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PERCEPTIONS, PREFERENCES, AND EXPERIENCES OF TUBERCULOSIS EDUCATION AND COUNSELLING AMONG PATIENTS AND PROVIDERS IN KAMPALA, UGANDA: A QUALITATIVE STUDY

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Abstract

Tuberculosis (TB) education seeks to increase patient knowledge about TB, while TB counselling seeks to offer tailored advice and support for medication adherence. While universally recommended, little is known about how to provide effective, efficient, patient-centred TB education and counselling (TEC) in low-income, high HIV-TB burden settings. We sought to characterize stakeholder perceptions of TEC in a public, primary care facility in Kampala,

Uganda, by conducting focus group discussions with health workers and TB patients in the TB and HIV clinics. Participants valued TEC but reported that high-quality TEC is rarely provided, because of a lack of time, space, staff, planning, and prioritization given to TEC. To improve TEC, they recommended adopting practices that have proven effective in the HIV clinic, including better specifying educational content, and employing peer educators focused on TEC. Patients and health workers suggested that TEC should not only improve TB patient knowledge and adherence, but should also empower and assist all those undergoing evaluation for TB, whether confirmed or not, to educate their households and communities about TB. Community-engaged research with patients and front-line providers identified opportunities to streamline and standardize the delivery of TEC using a patient-centred, peer-educator model.

Keywords

patient-centred; patient education; counselling; patient preferences; HIV; sub-Saharan Africa; implementation science; Uganda; peer education; peer navigation; tuberculosis

BACKGROUND

Despite the widespread availability of highly effective treatment, tuberculosis (TB) remains a leading cause of death worldwide, with 1.5 million deaths reported in 2018, one-quarter of these in Africa (WHO, 2019). Early diagnosis and timely, appropriate treatment are critical to achieving TB control and elimination targets (Floyd et al., 2018; World Health Organization, 2015), while treatment nonadherence, interruption, and early discontinuation contribute to excess morbidity, transmission, drug-resistance, disease relapse, and avertable deaths (Cuneo, WD Snider, 1989; Menzies, R Rocher, I Vissandjee, 1993; Snider, 1982; WHO, 2019). TB treatment success rates remain well below the World Health Organisation (WHO) recommended target of 90% (Chaves Torres et al., 2019; Floyd et al., 2018), reaching only 71% globally (95% CI 64 to 78) and 76% (95% CI 73 to 80) in sub-Saharan Africa (Izudi et al., 2019). HIV has been associated with higher rates of TB treatment discontinuation (Agbor et al., 2014; Jacobson et al., 2015; Porco et al., 2013) and increased mortality (WHO, 2019; World Health Organization, 2018).

Studies have identified many different causes of nonadherence and treatment interruption, including gaps in knowledge about TB and low motivation to engage in TB treatment (Izudi et al., 2019; Munro et al., 2007; Sumartojo, 1993; Thiam et al., 2007; van Hoorn et al., 2016; WHO, 2003). Among TB-HIV patients, higher rates of adherence to antiretroviral therapy (ART) than to TB therapy have been described and attributed to lower knowledge about TB and more negative attitudes towards TB disease and treatment, relative to HIV (Daftary et al., 2014). Interventions to ensure routine attendance at TB clinic visits, and, for people living with HIV and AIDS, adherence to both TB treatment and ART have been shown to reduce treatment interruption (Alipanah et al., 2018; Munro et al., 2007) Treatment adherence support has the potential to increase uptake of other related TB services, such as contact investigation and preventive therapy (Fox et al., 2019)

TB education and counselling (TEC) is universally recommended as part of treatment (TB CARE I, 2015; Uganda Ministry of Health, 2010; WHO, 2014) TB education (*i.e.*,

interventions to enhance knowledge, attitudes, and practices) is designed to provide general knowledge about TB and explain treatment requirements. Counselling (*i.e.* interventions to provide tailored guidance on managing treatment and problem-solving skills) is designed to address stigma, fears of side effects, and low self-efficacy (Lawn, 2000; M'Imunya, JM Kredo, T Volmink, 2012; Rajeswari et al., 2005; WHO, 2014; Wynne et al., 2014) TEC is associated with improved treatment adherence (Morisky et al., 1990; Thiam et al., 2007; van Hoorn et al., 2016; Yoeli et al., 2019) and decreases the proportion of patients who become lost to follow-up from treatment (Liefvooghe et al., 1999; Mbuagbaw et al., 2015) A randomized trial of individualized counselling to enhance knowledge, motivation, problem solving, and mobilization of social support at each patient visit in Pakistan reported a 13% relative risk reduction in the rate of being lost to follow-up compared to usual care (Liefvooghe et al., 1999) Moreover, independent of the effects on treatment outcomes, TEC has the potential to improve patient well-being, consistent with renewed efforts to make TB care more patient-centred, a priority of the WHO END TB Strategy (World Health Organization, 2015) Patient-centred TEC addresses specific barriers to delivery or uptake of recommended interventions, as well as the more general psychosocial aspects of illness as a lived experience (Constand et al., 2014; Daftary et al., 2016; Institute of Medicine, 2004)

In previous work on TB contact tracing in Kampala, Uganda, including at Kisenyi Health Centre, we learned that TEC was neither routinely provided nor prioritized for patients initiating TB treatment (Ayakaka et al., 2017; Gyimah & Dako-Gyeke, 2019). In this qualitative study, we sought to characterize the needs, perceptions, and preferences of patient and healthcare workers (HCW) related to TEC in Kampala, Uganda, to inform design of future interventions to strengthen delivery of TEC, with the ultimate goal of improving management and outcomes of TB treatment in high HIV-TB burden settings.

