Integrating Patients into Integrated Care: Perspectives from Individuals Coinfected with Tuberculosis and HIV

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Abstract

Background: Tuberculosis (TB) and human-immunodeficiency virus (HIV) infections are intertwined through complex biological and social pathways that affect over one million people worldwide. Mitigation of the co-epidemic is undermined by a failure to integrate TB and HIV healthcare services as a result of critical clinical, operational and social challenges. The social challenges of TB/HIV coinfection and integrated care are least understood.

Objectives: This research examines the social contexts of TB/HIV illness and related healthcare from the perspective of patients coinfected with TB and HIV.

Methods: The study was set within a constructivist-interpretivist theoretical framework. Non-participant field observations and semi-structured in-depth interviews were held with 40 coinfected adults (24 women, 16 men) and 8 healthcare workers at 3 ambulatory clinics in KwaZulu-Natal, South Africa, providing varying models of TB and HIV care. Subjective meanings of illness and healthcare were analyzed in relation to patients’ social contexts.

Findings and Interpretations: Coinfection exposes patients to a double and unequal form of social stigma around TB and HIV. Affected individuals construct dual identities and negotiate selective disclosure of TB over HIV in order to manage this double stigma. Their experiences with stigma are bound by social, structural and gendered inequalities, and mediate their decisions to disclose, access and adhere to medical care. Coinfection also exposes patients to pluralistic, disparate and fragmented forms of healthcare delivery. Experiences with stigma and
with distinct cultures of TB and HIV care affect their decisions for integrated healthcare. While integration may allow for some technical and clinical efficiency, it may also heighten some patients’ social burden of illness as a result of HIV disclosure and stigmatization.

**Conclusion:** Integration efforts should consider the social contexts of TB/HIV coinfection, social consequences of patients’ health decisions, and paradigms within which such efforts are set in the design and execution of successful interventions.
Dedicated to the memory of my father, Ravindra
Acknowledgments

This thesis is a humble attempt to promote the voices of individuals affected by tuberculosis and HIV. I am indebted to the forty-eight women and men who participated in this endeavour for sharing a part of their worlds with me and for permitting me to share it with others, and to the staff at the Centre for the AIDS Programme of Research in South Africa (CAPRISA), Prince Cyril Zulu Communicable Disease Centre, Grey’s Hospital and Howick Clinic for their generosity and goodwill.

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<th>Description</th>
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<tr>
<td>AIDS</td>
<td>Acquired immunodeficiency syndrome</td>
</tr>
<tr>
<td>ART</td>
<td>Antiretroviral treatment</td>
</tr>
<tr>
<td>ARV</td>
<td>Antiretroviral (treatment)</td>
</tr>
<tr>
<td>BCG</td>
<td>Bacille Calmette Guerein (vaccine)</td>
</tr>
<tr>
<td>CAPRISA</td>
<td>Centre for the AIDS Programme of Research in South Africa</td>
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<tr>
<td>CD4</td>
<td>Cluster of differentiation or cell count, measured as cells/mm$^3$</td>
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<tr>
<td>CDC</td>
<td>Centre for Disease Control</td>
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<tr>
<td>CPT</td>
<td>Cotrimoxazole preventive therapy</td>
</tr>
<tr>
<td>DOH</td>
<td>Department of Health</td>
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<tr>
<td>DOTS</td>
<td>Directly-observed therapy, short-course</td>
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<tr>
<td>EPTB</td>
<td>Extra-pulmonary tuberculosis</td>
</tr>
<tr>
<td>HBM</td>
<td>Health Belief Model</td>
</tr>
<tr>
<td>HIV</td>
<td>Human immunodeficiency virus</td>
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<tr>
<td>HST</td>
<td>Health Systems Trust, South Africa</td>
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<tr>
<td>ILO</td>
<td>International Labour Organization</td>
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<tr>
<td>IPT</td>
<td>Isoniazid preventive therapy</td>
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<tr>
<td>IRIS</td>
<td>Immune reconstitution inflammatory syndrome</td>
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<tr>
<td>IUATLD</td>
<td>International Union Against Tuberculosis and Lung Disease (The Union)</td>
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<tr>
<td>KZN</td>
<td>KwaZulu-Natal</td>
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<tr>
<td>LTBI</td>
<td>Latent tuberculosis infection</td>
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<tr>
<td>M/XDR-TB</td>
<td>Multi or extensively drug-resistant tuberculosis</td>
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<tr>
<td>NGO</td>
<td>Non-governmental organization</td>
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<tr>
<td>NTCP</td>
<td>National Tuberculosis Control Programme</td>
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<td>STI</td>
<td>Sexually transmitted infection</td>
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<td>TB</td>
<td>Tuberculosis</td>
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<tr>
<td>TPB</td>
<td>Theory of Planned Behaviour</td>
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<tr>
<td>TST</td>
<td>Tuberculin skin test</td>
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<tr>
<td>TRA</td>
<td>Theory of Reasoned Action</td>
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<tr>
<td>UKZN</td>
<td>University of KwaZulu-Natal</td>
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<tr>
<td>UNAIDS</td>
<td>Joint United Nations HIV/AIDS Programme</td>
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<td>UNGASS</td>
<td>United Nations General Assembly Special Session on HIV/AIDS</td>
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<td>US</td>
<td>United States of America</td>
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<tr>
<td>VCT</td>
<td>Voluntary counseling and testing</td>
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<td>WHO</td>
<td>World Health Organization</td>
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<td>ZAR</td>
<td>South Africa Rand</td>
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Chapter 1

Introduction

“One can see it even if one is trying not to reveal it. But clearly the face of AIDS, people know it today.”

(Person with tuberculosis, South Africa, 2005)

Tuberculosis (TB) and human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) are inextricably linked through complex biological and social pathways. They accelerate each other’s progression and perpetuate synergistic rates of morbidity and mortality. Globally, HIV is the strongest risk factor for the development of TB disease and TB is the leading opportunistic infection and AIDS-defining condition among people living with HIV (UNAIDS, 2008; UNAIDS, 2009; UNAIDS/WHO, 2006; WHO, 2010a). In 2009, the global incidence of new TB cases exceeded 9 million, of which 12% were estimated to be HIV-positive (WHO, 2010a). About one-third of all people living with HIV worldwide are infected with the TB bacillus, either latently or actively, and nearly one-half million individuals succumb to coinfection each year (UNAIDS, 2009; WHO, 2010a). Every region across the globe is affected by the TB/HIV syndemic but it is most pervasively experienced in sub-Saharan Africa.

The escalating global burden of coinfection has prompted public health institutions to consider an alternate, integrated strategy of healthcare. In place of vertical health programs for infectious disease control, the World Health Organization (WHO) has prioritized integration of TB and HIV healthcare services as a means to decrease the incidence and impact of both infections. Integrated strategies involve improvements in TB and HIV testing, prevention, treatment and supportive services through coordinated and collaborative efforts between individual TB and HIV programs (WHO, 2004). However, countries experiencing the highest burden of coinfection are also the most resource-poor. Planning and execution of informed integrated interventions in these settings is, at once, imperative and onerous as a result of multi-level challenges and deficiencies (WHO, 2008a).

Over the past decade, extensive research has been directed towards the resolution of clinical obstacles to the management of TB/HIV coinfection, and overcoming technical challenges to the delivery of dual care including operational issues around integration. However, social aspects of
coinfection that are critical to the integrative process remain largely neglected and inadequately explored. Central to this is the phenomenological experience of illness, and of healthcare, that are relevant from the perspective of infected individuals, particularly in relation to their social, cultural, political, historical and economic contexts. Unless we understand how individuals live with TB and HIV and how this relates to their decisions for TB and HIV care, we might fail to devise a successful and sustained public health response to curb the dual epidemic.

This dissertation reports findings from a qualitative study that critically analyzes the experience of dual diagnosis and dual healthcare for individuals infected with TB and HIV. The study objective is to examine the social contexts of TB/HIV illness from the perspectives of coinfected patients as they access and utilize healthcare for TB and HIV in South Africa. South Africa is at the epicenter of the TB/HIV co-epidemic, hosting one in every four of the world’s dually infected cases despite sharing a small fraction of the world’s population. The most recent national reports estimate nearly three-quarters of all newly diagnosed TB patients are coinfected with HIV, and a majority of TB-related deaths are attributable to the virus.

The study addresses the dearth of scientific inquiry on the sociomedical and experiential aspects of illness and healthcare that underlie the exorbitant impact of TB and HIV/AIDS in settings such as South Africa. The objectives are aimed to expand the dominant biomedical discourse around TB/HIV towards considering more socially relevant aspects of illness in the planning and delivery of related healthcare services. They were borne of an earlier experience in South Africa, when I encountered a group of inpatients at a specialized TB hospital in Durban who shared with me their experiences with HIV testing at the dawn of the national antiretroviral rollout (Daftary et al., 2007). I was drawn to their poignant and deeply expressive narratives that were missing in hospital reports and national registries. I became keen to examine the social manifestations and impact of HIV-associated TB against the backdrop of healthcare restructuring, and was thus motivated to design and implement the current research for my doctoral dissertation.

