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## Social constraints to TB/HIV healthcare: accounts from coinfecting patients in South Africa

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### Abstract

There is a growing imperative to improve the coordination and collaboration of TB and HIV healthcare services in response to escalating rates of TB/HIV coinfection. Patient-specific challenges associated with the delivery of TB/HIV care have been minimally explored in this regard. As part of a larger study conducted in South Africa, this article highlights coinfecting patients' experiences with TB and HIV healthcare in light of their broader social environments. Qualitative, in-depth interviews were conducted with 40 adult, coinfecting patients (24 women, 16 men) and 8 key-informant healthcare workers at 3 urban/peri-urban, ambulatory, public health clinics in the high-burden province of KwaZulu-Natal. Transcribed interviews were analyzed under a modified grounded theory approach to capture subjective meanings of healthcare experience subsequent to patients' co-diagnosis with TB and HIV. Emerging analytic themes highlighted critical sociomedical constraints to TB/HIV care in relation to patients' income and employment, eligibility for social assistance and antiretroviral treatment, fears around illness disclosure, social and material support, and treatment adherence. Patients' healthcare experiences were bound by their poor access to essential resources, multiple life responsibilities, disparate gender roles, limits within the healthcare system and the stigmatizing social symbolism of their illness. Overlapping social inequalities perpetuated coinfecting patients' experiences with stigma and collectively mediated their health decisions around disclosure, adherence and retention in medical care. The study urges a contextualized understanding of the social challenges associated with TB/HIV healthcare, and helps inform more patient-sensitive and socially-responsive interventions against the co-epidemic.

### Introduction

The confluence of the tuberculosis (TB) and HIV/AIDS epidemics is most severely experienced in South Africa, where the social drivers of infection are both unique and severe. The stratified migrant labour system, perpetuated during apartheid, and the social inequality that persists to date are considered key determinants to TB, sexually-transmitted infections and more recently, HIV transmission (Abdool Karim, Churchyard, Abdool Karim, & Lawn, 2009; WHO, 2010). National reports indicate that 73% of incident TB cases are HIV-coinfecting, and 84% of TB deaths are attributable to AIDS (Padarath & Fonn, 2010). HIV prevalence is 3–6 fold higher among women, and those living in poverty are disproportionately affected (Abdool Karim, et al., 2009).

The Department of Health has pooled resources to improve coordination and collaboration between TB and HIV programs, and decrease the burden of coinfection in people at risk for

or living with TB or HIV (DOH, 2004; NTCP, 2004). In 2009 however, fewer than 50% of TB patients knew their HIV status and less than 8% of HIV patients were screened for latent TB infection. Only 42% of eligible coinfecting patients received antiretroviral treatment (ART), reflecting serious challenges to the uptake and delivery of joint services (Padarath & Fonn, 2010; WHO, 2010).

Relatively little is understood about patient-specific challenges to TB/HIV healthcare. Studies show that HIV testing and diagnosis of coinfection are impeded by TB patients' fear of HIV/AIDS (Daftary, Padayatchi, & Padilla, 2007; Mahendradhata, Ahmad, Lefevre, Boelaert, & Van der Stuyft, 2008; Yi et al., 2009). In many high-burden settings, TB symbolizes AIDS and stigmas associated with HIV are transferred upon persons exhibiting signs of TB (Bond & Nyblade, 2006; Daftary, et al., 2007). Consequently, TB suspects delay health-seeking against anticipation of an HIV co-diagnosis (Mavhu et al., 2010; Ngamvithayapong, Winkvist, & Diwan, 2000). Studies with coinfecting patients show that coinfection is associated with poorer mental health and quality of life (Deribew, Tesfaye, et al., 2010; Deribew et al., 2009). The financial burden is also estimated to be higher (Sadoh & Oviawe, 2007), and the costs of dual treatment have been associated with decreased ART uptake (Sadoh & Oviawe, 2007; Zachariah et al., 2006). Inadequate social and employer support, food insecurity, poverty, stigma and nondisclosure are further found to inhibit adherence to TB or HIV treatment (Gebremariam, Bjune, & Frich, 2010; Naidoo, Dick, & Cooper, 2009).

