Challenges in tuberculosis care in Western Uganda: Health care worker and patient perspectives

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1. Background

In 2012, there were 8.6 million incident cases of Tuberculosis (TB) globally, and 940,000 deaths worldwide (World Health Organisation, 2013). Twenty-two high burden countries, mostly in Sub-Saharan Africa, contribute 80% of the world’s TB burden; Uganda is amongst them with an estimated 65,000 incident cases and 4,700 deaths (World Health Organisation, 2013). A major factor in the ongoing TB epidemic is the high burden of Human Immunodeficiency Virus (HIV) co-infection in Sub-Saharan Africa, which contributes to increased progression, transmission and mortality of TB (Lawn & Churchyard, 2009). TB is the most common cause of death in HIV infected individuals, and yet is largely considered separately from HIV infection (Corbett et al., 2003).

In 2012 Uganda had a TB incidence rate of 179/100,000 and 54% of TB patients were HIV positive (World Health Organisation, 2013). The TB mortality rate was 13/100,000 in HIV negative patients, and 25/100,000 in HIV positive patients (World Health Organisation, 2013). A number of Ugandan studies revealed that TB was the leading cause of death in HIV patients, many of whom died before TB was confirmed by laboratory methods (Amuron et al., 2011; Kyeyune et al., 2010; Moore et al., 2011). Morbidity is also high: TB was ranked as the 15th and HIV the 13th highest leading age-standardized rate of disability-adjusted life years (DALYs) in Uganda relative to comparator countries in 2010 (Institute of Health Information Metrics and Information, 2013).

One of the main components of the global strategy to fight TB is the World Health Organisation’s (WHO) Directly Observed Therapy, Short-course regimen (DOTS-Direct Observed Treatment Short Course). The five central tenants of DOTS are (1) political commitment with increased and sustained funding, (2) case detection through quality assured bacteriology, (3) standardized treatment with supervision and treatment support, (4) a continuous drug supply and management system and (5) a monitoring and evaluation system and impact measurement (WHO, 2011). Uganda’s National TB Control Program officially follows WHO recommendations on DOTS (Western Zone National TB/Leprosy programme Uganda. Annual TB/Leprosy report, 2009), however the high incidence and mortality discussed above suggest that the program is not working well, likely because of chronic underfunding leading to gaps between official TB program guidelines and implementation in the districts. The TB services are integrated into the general health care system, and minimal if any additional funding is allocated to

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active community involvement and ownership in the programs, which has been shown elsewhere to be key in the success of these programs (Suri, Gan, & Carpenter, 2007). TB control is an ongoing challenge for Uganda, and it is likely that the country will not reach the 2015 Millennium Development Goals (World Health Organisation, 2013).

In order to identify gaps between policy and practice, understanding challenges faced in the delivery of TB diagnosis and treatment is critical. It has long been appreciated that front line health care workers (including doctors, nurses, medical officers, community health assistants, and clinical lab technicians, amongst others) provide a critical perspective on health care delivery. In South Africa, community health care workers have helped to identify areas for improvement in TB and HIV programs, such as improvement in supervision and collaboration with other health care delivery programs (Suri et al., 2007). The patient perspective also provides valuable insight into how tuberculosis control programs work. A study of TB patients in Zambia identified a high number of health care encounters before diagnosis, high financial burden and a long travel distance as the main barriers to care; this perspective had important implications in subsequent health care reforms (Needham, Bowman, Foster, & Godfrey-Fausset, 2004). Okot-Chono et al. have outlined the barriers facing TB and HIV integration in Uganda; these include poor TB-HIV planning, co-ordination and leadership, inadequate provider knowledge, limited TB-HIV inter clinic referral (Okot-Chono et al., 2009). To date, no studies evaluating health care worker and patient perspectives of tuberculosis control programs have been conducted in Uganda. Local and country specific information is important to help to tailor TB programs to the cultural and behavioral context within the specific country; major variations in context exist between and within Sub-Saharan African countries. Our study aimed to explore health care worker and patient views on the major problems and challenges within the TB program in western Uganda.

