

**Perceptions and beliefs on tuberculosis and the influence on
health seeking behaviour**

A qualitative study in Kinondoni district, Dar es Salaam

Anne Kari Knutsen



**Centre for International Health
Faculty of Medicine and Dentistry
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National Institute of Medical Research
Tanzania
2010**

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This thesis is submitted in partial fulfilment of the requirements for the degree of Master of
Philosophy in International Health at the University of Bergen.

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Summary

Background and goal

Tuberculosis (TB) is one of the major health problems in the world. Early passive case detection and high treatment compliance is important for obtaining a successful TB control. One of the factors early case detection relies on is the human factor. The suspected TB case needs to recognize symptoms of TB and value them serious enough to report at a professional health facility. Cough for more than two weeks is considered to be TB suspect. The main goal of early case detection is to prevent continuously transmittance of *Mycobacterium Tuberculosis* in the communities. The detection rate of new smear positive TB in Tanzania is below 50%.

This study aims to contribute to the understanding of the human factor in health seeking behaviour. The main objective is to study whether knowledge, beliefs and perceptions of TB can influence the health seeking behaviour in a community in Dar es Salaam, Tanzania.

Method of investigation

This study had an exploratory qualitative design. Focus Group Discussions and Individual Interviews were used as methods for data collection in three study sites in Kinondoni Municipality from June to September, 2009. Nine FGDs and 15 INIs were conducted with total of 70 informants. The data were analyzed by using Systematic Text Condensation. Ethical clearance was granted from Medical Research Coordinating Committee in Tanzania and Regional Ethical Committee of Western Norway.

Principal results of the investigation

TB is perceived as a normal, common and treatable disease. The main symptoms are cough and fever. TB is believed to be the same as HIV / AIDS. There is a fear of seeking professional care for TB since the communities know that a TB patient will be assessed for HIV. There is a lack of knowledge and a misconception around the causality of TB. TB is

believed to be caused by hard work and dust. It can also be caused by bad spirits, bewitchments or inflicted upon one by God. TB caused by spirits or bewitchments can only be treated by prayers or traditional healers. Traditional healers believe injections can kill a patient treated at hospital. Hospital is the most preferred site of seeking care within the professional sector. Some would choose the folk sector as a first choice of care or as a second choice if hospital treatment fails. The TB patient would not be treated differently by his family, but within the community he would be stigmatized and face isolation. Low levels of understanding of TB were connected to seeking care at the folk sector.

Principal conclusions suggested by the results

The human factor is important for TB control. It would be useful for decision makers to consider the communities' health beliefs when developing educational and control plans for TB. The believed normality and commonality of the disease should be addressed in the plan work for case finding. More research is needed to assess the target populations' health beliefs.

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List Of abbreviations

DOT	-	Direct Observed Treatment
DOTS	-	Direct Observed Treatment Short Course, WHO recommended strategy to control TB
FGD	-	Focus Group Discussion
HBC	-	High Burden Countries
HBM	-	Health Belief Model
INI	-	Individual Interviews
MRCC	-	Medical Research Coordinating Committee
NIMR	-	National Institute for Medical Research
OPD	-	Out Patient Department
PTB	-	Pulmonary Tuberculosis
REK VEST	-	Regional Ethical Committee of Western Norway
STC	-	Systematic Text Condensation
TB	-	Tuberculosis
WHA	-	World Health Assembly
WHO	-	World Health Organization

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Background

Introduction

Tuberculosis (TB) is one of the major and still increasing health problems in the world. (1) For obtaining a good and successful TB control it is important to have high treatment compliance and an effective early passive case detection. To achieve the optimal TB control it is also important to have enough resources and health facilities including lab functions with adequate diagnostic equipment and qualified health staff that can investigate all TB suspects with accuracy and efficiency. In this complex task needed for controlling TB, the case of the human behaviour will always be a critical and important element. (2) Passive case finding rely on the individual's ability to recognize symptoms of TB and find them serious enough to seek help at a health facility. This depends on the person's level of knowledge and how he is received at the health facility. (3) The main goal of early case detection is to prevent continuous transmittance of TB in the community. (4)

Many factors influence the human aspect in TB control. Health seeking behaviour is influenced by culture, health related beliefs and personal experiences in a complex system. (2) Organizational problems in TB programmes, costs for the patient, stigma and social factors are factors influencing the control of TB. (5)

There have been many studies also in Tanzania around the problem of delays in health seeking behaviour. Most of these have assessed factors causing delays, but often the human aspects have been overlooked. Many health promotion programmes in the world have failed because there have not been taken into consideration the health behaviour of the target population. It would be beneficial in programme planning to take into consideration local health beliefs, knowledge and attitudes towards TB. (2)

In this thesis I will look at the human factor, especially the perceptions and beliefs the study population has on TB and connect it to the health seeking behaviour according to what triggers people whether to seek health care or not when having TB or symptoms of TB. The reason for exploring this issue is the high number of TB cases and the low detection rate of smear positive TB which is below 50% in Tanzania. (6)

Review of the literature

Tuberculosis in the world

The incidence of TB has increased from 9,3 million TB cases in 2007 to 9,4 million cases in 2008. For the year 2008 it was estimated that 11,1 million people were living with TB, and close to 2 million died. The same year only 5,7 million TB cases were reported for both new and relapse cases. Of these 2,7 million (57%) were smear positive pulmonary cases. The World Health Assembly (WHA) set the goals in 1991 that in 2000, later reset to 2005, that the treatment success rate should be 85% for new smear positive cases. This goal was reached for the first time in 2007 when the rate reached 86% worldwide. (1) Despite the good results in treating TB, the rates of detecting new cases still linger behind. WHA set a goal of detecting new cases of smear positive TB at 70%. This goal is still not met and the case detection rates have stagnated since 2006. Worldwide the case detection for all forms of TB was 61% in 2008. Of all regions Africa has the lowest rate of detecting new cases. (1)

Tuberculosis in Tanzania

The 22 countries with the highest burden of TB in the world account for 80% of the total number of all estimated TB cases. Tanzania ranks as number 14 of these 22 high burden countries (HBC). (7) TB as a major burden of disease in Tanzania has increased from 7% in 2000 to 8,3% in 2006. TB is the third major cause of all deaths after Malaria and AIDS for people over 5 years of age in the hospitals. (7-8) Each year about 2600 individuals die in Tanzania because of TB. (3) The high prevalence in HIV of 5,6% in the population of 15-49 years is thought to cause the increasing morbidity of TB. TB is most common for the age groups from 15-49 years, the same as for HIV. (8)

The estimated incidence of smear positive TB cases was 135 per 100 000 population in 2006. (7) The notified cases of smear positive TB cases in Tanzania were 24 500 in 2007, when the total number of all cases were 57 500. In 2007 Dar es Salam contributed to 24% of the total number of TB cases in Tanzania.(8)

The Direct Observed Treatment –Short Course (DOTS) programs have 100% coverage in Tanzania. (4) Through the DOTS program, the detection rate was 46% of new smear positive TB cases in 2007. This is far from reaching the target of 70%. (7) According to the annual report on TB and Leprosy (8), Tanzania intensified TB case finding from the beginning of 2008. Some main activities on active case finding programmes are investigating TB contacts, do TB screening in prisons and actively search for TB among patients at hospitals and in communities. (1)

Short on Tuberculosis

Tuberculosis is a communicable disease. It is spread by small airborne particles containing *Mycobacterium Tuberculosis*. It is spread when an infectious case is talking, sneezing or coughing. The small droplets are inhaled by the recipient. There is an estimated lifetime risk of developing TB of 10% in a newly infected young child. (9)

There are different types of TB; pulmonary TB and extrapulmonary TB. In the last one, the infection can be found elsewhere in the body, like in the spine, joints, bones or the central nervous system. About 20% of the total TB cases are the extrapulmonary. (9)

The pulmonary tuberculosis (PTB), especially the sputum smear positive PTB, is the one that is the most contagious. In the cases that are culture confirmed as PTB, 50 – 80 % will be smear positive. (9) One smear positive case can infect up to 15 new cases during a period of one year. (10)

The most important symptoms on PTB are chest symptoms like cough, haemoptysis, chest pain and breathlessness and systemic symptoms like weight loss, tiredness, fever and night sweat. Frieden (11) claims that patients having persistent cough for more than two weeks, should have a TB check up. The World Health Organization (WHO) has recommended passive before active case finding because the active case finding is not cost effective. This means that the patient himself have to seek health services for check up if he has a cough for more than 2 weeks or other symptoms thought to be TB symptoms. (6) A TB check up or a TB diagnosis is based on sputum smear, culture, pulmonary x-ray or a tuberculin skin test, where the sputum smear are the most and often the only feasible option in many developing countries. (9)

DOTS are recommended by the WHO and acknowledged internationally as a strategy for disease control to find and cure TB in order to stop the spreading of the bacilli. The strategy is based on government commitment, case detection by sputum smear microscopy and passive case finding, short course treatment standardized for 6 – 8 months, sustainable TB drug supply and a system for reporting and follow up of all patients and program performance. (11)

Health care sectors

People experiencing illness or disease, like symptoms on TB, will have their own way of explaining the illness and consider where to seek health care. Kleinman (12) has systemized the levels of health care where people seek for help in three sectors that is overlapping and interconnected. These sectors are the popular, folk and professional sectors. The popular sector has been estimated to take care of as much as 70 – 90% of all health care measurements. This sector includes all the things people are doing without counselling with traditional medicine or professional doctors. It can be self treatment like buying medicine from a pharmacy or use herbs or other remedies. Consultations and seeking advice from other lay persons or family and friends, often when this person has a similar experience is common. In the folk sector we find the people that are specialized in traditional medicine, but these health providers are not included in the official medical system. To deal with illnesses believed to be caused by bewitchment or divine punishment there are spiritual healers. Traditional healers or herb doctors deal with secular diseases. Common for the performers in the folk sector is that they share the same view of the world as the community they live in does according to how the disease appeared, the importance of symptoms and how to treat the illness or bad health.

The third sector is the professional sector which is the chosen and legally healing profession by the state. In most countries in the world, the biomedicine also called the western scientific medicine is the preferred one. It includes doctors, nurses and other health workers. (12) The health system today is not one singular system, but a multiplicity of health systems called medical pluralism. The medical pluralism includes the systems of the different cultural or ethnic groups with their own medical traditions. The introduction of foreign traditions in a

culture lead up to the medical pluralism and give people a range of choices of therapy. This complicates the health seeking behaviour. (13)

Cultural aspects of health

Culture is according to Taylor,1871 (12); “that complex whole which includes knowledge, belief, art, morals, law, custom and any other capabilities and habits acquired by man as a member of society”. Members of a community will inherit a set of guidelines which tells them how to behave and respond towards other people and towards supernatural forces and how to see the world. Hall (12) divides the culture in three different levels where the deepest or first level is the most difficult to change because it is the most hidden and stable level. It is a level where most people are not consciously aware of the rules and regulations that are taken as granted and that everyone knows but never states. In the second level there is a set of regulation, rules and beliefs that the members of a group would know, but they would rarely share this knowledge with people from outside. In the third level the culture is visible for the outsides and includes rituals, cultural dances, food, and clothing and so on. This level is the one easiest to manipulate and change.

Culture is not constant, it will always change when new impressions enter into the culture. Also between members of the same community there may be differences. Culture is influenced by a variety of factors like gender, age, personality, (individual factors), education, (educational factors), poverty, employment, (socio-economic factors), housing, roads and public transport (environmental factors). (12)

Rubel and Garro (5) explain that people have their own health culture which is an understanding obtained by informal education through family, friends and other in the community about the actual disease, what causes the problem and how to understand it. The health culture helps the ill person to interpret the symptoms of the disease and give the symptoms meaning. It will also help classifying the severity of the symptoms and to find out where to seek help. The health culture differs from person to person. The understanding a person has according to health culture, can influence how he recognizes and accepts changes in his physical or mental well-being. This understanding will determine where, when and to whom he will go to seek for help. An important point that can influence the collaboration and

understanding between a person seeking assistance and one giving this help is that a person's health culture not necessarily is the same as within the professional health workers. (5)

Health seeking behaviour

Health behaviour can be influenced by many factors. There are several theories that aim to explain people's health seeking behaviour. One of these is the Health Belief Model (HBM). This theory was developed in the 1950s to help understand why public preventive services were not used. Later on the theory has developed to include newer issues in prevention, detection of diseases and also lifestyle behaviours like the understanding of what motivates a person to decide what health actions to take. (14) The HBM look at factors that is important according to how people will respond to a health threat. These factors include how people perceive the severity of the threat or health problem and whether or not they perceive themselves to be susceptible to it. When presented for options to prevention actions or treatment to an illness people will value these actions according to which perceived benefits and adverse effects the actions will give them. To make a decision according to take health measurements when faced with a health problem, there must be a cue to action. These cues are based on previous experience and familiarity to similar situations. There will also be perceived barriers that have to be valued before health behaviour is decided. Self efficacy as perceived self competency before a change in life is a recently added factor in this theory. The mentioned factors will make the person decide either to believe in a personal health threat or believe in the effectiveness of health behaviour and the result of the decision will be a positive or negative health behaviour. (5, 14-15)

Another theory is the self-regulatory theory which focuses on the individual person's ability to cope with a health threat based on previous experiences and the information the new health threat poses. This demands a person that is an active problem-solver who is motivated to treat illness and avoid health threats. Some factors like the person's personality and his religious, social and cultural context are important in the coping strategy. Symptoms and beliefs on the illness causation and also environmental perceptions are interconnected factors existing in the process of coping with illness threats. (15)

Some researchers talk about the interpretation of the meaning of the symptoms rather than the symptoms on illness themselves as a motivator for people to seek help. When interpreting symptoms it is to find out what implications the symptoms will have for the daily life. These interpretations will guide the person to decide if, when and where he will seek for help. The decisions he makes are based on his own health culture and explanatory model of what the problem is. (5)

There is conducted several studies in Tanzania where the health seeking behaviour has been addressed. In a study from Ilala and Kinondoni Municipalities in Dar es Salaam it is found that 68% of the respondents visited a public health facility as a first response in seeking help. Only 3% sought a traditional health care provider as a first choice. (16) In Mpwapwa district in Tanzania, public health facility was the last option. The most preferred response in health behaviour was self treatment, followed by consultations with traditional healers. (17)

The Problem of low detection rates of tuberculosis

An essential component of the control of TB is the detection of smear positive pulmonary TB which is the most infectious. The goal is to identify and find the individuals who are the sources of the infection and who are spreading the bacilli in the community. Initiating treatment for these infectious cases will stop the chain of infection and the individual TB case will not transmit TB anymore. Minimizing the delay in treatment of TB will increase the chance of cure for the patient and decrease the transmission in the communities. (11)

Tanzania has a low detection rate for smear positive TB of under 50%. When looking at the high numbers of notified TB cases, there is an extensive gap between those that have been found and put on treatment and the estimated number of incident cases who is not detected. These will continue transmitting the disease in the communities. One TB case can infect up to 15 new cases during a year and in the light of this information alone it is evident that the finding of more TB cases is an important issue in order to increase the control of TB. (4)

When smear positive TB cases not is found and treated the disease can lead to long term dysfunction of the lungs or in many cases to death. TB mainly affects the group of people who are in the productive age, the consequences of the disease can be loss of job and

therefore hard times economically for the family and the TB case, especially when the diseased person is the main supporter in the family. In addition there might be substantial household costs connected to transport fees and treatment related costs like expenditures at pharmacies or traditional healers. (11) When there are many cases of TB in a community, also the communities' economy and productivity can be endangered. (18)

In a study from Dar es Salaam on duration of cough, the researchers found that among those who had a cough for over two weeks almost 13% had positive sputum smear PTB while almost 9% of those having cough for less than two weeks also were positive on smear examination. (6) Cough is very prevalent in most societies, 95% of those seeking help for this at primary health centres do not have tuberculosis. It is documented that most transmissions of the disease occur between onset of symptoms and the initiation of treatment. (19) In Tanzania case finding is mainly passive meaning that the person having persistent cough should be assessed for TB at a health facility, but he has to seek for the help based on his own knowledge and interpretation of the severity of the symptoms. (6) The patients self referral interval is the time passing from onset of symptoms until the patient report to a health facility. If this time is more that 30 days it will be considered as a patient delay. (3-4)

Several researchers have worked on the problem of delayed case detection in Tanzania the last decade. (3-4, 6, 10, 16, 20) Mfinanga et al (4) performed a study in 2006 in the three districts of Dar es Salaam where he found that 35,1% of patients experienced patient delay, 52,9% experienced diagnostic delay and 34,4% treatment delay. In a study from Mwanza district, it was found that 84,4% of the patients reported at a health facility later than 30 days after initiation of symptoms. (10) Irani et al report in a study conducted in Ilala District, Dar es Salaam an average of seven weeks between start of symptoms and final diagnosis. (20) In Pwani region Ngadaya et al found that 75,8 days are the mean time from onset of symptoms to seeking health care first time at a health facility. (3) Considering these studies it appears that many of the patients in Tanzania take long time before consulting health services. These patients continue transmitting the disease in the communities together with those who never report at a health facility. The main goals for most tuberculosis programmes are to reduce the transmission between individuals in the community hence the detection rates should be increased. (19)

The studies from Tanzania report various reasons for patient delay in seeking help. Irani et al give reasons like financial problems, seeking help from other health facilities first, slow progression of symptoms and presenting atypical symptoms. (20) Mfinanga also include factors like living far from the health facility, low education, no employment and a belief that tuberculosis is always associated with HIV. (4) These findings are consistent also with the study of Wandwalo and Mørkve. (10) Also Ngadaya (3) report that misconception between TB and HIV is a risk factor for delay. Having TB is perceived as the same as having HIV. TB stigma is increased by the interconnected relationship between TB and HIV leaving the patient in fear of revealing their HIV status to their neighbours. The stigma associated with TB is an important barrier to visit a TB facility because the visit will reveal the patients TB status to the public. (19) Indications among TB patients show that 32-44% is co infected with HIV in Tanzania. (17)

Storla et al (19) have in a systematic review listed some risk factors of delays. The risk factors are divided in factors contributing to patient related delays and health care delays. Within the patient delay category there are factors like abuse of alcohol, poverty, poor access to health care facilities, living in rural areas, old age, belonging to an indigenous group and attitudes, beliefs and knowledge on TB. Stigma and self-treatment are also associated risks for delays. Factors contributing to health care delay are coexisting chronic cough, having extrapulmonary TB, initial visit to traditional or private practitioner, absence of haemoptysis and poor health care infrastructure.