Following the imperative to promote collaborative TB/HIV care, there is a research need to understand the challenges associated with dual care from the perspective of affected patients. In this article, we highlight coinfecting patients' experiences with TB and HIV healthcare in light of their broader social environments. Our analysis represents one part of a larger study examining the social contexts of TB/HIV coinfection and integrated care in South Africa.

## Methods

### Setting

The study was set at three urban/peri-urban, ambulatory, public health clinics providing a range of TB and/or HIV services in KwaZulu-Natal. Provincial TB incidence approximates 1,066 per 100,000 population and adult HIV prevalence exceeds 26% (Padarath & Fonn, 2010).

The study received ethics approval from the University of KwaZulu-Natal, South Africa and University of Toronto, Canada.

### Data sources

A qualitative design (Patton, 2002) was employed to examine patients' subjective experiences. Over 6 months in 2009, coinfecting patients were actively recruited from outpatient queues on a site-alternating basis for participation in an in-depth, semi-structured interview. A purposive heterogeneous sample was sought to maximize the diversity of experiences analyzed (Patton, 2002). Initially, patients with variations in characteristics commonly expected to affect healthcare experience, such as gender, treatment stage, marital and employment status, were approached. Patients aged 18–50 years and a higher proportion of women were approached, following the higher prevalence of infection within these groups (Padarath & Fonn, 2010). Subsequently, sampling became more purposive in response to emerging themes, such as those related to ART and government subsidies. Of 44 patients approached, 3 declined to participate. One interview ended early due to a patient-

related time constraint. The final sample comprised 40 patients, approximately equally divided between the sites (N=14+13+13).

To further contextualize patients' healthcare experiences, 8 key-informant healthcare workers (HCWs), including doctors, nurses and site-managers, were also interviewed at the study sites (N=3+2+3).

Interviews were conducted privately on-site in English or *isiZulu* and audio-recorded after receiving participants' written, informed consent. Interview domains tapped into patients' experiences accessing and receiving TB and HIV healthcare, focusing on challenges encountered subsequent to their co-diagnosis. Patients were reimbursed ZAR50 (~USD7) for their time.

## Analysis

Interviews averaged 41 and 65 minutes with patients and HCWs, respectively. They were anonymized, transcribed, translated and analyzed using modified grounded theory (Denzin & Lincoln, 2000; Seale, Gobo, Gubrium, & Silverman, 2004). Transcripts were subjected to substantive coding to identify broad conceptual themes. This was followed by selective coding, where initial codes were reapplied to transcripts for active development of latent patterns and theoretical notions. Accounts were tied to patients' sociomedical circumstances for contextualized interpretations of experience.

## Findings

Patients' self-reported characteristics are shown in Table 1. All patients were receiving some form of TB and HIV healthcare, including 38 on TB chemotherapy (since 1 day to 10 months, at the time of interview) and 31 on ART (since 1 week to 5 years). Interview excerpts highlighting the study's qualitative findings are shared in Table 2.

### Income and employer support

Sustained access to food and money were imminent concerns for coinfecting patients. Many were unemployed or unable to maintain a steady income source. Several women, especially, had been abandoned by their partners. Patients typically returned to live with parents, siblings or extended family as they lost the means to support themselves. They described having insufficient food to tolerate drug-regimens and insufficient funds for transport. Save for weekly DOTS<sup>1</sup> collections, clinic appointments were generally farther away. Unable to afford bus fare, several patients panhandled or walked for hours to reach their clinic, despite physical debilitation.

