- People on TB treatment do not have enough to eat; as a result the tablets will kill them.
- Some people think that TB is transmitted by sexual intercourse just like HIV
- Anyone taking ARVs is a sinner or has been punished by God.

Responses to “In what ways can you reduce misunderstanding?” were as follows;

- By sensitizing communities, working with Neighborhood Health Committees, teachers, marketers, policemen and women
- The people doing sensitization are not the right people with experience
- Increasing the number of TB books so that the people in the community can have a chance to read.
- Information from the health workers.
- Tell right information

- Also people should be taught importance of taking TB/HIV drugs

Responses to “What are the problems people encounter in relationships when one partner has both TB and HIV?” included;

- Some people take less drugs for TB and some ARVs, they fear the pill burden
- Men usually leave women when they are sick
- Expectant mothers don't tell husbands after testing fearing that the marriage will break up.
- Relatives reject you
- Women treat husbands well. But husbands divorce women
- Stigma starts in the homes
- Men stigmatize their wives, marriages break
- When women are sick, their men go and marry other women.
- Men divorce women even if the men have not gone for testing.
- Men go for other women and start drinking beer.
- Women treat men well when they are sick, but men are cruel to their women when they are sick
- Men don't provide food, care and support. Some men even take women back to their parents.
- Men run away and go to girlfriends. Women show love and humility to their husbands
- People fear that they may die because that disease is incurable.
- Most marriages break. Husbands and wives separate because stigma in men is too much.
- Spouses are being accused of being prostitutes.

How do these reasons affect a TB patient's decision to seek HIV treatment?

- Patients stigmatise themselves and do not accept that they have HIV as well
- They lack support from families and friends and sometime the health care providers

- They will not go to the ART corner if referred or they will not go back for treatment

9.0 DISCUSSION OF FINDINGS

The discussion is centred around the objective of the study which seeks to identify socio-cultural, environmental and programmatic factors having positive and negative effects on DCT uptake and enrolment into HIV care.

The HIV/AIDS impact on the health care system is enormous. More than fifty percent of the hospital beds are occupied by patients with HIV and AIDS related illness in major hospital. This has led to burn out syndrome of care providers and care takers both at institutional level and at home (NAC, 2004).

The MDGs established by the United Nations provide both a framework and the opportunity for international cooperation to reduce poverty, including improving the health of the poor. As a disease of poverty responsible for the loss of more years of healthy life than any other communicable disease except HIV/ AIDS, TB is one of the priorities included in the MDGs. Goal 6, Target 8 (Millennium Development Goals indicators database 2006) – the MDG target relevant to TB – is to have halted the spread and begun to reverse incidence by 2015.

Tuberculosis control demands a comprehensive and sustained response, complementing measures to address the social and environmental factors that increase the risk of developing TB. Poor people bear most of the burden of illness, suffering and death caused by TB. The Stop TB Strategy should therefore be viewed as a key component of broader international, national and local strategies to alleviate poverty. It both builds on the DOTS strategy and expands its scope to address remaining constraints and challenges to TB control – an expansion that is critical to achievement of the MDG and related Stop TB Partnership targets for TB control. The Stop TB Strategy has six Principal components:

1. Pursue high-quality DOTS expansion and enhancement
2. Address TB/HIV and MDR-TB and other special challenges

3. Contribute to health system strengthening
4. Engage all care providers
5. Empower people with TB, and communities
6. Enable and promote research

It was found that there were more female respondents than male respondents. Male female TB/HIV infection ratio continue to vary in most countries. In Zambia currently 16% of adult population aged 15 to 49 or around one of every individual in this age group is HIV positive. The infection rate is higher among women (18%) than among men (13%). HIV prevalence rises from a level of 5% among 15-19 year olds to 25% among individuals in the 30-34 age group before falling to a level of 17% among the individuals aged 45 – 49. Women have much higher infection levels than men in the age group below age 35. In Africa, 30.8 million adults were infected by HIV and half of these (15.4 million) were women. (<http://www.avert.org/women.htm>). The current HIV infection rate for women in Zambia is four times higher than that of men (<http://www.lusakatimes.com>, Tuesday, March 11, 2008).