Knowledge, perceptions and beliefs on TB

A Kenyan qualitative study (2) of the community's perception of tuberculosis reveals that this disease is a "contagious, "sensitive" disease, difficult to diagnose and treat." It is believed that tuberculosis is of hereditary nature or caused by alcohol or smoking. The symptoms connected to the disease were those of tuberculosis in the later stages. Often the symptoms were interpreted as for instance malaria or to conditions like flu or bronchitis. Only when the symptoms were prolonged or worsened, did the patients seek help.

In a rural district in South Africa (21) it is believed that tuberculosis is the result of breaking cultural rules of abstinence from sex after the death of a family member. Only traditional

healers can cure the disease. This leads to delay in presenting at a health facility. Also in this study, alcohol and smoking is believed to spread the disease.

Disease caused by spirits, bewitchment, careless sexual behaviour and diseases inflicted upon someone because of bad luck are perceived causes of disease among Malawian traditional healers. (22) The healers do not believe that western medical treatment will cure the patient, including tuberculosis patients. This often leads to delay in tuberculosis treatment or that the patient does not seek help at a tuberculosis clinic at all.

In the study from Ilala and Kinondoni (16) all the respondents believed TB to be curable as long as one complied with the treatment. In this study almost 85% had a good knowledge of the mode of transmission of the disease, but only 60% had good knowledge on the treatment duration. Mengsho (17) on the other hand found that the knowledge on TB in the community of Mpwapwa district was poor. Here the respondents knew that TB is transmitted through air and the main symptoms are persistent cough and weight loss. They also knew that the duration of treatment to be cured is 8 months.

Methodology and analytical approaches

Rationale for the thesis

It is important to know why more than half of the population estimated to have smear positive TB fail to report to a health facility for testing or not are being detected by the health system to prevent further transmission of the disease. Is it because of lack of knowledge on TB according to symptoms and the person's ability to assess and find the symptoms serious enough to seek for help? Or maybe they start by treating themselves and seek counselling from family and friends? Some might seek treatment by the traditional healers? And how is TB perceived, what do people believe about TB? Does this prevent people from seeking help at a biomedical facility? What factors might prevent a population to seek help?

There is a lack of information around the human factors contributing to cases not reporting at a health facility or presenting with a delay in seeking health care at a health facility.

Early case finding is important in tuberculosis control in order to prevent transmission. An important factor in this frame is the one of human behaviour. Lifooghe et al (2) says; "The relationship between culture, health-related beliefs and health behaviour is complex." Health beliefs, personal experiences and attitudes are all important factors in health seeking behaviour. A better understanding of the human behaviour and the communities understanding and beliefs of tuberculosis is important in planning and implementation of a good control programme for this disease.

This study, therefore, aims at contributing to a better understanding of how beliefs and perceptions in a community can influence health seeking behaviour and delays in detecting tuberculosis cases.

The qualitative research methods can identify local perceptions and beliefs of tuberculosis and give a deeper and more detailed understanding of why people do or do not seek health care when falling ill.

Objectives

Main objective

To study whether knowledge, beliefs and perceptions of tuberculosis can influence the health care seeking behaviour in a community in Dar es Salaam, Tanzania

Specific objectives

- ❖ To determine patterns of health seeking behaviour in the community towards tuberculosis
- ❖ To assess knowledge of the causation, transmission and symptoms of tuberculosis within the community
- ❖ To explore the factors in the community that is influencing delays in seeking health care at a health facility
- ❖ To explore perceptions and beliefs on tuberculosis
- ❖ To assess social implications of tuberculosis for the patient on family and community level

Methods

Study setting

Tanzania is found in the eastern part of Africa, by the Indian Sea. The country had in 2009 a population of 39,5 million inhabitants. This number is based on an annual growth rate of 2,9% and the 2002 census. Tanzania is inhabited by a relatively young population where 65% are estimated to be below 25 years of age. Only 25% of the population live in the urban areas, the other 75% live in rural areas. Agriculture is the main source of living for most people. Around 70% of the population live within 5 km from a health facility. (8)

The study was carried out in Kinondoni district in Dar es Salaam, Tanzania. Dar es Salaam are divided in three districts which are Ilala, Temeke and Kinondoni. Kinondoni had a population of 1 088 000 in the 2002 census, 44 500 of these lived in Mwananyamala. There are about 10 600 households with an average size of 4,2 members per household. Goba has a population of 8517. There are 2 198 households with an average of 3,9 members per household. (23)

Kinondoni district was chosen because the inhabitants had different levels of socio-economic status, and there was not much research on the relevant topic in this district. Another factor contributing to the choice of study site was that the district hospital in Kinondoni had a strong tuberculosis clinic.

Kinondoni has 27 wards. The field work/data collection was carried out at Mwananyamala Hospital and within the community in Kinondoni district. Two wards were selected for this study; the first was Mwananyamala ward, because of the short distance to the referral tuberculosis clinic and this ward being an urban ward. The clinic is easily accessible to the inhabitants in the ward. Another ward, Goba was chosen because it is far from the district hospital and the tuberculosis clinic and therefore other answers from the informants can be expected. Goba ward is in a rural area, and has a dispensary, without diagnostic equipment in regards to TB.

I was expecting to get different answers in the two wards, which was important in order catch the diversity of the study population.

Study design

This was a qualitative study, using an exploratory design. The main focus in the qualitative exploratory design is to “gain insight into a problem by investigating people’s views on the problem.” (13) Qualitative methods are normally used to explore human experiences, motives, attitudes and thoughts. By focusing on the meaning of behaviour it will increase the understanding of why people act as they do in a situation. The qualitative method aim at analysing and understanding certain phenomenon’s that might not have been explored well previously rather than explaining the phenomenon. (24)

To explore and understand perceptions and beliefs on TB in Kinondoni it can be useful to use these qualitative methods. Qualitative methods often use techniques like interviews, observations and group discussions. The data collection instruments I chose to use in this study were semi structured interviews and focus group discussions.

Description of informants

The study population were recruited from both a hospital setting and from a community setting. The study population was composed by 32 males and 38 females with a total of 70 informants. (Table 1 in the appendices)

There were nine FGDs in this study with a total of 55 informants. Of these 25 were males and 30 were females. The categories for the 9 FGDs were; TB patients (2), TB staff (1), females (2), males (2) and leaders (2). The three last categories were those of the general population. There were one FGD conducted with each of these three categories both in Mwananyamala and in Goba. I saw the groups from the general population as some of the most important categories to get information on beliefs and perceptions and health seeking behaviour. I assumed that it would be in this group, together with the religious leaders and traditional healers, the key to why people don’t seek help when experience symptoms of TB could be discovered.

In the individual interviews the informants had different background. The total number of informants in the individual interviews was fifteen, eight were females and seven were males.

The categories for the 15 INIs were; TB patients and caretakers (4), TB staff (4), religious leaders (4) and traditional healers (3). The informants came from all three study sites.

I interviewed two patients, one male and one female. They were both TB smear positive and had been diagnosed 4 days and 2 weeks ago respectively. The two FGDs consisted by patients mixed according to sex. I also interviewed two care takers, both elderly females, none of them had ever gone to school. In the care system of the TB patients in Kinondoni, it is possible for them to choose home based DOT. If they choose this alternative they rely on a care taker that is normally a relative staying together with the patient. The caretaker will come together with the patient to the clinic and get drugs for one week at the time and make sure that the patient swallows the medicine daily. In order to assess the social implications a TB patient experience after getting the diagnosis and get an insight into how the TB patient is perceived by the family and the society I included these categories to the study population.

At the TB OPD at Mwananyamala hospital I interviewed three health workers. They were all TB coordinators, one in charge of the regional TB team, one a TB / HIV coordinator and one a TB / leprosy coordinator. All the coordinators were females and medical doctors. At the local dispensary in Goba I interviewed a female nurse that had worked with TB patients for many years. The FGD with staff from the TB OPD were working as nurses and lab technicians. The staffs was an important source to gain information since they had worked with and heard the TB patients stories and could share their knowledge with me, something they did very generously.

In Mwananyamala community I conducted interviews with two religious leaders, one Christian and one Muslim, and also one traditional healer. The Muslim religious leader worked as a Sheik as well. The Christian leader was fluent in Danish as he had lived there for several years. He was also leader for all the different Christian societies in Kinondoni. The informants in Goba were two religious leaders, Christian and Muslim, both males. The two traditional healers were one female and one male. The female traditional healer had started in the job only two years ago and had never seen or treated a TB patient when the male had inherited the “gift” from his father and worked for over ten years as a healer. It was important to grasp the diversity of meanings and information on the theme in question in order to include this group of informants since traditional healers is a part of the health system in

Tanzania. Religion is also strong in Tanzania and the leaders within the religions have often a lot of power to influence people and their behaviour.

Recruiting of informants

In this study I used purposeful sampling based on the aim that the data collected should give different views to try to answer the research question. A homogeneous population sample could give too narrow information and knowledge. Diversity in the sample population would lead to more varied information and also give the opportunity to grasp several nuances around the theme in question. (24) The recruitment was based on what was practical to do in the field and followed the inclusion and exclusion criteria and categories of informants. The sample size was not decided in advance, but followed the principal of theoretical saturation which is common to use in qualitative research. Theoretical saturation means to start analyzing the interviews immediately and when there is no new information appearing in the materials there is not necessary to continue collecting data.

TB patients and the caretakers were selected in the TB OPD at the Mwananyamala hospital by the nurse in charge and following the inclusion criteria. Staffs were also recruited from the OPD, but also from the dispensary in Goba. Both the members of the general population, religious leaders and traditional healers were recruited through local leaders within the respective wards.

Permission was sought from the relevant authorities in the community and at the health facility in order to contact potential informants.

Inclusion and exclusion criteria

The inclusion and exclusion criteria for the semi structured interviews were;

1. The TB patients were included if they were newly diagnosed and excluded if they were follow up patients.
2. Community members were included if they were influential leaders, religious leaders, traditional healers or care takers and excluded if they were not in these categories.

3. Health workers were included if they were working with TB patients and excluded if they did not work with TB patients.

For all categories informants were excluded if they were below the age of 18 years or had participated in the FGD`s.

All informants in the FGDs were over 18 years of age. Both male and female participants were recruited, from different social background.

The inclusion and exclusion criteria for the FGD groups were:

1. Tuberculosis patients were included if they were newly diagnosed patients from OPD at Mwananyamala tuberculosis health facility and excluded if they were follow up patients.
2. Members from community were included if they were community leaders/officials and excluded if they were non leaders.
3. Members from community were included if they were females / males and excluded if they were the opposite sex.
4. Health staff were included if they were working on TB patients and excluded if they were not working on TB patients or had participated as informants in semi structured interviews.

Data collection

The data collection was conducted in Kinondoni, Dar es Salaam, from 12th June to 8th September, 2009. I worked from an office at the NIMR Muhimbili office and left for field work after appointments were made in Mwananyamala and Goba wards. The first interviews were conducted 23rd July and the last 20th August.

Semi structured interviews

Semi structured interviews are meant to explore what people think and feel around the theme of interest. Normally a pre-developed interview guide is used during the interviews within

qualitative methods. Even if themes or questions are set in a particular order in the guide, it is important to be flexible. The conversation should be guided towards the topics under investigation, but not to be steered towards the information already known to us by asking leading questions. It is also important to evaluate and if needed add new questions when progressing with the interviews. (24) During the 15 individual interviews I conducted, several questions were added to gain more information on specific questions if interest. It was a goal to seek for the informants detailed descriptions of the phenomena I wanted to investigate, namely perceptions and beliefs on TB and also health seeking behaviour within different groups of informants.

Focus group discussions

FGD`s are organised discussions with selected groups of informants. A FGD is a rational way to collect qualitative data from many informants at one time but the group discussions will also give other kinds of information than in individual interviews because the setting is different. (24) This method for collecting data can be used when wanting to gain an insight of issues like the informants' views on beliefs, attitudes and health behaviours in the community. Normally the FGD consist of 5-8 informants, in this study the groups had from 4-9 participants. The duration of each FGD was less than one hour.

The INIs and FGDs were conducted by a trained moderator in the local language of Kiswahili. We used a pre-prepared question guide, translated into Kiswahili. The discussions and interviews were recorded, by digital recorder and in writing. All informants consented to the use of the digital recorder. Date, place and time of the INIs and FGDs were registered together with information about participants like age, sex and other characteristics.

Resources

I developed a interview guide as a tool in this research, based on a interview guide from Lifooghe`s study in Kenya. (2) I sought permission from Lifooghe to use her question guides. In this study there were several groups of informants and therefore there was a need to adjust the guide to fit each of the groups. This was especially important because I had to be assisted

by research assistants who did not have special knowledge to the theme of the thesis, to be able to conduct the interviews.

The interview guides were translated to the local language, Swahili. I did not do a back translation to English prior to the interviews, but through the translations of the transcribed materials the questions asked were also translated.

During the time period when I conducted the interviews, I saw that there was a need to ask additional questions to be able to explore interesting themes from earlier interviews and to get more in depth information. These additional questions were added into the guides and also translated to Swahili before the next interviews. The guides are attached in the appendices.

One barrier to this research was the language. I did not speak the local language Swahili, and the informants I wanted to interview did not speak English. Therefore I employed three social scientists as research assistants to help conducting the interviews and transcribing and translating the materials.

All the assistants were female in the early twenties. One had recently finished school, the two others had one year of experience. All of them had participated as assistants in qualitative research previously. All three spoke fairly good English and Swahili fluently.

The assistants conducted the FGDs and IDIs rotating between conducting the interviews and taking notes during the interviews. For the recording of interviews I used a digital recorder and saved the interviews on the computer after finishing the interviews.

The assistants transcribed all but three interviews in Swahili. I conducted three of the interviews myself because the interviewee spoke good English and accepted to be interviewed in this language. These interviews I also transcribed myself.

To translate the transcribed materials from Swahili to English, I employed social scientist who had done translation work previously.

Analysis of data

The analytical framework I chose to use in this thesis is the Systematic Text Condensation (STC) which is inspired by Giorgis Phenomenological analysis and described by Malterud. (24) The goal of the Phenomenological analysis is to develop knowledge based on the informants' experiences within the field of interest according to the research question. Giorgis recommend four steps in the analyzing process, the STC are based on these steps which are; To get a main overview of the transcribed text and identify major themes, identify units of meaning, abstract content of each meaningful unit and condensation of the content and interpretation of the meaning of the condensed text.