Patients employed prior to being diagnosed temporarily stopped work to access medical care. They enjoyed varying degrees of employer support. Those who were formally employed received some sick leave after disclosing they had TB. Compensation was provided during the early intensive phase of chemotherapy, and 2 patients received work-based DOTS. However, the situation was markedly different for the majority of patients engaged in informal or part-time work who had limited recourse to formal compensation or leave of absence. Several women working in temporary jobs were denied time off and then let go after TB diagnosis, against fear of their infectiousness. Patients believed it was due to an implicit (stigmatizing) association with HIV. They did not generally share their HIV illness at work.

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<sup>1</sup>Tuberculosis control in South Africa is based on the standardized approach of DOTS, or directly-observed therapy, short-course. The five tenets of DOTS are: political commitment, active case detection via bacteriological surveillance, standardized supervised treatment, secure drug procurement, and rigorous treatment monitoring and evaluation (NTCP, 2008).

Several patients were primary caregivers to their families. They stressed about the added difficulty of accessing sufficient resources for their dependents. Disparate gender roles and expectations were apparent. Men were considered financial providers, and shared the support of a spouse, mother or neighbor when looking after children. Women, in contrast, provided direct caregiving and financial support. They were expected to help with domestic chores, fend for older relatives, younger siblings, their own children and those of deceased relatives. They more intently described setting aside their illness to continue working for their family's wellbeing.

### **Access to social assistance**

Government-issued disability grants, applied for at HIV clinics and approved by district surgeons, were a common source of temporary financial aid. Eligibility was understood to be a function of patients' HIV status, specifically their CD4 count; TB was insufficient grounds for approval. That ART and TB chemotherapy could raise counts above the eligibility threshold left patients feeling powerless and resentful of the governing system of social assistance.

HCWs echoed how grant criteria neglected patients' complex social circumstances, with varying approval rates across districts. They believed CD4 counts were inadequate measure of the difficulties their patients endured to support themselves, with potentially negative effects on clinical outcomes. Several HWCs had dealt with patients who interrupted treatment to maintain counts below the grant eligibility threshold.

### **Disclosure versus support**

Following compromised access to financial, employer and social assistance, and the burden of caregiving, patients negotiated TB and HIV disclosure with caution and forethought. They needed to disclose illness in order to gain access to some social and financial support, but the degree of information shared was balanced against the risk of losing that support. For instance, several women, neither financially nor physically able to care for their children, disclosed they had TB and sought childcare from extended family. However, they feared this support would end if their families discovered they also had HIV, perceiving it would be less accepted. Other women had experienced break-ups in their relationships during earlier HIV disclosures to partners. Dreading the recurrence of such events, they avoided disclosing HIV to new boyfriends and used their illness with TB as justification for requesting money and for avoiding sex; but they also worried about how long such excuses would last.

Similarly, patients who received some employer support guardedly confined discussions at work to TB. Others acknowledged and feared prevailing public assumptions that tied TB to HIV/AIDS. They disclosed neither infection, afraid that any implicit allusion to HIV would result in termination of the support they had managed to earn thus far. They encountered greater difficulty adhering to clinic appointments; some altogether stopped work without providing a reason.

HCWs recounted the negative consequences of being identified as HIV-positive. They understood patients used TB as an "excuse" to stave off the perceived greater stigma associated with HIV. Letters requesting sick leave were thus carefully worded to employers, often on patients' explicit request, highlighting TB but without any reference to HIV.

### **Delays with ART**

Just as CD4 counts were tied to grant eligibility, they were additionally a criterion for access to ART. At the time of interview, the national rollout program mandated eligible patients' CD4 counts fall below 200 cells/mm<sup>3</sup>; having TB did not guarantee eligibility (NTCP,

2008). This concerned patients who knew of others that had succumbed to illness failing to meet the strict clinical criteria.

Several patients diagnosed with HIV years prior reported being denied ART initially due to their higher CD4 counts. They described how ART ineligibility and apparent physical wellbeing at the time had disinclined them from accessing further care, until they became ill with the more acute symptoms of TB. HCWs also expressed frustration with ART eligibility for TB patients, whom they believed needed urgent access regardless of set indicators. They believed oversaturation of the national program and poor policy dissemination to HCWs *vis-à-vis* TB and HIV co-treatment further aggravated treatment delays.

