

Women's Perspectives on Pathway
to Diagnosis of Pulmonary Tuberculosis
Women Voices from Community Level in Uganda

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Objectives: A qualitative study to explore the perceptions and ideas of women at community level in Uganda, about factors influencing their health care-seeking behaviour when symptoms that could indicate pulmonary tuberculosis. To let the women identify barriers to health care-seeking and to let them present ideas how to overcome barriers.

Method: Focus Group Discussions (72 informants) and In Depth Interviews (19 informants) were conducted in rural Uganda with women of reproductive age. For triangulation purposes discussions and interviews also included health care providers, traditional healers and a few men.

Main Results: The data showed a wide range of health care-seeking behaviours including no action at all, self-treatment using traditional herbs or western medicines, consulting traditional healers and consulting various formal or informal healthcare facilities. The data also identified many barriers that could prevent women from getting a proper diagnosis, including lack of financial resources, lack of power, male supremacy in decision-making, lack of knowledge, perceived corruption in healthcare facilities, fear of stigma and this fear heavily boosted by the idea that PTB equates HIV/AIDS.

Conclusion: These data support the idea that successfully fighting PTB among Ugandan women and increasing case finding, demands recognition that tuberculosis is a multifaceted disease: economical, social, psychological and medical. Therefore, approaches to eradicating tuberculosis must target different sectors and reach all levels of society.

Key words

Tuberculosis, women, health care seeking, barriers, gender.

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LIST OF ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
CB-DOTS	Community Based Directly Observed Treatment, Short course
DOTS	Directly Observed Treatment, Short course
DTLP	District Tuberculosis and Leprosy Program
FGD	Focus Group Discussion
HIV	Human Immunodeficiency Virus
IDI	In Depth Interview
MOH	Ministry of Health
NTLP	National Tuberculosis and Leprosy Program (Uganda)
PLHA	People Living with HIV or AIDS
PMTCT	Prevention of Mother To Child Transmission (of HIV)
PTB	Pulmonary Tuberculosis
TB	Tuberculosis
TFR	Total Fertility Rate (Average live births per woman 15-49 years)
XDR	Extensively Drug-Resistant (Tuberculosis)
WHO	World Health Organisation

1.0 INTRODUCTION

Tuberculosis (TB) is an important cause of illness and death globally, accounting for an estimated 9 million new cases worldwide (2009) and at least 1,6 million deaths each year. The average global detection rate of pulmonary TB (PTB) is estimated at 45%.(1). This means that more than half of patients with a disease which in most cases is possible to cure, get no diagnosis – and as a consequence no correct treatment. In low and middle income countries more than 75% of people with TB disease are under 50 years of age – normally the most economically productive ages. That contributes to increased individual poverty and deepens poverty at household and community level.

The WHO worldwide system for controlling and treating TB – Direct Observation Treatment, Short course (DOTS) – is depending on passive case finding (2). That means the patient herself has to perceive the illness. Then she needs knowledge enough to understand that she needs to get examined and treated and she needs to know where in the health system this is adequately offered. Besides she needs possibility to reach that health facility to request help – without being stopped by geographical, socio-economical or other barriers. In many parts of the world there are many gender specific barriers in this process of health care seeking – usually to the disadvantage of women (3; 4).

Among many efforts made worldwide to increase TB control the STOP TB Partnership was launched in 2000 and the first Global Plan to stop TB was implemented. But there are many long standing barriers to overcome before achievement of the global targets:: neglect of TB control by many governments, lack of financial and human resources to provide supervision and quality control, weakened health systems, poverty and population growth, lack of new diagnostics that could minimize laboratory overstrain, significant increase in drug resistance and recently extensively drug resistant TB (XDR). Though perhaps the greatest challenge for achieving the global TB targets has been the expanding HIV epidemic and the resulting increase in HIV-associated TB (5).

1.1 TB in the era of HIV

The ongoing HIV-epidemic fuels the TB epidemic. HIV is the most powerful known risk factor for reactivation of latent TB infection to active disease. HIV also promotes progression to active disease in recently acquired TB infection and increases the risk of recurrence of earlier treated TB. An HIV-negative individual with latent TB-infection has a LIFETIME risk of 5 – 10% to develop clinical disease, compared to someone who is HIV-positive who has a risk of 10% PER YEAR to develop clinical TB disease (6).

TB is one of the most common treatable HIV-related infectious diseases among people living with HIV/AIDS (PLHA) in high burden countries. Despite the fact that TB is basically curable, it is one of the leading causes of death among PLHA. Late TB diagnosis, resulting in more aggressive disease, contributes to increased death rates and TB may accelerate the progression of HIV-related immunosuppressant. TB is after

AIDS the greatest killer of young people and adults worldwide. Almost 5000 people die daily from TB – a disease possible to cure (6).

Globally there are 34 million people estimated HIV-positive 2009 – of these 22,5 millions living in Sub-Saharan Africa. New infected cases 2009 were estimated to 2,5 millions – of these 1,7 million in Sub-Saharan Africa. Estimated deaths from AIDS globally 2009 were 2,1 millions – of these 1,6 million in Sub-Saharan Africa. That means 6000 people die from AIDS daily worldwide (7). All these numbers give a perspective on the tremendous problem to handle when the percentage of co-infection in TB patients in Sub-Saharan Africa could be around 50 - 70%, and an estimated third of all HIV-patients are co-infected with TB. Globally only an estimated 14% of the TB patients that also were HIV-positive were identified by testing in 2009. That means TB-patients miss the opportunity of ART-treatment when needed or Cotrimoxazole prevention against other HIV-related opportunistic infections (1).

1.2 TB and poverty

TB thrives in conditions of poverty and TB also worsens poverty as it often hits people in the productive ages. There is a long history of documented linkage between TB and poverty at national, community and individual level. The last ten years some reviews of earlier literature were carried out confirming the linkages – although concerning low-income countries the documentation is far from comprehensive. The fundamental conclusion from these reviews was according to a Stop TB Partnership Symposia 2002: “while TB is not exclusively a disease of the poor, the association between poverty and TB is well established and widespread” (9).

There are barriers to accessing TB services that are excluding more people of poor and vulnerable groups in society, compared to more wealthy ones. These barriers include economic barriers, geographical barriers, health system barriers and socio-cultural barriers including stigma and lack of knowledge. All of these barriers more often exclude the poor from diagnosis and treatment (10). Globally the highest burden of TB is found in poor countries and within these countries the prevalence of TB is higher among the poor compared to more wealthy people (11).

1.3 TB and gender

Gender interacts with poverty. Of the 1,3 billion poorest worldwide 70% are estimated to be women. And two thirds of the 860 million people worldwide who cannot read or write are women (10; 11, 12).

The male to female ratio of PTB cases notified worldwide are approximately 2:1 (1). It is not known whether this reflects a genuine biological sex difference in incidence or if gender specific barriers exclude women from being diagnosed and notified. There are studies from different parts of the world, Bangladesh, India, Malawi, Columbia, indicating that different gender barriers could be part of the explanation, excluding women in various steps of the health care seeking process (12; 13; 16). In Vietnam

qualitative studies have shown gender differences in health care seeking and in delays in the health care system – to the disadvantage of women (3; 14). Qualitative studies from other parts of the world are limited – especially community based studies from Sub-Saharan Africa. As most performed studies, to understand the health care seeking process, have focused on already diagnosed TB patients, those with TB disease who for various reasons never reach to TB diagnosis will be excluded from the studies.

In Peru screening of household contacts of TB patients was studied. The study showed that four times as many female TB cases were detected with active case finding compared to when the usual self-report DOTS system passive case finding was used (17). A study in Vietnam showed almost equal prevalence of PTB among men and women when active case finding was used instead of the ordinary DOTS system with passive case finding (18). In a small study with house to house active case finding in the slum area Kampala Uganda disclosed more women with PTB than men. (19)

There is an ongoing discussion if the diagnostic method, which is the fundament of the DOTS system – sputum smear microscopy – is less appropriate for women, who do not as easily produce adequate sputum-samples as men. When TB-suspected women in Pakistan were carefully instructed how to produce sputum specimen – to avoid just producing saliva – substantially more women were diagnosed with smear-positive PTB. No such difference was noticed among carefully instructed men.(20) In ordinary health care women almost never get special instruction how to perform adequate specimen for sputum-smear. Hopefully new easy-to-use diagnostics under development will be proved to be as effective for women as for men.

According to research performed in developing countries fear of PTB-related stigmatisation can heavily influence health care seeking behaviour, usually to the disadvantage of women, as they bear the highest burden of stigmatising behaviour (3; 14; 16). Although qualitative research could help to understand the effect of stigma on health care seeking behaviour at community level in different settings, not enough such studies are performed related to today's complicated TB-situation with common TB/HIV co-infection, especially in Sub-Saharan Africa. There is a lack of documentation whether PTB-related stigma has been compounded by the HIV/AIDS-related stigma; which in that case could result in co-infected patients suffering from double stigma.

1.4 TB and pregnancy

In history there has been controversy as to the effect of PTB in pregnancy. Over time opinion has changed about the PTB influence on maternal and child perinatal morbidity and mortality (21). There is a limited amount of studies reflecting this issue in the complicated situation with high TB-HIV co-infection in Sub-Saharan Africa. Some recent studies indicate high risk of maternal and child morbidity and mortality if PTB is not diagnosed and treated early in pregnancy – especially if there is co-infection with HIV (22; 23). Besides without treatment there is the risk of infecting the newborn, the rest of the family and others in the vicinity. If PTB is diagnosed and treated early in pregnancy there are reports that negative effects on maternal and child health can be reversed (24). There is a lack of qualitative studies documenting pregnant women's

ideas and perceptions of symptoms that could indicate PTB and about health care seeking if such symptoms occur in pregnancy.

