Knowledge, attitudes and health seeking behavior towards tuberculosis in rural Uganda

Authors:
Esther Buregyeya 1, Asli Kulane 2, Robert Colebunders 3 4, Anne Wajja 5, Juliet Kiguli 1, Harriet Mayanja 5, Philippa Musoke 5, George Pariyo 1, Ellen M.H. Mitchell 6

Author Affiliations:
1 Makerere University School of Public Health, Kampala, Uganda,  
2 International Health, Dept of Public Health Sciences (IHCAR) Karolinska Institutet, Sweden,  
3 Institute of Tropical Medicine, Antwerp, Belgium  
4 University of Antwerp, Antwerp, Belgium  
5 Makerere University School of Medicine, Kampala, Uganda  
6 KNCV Tuberculosis Foundation, The Hague, Netherlands

Short Title: Knowledge Attitudes and Care seeking for TB in Uganda

Corresponding Author: Esther Buregyeya,
Makerere University School of Public Health,
P.O. Box 7072, Kampala, Uganda
Telephone 256-752-420555 Fax: 256-414533531
Email: eburegyeya@musph.ac.ug or buregyeyaesther@hotmail.com

Word count (Text): 2,410
Word count (abstract): 201
OBJECTIVES: To assess knowledge, attitudes and health-seeking behavior about tuberculosis to inform the design of communication and social mobilization interventions.

SETTING: The study was conducted in the Iganga/ Mayuge Demographic Surveillance Site.

DESIGN: Eighteen focus group discussions and 12 key informant interviews were conducted between June and July 2008, including parents of infants and adolescents and key informant interviews with community leaders, traditional healers and patients with tuberculosis.

RESULTS: People viewed TB as contagious, but not necessarily an air borne pathogen. Popular TB etiologies included sharing utensils, heavy labor, smoking, bewitchment, and hereditary transmission. TB patients were perceived to seek care late or to avoid care. Combining care from traditional healers and the biomedical system was common. Poverty, drug stock-outs, fear of HIV-testing, and length of TB treatment, negatively affect health-seeking behavior. Stigma and avoidance of persons with TB often reflects an assumption of HIV co-infection.

CONCLUSION: The community’s concerns about pill-burden, quality of care, financial-barriers, TB-etiology, stigma, and preference for pluralistic care need to be addressed to improve early detection. Health education messages should emphasize the curability of TB, feasibility of treatment, and engagement of traditional healers as partners in identifying cases and facilitating adherence to treatment.

Keywords: Tuberculosis, qualitative, health seeking behavior, stigma, Uganda
INTRODUCTION

Tuberculosis (TB) is a leading cause of death in the developing world especially in sub-Saharan Africa, despite the introduction of Directly Observed Treatment Short-course (DOTS)(1-2). The DOTS Strategy, recommended by the World Health Organization (WHO) for the prevention and control of TB relies on passive case finding by sputum smear microscopy(3). Therefore, suspects are expected to be able to recognize TB symptoms and have positive attitudes towards TB management by formal health services. Various studies have found delays in TB case detection associated with poor perception of the health services, (4-5) fear of stigmatization(6) lack of knowledge about TB and traditional beliefs(7).

Studies performed in high burden countries reported many misconceptions about causes of TB such as: inter-generational TB transmitted through blood relationships(8); TB caused by over exertion (9), cold weather (10), and breaking cultural rules demanding sexual abstinence after the death of a family member(11).

As far as we know no qualitative study about knowledge and perceptions about TB has been performed in Uganda. Our study explored the communities’ knowledge and perceptions about TB and their health seeking behavior in preparation for a community-based TB sensitization in two districts.
METHODS

The study was carried out in June and July 2008 in the Iganga/ Mayuge Demographic Surveillance Site (DSS) which is located 120km east of Kampala. The DSS has a population of approximately 67,000 people. About 90% of it is rural and is predominantly an agricultural area. The main ethnic group is Basoga. This region has been well researched (12-19). Focus group discussion (FGDs) and key informant interviews (KIs) were conducted among both male and female parents/caretakers of infant and adolescents, school heads, opinion leaders and TB patients.