Several patients shared their personal reasons for deferring or discontinuing ART. For example, one patient refused ART until he had completed TB treatment. He said his partner had recently left him. He was encumbered by the stress of having to provide for his family and had lost the “amandla” or power to deal with multiple issues at once. Physical recovery from receiving several months of ART prompted another patient to discontinue treatment and stop attending his HIV clinic. It was only the physical deterioration caused by TB that prompted him to reconnect with medical care.

### Fears to adhere

Most patients were being co-treated at the time of interview. Some used telephone alarms or popular television broadcasts as reminders to aid adherence. At times, a partner or relative alerted them. Adherence cues, however, were not always accompanied by full disclosure. Patients described how others would remind them without knowing what the tablets were being used for. Often, patients had disclosed they were just receiving treatment for TB.

Fears of having to face the stigma associated with HIV affected many patients' adherence to co-treatment. They hid their medications, delayed or skipped a dose to avoid being labeled as sick. In the context of their communities, patients feared any illness would be perceived as HIV/AIDS.

Stigma also affected patients' retention in HIV care. The fear of being discriminated, and consequent inability to openly share their status when first diagnosed with HIV, pushed several patients to remain secretive and neglect accessing healthcare, particularly when asymptomatic. Now acutely ill with TB, patients believed they had compromised their health worrying about how others would perceive them.

The negative social consequences of being identified at HIV clinics accelerated some patients' decisions to “quit” attending, particularly when ineligible for ART. Conversely, the stigma associated with overt EPTB symptoms (e.g., enlarged glands) encouraged others to adhere. Adherence would assure them quicker recovery from physical symptoms – symptoms they perceived were more indicative of HIV.

### Discussion

This study illustrates how TB/HIV coinfecting patients' healthcare experiences are bound by inadequate access to resources, multiple life responsibilities, limits within the health system and the stigmatizing social symbolism of their illness. These competing constraints may be beyond patients' direct control and intercept with broader issues of socioeconomic and gender inequality to collectively mediate decisions around disclosure, adherence and retention in medical care.

### Socioeconomic constraints

The financial burden of accessing dual treatment, due to indirect medical costs and job loss, and having to juggle social responsibilities that were highlighted by this study have been suggested in prior research with coinfecting patients (Chileshe & Bond, 2010; Sadoh & Oviawe, 2007). Patients in this study additionally experienced frustration and distress around their limited access to social assistance. A recent national survey shows that people living with HIV are routinely denied access to government subsidies due to its stringent allocation around a CD4 count below 200 cells/mm<sup>3</sup>, which authors assess is an unreliable indicator of functional ability (Phaswana-Mafuya, Peltzer, & Petros, 2009). Accounts from our study echo how these markers may neglect the dual social morbidity of TB/HIV illness and day-to-day responsibilities that many coinfecting patients are unable to escape from.

Little or no income left study patients continually reliant upon others for access to essential resources including food, shelter, childcare and transportation. Dependency compelled them to negotiate illness disclosures and access support in ways that would invoke the least degree of stigma and discrimination. Studies from high-burden countries report that coinfecting patients often disclose just TB to escape the stigma associated with HIV (Coreil et al., 2010; Daftary, et al., 2007; Ngamvithayapong, et al., 2000). The selective disclosure of TB was apparent here as well, as patients struggled to gain support from their partners, families and employers, while mitigating their exposure to HIV stigma.

Poverty, unemployment, partner abandonment, dependency and the burden of caregiving appeared to be higher among women participants. They were in greater need for material support and had to balance access to income and childcare against illness disclosures more cautiously. Research with singly infected patients similarly shows how women's subordinate social position may leave them with little agency to prioritize their health (Johansson, Long, Diwan, & Winkvist, 2000; Krishnan et al., 2008; Tarimo, Kohi, Outwater, & Blystad, 2009). Their role in fulfilling family responsibilities impedes retention in HIV care (Geng et al., 2010).

