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Tuberculosis knowledge, attitudes and health-seeking behaviour in rural Uganda

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SUMMARY

OBJECTIVES: To assess tuberculosis (TB) knowledge, attitudes and health-seeking behaviour to inform the design of communication and social mobilisation interventions.

SETTING: Iganga/Mayuge Demographic Surveillance Site, Uganda.

DESIGN: Between June and July 2008, 18 focus group discussions and 12 key informant interviews were conducted, including parents of infants and adolescents and key informant interviews with community leaders, traditional healers and patients with TB.

RESULTS: People viewed TB as contagious, but not necessarily an airborne pathogen. Popular TB aetiologies included sharing utensils, heavy labour, 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 human immunodeficiency virus (HIV) testing and length of TB treatment negatively affect health-seeking behaviour. 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 aetiology, stigma and preference for pluralistic care need to be addressed to improve early detection. Health education messages should emphasise the curability of TB, the feasibility of treatment and the engagement of traditional healers as partners in identifying cases and facilitating adherence to treatment.

KEY WORDS: tuberculosis; qualitative; health-seeking behaviour; stigma; Uganda

TUBERCULOSIS (TB) is a leading cause of death in the developing world, especially in sub-Saharan Africa, despite the introduction of the DOTS strategy.[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] Suspects are therefore expected to be able to recognise TB symptoms and have positive attitudes towards TB being managed 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 stigmatisation,[6] lack of knowledge about TB and traditional beliefs.[7]

Studies performed in high-burden countries have reported many misconceptions about the causes of TB, such as inter-generational TB transmitted through blood relationships,[8] TB caused by overexertion,[9] cold weather,[10] and breaking cultural rules that require sexual abstinence after the death of a family member.[11]

To our knowledge, no qualitative study of the knowledge and perceptions about TB has previously been performed in Uganda. Our study explored the knowledge and perceptions about TB in the communities and their health-seeking behaviour in preparation for community-based TB sensitisation in two districts.

METHODS

The present study was carried out in June and July 2008 in the Iganga/Mayuge Demographic Surveillance Site (DSS), located 120 km east of Kampala, Uganda. This predominantly agricultural (90% rural) DSS, a region that has been well researched,[12–19] has a population of approximately 67 000; the main ethnic group is Basoga.

Focus group discussions (FGDs) and key informant interviews (KIs) were conducted among both male and female parents/caretakers of children and adolescents, school heads, opinion leaders and TB patients.

Eighteen FGDs were conducted, including six FGDs of young mothers/fathers/caretakers (aged <36 years)

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of children, six of mothers/fathers/caretakers of adolescents, and six of mature mothers/fathers/caretakers aged (⩾36 years). Key informants included two local council leaders (LCs) and two traditional healers, known as *mukalakasa*. Mukalakasa are men or women who 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 the LCs) was used to identify participants for the FGDs and KIs. FGDS were grouped by such factors as age and sex, as homogeneity of focus group participants can facilitate sharing.

Data collection instruments for FGDs and KIs were pre-tested. Interviews with health workers were conducted in English, while the other interviews were conducted in the local language, Lusoga. Tape recorders and notes were used to record the interviews. All interviews were transcribed by moderators, and 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 were coded, condensed and categorised into broad themes.[20] Respondents' quotations were identified and applied to emphasise 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 used for TB in the community

Most participants were aware TB is a serious disease, and cited different commonly used local names. The majority of the respondents mentioned *akafuba* (pulmonary TB), followed by 'TB', as the most commonly used names in the community. Other names used included *lukonvuma* (emaciation), *oluweero (*difficulty in breathing with wheezing) and *akalakiilo* (persistent dry cough). These names emerged from all the categories of respondents, except the health workers, who use Lusoga and medical 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, including one traditional healer, specifically mentioned a TB germ. However, the majority of the participants said that TB was an airborne disease/contracted by staying in the same environment as a TB patient. Sharing food and eating utensils with a TB patient (such as drinking straws for the local brew known as '*malwa*') was a common response that cut across all respondent categories. The majority of participants reported that TB is caused by smoking, and said that the effect is cumulative. Heavy manual work such as making bricks and carrying heavy weights was said to increase susceptibility. One traditional healer said that TB could be caught after being bewitched, which can only be successfully treated by traditional healers. Some FGD participants also reported that TB runs in families.