2. Methods

2.1. Setting

The study was conducted in Kabarole District (population estimate 455,000 in 2010, land area 4800 km²). The district health services consist of 47 health units with 75% of the population being less than 5 kilometres away from a health unit (Uganda Government, 2005). The district TB services follow the national TB control program (which is officially aligned with the STOP TB strategy), are organized by the District TB Officer, and are decentralized and offered through the various health units. Rural health clinics offer the standard 4 drug TB regimen (Isoniazid, Rifampin, Ethambutol, Pyrazinamide) and are supposed to directly supervise medication administration for all patients, however in reality very few patients are directly observed. Some rural clinics offer direct microscopy for diagnostic AFB smears, but few have functioning and staffed laboratories in reality. Patients who fail a first 6 month treatment, who default (discontinue their medications before completion), or who are very sick are admitted to the district referral hospital for the first 2 months of treatment and receive daily streptomycin injections in addition to the above 4 drugs. The district laboratory does have a functioning laboratory for AFB smears, cultures are not done (Western Zone National TB/Leprosy programme Uganda. Annual TB/Leprosy report, 2009).

For Kabarole district 2009, the cure rate (those who had a smear negative result at the end of treatment) was 15%, the treatment completion rate was 60% and the TB defaulter rate (patients that discontinue treatment before completion) was 12% (Western Zone National TB/Leprosy programme Uganda. Annual TB/Leprosy report, 2009). However, it is estimated that the true defaulter rate is much higher than the reported one.

2.2. Design

This study was part of a larger mixed-methods study to explore knowledge and stigma around HIV, TB and TB/HIV co-infection (Wynne, Richter, Jgangri, Rubaale, & Kipp, 2014; Wynne et al., 2012) Findings emerged as part of that study around issues surrounding the TB program and the challenges faced by health care workers and patients. This is a secondary qualitative analysis investigating those challenges.

2.3. Data gathering and analysis

Thirty two in-depth interviews were conducted. These included interviews with health care workers (4 nurses, a medical officer, a physician, and a community health assistant, n = 7), district health managers (n = 3), TB patients (n = 6), HIV patients (n = 7) and TB/ HIV co-infected patients (n = 9). Health care workers were recruited using snowball sampling (initial convenience sample of health care workers suggested colleagues that might be interested in participating), and patients recruited using a convenience sample with the assistance of nurses at each clinic. With the exception of the health managers, participants were recruited from two rural clinics (primary level care) and one district referral hospital (secondary level care). The health care managers were recruited purposively from the District Regional Office. Interview guides were developed in partnership with local stakeholders, and were informed by findings from the quantitative study component of community knowledge and stigma of TB/HIV co-infection (Wynne et al., 2014; Wynne et al., 2012). Interviews were semi-structured. Interviews lasted between 15 minutes and one hour. Interviews with health care workers and health managers were conducted in English by the first author (AW). Patient interviews were conducted and recorded in the local language, Rutooro, by the 4th author (LB), and translated into English (also by LB). A second independent translation of a sub-set of transcripts was compared to ensure quality.

Transcripts were analyzed using thematic analysis to code and categorize the data. Themes were developed from these categories. A sub-sample of transcripts was re-coded by the same researcher, and a sub-set were also coded by an independent researcher to ensure credibility and confirmability (agreement in coding tree was established) to contribute to the trustworthiness of the study. Qualitative results were additionally presented and discussed with participants and key informants (a local professor that acted as a mentor, and members of the District Health Services). This member checking confirmed and validated the themes.

This study received ethical approval in Canada from the University of Alberta Human Research Ethics Board, Health Panel, and in Uganda from Makerere University School of Public Health's Internal Review Board and the Uganda National Council for Science and Technology. Participants were given a detailed explanation of the study by one of the authors (AW or LB), and translated into English (also by LB). A second independent translation of a sub-set of transcripts was compared to ensure quality.