1.5 Uganda

Uganda, a member of the East African Community, has an estimated population of 31 millions. It is number 16 of 22 countries on the list of high-burden countries of TB globally (1). The TB disease burden was 2009 estimated to 106000 cases of TB and about 26000 estimated TB deaths (1). The HIV prevalence among TB cases was estimated to 30 % (1). Data from the third quartile 2007, when 37 % of new TB-cases were tested for HIV, showed that almost 60 % turned out to be HIV-positive (personal communication Dr Francis Adatu, NTLP Manager). There is an uncertainty in all these numbers and it is not possible to get real gender specific data. The Uganda NTLP estimated 2004 that about 33000 new TB cases reported annually were attributable to HIV. According to the numbers mentioned from 2007 on co-infection, these numbers are probably increasing.

Uganda adopted the DOTS strategy in 1996 and later the Community based DOTS (CB-DOTS) was implemented. The Uganda NTLP activities have been fully integrated into the primary health care system starting at the district level using the CB-DOTS. That means in an ideally functioning setting, you as a patient is supposed to get a proper diagnosis of PTB, as soon as you seek care yourself, and a proper supervised treatment, at community level.(2)

Although records show progressive improvement, Uganda is still far from realizing the WHO targets of TB control; 70% of DOTS case detection rate and 85% of treatment success rate by 2015. The Ugandan rates 2009 were 47% and 70% respectively (1). Part of the problem why targets have not been achieved could be attributed to gender roles among different communities, which determine the health seeking behaviour. A study in Uganda (Nakazzi 2005, personal message) indicated that women in most communities have the responsibilities of doing the household chores but have no finance control and no power in decision making. This would leave little possibility for women to seek medical care when having TB symptoms.

Uganda has managed to turn the HIV prevalence in the country down to a prevalence now estimated to be 6 – 7 % (7). A national population based HIV serological survey conducted by the Ministry of Health (MOH) 2004-05, revealed much more young women HIV-infected compared to young men. Among teenagers 15-19 years for every male infected there were nine females (ratio 1:9) and among all young people under 25 years for every male infected there were four young women (ratio 1:4) (8). Knowing the fact that latent TB infection with high frequency turns into TB disease in HIV positive individuals, this makes us expect more young women being at risk contracting TB disease. MOH has decided to intensify the TB/ HIV program integration to facilitate for co-infected individuals to get proper diagnosis and treatment for the two infections.

Fertility rate in Uganda is high, 7,1 – one of the highest globally – meaning 1.200000 pregnancies yearly (22). This also indicates that women spend a big proportion of their

reproductive years either as pregnant, post partum or lactating mothers. According to high officials in the PMTCT Program (Prevention of Mother to Child Transmission of HIV), MOH, this health service is now expanding, giving 60–70% of all pregnant women access to PMTCT services. The PMTCT services are planned within the national AIDS program and effectuated together with the ANC program. Within this framework is also supposed to be information about PTB and support to diagnosis of PTB, when suspected, among HIV-positive mothers, but this part is often missing, and not reaching at all those who do not know their HIV status. The PMTCT program has now expanded to all 74 districts in Uganda.(25) But it is not without problems. Lack of qualified staff to deliver the services is a big challenge. And still stigma and fear of practical consequences, if HIV status disclosed positive, keep women from accepting testing. That means they will not be enrolled in the PMTCT program and its services. According to the Demographic and Health Survey 2006, published 2007, the percentage of pregnant women, in the area including Iganga District, who were counselled and accepted HIV-testing approximated 12% (26). The corresponding number for the capital city, Kampala, was 58%. The plan for the PMTCT program is to make HIV-testing in ANC more or less compulsory. But still there is no proper strategy how to reach all the young women with possible PTB and facilitate the process to diagnosis and proper treatment.

2.0 GENERAL OBJECTIVE

The general objective of the study was to explore the perceptions and ideas of women in reproductive age, at community level, about factors influencing their health care-seeking behaviour when symptoms that could indicate PTB.

2.1 Specific objectives

1. To explore women's perception of health.
2. To explore women's perceptions and ideas of symptoms that could indicate PTB and if pregnancy influences these ideas.
3. To explore women's ideas of health care-seeking, and from where they seek advice, when symptoms that could indicate PTB and to explore if ideas are different in pregnancy.
4. To explore women's knowledge and ideas about PTB and their perceptions of TB-HIV relationship and PTB-related stigma and if ideas differ in relation to pregnancy.
5. To explore women's ideas about barriers to health care seeking when symptoms that could indicate PTB, if there are specific gender related barriers and if barriers differ in pregnancy. Explore ideas of ways to overcome barriers.

3.0 METHODOLOGY

3.1 Study design

This study adopted a descriptive exploratory design, exclusively employing qualitative methods of data collection; methods used were Focus Group Discussion (FGD) and In-Depth Interview (IDI).

The study focused on perception of symptoms of longstanding cough, fever and fatigue and ideas of health care seeking, on barriers in the health care seeking process and on ideas of stigma related to PTB. Other focal points of interest were levels of knowledge of TB and of TB/HIV relationship and possible sources of this knowledge. As a summary, before ending the interviews, women's ideas of ways to overcome barriers in this health care-seeking process were explored. For informant triangulation purposes also data from different kinds of health providers were collected.

3.2 Aim of the study

The aim of the study was to extract ideas from women's perspective, at community level, about the health care seeking process, when symptoms that could indicate PTB; long lasting cough, fever and fatigue. This could give a better understanding of why many women stay away from seeking health facilities when they experience this kind of symptoms. The purpose was to be able to forward a woman voice for better understanding of the complex pattern of women's health care seeking that constitutes the pathway to diagnosis of PTB. This could provide information to create a better platform for health care planning and management to improve PTB case finding among women. It could also offer a possibility for a women influence, from grass root level, when new tools are to be produced to improve PTB case finding

3.3 Study site

The study was carried out in Iganga District, Eastern Uganda, located about 150 Km east of Kampala. The majority of respondents included were residing in rural areas, being consistent with the fact that only a small proportion of people in the area lives in urban neighbourhood. The respondents were recruited from four villages and the small town of Iganga . Numbers of informants included from the different localities in FGDs and IDIs respectively were as follows:

Table 1: Localities against the numbers of FGDs and IDIs covered per locality. Numbers of informants in each FGD in brackets.

Area	FGDs	IDIs
Bubinga	2FGDs (7+12)	4 IDIs
Buseesa	1 FGD (7)	4 IDIs
Bulamagi	3 FGD (9+6+10)	6 IDIs
Ibaako	1 FGD (9)	2 IDI
Iganga town council	1 FGD (8) 1 group discussion (4 providers)	3 IDIs
Total	9 (72)	19

3.4 Study population

The study population consisted of women of reproductive age, 15–49 years, with a few exceptions. Women were targeted because, according to high officials in the Ugandan NTLP, case detection rate of TB is lower among women than among men. Besides, as women are the primary caretakers in the family, the impact of TB disease in women is not only severe for the individual, but also for family and society. There is also the risk in reproductive ages that TB could interfere with pregnancy. Moreover, literature suggests that gender-related, socio-economic aspects of TB seem to be neglected in current TB control models (13; 14).

Women were purposely selected for individual interviews (IDI) or for focus group discussions (FGD) from four different villages and Iganga town. After instructions from principal investigators and research assistants the sampling was performed by village or town council officials. Education level, age and approximated degree of household poverty were factors taken into consideration, when choosing informants, to attain best possible variation. But concerning each FGD the instruction was to make each FGD homogenous enough, especially concerning age and education, to allow everyone in the group to discuss freely.

Pregnant women were included; one FGD consisted entirely of pregnant women. The initial intention was also; if possible, to include an FGD consisting of previously treated female TB patients. This was not possible to arrange for logistic reasons. For informant triangulation purposes, we also included providers as informants, from both formal and informal health sector, among these two female traditional healers. Two male traditional healers were also invited, and had accepted to join, but could not make it because of disastrous rain. For logistical reasons there was no possibility to conduct these interviews later. In two FGDs also men were included, altogether eight of them, as another kind of triangulation, to see if other subjects would be brought up for discussion, and perhaps in a more provocative way, when men were included. The focus still was completely kept on women's situation. No clear difference was seen in the discussions, and women acted as informative when men were included as when exclusively women were included.

Box 1: Iganga District Profile

Iganga District covers a total area of 1,680 square Km.

It is divided into three counties of Luuka, Kigulu and Bugweri with 18 rural sub-counties, one town council, 112 parishes and 644 villages.

Population size and composition

The 2002 Population Census Report revealed for Iganga District a total population of 540,939 with an average annual growth rate of 3.4 percent between 1991 and 2002. During the 2002 census, there were 106,511 households and of these only 7% urban-based.

Age composition

- The district population was young with children (population below 18 years) consisting of 60 %.
- The proportion of the elderly (60 years and above) was 5%.

Education and literacy

- The literacy rate for the population aged 10 years and above was 68%.
- In rural areas among the illiterate, the female to male ratio was 2:1.

Socio-economic characteristics

- Most households (54%) were within a distance of ½ Km of a water facility with predominance in urban areas at 74% compared to rural areas at 52%. 74% of the households had access to safe water. About 65% were using borehole water.
- The agricultural sector as a base of income accounted for 82 % of the total population.

Household and housing characteristics, livelihood and poverty correlate

- 45% of households lived in dwelling units whose walls were built using stabilized bricks, with more prominence in urban areas at 59%.
- Iron sheet roofed units accounted for 75% followed by grass-thatched roofs at 24%. 80% lived in dwelling units whose floor was made of rammed earth.
- Main source (85%) for lighting “tadooba” (a traditional paraffin candle).
- In rural areas no toilet facility at all 13%, uncovered pit latrine 21%.

Health-related aspects

- 85% of the households accessed health services within a distance of 5Km.
- Just 14% of the households accessed health services in a distance of less than half a Km while 15% have to travel a distance of 5Kms or more.

Information, communication and transportation

- 57% of households depend on word of mouth as the main source of information.
- 41% of the households owned at least one radio and an equal proportion, 41%, depended on it as source of information.
- 47% of rural households owned a bicycle.

Source: Iganga District; Local Government District Planning (February, 2007): *2002 Population and Housing Census Analytical Report*.