I started with the first step, and got an overview over and familiarized with the transcribed text. In this process I only read the text and tried to identify themes after the reading. I decided to follow the themes from the interview guides because those themes were the same as I identified in the text. The themes that emerged were; knowledge, perceptions and beliefs, obstacles for seeking care, social implications, behaviours and fears.

The next step was to identify units of meaning from the text, going from themes to codes. In this step relevant information needed to answer the research question was separated from irrelevant text. I went through each line of text, underlined and coded units of meaning related to each theme. Several times during this step new codes appeared. When this happened I went back in the text once more to see if I could find other units within the same thematically meaning. When I had underlined all the units of meaning in the text, I collected them in a excel document where I wrote the informants on the horizontal line and the codes on the vertical line. All the lines in the transcribed text had been numbered before printed. In the excel document I used these lines when each unit of meaning that had been coded were placed in the cell belonging to the informant and under the code it belonged to. By making this table I easily could trace the code in the text later on. This was especially important when validating the findings after the analyzing process.

In the third step the knowledge of each code were abstracted by condensing the content in the units of meaning previously identified and put in the excel table. The codes were summed up in groups. For example the codes under the theme "knowledge" were divided into groups called; physical symptoms, mode of transmission, causes and treatment. These subgroups were then used to develop an artificial quote, a description carrying the content of each unit of

meaning. This description had a general form and tried to grasp the informants own words and meanings.

The last step was to sum up and retell the information still being loyal to the informants' voice. I tried to use expressions and words that the informants had used. In the process of writing up the information I developed headings and tried to group the information under the heading it would belong to. I also went back to the original text and found quotations that could illustrate the information in the new text.

At the end of the analytical process I used the original transcripts and the tables made in Excel and red it horizontally and then vertically all the time comparing the results to the data in the table. In this final part I tried to look for data that did not follow the mainstream. The findings were valued and compared to existing literature.

Ethical considerations

I sought ethical clearance from the Regional Ethical Committee of Western Norway (REK VEST) through the Centre of International Health, University of Bergen, Norway. The protocol was approved if I changed one word in the consent forms, which I did change. I also sought ethical clearance from Medical Research Coordinating Committee (MRCC), Dar es Salam, Tanzania. The protocol was reviewed by two independent reviewers. There had to be small changes in the protocol before I could resubmit for final approval, which I got in July.

I developed a consent form that all participants signed before the interviews when they had consented to participate in the study. The participants were informed about the purpose of this study and that they could withdraw from the study at any time. This would not involve negative consequences for themselves. None of the participants chose to withdraw from the study, all gave their written consent. One used the thumbprint. The consent forms were translated to Swahili. They are attached in the appendices of this thesis.

The informants were also asked and all approved of the use of the digital recorder during the interviews. They were informed of the use and destruction of the recordings. The recordings

will be deleted in June, 2010. The forms and digital recordings are kept safe and separated so that names and recordings cannot be connected to each other.

Presentation of results

Introduction

In this part I will present the main findings that I found when analyzing the collected data. The results are presented under subheadings mainly following the themes in the objectives, with a few additions. The quotes I have used to underline and illustrate the findings are presented as close to the informants' voice as possible. The texts I have been working with have mainly been translated from Swahili to English and therefore nuances and the wordings might not be precise, but I hope the meaning will be intact.

General perceptions and beliefs

In this study the informants in both FGD and individual interviews focused on TB as a normal, common disease.

"...now days TB is just a disease like Malaria, not a strange thing". (Caretaker)

It was seen as a curable disease and could be healed completely if the patient complied with the treatment. A patient in a FGD said this as a reaction to the disease:

"I was shocked, but I said since the disease is known now I will get cured. And after knowing that I also had no Malaria I was thankful to know the disease I had and that I can get medication and get cured. From what I see now I shall get cured."

TB was also seen as an infectious disease, which could be fatal. Some perceived TB as a disease given by or planned by God.

TB was strongly associated with HIV / AIDS, several of the informants in the individual interviews and FGDs felt that if you had TB it was the same as having AIDS.

“At the moment you say that you have TB, they directly take it negatively since they think TB and HIV/AIDS go hand by hand so if you tell people you have TB they consider that you have HIV/AIDS already.” (FGD, leaders)

A few informants divided TB in two types one related to sputum and one to the lungs, as this male from a FGD expressed:

“I think he should go to a TB clinic for sputum test as there are two types of TB, related to sputum and another related to lungs. So he will have to get the sputum tested and go for x-ray check up.”

During the individual interviews some of the traditional healers also explained TB as two different types. There was one original TB and one non original TB. The original TB could be treated at hospital and be healed there. The other type, which was the non original TB, looked like the original TB with the same sign and symptoms. But the non original TB was caused by people or by witchcraft and therefore it could not be treated with modern medicine at hospitals.

“...if it was by God it can be healed, but if it was inverted by people / witches it cannot be healed at the hospital, how can it be healed there while it is inverted by another person?” (Traditional healer)

The non original TB could only be treated and healed by a traditional healer. When a person was bewitched one of the major problems was that the patients mind was blinded by the forces so that he could not see or understand the problem by himself.

Religious leaders, both Christians and Muslims, talked about a TB caused by demons. A few of them said that they used prayers to heal this type of TB and all said that they knew colleagues that healed this disease using prayers. A witchdoctor / sheik that used the Quran to perform prayers said that:

“It (prayers) heals demon related TB and other problems caused by demons”.

A Christian leader had this to say about whether he believed that a person could get healed by prayers:

“Yes, they get healed, but these are abnormal cases which are associated with powers of darkness because there are some occasions that the doctor’s tests and check up results shows no infection or disease. This is then associated with bad spirits so the prayer becomes appropriate and the person gets healed.”

An overview of general perceptions and beliefs are shown in Table 2 and 3 in the appendices.

Local terms of Tuberculosis

Most of the informants used the terms TB and “kifua kikuu”. Kifua means chest and kikuu means main. The term “kifua kikuu” was said to be the main respiratory chest disease. In the FGD only one of the groups did not mention “Ngwengwe” as a term on TB. In the individual interviews “Ngwengwe” was mentioned by two informants only. It is a tribal name from Zaramo tribe, but also used by other groups. This name meant something which was strong and that a person having “Ngwengwe” coughed a lot and had TB. Other meanings of “Ngwengwe” were that the disease had no cure and that the outcome was AIDS. “Ngwengwe” was an uncontrolled disease. People having this disease were growing thin and they were hanging up their shoulders.

“It means growing thin, you know in the past a person with TB used to be very thin.”
(Health staff, FGD)

Other terms on TB mentioned were; “nding’ula milili” meaning that TB had no cure in the past, “ugungu lwala” meaning that in the past people with TB stayed at home for treatment until death and “gifumu” meaning a cough that disturbed people and that is difficult to recover from.

Transmission and causes of tuberculosis

Among the general population, bacteria as a cause of TB were mentioned only by a few informants as this male in a FGD:

“I believe (TB is curable) because those are bacteria which normally have cure as opposed to other diseases caused by virus.”

TB was believed to be caused by an immune system defect by five of the FGDs and by one individual interviewee:

“What I can say is; you cannot get TB unless your immunity level is low, it must be lowered for you to get TB. Every person has bacteria which cause TB but not the disease, once the immunity level goes down is when you get TB.” (Male, FGD)

Both in FGDs and in the individual interviews work environment played a great role in how the informants saw the cause of TB. Hard and tough work and work in a dusty area were the most common issues of environmental risk activities causing TB.

“Some get it by doing tough jobs like preparing dough for chapati and cakes, like sister Fuani who used to do the same job for a long time then later people thought she had this modern disease (HIV/AIDS) but it was TB.” (Female, FGD)

A patient in a FGD expressed it like this:

“I once used to stay in a place where we used to clean rice. Maybe that dust could go through the mouth up to the lungs hence cause this disease.”

Some of the informants in the FGD saw TB as a disease caused by neighbours or other members of the community, the sick person had been bewitched.

Some informants said that one could get TB from a TB patient, but did not know how. Most of the FGDs thought of transmission through air in a group of people, like in an overcrowded bus or a house, was a major reason for spreading TB.

“On my side, this disease is caused by air or working in dusty places.” (FGD, patients)

Among the informants in the individual interviews they said that TB was spread by airway transmission or by sharing things with a TB patient.

“I believe that it is caused by exchange of air and sneezing in a crowd of people”.

(Female TB patient)

“...through air or because I used to drink beer so maybe the glasses were dirty or someone with TB had used them.” (Patient, FGD)

One of the patients in this FGD disagreed and didn't really catch the mode of transmission. He said:

“When they say it spread by air, I deny it since I sleep with my wife but she does not have it.”

Coughing without covering the mouth and nose was also an important mode of transmission. Most of the FGDs and several informants in the individual interviews said that sharing things like the local brews, cigarettes, utensils and dishes was a mode of transmission of TB from one person to another. A Christian leader said:

“I don't think you can get the disease just by sitting next to the patient and talking, may be by sharing the plates are where the danger is.”

A female in a FGD said:

“Some say by smoking cigarettes you can get TB because when that smoke enters in the body it can destroy the lungs”

Only one of the informants in the individual interviews mentioned spitting as a mode of transmission, when three of the FGDs brought this up.

“Coughing up and spitting out carelessly hence someone doing cleanness at the same place might get infected through the dust...” (FGD, leaders)

Early signs of TB can easily be confused with other diseases presenting with cough as a witchdoctor /sheik saw it:

“Many relate it (TB) to normal cough and in the end he finds out it has eaten him internally”.

Avoiding being infected could be quite difficult since cough not necessarily means that a person has TB. This point of view was expressed by one of the caretakers:

“...it is not easy for instance in the cars or in a crowd of people to notice that someone has or has no TB as he might be coughing, but coughing is normal.”

One of the informants thought that shaking hands can contribute to transmitting TB, another one said that the virus can get into the water and when drinking the water you would be infected. A caretaker said:

“...TB does not only exist in the daladala (local tem for buss) and in a crowd of people, but rather the virus can get into the water and once you drink you may get TB, that is why TB is uncontrollable.”

One of the religious leaders mentioned that some people believe that people could get TB because of a sin. There was also some confusion or uncertainty of the mode of transmission and the cause of the disease. A Muslim leader thought that:

“It is difficult to know the ways of transmission, what I know is coughing.”

He also said:

“It just happens; some get it by drinking alcohol, others because of not taking health precautions.”

Signs and symptoms on TB

In the individual interviews staff members said that the general public knew sign and symptoms on TB, but that it differs in how much they know. In the answers all but two informants mentions cough or evening cough as a symptom on TB. Four said that the TB patient could experience fever / evening fever and lack of energy. Cough was one of the important and most acknowledged symptoms of TB. A witchdoctor / sheik said this about symptoms of TB:

“A TB patient often coughs too much to the point of facing difficulty in breathing, the exchange of air is very limited, tightening of the chest, so if I see this person I know he has TB.”

The symptoms of TB were often confused with symptoms of HIV / AIDS as this Christian leader express:

“...they have symptoms that are alike those who are infected with HIV / AIDS. But in the beginning people take coughing as just something that could end by itself so it's difficult for them to determine and understand that this applies for the both very lethal infectious diseases”.

All FGD groups mentioned coughing and fever as symptoms on TB. Other symptoms that came up in the FGD were chest pain, having blood in the sputum, feeling cold, night sweat, losing weight and growing thin and feeling tired or having a lack of energy. An overview of symptoms, causation and transmission of TB for FGDs and INI can be found in the appendices. (Table 4 and 5)

Treatment

All but two of the FGDs said that the treatment for TB was six months. In most of the FGDs it was important for the informants that the TB patient should follow the doctors' instructions in order to recover. The medicines should be taken properly once a day for the whole period of

treatment. When on treatment there were several things not to do like smoking, drinking alcohol and doing hard work.

In the individual interviews the informants focused on different issues. The health staff said that the patient could choose home based DOT or if the criteria for home based treatment were not present the patient had to come to the health facility every day, for six to eight months. At the health facility a nurse would make sure that the patient swallowed the medicine in front of her. They also gave health education to the patients and their caretakers. They gave information on how to prevent transferring TB to health staff treating them or to their relatives and others by cover their mouth and nose when coughing or sneezing and that after three weeks of treatment there would be a reduced risk of transmitting the TB disease to others. Several of the health workers were focusing on the time the patient had to come for their medicine. It had to be early morning, if the patient wanted to get the medicine at a later time of the day, this would be considered inappropriate. The TB patients were advised to continue working if their energy level allowed them to do so. They should also eat a balanced, nutritious diet, and not drink alcohol or smoke. The alcohol would make the patients to forget to take their medicine and give a decreased effect of the treatment and the smoking would irritate the lungs. This did not always comply with the information the patients had understood, like this FGD, patient said:

“They told me not to do hard work, not to do sex and not to eat cold things.”

The patients and their caretakers had understood that it was important to take the medicine properly, as instructed in the morning. They also had to eat a balanced, nutritious diet. They knew of the importance to cover their mouth when coughing or sneezing. A patient in a FGD said:

“I will improve my health by taking medicine while following the instructions and eating green vegetables.”

Religious leaders and traditional healers did not know that much about treatment of TB. Some knew that it would take six or eight months to treat a TB patient, when some said it took three months with injection of drugs or by pills. One of the traditional healers had never seen a TB patient and did not know how to treat him. A few said that the medicine had to be taken as

instructed by health staff. One of the traditional healers would give his own medicine to treat the TB patient. A Muslim leader said:

“...you can use local medicines, medicines from the roots.... in our home place when a person is sick we can use such kind of medicine.”

Health seeking behaviour

When asked about where a person, having symptoms like those of TB, would go first to seek for help, all FGDs answered that they would go to a hospital for check up and treatment first. At the same time six of the groups said that some people would see a traditional healer as a first option. In five of the groups they said that some people would go to the church as first response to disease. According to health staffs, many patients would treat themselves by buying medicines from the local pharmacy before they would seek help at a TB clinic several weeks later. A TB / Leprosy coordinator said:

“First of all they just buy this antibiotics from the pharmacy, they go there having coughing and buy amoxiline, ampicloxine and treating themselves maybe for two weeks, or for one week and then they will come here”.

In one of the groups they explained that the difference in choice of preferred level to seek care depend on understanding, those having low understanding would go to a pharmacy or traditional healer when those having a high understanding would go to a hospital or a TB clinic. Two of the groups explained that if a person has a strong belief or faith he would not seek for professional health care.

“...let`s say a person believes in prayer and go for prayer and gets healed, he will not continue medication from the hospital as he thinks he is going against God. There are people who believe in prayer more than hospital medicine. So this differs from person to person as some might decide to go for prayers while the situation is worsening and stick to that as he is well satisfied with Gods intervention until he dies.” (FGD, leaders)

One of the FGDs said that the patient might think that it is another disease and therefore he would stay at home instead of seeking medical help.

Most of the informants in the individual interviews said that hospital or a nearby health facility would be the first choice to go to. The patients and their caretakers denied going other places than to the hospital first. One of the traditional healers said that if the disease was not associated with witchcraft, the patient should go to a hospital for help. According to the staff, many of the patients went other places first. They went to church or the traditional healers or bought antibiotics at the pharmacy for self treatment first. A TB / HIV coordinator said this:

“Many come to hospital, but a few of them go to traditional healers.they are the ones that are transmitting in the community. And they come here wasted, so then the outcomes start to be bad.”

One of the staffs said that the patients came to the hospital after a period of cough and that none of them had a cough without taking something for it. None would come directly to the clinic. The staffs also pointed out that there has been a training of traditional healers in order to influence them to send TB suspects to a health facility to do a TB check up.

If the treatment were no effective or the patient did not get the help he needed, all the FGDs but two said that the patient would seek help from a traditional healer. Like this leader from a FGD said:

“...when they go to the hospital they are told it is Malaria, when the patients go back they say it is Pneumonia, after medication and no recovery that is when they decide to go for the traditional healers.”

Four groups said that the patient would go for more checkups at a health facility if the treatment did not work out in the first attempt. Some would also go to church when the hospital fails.