The analysis herein is most informed by the study protagonists – 40 diverse and vital women and men – together with a group of dynamic healthcare workers whom I encountered across three healthcare facilities in the province of KwaZulu-Natal. Interacting with their voices has been my life’s work for the past three years. I hope it makes for a constructive and insightful read.
The thesis is divided into 9 chapters. Following this introduction, in Chapter 2, I present a critical review of the literature related to TB/HIV coinfection with regards to the development and challenges of an integrated approach to TB/HIV healthcare. In Chapter 3, I outline the theoretical and methodological framework for the study in response to several guiding questions that emerge from the literature review. In Chapter 4, I present descriptive findings including relevant characteristics of patient participants and study sites, which inform my qualitative interpretations.

Subsequent chapters focus on analytic findings that inform conceptualization of a theoretical framework within which individuals’ lived experience with dual infection and dual care may be set. In Chapter 5, I characterize how the construction of dual identities and TB/HIV stigma impact coinfected patients’ (gendered) experiences with illness and illness disclosure. In Chapter 6, I embed patients’ illness experience within the context of broader social and structural inequalities including those related to class and gender, and demonstrate how the perpetuation of stigma in light of these inequalities mediate patients’ ability to access and adhere to care. In Chapter 7, I focus on patients’ specific experiences within the health system, particularly TB and HIV programs, to develop understanding of how program ‘cultures’ may influence patients’ decisions for integrated healthcare. Each analytic chapter begins with a presentation of relevant qualitative findings and ends with an interpretive discussion of these empiric findings, situating them in the broader literature base.

In Chapter 8, I synthesize and summarize the study’s key qualitative findings. In Chapter 9, I discuss the potential implications of the study for healthcare policy and practice, including the limitations of this thesis and directions for future research.
Chapter 2

Literature review

The breadth and scale of TB/HIV coinfection

The TB and HIV/AIDS epidemics are inextricably connected through complex biological, epidemiological and social pathways (IUATLD, 1999; Selwyn, 1993; WHO, 1992; WHO, 2002b; WHO, 2010a). HIV dramatically increases the risk of developing TB, including the development of primary progressive disease, activation of latent TB infection (LTBI), re-infection with TB, and TB relapse. The virus suppresses the immune system via destruction of the body’s CD4 T-lymphocytes that are essential to inhibition of the TB bacillus, *Mycobacterium tuberculosis* (Cahn et al., 2003; Corbett et al., 2006; Corbett et al., 2003; Lee et al., 2000). A 5-10% lifetime risk of progressing from latent infection to TB disease\(^1\) in an immunocompetent individual jumps to an annual risk of over 10% in people infected with HIV. This reflects a 20- to 37-fold TB risk-increase depending on the state of the underlying HIV epidemic (Corbett et al., 2003; Getahun et al., 2010; Selwyn, 1993). Tuberculosis, through cytokine secretion and enhanced viral transcription and replication, promotes HIV expression and greater vulnerability to other infections (Cahn et al., 2003). It is the leading opportunistic infection or AIDS-defining condition worldwide and the primary cause of mortality among people living with HIV (Chaisson & Martinson, 2008; Corbett et al., 2006; UNAIDS/WHO, 2006; WHO, 2009b).\(^2\) The relationship between TB and HIV is thus mutually aggressive.

The clinical etiology of coinfection is driven by the individual transmission of both pathogens. HIV is spread through the exchange of particular bodily fluids, most often via unsafe sexual practices and injection drug use (Selwyn, 1993). Tuberculosis, an airborne pathogen, is spread through droplet contact via coughing or sneezing in enclosed spaces. The global proliferation of TB is also routinely attributed to patient non-adherence to treatment (Gandy & Zumla, 2002). However, due to the disproportionate rates of transmission and clinical burden of TB and HIV among socially marginalized populations, they are also widely recognized as *social diseases* or diseases that are

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\(^1\) Unless otherwise stated in this thesis, TB or tuberculosis refers to active tuberculosis disease.

\(^2\) Globally, by proportion and number, TB is the leading opportunistic infection and cause of mortality among people living with HIV. However, in specific regions, other infections may pose greatest risk to people living with HIV. For example, *Pneumocystis pneumonia* is the commonest AIDS defining opportunistic illness in the United States (Buchacz et al., 2010).
socially, not just microbiologically or individually, determined (Chaisson & Martinson, 2008; Farmer, 1996; Fox, 2010).

The social determinants of TB/HIV coinfection, or social factors that influence its epidemiological burden (Krieger, 1994), are believed to parallel those of the individual TB and HIV epidemics: poverty, gender inequality, urbanization, overcrowding, social stratification, inequitable access to resources, and weak health service delivery mechanisms reflective of poor funding and/or political commitment (Abdool Karim et al., 2009; Fox, 2010; Gandy & Zumla, 2002; Harling et al., 2008; Padayatchi et al., 2010). In generalized HIV epidemics three across Africa, HIV coinfection among new TB cases is highest among women, and case-fatality is greatest among infants and young adults (Achmat, 2006; Marais et al., 2010a; UNAIDS/WHO, 2006). Maternal mortality related to coinfection exceeds 25% in some settings (Gandy & Zumla, 2002). In other regions, where TB and HIV are pocketed epidemics, most new TB infections occur among injection drug-users, prisoners, sex workers, homeless persons and recent immigrants, who are typically also at higher risk for HIV as a result of their inequitable social conditions (Lonnroth et al., 2010; Selwyn, 1993; WHO, 2008a). The social risks for contracting TB and HIV compound their microbiological interplay (Farmer, 1996; Gandy & Zumla, 2002; Lonnroth et al., 2010). Researchers have thus urged a renewed perspective on their spread, one that is tied to “a broader set of ‘bio-social’ processes” (Gandy & Zumla, 2002: p 390) that overarches the biological and behavioural pathways of transmission (Farmer, 1996; Gandy & Zumla, 2002).

Over the past two decades, TB incidence has paralleled increases in HIV prevalence (see Figure 2.1). From 2000 to 2009 the number of newly diagnosed TB cases coinfected with HIV rose from 0.5 million to over 1.1 million, reflecting 12% of incident TB cases worldwide (WHO, 2008a; WHO, 2010a). Coinfection accelerates rates of mortality, greater than that experienced with either TB or HIV alone. In 2007-08, 0.5 million of the world’s 1.8 million TB deaths were attributable to HIV, and deaths from TB accounted for 23% or 456,000 of the 2 million deaths classified to AIDS (WHO, 2009b).

The geographic distribution of coinfection varies across the six WHO global regions of the Americas, Africa, Europe, Eastern Mediterranean, Southeast Asia and the Western Pacific, with a significantly

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3 In generalized HIV epidemics, adult HIV prevalence is at least 1% and transmission is mostly heterosexual. In pocketed or epidemics, HIV prevalence is concentrated in particular groups that are at a higher risk of HIV exposure (UNAIDS, 2006).
greater burden of disease in the global South by proportion and by absolute number (WHO, 2009b; WHO, 2010a). Coincident with the high burden of individual TB and HIV infections, the majority of coinfection cases occur in Africa where over 1 million people with TB, or 37% of 2.8 million newly diagnosed TB patients, are dually infected with HIV. Nearly 80% of the global burden of coinfection is in Africa, followed by Southeast Asia (see Figure 2.2) (WHO, 2010a).

Since 1990, TB mortality has gradually declined in most WHO regions. However, it continues to be high in Africa, due to the overwhelming impact of the HIV epidemic. In 2007, for instance, HIV accounted for 377,000 or 51% of all TB-related deaths in Africa but only 5-19% of TB-related deaths in other parts of the world (WHO, 2009b).

**Figure 2.1: Tuberculosis incidence parallels HIV prevalence**

![Figure 2.1: Tuberculosis incidence parallels HIV prevalence](image)

Figures copied from the Global TB Report 2009 (WHO, 2009b: p 11), based on rates within high-burden countries in sub-Saharan Africa.

**Figure 2.2: Global distribution of HIV-positive TB cases**

![Figure 2.2: Global distribution of HIV-positive TB cases](image)

Figures copied from the Global TB Report 2008 (WHO, 2008a: p 20). * AFR or Africa includes all countries in the region except those countries shown separately; Americas excludes Brazil; Europe excludes the Russian Federation; Southeast or SE Asia excludes India.
Prioritization of TB/HIV healthcare

Mounting rates of TB/HIV coinfection as a result of the detrimental impact of HIV on global TB incidence were first acknowledged in the 1980s (WHO, 1992). In 1993, TB was declared a global emergency and a targeted strategy for TB control was devised: DOTS, or directly observed therapy, short-course, stood on five fundamental tenets of political commitment; active case detection via bacteriological surveillance; standardized supervised treatment; secure drug procurement; and, rigorous treatment monitoring and evaluation (see Appendix A for the current expanded Stop TB strategy). However, by 1999-2000, case detection rates were well below target even in countries that had fully implemented DOTS, with poor treatment success among those detected. As a result, less than a quarter of the world’s TB cases were successfully treated. The vertical DOTS approach was believed to compound resource constraints within high-burden regions in Africa and Asia, and prompted a shift towards more horizontal strategies of control. Decentralization and integration of TB-DOTS into primary healthcare services within the most heavily affected countries gradually led to improved rates of cure over the next decade (Raviglione, 2003; Raviglione & Pio, 2002).