Description of study respondents

72 informants participated in FGDs while 19 informants participated in IDIs. The bulk of the respondents were ordinary women between 15 - 49 years of age. Eight men altogether participated in two mixed FGDs. In the 19 IDIs, only two informants were men, of the provider category. About half of the informants just have primary education, often three or four years of schooling. Of those who started secondary education most had dropped out after a few years. In terms of occupation the biggest proportion of the respondents derived their livelihood from subsistence peasant farming. Some of them combined peasant farming with petty or small business; such as tailoring or small shops selling household items. Two IDIs were performed with traditional healers. A few participants in FGDs and IDIs were salaried workers; these included two primary school teachers, a pre-primary nursery school teacher and three private health service providers. Other health service providers were those four who participated in a group discussion of service providers at Iganga hospital. Because two of the invited providers got acute hindrance to participate it did not fulfil the criteria of an FGD; so it was a group discussion by definition.

The number of informants can seem unusually high to be a qualitative study. The planning was, following advice from other researchers, because of logistical difficulties in recruitment, done so we would not at the end find us sitting without necessary material. That means planned for drop-outs and cancelled groups that often happen during rainy season. But drop-outs were rare, and then other persons readily entered the groups. And all groups were discussing – no silent groups. Some of the informants were exclusively included for triangulation purposes.

For characteristics of informants by criteria and number of informants see Table 2 below.

Table 2: Characteristics of informants of the study; by criteria and number of informants.

IDI=19			FGD=72		
Sex	Female	17	Sex	Female	66
	Male	2		Male	8
Education	Primary any year	10	Education	Primary, any year	38
	Secondary any year	8		Secondary, any year	35
	University any year	1		University Any year	1

Livelihood	Farming, (subsistence)	4	Livelihood	Farming, (subsistence)	48
	Small business	4		Small business	12
	Salaried worker	4		Salaried worker	4
	Health provider	5		Health provider	4
	Traditional healer	2		Traditional healer	-
	Student	-		Student	6
Setting	Urban	3	Setting	Urban	10
	Rural	10		Rural	64
Marital status	Married	13	Marital status	Married	58
	Single	1		Single	10
	Divorced/widowed	5		Divorced/widowed	6

3.5 Data collection methods

The study was qualitative and elicited information from focus group discussions (FGDs) and “in-depth interviews” (IDIs). What is referred to as IDI is not real individual deep interviews but semi-structured, qualitative interviews (24).

FGDs were used because it is a suitable method for studying knowledge topics, opinions and practices in the health care system. Initially it was anticipated that at least nine FGDs would be carried out, but saturation point, that is when more FGDs do not elicit more information, was to decide the number. Each FGD is supposed to consist of not fewer than six but not more than twelve participants. Participants were selected on the basis of age, education and household poverty; trying to create groups homogenous enough to make people easily discuss with each other, but providing as good variation as possible among the entire group of FGD informants.

IDIs were used because individual interviews are good to use for exploration of the individual complexity in a process; in this study the complex pattern constituting the pathway to a possible diagnosis of PTB. Usually the intention in the IDI is to make a deep exploration of the individual ideas and perceptions. In this study, with a broad area of interest and both cultural and semantic barriers, the research team was before start aware of that the expected level of exploration could not be very deep. The research assistants followed an interview guide, not to miss points of interest, but there was a readiness to follow the informant’s way of thinking about the discussed topics. The criteria for selection of IDI informants were more or less the same as used for FGDs; to create variation in the group of informants. Also concerning IDIs the saturation point was to decide the number of interviews performed, but considering the logistic situation explained before.

The research team consisted of two principal investigators and three research assistants. One of the principal investigators, Frank Mugisha, is an experienced researcher with a qualified background regarding qualitative research. He is a Ugandan sociologist by profession, with research education from Uganda and Holland, and he provides extensive knowledge and interest in Ugandan women's situation. The other principal researcher, the author of this MPH essay, is a Swedish Gynaecologist with experience of work with women in developing countries and who now, after many years as a Swedish Gynaecologist, synchronized with that work, performs public health studies in Sweden. The focus is on global health and specially Tuberculosis in women perspective. The two researchers' different backgrounds and perspectives created a rich platform for discussions and planning of this study.

The bulk of FGDs and IDIs were performed by the three female research assistants, all of them with the local language of Lusoga as their mother tongue, and with adequate knowledge of English. They were specially trained for this study; to perform the interviews and to understand the purpose of the interviews. They were trained and supported by the principle researchers, especially Frank Mugisha. Written topic guides were used – written both in English and Lusoga, the latter translated by a special interpreter. The research assistants had used the topic guides first in training situations to be aware of language difficulties concerning specific words and conceptions that are not easily explained in Lusoga. The interviews were mainly conducted in the local language. Written consent was given by all participants in local language or English whatever preferred. Five IDIs with English-spoken respondents were facilitated by one of the principal investigators. All IDIs and FGDs were facilitated by at least one research assistant and one note-taker, this one also tape-recording the session, not to risk missing information. The intention was to transcribe and translate all discussions and interviews within 24 hours. But for logistical reasons, like acute disease and shortage of electricity, this was not always possible and transcriptions had to be completed beyond 24 hours. Every evening, after the data collection sessions, a team-meeting was kept to discuss the work of the day, obstacles, possible improvements and if any of the planned activities for any reason had to be reconsidered.

The interviews sometimes took place indoors, like in an empty school building or in a private small house. In other places the interviews took place outdoors, in the shadow from a huge tree, with all ordinary life going on a small distance away. Sometimes there was a small interruption by a motorbike or a crying child or children coming chattering, carrying water from the bore-hole, making it impossible, for a short while, to continue the discussion. Some disastrous rain showers created bigger problems. Even when the team and all the respondents were invited into a private home to continue the discussion, when the sky suddenly opened, it was usually impossible to keep talking, or to manage the tape-recording, as the heavy rain drowned all sounds.

3.6 Data analysis

Qualitative content analysis was used as the analysing tool. Mostly the analysis refers to manifest content, but also some latent content was explored, for instance concerning gender based stigma, but interpretation is not on a very abstract level (27; 28).

The process of analysing started already in discussions, when the process of data collection proceeded, and some ideas of the material emerged. These ideas could also be used in the following interviews to elucidate some especially interesting emerging ideas. After complete transcription of all interviews the two researchers went through the material separately. Then data was discussed regarding some obscurities and in a few cases the research assistants had to be contacted for clarifications. After discussion and a brief verbal summary of findings, and a kind of consensus on the body of the content, each researcher individually worked through the data creating codes and preliminary categories. The following meeting disclosed a striking consistency between the researchers, despite the differences in background, in their ideas about developing codes and in the ongoing process of coding the extensive material. The coding procedure was never something going on along a straight line but more like proceeding along a tangled coil. There was a continuous interaction between creating codes, coding, developing categories, grouping categories and sometimes failing to find consistency between codes and categories and then reconsidering the coding or the categorizing. This process of coding was followed by a long period of time with a series of meetings and repeated e-mail discussions on the extensive material regarding interpretations of content, the finalizing of the categories and the emergence of sub-themes and themes.

Often the conception of theme in qualitative analysis refers to a latent content. Here it was used even referring to a more pragmatic analysis of manifest content, without very deep interpretation. After repeated discussions some sub-themes/themes were developed like: “A barrier in health care seeking is that PTB in the community obligatorily means AIDS”; “Consulting traditional healers is considered a normal procedure even in pregnancy”; “Fear of social consequences, if getting a diagnosis of PTB or HIV, makes women try to hide their symptoms instead of seeking health care”.

To develop the previous themes was rather obvious, when analysing the data on a more or less manifest level. More reflection and discussion was needed to reach, as an example, the theme of “Gender-based stigma as a strong barrier for health care-seeking when symptoms indicating PTB”. Respondents had initially denied, as an answer to the direct question on gender based differences, that there is a difference in stigma directed towards women and men “getting TB is the same whether you are man or women”. Approaching the same issue indirectly, through questions on related issues, the emerging picture was different. When codes and categories were worked through, and sub-themes developed, with a bit more of interpretation of latent content, this clearly exposed that women all the time experience and expect more stigmatizing behaviour, in relation to PTB and HIV, than men.

3.7 Quality assurance

Quality assurance includes observing and eliminating possible destructive effects on the data and the results all along the study process. In a study involving both a semantic and a cultural transformation and translation of ideas and conceptions, there is of course a big risk of distortion of data.

To be able to reach trustworthiness in the research procedure the process was carefully planned and realized.(29) To start with three research assistants were recruited; of female sex and from childhood familiar with the local language Lusoga, the language of the study area. This language is different compared to the language Luganda usually used for instance in Kampala, the capital city .The research assistants were also familiar with research processes and with English language.

To start with the topic guides for IDIs and FGDs, slightly different, were translated into Lusoga by a special interpreter. The topic guides were then translated back into English, by another person, to reassure that important information and conceptions were not changed in the translation process. The research assistants were then trained in using the topic guides by the Ugandan researcher who had vast experience in this kind of work, and also had some knowledge of Lusoga. In the first period of data collection all three assistants transcribed and translated the same parts of some interviews, to be able to compare and discuss critical words and concepts, among each other and with the researchers. Consensus could be reached in how to interpret and translate especially difficult words to catch the best connotation.

Every evening during field work, after daily data collection session, the team met to discuss technical difficulties and challenges. One challenge was shedding of electric power in Iganga District. This periodically meant a few hours of electricity supply every second day. This was a practical obstacle for transcriptions as replace lightening for office use was not sufficient. It also meant a risk of contracting stomach problems as food could not be kept cool enough; not even in small restaurants. The meetings gave a possibility to discuss special problems experienced in interview situations and to find practical solutions to practical obstacles that all the time occurred. This was a way to optimize the quality of the following interviews.

One part of the process to assure credibility can be that the researchers have different backgrounds and by this possibility to shed light on the research process, including the analysis, using a variety of aspects. In this study the two researchers showed different backgrounds in profession, research tradition and research experience. A Ugandan Sociologist with vast experience of qualitative research in combined African and European context together with a Swedish Gynaecologist with a Swedish theoretical research framework and little experience of practical qualitative research but with extensive experience of interviewing women regarding difficult topics. The differences constituted a good platform for creative discussions.

