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Integrating patients' perspectives into integrated TB/HIV healthcare

Amrita Daftary[1] and **Nesri Padayatchi**[2]
[1]ICAP, Mailman School of Public Health, Columbia University, New York, USA

[2]Centre for the AIDS Programme of Research in South Africa (CAPRISA), University of KwaZulu-Natal, Durban, South Africa

Abstract

Background—Escalating rates of TB/HIV coinfection call for improved coordination of TB and HIV healthcare services in high-burden countries such as South Africa. Patient perspectives, however, are poorly understood in the context of current integration efforts.

Method—Under a qualitative research framework, we interviewed 40 HIV-positive adult TB patients and 8 key-informant healthcare workers across 3 clinics in KwaZulu-Natal province to explore non-clinical and non-operational aspects of TB/HIV healthcare.

Findings—Qualitative analysis highlighted critical social and ethical considerations for the concurrent delivery of TB and HIV care. Coinfected patients navigating between TB and HIV programs are exposed to missed opportunities for TB and HIV service integration, fragmented or vertical care for their dual infections, and contrasting experiences within TB and HIV clinics. These intersecting issues appear to affect patients' health-related decisions, particularly HIV nondisclosure to non-HIV healthcare workers, and their preferences for integrated healthcare.

Conclusion—Our study highlights the imperative to address service fragmentation, HIV medical confidentiality and provider mistrust within the healthcare system, and the *cultural* differences associated with TB and HIV disease control.

Keywords

South Africa; TB/HIV coinfection; service integration; qualitative methods

Introduction

Approximately 60% of newly diagnosed TB patients in South Africa are coinfected with HIV, calling for improved integration of TB and HIV healthcare (1, 2). Efforts to date are largely based on program cross-referrals, with some innovative projects promoting co-located services and shared clinical teams (3, 4). Yet as many as 46% of TB patients remain unaware of their HIV status and up to 56% of those eligible are not on antiretroviral therapy (ART), pointing to multifactorial challenges with integration (1). Patient perspectives have seldom been included in the planning of integrated interventions (5–7). In 2009, we conducted a broad study to examine the social contexts of TB/HIV illness and integrated healthcare. This article highlights patients' experiences with TB and HIV programs to enhance the frameworks from which collaborative efforts are planned.

Corresponding author: Amrita Daftary, ad2254@columbia.edu.

Methods

A prospective qualitative study was conducted from February-August 2009 in KwaZulu-Natal province, with 1131 per 100,000 TB cases reported annually and 23% adult HIV prevalence (8). Data was collected from 3 peri-urban ambulatory public sector sites: a TB-DOTS clinic referring patients out for HIV testing and follow-up; an HIV-ART clinic screening patients for TB with referrals for confirmation and treatment; and, a partially-integrated HIV-ART clinic co-located with a TB clinic, providing dual services under one roof but in distinct areas with distinct clinical teams.

The study's qualitative methods and sample are described elsewhere (9, 10). Forty adult HIV-positive TB patients, actively recruited via heterogeneous purposive sampling (11) from site outpatient queues, consented to participate in a private, in-depth, audio-recorded interview (N=14+13+13). They were each compensated ZAR50 (~USD7). Eight key-informant healthcare workers (HCWs), comprising doctors, nurses and health professional managers, were similarly interviewed to contextualize patients' responses (N=3+2+3). Questions were open-ended and exploratory, to record a naturalistic characterization of participants' perspectives based on their unique circumstances (12, 13). They were directed by the study's broader objective to examine the social contexts of coinfection. Herein, we focus on responses related to participants' healthcare perceptions and/or decisions, based on their personal experiences.

Interviews averaged 41 and 65 minutes with patients and HCWs, respectively. They were anonymized, transcribed, translated and collectively analyzed by the study team using modified grounded theory (11, 14). Transcript segments were categorized under broad codes (substantive coding). Codes deemed critical were then re-applied to transcripts for the organic development of theoretical concepts, latent patterns and themes (selective coding). Accounts were examined with consideration to participants' sociomedical contexts that are distinctly analyzed (9, 10).