Marriage break down

The study has helped reveal the reason why women feel they have a higher infection rate than men. This is attributed to the fact that ‘Men are prostitutes, they are the ones who bring diseases to the homes and women are full time housewives.’ The study also revealed that a lot of couples seem to have different views on TB and HIV. One key informant stated that ‘many couples don’t have the knowledge of how easy it is to be infected with both’ and that ‘it is very difficult to convince a man that you can have both HIV and TB at the same time’. This has caused a lot of stress on many marriages. There is no trust as the partner who is diagnosed first is seen to have been promiscuous and therefore, has brought these two diseases on to the family. According to one key informant: ‘Marriages have broken down!’ Husbands have deserted their wives because ‘they feel it is expensive to look after a woman who has both HIV and TB at same time as a result, they opt to ‘leave no food at home’. The other cause of the marriage break down is attributed to the long waiting time at the clinic. This brings a lot of suspicion to the other marital partner. ‘We take a lot of time at the clinic and so when you go back our spouses think that we

were not at the clinic'. The issue of long waiting times has been attributed to the Human Resource in Health (HRH) crisis that is currently facing the country.

Long waiting times at clinic

The study found out that participants complained of long queues at the clinics and the long time that they spent waiting for treatment. The issue of human resource crisis, the critical shortage of qualified Human Resources for Health (HRH) is now acknowledged as a global challenge and a major obstacle to the on-going implementation of the MDGs, particularly in the developing countries. The crisis was reported to be most severe in Sub-Saharan Africa where shortages of core health workers were estimated at 1 million, representing approximately two times the core health workers in posting. Even though this crisis is being largely attributed to a number of factors, particularly the low outputs from health training institutions, and the increased mortality levels among health workers due to HIV/AIDS and the exodus of qualified health workers from developing countries to richer countries could be highlighted as the two most common contributing factors. For example, it is estimated that during 2002/2003 period alone, more than 3,000 nurses from Ghana, Kenya, Nigeria, South Africa, Zambia and Zimbabwe were registered to practice in the UK (Buchan and Dolvo, 2004).

Zambia is among the Sub-Saharan African countries that are severely affected by the HRH crisis, with critical shortages of appropriately qualified health workers at all the levels of the health care delivery system. The crisis is so severe that it is significantly undermining the country's efforts to implement key health programmes and the MDGs. The World Health Organisation (WHO) defines an adequate workforce as having, at least 2.3 doctors, nurses and midwives available per 1,000 people, and considers countries operating below this threshold as not capable of providing adequate basic, life-saving services (WHR, 2006). Zambia has been operating below this threshold. According to the available staffing information obtained from the JAR 2006 Report (JAR 2006 Report, MOH, 2007), in 2004 the ratio for Zambia was at 0.79 per 1,000 people (646 doctors, 6,096 nurses and 2,273 midwives, against an estimated population of 11,362,000). In 2007, it was estimated that there were 1,290 doctors, 8,165 nurses and 2,775 midwives working in the Zambian public health service, serving a population of 12,461,349 people (HMIS, 2007), which gives a ratio of only 0.98 / 1,000.

Given the above stated reasons, the time patients spend at the health facility is, therefore, increased. The patients are too ill and weak to stay in a queue for a long time. Coupled with this, some need to spend time looking for food as they could have lost their jobs which provided steady income. All these could be barriers as to why TB/HIV coinfecting patients do not enrol at the ART clinic.

Stigma and discrimination

AIDS-related stigma refers to the prejudice and discrimination directed at people living with HIV/AIDS (PLWHA), and the groups and communities that they are associated with. It can result in people living with [HIV/AIDS](#) being rejected from their community, shunned, discriminated against or even physically hurt.