Eighteen FGDs were conducted; including six FGDs of young mothers/fathers/caretakers (below 36 years of age) of infants, six FGDs of mothers/fathers/caretakers of adolescents, six FGDs of mature mothers/fathers/caretakers aged (36 years and above). Key informants included; two local council leaders (LCs) and two traditional healers, known as ‘Mukalakasa’. In this context, Mukalakasa are either men or women and provide herbal and/or spiritual healing. Interviewees also included two TB patients, two religious leaders (a Muslim and a Christian), two elders and two sub-county TB supervisors (health assistants).

FGDs and KIs were conducted at the village level. A purposive sampling method (with the help of LCs) was employed to obtain the respondents for FGDs and KIs. In addition, because homogeneity of focus groups participants can facilitate sharing, FGDS were convened by grouping on such factors as age and gender.

The FGDs and KIs data collection instruments were pre-tested. Interviews with health workers were conducted in English. The other interviews were conducted in the local language, Lusoga. Tape recordings and notes were used to record the interviews. All interviews were transcribed by moderators; those in Lusoga were translated into English.

Analysis of the KIs and FGDs used thematic and content analysis. Transcripts were first read several times to get an overall picture and then meaning units(20) were coded,
condensed and categorized into broad themes (20). Respondents’ quotations were identified and applied to emphasize particular subjects discussed.

An experienced anthropologist supervised the research assistants during pilot-testing and fieldwork. Verbal informed consent was obtained from all participants. The study was approved by the Makerere University School of Public Health Institutional Review Board and the Uganda National Council for Science and Technology.
RESULTS

Names of TB used in the community
Most participants were aware TB is a serious disease and cited different local names commonly used. The majority of the respondents mentioned *Akafuba* (pulmonary TB) followed by ‘TB’ as the commonly used names in the community. Other names used included *lukonvuma* (emaciation), *Oluwero* (difficulty in breathing with wheezing), and *Akalakiilo* (persistent dry cough). These names emerged from all the categories of the respondents, except the health workers who use Lusoga terminology distinctly.

“TB is not dry cough Kalakiilo, it is productive cough…It is whooping cough that is Kalakiilo”

KI health assistant

Beliefs about causality
Only a few key informants specifically mentioned a TB germ, including one traditional healer. However, the majority of the participants said that TB is airborne/ staying in the same environment with a TB patient. Sharing food and eating utensils with a TB patient (such as drinking straws of the local brew known as “malwa.”) was a common response and cut across all respondent categories. The majority of participants reported that TB is caused by smoking and said that the effect is cumulative. Doing heavy manual work, like making bricks and carrying heavy weights increased susceptibility. One traditional healer said that there is TB that one can get after being bewitched and it is only successfully treated by traditional healers. Also some FGD participants reported that TB can run in families.

“For me, I think if in your lineage there was a TB patient, then you can get it through inheritance”

FGD for younger mothers

Signs and symptoms of TB
The majority of participants associated TB with prolonged cough and at times chest pain. Some respondents mentioned that there is loss of weight, fever, a difficulty in breathing and coughing up blood. Infrequently TB was conflated with asthma or a dry cough associated with wheezing (*Oluweero*) that is usually triggered by a cold weather.
One can tell you that I feel pain in the chest, I make a wheezing sound when it is cold, I feel pain in the lungs. That is how a TB patient presents” KI Traditional healer.

“The breathing is not the usual one, one can breathe like a pussy cat” FGD Young Women

**Who gets TB**

There was near consensus that everybody can be affected by TB, however some groups were perceived to be at a greater risk than others. Higher risk groups included; smokers and those 40 years and above. Men tended to see TB as a disease of older people, especially men, due to having smoked, done heavy work, and weakened bodies. By contrast, some younger women and men reported that women were more at-risk because of their role as the caretakers of TB patients, working a lot in the fields, and child bearing. HIV infected persons were also perceived to be at greater risk of getting TB. Some reported that when one has TB it is automatic that they also have HIV.