### Health system constraints

Prevailing health system deficiencies and policies inhibited study patients' optimal access to co-treatment. Program saturation and poorly trained HCWs may have exacerbated ART delays among potentially eligible patients. These challenges are noted in similar resource-constrained settings (Abdool Karim, et al., 2009; Harries et al., 2005). Going forward, implementation of the latest recommendation to initiate ART in TB patients regardless of CD4 counts should expedite co-treatment among all coinfecting patients (WHO, 2009).

Health system constraints appeared to compound study patients' personal predispositions to default from HIV care. Research from Zambia reveals how system barriers merge with social and economic barriers, and disable patients from accessing HIV treatment (Chileshe & Bond, 2010). Our findings extend insight to the intersection of these challenges, as ART ineligibility encouraged several patients to delay or avoid seeking HIV care in light of their compromised socioeconomic circumstances.

The study points to accelerated attrition among patients who felt physically well. Within lower income settings, attrition is also found to be significantly higher among patients with higher CD4 counts who are ineligible for immediate ART. 'Defaulters' cite stigma as their primary reason for non-retention (Geng, et al., 2010). In our study, a desire to avoid being labeled with HIV reveals how stigma influenced patients' decisions to "quit" care. It may also help explain the high rate of attrition recorded by national HIV programs (Padarath & Fonn, 2010).

## Stigma

Stigma underscored coinfecting patients' healthcare experiences and influenced illness disclosures to partners, families and employers. The relatively greater stigma associated with HIV that has been identified in prior research (Daftary, et al., 2007; Deribew, Hailemichael, et al., 2010), encouraged patients to disclose TB over HIV. The threat of being exposed as HIV-positive also discouraged patients from accessing HIV care, in some cases despite access to ART. Stigma further prompted patients to skip medication doses. Similar reasons for nonadherence have been documented with TB/HIV coinfection (Gebremariam et al., 2010; Naidoo et al., 2009), particularly when patients lack concurrent social support (Shin et al., 2008).

Our study highlights that stigma may have unequal effects on adherence to TB chemotherapy compared to ART or HIV care. While patients stopped attending their HIV clinic for fear of being identified, they did not always report similar actions against accessing TB services.

Following their selective disclosures, some patients pretended they were just receiving TB treatment. This corroborates findings from a recent qualitative study, where TB treatment forged a safe space within which coinfecting patients concealed receiving ART (Gebrekristos, Lurie, Mthethwa, & Karim, 2009). Here too, TB treatment allowed patients to hide being co-treated for HIV and be protected against the corresponding stigma of HIV/AIDS.

The role of stigma in patients' decision-making was often non-linear. The stigma of being identified as HIV-positive triggered clinic attrition and non-adherence among some patients. However, the stigma of visible symptoms (e.g., EPTB, thinness) assured adherence among others, as it allowed them to shed the label associated with their physical appearance.

Social scientists theorize that disease-related stigma reproduces the effects of existing social inequalities. It is the foundation of these inequalities, and the accompanying loss of power and social status, which renders stigma to be disproportionately experienced by individuals who are also the most marginalized (Link & Phelan, 2006; Parker & Aggleton, 2003). Our study exemplifies how economic disparities, unequal gender roles, and poor access to social assistance and ART perpetuated patients' susceptibility to stigma, and rendered their healthcare decisions to be socially informed. Patients negotiated access to support through selective illness disclosures, and balanced their clinical needs against a perceived unequivocal need to be socially accepted.

## Study limitations

Qualitative analysis precludes drawing associations between patient characteristics and healthcare experiences, and our findings may not be generalizable to all coinfecting patients. However, the study offers novel, in-depth insight to patient-specific issues that may affect TB/HIV healthcare outputs in similar high-burden settings.