AIDS stigma and discrimination have been seen all over the world, although they manifest themselves differently between countries, communities, religious groups and individuals. They are often seen alongside other forms of stigma and discrimination, such as racism, homophobia or misogyny and can be associated with behaviours often considered socially unacceptable such as prostitution or drug use (<http://www.avert.org/women.htm>).

Stigma and discrimination continues to pose a major challenge to the fight against HIV and AIDS. The study demonstrated that stigma continues to be a major problem with TB patients who have HIV as well. The combination of both TB and HIV continues to reinforce the stigma and discrimination. Stigma seems to be from both sides, within the individual, known as self stigma, and from others in the family and community. One of the key informants stated that ‘people start talking, fearing you that you are already dead, groups in the communities talk a lot and they say that if you have HIV and TB at the same time then you are already dead’.

Another stated that ‘People start fearing you when you cough. They even look the other side’, and ‘some people start to question and ask why me having both problems and not others, does it mean that God does not love me’. There is clearly a need to address the issue of stigma. Some strides have been taken to address this issue by developing a stigma index levels.

The location of the ART clinic is also coming under a lot of discussion. One respondent pointed out that ‘it’s too embarrassing to stay at the ART clinic building where everyone can see you’

and ‘people are very harsh, they don’t choose what to say to you or care how you feel at the ART corner’. Others felt that this is the main reason why some clients do not go to the ART clinic. ‘Some don’t want to go to the clinic; they don’t care for their lives’. ‘Because of this, people opt to self medicate themselves by purchasing drugs from the streets and from chemists’. One key informant stated that ‘Some buy the drugs from the drug stores’. The issue of self medication is one of the major challenges facing health care professionals and the Pharmaceutical Regulatory Board. Much work is being done to try and regulate the prescription and dispensing of medication.

Issues that emerged from the interviews point to the fact that patients with symptoms suggestive of TB initially seek care from a wide array of health-care providers before they can approach the public sector TB services. These may include private clinics operated by formal and informal practitioners, and institutions owned by the public, private, voluntary and corporate sectors, e.g. general and specialized public hospitals, nongovernmental organizations (NGOs), prison, military and health insurance organizations. These non-NTP providers may serve a large proportion of TB patients and suspects but may not always apply recommended TB management practices or report their cases to NTPs. The size, type and role of these non-NTP providers vary greatly across and within countries: in some settings there are large private and NGO sectors while in others there are public sector providers (such as general and specialized hospitals) that operate outside NTPs. Evidence suggests that failure to involve all care providers used by TB suspects and patients hampers case detection, delays diagnosis, causes improper diagnosis as well as inappropriate and incomplete treatment, increases drug resistance and places a large and unnecessary financial burden on patients (Uplekar et al 2001).

The basic premises of PPM are that the financial resources to establish and sustain the collaboration are provided or facilitated by the NTP, that drugs are provided free of charge or heavily subsidized, and those fees for tests and consultations are waived or kept to a minimum. The feasibility, effectiveness and cost-effectiveness of involving different types of care providers using a PPM approach have been demonstrated, and WHO has produced guidelines on how to engage all care providers in TB control (WHO 2006).

Misconceptions

Misconceptions continue to plague the HIV and Tb programmes. Communities continue to face the challenges of having so many misconceptions and myths in their midst. These misconceptions have led to clients not taking medications, seeking alternative therapies to medications and also seeking help from the traditional healers. This is more so when someone has both TB and HIV. 'It's very difficult to accept someone who has both illnesses at the same time'. Some of the misconceptions relate to education 'If they were educated they would not have both HIV and TB at the same time' while others state that 'they think that if you have TB and HIV at the same time you are already dead'. Despite all these misconceptions, people still appreciate the benefits of starting treatment. 'Some say it's important to start ART and TB fast so that you can survive and take care of your children'.