A scrupulous analysing process of the data was an agreed necessity and both researchers went through the material separately and together several times to develop codes and

categories and letting sub-themes and themes emerge. Complete consensus was not reached instantly regarding some developed themes and then the process had to be reversed and redone and by this procedure it was possible to reach agreement.

The analysing process was allowed to take a long time to give possibility to thoroughly evaluate the comprehensive data. And also to time after time go back to the interviews to cheque about details and ideas. After the analysing process, as a control if trustworthiness could have been reached, interviews have been read all through again, to cheque if the content is adequately covered by the analysis.

3.8 Ethical considerations

This research was granted ethical approval by the Higher Degrees Research and Ethics Committee of Makerere University School of Public Health and the Uganda National Council for Science and Technology. All participants got verbal information in local language and written information in English or local language, according to preference. All respondents provided signed written consent to be interviewed.

3.9 Collaboration

This research was performed as a collaborate effort between three institutions:

1. **The National Tuberculosis and Leprosy Program (NTLP) Uganda.** The National program Manager of the NTLP, Dr Francis Adatu-Engwau, was one of the co-investigators and the collaborating link between the NTLP and RCQHC.
2. **The Regional Centre for Quality of health Care (RCQHC),** Institute of Public Health, Makerere University, Uganda. One of the co-investigators, Dr Chilunga Puta is the Infectious Disease Advisor at the RCQHC. In addition, one of the principal investigators, Frank Mugisha, is affiliated to the RCQHC as a social scientist and researcher.
3. **The Nordic School of Public Health (NHV),** Gothenburg, Sweden. The faculty at NHV is recruited from the Nordic countries and within the Nordic area NHV is unique in the field of interdisciplinary postgraduate education and research in public health. Professor Anders Möller was the Tutor for one of the principal investigators, Dr Git Wikström, in her MPH work.

4.0 RESULTS

4.1 Introduction

The interviews resulted in abundant data as the majority of respondents promptly gave their opinions on discussed topics. Most of them sincerely expressed satisfaction that someone showed any interest in their village, and in their situation, and wanted to be

assured that something concrete really would come out of this effort. The results to some extent turned out to be the expected. The intention was to get a more complete picture that could answer the initial research question; why do women too often stay away from health care seeking when experiencing symptoms that could indicate PTB?

The analysis of the comprehensive data will be presented compiling the results more or less in accordance with the specific objectives.

- Women's perceptions and ideas of health
- Women's ideas and perceptions of symptoms that could indicate PTB; cough for weeks, fever and fatigue, and if pregnancy influences these ideas.
- Women's health care seeking when symptoms that could indicate PTB and if pregnancy influences health care seeking.
- Women's knowledge and ideas of PTB and their perceptions of TB-HIV relationship and PTB-related stigma and if ideas differ in relation to pregnancy.
- Women's ideas of barriers to health care seeking when symptoms that could indicate PTB, if there are gender specific barriers and if barriers differ in pregnancy. Women's ideas of how to overcome barriers.

4.2 Women's perception and ideas of health

All respondents were as an introduction, even before mentioning tuberculosis, asked what they understood by the concept of being healthy. A range of mixed ideas emerged, mostly disclosing a functional idea of health.

First, respondents repeatedly indicated that being healthy means the ability to perform uninterrupted physical activity and having the strength and energy to do daily normal work (*emirimu adha bulidho*). In this context normal work ranges from manual chores women do in their daily life, including hard work in the field, to breastfeeding. In other words, when lactating mothers are able to breast-feed their offspring and besides perform all the other work, then this suggests that such a mother is healthy.

Second, they considered having wealth or money (*obugaigha/emaali*) to be an indicator of good health. On the other end of the scale they claimed that poverty demonstrates insufficient health. Essentially, their idea was that someone who is wealthy is healthy as well. They also expressed that money over time has become a very important determinant of health. Money decides what kind of health care you can access if needed. They also linked access to adequate, valuable food and a balanced diet (*emere yomugaiso*) to be an indicator of good health and having appetite for this kind of food was perceived as another indicator.

Third, respondents expressed the idea that showing sign of proper hygiene is indicating good health. Their idea of good hygiene included sleeping comfortably (*okulambaala obulungi*), having proper housing (*enumba enungi*) and suitable toilet facilities. In addition, they expressed that good outward appearance in terms of being well dressed, smart and appearing physically fit connotes being healthy.

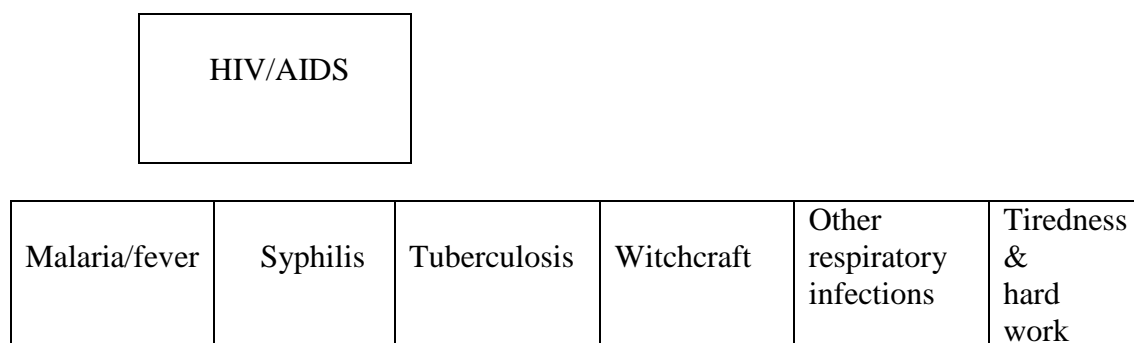
What was not clearly expressed in words, but could easily be interpreted from many of the respondents’ statements on health, was the idea, that as long as there are no signs that could implicate HIV/AIDS, someone is considered being at good health. That goes well together with the generally expressed idea, among respondents, that someone looking smart, being well-dressed, walking majestically, not being too slim, being able to do hard daily work and having the possibility to buy care and medicines when needed – this one is considered being healthy.

“A healthy person is the one who is strong and can carry out her/his normal activities and walk majestically.....when one walks majestically, “omutima guzaana bulungi” (normal heart beat) and free from thoughts.”

4.3 Women’s understanding of symptoms that could indicate PTB; cough for weeks, fever and fatigue

Throughout all FGDs and IDIs, before the facilitator even mentioned the word “TB”, women were asked to imagine how they would interpret symptoms, and what actions they would take, if they got a bad cough for some weeks, fever and fatigue. Strikingly, almost all women first indicated that these symptoms suggest HIV/AIDS. Other interpretations of possible ailments that were less frequently mentioned are graphically represented in figure 1

Figure 1: Interpretation of symptoms of bad cough for some weeks, fever and fatigue



HIV/AIDS in figure 1 is intentionally represented by a larger box than the others, because all respondents almost unanimously mentioned it as the most likely reason - more likely than any other condition. The women would address HIV/AIDS in various ways, for instance as “this currently common disease of these days” (*buno obudhwaire*) or “the fever (*omusudha*) of these days”.

Moreover, another likely condition, after HIV/AIDS, that respondents usually could associate with the mentioned symptoms was malaria or “fever”. The local terminology for malaria and fever is the same (*omusudha*) so it may be hard to distinguish between the two. Further, women mentioned that symptoms could be suggestive of syphilis (*kabotongo*) or TB (*akafuba*) because according to many women TB, HIV/AIDS and syphilis share the same symptoms. Even the few, who said they would suspect TB if someone had a persistent cough, not responding to treatment, at the same time added that TB would be indicative of HIV/AIDS.

According to respondents, such symptoms of long-lasting cough, fever and fatigue, especially if a woman is not pregnant, could be due to either witchcraft or an attack by ancestral spirits. It was stressed that it is not uncommon for traditional healers to persuade women to accept such perceptions. Also it was told that such conception about witchcraft and spirits is normal believe in some villages, and that older relatives may try to persuade women to believe in this explanation. But there was disagreement from other respondents in this question. It was said that in the modern times of today there is no place for interpreting symptoms in that outdated way, that nowadays there are other explanations and ways of getting to diagnosis.

Repeatedly respondents emphasized that these symptoms simply could emerge because of the constant heavy workload women live with; both hard work in the fields and household chores including fetching water. And these comments whenever they were expressed in the discussions resulted in approval from the others.

“Since we have many diseases exhibiting similar symptoms, but HIV/AIDS being prominent and The Disease of The Day, I would suspect that it is it (HIV/AIDS) and may just remain at home without seeking help”.

4.4 Women’s ideas of symptoms of bad cough fever and fatigue when pregnant

When respondents were asked whether pregnancy would change their ways of interpreting these symptoms of bad cough, fever and fatigue, strikingly there was consensus, as mentioned before, that such symptoms are seen as normal when pregnant; and as such there is no need to take special action. Repeatedly they talked about the constant hard daily work women have to perform, even when they are pregnant. That hard work is considered as a part of, and aggravates, that kind of symptoms.

However, mixed perceptions emerged among respondents. Even if women agreed upon that these symptoms are expected and normal in pregnancy, some women expressed clearly, that you have to be careful when you are pregnant and not forget about HIV/AIDS, syphilis, TB and other diseases, even in pregnancy.

If not accepting the mentioned symptoms as normal in pregnancy, to some respondents it seemed most obvious to attribute symptoms to witchcraft. This witchcraft was told to be specially related to co-wives in polygamous relationships. But in some of the FGDs

there was strong opposition to these ideas, with some respondents expressing that in these modern times it is not adequate to associate such symptoms with witchcraft. Some respondents argued that it is important that pregnant women seek professional treatment – by this addressing western medicine in formal health facilities; normally ANC clinics. Other women had the idea that cough is not a symptom for the witchdoctor – it has to be combined with convulsions or signs of bad mental health to make one opt for a witchdoctor. In discussions with providers, the perception was supported that even pregnant women often go for traditional treatment. Both providers in formal and informal health facilities were aware that consulting traditional healers was a common option in health care seeking, even among pregnant women. But it was declared that as providers they could not always openly discuss this with their clients, and the providers seldom got to know what kind of treatment the client had got from the traditional healer

“...Whenever a woman conceives and she gets fever she will automatically take it that it is pregnancy causing the fever and cough as well. Like nr 3 has said – if the baby dies; that is when she will suspect AIDS, but before that happens there is no way you can convince her that it is AIDS.”