> For me, I think if in your lineage there was a TB patient, then you can get it through inheritance. (FGD, young mothers)

Signs and symptoms of TB

The majority of participants associated TB with prolonged cough and at times chest pain. Some respondents mentioned loss of weight, fever, difficulty in breathing and coughing up blood. Infrequently, TB was confused with asthma or the dry cough associated with wheezing (*oluweero*), usually triggered by 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 mothers)

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 aged ⩾40 years. Men tended to see TB as a disease of older people, especially men, caused by smoking, heavy labour and weakened bodies. Some young women and men reported that women were more at risk because of their role as the caretakers of TB patients, heavy work 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 one will automatically 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, young mothers)

Reasons for delays in seeking TB care included the use of self-medication, lack of money and the fear of

being labelled as sick, and in particular 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)

A fair number of respondents preferred the diagnostic tests performed in the biomedical sector. However, after diagnosis, some sought complimentary care by traditional healers. TB care was sought from traditional healers and private and public health facilities, but some also used 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 check-up 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, female 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 aetiology of TB, particularly the possibility of TB caused by bewitchment. Other motives for turning to 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)

> Traditional healers handle patients in a friendly manner, unlike government facilities. (FGD, mature fathers)

> Cultural belief . . . they think they are bewitched. They want to hear the view of the spirits '*jajjas*'. (KI, health assistant)

Although generally believed to be affordable, some young men thought traditional healers were 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)

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 mothers)

> The problem we get is that when someone comes and you charge him 5000 shillings, he can only pay 2000 shillings 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 of treatment, the 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 2000 tablets or 1000 injections . . . so some people would prefer to go to traditional healers. (FGD, young fathers)

The potential for cure

Most participants across all categories mentioned that TB drugs can cure, especially if instructions from health workers are followed and there is early treatment. A few participants reported that TB could be cured only if there is no HIV/AIDS (acquired immune-deficiency syndrome). The majority of the participants knew the correct length of TB treatment (6–8 months), others mentioned 2 months and one mentioned 'only 60 injections'. One traditional healer offered a TB treatment lasting only 3 weeks.

Stigma towards TB patients

TB patients were reported to be feared and discriminated against. This was ostensibly because of the fear of airborne infection. However, some acknowledged that stigma was also due to assumed 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 were 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, 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 mothers)

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 mothers)

DISCUSSION

Findings from this exploratory study reveal the community's knowledge and attitudes towards TB aetiology and treatment. Although most respondents were aware of TB and knew its symptoms, the belief that TB is hereditary or may be caused by witchcraft is similar to findings in other studies.[10,11] It is unclear whether alternative aetiologies delay health-seeking behaviour or increase the period of infectivity. As in other contexts, TB in Uganda is a social disease and presents problems such as stigma, which cannot be addressed by a conventional medical approach.[21] Persistent beliefs about TB transmission through the sharing of utensils and about hereditary transmission may foster conditions for stigmatisation of TB patients and their families.[22,23] We find that TB touches upon complex social forces, including risk of witchcraft, heavy labour, vices and poverty. Although treatment for TB is nominally free,[24] this study found hidden costs that may have inhibited health-seeking behaviour.

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 their empathy, the 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 relationship between formal and informal providers.

Lack of money for transport and the fact that traditional healers were more patient-centred were found to be reasons for 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' neglect of TB patients is an ongoing issue in many areas.[30–32] It was revealed that some TB patients only seek health care after being forced to by family members. This was also found in Gambia, where a close relative or a neighbour often 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 comorbid patients could not be cured created 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 care seeking among TB patients.

Limitations

Focus groups and interviews offered a timely window into the range of understanding about TB; however, 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 individual power to overcome them.

CONCLUSIONS

This study highlights the varied aetiological concepts, the range of health-seeking options to which patients resort and the reasons for their choice. There is a perception that TB patients seek care late and often 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 the heavy pill burden. People mistakenly assume that TB associated with HIV/AIDS cannot be cured. These barriers can be brought down by bringing the health services closer to the community, sensitising the community about TB and improving the attitudes and behaviour of health workers towards TB patients. This study suggests that funds or other incentives may be beneficial for TB patients to encourage treatment seeking and adherence. The involvement of traditional healers in community-based DOTS could enhance detection and cure.