Lack of food

The issue of food continues to pose major challenges to the fight of TB/HIV infection and co-treatment issues. Many clients on TB and ART treatment site lack of food as a major concern when taking medications. This may be contributed to the high Poverty levels in the country. The Living Conditions Survey (2006) states that in the analysis of households' self-assessment of poverty by rural and urban residence indicate, high percentages of households in rural areas (47.7%) are very poor compared to 26 % in urban areas. The proportion of households that are living in moderate poverty is higher in urban (57.5 percent) than in rural areas (46.4 percent). The study was undertaken in Lusaka district, which has a 10% of people being very poor and 12% being moderately poor. It was not surprising that a number of respondents complained of the problem of lack of food.

Vegetables, fruits and meat and among the food needs and desires accompany TB. The health care providers also emphasize the need to take medication with food at all times. The TB patients and their families have to struggle to satisfy the 'hunger' during the TB patients' illness. This is seen in their effort to provide 'special foods' for the patients and this brings about food insecurity and tensions in families. However some studies have concluded that better nutrition does result in better outcomes of treatment (Ncayiyana and Daniel, 2007).

Fear

A number of respondents attributed their TB/HIV co-infection status to 'witchcraft'. Family members were mentioned as having bewitched the patients because of 'success in businesses or 'a good job'. The other type of fear mentioned was that related to 'Satanism', where the patient feels he/she has been 'sacrificed', and therefore, there was no possibility that he/she will recover from this illness at all. These types of fear have been documented in other countries such as Malawi by Peters, Kambewa and Walker, 2007 and in West Africa by Fairhead et al. 2006). In the study, fear was also related to the death penalty

Depression and Mental Health

Most TB patients are mobile, but when co-diagnosed with HIV, they experience a contraction of space due to the illness which reduces their mobility as well as the poverty and the isolation that accompanies TB/HIV. Contracted space reduces both livelihood opportunities and the degree to which assistance can be accessed and shared across government, NGOs and a dispersed network of kin and friends (Bond et al,2009). As a result, both TB patients and their care givers are unable to venture out in search of a livelihood or to strengthen relationships. In the long run they fall out of friendship/kinship circles as well as income to support their special needs. Ogden et al (1999) refer to this situation of TB patients needing money for treatment yet unable to earn a living as being "doubly impoverished".

Most TB patients interviewed lost their jobs or business upon being sick. When they felt better, their economy still could not pick up either because they could not get into employment as before or because they lost all their capital and had nowhere to start their businesses from. This leads to a lot of mental strain on the part of the patient. Most of the TB patients go into depression (n=18) and die from this disease. Other patients go into depression because of being deserted by their spouses, families and/or friends.

Drugs/Pill burden

Most patients with TB have symptoms that gradually increase in intensity. By the time they start TB treatment, most of them are extremely frail and ill. For those that are co-infected with HIV, the possibility of taking ART drugs as well as TB treatment is frightening. They feel both 'drugs are too strong' and can 'finish you off!' One respondent stated that 'the drugs are too many and

too strong for one person to take'. It was also believed that patients 'feared' taking the TB and HIV medications together due to the 'precautions' that come with some of the medications. 'People fear to be taking double medicines because some forget these precautions'. In certain combinations of drugs clients are given instructions on how to take the medications. These instructions may seem rather difficult for clients to adhere to. Other concerns (n=18) 'these drugs kills, they make you look too fat than before.' The respondents in the study also stated that the medication for TB and HIV were too much. 'These medicines are too much for the TB patient, they can suffocate you.' It is therefore gratifying that the TB treatment has been compiled and most patients expressed their happiness on this development.

The JAR report of 2007 states that there have been a continued shortages and erratic supply of essential drugs and medical supplies, due to a host of challenges including procurement and logistics management problems. However, despite the significant efforts and achievements recorded in 2006 in the reorganization of the procurement and supply system, shortages of some vaccines, anti-malaria drugs and family planning commodities were experienced, among these, TB drugs in some places.