By the end of the 20th century, the unsuppressed HIV epidemic (and rising rates of TB drug-resistance) threatened to hamper the progress accomplished with global TB control. In response to the escalation of HIV-associated TB, the WHO promoted research and surveillance on coinfection with increased alliances between TB and HIV programs. Healthcare for coinfection, however, remained poorly delivered in many settings. TB-DOTS was deemed inadequate to meet the aggression of HIV, prompting the WHO’s Stop TB Department and the Department of HIV/AIDS to establish a Global TB/HIV Working Group (Corbett et al., 2006; Raviglione, 2003; Raviglione & Uplekar, 2006; WHO, 2002b). Between 2002 and 2004, the Group published three important policy documents: Strategic Framework to Decrease the Burden of TB/HIV (WHO, 2002b); Guidelines for Implementing Collaborative TB and HIV Programme Activities (WHO, 2003); and, Interim Policy of Collaborative TB/HIV Activities (WHO, 2004). Collectively, they drive the current model for delivering TB/HIV healthcare (see Appendix B for details), the salient components of which are as follows:

- To establish mechanisms for collaboration between TB and HIV programs, such as via coordinating bodies, joint TB/HIV planning, monitoring and evaluation, HIV surveillance;
- To decrease the burden of TB in people living with HIV, including intensified TB case finding and treatment among people living with HIV followed by isoniazid preventive therapy (IPT) for those without active TB;
To decrease the burden of HIV in TB patients, through HIV testing of TB patients and, for those TB patients infected with HIV, cotrimoxazole preventive therapy (CPT) against other opportunistic infections, and antiretroviral therapy (ART); and,

To enhance infection control in healthcare and congregate settings.

Intensified TB case finding, IPT and infection control are also termed the 3 I’s for TB and HIV control.

The WHO model for TB/HIV healthcare is based on the premise that case management for coinfection may be best attained through enhanced TB and HIV program collaboration leading to integration, with the aim of achieving improved clinical efficacy and program efficiency (WHO, 2003). The essential goals of integration are to reduce TB and HIV transmission, disease and death. The degrees to which the WHO model is adopted within national ministries of health depend on the burden of coinfection estimated within specific countries, as outlined in Table 2.1.

### Table 2.1: WHO country-specific recommendations for TB/HIV healthcare

<table>
<thead>
<tr>
<th>Category</th>
<th>Criteria</th>
<th>Recommended activities</th>
</tr>
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| **III**  | National adult HIV prevalence rates <1%  
and  
No administrative areas with adult HIV prevalence ≥1% | Conduct HIV surveillance among TB patients and implement activities that decrease the burden of TB among HIV-positive persons. |
| **II** (e.g., India, Argentina)<sup>a</sup> | National adult HIV prevalence rates <1%  
and  
Administrative areas with adult HIV prevalence ≥1% | Implement all TB/HIV collaborative activities in areas with adult HIV prevalence ≥1% and the same activities as Category III in other parts of the country. |
| **I** (e.g., Brazil, South Africa)<sup>a</sup> | National adult HIV prevalence rates ≥1% (generalized epidemic)  
or  
National HIV prevalence among TB patients ≥5% (concentrated epidemic) | Implement all activities described in the model. |


- a: Country examples based on estimates of national HIV prevalence and HIV prevalence among TB patients reported by UNGASS Country Reports 2007 (UNGASS, 2007), and Global TB Control Report 2008 (WHO, 2008a), respectively.
- b: ‘Administrative areas’ refers to particular identifiable population groups such as TB patients and injection drug users.

**Global implementation of TB/HIV healthcare**

There are no specific procedures on how integration of TB and HIV healthcare should be executed on ground, and the application of WHO recommendations varies greatly across affected regions (WHO, 2010b). Perhaps attributable to their higher burden of disease and challenges experienced
with implementation, the majority of reports on integrated TB/HIV interventions are based on the African experience in countries considered to be Category I by the WHO.

One of the earliest joint TB/HIV control efforts was the ProTest Initiative piloted in Malawi, South Africa, Uganda and Zambia between 1999 and 2001. Derived from the promotion of voluntary counseling and testing, ProTest served as a vehicle linking patients attending TB, primary healthcare and sexually transmitted infection (STI) clinics to HIV testing and supportive services. Tuberculosis programs were especially recognized as optimal entry points for voluntary HIV counseling and testing (VCT) and CPT, and gradually in a growing number of settings, for ART (Godfrey-Faussett et al., 2002). Following the introduction of internationally negotiated drug prices and expansion of ART access in the global South, several Category I countries learned from the ProTest Initiative and scaled up efforts for coordinated TB and HIV care (Nunn et al., 2007).

Of the 63 countries accounting for 97% of the world’s HIV-positive TB cases that the WHO prioritized for implementation of TB/HIV interventions, two-thirds established coordinating bodies, developed a joint plan and implemented HIV surveillance programs by 2008. About 50 countries passed policies for HIV counseling and testing of TB patients, provision of CPT and ART for those coinfected, and intensified TB case finding among HIV-positive persons. Far fewer countries established policies for TB infection control (n=34) and IPT (n=29) (WHO, 2008a).

Between 2002 and 2007 the number of notified TB patients aware of their HIV status rose significantly from less than 1% across 9 countries to over 16% across 135 countries due to the extensive scale-up of HIV counseling and testing services (WHO, 2008a). By 2009, 63% of TB cases worldwide were successfully detected (including individuals with and without HIV). Of newly detected TB cases, the HIV status was known for 1.6 million or 26% (see Figure 2.3). In Africa, 49% of TB cases were successfully detected and the HIV status was known for 55% of them (WHO, 2010a).

While absolute numbers of coinfected individuals receiving CPT and ART worldwide exceeded 300,000 and 140,000 by 2009, respectively, the proportion of eligible individuals on CPT fell from 96% to 75% and those on ART fell from 52% to 37% between 2002 and 2009. The disparity reflected the slower pace of treatment scale-up, and the lower numbers of facilities providing ART in comparison to those offering HIV testing and TB treatment (WHO, 2009b; WHO, 2010a; WHO, 2010b). Thus, while detection of HIV coinfection has improved, subsequent treatment and support for known coinfected persons remains poor.
Recent cost analyses show that treatment and transportation costs are significantly higher for co-infection compared to either TB or HIV (Sadoh & Oviawe, 2007). Pilot evaluations show that concurrent care is associated with a significant reduction in these healthcare costs (Cerda et al., 2011). Studies such as these call for more integrated forms of TB and HIV care. Pilot and small-scale integration projects emanating from high-burden regions show innovation in the design and delivery of TB/HIV healthcare in light of the escalating co-epidemic (Abdool Karim et al., 2009; Friedland, 2004; Harries et al., 2010; Marais et al., 2010b; WHO, 2010b). Examples include cross-referrals between TB and HIV programs in Benin, the Democratic Republic of Congo, India, Malawi, Mozambique and Uganda, partially integrated projects in Rwanda and Tanzania, and a few instances of fully integrated ‘one-stop’ service models in Malawi and South Africa (IUATLD, 2008; USAID, 2007; WHO, 2010b). However, guidance and insight towards sustained national interventions are still limited. Differential rates of disease incidence and mortality, diversity in government policy, access to resources, competencies of individual TB and HIV programs, and health systems overall, likely preclude the dissemination of an archetypical model of TB/HIV care, both across and within high-burden countries (Atun et al., 2010a; Atun et al., 2010b; Bakare, 2007; Friedland, 2004; Friedland et al., 2007; Shigayeva et al., 2010; WHO, 2010b). There is a growing policy and practice imperative to devise interventions that are informed by local needs so they may support TB and HIV healthcare in ways that are tailored to local clinical, operational, as well as social contexts.
This imperative for improved guidance on TB/HIV healthcare calls attention to several issues, including the structure of TB and HIV programs, approaches to TB and HIV disease control, organizational frameworks for integrating TB and HIV services, and the clinical, operational, and social challenges of TB/HIV healthcare. A critical examination of these issues forms the basis of this literature review. First however, I highlight the special case of South Africa, a country that is most deeply impacted by coinfection and motivated development of the current study.

**The case of South Africa**

South Africa is by far the country most heavily affected by TB/HIV coinfection. It shares over 25% of the world’s HIV-positive TB cases despite hosting only 0.7% of the world’s population (WHO, 2010a). Home to the highest adult HIV prevalence (19%) and fifth highest TB incidence (971 per 100,000 of the population), it offers a potent environment for the spread of coinfection (Abdool Karim et al., 2009; Day & Gray, 2010; Padayatchi et al., 2010; WHO, 2009b).