Many in the individual interviews would get a second opinion from a health facility when it didn't work out the first time at the hospital. A few mentioned traditional healers or local medicine as the next step. As a Muslim leader said:

“... after the specialists from the hospital failing to cure it, then when something is not possible in one place you try another place, but it has to follow when one side fails to solve the problem.... for example you can tell him / her to use roots from neem tree (mwarobani) because it is also the medicine, I can tell him / her to dig for the roots and boil them in water, then he / she can use the boiled fluid as medicine.”

Most of the time it is relatives like family and friends that advised a sick person to seek for help. But also religious leaders would advise a sick person to seek help at a hospital:

“...we then make him understand the symptoms. You will know what the person is suffering from as he tells the history from where he started feeling unwell and how he feels. Then we start with a prayer, then we discuss what to do, advice him not to stay at home, advice him that there is nothing impossible so he should go to hospital for health care and health advice.”

In the individual interviews, some of the traditional healers and religious leaders appointed themselves as the one who give advice and decide whether the patient should seek for help or not. The traditional healer was in these cases head of the family and a ten cell leader.

An overview of health seeking behaviour from FGDs and INIs can be found in the appendices. (Table 6 and 7)

Causes for delays in health care seeking

There were several causes for delays that appeared during the interviews. (Table 8 and 9 in appendices) When asked for causes that prevent people to seek for help many of the informants mentioned lack of money as an obstacle. When falling ill the patient or his family had to pay for transport and check up at the hospital.

“...the first to think of is money because to get to the health facility you need money, to get service you need money. His belief may be positive about the hospital but money is a big problem.” (Christian leader)

The patient would not be able to work, giving the family a decrease in income. This would put the family in a difficult economic situation. One of the patients in a FGD even said that some would stay at home until they died because they didn't have money to pay for the services:

"...poverty and lacking fare. For example one may be willing to go to hospital but has no money for fare, check up, medication and food. All this make people stay home until they die."

A TB / Leprosy coordinator said this:

"...most of them when they are coming here, they think they have to pay something to be treated. So I think most of them are very poor."

Living far away from the hospital was not seen as a big problem since there were small hospitals or health centres nearby for most of the informants. But some of the FGD participants from Goba brought this up as a problem for people in their ward:

"...I think the basic thing to do is to go to the hospital even if the hospital is far from where we live...it is an economical issue, most of us have not enough money..." (FGD, leaders)

Job was an obstacle for many of the informants, both in FGDs and individual interviews. Several of the FGDs said that TB patients had to or were advised to quit job. This gave the patient and his family economic problems. For the community there would be a decrease in the production when they were losing their manpower. A Muslim leader said:

"Firstly the patient becomes unable to participate in the production activities due to their health condition hence the patient becomes unable to work, also economic wise becomes a big problem since the patient cannot work anymore".

The health staff in individual interviews had noticed that several patients lost their jobs or that their employers gave them great difficulties when trying to return to work.

Knowledge or peoples lack of knowledge was one factor many of the informants found to be an obstacle to seek health care. People didn't understand the disease TB, with its signs and symptoms.

“In our community people just know the name (TB) but do not really understand it. This is because you cannot know until the doctor told you.” (TB patient, FGD)

At the same time many also said that the level of understanding was increasing. The knowledge on TB differed according to educational level and social status and religious beliefs. If a person had higher education, he would go to the hospital earlier than if he had no or low education. A person with low educational level would seek help at a traditional healer before going to the hospital. A nurse said:

“You know, we differ in understanding, some have the knowledge and other's don't have. For those unknowledgeable they think they have been bewitched while those having knowledge rush to the hospital.”

Because the lack of knowledge on symptoms of the disease, one of the patients did not consider the possibility that TB could be the cause of his problem.

“For example, I was sick but I did not know it could be TB.” (TB patient, FGD)

Low level of understanding or knowledge was also connected to religious beliefs and by some seen as a major obstacle to seek help at a hospital. This male in a FGD said this:

“About faith issues there might be Christians as other groups that believe they are protected by the blood of Jesus so they cannot get TB, as a result they do not seek medical care believing they are protected while TB is eating him... The issue of faith is very strong. As a matter of fact if you offer counselling service it will not help much as people hold on to their faith.”

Some of the religious leaders were occupied by the thought that religious beliefs can have a negative effect on health care seeking behaviour when people who have been healed by prayers develop rigidity towards seeking help at the hospitals. Also in the FGDs strong beliefs

came up as an obstacle to seek help because it is through their own beliefs people decide whether to go to hospital or to see a traditional healer or go for prayers to get well. Some of the informants in the individual interviews mentioned that religious beliefs or traditional beliefs could have a negative effect because some people went for prayers before seeking hospital care, or visited the traditional healer first.

“We have people we call the duanies....they feel they are very committed to God. So sometimes they can pray for people, they want to finish the treatment without drugs or doctors....and they have big convincing powers”. (TB / HIV coordinator)

Bewitchment can also be an obstacle to seek help because the sick person has been blinded by the witch or by a person. As a traditional healer explained in this way:

“...when you are bewitched and this person intends to see you dead, the intention is for you not to live anymore so he will make sure you don't think about seeing a doctor or traditional healer. Especially if the disease was not detected at the hospital their mind is made blind so you may not know the problem, so there must be someone to remind you to go for traditional medicine...”

Among traditional healers another aspect of beliefs that could contribute to the barriers of seeking health care was the low trust in hospital care for diseases that were thought to have no cure. Like this traditional healer expressed:

“...if my child fall sick I would first find out what the problem is, for example it could be yellow fever and I can't take him to hospital for this, I just give him traditionally medicine and he recovers... but those who do not understand take their patient to the hospital where the treatment can't heal and the child dies...”.

Another statement from the same healer showed the negative belief in modern medicines and treatment:

“...I believe such diseases are not for the hospital, for example the very high fever in children cannot be treated at the hospital because the first thing they do is to inject the

child, because this is something that sucks the blood the child must die as the thing is still inside.”

Not only the traditional healers had this belief, it was also expressed by this female from a FGD:

“There are some people who believe in the traditional medicines and they believe the hospital medicines can kill as the result they may lose the patient.”

Several of the patients and caretakers had experienced health system delays by reporting at the hospital repeatedly, but getting other diagnosis and treatments. The female patient interviewed had been seeking help, diagnosed and treated for several other diseases before she was tested for TB.

“I was sick for a long time, they took a Malaria check up and decided to give me a Quinine dose and after finishing I didn't recover so they told me it might be Typhoid...but still I didn't recover. My back was aching, my legs were also aching, and that is when I decided to go for TB Check up.”

A few individual informants saw the head of the house as an obstacle, especially for children and women to be allowed to seek help. The elders, parents or the man in the family were the decision makers. Women falling ill often would find themselves in a difficult position. A Christian leader said:

“...a husband can be strong enough to hinder a woman to take measures or children... and for women that have a lot of housework to do cannot go far for a medicine or measures that need economy, unless they get consent from their husbands or elders in the family.”

Fear of being tested for HIV was also one obstacle to go to a health facility mentioned by a few of the individual informants. All patients tested positive for TB, had to be screened for HIV, which was a more feared disease than TB. Several of the FGDs said that the patient would keep the TB status a secret because they would fear the families or communities reactions to the news. A Muslim leader said this:

“The major obstacle is fear of going for check up as they might be told they have HIV”.

This theme also appeared in the FGDs. A male expressed it like this:

“You know, TB is associated with HIV, so a person may be afraid to go for service thinking people might believe he has HIV, because at the clinic or hospital they check everything. “

Attitudes towards Tuberculosis patients

In the FGDs the participants said in most of the groups that a TB patient would not be isolated, abandoned or stigmatized by families when seven of the FGD expressed that there would be a negative change of attitude in the communities. (Table 10) In the community there would be talking and investigations around the diseased.

“The neighbours can talk, even discriminate me, they can say; look at her, she has been growing thin, but only God knows.” (FGD, patient)

The patient would fear this and might try to keep the disease a secret. Some also said that the patient would experience a limitation of freedom. Only three of the groups, included one of the patient groups said that a TB patient would be seen as a normal person in the community. Few of the FGD participants with TB patients or the patients and caretakers interviewed individually noticed any difference in behaviour towards themselves from their relatives or in the community after they got their TB diagnosis. As expressed by a patient in a FGD:

“My family accepted me considering that this is the normal disease...”

On the other side one of the patients from the same group experienced this:

“My friends are discriminating me, they are afraid I will infect them.”

One of the patients in the individual interviews experienced being isolated and things and utensils were separated from what the other family members used. This patient also experienced being abused by family members and that he lost the respect from the younger.

“They isolated me, they abused me because they knew I couldn’t do anything to them since I was very weak.” (Male TB patient)

Most of the health staff in the individual interviews said that Tb patient often experienced being separated from their families, some had to find another place to live during treatment. The patients were stigmatized and separated like they had to sit and eat alone and the utensils were also separated. One of the caretakers currently taking care of a brother said that:

“...if you are taking care of a TB patient you must be sure she / he has his own plate, spoon and everything until he is healed...”

A nurse expressed the opposite by saying that:

“...previous understanding was limited, now day’s people don’t even get surprised, they don’t abandon them, they sit and talk to them nicely.”

The religious leaders and traditional healers would see the disease as something normal and common. They would therefore make no changes in how to treat the patient. But some also said that there were people in the community or in the TB patient’s families that would act differently. Some patients were stigmatized and abandoned. Some would see the patient as infectious and it would be difficult to visit such a patient and he would easily be isolated. A Muslim leader said this:

“The matter of treating the patient depends on how a person understand the problem and they are willing to cooperate with him / her, others see it as something which is not normal as the result they isolate the TB patient...”

One of the religious leaders was aware of his responsibility as a leader and said that when the religious leaders’ closeness to a TB patient disappears, the community would follow.

Discussions

Introduction

In this part I will discuss the main findings and the methods and I have used in this study together with the limitations of the study. I wanted to focus on health seeking behaviour according to why the detection rates of smear positive TB are low in Tanzania and connect the behaviour to the human factors causing delays. The way people perceive TB and what they believe about the disease and if these can contribute to the patient delays is the main focus in this thesis. Beliefs on symptoms, causation and transmitting of the disease are important issues to understand how TB is perceived by people.

There are many factors influencing health behaviour. Different models for understanding of behaviour are presented previously in this thesis. The human factor is important in the understanding of why a large population of TB cases delay or do not report at a health facility for diagnostics and treatment. The health culture of the individual person decide if, where and when health actions will take place. How a disease or illness is perceived may be essential the decision of what level of care the patient seek for.

Discussion of findings

Perceptions and beliefs on TB

One of the main findings in this study suggests that TB is perceived as a normal and common disease. It is well known in the communities that TB can be cured if the TB patient is put on treatment early and comply with it. When a disease is perceived as normal and treatable, it might be valued less severe and threatening. This might lead to delayed health seeking because of a decreased motivation for seeking care. In a study from 1989 Westaway (25) found that those who knew a TB patient would perceive the disease as more common and therefore has a low what she calls “illness recognition” but a high level of “illness danger” which would lead to a delayed self referral to a health facility. (15) In other studies, like the one of Lifooghe from Kenya (2) it is found that TB is perceived as a dangerous, infectious

and fatal disease, and there is doubts about the curability of the disease. Only a few of the informants in the present study perceived TB as infectious and fatal.

I found that TB is strongly associated with HIV / AIDS. This complies with several studies in Tanzania (3-4, 10) presented earlier in this theses. There is a fear among people that neighbours and friends shall reveal that a person has got TB and believe that this person also is HIV positive. Because of the association between TB and HIV the stigma around TB might have been reinforced by the stigma around HIV and can be an important reason for delayed approach at a health facility. However in this study I discovered also another side to the fear around HIV. Several of the informants expressed a fear to go to a TB check up because they knew that they would be screened for HIV. A finding from Kenya support this saying that many patients conceal their TB status and fear visiting health centres because there HIV screening often will be included. Many of the informants did not want to know their HIV status suggested because of the stigma related to the disease. (26) Knowing that HIV is an incurable disease, the high prevalence of HIV in the community and the stigma attached to the disease, many would probably be reluctant to seek care. A similar finding is also reported in a study from Rwanda. (27) This result contradict the study from Pwani region in Tanzania (3) suggesting that HIV testing following TB diagnosis would not affect the health seeking behaviour.

The disease is mainly believed to be spread by airway transmission and by sharing with a TB patient. Transmission was connected to overcrowding in for example buses or at homes and TB patients coughing or sneezing without covering their mouth. This is similar to findings Kilale presented in his study from 2008 (16) in which he conclude that 84% of his study population has a good knowledge n the transmission of TB.

I found in this study a lack of knowledge and some misconceptions around causation of TB. TB is believed to be caused by hard and tough work in a dusty environment and also by an immune system defect. Within some groups, witchcraft or sorcery was important causes of TB. None of the FGDs mentioned germs or bacteria as a cause for the disease, while just a few in the individual interviews mentioned this as a cause. This indicates that the informants have low understanding of the causation of TB. The study from Rwanda (27) classified cough - related illnesses as: biomedical, environmental, socio –economic, cultural and supernatural. In the present study the causes were to be found within all these categories except the cultural

with the Rwandan study define as inheritance. The results in the present study have a few similarities with a study from Mpwapwa district in Tanzania (17) according to causes such as smoking cigarettes and witchcraft as causes of TB.

In my study several of the informants presented beliefs of different causations. TB could be caused by bad spirits or by demons, bewitchment caused by people that want to hurt or damage the bewitched person, or inflicted upon a person by God. The TB caused by demons would best be treated by spiritual healing or prayers. A bewitched person could be treated or healed by the traditional healers. They also believed that the modern medicine could not treat this kind of TB patient, especially injecting drugs into the patient could cause death to the patient. The TB caused by God was the “normal” TB disease, which everybody could get and that could be completely healed by compliance to hospital medicines. The sign and symptoms of the different TB diseases appeared to be the same when caused by God, bewitchment or spirits. A study from Malawi described similar beliefs about causation of TB. (28) Even though only a few are seeking care within the folk sector, those who do would experience a delayed approach to the professional sector. The traditional healers claimed that they would refer all TB suspects to the hospitals except those that were bewitched or possessed by demons, which they alone would be able to treat.

During my stay at the hospital in Mwananyamala the health staff expressed their concern about the religious beliefs. According to the staff this was an increasing problem. Many patients believed in the healing by prayers and did not seek professional care until it was late. They felt that the problem with traditional healers were decreasing because the government had launched a program for educating the healers and to convince them to send all suspected TB patients directly to the hospital for assessment. It is important to continue this educational work and also include religious leaders into this program.

Health seeking behaviour

Cough and fever are the most prominent symptoms of TB known by the population in this study. Symptoms like chest pain, losing weight, blood in the sputum, feeling cold, night sweat and lack of energy were less known. This finding correlates with other Tanzanian studies assessing knowledge on TB. (3-4, 10, 16-17, 20) Early symptoms of TB can easily be

mistaken for different infections like malaria and common cold or chronic lung diseases. Symptoms of TB were often confounded with those of HIV. Cough is very prevalent in the communities. Interpreting the symptoms and the implications they will have on daily life activities might judge the symptoms and their meaning as less serious and the person would seek for care in the popular sector. Although few of the informants said explicitly that they were treating themselves it would be 70 – 90 % of the population that started the treatment in the popular sector according to Kleinman. (12) The self treatment consists of self medication, receiving advice from lay persons in the family or community around the ill person, or using local herbs or other remedies. When the symptoms are interpreted to get worse the ill person will start to seek care on the outside of the popular sector. In this study most of the informants said they would chose care within the professional sector like at a hospital as the first option.

None of the informants admitted to use the folk sector like traditional healers or religious prayers. During my field work period I heard several discussions around the traditional healers. They were not very acknowledged at the time because they (some) hunted and killed albinos and used some of their body parts in their traditional medicine and rituals. I think many would be reluctant to openly admit to seek help at traditional healers because of the bad reputation they got because of this situation. However many of the informants felt that other people would seek help within these services either as first choice or as a second choice if hospital treatment failed. This would also rely on those other people's level of understanding of TB. The result I found in this study comply with two studies from Dar es Salam stating that most of the health seeking patients interviewed sought medical care in the professional sector. Only a few patients sought traditional healers. There was no information on self treatment or other measures taken within the popular sector. (4, 16)

Discussion of method

This study was an exploratory qualitative study. I have used both methodology and source triangulation to ensure validity and reliability of the study. Within the methodology triangulation, both focus group discussions and individual interviews were used. Different types of informants were used in the source triangulation. In the study the informants were close to equally distributed according to sex and the ages of the informants ranging from 18 -

70 years. The informants were only interviewed once. The interview time lasted from about 20 minutes for the shortest interviews to 1 hour and 15 minutes for the longest interview.