METHODS

Setting

Uganda has a high prevalence of TB (253 per 100,000) and HIV (6% among 18–49-year-olds) (Uganda Ministry of Health, 2017). In 2019, the estimated TB incidence rate in Uganda was 200 per 100,000 population and the mortality rate was 35 per 100,000 population (Uganda Ministry of Health, 2019). In Uganda, primary health centres provide all health services for TB and HIV free-of-charge, including integrated diagnostic testing and treatment for both conditions. This study was carried out at Kisenyi Health Centre, a high-volume, public, primary care facility in Kampala, Uganda. The facility is located in a crowded commercial area and serves a large population of urban refugees, immigrants, and low-income households. Kisenyi registers over 750 TB patients per year with the national TB program, and in 2018 reported a treatment success rate of 75%, similar to the national rate of 72% (WHO, 2019). From routine data, approximately half of all TB patients at Kisenyi are co-infected with TB, higher than the rate of 40% reported nationally in 2019 (World Health Organization, 2020).

National TB treatment guidelines (Uganda Ministry of Health, 2010) specify that routine TEC should be provided to all patients taking TB treatment, but do not specify who should provide TEC or when and how frequently TEC should be provided during treatment. The

Ministry of Health does provide health workers with a laminated 24-page TB and HIV Health Education Flipchart that covers the etiology and manifestations of TB disease, symptoms, transmission, testing, treatment and side effects, prevention, and HIV-TB interactions, using short textual explanations and cartoons. At Kisenyi, TEC is usually provided by the nurses and community health workers who run the TB clinic. Patients are seen first in the general out-patient department (OPD) where all patients are screened for TB symptoms and possible TB patients are identified and referred to the on-site laboratory for TB evaluation. In the OPD, the first TB education session is provided in a group format to all patients in attendance, including those without TB symptoms. TB patients later receive their first in-depth individual counselling session at the time of TB diagnosis and treatment initiation, with subsequent counselling sessions planned for the follow-up visits scheduled biweekly for 2 months and then monthly for 4 months. In addition, all persons living with HIV (PLHIV) receive both individual and group counselling to improve knowledge and adherence in antiretroviral therapy clinics at Kisenyi and elsewhere in Kampala, regardless of TB status. Each clinic day, PLHIV attending the HIV clinic at Kisenyi are screened for symptoms of TB and referred for testing to the TB clinic if presumed to have TB.

Study design and population

We conducted a formative, qualitative study of patient and provider perceptions, preferences, and experiences related to TEC. This included four focus group discussions (FGDs) with HCWs based at the TB and HIV clinics, and seven FGDs with TB patients between September 2017 and December 2018. After observing that TB patients living with HIV were not well-represented in the first five patient FGDs, we conducted two additional FGDs with HIV-TB patients only.

Recruitment

We invited all HCWs available on the clinic roster from the TB and HIV clinics to participate in the FGDs. We also recruited a convenience sample of recently registered active TB patients for FGDs whenever at least four patients were simultaneously present and available at the clinic. We excluded patients unable to provide informed consent, and those not conversant in English or Luganda. We compensated all patients and providers with 10,000 Ugandan shillings (~3 USD) for their participation.

Data collection and instruments

The FGDs were conducted at Kisenyi Health Centre by trained research staff fluent in both Luganda and English. Facilitators included a male social scientist, two female medical officers and a female social worker as the note taker. Two or three people from the research team facilitated each FGD. English was used during HCW FGDs, and either English or Luganda for patient FGDs, according to patient preferences.

The HCW FGD guide included seven open-ended questions exploring participant perceptions of TEC and their understanding of current practices (Appendix I). The patient FGD guide (Appendix II) included five questions exploring patients' experiences with and perceptions of TEC, and their suggestions for improving its provision and reach. Prior to each patient discussion, the moderator provided a definition of education and counselling

and invited participants to offer their opinions on these services at the facility, including opportunities for improvement. Health care workers were explicitly asked about the quality of education and counselling. We considered any feedback from patients and health care workers on areas for improvement as assessments of quality. Discussions were recorded and transcribed for analysis. Those conducted in Luganda were professionally translated into English. The research team (IA, JMG, MAH, AH, JLD) held a debriefing session after each FGD; topics and themes requiring further exploration were added as prompts for subsequent FGDs.

Analysis

Transcripts were imported into Atlas.ti (Scientific Software Development GmbH, Berlin, Germany) for inductive analysis. Two authors (IA, AH) read all transcripts independently to explore the full data during each round of data collection, then carried out open-coding to identify concepts that emerged from the data in each round. The two reviewers created an initial codebook that was iteratively updated as novel codes emerged. Finally, after completing both rounds of review, we compared and contrasted codes between the rounds in an iterative process designed to compensate for the underrepresentation of TB patients living with HIV in the first round of data collection (Lindsay, 2018; Saldana, 2013). In instances where all authors agreed that two codes represented the same theme, the codes were collapsed. Once all text had been coded, the authors re-read the transcripts in view of the new codes. This led to the development of categories that were then organized into overarching themes (Saldana, 2013; Sargeant, 2012; Thomas, 2006). The codebook was then discussed, further refined, and reapplied with guidance from a doctoral-trained social scientist (MAH).

