The contrasting cultures of HIV and tuberculosis care

Amrita Daftary\textsuperscript{a,b}, Liviana Calzavara\textsuperscript{c} and Nesri Padayatchi\textsuperscript{b}

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Introduction

Approximately 13\% of the newly diagnosed tuberculosis (TB) cases, or 1.1 million people worldwide, are co-infected with the HIV. In 2011 alone, HIV-associated TB contributed to over 430,000 deaths, the majority of which were in sub-Saharan Africa \cite{1}. The WHO has recommended enhanced HIV and TB program collaboration and service integration to facilitate the concerted prevention, treatment and support of these commonly occurring co-infections, and mitigate their dual impact. The principle of ‘two diseases, one patient’, however, remains unrealized within many high-burden countries as a result of significant challenges associated with co-diagnosis, co-treatment and TB infection control, as well as financial and human resource constraints \cite{2–4}. We call attention to the distinct paradigms underlying HIV and TB service delivery, or the distinct ‘cultures’ of HIV and TB care, as an additional consideration to integration efforts.

Discussion

Historically, TB control has been based in a traditional public health approach \cite{3,5,6}. Since the 1990s, prevention and treatment measures have been standardized under the WHO DOTS strategy. Whereas this framework brings together critical tenets of infectious disease control – political commitment, case detection, drug procurement, treatment supervision, and monitoring and evaluation – it emphasizes the direct observation of treatment intake or DOT \cite{7}. The emerging challenges of HIV and drug-resistant TB have prompted several modifications to this framework, including greater community involvement, patient education, service decentralization, HIV–TB collaboration, and research \cite{8,9}. However, most TB programs today continue to function under a model of care that targets the proximal, biomedical determinants of infection and maximizes TB case detection, case notification, treatment adherence, and cure \cite{3,8,10}.

HIV control, in contrast, has been rooted in a patient-sensitive, individualized approach from its inception \cite{3,6}. Clinical guidelines exist, but there is much less global standardization of care, not unrelated to the rapid evolution of scientific advancements and treatment access \cite{3,11}. While ‘case detection’ and adherence are prioritized, HIV programs pay equal attention to patient education, privacy, and empowerment, driven by activism and an inherent mandate to safeguard individual rights from the effects of stigma and discrimination \cite{12,13}. HIV programs traditionally support voluntary or consensual testing as opposed to routine, in some cases mandatory, TB screening \cite{10,12,13}. The social determinants of health, such as poverty and gender inequality, are at the forefront of HIV management. This mindset, although slowly emerging, remains comparatively infrequent within most TB programs.

\textsuperscript{a}ICAP, Mailman School of Public Health, Columbia University, New York, USA, \textsuperscript{b}Centre for the AIDS Programme of Research in South Africa (CAPRISA), Nelson R. Mandela School of Medicine, University of KwaZulu Natal, Durban, KwaZulu Natal, South Africa, and \textsuperscript{c}CIHR Social Research Centre in HIV Prevention, Dalla Lana School of Public Health, University of Toronto, Toronto, Ontario, Canada.

Correspondence to Amrita Daftary, PhD, ICAP, Mailman School of Public Health, Columbia University, 722 West 168th Street, 13th Floor, New York, NY 10032, USA.

E-mail: ad2254@columbia.edu

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So how have HIV and TB programs come to reflect such disparate paradigms of care? In the early 1990s, when the problem of co-infection emerged, social scientists noted that the different approaches to HIV and TB management were a product of their distinct clinical etiologies and trajectories [5,6,12,13]. HIV is primarily transmitted through intimate contact (e.g. sexual practices, needle sharing), whereas TB is spread via airborne, nonintimate contact (e.g. cough). Transmission of HIV, relative to TB, involves more conscious behavioral pathways, notwithstanding their shared social determinants. HIV prevention therefore mandates working with patients, and the greater involvement of people living with the virus is now intrinsic to HIV policy and practice [14]. Enforced compliance through collective government approaches or medical coercion, as has been seen with TB management, is perceived to be counterproductive to sustained behavioral change [6,15].

HIV is also a lifelong, incurable illness with a persistent infectious stage. TB may be rendered both noninfectious and curable with 6–12 months of treatment. Relatively authoritarian measures such as routine screening, treatment supervision and, in some cases, mandatory treatment may be easier to implement when a cure is probable, as with TB, but difficult to sustain over a lifetime, as with HIV [12,13]. The impact of stigma, often more acutely experienced in cases of HIV, likely reinforces the emphasis on patient privacy and confidentiality within HIV programs [6]; consider the different approaches of tracing and disclosing to TB versus HIV ‘contacts’. Indeed, the HIV community’s critique of policies that criminalize nondisclosure is further testimony to their intolerance for collective approaches that may compound HIV stigma and infringe on individual patient rights [15].