There was a time limit to the field work. When the ethical clearance was granted, there had to be arranged appointments for all interviews on the different study sites. All except three interviews were conducted in the local language Swahili. It took some time before the first interviews had been transcribed and translated to English. There were several factors that might have influenced the quality of the data collected due to this time limit. It took a long time before I was able to read and understand what had been said during the interviews. The plan was that one of the assistants should translate everything to English during the interview, I would then have been able to probe interesting lines of information and also used this in the next interviews. Considering the locations the interviews were held, which was quite noisy with car traffic and people chatting in the rooms around, it seemed to be too disturbing to use simultaneous translations as well. It was also therefore also difficult to know when theoretical saturation had been reached, within some groups of informants there could have been more interviews to get more information. These problems due to language would probably have been solved in a better way with more experience in the interview situation.

Another challenge I faced due to language that could have influenced the results were those of the use the interview guides. The study was flexible and allowed changes in way questions were asked and to some extent the order of the questions in the guides during the course of field work. What I discovered when the translated materials was returned to me was that the assistants had changed some questions to a meaning of no interest of the study. This might be due to a not good enough communication with and training of the assistants before the interview sessions and the lack of experience or knowledge they had within the field of TB.

The transcriptions from Swahili recordings to Swahili text have not been checked for accuracy and are therefore a potential bias in the study. The translated work have been checked for accuracy and found reasonable good even if it is not always directly translated word for word. Despite these limitations of the study, the reliability of the results might not have been affected too much.

By using purposeful sampling and rely on leaders or those in charge to pick out informants, there will always be a risk of selection bias since they might have chosen people they know

from before. At the same time the qualitative research design do not require a randomized study population. The aim of the data collection was to give different views to try to illuminate the research question. A homogeneous population sample could give a too narrow data collection. Even though the informants in the focus groups new each other, I don't think it would disturb the replies and information they gave during the interview sessions too much since the questions were asked in a manner where they could reply by using third person. The informants did therefore not directly have to revile sensitive information about themselves in the groups.

The interview situation also needs to be discussed. In the first FGD that was conducted, the assistant functioning as moderator, used the interview guide and asked all the questions to each participant. There was no discussion between the participants. This led to a slightly different kind of data and the technique used could more be called a group interview than a FGD. However when the data from this group was analysed they did not differ from the results from the next group.

Results from qualitative research cannot be generalized. I have tried to find answers to the objectives set for the study and I believe that the results I have found and presented in this thesis is the truth for the study population. Many of my findings correlate to other studies from both Tanzania and elsewhere.

Conclusion

In this study I found that TB is perceived as a normal disease that can be cured when complying with treatment. TB patients are mostly treated as before the diagnosis by their families, while the community is more sceptical and might isolate and stigmatize the TB patient more than the close family will do. Since TB is strongly associated with HIV the effect of the stigma connected to the HIV disease will be fortified and affect the TB patients.

The patterns for health seeking behaviour consist of care mainly sought through the professional sector like hospitals. The folk sector including the traditional and spiritual healers are causing some delays by treating patients presenting with symptoms of TB believed by the healers to be caused by bad spirits or the patient being bewitched by people. The already existing program for educating traditional healers to recognize and refer suspected TB cases should be continued and religious leaders should be included in this program.

The knowledge of TB is reasonable good for this study population. However the knowledge of what causes TB is poor and should be considered when planning control programmes for TB. Cough and fever are well known symptoms on TB, but are often interpreted as other diseases. Cough and fever alone are not given enough value to trigger people to seek for help. More effort should be taken in information campaigns or education programmes to promote the recognition of symptoms of TB.

The main findings in this study indicate that it might be useful for development of plans and control programmes for TB to consider people's health beliefs and how the community perceive the disease. It would also be useful to do further research within this field and especially to assess the health beliefs for the target groups of the TB control plans. The human factor in health seeking behaviour is complex. There is no single factor alone being the main obstacle for people to seek medical care, but rather several factors that influence people's choices.

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Appendices

Tables

Table 1 Informant characteristics

Group	Category	Age	Sex	Tribe	Education
FGD 1	TB pt 8 inf	18-60	5M,3F	Mzigua Mdigo Mluguru, Myao, Mdengerelco, Makonde, Mfipa, Zaramo	STD 7,STD 7, Primary school (STD 7), STD 4, STD 7, STD 7, Form 4, Form 2
FGD 2	TB pt 6 inf	30-55	4F,2M	Mpogolo, Mkerewe, Mkwere, Mnyiramba, Mchaga, Mpare	STD 8, High learning, STD 8, STD 5, STD 7, STD 7
FGD 3	HW 4 inf	35-57	F	Mnyamwezi, Mnyakyusa, Mgogo, Mngoni	Secondary (F4), Form 4, Form 4, Form 4
FGD 4	Lead, com 9 inf	29-65	7M,2F	Mbungu, Mzaramo, Mngindo, Mnyamwezi, Mzaramo, Mmanyema, Mzaramo, Mnyakyusa, Mruguru	Degree, Form 4, STD 7, STD 7, STD7, Diploma, Form 4, Form 4, Form 4
FGD 5	F, com 5 inf	25-34	F	Mhaya, Mpare, Mndengeleko, Mmwela, Mzaramo	Form 4, Form 6, SD 7, Form 4, STD 7
FGD 6	M, com 5 inf	21-34	M	Mgogo, Mzigua, Mnamwezi, Mzaramo,Msulcma	Secondary (form 3), Primary, Primary, Primary, Secondary (F3)
FGD 7	Lead, com 7 inf	46-60	1M,6F	Mmakonde, Mmakonde, Mzaramo, Mngoni, Mpogoro, Mndengeleko, Mngoni	Form 4, STD 7, Form 2, STD 7, STD 7, STD 7, STD7
FGD 8	F, com 6 inf	30-59	F	Mdengereko, Mpogolo, Mzaramo, Mchanga, Mpogolo, Mpogolo	STD 2, STD7, STD 7, Form 4, STD 7, STD 7
FGD 9	M, com 5 inf	25-30	M	Mpare, Mmwela, Mnyaturu, Mzaramo, Mkwere	Diploma, STD 7, Certificate,
In-d 1	HW	33	F	Mpare	Diploma in clinical medicine
In-d 2	TB pt, m	39	M	Mgogo	Darasa saba
In-d 3	TB pt, f	42	F	Mzigua	Darasa la saba
In-d 4	HW	37	F	Haya	Advanced diploma in clinical medicine
In-d 5	Tb carer	70	F	Mdengereko	Sijasoma
In-d 6	Tb carer	70	F	Mmwela	Hatukusoma
In-d 7	Hw	53	F	Mpare	Advanced diploma
In-d 8	Musl	40	M	Mrangi	Kidato cha 4
In-d 9	Chris	32	M	Mnyaturu	STD 7
In-d 10	HW	51	F	Mntiramba	Diploma
In-d 11	Trad H,f	34	F	Mwela	Primary School
In-d 12	Trad h,m	39	M	Mzaramo	STD 7
In-d 13	Chris	45	M	Haya	Handelsskole (DK)
In-d 14	Trad,h,m	60	M	Imberrenko	Primary
In-d 15	Musl	50	M	Mpemba	Form 3

**Table 2
FGD**

	Perceptions	Beliefs
Patients	Normal disease	—
Patients	Normal disease Curable disease	TB / HIV goes together
Staff		TB / HIV goes together
Leaders , Goba	Normal disease Curable disease No cure Infectious	TB / HIV goes together Being bewitched There is no TB TB can be healed by prayers
Females, Goba	Normal disease Curable disease Infectious Deadly disease Dangerous	TB / HIV goes together Hospital medicine can kill Two or more types of TB
Males, Goba	Normal disease Curable disease	TB / HIV goes together Being bewitched Protected against TB by the blood of Jesus Two or more types of TB
Leaders, Mwananyamala	Curable disease No cure Infectious Being bewitched	TB / HIV goes together A disease from God TB can be healed by prayers Do not believe TB can be healed by prayers Two or more types of TB
Females, Mwananyamala	Curable disease Being bewitched Deadly disease	TB / HIV goes together Do not believe TB can be healed by prayers Two or more types of TB
Males, Mwananyamala	Curable disease Deadly disease	TB / HIV goes together TB can be healed by prayers Do not believe TB can be healed by prayers Two or more types of TB

Table 3

	Perceptions	Beliefs
In-d 1	HW Can be cured if treated	Some think prayers can cure TB / HIV is going together
In-d 2	TB pt, m Normal disease	
In-d 3	TB pt, f Normal disease	
In-d 4	HW	TB / HIV is going together If continue sexual intercourse TB will not be cured Having TB are the same as having HIV
In-d 5	Tb carer Can be cured if treated Normal disease Normal disease from God	
In-d 6	Tb carer Normal disease	
In-d 7	Hw Can be cured if treated Infectious disease	TB / HIV is going together Having TB are the same as having HIV Caused by witchdoctors If continue sexual intercourse TB will not be cured
In-d 8	Musl Can be cured if treated Some take it not normal	Having TB are the same as having HIV
In-d 9	Chris Can be cured if treated Serious disease Can be healed by prayers	When test show no infection – associate with bad spirits / dark powers
In-d 10	HW, Goba Can be cured if treated Prayers to Good to help them recover	Having TB are the same as having HIV
In-d 11	Trad H,f Can be cured if treated Normal disease The disease is only under Gods control / planning	
In-d 12	Trad h,m Normal disease Normal disease from God Serious disease Can be cured if treated	Having TB are the same as having HIV TB and HIV has go the same symptoms Two types; original and non original. Non original inverted by people / witches. Cannot be treated at hospital If given by God – treatable at hospital
In-d 13	Chris Can be cured if treated Difficult to cure Serious disease	TB and HIV has go the same symptoms
In-d 14	Trad.h,m Can be cured if treated Normal disease Serious disease Prayers to Good to help them recover, I treat by praying for them	Some think prayers can cure Having TB are the same as having HIV Two types; original and non original. Non original inverted by people / witches. Cannot be treated at hospital Prayers heal demon related TB
In-d 15	Musl Can be cured if treated Normal disease Normal disease from God The disease is only under Gods control / planning Some goes for prayers and recover	Having TB are the same as having HIV Two types; original and non original. Non original inverted by people / witches. Cannot be treated at hospital

Table 4
FGD

	Symptoms	Causation	Mode of transmission
Patients	Cough Chest Pain Fever Night sweat Feeling cold Weight loss Loss of appetite Tiredness Deteriorating health	Immune system defect Riding bicycle Hard / tough job Job in dusty areas By air	Infection through others Sleep in same room Breathe in a group / through air Sharing (brews, cigarette, utensils) Spitting Denial of “by air”
Patients	Cough Chest pain Fever Night sweat Blood in sputum Feeling cold Tiredness	Hard / tough job Job in dusty areas By air Environment contributes Weather conditions Congestion of people	Infection through others Breath in a group / through air By dust /smoke In a crowd Cough with open mouth Sharing (brews, cigarette, utensils) Sexual intercourse Wash hands in unclean water
Staff	Cough Fever Night sweat Feeling cold Lose weight	Cough in a crowd Spitting	In a crowd Cough with open mouth Spitting Not enough food Drink unboiled milk Environment / crowd at home
Leaders , Goba	Cough Chest pain Fever Feeling cold Blood in sputum Lose weight Loss of appetite Changes in appearance	Immune system defect Poverty	In a crowd Sharing (brews, cigarette, utensils) Sexual intercourse
Females, Goba	Cough Fever Ribs tightening Stabbing pain	Immune system defect Hard / tough job Job in dusty areas Smoking	Breath in a group / through air By dust /smoke Cough with open mouth Environment / crowd at home
Males, Goba	Cough Productive cough Fever Chest pain Night sweat Lose weight	Immune system defect By bacteria in air Don’t know	Infection through others
Leaders, Mwananyamala	Cough Difficulties in breathing Fever Night sweat Tiredness	Environment contributes Smoking	Breath in a group / through air By dust /smoke Cough with open mouth Sharing (brews, cigarette, utensils) Spitting
Females, Mwananyamala	Cough Chest pain Fever Night sweat Tiredness Headaches	Hard / tough job Job in dusty areas Environment contributes Weather conditions Lack of education By nursing a TB patient	Breath in a group / through air In a crowd Cough with open mouth Sharing (brews, cigarette, utensils) Not enough food
Males, Mwananyamala	Cough Fever Tiredness Feeling dizzy Feeling sick	Immune system defect Job in dusty areas	Infection through others Breath in a group / through air In a crowd Sharing (brews, cigarette, utensils)

Table 3	Symptoms	Cause	Mode of transmission
In-d 1	HW They know signs Concentrate on cough Cough for a period Fever, chest pain = malaria Weight loss, night sweat = HIV	Because of; cooking, staying near the fire, doing hard work, carry heavy things, driving all day, work in dusty area Can get Tb from anywhere, have to be a source of mycobacterium	
In-d 2	TB pt, m Fever / evening fever Back pain Feeling cold Loss of appetite	Overcrowding (in a bus or home)	Airway transmission Through cough or sneeze
In-d 3	TB pt, f Lack of energy Don't know symptoms Vomiting Diarrhea Low health condition	Contamination with dust	
In-d 4	HW They know signs They differ on how much they know	Work in a dusty area Cigarette smoking	Airway transmission Many don't know the mode of transmission They know its sputum Share food / plates with a patient Sitting together with a patient Sexual intercourse
In-d 5	Tb carer Cough, evening cough Coughing up blood Fever / evening fever Feeling cold Chest tightness	The virus get into the water, when drinking you get infected Overcrowding (in a bus or home)	Share food / plates with a patient Sitting together with a patient
In-d 6	Tb carer Cough, evening cough Don't know symptoms		Don't know the mode of transmission
In-d 7	Hw They know signs Cough, evening cough Coughing up blood Fever / evening fever	Doing hard work Work in dusty area Caused by witch doctors	Spit in a public area
In-d 8	Mus l Cough, evening cough Fever / evening fever Lack of energy	Doing hard work Work in dusty area Lack of food, milk Because of the environment we live in The air we breathe can be the reason	Airway transmission
In-d 9	Chri s Cough, evening cough Lack of energy	Because of the environment we live in Cigarette smoking	Airway transmission Share food / plates with a patient Not by sitting together Only understand you can get it from a TB patient
In-d 10	HW, Gob a Cough for a period They differ on how much they know	Overcrowding (in a bus or home)	The virus is spread as people breath or cough Only understand you can get it from a TB patient
In-d 11	Trad H,f Cough, evening cough		Airway transmission Share food / plates with a patient
In-d 12	Trad h,m Cough, evening cough Shoulders uplifted Growing thin	Drinking alcohol	Only understand you can get it from a TB patient
In-d 13	Chri s Cough, evening cough Lack of energy Growing thin	Some say because of a sin Overcrowding (in a bus or home)	Airway transmission Share food / plates with a patient Shake hands
In-d 14	Trad .h,m Cough, evening cough Chest tightness Difficulty in breathing	Drinking alcohol Overcrowding (in a bus or home)	Share food / plates with a patient
In-d 15	Mus l Cough, evening cough Difficulty in breathing Stomach crumps	Just happens People don't take health precautions Overcrowding (in a bus or home)	

Table 6
FGD

	Where to seek help first	The next step
Patients	Hospital See a doctor	Check for other diseases Go for more TB check ups Some go to witch doctors / traditional healers
Patients	Hospital Some go to traditional healer	Some go to witch doctors / traditional healers
Staff	Hospital Some go to traditional healer Some go to the church	Some go to witch doctors / traditional healers Some go to church Self-treatment
Leaders , Goba	Hospital See a doctor Some go to traditional healer Some go to the church Hospital / traditional healer at the same time	Go for more TB check ups Some go to witch doctors / traditional healers Some go to church
Females, Goba	Hospital Some go to traditional healer Some go to the church	Check for other diseases Go to hospital
Males, Goba	Hospital High understanding – hospital Low understanding – traditional healer or pharmacy Strong faith – no health care	Some go to witch doctors / traditional healers Some go to church Go for more TB check ups Go to hospital
Leaders, Mwananyamala	Hospital Some go to traditional healer Some go to the church	Check for other diseases Go for more TB check ups
Females, Mwananyamala	Hospital Some go to traditional healer Strong faith – no health care	Go for more TB check ups Go to hospital
Males, Mwananyamala	Hospital See a doctor Some go to the church Believe it is another disease – stay at home	Go for more TB check ups Some go to witch doctors / traditional healers Some go to church No good to rush to traditional healer / church