**Care seeking for TB**

Respondents suggested that TB patients tend to seek care late, when they are bedridden, coughing blood, or too weak to do their normal duties and need encouragement to seek care.

“Some TB patients are just forced to seek treatment…. like my father had TB but we just had to force him to go for treatment” FGD participants young women

Reasons for delays in seeking TB care included the use of self-medication first, lack of money, and the fear of being labeled sick, particularly being assumed to be co-infected with HIV.

“If you have money and you feel sick, you seek treatment early but if you don’t have money, then you take a long time.” FGD mothers of adolescents

“Some people use herbs like ’Namuvu’ for treatment because some fear injections, then others cannot afford money for transport to health centres”.

FGD young fathers of infants
A fair number of respondents preferred the diagnostic tests done in the biomedical sector. However after diagnosis, some sought complimentary care by traditional healers. TB care was sought from traditional healers, private and public health facilities but some also use self-medication. Combining care from traditional healers and the biomedical system was common.

“For me, I know we have traditional healers. We call them ‘Mukalakasa’. You go there ..........they give you a bottle of medicine .......... then you get better” FGD mothers of adolescents

“The reason why people go to a health centre is for blood checkup so that they know what they are suffering from, then get treatment. Even when they go back home, since they know what you are suffering from, then they can tell ‘Mukalakasa’ to give them his ‘bottle’ (medicine).” FGD women caretakers of adolescents.

“If one goes to hospital and is diagnosed with TB and given tablets....if one is not improving, then they come to us. You can give the TB patient two bottles of our treatment which lasts two weeks and they get fine” KI Traditional Healer

Factors influencing treatment choice
Reasons for seeking care from traditional healers included beliefs regarding the etiology of TB, particularly the possibility TB caused by being bewitched. Other motives for engaging the help of traditional healers included the potential for expedited treatment or immediate improvement, the potential for more friendly care, family tradition, lack of money for transport, lack of drugs in health facilities, inconvenient hours of operation, requests for “small money”, and proximity.

“Some go to traditional healers because they think they will get healed instantly” FGD, young fathers of infants

“Traditional healers handle patients in a friendly manner unlike government facilities.”
FD elder men

“Cultural belief...they think they are bewitched. They want to hear the view of the spirits ‘Jajjas’”

KI health assistant

Though generally believed that traditional healers were affordable, some young men perceived their treatment to be more costly and potentially misleading about the cause of TB.

“People rarely go to traditional healers because they are expensive yet in the health facilities the treatment is free.”

FGD young fathers of infants

Respondents felt poverty affected treatment completion regardless of where treatment was sought.

“The problem with follow-up while on treatment is lack of money to complete the treatment i.e. transport and motivating health workers.”

FGD young women

“The problem we get is that when someone comes and you charge him 5,000 shillings, he can only pay 2,000 shs and will not come back to bring the balance and he might not have recovered well and can infect other people”

KI traditional healer

“Most of them (patients) do not complete treatment because of money, but for me I help them…….I can give the patient the treatment then they pay the money later when they are fine”.

KI Traditional Healer

Fear of the duration, pill burden, and being tested for HIV discouraged community members from seeking biomedical solutions.

“Some people go to traditional healers because they prefer their medicine. In the health facility they can give a TB patient a total dose of 2,000 tablets or 1,000 injections…… so some people would prefer to go to traditional healers.”

FGD young men
The Potential for Cure
Most participants across all categories mentioned that TB drugs can cure, especially if one follows the health workers' instructions and gets treatment early. A few participants reported that TB can be cured only if one does not have HIV/AIDS. The majority of the participants knew the correct length of TB treatment (six to eight months), others mentioned two months and one mentioned ‘only 60 injections’. One traditional healer offered a TB treatment lasting only three weeks.

Stigma towards TB patients
TB patients were reported to be feared and discriminated against. This was ostensibly because of fear of air-borne contagion. However, some acknowledged that some stigma stemmed from the presumption of co-infection with HIV. Some individuals reported that sometimes TB patients are chased away from the communities. However, a few participants reported that TB patients are cared for and supported by close family members.