LIMITATIONS

This study used interviewers who were trained community members rather than professional interviewers. They transcribed their interviews and then translated them into English. Both of these procedures could result in errors; however measures, such as having a separate recorder for the interview and doing the translations immediately after each interview helped to ensure that transcription and translation errors were minimized.

This study was dealing with sensitive issues surrounding TB and HIV in a patient population and it was expected that some of the patients we approached would refuse to participate. Among those who did participate, some did not provide a complete response to all questions due to the stigma associated with the subject matter.

This study did contain some selection bias. Patients in the free list exercise may have been more likely to name people who were either highly critical or highly supportive of ART depending on

the patient's personal views towards ART. We also suspected that if more free-list patients had similar views, the information from the key informants they named would also be biased.

Finally, because a random sample was not used, the results from the survey questionnaire cannot be generalized to the entire TB patient population. They will, however, provide a good platform for further research and implementation design.

CONCLUSION

Progress on all of the health-related MDGs depends substantially on the strengthening of health systems. This is particularly true in Africa. If access to good-quality health services can be increased and sustained, this should have major benefits for TB control as well as other elements. Health system strengthening is defined as “improving capacity in some critical components of health systems, in order to achieve more equitable and sustained improvement across health services and outcomes” (WHO, 2002). Tuberculosis control programmes and their partners should participate actively in both country-led and global efforts to improve action across all major areas of health systems, including policy, human resources, financing, management, service delivery (as well as infrastructure and supply systems) and information systems. This means working across all levels of systems and with all actors in the public sector, non-state sector and communities and may incorporate: ongoing contributions to well-defined sector strategies and plans; helping build system-wide responses; and working on initiatives to devise, test and share new solutions. Many National Tuberculosis programmes (NTPs) began this type of work in response to health reform initiatives of the past 10 years.

It is true that the incidence of TB increases with the incidence of HIV as shown in the fig 2 above. These diseases should be treated as high priority public health problems. Therefore, government should allocate enough funding to both programmes. Partners should also help to reduce any duplication or distortions caused in local systems by rapid scaling up or by expanded financing for TB control efforts, and help to build coordination across disease-specific initiatives.

Sensitization

The study revealed that there was need to provide more information on the disease in the communities. The global TB strategy recommends advocacy, communication and social mobilization. In the context of wide-ranging partnerships for TB control, advocacy, communication and social mobilization (ACSM) embrace; advocacy to influence policy changes and sustain political and financial commitment; two-way communication between the care providers and people with TB as well as communities to improve knowledge of TB control policies, programmes and services; and social mobilization to engage society, especially the poor, and all allies and partners in the campaign to ‘Stop TB’. Each of these activities can help build greater commitment to fighting TB. Advocacy is intended to secure the support of key

constituencies in relevant local, national and international policy discussions and is expected to prompt greater accountability from governmental and international actors. Communication is concerned with informing, and enhancing knowledge among the general public and people with TB, and empowering them to express their needs and take action. Equally, encouraging providers to be more receptive to the expressed wants and views of people with TB and community members will make TB services more responsive to community needs. Social mobilization is the process of bringing together all feasible and practical intersectoral allies to raise people's knowledge of and demand for good-quality TB care and health care in general, assist in the delivery of resources and services and strengthen community participation for sustainability.

Other common misunderstandings that surround the TB/HIV co-infection the issue are that all those with TB have HIV. There is fear that taking TB/HIV drugs at the same time can kill a patient because both drugs are perceived to be very strong. There is also the fear of being deserted by a loved one if the patient is discovered to have both diseases. This came out as men leaving their female partners and females being cruel to their male partners if they discovered about their TB/HIV co-infection and co-treatment status. Generally, people in the community want a lot of sensitization on issues surrounding TB/HIV co-infection and co-treatment. This, they feel, will reduce the many misconceptions that surround the TB/HIV co-infection and co-treatment issue.