The methodology precludes drawing numeric associations between participants' characteristics and perspectives. Though recruited from three sites, participants discussed their healthcare experiences in general. The analysis is consequently more broadly reflective of TB and HIV healthcare experiences, and direct site comparisons are avoided. While findings may not be generalized to different models of integration, they offer novel insight on social aspects of TB/HIV healthcare that may inform integration efforts in similar high-burden settings.

The study received ethics approval from the University of KwaZulu-Natal, South Africa (ref: BF147/08) and University of Toronto, Canada (ref: 23946). Permission to collect data was granted by all sites and the KwaZulu-Natal Department of Health.

Findings

Patients included 24 women and 16 men averaging 34 years in age (range, 21–47 years). Twenty-five patients (12 women, 13 men) described being married or in a sexual relationship. Thirty patients (16 women, 14 men) stated they had one or more children. Nineteen patients (8 women, 11 men) were employed, and 20 patients (16 women, 4 men) were unemployed. The age of three patients and employment status of one patient were unknown. Twenty-eight and 12 patients had pulmonary and extra-pulmonary TB, respectively. All were accessing some TB and HIV healthcare, including 38 patients on TB treatment (since 1 day to 10 months, at the time of interview) and 31 patients on ART (since 1 week to 5 years). The sample was aptly heterogeneous enabling adequate contextualization of the following intersecting themes. Select interview excerpts (Table 1) help illustrate our analytic process.

Missed opportunities for integration

Key-informants highlighted several gaps with service integration. TB-HCWs recommended new TB patients or suspects for HIV testing, but considered repeat counseling and testing impractical during subsequent visits or DOTS-collections due to inadequate time and privacy. Similarly, HIV-HCWs screened new patients and ART-initiators for TB symptoms, but relied on patients to actively complain about cough, fever or night-sweats during follow-up visits.

Patients stated their TB doctors regularly inquired about their HIV status and treatment, when known, and HIV doctors similarly inquired about progress with TB care. However, several patients complained about receiving mixed messages on co-treatment, specifically access to ART while on TB chemotherapy, and believed this may have delayed ART initiation. HCWs admitted that poor dissemination of guidelines left staff and patients confused about TB/HIV protocols. HCWs feared losses to follow-up when ART was postponed during TB treatment, having dealt with patients who felt well post-chemotherapy with little incentive to continue accessing care.

Fragmented care

Patients collected ART at their HIV clinic during monthly HIV-doctor visits. They collected TB treatment weekly at their TB or local clinic under the DOTS program; at times, this corresponded with TB-doctor visits. Save for DOTS-collections, TB- and HIV-doctor visits were considered lengthy and inconvenient. Appointments were given by date, not exact times, mandating a 3–7 hour wait. Employed patients requested time off work, with some receiving compensation upon providing a medical note. However, most patients did not disclose HIV to employers, and accessed “vacation” or unpaid leave for HIV care.

Patients experienced logistic problems coordinating TB and HIV appointments. At the co-located site, they enjoyed the convenience of accessing dual services under one roof. However, appointments were not given within a shared timeframe mandating duplicate commutes for individual doctor visits; HCWs conceded appointments were not always made with consideration to their co-located team. Distinct queues further precluded patients from completing any one appointment in time to adhere to the other. The onus to maintain distinct days for TB and HIV appointments was even greater for patients attending non-integrated clinics. Coinciding appointments had caused at least one patient to miss an HIV appointment, delaying his commencement of ART.

Patients described being routinely referred to other infectious disease programs, primary healthcare clinics and/or hospitals for emerging issues that their TB and HIV clinics did not manage. They expressed frustration at having to endure additional commutes and time off work to be examined by different doctors. TB- and HIV-HCWs echoed their perceived mandate to attend to strictly TB- and HIV-related issues, respectively, considering their workload and limited resources. However, they also commiserated about the difficulties experienced accessing medical information from other facilities, noting patients remained the only informative link connecting their multiple service providers.