Table 7

		Where to seek help first	The next step
In-d 1	HW	Self-treatment Buy antibiotics at the pharmacy Come to hospital after a period of cough Some go to witch doctors Some go for prayers / church	
In-d 2	TB pt, m	Hospital Some go for prayers / church	
In-d 3	TB pt, f	Hospital Nearby dispensary	
In-d 4	HW	Hospital Some go to witch doctors	When things go bad they come (to hospital) Follow religious beliefs Traditional healers
In-d 5	Tb carer	Hospital	
In-d 6	Tb carer	Hospital	
In-d 7	Hw	Hospital	Follow religious beliefs Traditional healers
In-d 8	Musl	Hospital Nearby dispensary	Use local medicine from the trees (neem tree) When specialist from the hospital fails – try another place
In-d 9	Chris	Hospital Nearby dispensary Some go to witch doctors Some go for prayers / church	Traditional healers Change doctor Return to hospital
In-d 10	HW, Goba	Hospital Self-treatment Some go to witch doctors	
In-d 11	Trad H,f	Hospital Nearby dispensary Some go to witch doctors Some go for prayers / church	Hospital is final
In-d 12	Trad h,m	Hospital Some go to witch doctors If not associated with witchcraft – go to hospital	Traditional healers When hospital fails they come for traditional medicine Return to hospital
In-d 13	Chris		
In-d 14	Trad.h,m		
In-d 15	Musl		

Table 8
FGD

	Finances	Work	Education
Patients	Used the money for check up	Had to stay at home for 6 months Advised to quit job	Lack of education / understanding of TB Lack of knowledgeable persons for counselling
Patients	Poverty Lack money for fare / treatment Stay at home and die because of no money Have to pay when no job Close to service – reduces costs		Lack of education / understanding of TB Health behaviour depend on level of education
Staff	Expenses prevent to seek help Hard to afford Close to service – reduces costs		Understanding of TB is increasing Lack of knowledgeable persons for counselling We give education
Leaders , Goba	Lack money for fare / treatment Expenses prevent to seek help Hard to afford Too expensive Some value money before health	Advised to quit job Community lose manpower Decrease in production Decrease in family income Psychological problems	Lack of education / understanding of TB Low knowledge cause isolation When low knowledge people stop medication and seek trad medicine
Females, Goba	Depend on income	Illness decrease production Illness decrease income	Understanding of TB is increasing
Males, Goba	Too expensive Illness decrease income Have to leave money at home	Have to stop job Can only do light jobs	Lack of education / understanding of TB Health behaviour depend on level of education
Leaders, Mwananyamala	Expenses prevent to seek help Illness decrease income	Have to stop job	Understanding of TB is increasing
Females, Mwananyamala	Too expensive Financial collapse	Decrease in family income Advised to quit job	Health behaviour depend on level of education Lack of knowledgeable persons for counselling
Males, Mwananyamala	Poverty Lack money for fare / treatment Expenses prevent to seek help		Lack of education / understanding of TB

Table 9

Obstacles to seek for help

In-d 1	HW	Expenses; check up, treatment, fare, low income Distance; live far away Work; lose job, can't work Knowledge; lack of education on TB Fear of being tested / diagnosed with HIV Believe in traditional medicine Fear of isolation; separation, abandon
In-d 2	TB pt, m	Knowledge; lack of education on TB
In-d 3	TB pt, f	Fear of isolation; separation, abandon
In-d 4	HW	Distance; live far away Work; lose job, can't work Knowledge; lack of education on TB Fear of being tested / diagnosed with HIV Stigmatization Fear of isolation; separation, abandon
In-d 5	Tb carer	Expenses; check up, treatment, fare, low income Work; lose job, can't work
In-d 6	Tb carer	
In-d 7	Hw	Expenses; check up, treatment, fare, low income Distance; problem of distance is not there Fear of being tested / diagnosed with HIV Believe in traditional medicine Stigmatization Fear of isolation; separation, abandon
In-d 8	Musl	Expenses; check up, treatment, fare, low income Work; lose job, can't work Knowledge; lack of education on TB Fear of being tested / diagnosed with HIV Fear of isolation; separation, abandon
In-d 9	Chris	Expenses; check up, treatment, fare, low income Knowledge; lack of education on TB Believe in prayer before hospital Fear of isolation; separation, abandon
In-d 10	HW, Goba	Knowledge; lack of education on TB Domestic; elders, husband are decision makers
In-d 11	Trad H,f	Distance; problem of distance is not there Knowledge; lack of education on TB Stigmatization
In-d 12	Trad h,m	Expenses; check up, treatment, fare, low income Work; lose job, can't work Knowledge; lack of education on TB Stigmatization
In-d 13	Chris	Expenses; check up, treatment, fare, low income Knowledge; lack of education on TB Fear of being tested / diagnosed with HIV Domestic; elders, husband are decision makers
In-d 14	Trad.h,m	Expenses; check up, treatment, fare, low income Knowledge; lack of education on TB
In-d 15	Musl	Work; lose job, can't work Stigmatization

Table 10
FGD

	Family	Community
Patients	Accepted Helped / good care No change Continued as normal No isolation	Helped Consider as normal No discrimination No change No isolation Discriminated People afraid getting infection People talk / investigate Don't sit together
Patients	Accepted Helped / good care No change Continued as normal No separation No abandons	Not abandoned Understood Abandoned
Staff	No isolation	
Leaders , Goba	Isolated because of low knowledge Separation (plates etc) Health staff wear gloves	No isolation Encourage / give hope Isolate Abandoned People talk / investigate Seen as an infected person
Females, Goba	Continued as normal No isolation Separation (fam members)	Feel sorry People talk / investigate Don't sit together Isolate Asked if divorced
Males, Goba	Continued as normal Good care No abandons Separation (plates etc)	Consider as normal Stigmatized People talk / investigate Seen as an infected person Stigmatized
Leaders, Mwananyamala	Get closer Took it simple	Stigmatized People talk / investigate Abandoned Stigmatized
Females, Mwananyamala	Continued as normal No Change Some things are not to be shared	Stigmatized Don't sit together Abandoned Stigmatized
Males, Mwananyamala	Gave help/ good care Get closer No isolation No separation Isolated	Consider as normal People talk / investigate Don't sit together Isolate

Interview guide

Interview guides for: Focus Group Discussions

FGD; Interview guide for TB patients

1. (Characteristics of the group; female, male etc, questionnaire, individual form to fill in)
Short presentation of participants, name etc.
2. Can you explain how you travelled to come to this facility? (Probe for distance (time/km), cost, transport method like bus, taxi, by foot etc)
3. Someone I know told me he has tuberculosis. What do you know about this condition/disease?
4. What are the local names for this condition/disease? (Probe for their meaning)
5. Why do some people get this condition? (probe for all possible causes)
6. Can you explain how a person can get tuberculosis? (Probe; for all possible routs of transmission)
7. How can a person recognize that he / she have tuberculosis? (Probe for signs and symptoms of TB)
8. If a person fells ill with sign / symptoms mentioned above, what will he / she do? (Why)
9. If the condition does not improve, what will he / she do next? (Probe for all possibilities, and why)
10. Who are the people that would advice him / her to seek help with the health care provider/s mentioned above?
11. What instructions have you got about the treatment? (Probe for what information, how long time for the treatment)
12. How did you respond when you were told that you were suffering from TB?
13. What do you feel are the chances that your condition will be cured?
14. What was your spouses and family's reaction on receiving the news of your condition?
15. What do you think will be the likely reaction of your community members on knowing your condition?
16. Did you observe a change in behaviour towards you from the family members when they got to know your condition? From the community? What changed? (Probe!) Why do you think their behaviour changed?
17. What are the factors that hinder people from seeking health care when falling ill with this condition? (Probe for socio- cultural factors)

18. Where is it possible to get information about tuberculosis?
19. Can you explain how you feel about being here at the facility? How does the staff behave when they see you? What do you feel about the surroundings of the facility? (Probe for patient satisfaction issues)
20. What do you think can be done to improve the situation for people suffering from tuberculosis?

FGD; Interview guide for TB patients (Swahili)

1. (Aina ya kundi; wanawake, wanaume n.k, dodoso, fomu ya kujaza mshiriki) Utambulisho mfupi wa washiriki, jina n.k
2. Unaweza kueleza ni jinsi gani ulivyosafiri kuja hapa katika kituo hiki? (Dadisi umbali, muda/ km, gharama, aina ya usafiri kama vile basi, tax, kwa miguu n.k.
3. Kuna mtu ninayemfahamu aliniambia kuwa anaumwa kifua kikuu. Unafahamu nini kuhusu hali hii/ ugonjwa huu?
4. Ni majina gani ya mtaani umepewa ugonjwa huu? (Dadisi maana yake)
5. Ni kwa nini baadhi ya watu wanapata huu ugonjwa? (Dadisi njia zote zinazosababisha)
6. Unaweza kuelezea ni kwa jinsi gani mtu anaweza kuambukizwa ugonjwa wa kifua kikuu? (Dadisi njia zote za maambukizi)
7. Ni kwa jinsi gani mtu anaweza kujitambua kama ana kifua kikuu? (Dadisi dalili za kifua kikuu)
8. Kama mtu akijisikia anaumwa na ana dalili zilizotajwa hapo juu afanye nini? Kwa nini?
9. Kama hatapata nafuu afanye nini tena? (Dadisi uwezekano wote na kwa nini?)
10. Ni watu gani wanamshauri kutafuta msaada kwa watoa huduma ya kiafya waliotajwa hapo juu?
11. Ni maelekezo gani ulishapata kuhusu tiba? (Dadisi maelezo, tiba ni ya muda gani)
12. Ulifanya nini wakati ulipoambiwa kuwa unaumwa kifua kikuu?
13. Ni kwa njia zipi unafikiri hali yako inaweza kutibika?
14. Ni hatua gani mwenzi wako na familia yako walichukua katika kupokea habari ya hali yako?
15. Unafikiri ni hatua gani inaweza kuchukuliwa na watu wa jamii yako katika kujua hali yako?
16. Je, uliona mabadiliko ya tabia kutoka kwa wanafamilia yako wakati walipopata habari juu ya hali yako? Na kwa jamii yako je? Mabadiliko gani? (Dadisi) Kwa nini unafikiri tabia zao zilibadilika?
17. Ni sababu zipi zinazozuia watu kufuata huduma za kiafya wanapokuwa na hali kama hii? (Dadisi sababu zinazotokana na mila na desturi)

18. Wapi ni rahisi kupata habari zinazohusu kifua kikuu zinaweza kupatikana?
19. Unaweza kueleza unajisikiaje kuwa hapa katika kituo hiki? Wahudumu wa afya wanakuwaje kitabia wanapokuona? Unajisikiaje kuhusu mazingira ya kituo hiki? (Dadisi kama wagonjwa wanaridhika)
20. Unafikiri nini kifanyike ili kuboresha hali ya wagonjwa wa kifua kikuu?

FGD; Interview guide for community members, general population

1. (Characteristics of the group; female, male etc, questionnaire, individual form to fill in) Short presentation of participants, name etc.
2. What are the main health problems in this community? (Probe for tb, if not mentioned)
3. Someone I know told me he/she has tuberculosis. What do you know about this disease?
4. What are the local names for this disease? What is the meaning of these names?
5. Could you tell me how a person gets tuberculosis? (Probe for all possible routs of transmission)
6. Why do some people get this disease? (Probe for possible causes)
7. How would a person know/recognize if he or she has tuberculosis? (Probe for all possible sign and symptoms)
8. If a person fells ill with (sign /symptoms mentioned above) what would he/she do first to get better?
9. If he/she does not get better, what would they do next? (Probe for all possibilities and a complete picture of health-seeking behaviour)
10. Where would he/she seek help first?
11. Who are the persons who would advise this sick person to seek help?
12. What do you think is the factors that hinder a person to seek heath care in a facility?
13. Do you know where the nearest tuberculosis facility is located? How do you get there? (Probe for; Distance, cost)
14. How do you think that someone that has tuberculosis is treated in the tuberculosis facility?
15. Do you have an idea of how long it would take to cure tuberculosis? What do you know about the treatment?
16. Do you believe tuberculosis is curable? Why / why not?
17. If a person you know told you he /she have tuberculosis, what would you feel towards this person?
18. How do you think your attitude towards this person will change?
19. How do you think his / her family will feel about this person?

20. If you hear that a person in your community has tuberculosis, how do you think people around him/her will react towards him/her? Do you think there will be a change in behaviour towards him/her?

FGD; Interview guide for community members, general population (Swahili)

1. (Aina ya kundi; wanawake, wanaume n.k, dodoso, fomu ya kujaza mshiriki) Utambulisho mfupi wa washiriki, jina n.k
2. Katika wilaya hii ni matatizo gani makubwa ya kiafya yaliyopo? (Dadisi hali ya kifua kikuu)
3. Kuna mtu ninayemfahamu aliniambia kuwa anaumwa kifua kikuu. Unafahamu nini kuhusu hali hii/ ugonjwa huu?
4. Ni majina gani ya mtaani umepewa ugonjwa huu? (Dadisi maana yake)
5. Unaweza kuelezea ni kwa jinsi gani mtu anapata ugonjwa wa kifua kikuu? (Dadisi njia zote za maambukizi)
6. Ni kwa nini baadhi ya watu wanapata huu ugonjwa? (Dadisi njia zote zinazosababisha)
7. Ni kwa jinsi gani mtu anaweza kujitambua kama ana kifua kikuu? (Dadisi dalili za kifua kikuu)
8. Kama mtu akijisikia anaumwa na ana dalili zilizotajwa hapo juu afanye nini kwanza ili kupona?
9. Kama hatapata nafuu afanye nini tena? (Dadisi uwezekano wote na picha kamili ya tabia ya ufuataji wa huduma za afya)
10. Ni wapi atatafuta msaada kwanza?
11. Ni watu gani wanamshauri huyu mgonjwa kutafuta msaada?
12. Ni sababu zipi zinazozuia wagonjwa wa kifua kikuu kutotafuta msaada katika kituo cha huduma ya afya?
13. Je, unafahamu kituo cha karibu kinachohudumia wagonjwa wa kifua kikuu kiko wapi? Unafikaje pale? (Dadisi; umbali, gharama n.k)
14. Unaonaje mtu mwenye kifua kikuu anapokuwa anatibiwa katika kituo cha kuhudumia wagonjwa wa kifua kikuu?
15. Je, unaelewa kifua kikuu kinatibiwa kwa muda gani? Unafahamu nini kuhusu matibabu yake?
16. Je, unaamini kuwa kifua kikuu kinatibika? Kwa nini?/ Kwa nini hapana?
17. Kama mtu unayemfahamu akikuambia anaumwa kifua kikuu, unajisikiaje na unamchukuliaje?
18. Unafikiri kwamba tabia yako kwa huyu mtu itabadilika?

19. Je, familia yake watajisikiaje kuhusu huyu mtu?
20. Unaposikia kwamba mtu katika jamii yako ana kifua kikuu, unafikiria watu wanaomzunguka watamchukuliaje? Unafikiri watabadili tabia kwa huyu mgonjwa?