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RÉSUMÉ

OBJECTIFS : Evaluer les connaissances, les attitudes et le comportement de recherche de soins en matière de tuberculose (TB) afin de servir d'information pour élaborer des interventions de communication et de mobilisation sociale.

CONTEXTE : Le Site de Surveillance Démographique d'Iganga/Mayuge, Ouganda.

SCHÉMA : On a mené, entre juin et juillet 2008, 18 discussions focalisées de groupe et 12 interviews-clé informatives en y incluant des parents de nourrissons et des adolescents avec en outre des interviews-clé informatives avec les leaders de la collectivité, les guérisseurs traditionnels et les patients atteints de TB.

RÉSULTATS : La TB est considérée comme contagieuse mais pas nécessairement due à un pathogène agissant par voie aérienne. Les étiologies les plus populaires concernant la TB comportent le partage d'ustensiles, la lourdeur du travail, le tabagisme, l'ensorcellement et la transmission héréditaire. On considère que les patients TB recourent tardivement aux soins ou même les évitent. La combinaison des soins provenant de guérisseurs traditionnels et du système biomédical est courante. Le comportement de recherche de soins est affecté négativement par la pauvreté, les ruptures de stock de médicaments, la crainte du test du virus de l'immunodéficience humaine (VIH) et la longueur du traitement de la TB. La stigmatisation et l'évitement des personnes atteintes de TB reflètent souvent une suspicion de co-infection VIH.

CONCLUSION : Pour accentuer la précocité de la détection, il faut tenir compte des soucis de la collectivité concernant le fardeau des médicaments, la qualité des soins, les barrières financières, l'étiologie de la TB, la stigmatisation et les préférences pour des soins pluralistes. Les messages d'éducation en matière de santé devraient insister sur la curabilité de la TB, la faisabilité du traitement et l'engagement de guérisseurs traditionnels comme partenaires pour l'identification des cas et l'amélioration de l'adhésion thérapeutique.

RESUMEN

OBJETIVOS: Evaluar los conocimientos, las actitudes y los comportamientos de búsqueda de atención de salud en materia de tuberculosis (TB), con el objeto de documentar la concepción de las intervenciones de comunicación y movilización social.

MARCO DE REFERENCIA: El centro de vigilancia demográfica de Iganga/Mayuge, Uganda.

MÉTODOS: Entre junio y julio del 2008 se condujeron 18 grupos de opinión en las cuales participaron los padres de lactantes y adolescentes y 12 entrevistas a informantes clave entre ellos informantes centrales de la comunidad, curanderos tradicionales y pacientes con TB.

RESULTADOS: Los participantes percibían la TB como una enfermedad contagiosa, pero no necesariamente causada por un microorganismo de transmisión aérea. Según las creencias populares, entre las formas de contraer la enfermedad se encuentran el compartir utensilios, el trabajo exhaustivo, el tabaquismo, los hechizos y los mecanismos hereditarios. Se observó que los pacientes con TB buscaban atención en forma tardía o evitaban hacerlo. Con frecuencia combinaban la atención por los curanderos tradicionales y el sistema biomédico. La pobreza, el agotamiento de las reservas de medicamentos, el temor a la infección por el virus de la inmunodeficiencia humana (VIH) y la duración del tratamiento antituberculoso ejercían un efecto negativo sobre el comportamiento de búsqueda de atención de salud. La existencia de estigmas y la evitación del contacto de las personas con TB suele corresponder a la suposición de una coinfección por el VIH.

CONCLUSIÓN: Con el objeto de mejorar la detección precoz, es preciso responder a las preocupaciones de la comunidad sobre la cantidad de comprimidos, la calidad de la atención de salud, los obstáculos económicos, el origen de la TB, los estigmas y la preferencia por una atención pluralista. Los mensajes de educación sanitaria deben destacar la curabilidad de la TB, la posibilidad de tratamiento y la participación de los curanderos tradicionales como socios en la detección de casos y como facilitadores del cumplimiento terapéutico.