

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

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

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28 **OBJECTIVES:** To assess knowledge, attitudes and health-seeking behavior about
29 tuberculosis to inform the design of communication and social mobilization
30 interventions.

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

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

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

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

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50 **Keywords:** Tuberculosis, qualitative, health seeking behavior, stigma, Uganda

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61 **INTRODUCTION**

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

71
72 Studies performed in high burden countries reported many misconceptions about causes
73 of TB such as: inter-generational TB transmitted through blood relationships(8); TB
74 caused by over exertion (9), cold weather (10),and breaking cultural rules demanding
75 sexual abstinence after the death of a family member(11).

76
77 As far as we know no qualitative study about knowledge and perceptions about TB has
78 been performed in Uganda. Our study explored the communities' knowledge and
79 perceptions about TB and their health seeking behavior in preparation for a community-
80 based TB sensitization in two districts.

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83 **METHODS**

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

92

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

101

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

106

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

111

112 Analysis of the KIs and FGDs used thematic and content analysis. Transcripts were first
113 read several times to get an overall picture and then meaning units(20) were coded,

114 condensed and categorized into broad themes (20). Respondents' quotations were
115 identified and applied to emphasize particular subjects discussed.

116
117 An experienced anthropologist supervised the research assistants during pilot-testing and
118 fieldwork. Verbal informed consent was obtained from all participants. The study was
119 approved by the Makerere University School of Public Health Institutional Review Board
120 and the Uganda National Council for Science and Technology.

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122

123 **RESULTS**

124

125 **Names of TB used in the community**

126 Most participants were aware TB is a serious disease and cited different local names

127 commonly used. The majority of the respondents mentioned *Akafuba* (pulmonary TB)

128 followed by 'TB' as the commonly used names in the community. Other names used

129 included *lukonyuma* (emaciation), *Oluwero* (difficulty in breathing with wheezing), and

130 *Akalakiilo* (persistent dry cough). These names emerged from all the categories of the

131 respondents, except the health workers who use Lusoga terminology distinctly.

132 "TB is not dry cough *Kalakiilo*, it is productive cough...It is whooping cough that is

133 *Kalakiilo*"

KI health assistant

134

135 **Beliefs about causality**

136 Only a few key informants specifically mentioned a TB germ, including one traditional

137 healer. However, the majority of the participants said that TB is airborne/ staying in the

138 same environment with a TB patient. Sharing food and eating utensils with a TB patient

139 (such as drinking straws of the local brew known as "*malwa*.") was a common response

140 and cut across all respondent categories. The majority of participants reported that TB is

141 caused by smoking and said that the effect is cumulative. Doing heavy manual work, like

142 making bricks and carrying heavy weights increased susceptibility. One traditional healer

143 said that there is TB that one can get after being bewitched and it is only successfully

144 treated by **traditional** healers. Also some FGD participants reported that TB can run in

145 families.

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

147 *inheritance* "

FGD for younger mothers

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149 **Signs and symptoms of TB**

150 The majority of participants associated TB with prolonged cough and at times chest pain.

151 Some respondents mentioned that there is loss of weight, fever, a difficulty in breathing

152 and coughing up blood. Infrequently TB was conflated with asthma or a dry cough

153 associated with wheezing (*Oluweero*) that is usually triggered by a cold weather.

154

155 *“One can tell you that I feel pain in the chest, I make a wheezing sound when it is cold, I*
156 *feel pain in the lungs. That is how a TB patient presents”* KI Traditional healer.

157
158 *“The breathing is not the usual one, one can breathe like a pussy cat”* FGD Young
159 Women

160
161 **Who gets TB**

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

170
171 **Care seeking for TB**

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

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

177
178 Reasons for delays in seeking TB care included the use of self-medication first, lack of
179 money, and the fear of being labeled sick, particularly being assumed to be co-infected
180 with HIV.

181
182 *“If you have money and you feel sick, you seek treatment early but if you don’t have*
183 *money, then you take a long time.”* FGD mothers of adolescents

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

186 FGD young fathers of infants

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

192
193 *“For me, I know we have traditional healers. We call them ‘Mukalakasa’. You go there*
194 *.....they give you a bottle of medicine then you get better”* FGD mothers of
195 adolescents

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

203
204 *“If one goes to hospital and is diagnosed with TB and given tablets....if one is not*
205 *improving, then they come to us. You can give the TB patient two bottles of our treatment*
206 *which lasts two weeks and they get fine”* KI Traditional Healer

207
208 **Factors influencing treatment choice**

209
210 Reasons for seeking care from traditional healers included beliefs regarding the etiology
211 of TB, particularly the possibility TB caused by being bewitched. Other motives for
212 engaging the help of traditional healers included the potential for expedited treatment or
213 immediate improvement, the potential for more friendly care, family tradition, lack of
214 money for transport, lack of drugs in health facilities, inconvenient hours of operation,
215 requests for “small money”, and proximity.

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

218
219 *“Traditional healers handle patients in a friendly manner unlike government facilities.”*

220 FGD elderly men
221 *“Cultural belief...they think they are bewitched. They want to hear the view of the spirits*
222 *‘Jajjas’”*

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

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

229 FGD young fathers of infants

230
231 Respondents felt poverty affected treatment completion regardless of where treatment
232 was sought.

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

235 FGD young women

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

239 KI traditional healer

240
241 *“Most of them (patients) do not complete treatment because of money, but for me I help*
242 *them.....I can give the patient the treatment then they pay the money later when they are*
243 *fine”.*

244 KI Traditional Healer

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

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

FGD young men

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252 **The Potential for Cure**

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

259

260 **Stigma towards TB patients**

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

267

268 *“We segregate them because we know TB does not cure,..... so we run away from them”*

269 FGD participant for young mothers.

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

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FGD young women

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

276 *“In most cases when the health workers find out that you have TB, they treat you with*
277 *fear of contracting the disease since it’s airborne.”*

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FGD young women

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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).

312 Respondents readily grasped that HIV/AIDS is associated with TB. However, the
313 mistaken perception that every TB patient is co-infected with HIV and that co-
314 morbid patients cannot be cured, creates barriers to care. TB suspects were
315 reported to fear going to health facilities because of HIV testing. This fear seems
316 to be more driven by HIV-related stigma, as found in Kenya(22) and elsewhere
317 (4, 34) and can hinder treatment seeking among TB patients.

318 **LIMITATIONS**

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

323

324 **CONCLUSIONS**

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

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340 **Authors' contributions**

341 EB, AS, JK, EMHM, AW, PM, and HM took part in designing the study, in tools
342 development, in data analysis and in manuscript writing. RC and GP took part in
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