## Conclusion

In foregrounding the voices of coinfecting patients, this study highlights important sociomedical constraints to the delivery of TB/HIV care (study implications are shown in Table 3). Medical anthropologist Farmer (1997) stated, "*those least likely to comply are those least able to comply*" (p 353), as a result of the systematic and disproportionate impact of social inequality on people's ability to access care. Our study shows how an underlying environment of poverty and socioeconomic disparity coincided with health system constraints and compounded vulnerability to stigma, thereby challenging patients'

experiences with healthcare. A contextualized perspective on TB/HIV care is thus urged to inform more patient-sensitive and socially-responsive interventions.

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**Table 1**

Socio-demographic and clinical characteristics of patient participants

| Patient characteristics                                | Total (%) | Women (%) | Men (%) |
|--|-----------|-----------|---------|
| Total  | 40        | 24 (60)   | 16 (40) |
| Age <sup>1</sup>                                       |           |           |         |
| Range (years)  | 21–47     | 21–47     | 22–46   |
| Average (years)  | 34        | 33        | 34      |
| Marital status   |           |           |         |
| Married or in a sexual relationship                    | 25 (63)   | 12 (50)   | 13 (81) |
| Single   | 15 (37)   | 12 (50)   | 3 (19)  |
| With 1 child   | 30 (75)   | 16 (67)   | 14 (88) |
| Employment status <sup>2</sup>                         |           |           |         |
| Employed <sup>3</sup>                                  | 19 (48)   | 8 (33)    | 11 (69) |
| Unemployed   | 20 (50)   | 16 (67)   | 4 (25)  |
| Unemployed due to TB or HIV (as % of total unemployed) | 12 (60)   | 10 (63)   | 2 (50)  |
| Type of TB   |           |           |         |
| Pulmonary  | 28 (70)   | 19 (79)   | 9 (56)  |
| Extra-pulmonary  | 12 (30)   | 5 (21)    | 7 (44)  |
| Diagnostic history <sup>4</sup>                        |           |           |         |
| Diagnosed with HIV during TB symptom investigation     | 22 (55)   | 12 (50)   | 10 (63) |
| Diagnosed with HIV after TB notification <sup>5</sup>  | 3 (8)     | 1 (4)     | 2 (12)  |
| Diagnosed with TB after HIV diagnosis <sup>6</sup>     | 14 (35)   | 11 (46)   | 3 (19)  |

<sup>1</sup>The exact age was unknown for 3 patients.

<sup>2</sup>The employment status was unknown for 1 patient.

<sup>3</sup>Ten patients said they were engaged in informal or temporary work (street/retail vendors, domestic workers, cleaners, taxi drivers, garden, paint or tile contractors, assisting with partner/family business). Seven patients said they were formally employed (by hospitals, business offices, police or security services). Two patients said they operated their own small businesses.

<sup>4</sup>The diagnostic history was not clear for 1 patient.

<sup>5</sup>Three patients said they specifically delayed HIV testing from 1 month to 1 year after TB notification.

<sup>6</sup>Fourteen patients said they developed TB between 9 months and 9 years after HIV diagnosis.

Table 2

## Interview excerpts highlighting study findings

**Income and employer support**

*No, [my mother and sister] is not working, even me and now am not working. Sometimes I've got no food. Sometimes I want to drink the tablet, I've got no food ... there's my problem. (F, 37y)*

*People cannot accept person with these diseases because they scared that she might infect others... Such that where I was working, they knew that I have this thing, such that they asked me to go. (F, 31y)*

*I couldn't tell [my employers]. They were going to make fun of me ... some people are so arrogant, they don't understand ... even with TB they don't understand, 'cause they think if you have TB, you have AIDS. (F, 23y)*

*I stayed, I continued at work. Then by [month], I realize that it's too difficult for me. It's not me who's working, it's my heart who is working because I'm supposed to support [my children]. (F, 30y)*

**Access to social assistance**

*That story about CD4 count for getting a grant is rubbish ... because many people can't use medication without eating ... You must be able to eat, so that that thing can work. If you only eat medication, that thing will work on you but your body will feel weak ... My grant close, I don't want to go back, 'cause I know I'm not going to qualify. (M, 34y)*

*The time goes on, I decided to leave the job ... When I was pressing this for TB, for them to try for with the pension so that my children can get food ... this pension, they didn't give me, they said my CD4 count, as it was saying [>200], I won't be able to get the one for TB. (F, 30y)*

*Unfortunately, if you go to certain department of social offices, you get a grant more easily than others. If you're going to [name of town] and they send you to their district surgeon, you got to be I think dead before you'll get a disability grant. Guys who've been really, desperately ill ... I tell them, get a wheelchair or carry them into the room, I said, because they might believe you then. (HCW)*

*There were quite a few patients on TB treatment ... they were cured and could have been discharged, but if you had ask them of their symptoms, they're quite clear ... they'll say 'No', they're still coughing, they still have night sweats... Its because they don't want the grant to stop ... And the same thing for the HIV ... they have the grant, which is meant to be temporary for a year, and then normally when their CD4 count is above 200, it's stopped. It's not renewed. And you see a lot of patients who know that already now, and they start to stop taking their medication because they want their CD4 count to drop because they don't want the grant to stop. (HCW)*

**Disclosure versus support**

*Now because I so sick, my cousins, they are looking after my son, and they bring him home on weekends. And I just feel I'm not ready to tell them. Because they will just like, they make a big deal out of the little petty things he does. He's only 6 years old and if I must tell them this thing, it'll be like oh ... They know I've got TB but they don't know about the HIV. (F, 36y)*

*I didn't tell [my employers]. I just said that I am suffering from TB, what else was I supposed to say ... they took me so good but I didn't tell them about the other thing. I don't know how would they behave if they can ever hear that I'm having that? (F, 47y)*

*Even now we are still together. The only thing is I haven't disclosed to him that I'm HIV ... We haven't been together since I was HIV diagnosed ... He comes and we chat, its nice ... I told him because he wanted to know what really makes me sick. I told him I have TB, but I'm planning to – how to start him because I don't know how I got it ... I still want the way of telling him. (F, 31y)*

*Patients sometimes find it convenient to have TB because it means that they can tell their employers that they're coming to collect TB treatment. Meantime they're also coming [to the HIV clinic] ... When they finish their TB treatment, some of the guys have been, 'What am I going to do now, because my boss knows I've finished TB treatment and I'm still going to come [to the HIV clinic]? What can I tell him?' and that's been quite an issue... they've lost their excuse. Some times we've actually written letters just to say that this patient requires essential treatment ... I just say, enough said, essential treatment. (HCW)*

**Delays with ART**

*You bring the person and you can see that this person is very sick. They will just check the person and find out that she is positive. Then they will refer the person to the nearest clinic ... it can take even 18 months, still attending up until she dies ... Out of ten people only two were they saying the CD4 is going down, all others are right ... but you can see that this person is finished. (F, 35y)*

*Sometimes when the doctor said, it was 200[X], he said I have to come back after 6 months. But I just ignored. My CD4 count was saying [>300], but I just forget about that up until its now, when I'm coming back. (F, 30y)*

*They did a letter because of course my CD was low. I must go that [HIV clinic], it was [<200] ... They told me that they won't be able to start me early because I have just started the TB treatment. They asked me to wait ... they told me to wait 3 months or 4 months, they will see how is my blood, then they will let me start. (F, 31y)*

*[My CD4 count] said [<200] ... They said I am supposed to use tablets, the ARVs ... I am going to use them but I just want to finished these ones for TB first ... I just said as I was sick, going to do CD4 count, didn't have power. (M, 25y)*

*The government is overloaded, so most of the patients are on the waiting list for too long, and they die. Most of them die whilst on the waiting list. But what I picked up is that the community is still confused about when the patient must take ARVs ... You'll find that even the healthcare workers outside are preaching this gospel ... stopping the patient from taking TB treatment and telling them, 'TB treatment is going to kill you if you take it whilst, when you on ARVs. So, park the ARVs, take the TB treatment'. Patients get confused, they get sick ... and they die. (HCW)*

**Fears to adhere**

*I hide ARVs. I hide them because I just lock my suitcase ... I will put them in my breast knowing that if it's for me to drink them, [my cousin] won't see me ... [TB] she knows because she even ask if I've drank them if she is available. Maybe I haven't them yet, then she will say, 'Hey, go and drink them'. (F, 31y)*

*I never took it yesterday ... House is always full. It's not easy to take tablets, 5 tablets and use it in front of people. They think, this man have got AIDS or you know like that. No, the shame is there ... That's only thing why I skip my TB sometimes, but I do it in the morning. They say there is no cover up. If you miss, you miss ... ARVs sometimes it goes the same too, it goes the same. (M, 34y)*

*I wanted this thing, this thing to be finished [points to enlarged neck, from glandular TB] ... because everybody ... they are looking at you, so I was so embarrassed. People are looking at you, so that's why what make me not forget to take this tablet. (F, 33y)*

*In 200[X], I make a CD4. I found my CD4 is also [ $<100$ ]. I was supposed to start ARVs. So I get a counselling, all that stuff ... When I start to use it, my body was so thin ... so when I using it, I become big. So I say, too big now so I decide to leave it. I leave it maybe it was the whole year, 200[X] up to 200[X]. So after that I found that now I am sick ... I asked myself what is going on inside now? So now I remember no, I leave that treatment ... I go to make a check up for the TB so I found out that I have TB ... told the doc that I got a, I leave to use my ARVs, my treatment. So he make a note for me so that I must got back to my clinic ... I was lying when they asked me. I said, I was going with a job so I didn't remember to make the, all different stuff so they believe me. (M, 37y)*

*When I first check, they said I must go to the clinic... I just said, you know what? I'm feeling well so what, why am I coming here? Because people are going to see me. I was still young. Why am I coming? ... People are going to laugh at me. They going to spread this ... it's not even a rumor, it's the truth, and I was scared of that. So I just said no, its quits, let me go back to my life. Why not do something else than come here every month ... imagine the rumor just going around, you know, people saying, you know 'I saw her at [clinic]', because you know the [clinic], it's so close to the road, like, the cars just pass. They just pass by. They can see. Even if you can't see them, they saw you. You can't say, 'No, you never saw me', so that's why I quit going there. (F, 21y)*

Note: Patient participants' self-reported CD4 counts, health-related timelines and diagnostic details, shared during study interviews, have been replaced with approximations to maintain confidentiality and anonymity.

**Table 3**

## Study implications for TB/HIV healthcare

|   |  |
|---|--|
| 1 | Address social and gendered inequalities affecting TB/HIV coinfecting patients in high-burden resource- constrained settings, together with clinical complications of coinfection.   |
| 2 | Tailor medical expectations (e.g., for healthcare retention and treatment adherence) to patients' socioeconomic circumstances and life responsibilities owed to their families.  |
| 3 | Consider how social inequalities and health system constraints collectively enable patients to be more vulnerable to disease-related stigma; patients' healthcare decisions may be bound by their social need to escape or resist stigma.    |
| 4 | Improve employer support (e.g., compensation and leave of absence) for patients infected with TB and/or HIV, through non-discriminatory and confidential channels of access.   |
| 5 | Improve government-based social assistance for patients infected with TB and/or HIV through broader eligibility criteria and an inclusion of social indicators for disability, especially for persons engaged in informal or temporary work. |
| 6 | Expedite access to antiretroviral treatment for all TB patients coinfecting with HIV, regardless of CD4 counts, in line with current World Health Organization recommendations for TB and HIV co-treatment.                                  |
| 7 | Disseminate up-to-date guidelines for TB and HIV co-treatment to patients and HCWs in TB, HIV and primary healthcare clinics.  |