Protection of human subjects

All participants provided written informed consent. The School of Medicine Research and Ethics Committee at the Makerere College of Health Sciences, the Uganda National Council for Science and Technology, and the Human Investigation Committee at Yale University approved the study.

RESULTS

Characteristics of study participants

All 25 HCWs available from the TB and HIV clinic rosters agreed to participate in one of three HCW FGDs (Table 1). The HCWs included 6 nurses, 5 counsellors, 4 CHWs, 4 clinical officers, 4 laboratory technicians, and 2 doctors. All participants had at least one year of work experience in the TB and/or HIV clinic (median 4; interquartile range (IQR) 1 – 7). Median age was 30 years (IQR 26 – 44), and fifteen (60%) were women.

Thirty-seven patients were approached, and all consented to and participated in one of seven FGDs: one FGD had seven patients, one had six patients, four had five patients each, and one had four patients (Table 2). The median age of the patient participants was 32 years (IQR 25 – 39), and 8 (22%) of them were women. Fourteen (38%) patients were living with

HIV, two (5%) had no HIV results available, and 21 (57%) had recently tested HIV-negative. Seven (19%) patients reported at least one prior TB episode.

Participants agreed that TEC was beneficial to patients, despite challenges to its delivery. They suggested that redesigning TB services to follow successful HIV service models could provide solutions to some of the challenges to TEC delivery. Below, we present the study findings under three broad domains: perceived benefits of TEC; perceived challenges to the delivery of TEC; and preferences for improvement of TEC.

Perceived benefits of TEC

Although not all patient participants reported having received TB education by the time of the FGDs, patients and HCWs agreed that TEC could improve knowledge, unravel myths about TB, and reduce stigma and discrimination.

“[TEC] should be here.... People out there discriminate us... Even your own relatives, they say so much, and people hate you.” (Male TB patient, TB FGD)

Moreover, the effects of TEC could go beyond the individual patient to benefit the wider community if patients receiving TEC could in turn educate household members and other treatment supporters about TB.

“...when you get to learn more about this infection you can as well teach people at home to avoid it.” (Male TB patient, TB-HIV FGD)

Respondents believed that sharing knowledge in this way could improve patient adherence, as well as facilitate earlier detection of TB and increased access to care for affected individuals in families and communities (Table 3).

TEC improves patient adherence to medication—Several patients described how TEC improved their understanding and knowledge, motivating them to complete treatment.

“...I am one of those people who is not good at taking medication at all. But going through the TB education and counselling has made it like a law for me to take the medication. Every time I hesitate to take my medicines, I remember that I will be taking myself backwards and undoing all the good I have done so far. So, the education I received completely changed the way I understood the need to take my medication.” (Male TB patient, TB FGD 2)

Many HCWs agreed that TEC was important for adherence; however, some also attributed treatment interruption to “patient weakness” – a lack of opportunity and motivation – rather than to a lack of knowledge or inadequate TEC.

TEC could increase household and community knowledge and reduce stigma—Participants from both groups felt that a greater emphasis on TEC could lead to a spill over of that TB knowledge from patients to the wider community, including patient family members. Patients felt that community members need to be better informed about how TB is transmitted; about how it is highly curable; and about when and where to seek evaluation for TB symptoms. They further suggested that CHWs could bridge this gap. Patients as well as HCWs noted that stigma exists even within the Kisenyi clinic.

“[HCWs in other departments] hear someone coughing and quickly send them to TB [the TB unit]. You have not even shown these people where TB department is, these patients might even get lost... so even our attitude needs to be improved.” (TB clinic HCW, HCW FGD 1)

HCWs pointed to the success of HIV education and counselling programs in raising knowledge and awareness as an example of how effective TEC could similarly raise awareness of TB in the community. Patients and HCWs suggested that TB is more stigmatized than HIV, both in the community and in the clinic, while simultaneously considered to be less serious than HIV because TB is curable. They thought that improved TEC could reduce enacted stigma and discrimination in both settings by encouraging a positive attitude toward TB patients and increasing knowledge about TB.

“If it is known like it is for HIV, then people will be aware of anyone coughing.... Someone will be cautious, and say, ‘is this TB’? And they will go and test after one week or two weeks.... So, it is more of benefit.” (TB clinic HCW, HCW FGD 1)

Perceived challenges to delivery of TEC

HCW and patient participants reported similar challenges to delivery of TEC from different but complementary perspectives. (Table 4).

Competing time and human resource demands—Both HCWs and patients were concerned about long wait times at the clinic. This was especially true for patients who had required more than one visit to receive the TB diagnosis. These individuals emphasized that long time periods spent at the clinic kept them away from their regular economic activities, leaving them feeling too distracted to benefit from the TEC sessions.

“If you are being taught and your thoughts are on something else, you do not gain much.” (Male TB patient, TB FGD 1)

HCWs acknowledged long wait times for patients at the TB clinic, due to human resource shortages and several competing demands including dispensing TB medications, updating registers, counselling and seeing both new and returning patients. For example, unlike the HIV clinic which employs dedicated counsellors, in the TB clinic, providers must both see and counsel the patients themselves, giving them only enough time for the baseline TEC session and not for TEC at follow-up.