HIV nondisclosure

Patients shared varying degrees of medical information with their various providers. While they all disclosed TB to non-TB HCWs, several patients disclosed HIV only when specifically or repeatedly asked by a non-HIV HCW or when they perceived it was necessary for their overall care. Patients hid their HIV status if they mistrusted non-HIV HCWs, including TB-HCWs.

HCWs acknowledged patients were more likely to share TB with all providers, but keep their HIV status from some. TB-HCWs commented patients may deny having HIV due to the associated stigma or when accompanied to appointments by relatives to whom they had not disclosed. Disclosure was sometimes inconsistent, with patients disclosing during one appointment but refusing to discuss HIV with another HCW. HIV-HCWs consequently understood they had full access to patients' clinical histories but their TB counterparts were only privy to TB-specific data. HIV-HCWs also felt bound against sharing their patients' HIV status with other HCWs due to patient-provider confidentiality, even at the co-located site. TB-HCWs, when aware, similarly felt obligated to keep patients' HIV illness private from other HCWs; some patients specified their serostatus be withheld from clinics attached to their work.

Contrasting clinic experiences

Patients compared their experiences at TB and HIV clinics. Those at the co-located site distinguished the "TB side" from "HIV side", pointing to marked differences in service delivery. Patients complained about the lack of individual attention and privacy at TB clinics, DOTS facilities and hospitals they were referred to, where they perceived an impersonal and rushed staff attitude. In contrast, they found service delivery was more personalized at HIV clinics. Patients said staff were more helpful, "friendly" and went beyond what was expected to make them feel comfortable and cared for.

Patients' appreciation for their HIV clinic was born with time. Initially, they worried about being recognized, embarrassed and judged. Gradually, they drew comfort from acknowledging their shared "situation" with other patients. This sense of perceived similitude mitigated their fear, guilt and shame, and lifted their burden of secrecy. Patients noted that if people were to gossip about seeing them at the HIV clinic, they would essentially be instigating gossip about themselves. HIV clinics thus became safe spaces where patients could speak openly about their infection (and coinfections). Several patients recognized staff from their communities. They believed some counselors were also HIV-positive (though HCWs stated staff disclosure to patients was atypical), fostering optimism for their own wellbeing.

In contrast, patients strove to maintain anonymity at TB clinics. They feared popular public perceptions tying TB to HIV could typecast them as HIV-positive. While everyone had HIV at HIV clinics, no one knew who was coinfected within TB clinics. Patients avoided opening up to other patients, perceiving a lack of the comfort and support they enjoyed at HIV clinics.

Patient preferences

Many patients at the non-integrated sites expressed interest in accessing dual services at one venue to save time and money. Some patients, however, preferred to attend separate clinics based on their disparate experiences within TB and HIV programs. In particular, they refused to access HIV services at their TB and/or DOTS clinic, fearing their status may be disclosed in an environment where they inherently perceived less comfort and trust. They preferred going to "different places" for TB and HIV treatment.

Some other patients preferred attending HIV clinics farther from home to avoid being recognized by neighbors. One patient started ART at a clinic near his family rural home. Despite having moved, he continued to take vacation leave for this long and expensive commute. He refused to initiate a transfer in HIV care. For patients like him, a lengthy commute was acceptable, indeed preferred, because it assured greater HIV confidentiality.

Patients diagnosed with HIV several years prior viewed the temporary nature of TB as insufficient grounds to alter their primary point of care, which they considered to be their HIV clinic. They had established a degree of comfort here and expected to have a "permanent" relationship going forward. One patient clearly voiced her preference: if she could not be treated for TB at her HIV clinic, she would rather have each infection managed separately. She echoed the views of others described earlier, who rejected integration at the point of TB service delivery.

Discussion

The study highlights novel sociomedical issues that have critical implications for TB/HIV healthcare policy and practice (Table 2). Some intersect with extant resource and operational deficiencies. For example, gaps in communication and follow-up between individual programs may have delayed ART for some study patients. Together with inadequate HCW training in TB/HIV co-management, they are shown to raise the potential for drug interactions and medical complications in similar high-burden countries (3, 4, 15, 16).