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3. Results

Health providers and patients identified many challenges facing the TB program in Kabarole district. These range from individual level factors experienced by patients, to overarching health systems weaknesses. The main findings can be described in the following categories: Individual factors (delay in diagnosis and
3.1. Individual factors: delays in diagnosis

A pattern of common experience emerged amongst the TB patients when recounting their journeys from first symptoms to TB diagnosis; self-treatment is often attempted for initial cough symptoms, then as symptoms worsen repeated visits to rural health centers result in multiple rounds of ineffective medications. After six or more months coughing (often blood), the patients find their own way to a hospital and are finally screened for TB. The following patient’s story was typical:

“I spent like eight months coughing every day. I would go to the nearby health unit and get treatment but there was no improvement. There was no change, now I told my parents to look for money and go to [the referral] hospital for check-up maybe its TB.” (TB patient, referral hospital)

One clinician explained why so many patients face repeat visits to health centres without being screened for TB:

“Many of the health centers that are close by to them [the patients], some of these health centers may not have sufficiently qualified staff to screen for TB or even the ability to refer the patient away to a referral hospital like this one. The patients may die because the diagnosis has been delayed.” (Clinician, referral hospital)

Once patients have been assessed for TB, the diagnostic capabilities of the health centres and laboratories create further delays. Due to shortages of equipment and personnel, very few of the rural health facilities have functional laboratories. This was identified as a major challenge by this health manager:

“Laboratory personnel are scarce, of the sixteen lower health facilities where we are supposed to have a fully functional laboratory team only five [are functional]: the Microscopes are not there.” (District health manager)

Even when microscopy labs are functioning, the reliance on sputum for diagnosis causes delays in diagnosis of atypical TB; a problem that is becoming increasingly common according to this health manager: “We are getting more pulmonary negatives, extra pulmonary, disseminated TB: sputum negatives are becoming many”. This shift in TB presentation was identified as a challenge by health providers:

“A challenge to me is about TB in HIV [patients] because we realize that most of them can’t even produce sputum, and then one issue is that they can have extra-pulmonary TB, it becomes very hard for us clinical officers [to diagnose extra-pulmonary TB]” (Clinical officer, rural health unit).

When asked why she thought that people are still dying of TB even though it is treatable, this clinical officer stated: “I believe we may be losing people because of that they may be having extra-pulmonary TB.” (Clinical officer, rural health unit)

3.2. Individual factors: financial burden

A major theme that emerged was the financial burden that TB patients experience. The most significant cause of this was the transport costs to get to the clinic each month to pick up their drugs. A rural health assistant explained:

“Patients travel long distances, their treatment is for 8 months, every month going to the health facility. It’s costly for them- of course they have other activities they’re supposed to be doing at home but they use that time coming for drugs which can be a challenge to the community. I wish everybody could be on DOTS” (Rural health assistant).

Patients are often unable to come to the health centre because they cannot find the money for transport, either initially, which results in their condition deteriorating before seeking care, or for follow-up visits, which results in treatment default. TB treatment involves certain direct costs, such as for diagnostic tests and for hospitalization, as this TB patient recounted: “After [being diagnosed with] TB, I spent 14 days in the hospital, after that I was discharged because you have to pay for the bed every day and I could not afford to pay that money” (Female TB/HIV patient, rural health unit). In addition, indirect costs of TB are also incurred. These include not being able to work to support themselves or their family (either due to weakness or because of health care workers’ instructions not to do heavy lifting), and the costs involved in maintain sufficient nutrition, as one young woman described:

“I was on treatment when my mother was working and I was used to good feeding, but when my mummy stopped working [we couldn’t afford food] and whenever I took my TB drugs I would feel bad and I stopped it” (Female TB/HIV in-patient, referral hospital).

3.3. Health care worker training

Health Care Workers identified a need for more training on TB. They felt that “there are few people who are trained about TB” (nurse, rural health unit), especially with regards to TB/HIV co-infection and co-treatment.