The epidemiological burden and social drivers of TB and HIV across the country are both unique and severe. The stratified migrant labour system that was perpetuated during apartheid and the social inequality that has persisted post-apartheid are key determinants to the transmission of TB, STIs and more recently, of HIV (Abdool Karim et al., 2009; Coovadia et al., 2009; Gibson, 2001; Packard, 1989; van Rensburg et al., 2005). The WHO (2010a) reports that 58% of an estimated 490,000 newly diagnosed TB patients (over 280,000 persons) are HIV coinfected. National reports indicate the figure is closer to 73% (Day & Gray, 2010). Most (80%) HIV infections are spread heterosexually, followed by mother-to-child transmission (Padayatchi et al., 2010). HIV prevalence in women is three to six times higher than in men; average life expectancies are reduced to 51.6 and 48.4 years, respectively, and those living in poverty are most disproportionately affected (Abdool Karim et al., 2009). In 2008, 193,000 or 84% of all TB deaths were attributed to HIV (WHO, 2009b).

**National response**

As a result of apartheid, the South African health system was left fragmented, underdeveloped and racially divided at the advent of the country’s TB/HIV crisis (Abdool Karim et al., 2009; Coovadia et al., 2009; Harrington, 2010). It was further devitalized during a subsequent era of political

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4 The WHO (2010a) figure is based on the rate of HIV prevalence in incident TB cases that were tested for HIV. However, 51% of TB cases in South Africa were not tested for HIV and did not contribute to the WHO figure. National estimates, instead, are higher as they are based on an estimated prevalence of HIV in all incident TB cases (Day & Gray, 2010).
“denialism, ineptitude, [and] obtuseness” (Abdool-Karim et al., 2009: p 921) against the escalating impact of HIV/AIDS. While TB programs achieved a degree of collective organization, disease control was continually hampered by the spread of HIV and corresponding apathy on the part of governing authorities. Though the first case of AIDS was identified in 1982, it was only in the year 2000 that a social movement comprising community organizations, activists, scientists, HCWs, and trade unions was able to rally for concerted political address to the problem of HIV and for equitable access to treatment. In 2003 (according to many scientists, three years too late), the government dispensed a free national ART program. In 2004, TB was prioritized as a national crisis (Abdool Karim et al., 2009). The Department of Health subsequently pooled forces to develop a Joint Strategy for HIV/AIDS and TB Control (NTCP, 2004; DOH, 2004). Up until 2009, however, TB patients were not prioritized for ART, contributing to their persistently high mortality rates (Padayatchi et al., 2010).

Healthcare outputs within the country’s TB and HIV programs remain suboptimal. Recent TB reports show that 22% of TB cases are not detected and treatment success is not achieved in 26% of detected cases. HIV programs do not report rates of HIV testing in the general population, but recent reports show that over 36% of eligible patients are not placed on ART. Cumulative losses to follow-up within HIV programs are also reported as having increased from 14% at 12 months to 29% at 36 months, representing difficulties with retaining patients in care (Padayatchi et al., 2010).

As a result of individual program deficiencies, outputs related to coinfection are similarly poor. In 2009, only 49% of TB patients were aware of their HIV status (WHO, 2010a), barely up from 45% in 2005 (Grimwood et al., 2006). While 71% of coinfected patients began CPT, only 42% of those eligible received ART. Less than 8% of all HIV patients were screened for LTBI; only 3-5% of those eligible started IPT (Padayatchi et al., 2010; WHO, 2010a). A few pioneering interventions for TB/HIV care include those developed at the Church of Scotland Hospital in Tugela Ferry, eThekwini TB/HIV Clinic in Durban, and the Médecins Sans Frontières Clinic in Khayelitsha (Abdool Karim et al., 2009; Friedland et al., 2007). Overall, however, integration of TB and HIV healthcare remains inadequate.

**The structure of TB and HIV programs**

The organizational structure of TB and HIV programs may influence how joint efforts between the two programs evolve. While horizontal programs cater to a wide range of health needs through multi-sectoral and decentralized approaches to care, TB and HIV programs, for the most part, have developed as vertical programs within national health systems. The extraordinary threat posed by
either infection, HIV being more recent, justified the establishment of separate administrative structures to develop more sophisticated clinical and technical tools for their targeted control (Criel et al., 2004; Oliveira-Cruz et al., 2003; Wang et al., 2007).

While vertical programs are found to efficiently address targeted health sector needs, they are also criticized for their linear, top-down approach to program implementation, neglect to local contexts, and for diverting resources away from other health crises (Criel et al., 1997; Oliveira-Cruz et al., 2003). They are routinely characterized as “stovepipes” (Charns, 1997: p 414) or silos within health systems as they cultivate a highly singular purview, and may cause some fragmentation of care. In the late 1990s, for instance, the blanket global application of TB-DOTS was criticized for its failure to consider the socioeconomic and cultural contexts influencing local service delivery, resulting in its poor uptake within many high-burden countries (Raviglione & Pio, 2002). Both TB and HIV programs are also called out for diverting attention and funds away from other public health problems, and from failing to share resources or to adequately contribute towards general health system strengthening (Enarson et al., 2009; England, 2008; Wang et al., 2007).

Now, although TB and HIV programs are traditionally perceived as vertical and centralized, many activities have been decentralized to overcome the disadvantages of a stovepipe approach and to expand their outreach and scope. Today’s TB and HIV programs incorporate key aspects of horizontal healthcare delivery depending on the demographic and epidemiologic profile of infection, access to funds, structure of health systems, and national politics and priorities within affected countries. Examples include TB case finding teams, mobile VCT clinics and ART collection sites (UNAIDS, 2008; WHO, 2005). In many high-burden countries, though HIV funding remains vertical in structure, prevention and treatment services are being integrated into the primary healthcare sector (UNAIDS, 2008). While decentralization of some TB services such as DOTS collection mimics a horizontal approach to care, drug procurement remains centralized mimicking a relatively vertical approach (Raviglione & Pio, 2002). The rigid theoretical dichotomy between vertical and horizontal service delivery is thus more fluid in healthcare practice (Criel et al., 2004; Oliveira-Cruz et al., 2003).

**Distinct approaches of TB and HIV control**

The distinct approaches to TB and HIV service delivery are likely a result of their diverse epidemiological, historical and political underpinnings, and may adversely affect collaborative efforts. Tuberculosis control is based on a traditional, standardized public health approach with
firmly established clinical and operational algorithms for care (Bayer et al., 1993; Friedland, 2004; Selwyn, 1993). The WHO’s DOTS strategy, established in 1995, represents the hallmark of TB prevention and treatment. While the challenges of drug-resistant TB and HIV/AIDS have prompted some modifications to traditional DOTS (see Appendix A), the present design of TB programs continues to reflect a relatively regimented, top-down modus operandi that targets more proximal determinants of disease to maximize case detection, treatment adherence and cure (Corbett et al., 2006; Gittler, 1994; Raviglione, 2003; Raviglione & Pio, 2002; Raviglione & Uplekar, 2006).

HIV control, in contrast, developed under a patient-driven, individualized approach from its inception (Corbett et al., 2006; Selwyn, 1993). While guidelines do exist, there is much less global standardization of care compared to TB (Coetzee et al., 2004; Corbett et al., 2006; Wang et al., 2007). Disease control strategies are driven by community involvement and empowerment, protection of patients’ civil rights, and rejection of coercive interventions that are not uncommon in TB programs (e.g., voluntary HIV testing compared to routine TB screening, or mandatory TB treatment in some countries) (Coetzee et al., 2004; Gittler, 1994). HIV programs’ attention to treatment literacy, as opposed TB treatment supervision (also believed to strip patients from exercising control over their condition (Atkins et al., 2010)), is tied to patients’ greater adherence to HIV-based care (Abdool Karim et al., 2009; Lawn and Wood, 2007). The upstream causes of illness (i.e., social determinants) such as poverty, disempowerment and gender inequality are at the forefront of HIV management. This mindset, while slowly emerging, is still comparatively infrequent within most TB program paradigms.

The different public health approaches for TB and HIV control may be partly explained by their disparate modes of transmission, as was highlighted by social scientists during the early 1990s when the problem of coinfection came to the forefront (Bayer et al., 1993; Gittler, 1994; Hansell, 1993; Selwyn, 1993). While HIV is primarily transmitted through intimate contact involving more conscious behavioural pathways (e.g., sexual practices, drug use), TB is transmitted through relatively non-intimate actions (e.g., cough). HIV prevention strategies therefore mandate working with patients; enforced compliance through collective government approaches, as is seen with TB control, may be counterproductive to behavioural change (Hansell, 1993; Selwyn, 1993). The relatively easier airborne spread of TB on the other hand, may endanger far greater numbers of people; TB control has thus historically prioritized protection of the collective over individual rights (Gittler, 1994). Over the years, despite a gradual resolve to promote community involvement and empowerment (Atkins
et al., 2010; Macq et al., 2007; Miti et al., 2003; Rifat et al., 2008), TB programs may have alienated patients through their fundamentally top-down approach to disease control. In contrast, civil libertarians and HIV public health bodies have long recognized that cooperation between professionals within the health system and advocates outside the official boundaries of such a system are necessary to control the spread of AIDS (Bayer et al., 1993; Gittler, 1994; Hansell, 1993).

The distinct clinical trajectories of TB and HIV may also distinguish how healthcare is delivered. HIV is life-long and incurable with a persistent infectious stage, whereas TB lasts 6-12 months when treated and may be rendered non-infectious and curable. Coercive, even paternalistic, measures may be easier applied for a short term when cure is assured, as with TB. This would be difficult to sustain over a lifetime, as with HIV (Bayer et al., 1993; Gittler, 1994; Hansell, 1993; Selwyn, 1993).

HIV and TB control are also associated with historically disparate levels of political momentum. Governments across the world more easily formed consensus on the etiology and impact of TB. Consequently, policymakers and health professionals developed disease control strategies with little involvement of affected communities (Gittler, 1994; Raviglione & Pio, 2002). HIV/AIDS on the other hand, garnered fragmented political support during its initial outbreak, even outright denial in some cases, not unrelated to its association with behaviours perceived to be immoral and illicit. Affected communities consequently fought from the ground-up to mobilize grassroots movements as a means to elicit global consensus and a concerted response (De Waal, 2006). The Gay Civil Rights Movement in the United States (US) and Brazil, and South Africa’s Treatment Action Campaign are arguably some of the most powerful voices of HIV resource mobilization (Achmat, 2006; Harrington, 2010; Parker, 2009; Slack, 2001).

Tuberculosis advocacy thus lacks the same populist, grassroots support as HIV, and this deficiency in meaningful patient and community involvement is tied to the absence of sustained and targeted political and financial support for TB programs (Achmat, 2006; Raviglione & Pio, 2002). In comparison to HIV, TB research has remained stunted for several decades. The last truly novel and effective anti-TB drug was discovered nearly half a century ago. Adoption of an unquestioning mindset to established TB protocol compounds the dearth of innovation in the field (Abdool Karim et al., 2009; Akugizibwe & Ramakant, 2010; Marais et al., 2010b). Further, while HIV imposes high mortality and morbidity in resource-poor countries, it is also recognized as an important local issue within industrialized nations from where many early public health efforts arose. On the other hand,
TB imposes most of its detrimental impact in poorer countries that have little monetary power to initiate novel research or action (Achmat, 2006; Farmer, 1996).

As a result of their disparate etiologies, disease trajectories and epidemiology, TB and HIV programs attract relatively different forms and levels of political commitment, social advocacy and support, and are based in diverse approaches to healthcare delivery. These differing approaches may challenge how collaborative efforts evolve, but very few researchers have discussed it in the context of integration (Abdool Karim et al., 2009; Coetzee et al., 2004; Friedland, 2004; Wang et al., 2007). They have not been empirically examined in terms of their potential manifestation in the integrative process between TB and HIV programs or their influence on the success of integrated TB/HIV care.

Organizational frameworks for integration

Having reviewed the structure and distinct approaches to service delivery within TB and HIV programs, the organizational frameworks for TB/HIV integration also warrant some consideration. Health policy analysts have defined integration as “the process of bringing together common functions within and between organizations to solve common problems, developing a commitment to shared vision and goals and using common technologies and resources to achieve these goals” (Oliveira-Cruz et al., 2003: p 69). Integration thus reflects a move away from vertical towards more horizontal approaches to service delivery (Atun et al., 2010b; Criel et al., 1997; Shortell et al., 1993).

Tuberculosis and HIV healthcare integration calls for a collaborative process comprising coordination between two traditionally but not exclusively vertical programs. As TB and HIV programs are pushed to work in partnership, each program is also pushed to streamline horizontally with primary healthcare, and to integrate prevention, treatment and supportive services along a multi-sectoral continuum of patient care. HIV programs are further collaborating with other vertical programs such as STI care that are, in turn, being pressed to integrate with the primary heath sector (French et al., 2006; Mayhew, 1996; UNAIDS, 2008; WHO, 2004; WHO, 2009b). From a healthcare perspective, integration may allow for more comprehensive patient care and improve the functioning of health systems overall (Atun et al., 2010b; Charns, 1997; Miller, 1996; Shortell et al., 1993). From an administrative perspective, integration is an efficient way to deal with two (or more) interconnected (and overlapping) problems at once (Aiken & Hage, 1968). From the patient’s perspective, integration may ease their navigation of the health system (Brooks et al., 2007).
Dimensions of integration

The WHO has encouraged a paradigm of TB/HIV care that focuses on two diseases, one patient (WHO, 2006). While formal organizational theories are seldom applied to TB and HIV program alliances (Friedland, 2004; Shigayeva et al., 2010; Wang et al., 2007), they have been applied to health system integration more generally (Atun et al., 2010b; Contandriopoulos et al., 2003; Criel et al., 1997; Criel et al., 2004; Miller, 1996; Shigayeva et al., 2010; Shortell et al., 1993). Facets of these may be used to understand the integrative process for TB/HIV care, particularly in light of WHO’s recently published examples of cross-referrals, partially and fully integrated projects (WHO, 2010b).

Figure 2.4: Dimensions of integration for TB/HIV healthcare

Drawing on the work of Shortell (1993) and Miller (1996), health services researcher Contandriopoulos (2003), illustrates how integration within the health system may be analyzed through four dimensions that are all aimed at enhancing patient care (see Figure 2.4).

According to Contandriopoulos, the first and most fundamental dimension of healthcare integration is clinical or medical and involves the establishment of a multi-disciplinary clinical team. In the context of TB/HIV, examples would include concurrent treatment programs for TB and HIV, and merged adherence support and staff education programs formed in South Africa and Zambia (Dong et al., 2007; Friedland et al., 2007; Jack et al., 2004; Miti et al., 2003).
The next dimension of integration is operational or functional, where specified overlaps in activities and information sharing are achieved through the creation of a structural agency, such as the WHO’s Global TB/HIV Working Group. Integration could then occur on the basis of shared space and/or time through a process of sequential, reciprocal or collective coordination (see Figure 2.5) (Contandriopoulos et al., 2003; Criel et al., 1997; French et al., 2006; Wang et al., 2007).

**Sequential** coordination would imply TB patients are referred for HIV testing or ART after completing TB treatment. However, this is likely inadequate considering the rapid clinical progression of coinfection, and in light of evidentiary studies that urge the simultaneous treatment of coinfection towards improved patient survival (Abdool Karim et al., 2010). At present, most collaborative efforts for TB/HIV care follow what Contandriopoulos (2003) terms **reciprocal** coordination: individual programs have separate clinical teams but respect each other’s goals, and manage patients with consideration of the other team’s goals. Reciprocity relies on effective cross-referrals and communication, as the WHO identifies is commonplace in Malawi, India and Mozambique (Friedland et al., 2007; WHO, 2010b). A recent project from Zambia coined this as a “separate but linked” (Harris et al., 2008: p 775) approach to TB/HIV care. “Nesting” (Wang et al., 2007: p 190) may be considered another form of reciprocal coordination, where one service of a program is nested within another established program (e.g., VCT at a TB treatment centre). The WHO exemplifies such partially integrated programs in Rwanda and Tanzania (WHO, 2010b).

While cross-referrals may help connect health programs, breakdowns have been documented with TB/HIV care (Coetzee et al., 2004; USAID, 2007) and are discussed ahead in this chapter. In the context of clinical spheres such as mental health, oncology and other infectious diseases, breakdowns have been tied to program inefficiencies, poor documentation, characteristics of referring and referred providers, resource access and utilization, waiting times, and embarrassment or stigma associated with referred conditions (Brandt et al., 2008; Ireson et al., 2009; Schulte & Mehler, 2001; Shortell & Anderson, 1971). Health analysts such as Dartington (1979) also describe the phenomenon of “dumping” or the “disposal” (p 23) of patients between programs – a critical adverse effect of referrals made within poorly integrated systems of healthcare, when no one program takes on the responsibility of managing an overlapping health issue.

A more unified model of integration is **collective** coordination, where programs assume joint responsibility for individuals affected by multiple problems that lack distinct borders and whose
development with respect to time or degree is inexact (Contandriopoulos et al., 2003). Such an approach to care fits ideally with the needs of TB/HIV coinfected patients; shared case-management is believed to improve survival (Maher et al., 2005; Reid et al., 2006). However, relatively few TB/HIV interventions have moved beyond the reciprocal level to this more comprehensive level of coordination. An example is the joint TB/HIV clinic of Khayelitsha in South Africa that provides a ‘one-stop’ service for both infections with shared medical records (Abdool Karim et al., 2009; Friedland et al., 2007). The WHO describes this level of collaboration as fully integrated (WHO, 2010b). In organizational theory, it also represents a move towards managerial integration.

Figure 2.5: Application of integration frameworks to integrated TB/HIV care

Managerial integration involves actors and stakeholders at the point of program policymaking and resource allocation. According to Contandriopoulos (2003), it warrants a conscious move to merge individual programs’ organizational values and pool funding sources. This remains infrequent in the case of TB/HIV perhaps due to their distinct historical underpinnings that were discussed earlier. A final dimension upon which integration may be considered relates to Shortell’s (1993) notion of a “holographic” (p 20) or umbrella organization. Systemic integration reinforces clinical, operational and managerial cooperation to maximize each program’s effectiveness and sustainability based on a
solid foundation of financial, technical and human resource capital (Contandriopoulos et al., 2003; Shortell et al., 1993). However, this form of complete integration or merging between programs would likely impose an overwhelming degree of responsibility on resource-poor programs in countries most heavily affected by TB and HIV (Bakare, 2007; WHO, 2004).