“... Part of the challenge is like unlike in the HIV clinic where we have counsellors who are dedicated to provide information and give time to these patients in the TB units all over Uganda we do not have counsellors... one nurse cannot provide adequate counselling when he or she is going to attend to fifty patients so in the end the patients do not benefit so much in the counselling.” (TB clinic HCW, HCW FGD 1)

Limited space at the TB clinic—HCWs noted that the limited space at the TB clinics affected their ability to provide general TB education, during the long periods that patients spent waiting for diagnostic evaluation and treatment.

“...There is no waiting area...the issue is space.” (TB clinic HCW, HCW FGD 1)

Lack of integration of TB-HIV care—The use of separate individual patient records in the HIV and TB clinics exacerbated communication gaps, so that TB clinic staff were usually not aware of what services a patient had received at the HIV clinic. HCWs suggested that, given the strong association between TB and HIV, improved integration of TB and HIV services across both clinics might improve treatment outcomes.

‘... At the end of it when they have completed 6 months of anti-TBs then we discover that they have not been taking ARVs. (HIV clinic HCW, HCW FGD 1)

They noted that in addition to improved coordination between the HIV and TB clinics within a health facility, in-service training on HIV management for TB clinic staff and on TB management for HIV clinic staff was necessary.

“... You need to educate them on HIV and TB together because they are taking a whole package together...” (HIV clinic HCW, HCW FGD 1)

Lack of interpreter services—A lack of interpreter services was an additional barrier, with some HCWs experiencing difficulties with TEC when the patient did not speak the most commonly used dialects.

“... but the challenge I have is that sometimes there is a language barrier. I use English, but in most [patients] complain, we don’t know English, so after using English I try and interpret in Luganda, I use a little Luganda, I was suggesting if we can have someone to translate, we can do it.” (TB clinic HCW, HCW FGD 4)

Preferences for improvement of TEC

Participants offered suggestions for how TEC should be organized for maximal efficacy. While patient and HCW preferences often converged, the reasons underlying these preferences often diverged. Patients identified a need for services that improved the care experience, while HCWs preferred solutions to ease their workloads (Table 5).

Preferences for group TEC sessions with opportunities for discretionary individual counselling—Patients and HCWs both valued group education and counselling. Patients believed that group sessions allowed them to learn from questions posed by others in the group and provided extra opportunities to learn from each other’s experiences.

“So, when we come together as TB patients and learn from each other... In addition, the questions you might have as an individual you will ask as an individual and yet if you are in a group, you will also hear what others have to say, including things you might have forgotten!” (Female TB patient, TB FGD)

Patients acknowledged however that individual sessions should supplement group sessions and that individual sessions were needed to provide opportunities to discuss private issues that they might not wish to share in a group setting. Patients also felt that individual sessions could allow them to provide individual context for their questions and to ask questions that went beyond the routinely provided information.

“...But each of us have our questions that we cannot speak about in public; we need a way where someone can meet a health worker in private.’ (Male TB patient, TB FGD 5)

In exploring preferences for either group or individual TEC, patients drew on their present TEC experience, on experiences from the HIV clinic for the TB-HIV patients and from previous TB treatment for those for whom this was not an initial TB episode.

HCWs preferred group TEC because it reduced the time spent on TEC and therefore on their overall workload. However, they cautioned that new patients needed individual sessions at the beginning of treatment.

“We could also encourage the group counselling; this way we reduce the time we are spending on each client... if we talk to them as a group, we reduce the waiting time. It [the group counselling] is difficult for the new clients though.” (HIV clinic HCW, HCW FGD 4)

They reasoned that new patients were usually anxious about receiving a TB diagnosis and individual TEC sessions were most appropriate at treatment initiation to verify each patient’s understanding and knowledge about TB and motivation to take medication.

Desire for more consistent and standardized provision of and training for TEC

—Participants reported that most TEC occurred in a single session at treatment initiation. Most patients and healthcare providers preferred continual TEC throughout treatment to a single ‘comprehensive’ session at treatment initiation; they felt that the subsequent sessions should focus on reinforcing their knowledge, clarifying uncertainties and giving reminders, and providing new information relevant to their stage of treatment.

“Each time I return to pick medication, I should receive TEC.” (Male TB patient, TB FGD 1)

“Whenever they come visit, I think it’s important to put in some more information so that they get reminded.” (TB clinic HCW, HCW FGD 4)

HCWs noted that the standard schedule of follow-up visits facilitates continual TEC and pointed out the additional need to standardize TEC, including continued training to develop and maintain the skills of personnel.

“So, what I am saying, counselling skills, in some people, [they are] half-baked. So, when you are fully having counselling skills... [Even] if there is no time but the patient will appreciate what you have done.” (TB clinic HCW, HCW FGD 4)

Preferences for TEC providers—There was less agreement among patients and HCWs regarding who should provide TEC. HCWs simply emphasized that those delivering TEC be well-trained and skilled.

Several patients preferred for TEC to be provided by doctors because they felt that doctors had the best training and knowledge about TB.

“I prefer the doctor because it is easy for them to understand your complaints and find a solution. And this might not be the same with the CHWs who might have to consult first.” (Male TB patient, TB FGD 1)

However, these patients acknowledged that this might not be feasible given the small number of available doctors. They agreed that the most important aspect was for the counselling to be provided by HCWs with specific training on TEC, irrespective of their cadre.

