



HIV and tuberculosis: The construction and management of double stigma

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ABSTRACT

Mitigation of the tuberculosis (TB) and HIV syndemic is undermined by critical clinical, operational and social challenges of which the social aspects have been least explored. This paper examines the lived experience of TB disease and HIV from the perspective of affected individuals to analyze how they may think about their dual illness; how they understand their illness with TB in relation to HIV, and vice versa; and how they characterize their (stigmatized) experiences in the context of their perceptions and identities. From February–August 2009, qualitative, semi-structured interviews were conducted with 40 adults with HIV and TB disease at three ambulatory clinics in KwaZulu-Natal, South Africa. Subjective meanings of illness experience were analyzed using modified grounded-theory. Emergent themes on illness perception and disclosure revealed how patients constructed dichotomous identities associated with TB and HIV through social constructs of *moral susceptibility* and *(im)permanence*. Each identity was associated with relatively disparate degrees of stigma as a product of labeling, negative stereotyping and discrimination. HIV bore the least desirable identity and invoked the greatest stigma. However, the confluence of the two epidemics rendered TB symbolic and symptomatic of HIV, and enhanced the visibility of AIDS. Dual illness thus introduced a paradox to patients' identity constructions, and produced a unique, overlapping double stigma. This facilitated new forms of stigma against TB, and aggravated existing stigma against HIV. It also conferred visibility to some forms of extra-pulmonary TB. Patients managed their double stigmas through novel forms of information sharing that relied on segregating their dual illness identities. Patients deflected the dominant stigma of HIV through concurrent processes of HIV 'othering' – their symbolic distancing from persons affected by HIV, and 'covering' – their selective disclosure of illness (and identity associated) with TB over that of HIV. Findings call for greater consideration to the complex role of stigma in the delivery of TB/HIV healthcare.

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Introduction

Tuberculosis (TB) and human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) are intimately linked. Tuberculosis is the leading opportunistic infection among people living with HIV, and HIV is the strongest risk factor for developing TB disease. In 2009, 12% of over 9 million new TB cases worldwide were HIV-positive, equaling approximately 1.1 million people (WHO, 2010). South Africa is the most heavily affected country, where 73% of all TB cases are HIV-positive (Padarath & Fonn, 2010).

While extensive research has addressed the clinical and operational challenges of this TB and HIV syndemic (Kwan & Ernst, 2011), the social aspects remain relatively unexplored. The majority of related research focuses on problems associated with diagnosing both infections, including fear and stigma around HIV testing by TB patients (for example, see Daftary, Padayatchi, & Padilla, 2007; Yi

et al., 2009) and delayed health-seeking by patients exhibiting signs of TB, due to the anticipation and subsequent stigma related to HIV discovery (see Mavhu et al., 2010; Ngamvithayapong, Winkvist, & Diwan, 2000).

Fewer studies examine the social contexts of TB/HIV illness once a dual diagnosis is confirmed, that is, once patients become aware or notified they have TB disease and HIV. They show the economic and emotional burden of TB/HIV is greater than that experienced with TB or HIV alone, perpetuating a lower quality of life that is significantly associated with higher perceived stigma (Deribew et al., 2009; Sadoh & Oviawe, 2007). Qualitative studies further show HIV-positive TB patients suffer complex challenges to adherence, less related to their higher pill burden (as is often postulated) but rather to stigma, nondisclosure, lack of support, poverty, and feelings of hopelessness and helplessness (Gebrekristos, Lurie, Mthethwa, & Karim, 2009; Gebremariam, Bjune, & Frich, 2010; Naidoo, Dick, & Cooper, 2009). Recent ethnographic work also highlights how social barriers, particularly broken relationships, stigma and nondisclosure, along with

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economic and health system deficiencies, collectively debilitate patients and challenge their ability to access dual care (Chileshe & Bond, 2010). These studies urge further examination of the social challenges of TB and HIV, particularly around stigma associated with a dual diagnosis.

Stigma associated with TB or HIV

Conceptualizations of disease-related stigma most often borrow from Erving Goffman (1963) who defined stigma to be “an attribute that is deeply discrediting” (p 3). Goffman specified that attributes are not discrediting or stigmatizing of their own accord but rather in confirming the relational and relative normalcy of another. This difference between “normal” or acceptable and “tainted” (p 5) or undesirable is the platform from which individuals possessing certain (acceptable) attributes may stigmatize those possessing other (undesirable) attributes (Goffman, 1963).

Drawing from this, contemporary scholars suggest the labeling of particular traits as undesirable is socially created, and used as a tool to assert dominance over individuals who are already marginalized on the basis of extant inequalities such as those related to race, class, religion or gender (Link & Phelan, 2006; Parker & Aggleton, 2003). These later conceptualizations of stigma tie back to the social determinants of infectious diseases, such as poverty, urbanization and social stratification (Farmer, 1996; Gandy & Zumla, 2002). They allow for stigma to be conceived of as a socially constructed phenomenon rather than just an individualistic issue.