RECOMMENDATIONS

1. Community participation in TB care implies establishing a working partnership between the health sector and the community – the local population, especially the poor, and TB patients, both current and cured. The experiences of TB patients help fellow-patients to cope better with their illnesses and guide NTBLCP in delivering services responsive to patients' needs. Ensuring that patients and communities alike are informed about TB, enhancing general awareness about the disease and sharing responsibility for TB care can lead to effective patient empowerment and community participation, increasing the demand for health services and bringing care closer to the community. To this end, NTBLCP should provide support to frontline health workers to help them create an empowering environment, for example, by facilitating the creation of patient groups, encouraging peer education and support, and linking them with other self-help groups in the community. Selecting community volunteers and identifying how they could contribute to TB care should be the joint responsibility of the local NTBLCP staff, TB patients and representatives of the community. The training requirements of community volunteers may vary from setting to setting, ranging from “on-the-job” instruction to more formal short courses provided by NTBLCP staff. Community volunteers also need regular support, motivation, instruction and supervision. Evidence shows that community based TB care is cost-effective compared with hospital-based care and other ambulatory care models. Inspiring communities and obtaining their continued support in identifying and providing care for people with TB is essential to sustain community TB initiatives.
2. Integration of the TB and HIV programmes is essential and this should start at the central level in the Ministry of Health. The two programmes are run separately, one in the Directorate of Public Health (TB) and the other (HIV), in the Directorate of Diagnostic and Clinical Care. Once this is done, the programmes at the Health Centre level will also be integrated.
3. There is also need to reduce diagnostic delay in government health institutions and the provision of a comprehensive nutritional and social programme that oversee the needs of TB patients and people living with HIV (PLWH).

4. The community and the TB patients need to be educated on the dangers of self medication and the negative consequences of the same.
5. The National Tuberculosis and Leprosy Control (NTBLC) Programme in Zambia should develop and maintain strong stewardship capacity in order to guide and oversee collaboration between private and public health care providers in issues related to TB/HIV at all levels of health care provision. The first step in doing this involves mapping all relevant public and private health care providers in a given setting. Next, suitable roles for them in implementation of the Stop TB Strategy should be identified.
6. There should be a deliberate policy in place to motivate care givers of the TB/HIV co-infected patients. Both diseases require one to need care and support for a long time. The people giving this care and support need to be helped emotional and financial wise. Once they are empowered, they will give better care and support to the patients, and as such, there will be better patient turnout.
7. World Food Programme (WFP) used to provide food supplementation in the form of High Energy Protein Supplements (HEPS) with a little payment from the Government of Zambia. However, this could not be sustained and as a result, the WFP has stopped providing this supplement. Therefore, there is need for government to reconsider this and provide food supplements to TB/HIV patients by any means possible.
8. Prostitution is considered to be the evil behind the spread of TB/HIV. There is need for government to look into this vice and curd it
9. Stigma remains the single most important barrier to public action. It is a main reason why too many people are afraid to see a doctor to determine whether they have the disease, or to seek treatment if so. It helps make AIDS the silent killer, because people fear the social disgrace of speaking about it, or taking easily available precautions. Stigma is a chief reason why the AIDS epidemic continues to devastate societies around the world. The NTBLC should devise measures that will continuously address the issue of stigma, for example, air more programmes on TB/HIV in the national media.

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APPENDICES

Appendix 1



THE UNIVERSITY OF ZAMBIA

SCHOOL OF MEDICINE

DEPARTMENT OF COMMUNITY MEDICINE

INFORMED CONSENT FORM

TITLE OF RESEARCH PROJECT: A study of the barriers to accessing HIV care and treatment services by TB patients who are co-infected with HIV in Lusaka District clinics

Dear

INTRODUCTION

My name is I am interviewing you on behalf of Loyce Chatepa Munthali, who is a student in the Masters of Science in Public Health program of the University of Zambia. We are conducting the above mentioned research project to evaluate the impact of the TB/HIV integration programme in Lusaka District Clinics and would appreciate it if you could participate in this study. Please be reminded that participation in this research project is purely voluntary. You have the right to decline to participate or withdraw from the research project at any time. Participation in this study would mean the researcher would ask you questions about your status of tuberculosis and HIV infection. We are asking for your general impressions about the way TB patients respond to the services offered. You do not have to provide your individual personal views but the general perception among the TB patients and the community. This information will be used to assess current programs and make recommendations for their improvement.