“We need trainings on the relationship between TB/HIV, on co-treatment of TB/HIV… we are not good at that. Yes we know Rifampicin, and Nevirapine [have] antagonistic interactions, but we need more. You know when you go for training and there is one hour for TB/HIV it’s not elaborate, but if we have more trainings, a whole week on TB/HIV co-treatment.” (Clinical officer, rural health unit)

The lower level health centres are especially affected, with sometimes only one person with any training on TB, and nurses relying on their training outdated from school, even if they had finished school 10 years ago. As one physician outlined, consistent drug supply is not sufficient if the health care workers are not able to identify and treat TB:

“We need at least to have capacity building in the lower health centres. Actually they are equally able to provide TB treatment because they do get TB drugs, but some of [the drugs] may expire there because [the nurses] have not been identifying the patients, they have not diagnosed, they have not treated.” (Clinician, referral hospital)

Inconsistent quality and lack of microscopy technicians was also identified as a challenge in TB care. One strategy to make up for this was described by a rural clinical officer:

“…because there are not many lab assistants we train nursing assistants as microscopists, there are some who are very good but there are some who are not so good.” (Clinical officer, rural health unit)

Health care workers felt that current training strategies were insufficient. Reminder posters are sometimes put up in clinics to “assess TB if [the patient] cough more than two weeks” but it was felt that “it may not be easy [to assess for TB] if someone has not taken part in the trainings” (Clinical officer, rural health unit). Also, passive training strategies such as providing books or...
Health care workers identified many challenges within the context in which they work, many of which revolved around the challenges of working in a rural area. A nurse described: “the problem is the gap from the village to the hospital; on the way there you don’t know what happens” (Nurse, referral hospital).

Health care workers expressed frustration at not being able to manage patients using the DOTS program which they felt was beneficial and easier for the patient; health providers knew the recommendations but their programs were unable to follow DOTS strategy.

“TB patients are supposed to be supported at home, that is DOTS– he is supposed to be observed by his treatment supporter when swallowing tablets daily and then the health worker is supposed to go and take the medicines every 2 weeks. But actually the coverage [of DOTS] is low because of lack of resources. We have no funds to support people to go down there [to the villages]. The Ministry of Health doesn’t actually have money to give the [national TB program] to support DOTS. The districts receive Primary Health Care funds, but they are not adequate to support [DOTS]- they [the government] are not prioritizing TB DOTS strategy.” (District health manager)

The lack of resources primarily affects funds for transport out into the villages, and personnel for community visits. A rural health assistant (whose job involves following TB patients on DOTS), highlights this: “Of course when we get a little fuel, of course it’s a priority they are supposed to be on DOTS, we have to consider to at least put a few patients on DOTS” (Rural health assistant). At the main TB clinic ward in the district hospital, they haven’t been privileged to retain their health assistant:

“DOTS has been stopped. The one who used to do it has left because of payment, he said he can’t do the work without being paid. So, he left. They say there is no money [to hire someone], so, that’s why we can’t do it now; we’re just registering them and informing the nearest health center with a letter so that they continue following them up there.” (Nurse, referral hospital)

Without the capacity to follow up with patients when they don’t visit to the health centre to collect their drugs, health care workers are not able to determine whether TB patients have defaulted, died, or transferred to another health centre. It is not uncommon for patients to decide to be treated at a different health centre, because of the way health centres are located, however no mechanism is in place to track those patients.

Financing of the district health system was highlighted “The Primary Health Care Package [funding package from the Ministry of Health] has been reduced. This comes late; the whole quarter from October, November, and December we didn’t have the funds” (District health manager). Funding that TB services get is not adequate and not directed at the right problems. Many of the routine services in the district health system rely on inconsistent funding from external non-governmental organisations (NGOs), most of whom have HIV/AIDS focused mandates. Services such as CD4 cell counts, polymerase chain reaction (PCR) for infant blood tests and post-test clubs have all previously been supported by sponsors who have now withdrawn funding, transferring the costs to the patients directly. For TB services, there are fewer organizations involved but still have a significant role: “Last year we got support [for DOTS] from the Global Fund, it came [only] once for 4-6 months” (District health manager). That said, TB medications have come from the German Relief Leprosy Association through the Ministry of Health for many years, and health providers reported a consistent TB drug supply with no stock outs.

4. Discussion

It is not difficult to link the insufficiencies in the health care system with the poor outcome of TB patients: lack of health care worker training is resulting in extensive delays in diagnosis, and lack of financial priority placed on the TB program transfers the financial burden to the patient.