Stigma is thus part of the broader context of illnesses such as TB and HIV that attract a greater degree of social undesirability. Individuals with HIV are routinely stigmatized, discriminated and excluded within their communities (see Campbell, Foulis, Maimane, & Sibiyi, 2005; Mbonu, van den Borne, & De Vries, 2009; Sontag, 1991; UNAIDS/WHO, 2005). They are labeled as outcasts and immoral due to the socially taboo circumstances through which the virus is transmitted (e.g., sexual practices, drug use), its high prevalence in marginalized communities and association with death (Farmer, 1996; Mbonu et al., 2009; Parker & Aggleton, 2003).

Tuberculosis, an older infection, also invokes stigma and discrimination. Historically, TB patients were demonized and isolated due to fear of their infectivity (see Courtwright & Turner, 2010; Packard, 1989), but the distribution of curative, affordable chemotherapy in the 1960s–1970s significantly diminished stigma associated with TB (Sontag, 1991). The subsequent HIV pandemic and TB resurgence, however, have renewed suspicions about TB patients (Johansson, Long, Diwan, & Winkvist, 2000; Nnoaham, Pool, Bothamley, & Grant, 2006).

Both TB and HIV are highly prevalent among groups already considered undesirable in the broader social hierarchy. HIV stigma reifies inequalities against sex workers, men who have sex with men, the poor and women (Link & Phelan, 2006; Parker & Aggleton, 2003). Tuberculosis also reasserts prejudices on groups at greatest risk for infection, including people living in impoverished, overcrowded areas and immigrants from TB-endemic countries (Farmer, 1996; Gandy & Zumla, 2002). The intersection of disease-related stigma and social inequality renders individuals from these marginalized groups to experience a greater degree of discrimination. The consequences are multifarious; stigma is associated with low uptake of HIV testing and TB-related services, and poor adherence and retention in HIV care and TB treatment (see Courtwright & Turner, 2010; Mbonu et al., 2009).

Stigma associated with TB and HIV

Studies measuring disease-related stigmas show that TB, TB/HIV patients and general community members all perceive significantly

higher levels of stigma against HIV and TB/HIV compared to TB alone (Deribew et al., 2010; Mak et al., 2006), with HIV-positive persons regarded as more blameworthy compared to persons with just TB (Mak et al., 2006). Studies have additionally tried to examine how TB/HIV stigma is socially produced. Comparative work highlights the social drivers of TB stigma differ across geographic contexts: in Southeast Asia, it is tied to negative effects on marital prospects whereas in southern Africa, it is linked to strong associations with HIV (Somma et al., 2008). Research examining delayed health-seeking by TB patients also shows that in high HIV prevalence areas, discriminatory attitudes against HIV are being transferred to individuals presenting with TB (Mavhu et al., 2010; Ngamvithayapong et al., 2000). A perceived similarity in symptoms, such as weight loss and fatigue, perpetuates stigma against TB and creates a double stigma of TB and HIV (Bond & Nyblade, 2006; Daftary et al., 2007; Nnoaham et al., 2006).

The prevalence of multiple stigmas is recorded among individuals affected by overlapping characteristics that provoke routine social stigmatization. For example, multiple stigmas are documented among HIV patients in the context of their minority ethnicity, race, sexual orientation and/or gender, and are linked to delayed health-seeking and compromised adherence (Mawar, Saha, Pandit, & Mahajan, 2005). So how do patients manage these multiple stigmas? In his original analysis, Goffman (1963) described how people cope with stigma based on the conspicuity of their undesirable attributes. In the case of less visible attributes, individuals may deflect stigma by “passing” (Goffman, 1963, p. 73) or simply hiding their condition. People with asymptomatic HIV routinely ‘pass’ as normal when they conceal their HIV status. Nondisclosure may be considered the most common HIV stigma management strategy (Serovich, 2001). Due to its link with HIV, nondisclosure of TB is also becoming commonplace (Bond & Nyblade, 2006; Daftary et al., 2007; Ngamvithayapong et al., 2000).

A few empiric studies show how persons with multiple undesirable attributes manage overlapping stigmas by aligning themselves with particular protective self-identities. For example, women with mental illness are found to resist the stigmas associated with their health, minority ethnicity, poverty and gender by identifying more strongly with their religion and faith (Collins, von Unger, & Armbrister, 2008). Gay men create symbolic boundaries and physically distance themselves from other gay men living with HIV in an attempt to minimize the double stigma associated with their sexual orientation and its association with AIDS (Kowalewski, 1988). In high HIV prevalence communities, patients and their families commonly disclose illness and/or death to be a result of TB compared to HIV, in order to be protected from HIV-related stigma (Coreil et al., 2010; Daftary et al., 2007; Ngamvithayapong et al., 2000). There is a research need to consider stigma management in the context of TB/HIV. Understanding the construction and negotiation of this stigma may inform the delivery of TB/HIV healthcare.

This paper highlights how individuals with HIV and TB may think about their illness and themselves; how they understand their illness with TB in relation to HIV, and vice versa; and how they characterize their (stigmatized) experiences living with both infections. It represents the first part of a study that was designed to examine the social contexts of TB/HIV illness in relation to (i) the lived experience of a dual diagnosis, (ii) patients’ social and structural realities, and (iii) access and decisions around TB/HIV healthcare. Subsequent objectives, addressed in future papers, will lend insight on how patients’ characterizations may be further interpreted against a backdrop of their wider social environment, and linked to decisions around the public health shift to integrate TB and HIV services.

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