PURPOSE OF THE RESEARCH PROJECT

To identify factors contributing to under utilization of HIV Services by TB patients who are co-infected with HIV.

STUDY PROCEDURES

After you have signed the consent form, and all clarifications concerning this research project made, you will be asked 3 questions about the community's perceptions of TB/HIV co-infection and available care .You will be asked to list all the possible answers that you can think of. You will also be asked to name a key person in your community who helps in solving or is knowledgeable about these problems. The interviews will be conducted between 08.00hrs to 12.00hrs here in this clinic and last approximately one hour. A separate room will be used to insure little risk of interruption.

RISKS

There are no risks involved in this research project. You will not be forced to answer any question. You have the right to refuse to participate in this study or seek any clarification whenever necessary. If you refuse to participate, or withdraw from the study it will not affect your access to care or quality of care or treatment. Participation in the study will also not affect your access to care or quality of care or treatment.

You may be uncomfortable discussing some of the interview topics but you are free to decline to answer a question or withdraw from the interview at any point.

BENEFITS

There will be no direct benefit for you by participating in this research project. However, the information obtained in this research project will be used to design interventions to improve the TB/HIV integration activities for those patients who are TB/HIV co-infected.

CONFIDENTIALITY

Your participation in this study is purely voluntary. The interviews will be conducted in a separate place where you will not face interference from any third party. Care will be taken to maintain privacy. You will not be forced to answer any questions. Your name will not be written

on any study forms; only a study number will be used. Any information that ends up being used in reports or articles will not be linked to your name or any identifying characteristics. The information collected through interviews will be stored in a locked room with access to the researcher and her team only.

The information collected will be analysed and used to improve TB/HIV treatment outcomes.

INFORMATION AND CLARIFICATION

You have the right to withdraw from this study or seek clarification whenever necessary.

For any clarification or information, you are welcome to contact any one of the researchers during and after the research. Below are the names of the people you can contact either through cell phone or in person, whichever is convenient to you.

If you agree to participate in this research project, please sign the consent form below.

CONSENT TO PARTICIPATE IN THE RESEARCH PROJECT

I ----- have been fully informed of this research project, its risks, benefits and confidentiality, and I agree to participate willingly.

Sign/Thumb print ----- Date: -----

Witness (Name): -----

Sign: ----- Date: -----

For questions about this study or a research-related injury, contact:

Loyce Munthali RN, RM, BSc Nursing
UNZA, School of Medicine,
Dept. of Community Medicine
P.O. Box 50110,

Lusaka, Zambia.
Cell: 096 6 755 091

Professor Seter Siziya
UNZA, School of Medicine,
Dept. of Community Medicine
P.O. Box 50110,
Lusaka, Zambia.
Cell: 260-96-748988 / 95-752646
Fax: 260-1-256181

For questions about your rights as a research subject, contact:

Mrs. E. Nkandu,
Chairperson of the Research Ethics Committee,
University of Zambia, Nationalist Road, Lusaka, Zambia.
Tel: 252641/256067/ Fax: 01 250753.

Appendix 2

FREE LISTING FORM 1

Site _____ Age _____ Gender _____ Interviewer _____ Date _____

Primary Question

“What do TB patients and people in the community

Secondary Question

Can you give us a short description

think about having both TB and HIV at the same time?” of your response?

1. _____	_____
2. _____	_____
3. _____	_____
4. _____	_____
5. _____	_____
6. _____	_____
7. _____	_____

FREE LISTING FORM 2

Site _____ **Age** _____ **Gender** _____ **Interviewer** _____ **Date** _____

Primary Question

“What do TB patients and people in the community think about offering HIV testing at TB corner?”

Secondary Question

Can you give us a short description of your response?

1. _____	_____
----------	-------

2. _____	_____
3. _____	_____
4. _____	_____
5. _____	_____
6. _____	_____
7. _____	_____
8. _____	_____
9. _____	_____
10. _____	_____

FREE LISTING FORM 3

Site _____ **Age** _____ **Gender** _____ **Interviewer** _____ **Date** _____

Primary Question

“What are the reasons that TB patients with HIV do not enroll at ART clinics?”

1. _____

2. _____

Secondary Question

Can you give us a short description of your response?

3. _____

4. _____

5. _____

6. _____

7. _____

8. _____

9. _____

10. _____

Key Informant Questions

KI Question	Nyanja	Bemba
Tell us about the common misunderstandings and issues of ignorance around TB/HIV co-infection and co-treatment	Tiuzenikoni pa ku samvesesa ndi kusadziwa bwino pa nkhani za kudwala chifuba cha TB ndi kadoyo ka HIV pamodzi ndi kuthandidziwa pavonse?	Twebeniko iflandwa ilingi pakukana umfwikisha no kukana ishiba palwa kundapwa pa malwele yabili aya TB na HIV?
In what ways can we reduce these misunderstandings?	Kodi nimunjila bwanji mwamene tinga chepetse kusanvesesa uku?	Nimunshilanshi twinge chefyako ukukana umfwikisha?
Tell us about the problems that come up in relationships when 1 partner has both TB and HIV	Tiuzenikoni pa mabvuto yamene yamabwela muvikwati ngati umodzi apezeka namatenda ya TB pamodzi ndi HIV?	Twebeniko pamafya aya sangwa mufyupo nga umo asangwa na malwele yabili TB na HIV?

Tell us more about how men treat their wives after finding out their wives have TB and HIV	Tiuzenikoni mwamene amuna asungila akdzi ao ngati baziba kuti bali na matenda ya HIV na TB pamodzi?	Twebeniko ifyo abaume basunga abakashi babo panuma yakwishiba ukuti abakashi babo balikwata amalwele yabili TB na HIV?
Tell us more about how women treat their husbands after finding out their husbands have TB and HIV	Tiuzenikoni mwamene akazi asungila amuna ao ngati baziba kuti bali ndi kadoyo ka HIV na chifuba cha TB pamodzi?	Twebeniko ifyo abakashi basunga abaume babo panuma yakwishiba ukuti abaume babo balikwata amalwele yabili TB na HIV?
How does self-stigma or denial affect people's acceptance of testing	Kodi kuzinganizila zoipa ndi kuzikana kuvutista bwanji kuvomela kupimiwa ndi	Nimunshilanshi ukuipatulula nokuimwenamo kukumya ukusuminisha ukpimisha no

and treatment?	kuthandiziwa?	kundapwa?
What are some of the reasons that people think TB/HIV co-infection means they will die?	Kodi zifukwa zabwanji zamene bantu baganiza kuti bakufa ngati bapezeka na matenda ya TB ndi HIV pathawi imodzi?	Finshi ifilenga abantu bambi ukutontonkanya ukuti nganakwata amalwele yabili TB na HIV kuti bafwa?
How do these reasons affect a TB patient's decision to seek HIV treatment?	Kodi nimunjila bwanji mwamene vifukwa ivi vingamuvutisile kuvomela kufuna ku thandiziwa pa HIV muntu odwala chifuba cha TB?	Bushe ifi kuti fwalenga abalwele ba TB na HIV ukukana ubwafwilisho bwa kundapwa?
How can we make the treating both TB and HIV at the same time more	Kodi tingalengesa bwanji thandizo ya TB na HIV kuvomeledwa mokwana?	Kuti twachita shani ukuti abantu bakalesumina ukunwa umuti wa TB na HIV?

acceptable (taking both ARV's and TB medicine at the same time)?		
--	--	--