FGD; Interview guide for health staff

1. (Characteristics of the group; female, male etc, questionnaire, individual form to fill in)
Short presentation of participants, name etc.
2. What are the main health problems in this district? (Probe for TB situation)
3. What do you think the general population know about tuberculosis?
4. What are the local names for tuberculosis? What is their meaning?
5. Could you tell me how a person gets tuberculosis? (Probe for possible routs of transmission)
Have you heard anything about how people believe it's possible to get tuberculosis?
6. What are the causes of tuberculosis?
7. How do you think a person would know/recognize if he or she has tuberculosis? (Probe for all possible sign and symptoms)
8. If a person fells ill with tuberculosis what do you think he/she would chose to do first to get better?
9. If he/she does not get better, what would he/she do next? (Probe for all possibilities and a complete picture of health-seeking behaviour)
10. Where would he/she seek help first?
11. Who do you think are the persons who would advise this sick person to seek help?
12. When people present at the health facility, how long time since they experienced the first symptoms of disease?
13. What are the factors that will hinder a TB case seeking help at a health facility? (Probe for all possible reasons, why..)
14. What are the factors that make patients drop out of treatment?
15. What are the factors that will make it easier for a TB case to seek help at a health facility? (Probe for all possible reasons, why..)
16. What are the instructions you give to the patients about the treatment? (probe for length of treatment, DOTS strategy)
17. What are the chances to be cured of tuberculosis? What information do you give to the patients about this?
18. What do you feel are the challenges of treating TB cases in this district? (Probe why, how in each challenge)

19. How do you feel that the tuberculosis patient is treated in the tuberculosis facility by the staff? What do you feel about a person getting tuberculosis?
20. How does tuberculosis patients normally respond or react when they are told that they have tuberculosis?
21. How do you think his/her family will react towards him/her? How will the community react? Do you think there will be a change in the behaviour towards him/her?
22. What do you think can be done to improve the situation for Tb cases? (Probe; how, why)

FGD; Interview guide for health staff (Swahili)

1. (Aina ya kundi; wanawake, wanaume n.k, dodoso, fomu ya kujaza mshiriki) Utambulisho mfupi wa washiriki, jina n.k
2. Katika wilaya hii ni matatizo gani makubwa ya kiafya yaliyopo? (Dadisi hali ya kifua kikuu)
3. Unafikiri watu kwa ujumla wanafahamu nini kuhusu kifua kikuu?
4. Kifua kikuu kinaitwaje kwa majina ya mtaani? Nini maana yake?
5. Unaweza kuelezea ni kwa jinsi gani mtu anapata ugonjwa wa kifua kikuu? (Dadisi njia zote za maambukizi)
6. Nini kinachosababisha kifua kikuu?
7. Unafikiri ni kwa jinsi gani mtu anaweza kujitambua/ kugundua kama ana kifua kikuu? (Dadisi dalili za kifua kikuu)
8. Kama mtu akijisikia anaumwa kifua kikuu unafikiri ni nini atachagua kufanya kwanza ili kupata nafuu?
9. Kama hatapata nafuu afanye nini tena? (Dadisi uwezekano wote na picha kamili ya tabia ya ufuataji wa huduma za afya)
10. Ni wapi atatafuta msaada kwanza?
11. Ni watu gani unafikiri watamshauri huyu mgonjwa kutafuta msaada?
12. Watu wanapofika katika kituo cha huduma ya afya, inakuwa ni muda gani tangu walipoona dalili za mwanzo?
13. Ni sababu zipi zinazozuia wagonjwa wa kifua kikuu kutotafuta msaada katika kituo cha huduma ya afya? (Dadisi sababu zote, kwa nini..)
14. Sababu zipi zinazopelekea wagonjwa wa kifua kikuu kukatisha matibabu?
15. Ni vitu gani ambavyo vinaweza kumrahisishia mgonjwa wa kifua kikuu kufuata msaada katika kituo cha huduma ya afya? (Dadisi sababu zote, kwa nini..)
16. Ni maelekezo yapi unampa mgonjwa kuhusu tiba? (Dadisi muda wa tiba, mpangilio wa DOTS)

17. Ni nafasi zipi ambazo kifua kikuu chaweza kutibika? Ni maelezo gani unawapa wagonjwa kuhusiana na swala hili?
18. Unahisi ni changamoto zipi zilizopo katika kutibu kifua kikuu katika wilaya hii? (Dadisi kwa nini, kiviipi katika kila changamoto)
19. Kwa kawaida unajisikiaje mgonjwa wa kifua kikuu anapokuwa anatibiwa katika kituo na mhudumu wa afya? Unajisikiaje kuhusu huyo mgonjwa wa kifua kikuu?
20. Kwa kawaida wagonjwa wa kifua kikuu wanapokeaje hiyo hali wakati wanapoambiwa kuwa wana kifua kikuu?
21. Unafikiri familia wanachukua hatua gani kwa mgonjwa? Jumuiya wanachukua hatua gani? Unafikiri kutakuwa na mabadiliko ya tabia kwa wanajamii?
22. Unafikiri nini kifanyike ili kuboresha hali ya wagonjwa wa kifua kikuu? (Dadisi; kiviipi, kwa nini)

Guides for in depth interviews

Interview guide for health workers

1. Characteristics; (Questionnaire, form to fill out)
2. What are your profession? Can you explain what responsibilities you have in your work? How long time has you worked with tuberculosis patients?
3. What are the major health problems in this district? Can you tell me how the tuberculosis situation is in this district?
4. What do you think people (general population) know about tuberculosis?
5. What are the local names of tuberculosis? What is the meaning of these names?
6. How do you think people / patients believe it's possible to get tuberculosis? (Probe for all possible causes)
7. What do you think people know about signs and symptoms of TB?
8. If a person falls ill with tuberculosis what do you think he/she would do first to get better?
9. If he/she does not get better, what would he/she do next? (Probe for all possibilities and a complete picture of health-seeking behaviour)
10. Who do you think the persons who would advise this sick person to seek help are?
11. Why do patients not seek help at a health facility as a first option?
12. When people present at the health facility, how long time since they experienced the first symptoms of disease?

13. What do you think is the factors that can hinder a person to go to a health facility to seek help?
14. What are the factors that make patients drop out of treatment?
15. What are the instructions a TB case will get on treatment? (DOTS)
16. What do you think people believe are the chances to be cured of tuberculosis?
17. How do you think a person getting tuberculosis will feel and react to receiving this diagnosis?
18. How do you think his/her family will react towards him/her? How will the community react? Do you think there will be a change in the behaviour towards him/her?
19. Do you know about any information / or educational programmes in the district where people can get information about TB? (Probe for different programmes)
20. What do you feel are the major challenges in treating TB cases in this district?
21. In your opinion, is there anything that can be done to improve the situation for TB cases? What, why.

Interview guide for health workers (Swahili)

1. Characteristics; (Questionnaire, form to fill out)
2. Kazi yako ni nini? Unaweza elezea majukumu uliyonayo kazini? Umekuwa ukifanya kazi na wagonjwa wa kifua kikuu kwa muda gani sasa?
3. Ni maradhi gani makubwa ya kiafya katika wilaya hii? Unaweza kuniambia hali ya kifua kikuu katika wilaya hii?
4. Unadhani watu (jamii kwa ujumla) inaelewa nini kuhusu kifua kikuu?
5. Majina mengine/mbadala ya kifua kikuu? Nini maana ya majina hayo?
6. Unadhani watu/wagonjwa wanaamini wamepataje kifua kikuu? (peleleza vyanzo vyote vya maambukizi)
7. Unadhani watu wanafahamu nini kuhusu dalili za kifua kikuu?
8. Kama mtu anaumwa kifua kikuu, unadhani afanye nini kwanza ili apate nafuu?
9. Iwapo hatapota nafuu, nini kifanyike? (chunguza uwezekano na picha kamili ya tabia ya kutafuta tiba)
10. Unadhani nani anayemshauri mgonjwa huyu kwenda katika kituo cha afya?
11. Kwanini wagonjwa hawaendi katika kituo cha afya mapema?
12. Watu wanapokuwa katika kituo cha afya, wanakuwa na muda gani tangu wahisi dalili za awali za ugonjwa?
13. Unadhani ni vikwazo gani huwazuia watu wasiende kutafuta msaada katika kituo cha afya?
14. Sababu zipi zinamfanya mgonjwa asiendelee na matibabu?

15. Ni maelekezo gani mgonjwa wa kifua kikuu atapata katika tiba?(DOTS)
16. Unadhani watu wanaamini kuna uwezekano wa kupona kifua kikuu?
17. Unadhani mtu aliyepata kifua kikuu anajisikiaje na hufanya nini anapopata kipimo hiki?
18. Unadhani familia yake itamchukuliaje? Jamii itamchukuliaje? Unadhani kutakuwa na mabadiliko kitabia juu yake?
19. Unafahamu kuhusu programu yoyote juu ya taarifa / au elimu ambapo watu watapata elimu kuhusu kifua kikuu katika wilaya yako?(dodosa ujue programu tofauti)
20. Unahisi nini vikwazo katika kutibu kifua kikuu katika wilaya hii?
21. Kwa fikra zako, kitu gani kifanyike ili kuboresha matibabu ya kifua kikuu? Nini , kwa nini

Interview guide for TB patients

1. Characteristics; (Questionnaire, form to fill out)
2. What have brought you to this facility today? What is the distance (time/km), cost?
3. Why did you decide to come to this facility?
4. (If TB is mentioned :) How did you know it was tuberculosis? What do you know about this condition/disease? (Probe for signs and symptoms of TB)
5. What are the local names for this condition/disease? Probe for the meaning of the names.
6. What do you believe caused your health problem? (Probe for causes of transmission)
7. How long time ago did your health problem start?
8. What were the first sign/symptoms of your condition?
9. When your problems started, what was your first action to improve your health problem?
10. If there was no recovery, what was your next action? (Probe for reasons why in each action taken? Probe for advises given in each action)
11. In your opinion, which factors were hindering you from taking actions when you fell ill? (Probe for factors, how did they hinder to seek help, why?)
12. Who advised you to seek help with the health care provider/s?
13. If a health facility was not your first option to seek help for your health problem, what made you go elsewhere? Where did you go? Why did you choose this option?
14. What are the advises and prescriptions you got from the health care provider? (Probe)
15. What instructions were you given about the medicines? (Probe for length of treatment, side effects of drug, why he/she have to come to the facility to get the drug...)
16. Can you explain how you feel about being here at the facility? What do you feel about the surroundings of the facility? (Probe for patient satisfaction issues)
17. What do you feel are the chances that your condition will be cured?
18. How did you feel when you were told that you were suffering from TB?

19. What was your family's reaction on receiving the news of your condition?
20. What do you think will be the likely reaction of your community members on knowing your condition?
21. Did you observe a change in behaviour towards you from the family members when they got to know your condition? From the community?
22. Have you ever had any information about tuberculosis? What kind of information did you get? In what way was the information useful / not useful?
23. What do you think can be done to improve the situation for TB patients?
24. Can you tell me something about what you feel is most difficult in the situation being a TB patient?

Interview guide for TB patients (Swahili)

1. Characteristics; (Questionnaire, form to fill out)
2. Kwa nini upo hapa leo? Kuna umbali gani na utokako (muda/km), gharama?
3. Kwanini umeamua kuja katika kituo hiki?
4. (Kama atataja kifua kikuu) ulijuaje ni kifua kikuu? Unafahamu nini kuhusu ugonjwa huu/hali hii? (uliza kwa namna nyigi upate dalili zote za kifua kikuu)
5. Je ugonjwa huu una majina mengine /mbadala? Ulizia maana ya majina hayo?
6. Unaamini nini kimesababisha tatizo hili? (peleleze vyanzo vya maambukizi ya kifua kikuu)
7. Tatizo hili liianza lini/ una muda gani na tatizo hili?
8. Nini dalili za awali za ugonjwa huu?
9. Tatizo hili lilipojitokeza, hatua gani za awali ulichukua ili kuondokana na tatizo hili la kiafya?
10. Kama usingepata nafuu, ungefanya nini? (uliza zaidi sababu za kuchukua kila hatua?uliza kwa ushauri utolewao katika kila hatua/kitendo)
11. Kwa mtazamo wako, vikwazo vipi vilikukwamisha wewe kuchukua hatua ulipoanza kuumwa? (uliza zaidi ujue vikwazo, na jinsi gani vilimkwamisha kupata matibabu, kwa nini?)
12. Nani alikushauri utafute matibabu kwa watoa huduma za afya?
13. Iwapo kituo cha afya hakikua chaguo lako la awali kukupatia tiba ya tatizo hili, nini kilikufanya uende sehemu nyingine? Ulienda wapi? Kwanini ulichagua kwenda huko?
14. Ni ushauri na tiba gani ulivipata kutoka kwa mtoa huduma ya afya?(chunguza zaidi)
15. Ni maelekezo gani ulipewa kuhusu dawa? (uliza juu ya urefu wa tiba, madhara ya dawa, sababu za yeye kuja kituo cha afya kupata dawa...)

16. Unaweza kuelezea unajisikiaje kuwepo hapa katika kituo cha afya? Unajisikiaje kuhusu mazingira ya kituo hiki?
17. Unahisi kuna uwezekano wa kupona?
18. Ulijisikiaje ulipoambiwa kuwa unaumwa kifua kikuu?
19. Familia yako ilichukuliaje taarifa kuhusu hali yako hiyo?
20. Unafikiri jamii yako italichukuliaje jambo hili wakijua hali yako?
21. Umeona mabadiliko yoyote ya kitabia ya wanafamilia wako juu yako walipojua hali yako? Kutoka kwa wanajamii?
22. Umeshawahi kupata taarifa yoyote kuhusu kifua kikuu? Ulipata taarifa ya namna gani? Kwa namna gani taarifa hiyo ilikuwa ya manufaa / haikuwa ya manufaa?
23. Unadhani nini kifanyike kuinua hali ya wagonjwa wa kifua kikuu?
24. Unaweza kuniambia unahisi ni nini kigumu zaidi uwapo mgonjwa wa kifua kikuu?

Interview guide for community level

1. Characteristics; (Questionnaire, form to fill out)
2. What are the main health problems in this community? (Probe for tb, if not mentioned)
3. Someone I know told me he/she has tuberculosis. What do you know about this disease?
4. Which local names do you know for this disease? What is the meaning of these names?
5. Do you see any persons having this disease through your position? Can you explain in what way you are involved in these persons?
6. Could you tell me how a person gets tuberculosis? (Probe for all possible routs of transmission)
7. Why do some people get tuberculosis? (Probe for causes of tb)
8. How would a person know/recognize he/she has tuberculosis? (Probe for all possible sign and symptoms)
9. If a person fells ill with (sign /symptoms mentioned above) where would he/she seek help?
10. If he/she does not get better, what would he / she do next? (Probe for all possibilities and a complete picture of health care seeking behaviour)
11. What would you think are factors that will hider a person to seek health care? Why?
12. Who are the persons who would advise this sick person to seek help?
13. Do you believe tuberculosis is curable? Why/why not?
14. How do you think the family will react when a person tells them that he/she has got tuberculosis?
15. How will the community react towards a person with tuberculosis?
16. What do you feel about persons that have got tuberculosis?

17. What do you think can be done to improve the situation for TB patients?

Interview guide for community level (Swahili)

1. Characteristics; (Questionnaire, form to fill out)
2. Ni maradhi gani makubwa katika jamii hii? (ulizia kifua kikuu, kama hakijatajwa)
3. Kuna mtu namfahamu kaniambia ana kifua kikuu. Unaelewa nini kuhusu huu ugonjwa?
4. Unafahamu majina mengine/mbadala ya ugonjwa huu? Nini maana ya majina haya?
5. Umshaona watu wenye ugonjwa huu kupitia nafasi yako? Unaweza kueleza ni kwa jinsi gani uliwasaidia watu hawa?
6. Unaweza niambia ni jinsi gani mtu anapata kifua kikuu? (peleleza zaidi juu ya uwekano wa maambukizi)
7. Kwanini baadhi ya watu wanapata kifua kikuu? (peleleze vyanzo vya maambukizi ya kifua kikuu)
8. Mtu anajua kwamba ana kifua kikuu? (ulizia uwezekano wa dalili zote)
9. Iwapo mtu anaumwa (akiwa na dalili zilizotajwa hapo juu) wapi atapata msaada wa matibabu?
10. Iwapo hatapota nafuu, nini kifanyike? (chunguza uwezekano na picha kamili ya tabia ya kutafuta tiba)
11. Ni vikwazo gani hukwamisha mtu kutafuta huduma ya afya? Kwanini?
12. Ni watu gani huwashauri wagonjwa kutafuta huduma ya afya?
13. Unaamini kifua kikuu kinatibika? Kwanini/ kwanini sivyo?
14. Unahisi wanafamilia watachukuliaje hali hii pale mtu akiwaambia amepata kifua kikuu?
15. Jamii itamchukuliaje mtu mwenye kifua kikuu?
16. Unamchukuliaje mtu aliye na kifua kikuu?
17. Unadhani nini kifanyike kuinua hali ya wagonjwa wa kifua kikuu?

Interview guide for Traditional healers

1. Characteristics; (Questionnaire, form to fill out)
2. Can you tell me about your profession?
3. In your opinion, what is the main health problem in this community?
4. The people who comes to you, for which conditions do they seek your help?
5. What do you know about the disease tuberculosis?
6. Which local names do you know/use for this disease? What is the meaning of these names?