“I think anyone who is trained to counsel and has the interest to pass the information [to patients] ... can do the counselling.” (TB clinic HCW, HCW FGD 4)

In addition to these preferences and as a solution to the human resource and time constraints, participants suggested that former TB patients, peer educators, and community health workers could be trained to provide TEC.

“...a former TB patient, who knows well how TB feels, who knows how tablets are swallowed...they know what it means to take TB medicines because it is not easy to take this medicine and should be the ones to educate TB patients.” (Female TB-HIV patient, TB FGD 7)

This idea resonated most with TB patients who were also living with HIV. HCWs also liked this idea but cautioned that peer educators must be appropriately paid and motivated.

Patient suggestions to improve and spread the benefits of TEC included making the wider community more aware of TB and TB services through education provided by community health workers and by radio and television advertisements. They also felt that the visibility and availability of TB services should be increased. In their opinion, these interventions would reduce the stigma they felt from the community and enable easy and quick access to TB services.

Other suggestions—Participants mentioned the possibility of using other means to supplement face-to-face TEC, including mobile phone text messages or recorded audio messages that they could access on their phones and play back at appropriate times.

“I think the issue would be what kind of message; on WhatsApp or a normal SMS? The advantage is that it is not time consuming to deliver and to listen to. It doesn't matter what you are doing. You can be able to take some time off to listen to the messages. And that is helpful; I think it can be additional but not equal to in person education because I will not ask the phone. Whatever messages are on the phone are all I will get and I cannot ask further questions and gain deeper understanding and yet when we are together we see new things; we hear and ask questions.”(Male TB patient, TB FGD 1)

They acknowledged the limitations of messaging, such as the need to be literate enough to access and read messages and the inability to clarify recorded messages, but they thought that overall, phone messaging would be helpful in enhancing TEC for those patients who could access and use the technology.

“...there even those who just cannot read a message and you find them all on the phone but unread.”

Patients suggested additional educational materials like brochures and pamphlets, and some requested that community health workers perform household visits and educate their families as well. These suggestions underscored their desire to have a more comprehensive understanding of TB. HCWs felt that community health workers could provide additional TEC in households in order to compensate for the lack of comprehensive TEC at the health facilities.

“I also think it is good to have TB education here but also provide more reading material so that when you get home and you have forgotten something you can still get it from the reading materials.” (Male, TB-HIV patient, TB FGD 7)

DISCUSSION

Although universally recommended, TEC is often either brief and non-standardized, or non-existent in high TB-burden settings in Africa (Ayakaka et al., 2017; Loeliger et al., 2016). This study sought to explore patient and health worker perspectives on TEC in a busy health centre in a crowded urban setting in Kampala, Uganda. Patients and providers valued TEC and believed it had far-reaching benefits for patients and the community, but described a need to streamline its delivery to be timelier, effective, efficient, and patient-centered. Both patients and providers had suggestions for improving TEC delivery, particularly the idea of adapting the model of peer educators and counsellors popular in the HIV clinic to improve patient-centeredness and reduce the work-load for providers. The expected benefits included not only improved TB knowledge and adherence, but also reduced stigma, enhanced patient experience, and improved community knowledge about TB disease.

The lack of standardization of the content and timing of TEC was perceived to be a major disadvantage and both patients and health workers felt that the delivery of TEC must be structured to better meet their needs and time schedules. For the patients, time spent awaiting a TB diagnosis meant that they often had to forego crucial economic activities and this opportunity cost was high. For health workers, there was often not enough time to deliver comprehensive TEC and perform other essential activities for the large number of patients, so TEC was shortened or skipped. Indeed, in our previous work, we found that TEC was assigned a low priority in the context of heavy clinic workloads and understaffing (Ayakaka et al., 2017). However, long wait times for laboratory results and/or treatment initiation provide an opportunity to initiate TEC earlier, and both patients and providers liked the idea of group counselling, especially prior to diagnosis. TEC provided to those not confirmed to have TB would nonetheless help increase TB knowledge in the community. While opinions varied, most patients and HCWs felt that continual counselling at every refill appointment would increase motivation, provide social support, and enhance adherence. Standardizing the content, mode of delivery, and timelines for TEC to fit patient and health care worker preferences could further streamline the process and help assure quality, details that are currently missing from national and international guidelines (Uganda Ministry of Health, 2010; WHO, 2010, 2014; World Health Organization, 2017). Médecins Sans Frontières (MSF) has developed patient support, education and counselling guidelines that

comprehensively lay out protocols for delivery of TEC, including content that addresses both biomedical and biosocial concerns and a timely, relevant, and longitudinal schedule for its delivery (MSF, 2018).

Participants repeatedly compared the counselling experiences in the TB and HIV clinics to identify opportunities to improve TEC. In particular, patients proposed that TEC adapt successful models already operating in the HIV clinic, including standardization of education and counselling protocols and use of peer educators (Adeomi et al., 2014; Hall et al., 2010; O'Malley et al., 2017). TB-HIV patients already attending the HIV clinic placed greater emphasis on the value of TEC than TB patients not living with HIV and emphasized disparities in service provision between the two clinics. While these disparities may reflect the greater resources available to HIV programs as compared to TB programs in Uganda (\$693 vs. \$22 million in 2019) (Matsubayashi et al., 2011; Uganda Ministry of Health., 2019; World Health Organization, 2020), the transfer of best practices from the HIV clinic to the TB clinic provides another opportunity to leverage HIV investments to strengthen health systems. For example, HIV clinics have evolved more efficient care processes that employ dedicated counsellors and efficient models of care that provide patient education and counselling during waiting times, thereby enhancing benefits and shortening visits (Amanyire et al., 2016; Castelnovo et al., 2009).

Patients were also eager for the wider community to learn more about TB through better-informed TB patients and mass media campaigns. They suggested that improving TB literacy in the population would have secondary benefits beyond knowledge and adherence, including higher rates of disclosure of HIV and TB status and reduced stigma. These and other benefits are well described in the HIV literature, where the positive spill-over effects of education have been shown to increase HIV status awareness, avert secondary complications, and lower healthcare costs for patients (Kanekekar, 2011; Ruzagira et al., 2017; Sommerland et al., 2017).

Finally, patients have other TEC needs that go beyond increased TB knowledge, such instruction on adherence and visit planning strategies to avoid treatment interruptions and losses to follow-up. However, some HCWs attributed treatment interruptions primarily to a lack of motivation rather than to a lack of knowledge or to structural barriers to adherence, using language that suggests that they blame patients for these adverse outcomes. In other settings, the kinds of negative perceptions and attitudes among health workers are associated with feelings of alienation among patients, as well as delays in diagnosis and loss of patients from the formal health system (Bulage et al., 2014; Chimbatata et al., 2017). This pattern has also been well reported in the HIV literature, where adopting more patient-centred attitudes has led to consequent reductions in stigmatizing behavior (Bond & Nyblade, 2006; Dapaah, 2016; Flickinger et al., 2016; Vorasane et al., 2017). This may be partly attributable to the special emphasis on bio-social as well as bio-medical concerns as part of the global HIV response, an approach that might also benefit TEC (Castro & Farmer, 2005; Deacon, 2006; *Global HIV/AIDS Response: Epidemic Update and Health Sector Progress Towards Universal Access: Progress Report 2011*, 2011; Mayer et al., 2012; Paz-Soldán et al., 2013; World Health Organization, 2016).

Study strengths

The study had multiple strengths. First, we sampled TB patients, including persons living with HIV, to saturation, and also enrolled all HCWs at the health centre, to obtain a broad perspective on TEC. Second, this study describes not only the barriers faced by TB patients and HCWs, but also their suggested solutions. Sourcing solutions from the ideas and lived experiences of patients and HCWs through community-engaged research provides a concrete strategy for making TB care more patient-centred. Finally, in-light of the paucity of data about how to best deliver TEC in high burden settings, this study provides insights on how to tailor TEC for successful implementation.

Study limitations

There were also some limitations. We did not collect information about the content of the education and counselling. Some but not all participants had received TEC before the focus group discussions, but we did not record this information and were therefore unable to determine how actual experience with TEC influenced participant suggestions. Although health care workers acknowledged that TEC was not standardised, more practice-based research is needed on what is covered and how the content of education and counselling interacts with the mode of delivery. Second, our clinic-based, convenience sampling strategy may over-represent TB patients who are more highly engaged in their TB care than the average TB patient. We also did not examine how gender may influence education and counselling preferences, an important area for future research. Finally, our findings may not be generalizable as they provide perspectives from only one, urban healthcare facility. Nonetheless, as additional contextual information is collected, these findings may inform the design of interventions to deliver TB education and counselling more effectively in other high-volume settings.

CONCLUSION

Overwhelmingly, participants saw the value of TEC in expanding community knowledge, reducing TB stigma and improving TB treatment outcomes. Participants identified clear benefits of TEC and opportunities to improve TEC in resource-constrained TB clinics. Some of their priorities include standardizing TEC, dedicating physical space to TEC, integrating TB care with HIV care, expanding TEC training among healthcare providers, and providing TEC during clinic waiting periods. To realize these opportunities within current resource constraints for TB programs, patients and HCWs suggested adapting peer educator models and other low-cost strategies that have succeeded in HIV clinics.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1:

Characteristics of participants in each health care worker focus group discussion

	Sex	Age, years	Experience, years	Health Care Worker Focus Group Number
1.	F	24	1	HCW FGD 1
2.	F	25	5	
3.	F	27	7	
4.	M	25	5	
5.	M	38	5	
6.	M	33	8	
7.	F	50	5	
8.	F	29	1	HCW FGD 2
9.	F	36	10	
10.	F	48	11	
11.	M	22	1	
12.	M	18	1	
13.	M	29	4	
14.	M	46	10	
15.	F	36	1	HCW FGD 3
16.	F	27	1	
17.	F	26	2	
18.	F	44	2	
19.	F	47	3	
20.	F	28	3	
21.	F	44	5	
22.	F	40	16	
23.	M	23	1	
24.	M	30	4	
25.	M	50	19	

Abbreviation: F, female; M, male.

Table 2:

Characteristics of participants in each TB patient focus group discussion

	Sex	Age, years	Occupation	Education level	HIV status	TB episodes	TB Patient Focus Group Number
1.	F	27	Factory worker	Primary	Unknown	1	TB FGD 1
2.	M	32	Businessman	Secondary	Negative	2	
3.	M	45	Builder	Secondary	Positive	2	
4.	F	30	Housewife	Primary	Negative	1	
5.	M	40	Self-employed	Primary	Negative	1	
6.	M	49	Business	Secondary	Negative	1	
7.	M	32	Shopkeeper	Secondary	Positive	1	
8.	M	39	Motorcycle rider	Secondary	Negative	1	TB FGD 2
9.	M	25	Businessman	Secondary	Negative	1	
10.	M	32	Plumbing	Secondary	Unknown	2	
11.	M	39	Builder	Primary	Negative	1	
12.	M	17	Cleaner	Secondary	Negative	1	
13.	F	18	Student	Secondary	Negative	1	TB FGD 3
14.	M	18	Student	secondary	Negative	1	
15.	M	63	Car mechanic	Primary	Negative	1	
16.	M	54	Business	Secondary	Positive	1	
17.	M	39	Not working	None	Negative	1	
18.	M	39	Motorcycle rider	Secondary	Negative	1	TB FGD 4
19.	M	25	Businessman	Secondary	Negative	1	
20.	M	32	Plumbing	Secondary	Unknown	2	
21.	M	39	Builder	Primary	Negative	1	
22.	M	17	Cleaner	Secondary	Negative	1	
23.	M	23	Casual labourer	None	Negative	1	TB FGD 5
24.	M	31	Storekeeper	Primary	Negative	1	
25.	M	22	Surveyor	Secondary	Negative	1	
26.	M	24	Maize mill manager	Secondary	Negative	1	
27.	F	38	Businesswoman	Secondary	Positive	1	TB FGD 6
28.	F	22	Unknown	Secondary	Positive	1	
29.	F	28	Unknown	Unknown	Positive	1	
30.	M	34	Unknown	Unknown	Positive	1	
31.	M	30	Unknown	Unknown	Positive		
32.	M	32	Businessman	Primary	Positive	1	TB FGD 7
33.	M	28	Motorcycle	Secondary	Positive	2	
34.	M	36	Saloon attendant	Primary	Positive	1	
35.	M	43	Businessman	Secondary	Positive	1	

	Sex	Age, years	Occupation	Education level	HIV status	TB episodes	TB Patient Focus Group Number
36.	F	20	Businesswoman	Primary	Positive	2	
37.	F	47	Businesswoman	Secondary	Positive	2	

Abbreviation: F, female; M, male.

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Table 3:

Perceived benefits of TEC

Benefit	Quote
TEC improves patient adherence to medication	<p><i>'... In my case, I am one of those people who is not good at taking medication at all. But going through the TB education and counselling has made it like a law for me to take the medication. Every time I hesitate to take my medicines, I remember that I will be taking myself backwards and undoing all the good I have done so far. So, the education I received completely changed the way I understood the need to take my medication.'</i> (Male TB patient, TB FGD 2)</p> <p><i>'... it helps them on adherence because they would know when to take drugs, their side effects and in case they miss what comes out.'</i> (TB clinic HCW, HCW FGD 1)</p>
TEC could increase household and community knowledge and reduce stigma	<p><i>'[TEC] should be here.... People out there discriminate us; everywhere including our families. He has TB, open the windows... we are discriminated against.... Even your own relatives, they say so much, and people hate you.'</i> (Male TB patient, TB FGD)</p> <p><i>'... You know, when you get to learn more about this infection you can as well teach people at home to avoid it...'</i> (Male TB patient, TB-HIV FGD)</p> <p><i>When I came back today, one of the health workers said, 'Do not infect me with your TB, get this thing [mask] and cover your mouth.'</i> (Female TB patient, TB FGD 3)</p> <p><i>'[HCWs in other departments] hear someone coughing and quickly send them to TB [the TB unit]. You have not even shown these people where TB department is, these patients might even get lost... so even our attitude needs to be improved.'</i> (TB clinic HCW, HCW FGD 1)</p> <p><i>'Most people know HIV; this is how they get HIV; this is how it can present. But when it comes to TB, someone coughs for over a month and he goes to the pharmacist, doing self-medication. I think counselling will do a great deal in people knowing if I cough and I am taking medicine, nothing is changing it might be pointing to TB. That can be known in the population. If it is known like it is for HIV; then people will be aware of anyone coughing Someone will be cautious, and say, 'is this TB'? And they will go and test after one week or two weeks.... So, it is more of benefit.'</i> (TB clinic HCW, HCW FGD 1)</p>

Abbreviations: CHCW, community health worker; FGD, focus group discussion; HCW, health care worker; TB, tuberculosis; TEC, TB education and counselling.

Table 4.

Challenges to delivery of TEC

Challenges	Quote
Competing time demands and human resource shortages	<p>'In my opinion... we are not economically stable in terms of income... the doctor or health worker is teaching and you as a patient have been promised some money and are expecting money from someone... you are expectant... you are likely to tell the health worker that today, I will not be able to attend the education. Can I just get the medication and go? So that I can access the money promised, because, we need the money to cater for our needs.' (Male TB patient, TB FGD 1)</p> <p>'If you are being taught and your thoughts are on something else, you do not gain much.' (Male TB patient, TB FGD 1)</p> <p>'... we come very early in the morning [to the TB clinic], but I do not know whether health workers are few...'. (Male TB-HIV patient, TB FGD 7).</p> <p>'...so, you find someone sitting the whole day and they get tired and go away, that means we will not be able to track whether they were here or not and that means they will have inadequate counselling... and their adherence will be poor.' (TB clinic HCW, HCW FGD)</p> <p>'... part of the challenge is like unlike in the HIV clinic where we have counsellors who are dedicated to provide information and give time to these patients in the TB units all over Uganda we do not have counsellors... one nurse cannot provide adequate counselling when he or she is going to attend to fifty patients so in the end the patients do not benefit so much in the counselling.' (TB clinic HCW, HCW FGD 1)</p> <p>'Yeah, so in most cases I want to be honest... when the patients are beginning their treatment, they really get comprehensive counselling. Only the other times when they come for refill, and you don't have the time to go over things repeatedly, then you just do chap, chap [quickly]'. (TB clinic HCW, HCW FGD 4)</p>
Limited space in the TB unit	<p>'...there is no waiting area... Yes, the issue is space'. (TB clinic HCW, HCW FGD 1)</p>
Lack of integration of TB-HIV care	<p>'...I don't know whether they do not have the information because I do not see them counsel HIV positive clients. Me, I do not have information on TB... So likewise, even me I would not counsel someone with TB, so, we are the same. You need to educate them on HIV and TB together because they are taking a whole package together... [especially], when they come back for review.' (HIV clinic HCW, HCW FGD 1)</p> <p>'... At the end of it when they have completed 6 months of anti-TBs then we discover that they have not been taking ARVs. They say that you see the side effects of efavirenz, you see this and this, just because they are not reviewed [for adherence to both TB medications and ARVs] on each visit so you find that they are not taking.' (HIV clinic HCW, HCW FGD 1)</p>
Lack of interpreter services	<p>'... but the challenge I have is that sometimes there is a language barrier. I use English, but in most [patients] complain, we don't know English, so after using English I try and interpret in Luganda, I use a little Luganda, I was suggesting if we can have someone to translate, we can do it.' (TB clinic HCW, HCW FGD 4)</p>

Abbreviations: CHW, community health worker; FGD, focus group discussion; HCW, health care worker; TB, tuberculosis; TEC, TB education and counselling.

Table 5.

Preferences for improvement of TEC

Preference	Quote
Preference for group TEC sessions with the opportunity for discretionary individual counselling	<p>'So, when we come together as TB patients and learn from each other... In addition, the questions you might have as an individual you will ask as an individual and yet if you are in a group, you will also hear what others have to say, including things you might have forgotten! Someone will ask about them and you will gain from being there.' (Female TB patient, TB FGD)</p> <p>'... we have different challenges and sometimes health workers never get to know about our challenges. Even with the availability of counsellors, when you get to them, they ask what is on the form and what you are suffering from... but each of us have our questions that we cannot speak about in public; we need a way where someone can meet a health worker in private.' (Male TB patient, TB FGD 5)</p> <p>We could also encourage the group counselling; this way we reduce the time we are spending on each client... if we talk to them as a group, we reduce the waiting time. It [the group counselling] is difficult for the new clients though.' (HIV clinic HCW, HCW FGD 4)</p>
Desire for more consistent and standardized provision of and training for TEC	<p>'Each time I return to pick medication, I should receive TEC.' (Male TB patient, TB FGD 1)</p> <p>'It would be good to repeat due to forgetting. You might come here, and you find the health worker educating someone or some people, you sit in and listen. Because you might already have had your medication and are taking it but when you come and find a session, it helps you learn a bit more and it would help me a lot.' (Male TB patient, TB FGD 2)</p> <p>'...we interact these patients at the time of diagnosis, then every 2 weeks when they are in the initial phase and then monthly in the continuation phase. And so, whenever they come visit, I think it's important to put in some more information so that they get reminded.' (TB clinic HCW, HCW FGD 4)</p> <p>'So, what I am saying, counselling skills, in some people, [they are] half-baked. So, when you are fully having counselling skills... [even] if there is no time but the patient will appreciate what you have done.' (TB clinic HCW, HCW FGD 4)</p>
Preferences for TEC providers	<p>'I think anyone who is trained to counsel and has the interest to pass the information [to patients] ... can do the counselling.' (TB clinic HCW, HCW FGD 4)</p> <p>'I prefer the doctor because it is easy for them to understand your complaints and find a solution. And this might not be the same with the CHWs who might have to consult first. They on their own might not have learnt about what you are asking about and must consult their seniors and yet for the doctor this is what they study, and they have the experience. They are therefore able to tell you that this is what it is.' (Male TB patient, TB FGD 1)</p> <p>'In my opinion, the health worker who when I come here treats me and gives me my medication should be the one to offer me TB...counselling' (Male TB patient, TB FGD 2)</p> <p>'... a former TB patient, who knows well how TB feels, who knows how tablets are swallowed, should be the right person... take him or her for training and that person, right from what he/she experienced, ... remember that person has suffered from TB before, just the same way it is when it comes to HIV, it is the HIV infected persons who give those health education talks, those who take ARVs [antiretroviral drugs], who know how hard it is to take ARVs, are the ones who educate us. It should be done in a similar way. You should get people who have ever been infected with TB, who have ever been on TB medication...they know what it means to take TB medicines because it is not easy to take this medicine and should be the ones to educate TB patients. That is what I propose.' (Female TB-HIV patient, TB FGD 7)</p>

Abbreviations: CHW, community health worker; FGD, focus group discussion; HCW, health care worker; TB, tuberculosis; TEC, TB education and counselling