"We segregate them because we know TB does not cure,...... so we run away from them”
FGD participant for young mothers.

“Generally, it’s only one-tenth who do not segregate TB patients. The rest segregate them for fear of getting TB. If it’s a child, you can’t allow him/her to play with your children.”
FGD young women

Health workers were thought to discriminate also, with the exception of one TB patient who reported being treated well.

“In most cases when the health workers find out that you have TB, they treat you with fear of contracting the disease since it’s airborne.”
FGD young women
DISCUSSIONS
Findings from this exploratory study reveal the community’s knowledge and attitudes towards TB etiology and treatment. Though most respondents were aware of TB and knew its symptoms, the belief that TB is hereditary or is caused by witchcraft is similar to what has been found in other studies (10, 11). It is unclear whether alternative etiologies delay health-seeking behavior or increase the period of infectivity. As in other contexts, TB in Uganda is a social disease and presents problems such as stigma, that cannot be addressed by a conventional medical approach (21). Persistent beliefs about TB transmission through sharing of utensils and inheritance may foster conditions for stigmatization of TB patients and their families (22-23). We find that TB touches upon complex social forces including risks of witchcraft, heavy labor, vices, and poverty. Though treatment for TB is nominally free (24), this study finds hidden costs which inhibit health seeking behavior.

Pluralistic health seeking as described here has been found elsewhere (22, 25). The fact that TB suspects who initially seek care in health facilities, may later go to the traditional healers for treatment could be a function of the empathy afforded, pill-burden or potentially a desire by patients to identify a deeper, perhaps hidden, meaning or narrative for their illness (26). Whether combining biomedical and traditional care results in TB treatment default and/or drug resistance development is widely debated (25, 27-28) and may depend on the relationships between formal and informal providers.

Lack of money for transport and traditional healers being more patient-centered were found to be reasons not seeking care from health facilities. Similar findings were observed in Uganda and Kenya (12, 29) where traditional healers are reported to be more easily accessible and friendly. Studies have also observed that health workers mistreatment of TB patients is an on-going issue in many regions (30-32). It was revealed that some TB patients only seek health care after being forced by family members. This was also found in Gambia where often a close relative or a neighbor had to intervene (33).
Respondents readily grasped that HIV/AIDS is associated with TB. However, the mistaken perception that every TB patient is co-infected with HIV and that co-morbid patients cannot be cured, creates barriers to care. TB suspects were reported to fear going to health facilities because of HIV testing. This fear seems to be more driven by HIV-related stigma, as found in Kenya (22) and elsewhere (4, 34) and can hinder treatment seeking among TB patients.
LIMITATIONS

Focus groups and interviews offered a timely window into the range of understandings on TB, but an ethnographic approach may have provided a more nuanced understanding of the myriad of contextual political, economic, and social forces that may drive health seeking in the districts and how residents exert agency to overcome them.

CONCLUSIONS

This paper highlights the varied etiological concepts, range of health-seeking options to which they resort to and reasons for their choice. There is a perception that TB patients seek care late and via traditional healers. Barriers to care-seeking from health facilities include: lack of money for transport, belief in instant healing from traditional healers, fear of HIV testing, lack of interpersonal skills among health workers, and pill-burden. People mistakenly assume that TB associated with HIV/AIDS cannot be cured. These barriers can be reduced by bringing the health services closer to the community, doing community sensitization about TB, and improving the attitudes and behavior of health workers towards TB patients. This study suggests that funds or other incentives may be beneficial for TB patients in order to encourage treatment-seeking and adherence. The involvement of traditional healers in community-based DOTs could enhance detection and cure.

Acknowledgements

Authors' contributions

EB, AS, JK, EMHM, AW, PM, and HM took part in designing the study, in tools development, in data analysis and in manuscript writing. RC and GP took part in manuscript writing. All authors approved the final manuscript. The authors wish to recognize the contributions of Suzanne Verver (KNCV), Fred Nuwaha (MUSPH), Stefan Peterson and Netta Beer from Karolinska Institute, Sweden.
**References**