A review of the various dimensions upon which TB and HIV healthcare may be integrated elicits a greater understanding of the frameworks upon which related interventions rest. However, they are underscored by critical clinical, operational and social challenges that are discussed below.

**Clinical challenges to TB/HIV care**

Clinical challenges of TB/HIV care reflect disease specific issues around TB/HIV coinfection. They have been most widely researched in the literature, via biomedical and quantitative study designs.

**Diagnostic difficulties**

Difficulties with diagnosing TB in HIV-positive persons hamper early TB case detection, treatment initiation and overall survival of coinfected patients. During the early stages of HIV, TB commonly presents as pulmonary (akin to that seen among HIV-negative persons) and may be diagnosed using widely available clinical tools. However, as the immune system deteriorates, the clinical picture becomes progressively non-specific and atypical (Cahn et al., 2003; Reid et al., 2006). Between 40% and 80% of coinfected patients develop extra-pulmonary TB (EPTB) compared to 10% to 20% in patients without HIV (Sterling et al., 2010). Radiographic findings and tuberculin skin tests (TST) are often unreliable, and differential diagnosis against other respiratory and HIV opportunistic infections becomes problematic. Accurate TB detection requires more sophisticated and expensive tools, and death from undiagnosed TB is common in low resource areas (Corbett et al., 2006; Reid et al., 2006).

Diagnosing HIV in TB patients is relatively uncomplicated from a clinical or technical standpoint, through highly specific and sensitive HIV tests (CDC/WHO, 2005). Globally however, less than 40% of people living with HIV (UNAIDS, 2009), and only 26% of all TB patients (WHO, 2010a), are aware of their HIV status as a result of non-clinical challenges that are discussed further ahead.

**Partial prevention**

Tuberculosis can be prevented to a limited extent. The Bacille Calmette Guerein vaccine (BCG) may be effective against serious forms of TB, and reduce the severity of childhood TB. However, it is
contraindicated in HIV patients due to the risk of disseminated BCG infection, and its diminished efficacy to guard against the development of TB in adults in general (De Cock et al., 1996).

Treatment with isoniazid or IPT is identified as a preventive tool against TB. It reduces the risk of developing TB by 33% among HIV patients on ART, and up to 64% in patients exhibiting a positive TST (Woldehanna & Volmink, 2004). IPT does not, however, prolong survival or reduce all-cause mortality (Corbett et al., 2006; Reid et al., 2006). Researchers have also expressed concerns about the actual duration of protection granted by isoniazid, due to the risk of repeated exposures in endemic settings, and the propagation of drug resistance (Corbett et al., 2006; De Cock et al., 1996).

Clinical tools for HIV prevention include medical male circumcision that may reduce transmission risk by 56%, and ART-containing vaginal microbicides that may impose a time-sensitive protective effect of up to 54% (Kurth et al., 2010). Their effectiveness needs to be examined in larger cohorts.

**Co-treatment**

Treatment of TB for 6 to 9 months reduces transmission and renders patients cured, including those with HIV (Reid et al., 2006). ART reduces the risk of HIV-associated TB and case-fatality by over 70% (Corbett et al., 2006; Lawn et al., 2009), and the risk of other opportunistic infections and related mortality by 60% to 90% (Reid et al., 2006). However, despite ART, TB risk remains higher than among HIV-negative persons suggesting it is not entirely immune-restorative (Sterling et al., 2010).

WHO guidelines for TB/HIV co-treatment were initially based on patients’ CD4 levels and WHO HIV/AIDS clinical staging, upon which high-burden countries formed clinical policy (Reid et al., 2006). In 2009-10, studies from South Africa and Cambodia showed that early concurrent treatment significantly improve patients’ survival regardless of their CD4 counts, based on which the WHO made two new recommendations: (i) coinfected patients not already on ART should commence ART within 8 weeks of TB treatment initiation, regardless of their CD4 count; and (ii) coinfected patients on ART should commence TB treatment immediately following TB diagnosis (WHO, 2009a; WHO, 2010b; Abdool Karim et al., 2010). Many high-burden countries, however, suffer from inconsistent drug supplies, unclear prescribing guidelines, and continue to delay ART administration, as a result of critical operational issues (Harries et al., 2010; Maher et al., 2005; Stein et al., 2007). The uptake of TB/HIV co-treatment is also conditional on patient-specific issues, which are discussed further ahead.
Co-treatment is associated with serious drug interactions, and may endanger patients in resource poor settings to a greater extent due to their reduced access to less toxic but more costly combination regimens. Higher pill burden and drug toxicities may aggravate patient non-adherence, treatment failure and/or drug resistance (Chamie et al., 2010; Gebremariam et al., 2010; Kwara et al., 2005; Reid et al., 2006). Co-treatment is also associated with immune reconstitution inflammatory syndrome (IRIS), which may occur in HIV patients shortly after ART initiation but with a (higher) 30% to 40% risk in patients receiving concurrent TB therapy (Abdool-Karim et al., 2004). While it is seldom associated with death and does not warrant treatment discontinuation, IRIS may temporarily worsen respiratory or radiological features making it difficult to differentiate against treatment failure, drug reactions, and/or the onset of another opportunistic infection. It thus complicates clinical algorithms for coinfection (Kwara et al., 2005; Reid et al., 2006; Wood, 2007).

An inexpensive, safe and successfully utilized tool to prevent other HIV opportunistic infections, CPT may reduce mortality by up to 48% in coinfected patients (Corbett et al., 2006; Reid et al., 2006).

**Infection control**

Tuberculosis is an airborne pathogen. Transmission within congregate settings such as healthcare facilities is a significant clinical (and operational) challenge facing the delivery of dual services in physically enclosed spaces. Health facility waiting areas often seat high numbers of immunocompromised (including HIV-positive) persons who may be uninfected but most susceptible to developing primary TB disease from exposure to the TB bacillus (Bock et al., 2007; Cahn et al., 2003; Corbett et al., 2006; De Cock et al., 1996; WHO, 2010b).

The risk of nosocomial TB transmission warrants the use of multiple infection control measures in the delivery of TB/HIV care. Environmental measures include air-filtration systems, ultraviolet lighting, and pressure-controlled rooms. While they have the greatest preventive impact, they remain unaffordable in most areas. Administrative measures include TB control education, prompt case identification, separation of infectious patients, and respiratory hygiene. Personal respirators or facemasks also mitigate transmission but are less used in high-burden countries due to inadequate supplies, and poor infection control education and application (Harries et al., 1997; Howard & El-Sadr, 2010; Joshi et al., 2006; Mehtar, 2008).
Operational challenges to TB/HIV care

Operational challenges to TB/HIV care include barriers faced by health systems or individual health programs. They are now recognized to a greater degree as national ministries struggle to keep up with WHO recommendations for TB/HIV control, and as pilot integration projects attempt to expand their scope. They intersect with the organizational frameworks for integration and the more disease-specific issues of TB/HIV care that were discussed earlier, and are most often highlighted in TB policy or program reports and by TB researchers involved with empiric interventions for TB/HIV care.

Financial resource gap

Financial constraints in resource-poor countries pose the greatest system-level barrier to TB/HIV care (Chaisson & Martinson, 2008; Harries et al., 2006; Nunn et al., 2007). The highest deficits for national TB and HIV programs are observed in Africa (UNAIDS, 2008; WHO, 2008a), and translate to deficits for healthcare integration. The global funding gap for TB control between 2006 and 2015 is estimated to be $31 billion overall, of which approximately $4 billion is related to unmet TB/HIV related activities (Nunn et al., 2007). The global funding gap to reach universal access to HIV treatment in the same time period is estimated to be $5 billion (UNAIDS, 2008). Among the 22 countries recording the highest burden of TB, most allocate no more than 3% of their national TB budgets for joint TB/HIV activities (Jassal & Bishai, 2010; WHO, 2009b). While national HIV programs may allocate a portion of their budget for TB/HIV care, they do not report these figures.

Outside of national governments, the Global Fund to Fight AIDS, Tuberculosis and Malaria remains the single major financer of TB and of TB/HIV care; over 90% of approved proposals include a specific mandate to improve collaboration between TB and HIV programs. However, major funding sources for HIV, such as the US President’s Emergency Relief Fund and the World Bank, target ART promotion without any specific mandate for patients coinfected with TB (Nunn et al., 2007).