Over the years, HIV and TB programs have attracted diverse levels of social and political momentum. Governments worldwide have less readily formed consensus on the cause and impact of HIV, in part, due to its association with behaviors perceived to be immoral and illicit. As a result, early HIV programs met fragmented political support and denialism in some cases [16,17]. Affected communities rallied from the ground-up to mobilize grassroots movements as a means to elicit global consensus and a concerted response [14,16,17]. HIV activists, including persons living with HIV, were and arguably remain some of the most powerful voices of HIV resource mobilization [13,14,16]. HIV advocacy was also largely spearheaded by gay men, who were already part of an established community [5,13]. TB advocacy has lacked this populist grassroots support [14,16]. Instead, TB programs have been criticized for alienating affected communities through their top-down approach to disease management. The lack of patient involvement in decisions governing treatment access and adherence has been tied to the absence of commensurate TB advocacy and support worldwide [7,16]. Only recently have TB practitioners started to reverse their longstanding use of incriminating terms such as ‘suspects’ to describe people affected by TB, which would be unthinkable to apply in the context of HIV [18].

In comparison to HIV, operational and implementation research for TB, including drug development, has progressed at a much slower pace. Alongside an array of antiretroviral agents, bedaquiline represents one of the only truly novel antituberculosis agents to be approved in decades [19]. The adoption of an unquestioning mindset to established protocols has been argued to compound the dearth of innovation in TB research [2,14]. Furthermore, that HIV is recognized as an important public health concern within many industrialized nations has armed HIV programming with access to greater resources. The impact of TB, on the contrary, remains concentrated within poorer countries that have less monetary power to initiate novel research or action [16].

HIV and TB programs thus appear to have become rooted in diverse approaches to healthcare delivery. Yet, in our quest for optimizing their concurrent management, comparatively few studies have drawn attention to these distinctions. In sharing their early experiences with service integration in South Africa, Coetzee et al. [20] and Friedland et al. [21] commented on the different programmatic approaches within HIV and TB clinics. Abdool Karim et al. [2] have suggested that the greater attention to patient education and treatment literacy, and address to the social implications of HIV, may help explain the relatively higher rates of adherence and retention recorded within some HIV programs. Indeed, the lack of community empowerment, believed to be perpetuated by a DOT approach, has been associated with high rates of patient attrition from TB clinics [8,16]. In KwaZulu Natal province, we found co-infected patients’ comparative experiences within HIV and TB clinics not only reflected the different ‘cultures’ of health care delivery within HIV and TB programs, but additionally influenced patients’ decisions for service integration [22]. The interpersonal attitude perceived within TB clinics, in contrast to the compassion and privacy experienced within HIV clinics, dissuaded some patients from disclosing HIV to their TB and DOT providers and from accessing dual services within the structure of a TB program [22]. A recent study including patients co-infected with HIV and drug-resistant TB found adherence to antiretroviral therapy (ART) was significantly higher than to second-line TB treatment [23]. In related qualitative work, we analyzed how co-infected patients’ dissatisfaction with TB services, characterized by alienating experiences with TB notification and treatment supervision, negatively influenced adherence to TB treatment. By contrast, patients’ greater involvement in HIV treatment and ART education provided them with a sense of ownership that reinforced preferential adherence.
to ART [24]. These data highlight how divergent models of HIV and TB healthcare may influence patients’ decisions toward service integration and adherence, which collectively may impact treatment outcomes for co-infection.

In conclusion, we urge HIV and TB programs to address their ‘cultural’ differences in framing collaborative efforts (see Fig. 1), so that services may be delivered under a cohesive and complementary approach that meets the sociomedical needs of co-infected patients. Agencies such as the WHO and United States Centres for Disease Control are beginning to champion a public health approach to HIV care, comprising stricter treatment initiation criteria, standardized first-line and second-line regimens, provider-initiated screening and testing with opt-out mechanisms, and the application of DOT-based models to ART [4,25,26]. Although these efforts reflect some blurring of the differences between the two programs, they have had to contend with the enduring climate of HIV ‘exceptionalism’ [25], particularly around treatment readiness and individualized consent to testing and treatment. Commensurate efforts are needed around the more widespread adoption of patient-sensitive approaches to care within TB programs [4,15,16].

Realistic address to the distinct paradigms underlying HIV and TB control must also consider how to marry the holistic philosophy of HIV care with the focused strategy of TB management in the context of available financial and human assets.

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Conflicts of interest

There are no conflicts of interest.

References