7. Could you tell me how a person gets tuberculosis? (Probe for all possible causes)
8. How would a person know/recognize if he/she has tuberculosis? (Probe for all possible sign and symptoms)
9. If a person feels ill with (sign /symptoms mentioned above) where do you think he/she would seek help first?
10. If he/she does not get better, what would they do next? (Probe for all possibilities and a complete picture of health-seeking behaviour)
11. Is there any factors that will hinder a person with this condition to seek help? Why?
12. Who are the persons who would advise this sick person to seek help?
13. If you are the first health carer a person that have this condition contact, how will you advice him / her?
14. What is the treatment you would prescribe for a TB case?
15. Do you believe tuberculosis is curable? Why/why not?
16. Can this disease be treated successfully in a health facility? What do you know about the treatment in the health facilities?
17. How do you think the family will react when a person tells them that he/she has got tuberculosis?
18. How will the community react towards a person with tuberculosis?
19. What do you feel / think about persons that has got tuberculosis?
20. What do you think can be done to improve the situation for tuberculosis patients?

Interview guide for traditional healers (Swahili)

1. Characteristics; (Questionnaire, form to fill out)
2. Waweza niambia kuhusu kazi yako?
3. Kwa mtazamo wako, Ni maradhi gani makubwa katika jamii hii?
4. Watu wanaokuja kwako, wanakuja kwa ajili ya maradhi/ shida gani?
5. Unaelewa nini kuhusu ugonjwa wa kifua kikuu?
6. Unafahamu majina mengine/mbadala ya ugonjwa huu? Nini maana ya majina haya?
7. Unaweza niambia mtu anapataje kifua kikuu? (peleleza zaidi juu ya uwezekano wa maambukizi)
8. Mtu anajuaje kuwa amepata kifua kikuu? (uliza ujue dalili zote)
9. Iwapo mtu anaumwa (akiwa na dalili zilizotajwa hapo juu), unadhani wapi aende kwanza ili kupata matibabu?
10. Iwapo hatapata nafuu, nini kifanyike? (chunguza uwezekano na picha kamili ya tabia ya kutafuta tiba)

11. Je kuna vikwazo vyovyote vitakavyomkwamisha tu huyu kutafuta tiba? Kwanini?
12. Ni watu gani huwashauri wagonjwa hawa kutafuta huduma ya afya?
13. Iwapo wewe utakuwa mtoa huduma ya afya wa kwanza kwa mtu mwenye maradhi haya, nini ushauri wako kwa mgonjwa huyu?
14. Ni tiba gani utampatia mgonjwa huyu?
15. Je unaamini kifua kikuu kinatibika? Kwanini/kwanini sivyo?
16. Je ugonjwa huu unaweza tibika kabisa katika vituo vya afya? Nini unafahamu kuhusu iba itolewayo katika vituo hivyo?
17. Unahisi wanafamilia watachukuliaje hali hii pale mtu akiwaambia amepata kifua kikuu?
18. Jamii itamchukuliaje mtu mwenye kifua kikuu?
19. Unamchukuliaje /unamfikiriaje mtu aliye na kifua kikuu?
20. Unadhani nini kifanyike kuinua hali ya wagonjwa wa kifua kikuu?

Questionnaire

Date	
No	

Name;

Age;

Sex ;

Mal

Fema

Ethnic group;

Marital status;

Education;

Questionnaire, Swahili

Tarehe	
Namba	

Dodoso;

Jina;

Umri;

Jinsia ;

Mme

Mke

Kabila;

Hali ya ndoa;

Kiwango cha elimu;

Consent forms

Informed consent form for community members

We are seeking your participation in a research study which aims at contributing to a better understanding of how beliefs and perceptions in a community can influence health seeking delays in tuberculosis cases. Before you agree to participate in this research study, it is important that you read/hear the following explanation of this study.

We are asking you to participate in this study because you are a member of this community and because we believe that you might have important information about how this disease is perceived in the community.

By accepting to participate you can contribute by helping other people in the future – the study might contribute to increase the awareness of the disease in the community.

Participation in the study involves taking part in a group discussion on the relevant issue. The discussions will last for approximately one hour. The discussions will be audiotaped by the researcher and later transcribed for the purpose of data analysis. There will not be any identifying names on the tapes. The tapes will be destroyed after completion of the study.

The information obtained from you will be kept confidential to the extent legally possible. The results of the study might be published in professional papers or presented at professional meetings. Your name will not be mentioned in any papers or other work. There will be no implications to your current and future status, including health care services in this area.

Participation in this study is voluntary and free of charge. You are free to withdraw from the study at any time, also after consenting to participate in the study. This will not involve any consequences for you and you will not be asked for any reason to withdraw your participation.

Thank you for your co-operation.

This study is conducted by;
Anne Kari Knutsen,
Masters degree student at the University of Bergen, Norway

Study Participant:

I have read/been explained every information given to me regarding this study and have given my consent to participate.

Date:

Signature of study participant:

Thumb print of study participant:

FOMU YA RIDHAA YA KUSHIRIKI KWA WANAJUMUIYA

(Informed consent form for community members)

Tunahitaji ushiriki wako kwenye utafiti wenye nia ya kuongeza uelewa juu ya jinsi ambavyo imani na maono/mielekeo ya wanajuiya vinavyoweza kuchangia uchelewaji wa upatikanaji wa huduma ya afya kwa wagonjwa wa kifua kikuu.

Kabla hujaridhia kushiriki katika utafiti huu, ni muhimu ukasoma/kusikiliza maelezo ya utafiti huu.

Tunahitaji ushiriki wako kwa kuwa wewe ni mmoja wa jumuiya hii na kwa sababu tunaamini kuwa unaweza kuwa na habari za muhimu kuhusu jinsi gani ugonjwa huu unachukuliwa/unafikiriwa na watu wa jumuiya hii.

Kukubali kwako kushiriki kunaweza kuwa msaada kwa watu wengine siku za mbeleni – Utafiti utaongeza uelewa wa ugonjwa huu kwenye jumuiya.

Ushiriki utajumuisha majadiliano kwenye makundi kuhusu masuala muhimu. Majadiliano yatadumu kwa takribani saa moja. Majadiliano yatarekodiwa na mtafiti na baadae yatawekwa kwenye maandishi kwa ajili ya uchambuzi wa data. Hakutakuwa na kutaja majina kwenye kaseti. Kaseti zitaharibiwa baada ya utafiti kuisha.

Taarifa zitakazopatikana kutoka kwako zitahifadhiwa kwa siri kubwa iwezekanavyo. Matokeo ya utafiti yanaweza kuchapishwa kwenye majarida ya kitaaluma au kuwakilishwa kwenye mikutano ya kitaaluma. Jina lako halitatajwa kwenye jarida lolote au pengine popote. Hakutakuwa na madhara yoyote kwako, ikishirikisha huduma za afya kwako katika eneo hili.

Ushiriki katika utafiti huu ni hiari na bila ya malipo. Unaruhusiwa kujitoa katika utafiti muda wowote, hata baada ya kuridhia kwa maandishi bila kutoa maelezo yoyote. Kwa kufanya hivyo na hautaulizwa sababu za kujiondoa katika utafiti.

Asante kwa ushirikiano wako.

Utafiti huu unafanywa na;
Anne Kari Knutsen,
Mwanafunzi wa shahada ya pili, chuo kikuu cha Bergen,
Norway.

Study Participant:

Nimesoma/kuelezwa maelezo yote kuhusu utafiti huu na nimetoa idhini ya kushiriki.

Tarehe:.....

Sahihi ya mshiriki:.....

Dole gumba la mshiriki:

Informed consent form for tuberculosis patients

We are seeking your participation in a research study which aims at contributing to a better understanding of how beliefs and perceptions in a community can influence health seeking delays in tuberculosis cases. Before you agree to participate in this research study, it is important that you read/hear the following explanation of this study.

We are asking you to participate in this study because you are a member of this community and because we believe that you might have important information about how this disease is perceived in the community.

By accepting to participate you can contribute by helping other patients in the future – the study might contribute to increase the awareness of the disease in the community and that people might seek help early when falling ill of tuberculosis. You will also get an opportunity to discuss feelings, perceptions and concerns of falling ill with tuberculosis.

Participation in the study involves taking part in a group discussion on the relevant issue. The discussions will last for approximately one hour. The discussions will be audiotaped by the researcher and later transcribed for the purpose of data analysis. There will not be any identifying names on the tapes. The tapes will be destroyed after completion of the study.

The information obtained from you will be kept confidential to the extent legally possible. The results of the study might be published in professional papers or presented at professional meetings. Your name will not be mentioned in any papers or other work. There will be no implications to your current and future status, including health care services in this area.

Participation in this study is voluntary and free of charge. You are free to withdraw from the study at any time, also after consenting to participate in the study. This will not involve any penalty for you and you will not be asked for any reason to withdraw your participation. A decision to participate or not will not influence in any way the care you receive at the health care centre/hospital.

Thank you for your co-operation.

This study is conducted by;
Anne Kari Knutsen,
Masters degree student at the University of Bergen,
Norway

Study Participant:

I have read/been explained every information given to me regarding this study and have given my consent to participate.

Date:

Signature of study participant:

Thumb print of study participant:

FOMU YA RIDHAA YA KUSHIRIKI KWA WAGONJWA WA KIFUA KIKUU
(Informed consent form for tuberculosis patients)

Tunahitaji ushiriki wako kwenye utafiti wenye nia ya kuongeza uelewa juu ya jinsi ambavyo imani na maono/mielekeo kati ya wanajuiya vinavyoweza kuchangia uchelewaji wa upatikanaji wa huduma ya afya kwa wagonjwa wa kifua kikuu.

Kabla hujaridhia kushiriki katika utafiti huu, ni muhimu ukasoma/kusikiliza maelezo ya utafiti huu.

Tunahitaji ushiriki wako kwa kuwa wewe ni mmoja wa jumuiya hii na kwa sababu tunaamini kuwa unaweza kuwa na habari za muhimu kuhusu jinsi gani ugonjwa huu unachukuliwa/unafikiriwa na watu wa jumuiya hii.

Kukubali kwako kushiriki kunaweza kuwa msaada kwa wagonjwa wengine wa kifua kikuu siku za mbeleni – Utafiti huu utaweza kuchangia uelewa wa ugonjwa huu kwenye jumuiya na kusaidia watu kufuata msaada mapema wanapougua ugonjwa wa kifua kikuu. Pia utapata nafasi ya kujadili hisia, maono na mashaka yako kuhusu kuugua kifua kikuu.

Ushiriki katika utafiti huu utajumuisha majadiliano kwenye makundi kuhusu masuala muhimu. Majadiliano yataadumu kwa takribani saa moja. Majadiliano yatarekodiwa na mtafiti na baadae yatawekwa kwenye maandishi kwa ajili ya uchambuzi wa data. Hakutakuwa na kutaja majina kwenye kaseti. Kaseti zitaharibiwa baada ya utafiti kuisha.

Taarifa zitakazopatikana kutoka kwako zitahifadhiwa kwa siri kubwa iwezekanavyo. Matokeo ya utafiti yanaweza kuchapishwa kwenye majarida ya kitaaluma au kuwakilishwa kwenye mikutano ya kitaaluma. Jina lako halitatajwa kwenye jarida lolote au pengine popote. Hakutakuwa na madhara yoyote kwako, ikishirikisha huduma za afya kwako katika eneo hili.

Ushiriki katika utafiti huu ni hiari na bila ya malipo. Unaruhusiwa kujitoa katika utafiti muda wowote, hata baada ya kuridhia kwa maandishi bila kutoa maelezo yoyote. Kwa kufanya hivyo na hautaulizwa sababu za kujiondoa katika utafiti. Uamuzi wako wa kushiriki au kutoshiriki hautaathiri kwa namna yoyote huduma unazopata kutoka kituo cha afya/hospitali.

Asante kwa ushirikiano wako.

Utafiti huu unafanywa na;
Anne Kari Knutsen,
Mwanafunzi wa shahada ya pili katika chuo kikuu cha Bergen, Norway.

Study Participant:

Nimesoma/kuelezwa maelezo yote kuhusu utafiti huu na nimetoa idhini ya kushiriki.

Tarehe:.....

Sahihi ya mshiriki:.....

Dole gumba la mshiriki:

Informed consent form for individual interviews

We are seeking your participation in a research study which aims at contributing to a better understanding of how beliefs and perceptions in a community can influence health seeking delays in tuberculosis cases. Before you agree to participate in this research study, it is important that you read/hear the following explanation of this study.

We are asking you to participate in this study because you are a member of this community and because we believe that you might have important information about how this disease is perceived in the community.

By accepting to participate you can contribute by helping other people in the future – the study might contribute to increase the awareness of the disease in the community.

Participation in the study involves taking part in an individual interview on the relevant issue. The interview will last for approximately one hour. The interview will be audiotaped by the researcher and later transcribed for the purpose of data analysis. There will not be any identifying names on the tapes. The tapes will be destroyed after completion of the study.

The information obtained from you will be kept confidential to the extent legally possible. The results of the study might be published in professional papers or presented at professional meetings. Your name will not be mentioned in any papers or other work. There will be no implications to your current and future status, including health care services in this area.

Participation in this study is voluntary and free of charge. You are free to withdraw from the study at any time, also after consenting to participate in the study. This will not involve any penalty for you and you will not be asked for any reason to withdraw your participation.

Thank you for your co-operation.

This study is conducted by;
Anne Kari Knutsen,
Masters degree student at the University of Bergen, Norway

Study Participant:

I have read/been explained every information given to me regarding this study and have given my consent to participate.

Date:

Signature of study participant:

Thumb print of study participant:

FOMU YA RIDHAA YA KUSHIRIKI KWA MTU MMOJA MMOJA
(Informed consent form for individual interviews)

Tunahitaji ushiriki wako kwenye utafiti wenye nia ya kuongeza uelewa juu ya jinsi ambavyo imani na maono/mielekeo ya wanajuiya vinavyoweza kuchangia uchelewaji wa upatikanaji wa huduma ya afya kwa wagonjwa wa kifua kikuu.

Kabla hujaridhia kushiriki katika utafiti huu, ni muhimu ukasoma/kusikiliza maelezo ya utafiti huu.

Tunahitaji ushiriki wako kwa kuwa wewe ni mmoja wa jumuiya hii na kwa sababu tunaamini kuwa unaweza kuwa na habari za muhimu kuhusu jinsi gani ugonjwa huu unachukuliwa/unafikiriwa na watu wa jumuiya hii.

Kukubali kwako kushiriki kunaweza kuwa msaada kwa watu wengine siku za mbeleni – Utafiti utaongeza uelewa wa ugonjwa huu kwenye jumuiya.

Ushiriki utajumuisha majadiliano kwenye makundi kuhusu masuala muhimu. Majadiliano yataadumu kwa takribani saa moja. Majadiliano yatarekodiwa na mtafiti na baadae yatawekwa kwenye maandishi kwa ajili ya uchambuzi wa data. Hakutakuwa na kutaja majina kwenye kaseti. Kaseti zitaharibiwa baada ya utafiti kuisha.

Ushiriki katika utafiti huu utajumuisha majadiliano ya mtu mmoja mmoja kuhusu maswala muhimu. Majadiliano yataadumu kwa takriban saa moja. Majadiliano yatarekodiwa na mtafiti na baadae yatawekwa kwenye maandishi kwa ajili ya uchambuzi wa data. Jina lako halitatajwa kwenye jarida lolote au pengine popote. Hakutakuwa na madhara yoyote kwako, ikishirikisha huduma za afya kwako katika eneo hili.

Ushiriki katika utafiti huu ni hiari na bila ya malipo. Unaruhusiwa kujitoa katika utafiti muda wowote, hata baada ya kuridhia kwa maandishi bila kutoa maelezo yoyote. Kwa kufanya hivyo na hautaulizwa sababu za kujiondoa katika utafiti.

Asante kwa ushirikiano wako.

Utafiti huu unafanywa na;
Anne Kari Knutsen,
Mwanafunzi wa shahada ya pili, chuo kikuu cha Bergen,
Norway.

Study Participant:

Nimesoma/kuelezwa maelezo yote kuhusu utafiti huu na nimetoa idhini ya kushiriki.

Tarehe:.....

Sahihi ya mshiriki:.....

Dole gumba la mshiriki: