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Social constraints to TB/HIV healthcare: Accounts from coinfected patients in South Africa

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There is a growing imperative to improve the coordination and collaboration of tuberculosis (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 coinfected patients' experiences with TB and HIV healthcare in light of their broader social environments. Qualitative, in-depth interviews were conducted with 40 adult, coinfected patients (24 women and 16 men) and eight key-informant healthcare workers at three 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' codiagnosis 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 coinfected 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.

Keywords: South Africa; patient perspectives; TB/HIV coinfection; integration; qualitative methods

Introduction

In South Africa, approximately 73% of new TB cases are HIV-coinfected and 84% of TB deaths are attributable to HIV/AIDS (Padarath & Fonn, 2010). Women and those living in poverty are disproportionately affected (Abdool Karim, Churchyard, Abdool Karim, & Lawn, 2009). Integration of TB and HIV services may decrease the clinical and social impact of coinfection. However, fewer than 50% of TB patients know their HIV status and only 42% of those eligible receive antiretroviral treatment (ART) (Padarath & Fonn, 2010; WHO, 2010).

Relatively little is understood about patient-specific challenges with TB/HIV healthcare. We highlight coinfected patients' perspectives toward understanding their experiences with dual care. Our analysis stems from a broader examination of the social contexts of TB/HIV coinfection.

Methods

This qualitative study was set at three urban/periurban, ambulatory, public sector clinics providing TB and/or HIV services in KwaZulu-Natal province, with a TB incidence of 1066/100,000 population and 26% adult HIV prevalence (Padarath & Fonn, 2010). Over 6 months in 2009, 40 coinfected adults participated in a private, audio-recorded, in-depth interview ($N = 14 + 13 + 13$). Heterogeneous sampling (Patton, 2002), including patients of varying treatment stage, marital, and employment status, maximized the diversity of experiences analyzed. Patients aged 18–50 years and a higher proportion of women were purposively recruited, following their higher HIV prevalence (Padarath & Fonn, 2010). Open-ended interviews were tailored to patients' individual circumstances, specifically their healthcare experiences subsequent to co-diagnosis. Eight key-informant healthcare workers (HCWs) were also interviewed to contextualize patients' responses ($N = 3 + 2 + 3$). All participants provided written, informed consent. Patients were compensated ZAR50.

Interviews averaged 41 and 65 minutes with patients and HCWs, respectively. Transcripts were anonymized and analyzed using modified grounded theory (Denzin & Lincoln, 2000; Seale, Gobo, Gubrium, & Silverman, 2004). Substantive and selective coding identified emergent themes and

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latent patterns toward the development of theoretical concepts. The study received ethics approval from University of KwaZulu-Natal, South Africa and University of Toronto, Canada.

Heterogeneous, purposive sampling and qualitative analysis precluded drawing conclusive associations between participants' characteristics and healthcare experiences. Self-reported data were not objectively validated. Findings may not be generalizable, particularly to rural patients and those not yet diagnosed or accessing care. However, they offer novel insight to patient-specific challenges that may affect TB/HIV healthcare outputs in similar high-burden settings.

Findings

Patients' self-reported characteristics are shown in Table 1. All were accessing healthcare services, including 38 on TB chemotherapy (since one day to 10 months) and 31 on ART (since one week to five years). Interview excerpts highlighting the study findings are shared in Table 2.

Income and employer support

Coinfected patients, particularly women abandoned by their partners, were imminently concerned about sustained access to resources. Unemployment forced many to live with extended family. Patients described having inadequate food to tolerate drug regimens and insufficient funds to commute to clinics. Those employed had to discontinue work temporarily to access care. Formally employed patients received some compensation for TB, but most others engaged in informal/part-time work received no support. Several women who were let go after disclosing TB believed it was due to an implicit (stigmatizing) association with HIV. Patients did not disclose HIV at work.

Most patients were primary caregivers to their families. Men were considered financial providers and generally supported by their partner, mother or neighbor when looking after children. Women were considered direct caregivers and financial providers. They tended to siblings, older relatives, children including those of deceased relatives, and more intently described setting aside their illness to earn for their dependents.

Table 1. Sociodemographic and clinical characteristics of patient participants.

Patient characteristics	Total	(%)	Women	(%)	Men	(%)
Total	40		24	(60)	16	(40)
Age[a]						
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[b]						
Employed[c]	19	(48)	8	(33)	11	(69)
Unemployed	20	(50)	16	(67)	4	(25)
Unemployed due to TB or HIV (as% total unemployed)	12	(60)	10	(63)	2	(50)
Type of TB						
Pulmonary	28	(70)	19	(79)	9	(56)
Extrapulmonary	12	(30)	5	(21)	7	(44)
Diagnostic history[d]						
Diagnosed with HIV during TB symptom investigation	22	(55)	12	(50)	10	(63)
Diagnosed with HIV after TB notification[e]	3	(8)	1	(4)	2	(12)
Diagnosed with TB after HIV diagnosis[f]	14	(35)	11	(46)	3	(19)

[a]The exact age was unknown for three patients.
[b]The employment status was unknown for one patient.
[c]Ten patients said they were engaged in informal or temporary work (street/retail venders, domestic workers, cleaners, taxi drivers, garden, paint or tile contractors, and assisting with partner/family business). Seven patients said they were formally employed (by hospitals, business offices, and police or security services). Two patients said they operated their own small businesses.
[d]The diagnostic history was not clear for one patient.
[e]Three patients said they specifically delayed HIV testing from 1 month to 1 year after TB notification.
[f]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)

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)

Table 2 *(Continued)*

[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)

F, female patient; M, male patient; HCW, key-informant healthcare worker.
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.

Social assistance

Eligibility for government-issued disability grants was understood to be based on patients' CD4 counts. Tuberculosis did not guarantee approval. That ART and TB chemotherapy raised counts above the eligibility threshold left many patients feeling powerless and resentful of the social assistance program. HCWs echoed how grant criteria neglected patients' social circumstances, with potential negative clinical consequences. They had treated patients who defaulted from care to maintain low CD4 counts.

Disclosure versus support

Patients balanced illness disclosure against the loss of social support. Women, in greater need of financial and material aid, routinely disclosed TB in exchange for childcare support but feared it would end if their HIV status became known. Those who had experienced breakups during earlier HIV disclosures avoided disclosing to new boyfriends. They used TB as justification for requesting money and avoiding sex. HCWs recounted their patients used TB as an "excuse" to stave off the greater perceived stigma associated with HIV.

Patients who accessed employer-support confined discussions at work to TB. Others feared prevailing public assumptions tying TB to HIV and disclosed neither. They encountered greater difficulty keeping clinic appointments; some altogether stopped work without providing a reason. HCWs had to carefully word letters to employers, on patients' explicit request, highlighting TB but without any reference to HIV.

Delays with ART

During the study, the national ART program mandated eligible patients' CD4 counts fall below 200 cells/mm^3, regardless of TB coinfection (NTCP, 2008). This worried patients who had witnessed others succumb to illness waiting for their counts to drop. HCWs voiced that TB patients should initiate ART irrespective of set indicators. They complained that program saturation and the poor dissemination of TB/HIV protocols further aggravated co-treatment delays.

Several patients diagnosed with HIV years prior were initially denied ART due to their higher CD4 counts. ART ineligibility and apparent physical well-being disinclined them from accessing care until they became acutely ill with TB. Some other patients deferred or discontinued ART despite clinical eligibility. One patient, stressed after his partner left him, lost the "amandla" or power to deal with multiple issues at once. He refused to initiate ART until completing TB treatment. Another patient stopped ART once he started to gain weight. It was only the physical deterioration caused by TB that prompted him to reconnect with HIV care.

Fears to adhere

Patients used telephone alarms or popular television broadcasts as cues for adherence. Sometimes, a partner or relative reminded them despite being unaware of the patients' HIV illness; often, patients had disclosed they were just receiving treatment for TB. Others feared any illness could be perceived as HIV and routinely hid their medications, delayed, or skipped a dose to avoid being exposed and stigmatized.

The fear of being discriminated against pushed several patients to remain secretive about having HIV and neglect accessing care, particularly when they were also asymptomatic and/or ineligible for ART. Conversely, the fear of being labeled due to overt symptoms, such as enlarged lymph glands, promoted adherence among some patients with extrapulmonary TB. They were keen to shed symptoms that they perceived were more indicative of HIV.

Discussion

To our knowledge, this is one of the first studies examining coinfected patients' experiences navigating TB and HIV healthcare. Findings highlight how competing constraints, many beyond patients' direct control, intercept with broader issues of socioeconomic and structural inequality to collectively mediate health decision-making.

Socioeconomic constraints

While the financial burden of coinfection, due to indirect medical costs and job loss, is suggested by prior research (Chileshe & Bond, 2010; Sadoh & Oviawe, 2007), patients' limited access to social assistance is poorly documented. A recent survey highlights government subsidies are routinely denied to patients with a CD4 count above 200 cells/mm^3, despite this being an unreliable indicator of their functional ability (Phaswana-Mafuya, Peltzer, & Petros, 2009). Our study substantiates how clinical markers may neglect the dual morbidity and social constraint that coinfected patients are unable to escape from. Studies also show coinfected patients disclose TB to escape HIV-associated stigma (Coreil et al., 2010; Daftary, Padayatchi, & Padilla, 2007; Ngamvithayapong, Winkvist, & Diwan, 2000). In our study, selective disclosures were additionally motivated by patients' need to access resources, which may have been denied had they disclosed HIV.

Unemployment, partner abandonment and the burden of caregiving appeared to be higher among women participants. In greater need of financial and child support, they balanced illness disclosures more cautiously. Research shows their subordinate social position and family obligations may leave women with little agency to prioritize their health (Johansson, Long, Diwan, & Winkvist, 2000; Krishnan et al., 2008; Tarimo, Kohi, Outwater, & Blystad, 2009), and disproportionately impede their retention in care (Geng et al., 2010).

Health system constraints

Health system deficiencies and stringent policies inhibited study patients' access to co-treatment. A study from Zambia reveals system-level and socioeconomic barriers collectively disable patients from accessing ART (Chileshe & Bond, 2010). Our study further highlights how these structural barriers, particularly ART ineligibility, may compound patients' predispositions to interrupt care. Recent recommendations to initiate ART in all TB patients, regardless of CD4 counts, should expedite co-treatment and facilitate healthcare retention (WHO, 2009).

Our study points to accelerated attrition among patients who felt physically well. Attrition is found to be greater among patients with high CD4 counts who are ineligible for ART (Geng et al., 2010). We found the stigma associated with HIV additionally influenced physically well patients' decisions to "quit"

Table 3. Study implications for TB/HIV healthcare.

1. Address socioeconomic and structural inequalities affecting TB/HIV coinfected 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' social circumstances and life responsibilities owed to their families.
3. Consider how social and gender-based 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 leaves 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 coinfected with HIV, regardless of CD4 counts, in line with current World Health Organization recommendations for TB and HIV cotreatment.
7. Disseminate up-to-date guidelines for TB and HIV co-treatment to patients and HCWs in TB, HIV and primary healthcare clinics.

care. This may explain the high loss to follow-up recorded by national HIV programs (Padarath & Fonn, 2010).

Stigma

Stigma underscored study patients' health decisions. The relatively greater stigma of HIV encouraged patients to disclose TB over HIV and prompted non-adherence, as has been shown in prior work (Daftary, Padayatchi, & Padilla, 2007; Deribew et al., 2010; Gebremariam, Bjune, & Frich, 2010; Naidoo, Dick, & Cooper, 2009). Our study highlights that the effect of stigma may persist despite ART access and unequally with regards to TB versus HIV care. Patients who interrupted HIV treatment did not report similar actions vis-à-vis TB. The role of stigma in patients' decisions may also be non-linear. The stigma of being identified at clinics and labeled with HIV discouraged adherence among some patients. However, the stigma of HIV-associated symptoms encouraged adherence among others.

Social scientists theorize that disease-related stigma reproduces the effects of existing social inequalities. It is the foundation of these inequalities, and accompanying loss of power and social status, that renders stigma to be disproportionately experienced by individuals who are also the most marginalized (Link & Phelan, 2006; Parker & Aggleton, 2003). Our study exemplifies how socioeconomic and structural disparities, including gender-based inequality and ART ineligibility, may perpetuate patients' susceptibility to stigma and render their healthcare decisions to be socially informed.

In foregrounding the voices of coinfected patients, this study highlights important social constraints to TB/HIV healthcare (we share the study implications in Table 3). Inclusion of this contextualized perspective is urged toward developing more patient-sensitive and socially responsive interventions.

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