Inadequate funding of programs within the public health sector translates to poor infrastructure and a lower quality of care in many resource poor settings. Studies from India, Malawi and South Africa show that perceived inefficiencies in TB and HIV programs prompt patients’ attrition from the public sector and movement into private and alternative healthcare settings despite their low income. This perpetuates delayed diagnosis and treatment initiation for TB and for HIV (Kanyerere & Aase, 2005; Moshabela et al., 2010; Ross, 2008; Skordis-Worrall et al., 2010; Wilson & Perumal, 2003).
Human resource constraints

Workforce developments fall short of what is needed to mitigate the impact of coinfection (Abdool Karim et al., 2009; Harries et al., 2005; Nunn et al., 2007). Only one-half of the world’s high-burden countries with TB address collaborative TB/HIV training or staffing needs in their human resource plans (WHO, 2009b). Research from South Africa shows that less than one-third of doctors working in TB facilities are trained in HIV care despite the high rate of coinfection (Loveday et al., 2007). Other project evaluations show providers lack sufficient training to diagnose EPTB that is common in HIV patients, with no training in TB/HIV co-treatment (Loveday et al., 2007; USAID, 2007). Many healthcare workers (HCWs) are also personally infected with TB and/or HIV (Menzies et al., 2007; Shisana et al., 2004). Qualified medical personnel routinely escape to the private sector for better salaries and work conditions, or leave high-burden countries altogether (Harries et al., 2005; Kohi et al., 2010; Schneider et al., 2006). Staff shortages and burnout, poor morale and low pay, coupled with high occupational risk compound the human resource crisis (Harries et al., 2005; Loveday et al., 2007; Schneider et al., 2006; USAID, 2007). Negative staff attitudes towards patients infected with TB and/or HIV are also tied to patient mistrust and their lower utilization of services, as was found in studies from Indonesia and Ethiopia (Gebremariam et al., 2010; Mahendradhata et al., 2008).

Data reporting and classification errors

To date, data on the distribution and impact of coinfection is heavily weighted by figures arising from national TB compared to HIV programs (Gunneberg et al., 2008; Nunn et al., 2007). This may be because coinfected patients routinely become aware of their HIV status after developing symptomatic TB; TB programs are often their entry points to medical care (Maher et al., 2005). Tuberculosis programs also place great emphasis on data recording and reporting, following from the primary tenets of DOTS-based control. In 2007, UNAIDS stipulated national HIV programs to report on TB incidence among known HIV-positive persons, and the proportion placed on dual treatment (UNAIDS, 2007). HIV programs have thus gradually increased reporting their outputs on TB/HIV healthcare, but their indicators often differ from figures reported by their TB program counterparts, as well as from NGOs that report for UNGASS.5

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5 Two examples help illustrate some of these discrepancies: (i) Thailand’s HIV program reported 7.6% of TB cases were HIV-positive in 2006 (UNGASS, 2008: p 48), whereas the TB program reported a rate of 11% for the same year (WHO, 2008a: p 149). (ii) UNAIDS highlighted that 46% of countries with generalized HIV epidemics reported making VCT available for their TB patients in 2008, but NGOs reported a figure of 27% for the same year (UNAIDS, 2008: p 151).
Some data overlap or discrepancy may be expected as patients continuously alternate accessing care from TB and HIV clinics during the course of their dual illness. Healthcare surveys may also include different population segments, resulting in the duplication or omission of some data between individual programs. However, inadequate efforts are made by national coordinating bodies to mitigate these discrepancies (Gunneberg et al., 2008; Nunn et al., 2007). Undiagnosed TB (Corbett et al., 2006), and TB death certificates that omit reporting HIV as the underlying cause of mortality (Groenewald et al., 2005) further compound inaccuracies about HIV-related deaths. In its most recent Global TB Reports, the WHO’s TB Department published data emanating from national TB and HIV programs side by side (WHO, 2009b; WHO, 2010a). Going forward, this transparency should offer a more comprehensive picture of the global breadth and scale of TB/HIV coinfection.

**Logistic issues**

Notwithstanding consideration of the optimal design or dimension of integration within specific settings that was discussed earlier, the logistic issues of physical space, number, and proximity of TB and HIV facilities also challenge the effective coordination of TB and HIV care. At present, TB and HIV programs in most heavily affected countries continue to earn distinct funding and, save for a few projects, operate separate clinical teams. HIV and TB clinics are not typically built proximally to one another (Friedland et al., 2007). Malawi, for example, was found to have 44 TB registration and 101 ART facilities, few of which were closely located. While a coinfected patient may travel no more than 5 kilometres to collect ART, s/he may travel as far as 20 kilometres for TB care (Harries et al., 2006).

Another logistic obstacle to dual care is discrepant communication and information sharing between and among policymakers and providers (Friedland et al., 2007; USAID, 2007; Wandwalo et al., 2004). Observational evaluations from Ugandan hospitals found that although district managers adopted a joint TB/HIV policy, staff were unaware of it, much less the details of implementation (USAID, 2007). In South Africa, a cross-referral pilot plan revealed a high degree of service duplication and staff underutilization due to poor communication channels between TB and HIV HCWs. Separate medical records for coinfected patients resulted in missed opportunities for initiating CPT (Coetzee et al., 2004). Communication gaps perpetuate the clinical difficulties of dual diagnoses and co-treatment, and raise the potential for (missed) drug interactions and complications (Loveday et al., 2007; USAID, 2007). The pathways by which communication failures and referral breakdowns occur with TB/HIV care, particularly in relation to their impact on patient care, are as yet poorly understood.
Social challenges to TB/HIV care

The social challenges of TB/HIV care encompass the relatively non-technical and non-clinical aspects of coinfection and dual care. They centre on issues specific to the patient, rather than just the clinical disease or healthcare system. They are addressed to a lesser extent in the literature.

Social challenges related to either TB or HIV

As introduced earlier on, both TB and HIV are considered to be social diseases in that they are largely socially determined and impose significant social impact. The clinical burden of infection often parallels social inequalities, and disproportionately affects impoverished communities, women and children (Chaisson & Martinson, 2008; Charles & Pape, 2006; Farmer, 1996; Fox, 2010).

Substantial attention has been invested into understanding the overlapping social challenges faced by HIV-positive persons including poverty, food insecurity, gender inequality, racism, stigma, discrimination, and a lack of family, partner and employer support. These social challenges deter HIV patients from disclosing their illness, and accessing or retaining medical care that in turn, translate to their poor clinical outcomes (see Campbell et al., 2006; Cantrell et al., 2008; Eide et al., 2006; Gardezi et al., 2008; Geng et al., 2010; Medley et al., 2004; Parker & Aggleton, 2003; Squire, 2007).

Similarly, but to a lesser extent, challenges to TB care have been examined through a social lens. Tuberculosis patients also face critical social constraints, not dissimilar to those seen with HIV patients, which inhibit their ability to utilize available medical services; for example, poverty, poor living and work conditions, stigma, isolation and discrimination (see Edginton et al., 2002; Farmer, 1997; Johansson et al., 2000; Nnoaham et al., 2006). Notwithstanding the depth of information that emanates from literary works about HIV or TB (suggested citation are by no means an exhaustive list), relatively little is understood about such social issues in the context of TB/HIV coinfection.

Intersection between clinical, technical and social challenges to TB/HIV care

Social constraints to TB/HIV care underlie or contribute to many of the disease and health system related challenges discussed earlier. For instance, the misclassification of AIDS deaths as TB on some patients’ death certificates is linked to the desire of families to be protected from discriminating insurance policies and high funeral costs, and be shielded from the stigma of HIV (Groenewald et al., 2005). Patients’ decisions to access private clinics or traditional healers may be triggered by a lack of
infrastructure and resources at public clinics but also relate to discrimination by some HCWs and to prevailing sociocultural norms (Moshabela et al., 2010). The poor uptake of HIV testing may have little to do with the efficacy of the test or the (now abundant) availability of testing centres, but rather reflects patients’ beliefs and fears around HIV/AIDS (Solomon et al., 2004).

These examples all point to the broader social contexts of coinfection. Social science researchers (Boyce et al., 1998; Fife, 1994) help define the social context of illness as the interpersonal conditions or circumstances that may be extrinsic to individuals, but which influence their personal predisposition or inclination to think, act or behave in particular ways with respect to their health and wellbeing. Extrinsic circumstances reflect social structures or broader patterns that govern how societies are organized, such as cultural or institutional norms, social stratification, resource distribution, and gender roles. In the words of sociologist Anthony Giddens (1986), “the structural properties of social systems, in other words, are like the walls of a room from which an individual cannot escape but inside which he or she is able to move around in whim” (p 174). Individuals may thus have agency or the personal ability to act or (seek healthcare) in particular ways but their decisions are shaped and limited by the structural properties of the societies in which they are bound (Prasad, 2005). Structural contexts are thus inherently a part of the social contexts of illness.

The social contexts of TB/HIV coinfection are interpreted and understood by individual patients, and intersect with clinical and health system contexts. Understanding these social contexts is highly relevant for understanding the overall (and intersecting) challenges to TB/HIV care. To date, research examining the social contexts of TB/HIV coinfection centres around two main themes: the social challenges of diagnosing coinfection and those faced with being coinfected.