Patients experienced a typical pattern of repeated visits to health units and treatment with ineffective medications before seeking care at higher level health centres when their symptoms progressed. This is similar to a study in Zambia which found that patients had multiple encounters with health services before being diagnosed (Needham et al., 2004). This study (Needham et al., 2004) only offered the perspective of patients who did eventually receive a diagnosis of TB; however a study of HIV deaths in Uganda found that a significant percentage of the HIV deaths were due to undiagnosed TB (Moore et al., 2011). Health care workers clearly expressed a need for more training; their current skills are insufficient to tackle the growing burden of TB/HIV co-infection and treatment. Lack of support for training on TB/HIV co-infection specific issues has previously been identified as a major barrier to both TB and HIV programs in Uganda (Okot-Chono et al., 2009). Globally, the lack of adequately trained and qualified staff has been identified as one of the major factors preventing the successful achievement of TB targets (Harries et al., 2005). This lack of knowledge is likely leading to the extensive delays in diagnosis experienced by patients, since health care workers in the more peripheral health centres do not know the signs and symptoms of TB and therefore don’t screen for them. This has similarly been identified as a major cause of delay in diagnosis in South Africa (Heunis et al., 2001). Even when health care workers do suspect TB, many health centres do not have the laboratory capacity to test for TB, and there is an ineffective or non-existent referral system to the health centres with laboratory facilities that can diagnosis TB. This is further compounded by the increasing burden of extra pulmonary TB, which often goes undiagnosed due to the reliance of the TB program in the district on sputum smears alone as a diagnostic tool. Similar results regarding causes of delays to TB diagnosis were found in a review of 58 studies (from all over the world, of which 15 were from Sub-Saharan Africa); repeated visits to lower level health centres resulted in ineffective antibiotic treatment without proper referrals to TB services, extra pulmonary and negative smears were also found to be contributing factors (Storla, Yimer, & Bjune, 2008). Diagnosis of extra-pulmonary TB is difficult and often based on clinical diagnosis since biopsies are frequently unfeasible in this context. As such, the training of health care workers on common extra-pulmonary presentations of TB should be strengthened given the increasingly prevalence of extra-pulmonary TB in this context.

Uganda (and Kabarole district) officially complies with the WHO’s DOTS program; however this study clearly shows that this is not the reality on the ground. Previously functioning DOTS programs are being neglected. This is disturbing; without the resources to support DOTS, the costs of follow up (time and transport costs to the clinic to pick up medication each month), are transferred to the patient. This financial burden includes direct hospital costs, transportation costs, loss of income and cost for
special food requirements. These financial burdens have been reported elsewhere, highlighting TB’s status as an “economic disease” (Cramm, van Exel, Moller, & Finkenflugel, 2010; Suri et al., 2007). The financial burden of TB treatment leads to treatment default and failure, and ultimately poor national TB outcomes (Storla et al., 2008; Western Zone National TB/Leprosy programme Uganda. Annual TB/Leprosy report, 2009). Poor-pro

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 References


 5. Conclusions and recommendations

 The TB program in western Uganda is seriously neglected, which will continue to perpetuate poor patient outcomes and ongoing transmission. In depth training for health care workers, especially at primary health centers, is needed to better identify TB and manage TB/HIV co-infected patients, and would be welcomed by health care workers. This would be a realistic and cost-effective approach. Overall health system strengthening is needed, including referral systems tracking patients between health centres. It would be unrealistic to recommended unilateral funding increases in this context, instead a “re-framing” of TB as part of the HIV problem is necessary, especially amongst NGOs with healthy budgets but narrow HIV mandates; excellent guidelines for NGOs are available for integrating TB and HIV services (Mburu & Richardson, 2013). A specific priority should be placed on re-funding previously functional community based DOTS program to alleviate the financial burden on patients. A renewed commitment to the central tenets of DOTS are necessary, with specific emphasis on political commitment (and sustained funding), case detection through quality assured bacteriology, and standardized treatment with supervision and treatment support. TB control can be achieved at very low cost; overall, a greater priority must be placed on TB programs in this area in order to re-gain lost ground and move forward in the fight against TB.

 Conflict of interest statement

 The authors report no real or perceived vested interests that relate to this article (including relationships with pharmaceutical companies, biomedical device manufacturers, grantors, or other entities whose products or services are related to topics covered in this manuscript) that could be construed as a conflict of interest.