Service co-location did not guarantee integration in this study. The lack of a single clinical team coupled with poor coordination between teams prevented patients from accessing concurrent care and experiencing the intended efficiency of an integrated program. The ethical and legal repercussions of nonconsensual HIV disclosure and patients' right to confidentiality barred HCWs at all sites from sharing relevant medical information, inhibiting transparent pathways of communication.

While HIV and especially TB programs may each decentralize and integrate into primary healthcare streams (1, 17, 18), this study highlights the challenges of collaborating effectively with one another. The jettison of study patients between TB and HIV clinics promoted mixed messaging between patients and TB and HIV providers, leading to fragmented healthcare. Service specialization additionally created a system of cross-referrals that was tedious and unreliable. The 'dumping' or 'disposal' of patients between programs is documented as a critical adverse effect of referrals made within poorly integrated systems of care, when no one program takes on the responsibility of managing overlapping health issues (19). As the sole common thread connecting various programs, coinfected patients may bear the sole responsibility of disclosing relevant information, particularly their HIV status, across the different clinics they attend. In this study, provider mistrust discouraged patients from disclosing their HIV status at non-HIV clinics. HIV nondisclosure, more commonly examined in the context of patients' partners, families or social networks, may thus extend into the healthcare system. Research shows 13–26% of HIV-positive patients conceal their serostatus from allied health providers (20, 21), but this is seldom acknowledged in the context of integration. HIV nondisclosure and medical confidentiality, while key to mitigating stigma, may compound problems of vertical care and impede integration efforts.

Study patients enjoyed a perceptible friendliness, privacy and compassion from staff and patients at HIV clinics, compared to a lack of the same at TB clinics. Their accounts are telling of TB and HIV programs' distinct approaches to healthcare delivery. Bioethicists analyzing the underlying paradigms of infectious disease control in the advent of the AIDS epidemic have compared the top-down, standardized modus operandi of the TB-DOTS framework to the relatively more holistic, individualized approach of HIV care (22, 23). While TB programs prioritize case-finding, notification, adherence and cure, HIV programs are typically more attentive to patient privacy and trust (22–25). These disparate *cultures* of TB versus HIV control are likely shaped by their disparate etiologies and political histories. Nonetheless, they may influence patients' decisions to disclose HIV to non-HIV HCWs (as discussed earlier) and access integrated care at HIV, but not TB, clinics.

HIV-associated stigma underscored study patients' health decisions. The fear of being labeled with HIV is found to be a primary deterrent among TB patients refusing to attend an integrated program (26). Community perceptions linking TB to HIV are widely described in endemic areas, discouraging TB patients from accessing HIV-related care (27–29). In this study too, stigma influenced patients' decisions to maintain non-integrated care and sustain longer commutes. The fear of discrimination by patients unlike them probably enhanced their affinity toward HIV clinics. The comfort and security derived from peers due to their shared negative experiences is commonly documented among people living with HIV (30, 31).

Conclusion

This study is one of the first to consider patients' perspectives during a critical shift in TB/HIV healthcare. Findings were shared with the study sites to help develop awareness and sensitivity around the social aspects of TB/HIV illness. While we cannot claim significant changes to site policies, the study enhanced staff cognition of patients' stated concerns related to service coordination, HIV stigma and confidentiality, and provider interactions. We thus responded to the World Health Organization's recent call to investigate and address sociocultural differences and contexts in implementing collaborative care (32). Successful integration warrants improved program collaboration, patient-provider trust and communication, stigma mitigation, and a shift from vertical toward more comprehensive models of care. We urge HIV programs to address TB control as standard of care, and for patient-sensitivity and trust to become inextricable to the *culture* of TB control.