4.5 Women’s ideas of requesting advice when symptoms that could indicate PTB

In all FGDs and IDIs respondents were asked from where they would seek advice if they experienced the mentioned symptoms. Apart from a few women, who said that they would not ask advice from anybody, generally women would request advice from senior relatives - especially mothers-in-law and grandmothers. One given reason for consulting elders was because women expect them to have experience of special women disorders in reproductive age, including pregnancy. The elders’ perceptions therefore become critical in interpreting and giving explanations for various symptoms – for instance persistent cough. Many respondents also indicated seeking information from their friends, whenever possible, for instance when collecting water at the borehole. Only a few women mentioned religious ideas, like relying on the providence of God, or consulting an imam or a priest.

Some respondents mentioned consulting siblings and husbands. It was clear though that only a few women primarily would consult their husbands. Some even said directly that consulting the husband in such a question would create real problems. It was declared that the question whether to consult the husband or not was depending on the relation between the spouses. Some women claimed that their husbands would do anything possible to find care for his wife. But it was explained when there is mistrust between spouses it would be of no use even raising the problem for discussion, as the husband would deny the wife any financial support. For such women the situation could be even more complicated if the husband suspected that the bad cough could be a symptom of HIV/AIDS. A polygamous relationship was said to make it more hazardous to consult the husband.

“...I would ask advice from my mother or sister if they were around. ...if I asked my husband I would find myself in problems...”

4.6 Patterns of health care-seeking among women when long-lasting cough, fever and fatigue.

Regarding health care seeking among women when symptoms of bad cough, fever and fatigue the study does not indicate one clear pathway to reach a possible PTB diagnosis. The respondents exhibited a mixture of health care seeking behaviours that suggests a risk that only part of them would ultimately make it to an appropriate facility for PTB diagnosis, and then often with delay. Of possible actions suggested by the respondents these could be taken in any order and combination:

4.6.1 Home remedies or self-medication using herbal medicines:

Most respondents stated that herbal self-medication is pervasively used as the first intervention, when faced with symptoms of bad cough and fever. Apparently they use a combination of anti-cough and anti-malaria herbal medicines to also cover the very common malaria. Many women expressed that herbal medicine is readily available in their gardens or can be obtained from the neighbourhood. During discussions they freely listed the most commonly used herbal medicines available - *olubirizi*, *kigagi*, *musiwo*, *empafu*, *olukono*, *bombo* - and others, including eucalyptus home-made syrup. The use of these herbal medicines is complex. Respondents reported that many times these herbs are used in a cocktail or a herbal combination. It is boiled and used in steam bath, and they can drink part of the cocktail mixture. Alternative methods of using the herbal drugs are burning them to produce ash which the woman licks. Or just chewing the herbs not processed can be effective enough.

“..I say that it (the local herb) is a form of first aid. I use it first and when there is no improvement, then I proceed to the health unit.... you may use herbs ”olubirizi” because you may not have money for transport to take you to the health unit. So you decide to use “olubirizi” while looking for money...”

4.6.2 Self-medication using western medicines:

Most respondents reported self-medication using western medicines. Repeatedly reported was Septrine (cotrimoxazole), Panadol (paracetamol), Amoxyl (amoxicillin) or just “tablets” which they generally could not name. The reported source of medicine used for self-medication varied. Some women mentioned left-over drugs stored at home from previous regimens. Others reported buying them from open markets or from itinerant sellers walking by with loud-speakers, advertising drugs. Or medicine could be bought from ordinary *duukas* (shops for general merchandize) or local drug shops.

One reason given for the self-medication was easy accessibility in terms of cost and convenience. Many respondents intimated that near-by shops are ‘pocket-friendly’. Drugs are sold according to the amount of cash at hand by the buyer and not according

to the required dosage. Moreover, proxy purchasing is accepted and convenient. You can send a child for some tablets if you are sick at home. Besides, some women declared that they opt to self-medicate using western drugs from informal sources, because they either have limited access to the formal health system or they have lost confidence in the government health system.

4.6.3 No action taken outside home:

Respondents generally reported that there are many women “who do not take any action” if bad cough, fatigue and fever. Mentioned possible reasons for this lack of action:

- Lack of financial resources required in terms of travel costs, health care charges and other costs. Lack of general support. Respondents generally blamed husbands (but with exceptions) for not providing the necessary financial and practical support.
- Fear of stigmatization due to HIV/AIDS and PTB if tested at a health facility.
- Carelessness, laziness and lack of knowledge were reported as possible reasons.

Although these women were mentioned as taking no action at all, it usually meant using their own traditional herbs, from their own gardens or fields, as well as self-medicating using stored western medicines, the combination referred to as “*first aid*”.

4.6.4 Consulting traditional healers

Most respondents expressed that it is most common to use the services of local traditional healers. These are well known and women know them by name. They are consulted for different reasons, also for bad cough, fever and fatigue. But there were some respondents claiming that you usually do not seek a witchdoctor if the situation does not include convulsions or signs of mental illness.

In some FGDs intense discussions emerged on the topic of use of traditional healers. Some respondents – often with higher formal education – claimed that in the modern times of today’s Uganda there is no reason for going to traditional healers, since there are health facilities with modern equipment for diagnosing diseases and these resources should be the main choice when one is diseased. Others declared that it is not at all stupid to consult traditional healers and use their treatment. That this could be clever, to combine traditional ideas about illness and treatment with modern “western” ideas. The combination could be a way to cover for all possibilities if you get sick – even the possibility of being bewitched. Others then replied that many of the witch doctors are just money-makers cheating people. Consensus was not reached in these discussions.

Some important issues emerged from discussions about and with traditional healers.

- Many women visit traditional healers. This seems to be considered natural for any woman, even in pregnancy.
- Some traditional healers have basic knowledge of symptoms of PTB. Interviewed traditional healers confirmed that they receive patients with longstanding cough. If a client comes with symptoms possibly suggestive of PTB, the cough would be

treated for a few days, some trust created, and then the client would be referred for proper diagnosis in an adequate government health facility.

- Sometimes traditional healers as clients get women already diagnosed with PTB and on treatment. Some women prefer utilizing both traditional therapies and western medicine (i.e. anti-TB drugs). Both among respondents and traditional healers there was the idea that some symptoms of PTB are most successfully treated with traditional medicine, thus the justification for continuing dual therapy.

Some traditional healers have undergone training, as an initiative from formal health providers. One of the traditional healers who was interviewed reported having been trained several times through *Uganda ne ddagala lyayo Association*. This imparted basic knowledge about how to identify PTB and AIDS and when to refer clients to formal health facilities. Many women argued that some popular traditional healers have very efficacious treatment, to the extent that they have attracted distant clients as far as from Kampala city; more than 200 km away. Other respondents again claimed that there are deceivers among traditional healers, just making “money-business”.

“..Some think of going to the Traditional Healer first. If they don’t succeed they go to the health unit. They usually don’t get better from those herbs so they go to the health facility. They think of ancestral spirits disturbing you – even the Traditional Healer tries to persuade you about that.....Even a husband can have the idea his wife is being bewitched and take her and pay for the witch doctor.”

4.6.5 Consulting formal health facilities:

Seeking health care from the formal health system is not always a matter of course according to respondents. Formal health facilities include private-managed health clinics and government-managed health facilities including hospitals. Women who easily without expensive, tiresome transportation can access the health facilities, especially government health facilities, apparently seek services from there as long as drug supplies are available. It was often mentioned that there is no use of consulting the government health facilities when drugs are not in stock – “*they just prescribe something for you to buy*”.

Some respondents reported that they would get anxious and afraid if symptoms of bad cough, fatigue and fever, and their first response would be to straight away visit a formal health facility for diagnosis and treatment. On the other hand anxiety and fear of possible reason for the symptoms was by some women given as a reason for not seeking health facility at all.

To seek care from formal health facilities was often mentioned as a step to take when other ways of treatment failed. Many respondents, but as said before, not all, said they would first try self-medication of different kinds and visit a traditional healer before taking the step to consult a health centre or a hospital. Some women stated that the health facility they would choose if caught with persistent cough, fever and fatigue would be TASO (The AIDS Support Organisation).

“...For instance my mother was about to die from TB. We thought that she had been bewitched. We tried whatever we could with traditional medicine (healing) but in vain. Finally we took her to Buluba Hospital - TB was discovered..... got treatment, recovered and even gave birth to another child..... The Government hospitals they exist but they are not for us local people at grass root level because we have no money...”

4.6.6 Influence of pregnancy on health care seeking

Overall an ambiguous picture was emerging from the FGDs and IDIs in the context of health care seeking when a woman is pregnant. On one hand, respondents gave a picture of pregnancy being special; generating more attention also from a male partner who would not care so much when the wife is not pregnant. There was general consensus that, with a few exceptions, husbands would normally get worried about a pregnant wife, having such symptoms as longstanding cough, fever and fatigue. He would by all means support health care seeking if the woman consulted him. An exception could be a husband in a polygamous relationship.

On the other hand respondents generally declared that symptoms like longstanding cough, fever and fatigue are symptoms attributable to pregnancy and as such not require special action. Different examples were given by the respondents of situations when pregnant women were coughing a lot during pregnancy, but stopped directly after delivery. It was clear though, in IDIs and FGDs, that self-medication both with herbal medicine and western drugs is common even in pregnancy – though some women expressed hesitation to drink herbal medicine when pregnant. They would prefer only to use it for steam-bathing.

Whether to go to Traditional Healers or not, when pregnant, resulted in more discussions in the FGDs. There were women clearly declaring that when a woman is pregnant the only adequate facility to visit is the Ante Natal Care (ANC) clinic. Others reported that they as well, to be sure, would visit the traditional healer.

Striking in both IDIs and FGDs was the trust that respondents expressed towards the ANC. It was among the women no doubt that ANC should be visited on regular basis in pregnancy and that midwives work seriously. There were some complaints about money that was needed to pay to be “worked upon” in the clinics (even when it is supposed to be without payment), but nothing of the big mistrust and complaints expressed concerning other parts of public health facilities was presented concerning the ANC. There was also consensus that one could present symptoms like longstanding cough and fever to the staff in ANC. Some women clearly declared that no one would really take notice of your cough in the ANC clinic, while others had obvious expectations of being examined and getting treatment even concerning this kind of complaints.

“..us women in the village will tend to contribute these symptoms to the pregnancy thinking that it’s the one who brought on the cough, fever and

fatigue. So we wouldn't bother with a health facility..... If it were I, I would ask advice from the health worker when I go for ANC..."

4.7 Women's knowledge of PTB, ideas of TB/HIV relationship and PTB related stigma

4.7.1 Knowledge

The knowledge among respondents about TB was varying from almost total ignorance to what could be considered close to professional knowledge and perception. Among the few with the best knowledge concerning symptoms, ways of spread, diagnosis, relation TB/HIV and treatment, often a close personal experience of PTB was disclosed, usually a history of one or more close relatives with the disease. Most of the respondents showed some mixed knowledge but very few could tell that PTB is a separate curable disease, that it has a relation to HIV/AIDS but not obligatorily and that the disease is air borne. The striking result was that even many of those with the most complete knowledge had the idea that a PTB diagnosis obligatorily means that you are HIV-positive.

Misconceptions of different kinds disclosed to be common. Especially related to the cause of PTB and to the spread of the disease.

"There is hereditary TB, but few people know the fact. When one person in the family develops TB, another might develop it after a certain period...that is because it is hereditary. I am aware of that because every time I go for ante natal care, TB is one of the diseases we are asked about whether anyone in the family has ever had it..... Also if you have a pussycat in the house and it smells and drinks on something you are to take, then you get TB"

4.7.2 Source of knowledge

A close personal experience of PTB, usually in the close family, could result in a very good TB knowledge. That of course gives credit to health services where apparently the education has been very good at times. Some knowledge was said to be coming also from schools at ground level and from close health facilities; ANC was repeatedly mentioned as a source. But the demand from the respondents for a community based information about TB; symptoms, diagnosis, treatment and TB/HIV relationship was striking. They referred to the radio as a good source of information at times; especially for those who actually had access to a radio. But there were ideas of possible improvements concerning programmes and hours. And it was stressed that also other sources of information were needed.

Friends and neighbours as source of information was a bit of debate among the respondents of FGDs. As misconceptions and misinformation is abundant it is difficult

for a woman to know whether the information you get in your neighbourhood is relevant. It was noted that if someone more official to ask was in place at village level, like a village health worker or a community official, that could make health care seeking easier. But according to the respondents that system is not there in all settings.

“Friends can give you the idea that it is of no use seeking care; they tell that you will just get a diagnosis of HIV and as you have no money for ARV you will still just wait to die.... But we also hear that TB is spread through the air, that it affects the lungs, so we don't know how it causes. Others say that it is the result of HIV/AIDS, while others say that TB may be curable if treated well... What I know from before is that anyone can contract TB as long as you share mugs or plates with a TB patient.. ”

4.7.3 PTB Related Stigma

There was no doubt among respondents that stigma was an important issue in the PTB discussion. And that stigma was a big hindrance in the health care seeking process. As stated before PTB for most respondents obligatorily means HIV-infection. That made it almost impossible to discuss PTB-related stigma separated from HIV-related stigma. When the research assistants, according to instructions, tried to follow intensions of the written guides and stress the idea of PTB-related stigma, they often ended up disclosing that respondents still were discussing HIV-related stigma. For the respondents there was no difference. There was no proof for the idea that TB/HIV co-infected persons were hit by double stigma, seemed to be more or less the same whether co infection or not.

Respondents' ideas of PTB-related stigma in pregnancy gave a discordant picture. On one hand it was stated that a pregnant woman has such a heavy burden already, that people usually would like to support her instead of enforcing extra pressure by stigmatising her. On the other hand the idea emerged that a pregnant woman with PTB disease, and then by people obligatorily considered to be HIV-positive, is considered irresponsible getting pregnant. Both because she is supposed to give birth to a child that could get AIDS, and because the mother herself is supposed to die in a close future. These condemning ideas could be a heavy reason making the pregnant woman try to hide symptoms that could indicate PTB and/or AIDS and staying away from health care seeking.

“...some people feel stigma so they might fear to go to the health facility because their neighbours will say they have TB and TB is associated with HIV.....people afraid of contracting the disease, segregate her, people avoid sharing things, shaking hands – she remains isolated.... One can be seated in a corner and wag a finger at the TB case and say “look, she used to consider herself important but now she is HIV-positive”

4.8 Barriers

All respondents in IDIs and FGDs were asked about barriers that could impede women's health care seeking when symptoms like longstanding cough, fever and fatigue. Three levels of barriers emerged; at health system level, at community level and at family/individual level. Cross-cutting the other levels, the prominent feature of gender based barriers constitute a potent separate category – affecting most women to a certain extent. In analysing gender based barriers more of latent content was extracted from the data compared to the other sections.

The word “barrier” in this section always refers to health care seeking related to symptoms that could indicate PTB; long-standing cough, fever and fatigue.

4.8.1 Perceived health system barriers

Health system barriers are perceived concerning government health facilities according to respondents. A prominent barrier is lack of knowledge of the health system structure. That includes understanding of scheduled working hours, what diagnostic procedures can be done in the closest health facility and what procedures include a patient fee. For many women cough and possible TB disease means going to Buluba hospital in the neighbouring Mayuge district, at a considerable cost of transport. Buluba was the most appropriate facility for TB treatment 15 years ago, but after decentralization of the national TB program resources for PTB diagnosis and treatment exist in the nearby health facilities. The structure of Ante Natal Care services, where and when it is accessible and what procedures are available, seemed to be more well-known by respondents

Perceived lack of access to health care facilities because of distance to the health facility, cost of transport and other expenses in the health care seeking process was stated as a critical factor. As poverty is widespread this was explained as a common reason to stay away from health care seeking. Perceived costs at health facilities, even concerning TB diagnosis and treatment, were also mentioned as a reason to stay away. When other respondents declared that TB diagnosis and treatment is for free (consistent with real facts) some women still seemed to doubt the information. The cost as a barrier to access private health care was for many of the respondents so obvious that it was not even mentioned initially. Another barrier, resulting in opting for private health care instead, was said to be frequent episodes of stock out of medicines (supposed to be delivered for free) in government health facilities. Consulting private health facilities was by respondents supposed to give higher quality of care, but at a substantial cost. Trying to procure that money could sometimes mean a long delay in health care seeking or at the end no health care seeking at all.

Lack of trust and confidence in the government health care system was expressed as a key barrier to health care seeking. This included the perceived existence of different kinds of corruption among health facility staff. For instance the demand of bribes was told to be common, either in terms of direct money or indirectly like “*to buy soap*”. Another example of perceived corruption, in the shape of invented extra costs for private pockets, was respondents' ideas that stock-out of medicine was not always real.

There existed ideas that stock-outs could be pretended by some health worker wanting to prescribe medicines, supposed to be bought in this health worker's privately owned drug shop or pharmacy. Other respondents opposed the idea that bribes were extorted and that corruption could exist in prescribing medicines. In the following discussions it was stated by several respondents that if one failed to pay bribes he or she could not expect to "*be properly worked upon*". A perceived risk of lack of medical quality of care in government health facilities was disclosed. A risk that, according to most respondents, could be decreased if a bribe was paid for extra attention.

The perceived lack of privacy in most health facilities was also mentioned as a significant barrier, especially if a TB/HIV discussion could be expected. Some respondents declared that they would never go to the nearby health facility to discuss such a topic as TB/HIV, as anyone in the health facility could hear a discussion. That could result in instant spread of rumours in the neighbourhood. Also a perceived lack of respect and risk of stigmatising behaviour from the health worker could act as a barrier to health care seeking. Some respondents frankly declared that they would rather stay at home with this kind of symptoms, because they would not expect fair treatment at the health facility.

In contrast to the above mentioned distrust to government health facilities there was a general trust expressed towards the ANC services – even when these services are delivered in the same government building. There is trust despite the fact that midwives were said to be generally overloaded by work, having far too little time for each patient. Many women had the idea that even in ANC there would be the need of a small bribe to "*be better worked upon*", but this was not expressed as a real barrier.

Another key barrier that emerged from the discussions was the lack of information about PTB as a separate curable disease, from the health facilities reaching the grass root level. Outreach activities from the health facilities were almost never experienced by the respondents. Most of them could remember information about HIV, but TB information was said to be generally lacking.

One action referred to, by some respondents as a barrier to adequate health care seeking, but by others perceived as the best way of getting cured, is opting for a traditional healer when symptoms of cough, fever and fatigue. Consulting the traditional healer does not always exclude health care seeking at ordinary health facilities; it is simply considered a complement. Some traditional healers, as mentioned before, actually are referring patients, suspected to have PTB, to an adequate health facility for diagnosis. But as consulting a traditional healer can be at a considerable cost, there was a discussion among respondents if that cost could hinder the patient from further health care seeking.

"In the health facilities there is a lot of politics. Medical personnel always tell the patients that there are no free drugs; your Father (=the President) has not yet brought the drugs for you. So this can also be a barrier to seek help. So you end up dying like a rat!"

4.8.2. Perceived community level barriers

A prominent barrier to health care seeking, for the above mentioned symptoms, emerged from the interviews to be the strong social control in the community. That results in the risk of rumours and bad talk being spread about you, if it is known that you tested for PTB or HIV. Most people in the community do not have adequate knowledge about the two diseases and a lot of misinformation is spread. If someone is diagnosed with TB, that person is also obligatorily supposed to be HIV-positive. A heavy burden of social stigma is put on that person, resulting in isolation and other social consequences.

Another barrier at community level is the lack of community advice about appropriate health care seeking and lack of support when needed to get to the appropriate health facility. The system of community volunteer health workers could fulfil a good mission, but according to respondents it does not work in the TB context, perhaps as a result of lack of community support. Also the lack of community response to counteract misinformation, misconceptions and stigma is obvious according to the respondents.

A barrier that respondents were returning to in the discussions was the male supremacy in society – with men generally in the role as money controllers and decision makers. The lack of a gender focused society programming that could empower women and counteract women's continued dependency of men was brought up in the discussion in various ways. Time after time respondents came back to the issue of demand for community support of income generation for women. Not having an income of your own, to decide about yourself, was stated as one of the main obstacles in the process of health care seeking for women.

“Community stigma – how the community will look at it - and rumours – you become the topic in the whole community if you are seen going for testing.”

4.8.3. Perceived family/ individual level barriers

Also at individual level money, together with women's lack of power over the scarce family resources, were referred to as predominant barriers to health care seeking. Poverty is frequent and the wife usually is dependent on the prioritising and decision-making of the husband. According to respondents the problem of unsupportive husbands is common and even more so in polygamous relationships.

Another heavy barrier is stigma, striking hard at individual level, keeping many women away from health care seeking and testing. This stigma includes rumours and bad talk, if symptoms give suspicion of PTB or AIDS, resulting in isolation and social deprivation. Other stigmatizing behaviours bring about social consequences at individual and family level, including the risk of being divorced by the husband and excluded from the family. This also results in being left without any economical support. Also personal fear and anxiety about possible PTB/HIV diagnosis and the

practical consequences, including the risk of orphaned children, were told by respondents to keep women away from health care seeking.

An important barrier, that easily could be possible to reduce, according to respondents, is lack of knowledge regarding health system function, PTB as a separate curable disease, ways of spread of PTB and about TV/HIV relationship. As there is no obvious authority where to get information, besides from the health facility that the woman often does not trust, she can be left sitting there without knowing what to do, according to respondents, when experiencing symptoms that could mean PTB.

The phenomenon referred to as “laziness” is repeatedly mentioned by respondents as a possible barrier at individual level to health care seeking. That means women not caring about any health care seeking, but just staying at home when sick. Whether this is due to any other special reason besides lack of knowledge, lack of support, lack of money or fear of possible diagnosis was not possible to extract from the discussions.

“For me I would not bother to tell my husband about the symptoms and I would not go to the health facility. Even if the cough comes when he is at home I would cough quietly in order not to divorce me..... Already the suspicion of TB/AIDS would isolate you at home”

4.8.4 Gender related barriers

Respondents clearly declared that living in a society with accepted male supremacy, including family decision making and finance control, often does not leave much possibility for women’s decisions, neither in health issues nor in decisions about the family’s scarce resources. This was evident in the respondent’s comments on barriers, all through the interviews. It was a topic in the discussion about costs as a barrier in health care seeking and in the discussion about importance of husband’s support. It was stated that a woman could have all intentions to consult the health facility, in spite of the threat of social stigma, prepared to test for PTB and for HIV. But without financial and practical support from the husband she could be left without choice, just to stay at home in spite of her symptoms. But some respondents clearly declared that in their families there is a discussion and a joint decision between the spouses about important issues.

“You say if a pregnant woman has cough but no money, she will use “Ebiwadho bya kalitunsi” (=Eucalyptus tree bark). Do men also use this? No, they go to health facilities!” “

Respondents in different ways explained that many ways of stigmatizing behaviours towards people diagnosed with PTB, and then obligatorily expected to have AIDS, strike harder against women, even if men also get stigmatised. This was explained by the different roles men and women have in society. For instance the idea that a PTB-patient is supposed to be isolated, whether on treatment or not, strikes harder against women who have an important central role in the domestic life. It was reported as the ultimate stigmatizing action against a woman to put her aside “with her own cup and

spoon”, without accepting her as the normal midpoint in the house for cooking and feeding the children. Many respondents mentioned this risk of isolation as a conspicuous example of a barrier to health care seeking.

The perception of stigma was also said to be affected by the nature of family building. As the wife after marriage is expected to move to the husband’s house and to be a part of his extended family, she will at start be one with low status in that new family. It can take time before the young woman will get self-confidence in this new family situation, of course depending on individual qualities. A woman in this situation is more sensitive to any stigmatising action and this could act as a barrier to health care seeking.

The difference in gender based power between men and women is a barrier to health care seeking, as it makes women more vulnerable to practical consequences of stigmatizing behaviours. For instance the risk of being divorced or separated, and by this action being left without any financial support, if diagnosed with PTB/HIV, was mentioned as a reason to stay away from health care seeking. A man could also in rare situations be left by his partner in a corresponding situation, but as reported by respondents he would not be as practically vulnerable. He is not left completely without economical resources as he keeps the house and other financial resources.

There is also a gender aspect in the barrier constituted by lack of knowledge about health issues. Men in Uganda still generally have more formal education than women and more women are illiterate. Even more important; men have a better possibility to keep updated as they move around in the community, more than women have the possibility to do. Radio is an important source of information and knowledge in this area. Even if there is a radio in the family many women have less access to that, as it is considered to be the property of the husband. It is up to his choice what to listen to, and according to respondents, not many men want to listen to health education programs.

“For a woman with TB it is different because she is the one who gets involved in cooking food, the man he can sit at a distance. A man can easily have a separate cup, but a woman sometimes needs to drink from a cup with a child. People avoid eating her food because they fear. So you leave her alone preparing her own food because death scares! They say they think the same about them - wife and husband - I think it differs since people may say that he overworked, not spared himself – so many people may attribute the tuberculosis to his work, excusing him off”

4.8.5 Difference in Women’s ideas about Barriers when Pregnant

There was a contradictory picture given by respondents how pregnancy affects the barriers to health care seeking. On one hand there is the uniform idea that pregnant women get much better support of all kinds from the husbands, including health care seeking. There are even husbands ready to accompany the wife to the ANC visits. On the other hand the idea expressed by the respondents, that these symptoms, that otherwise could indicate PTB, are normal in pregnancy, will work as a barrier.

Resulting in the idea of no extra action is needed, the symptoms are supposed to disappear by itself after delivery.

Also the respondents' perceptions of how the barrier of stigma is affected by pregnancy give a contradictory picture. On one hand it is said that because a pregnant woman needs all support she is not in the same way the target of stigmatising behaviours. On the other hand respondents reported that a pregnant woman getting a PTB diagnosis, and by this anticipated having AIDS, is considered being irresponsible getting pregnant, as she will give the child HIV and because she is supposed to die in a close future. And the awareness of these ideas of course could act as a barrier.

What was reported by respondents as a reduced barrier in pregnancy, compared with not being pregnant, is that a pregnant woman can always consult the ANC clinic, also regarding this kind of symptoms. Some respondents expressed absolute confidence that the midwife would act adequately also regarding the question of cough. Other women showed more doubt that this kind of problems would be listened to, because of the high workload on the midwife. Also some respondents reported events, supposed to be from reality, when coughing pregnant women had been chased away from ANC clinics, without any diagnostic action or treatment, not to spread the cough.

“When you become pregnant, even a husband who has been refusing to give you money for medical attention will give it to you before you ask, because you will be producing a child for him. So there is a difference in his care for you.”

4.9 Women's Ideas about how to Overcome Barriers

Respondents were asked to give proposals for possible solutions to overcome barriers to health care seeking regarding long-standing cough, fever and fatigue. They could offer a lot of suggestions of measures to take to overcome barriers. Some of the suggestions did not seem very realistic while others seemed very appropriate. Overall women's ideas generally suggested institutional level solutions. Among the abundant suggestions three areas emerged:

- Economic empowerment of women – to decrease dependency on men.
- Health education and sensitization including TB/HIV, to get knowledge about PTB as a separate, curable disease and to reduce stigmatization behaviour.
- Improvement of access to health facilities and improvement of quality of care.

Empowerment of women

As respondents perceived that men's general supremacy is a big barrier they demanded actions to support women's money generation activities. Such initiatives had been there for a short time but vanished for some reason. Respondents generally were very clear about that without promoting women to be decision makers and money controllers in their own situations, nothing could be changed. A firm conviction was expressed that if women possessed money to their own dispose this would improve health as well as health care seeking for women and children.

Health Education and Sensitization

Respondents pleaded for a linkage between health facilities involved in PTB diagnosis/treatment and the community, which could improve transformation of adequate knowledge about PTB. This could address the pervasive misconceptions impeding PTB diagnosis and decrease different manifestations of stigma. Women emphasized that information and education should be offered at grass root level. One important point was to offer special information directed to men, by men, at places where men normally gather. This could be a way to make ordinary men really receive and accept the information. Respondents believed that stigmatizing behaviours would decrease with such a sensitisation process. Respondents had many suggestions how to use and how to improve radio messages; there are many FM-stations where to hire air-time. One way could be to have a special program for women late every evening when their daily work was finished; suggested was 10pm. Not all women have access to a radio but at least a good part could be reached by such information. There was also the idea of different amusing performances, like on-the-road theatres and music groups. All activities that will start the discussion about stigma and unfair treatment was said to be a good starting point, of course including schools and different interest groups like religious societies.

Improvement of access to health facilities and improvement of quality of care.

A necessary step to improve quality of health care was according to respondents to improve equipment and address the serious under-staffing in health facilities. They also mentioned better education for the health facility staff and suggested an open discussion about fees in health facilities, what procedures should be cost-sharing and what should be for free. Another critical point was to address the problem of inadequate interpersonal relationships and poor attitudes among some health service providers towards patients.

Some other special suggestions by respondents

- Don't allow men to divorce because the wife is HIV-positive!
- Husbands that refuse their wives to go to health facilities should be arrested!
- We could say we should work harder – but no use – prices for our products go down. Government should act for price stability – then we could afford health care seeking when sick.
- Those who stigmatize others should be arrested or taken to the police.
- Special male information and sensitizing discussing groups. This could support women and make men abandon divorce habit if the wife gets TB/HIV.
- A special card to prove that you have done a cheque-up. To show to L.C (Local Council). To be done in every household – to prevent spread of disease.
- People should stop relating TB to HIV; TB has been there even before HIV.

5.0 DISCUSSION

The conception of “being healthy” turned out to be mostly functional among the respondents. If you can go on performing your daily hard work you are considered healthy. From the definitions of being healthy emerged the idea that as long as you behave like and have the appearance of someone who is free of HIV/AIDS you are considered healthy. This is consistent with the fact that less than half of rural women

knew that a healthy looking person can be HIV-positive according to the 2006 Uganda Demographic and Health Survey (23).

Poverty was, as expected, explained as a heavy barrier in health care-seeking. This is consistent with earlier research in various parts of the world (9; 10; 11). Sometimes though, women consult traditional healers, and that could be at a considerable cost; payment could be a goat. This gives a contradictive picture as the goat paid to that traditional healer is of great value and furthermore is supposed to be the property of the husband. If the treatment fails perhaps the resources are finished, with the result that further health care seeking is not possible.

The most striking finding was the perception of reasons for symptoms that could indicate PTB; longstanding cough, fever and fatigue. Almost unanimously HIV/AIDS was the first suggestion. Even those who mentioned TB as a possibility simultaneously added that in that case TB is an indicator of HIV/AIDS. The consequence of this lack of identification of PTB as a separate, curable disease is that it is no use to go for a diagnosis, as you don't believe there is any possible treatment. Providers confirmed this picture of lack of knowledge about PTB as a separate disease and that many misconceptions about TB exist. Our interviews disclosed also a considerable lack of knowledge about TB among some providers, serving outside the hospital. There has not been much written about this confusion TB/HIV and possible consequences for health care-seeking. A field to explore further.

Another striking finding was the tendency in pregnancy to explain the mentioned symptoms, which could indicate PTB, as something normal induced by pregnancy. And as such it was considered no use for special action or health care-seeking but just to wait for delivery and spontaneous recovery. This of course brings a risk of postponing diagnosis of PTB in pregnancy, with possible negative implications for outcome of pregnancy, and with the risk of spreading the disease in the close neighbourhood. There is no research related to this finding for comparison, but providers confirmed this idea among women. If this represents a more general idea it has to be addressed in the ANC clinics and in the health information given.

In the process of health care-seeking for these symptoms, the respondents disclosed one step passed by almost everyone, referred to as "first aid". That implies abundant use of traditional herbs, available to anyone, and "western medicines", self-stored at home or bought in an ordinary small shop nearby, by vendors without any medical knowledge. This way of using medicines is also common in pregnancy with the risk of using drugs potentially harmful to the child. According to the informants it seems to be an extensive misuse of antibiotics of many kinds, in suboptimal doses, resulting in an obvious risk of creating resistance to all accessible antibiotics. This misuse should be addressed by government health authorities.

Consulting traditional healers is for many women still a natural step to take. There were some debates among respondents in FGDs whether this is consistent with modern times or not. Even if some, mostly well-educated, women claimed that only health facilities are to be visited when you are sick, as that is the only way of getting a proper diagnosis, it seemed as if most women actually at times visit a traditional provider. That was

confirmed by healthcare facility providers and by traditional healers. Even in pregnancy it was considered a normal action to take. It became very clear in the discussion that the respondents are living in a society with an ongoing process of transition concerning health care-seeking. In some villages consulting the traditional healer is considered to be the normal procedure and offering the best possible help when you are sick. On the other hand there is also information about “western medicine” with technical resources and controlled medicines. There were respondents who declared that they “*just to be sure*” consult both sides if they feel sick. Just to be sure to be covered concerning diagnosis and treatment of the disease, but also safe in case ancestral spirits had caused the problems. A study, mostly exploring psychological distress, carried out in the same region 2008 on traditional healers, could verify that most clients, irrespective of reason for visit, consulted both traditional medicine and biomedical “western medicine”(31). Other relevant studies on traditional medicine reflecting this transition in Ugandan society could not be found.

Another of the heavy barriers perceived in this health care-seeking process is stigma. It was found impossible to discuss about PTB stigma distinguished from HIV/AIDS stigma as PTB for respondents obligatorily meant HIV/AIDS. To some extent that means ordinary people are more forward in the process of considering TB/HIV-care as a unity than the health system providers. But still there is the need to identify PTB as a separate disease, as this is the base for appropriate treatment. This study could not verify the idea of double stigma targeting patients co-infected with TB/HIV.

Stigma is a complicated subject and this study had no aim to go deeply into the process of identifying different kinds of stigma. A possible backside of a society with firm, often supportive, social bonding can be a hard social control, with the risk of bad talk and rumours if someone is crossing the accepted social borders; like contracting PTB or HIV/AIDS. This stigmatisation can result in bad social consequences like the risk of getting divorced and being left without any economical support. And this risk was verified by providers, but the hospital providers believed that this kind of problems has improved a bit, as a consequence of information and education for patients and relatives. Most of consequences of perceived stigma strike harder against women, because of different social roles in society for men and women. There are many questions about TB-related stigma possible to explore by further research. An advantage in this region would be if the researchers themselves were women speaking the local language. A review article 2010 on TB and stigmatization worldwide could conclude that studies up till now are inconclusive on gender aspects; even if there is a consensus that stigma affects PTB health care-seeking. More studies are recommended using validated gender specific tools, and investigating different subpopulations. Then results more effectively could be used for interventions. (16)

A deep mistrust related to government healthcare facilities was stated among respondents. This was based on perceived existence of corruption and quality of care. This study has no chance to validate these perceptions – this was never the aim of the study. Some of the mistrust could be based on rumours, lack of knowledge about the health structure and lack of self confidence. But according to discussion with different providers it can partly be consistent with reality. Overworked health staff with too little time and too little resources cannot always give enough time, care and attention to every patient. But referring to accusation about under table payment providers claimed that it

is forbidden in the hospital and not at all accepted. This exposed mistrust related to healthcare facilities is to some extent consistent with findings in a study performed in four districts in Uganda (Iganga not included) 2006 according barriers to the implementation of collaborative TB/HIV activities (30).

In contrast to the described mistrust above, a deep general trust was declared regarding ANC clinics, even when this ANC clinic is close to a health facility that is not generally trusted. Midwives were generally referred to as serious and hardworking. Even if some women claimed that some kind of under table payment was supposed to be donated even here. This statement of trust is consistent with the national Ugandan statistics stating that about 93% of Ugandan women consult an ANC clinic at least once when they are pregnant (23). This means for many young women that the ANC clinic is the only healthcare facility they ever visit. This could be a good opportunity to use in PTB case finding, to catch otherwise missed cases among women of reproductive age.

This study includes many limitations. Cultural and semantic limitations; a research team coming from the Big City, even including a Muzungu (“white”) doctor, and not all of the team understanding the local language. With these pitfalls - can informants present their feelings freely? So many issues to discuss and so many informants involved gives a wide range of input, but can make difficulties to explore the questions deeply. But the research assistants, skilled in qualitative methods, knowing the area well, explained to us researchers that women in this area, and in this social context, are not used to analysing their situation more deeply than what was done in these interviews and the focus groups. Women usually struggling hard for the everyday food for their children cannot allow themselves much of introspective activities. The team tried to be aware of these barriers and tried to make the informants as comfortable as possible in the FGDs and the IDIs. By this getting as valid information as possible.

The results cannot be claimed valid for all Uganda, or all Iganga region, or all women or all of any group. There are so many different subcultures in society where people experience facets of life differently. But the informants together brought a good idea about the complex pathway to diagnosis of PTB. And a fairly good idea of barriers to possible diagnosis. Barriers that hopefully can be cleared away by joint efforts.

6.0 CONCLUSIONS

To counteract the massive impact of increased spread of PTB in the community, and to improve notification rates of PTB specifically among women, there is the need to address PTB as the economical, social, psychological and medical disease it is. There is a need for using all existing economical, social and medical tools, to be able to address poverty, lack of knowledge and the heavy burden of stigma, partly gender related. All barriers in the health care-seeking process, especially for women, but also for men.

Among possible actions that in the long-term perspective could facilitate women’s pathway to diagnosis of PTB are:

- Community activities supporting women income generation could act as an effective tool to fight poverty and by this PTB in the community.
- Information campaigns directed to, and performed at, the grass root level in the community, addressing both PTB as a separate, curable disease and the TB/HIV relationship. This delicate assignment, if using a well-defined health promotion strategy, could fulfil a mission to increase knowledge about PTB and diminish PTB/HIV-related social stigma; by this facilitating women's pathway to diagnosis of PTB.
- Information about PTB, specially designed for and directed to men, delivered in places where men come together, could be one way of addressing gender based PTB-related stigma and other gender based barriers affecting women in the health care-seeking process. This could be one of several approaches for a gender focused society programming, at community level, to address and counteract discrimination of women in the community.
- ANC clinics could be a continuous source of knowledge about PTB as a separate, curable disease and about TB/HIV relationship, delivered in a more regular way than now, as a part of the pregnancy related health education given at the ANC visit. Hopefully successively more men will join their partners for the ANC visits. Shared information and knowledge between spouses could have a positive impact on stigma. As the ANC clinic is the only health facility many young women consult and trust, ANC could also be a possible institution for active screening of PTB, to find otherwise lost cases. But before such a programming could be implemented there is the need of adequate studies followed by adequate planning and management.
- A continuous work for more user friendly services at government health facilities could decrease some barriers in the health care-seeking process. This should include information about the structure of services delivered, outreach public health activities like basic information about PTB, information that PTB diagnosis and treatment is for free and about TB/HIV relationship. To be able to do this health workers need more support and continuous education and supervision.
- TB/HIV related continuous education for stakeholders including all levels of health providers, irrespective of employer, should be delivered at community level on a regular basis, to keep knowledge updated, as a private/public joint venture. This could also, to some extent, include all traditional providers in the local community. Providers of the basic information could be the Government together with NGOs.
- From Government level strengthen the vigilance of handling and sale of antibiotics, following the regulation which is already there in the national planning. This could perhaps make it less easy for women to use their scarce money for suboptimal doses of antibiotics, but instead use it for proper health care seeking. It could also decrease the risk of getting all antibiotics compromised by developed bacterial resistance.

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