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Table 1

Interview excerpts highlighting the study's qualitative themes

Missed opportunities for integration

The guidelines are not very clear… I think in government there's a big delay, and often they tell patients to complete TB treatment and then come back for the ARVs which shouldn't really be happening because by that stage, a lot of them become even more ill, more immunocompromised, and they sort of get lost in the follow-up in the system… because they may be feeling better after their TB treatment, they feel it's not necessary to even go back. (HCW)

Fragmented care

In [HIV clinic] where I am going, they are just doing the HIV/AIDS that's all. So if I've got any problem, if it's about my TB I have to come [to TB clinic]. If it's anything, I have to go to the local clinic… When I have taken my ARVs I got cramps all over and I told the doctor. He made me the letter to take it to the local clinic, and he said if you got something, maybe some pills, you must go there. (Age-unknown F)

Often you don't have any contact details of the exact doctor, and if you phone… you'll get someone who is busy and really unwilling to go and look through a file and system and find out. I mean I've had one experience where I tried to get hold of a patient and the doctor basically just told me no, she's too busy to help me… The only other option is for us to write a referral back… From the time I've been here, I've had only one person come back with the letter that was related to that, and that was only at the next visit… so there's another delay in that. (HCW)

HIV nondisclosure

Every Thursday I am taking the medication at [TB] clinic… even they can ask me, I can say I don't have [HIV] because they are talking too much. (37y M)

Very few patients offer that information voluntarily. You have to go into it. And often even when [they are] answering the questions, you know its sort of drawn out when it comes out slowly… So in my experience, most patients don't disclose very easily and that I think has a lot to do with the stigma associated with it. (HCW)

I'm not sure [TB-HCWs] know that all of their patients, that some of their patients are at [HIV clinic] because if the patient doesn't tell them, they won't necessarily know. (HCW)

Contrasting clinic experiences

The sisters at [TB] clinic, they don't have time. And at [HIV clinic], they understand, they ask you questions and they show that they care about you. It's not like they're doing their job but they ask you, how you feeling today? (23yF)

[TB clinic] no one is taking care of you that much, if you are in a right place, where you are. While [HIV clinic] you are taken care of… There is care [at HIV clinic]. There is a difference. It's not the [same] as [TB clinic]. [TB clinic], it's like a government hospital, you see? [HIV clinic], it's as if we are paying money, that way they take care of us. (38y F)

Sometimes, I find some people that I know… If I see them, I say 'hi' 'cause what's bringing that person here, it's the same thing that brings me here. (23y F)

[TB clinic], I go and take the tablets only. [HIV clinic], I stay and talk with the people. (36y F)

Patient preferences

I want the same date. If my [HIV] doctor said she wants to see me on Tuesday, I want to make that date together with the TB date and to save my money. (34y F)

I'm okay because it's different place. People are talking. People are talking, serious. So that is why I'm going to different places… [TB clinic] is not comfortable, but [HIV clinic] is the best. All the nurses they are right there… even the doctors, they are right. (37y M)

I don't want to go to [DOTS clinic], because people there talking too much… maybe they told the other people, see this one, maybe he got the TB… the other one think you got TB, maybe you've got AIDS… they read that if you sick, all the people now have got sick. (36y M)

It would be nice [to collect treatment] without going to the actual [clinic] and getting seen because that's in public and stuff. Yes I've accepted [my status] but I know I have to go a distance and come here, and be seen here. It's better than close to home. (21y F)

F=female; HCW=healthcare worker M=male.

Table 2

Study implications for TB and HIV program policy and practice

Findings	Implications
Missed opportunities for integration Fragmented care	• Improve coordination of TB and HIV clinic appointments • Enhance communication and medical information-sharing between TB, HIV and primary healthcare clinics • Disseminate co-treatment protocols to TB, HIV and primary healthcare clinics • Improve follow-up of cross-referrals between TB and HIV clinics • Avoid multiple referrals – expand scope of services for patients on TB and/or HIV treatment
HIV nondisclosure Contrasting clinic experiences Patient preferences	• Balance medical information sharing with patient-provider confidentiality, via patient consent and trust • Build patient-provider trust, patient sensitivity and privacy at TB clinics • Prioritize TB control and monitoring at HIV clinics • Address and mitigate HIV stigma within the healthcare system

PHC=primary healthcare