**Social challenges of diagnosing TB/HIV coinfection**

Studies that use a social lens to examine the delivery of TB and HIV care in the context of coinfection help identify patient-related challenges with HIV testing and TB diagnosis or related health seeking. They show that low rates of HIV testing among TB patients may be attributed to their fear of HIV disclosure, stigma and discrimination; need for partner’s consent; misconceptions around HIV and HIV treatment efficacy; guilt, shame and/or denial; fear of confidentiality, isolation, abuse and death; dissatisfaction or mistrust with health providers; and worry related to medical costs of testing and/or treatment (Daftary et al., 2007; Jerene et al., 2007; Kanara et al., 2009; Mahendradhata et al., 2008; Njozing et al., 2010; Yi et al., 2009). They are not dissimilar to barriers identified within the
general population (see Babalola, 2007; Castle, 2003; Day et al., 2003; Dinh et al., 2005; Kalichman & Simbayi, 2003; Maman et al., 2001; Worthington & Myers, 2003). However, a few studies highlight that TB patients may experience additional challenges in relation to dual diagnoses and treatments compared to the general population. (I was involved with the implementation of one such study, conducted with drug-resistant TB patients in South Africa (Daftary et al., 2007).) In these studies, some patients also refused HIV testing because they were overwhelmed by their TB diagnosis and preferred to deal with one illness, or stress, at a time. They wanted to complete TB treatment before being tested for HIV. Patients were also unsure about their concurrent access to or eligibility for ART (Daftary et al., 2007; Gebrekristos et al., 2005; Njozing et al., 2010). Further, women indicated a need for their partner’s consent to test (Daftary et al., 2007; Njozing et al., 2010).

In contrast to HIV, poor TB detection is routinely ascribed to programmatic deficiencies and the difficulty of diagnosing TB in persons presenting with atypical symptoms (Padayatchi et al., 2010; WHO, 2010a). Studies however, show that patients’ health-seeking behaviours may, to some extent, also contribute to delayed TB detection. Fears around stigma, discrimination and isolation; misconceptions about TB etiology and treatment; costs of care; dissatisfaction or mistrust against providers and the use of private and traditional practitioners, are found to deter patients from TB screening and from accessing TB care (see Edginton et al., 2002; Johansson et al., 2000; Needham et al., 2001; Nnoaham et al., 2006; Rajeswari et al., 2002; Skordis-Worrall et al., 2010). Some studies from high HIV prevalence settings additionally show that people commonly delay seeking care for TB symptoms as a result of their anticipated fear of discovering they may have HIV. In these settings, TB has become a sign for HIV and HIV stigma is transferred to persons known to have TB (Burapat et al., 2009; Kanyerere & Aase, 2005; Mavhu et al., 2010; Ngamvithayapong et al., 2000). The studies highlighted important gender differences. Qualitative analyses showed that men delayed seeking care as it undermined their sense of control and invulnerability to death (Mavhu et al., 2010), and women avoided accessing care because they felt stigmatized (Ngamvithayapong et al., 2000). Quantitative analyses showed that education levels were less relevant but that married persons, indicative of a more supportive environment, were more likely to seek care early (Kanyerere & Aase, 2005). One study also showed that patients’ fear of stigma and desire for confidentiality led them to seek private care (Burapat et al., 2009).

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6 The study, undertaken during my Masters degree, motivated the current analysis, as was indicated in Chapter 1.
Social challenges of being coinfected with TB and HIV

In contrast to the social challenges of diagnosis, relatively fewer studies have examined the social contexts of coinfection once a positive (TB and HIV) result is confirmed, that is, once patients are notified or become aware of their coinfected state.

The mental or emotional burden of TB/HIV coinfection may be significantly greater than that associated with either one infection. Quantitative studies from Ethiopia measured the risk of common mental disorders and lower quality of life to be higher among coinfected patients compared to those singly infected with TB, regardless of their age, gender, education, occupation, HIV stage or CD4 count (Deribew et al., 2010b; Deribew et al., 2009). Patients’ poor quality of life was, however, significantly associated with having a low income, depression, lack of family support, and higher perceived stigma (Deribew et al., 2010b).

The economic burden of coinfection may also be higher. A recent cost analysis from Nigeria found patients’ costs and the proportion of household income spent on TB and HIV treatment and related transportation were greater than that associated with just HIV or TB illness (Sadoh & Oviawe, 2007). The higher commuting costs of managing coinfections were also significantly associated with over 85% of eligible patients’ unwillingness to start ART in a study from Malawi, regardless of their gender, marital status, occupation, type of TB or distance to the ART facility (Zachariah et al., 2006).

Several studies have examined coinfected patients’ adherence to TB and/or HIV treatment. A quantitative study from Peru found patients’ non-adherence to ART was associated with their lack of social support (Shin et al., 2008). A study from India found that non-adherence to TB treatment among patients not yet on ART correlated with a lack of treatment counseling, visits to alternative healers, and ‘feeling better’ on treatment, but unrelated to stigma or treatment costs (Sardar et al., 2010). Patients’ age, gender and education were not significant factors (Sardar et al., 2010; Shin et al., 2008). With a similar focus on adherence, qualitative studies from South Africa and Ethiopia found coinfected patients’ adherence to TB treatment was aided by access to social and employer support but deterred by poverty, food insecurity, stigma and nondisclosure (Gebremariam et al., 2010; Naidoo et al., 2009), feelings of helplessness and hopelessness (Naidoo et al., 2009), and poor communication with HCWs (Gebremariam et al., 2010). While clinicians express concern about the greater threats to adherence arising from the duplicate pill burden and toxicities associated with co-treatment (Friedland et al., 2007; WHO, 2008a), qualitative studies reveal mixed findings. Interviews
An ethnography with six families affected by TB/HIV coinfection in rural Zambia is one of the only in-depth studies examining the social challenges of coinfection from the perspective of affected individuals (Chileshe & Bond, 2010). The study focused on patients’ access to ART. The authors demonstrated that economic barriers (access to work and money for food and transport), social barriers (broken relationships, stigma and nondisclosure in the home) and health system barriers (program inefficiencies and deficiencies), together with adherence to TB treatment, all challenged patients’ ability to access ART. Gender inequalities were also apparent – while men, unable to provide for their families, suffered a loss of esteem, women faced subordination in their homes and struggled to access a portion of the family’s resources (Chileshe & Bond, 2010).

These studies, conducted with known coinfected individuals, used diverse research designs and were conducted with various geographic populations. While they may not be directly compared due to their small number and different study methods, they show that common social constructs such as adherence and quality of life are unrelated to clinical indicators, and inconsistently related to common socio-demographic indicators. Except for the few qualitative studies, they fail to capture how such issues are faced and managed from patients’ own perspectives. The pathways of negotiating social support and other resources, and managing adherence or retention to care, for instance, remain unexplored. Further, save for the ethnography, the studies all tap into predetermined dimensions of illness such as quality of life, economic instability and deterrents to adherence.

Having said that, the ethnography, as well as studies conducted with patients who delayed or refused TB or HIV testing on account of their fear of a positive result, point to the role of stigma and urge further study of how individuals decide to access or utilize TB/HIV care. The studies also indicate a need to better understand the role of gender in patients’ burden of TB/HIV illness.

**The role of stigma in TB/HIV care**

Conceptualizations of stigma most often borrow from Erving Goffman (1963) who defined stigma to be “an attribute that is deeply discrediting” (p 3). Goffman stated stigma should be considered within “a language of relationships” (p 3), so that attributes are not considered to be 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 (normal) attributes may stigmatize those possessing other (tainted) attributes.

Medical sociologists and social science researchers have since drawn on the work of Goffman to further understand stigma and its consequences and management in the context of public health issues. Scambler (1998) differentiated between felt stigma, or the fear of discrimination perceived by individuals with undesirable attributes and enacted stigma, or an act of overt discrimination. He posited that felt stigma precedes and surpasses enacted stigma by causing individuals to conceal their undesirable attributes in ways that are ultimately more socially and emotionally disruptive than an overt act of prejudice (Scambler, 1998). More contemporary scholars such as Link & Phelan (2001; 2006) and Parker & Aggleton (2003) further suggest that the labeling of particular traits as undesirable is socially created, and used as a tool to assert dominance over people who are already marginalized within society on the basis of extant social inequalities such as those related to race, class, religion or gender. These later conceptualizations of stigma tie back to the social determinants of TB and HIV that were introduced in the beginning of this chapter (Farmer, 1996; Gandy & Zumla, 2002; Packard, 1989), and allow for stigma to be conceived of as a socially constructed phenomenon rather than an individualistic issue.

Stigma is part of the social contexts of illnesses that attract a greater degree of social undesirability, such as HIV and TB. Discrimination or the fear of being discriminated is a consequence of stigma that propels individuals to respond and act in ways that enable them to manage and resist the maximum degree of stigma (Gilmore & Somerville, 1994; Link & Phelan, 2001; Link & Phelan, 2006; Parker & Aggleton, 2003; Scambler, 1998). Stigma thus plays an important role in healthcare for TB and HIV.

**Stigma in relation to HIV and TB**

Disease related stigma is acknowledged as a crucial consideration, and challenge, to HIV and to a lesser extent, TB related care. Individuals with HIV are routinely stigmatized, discriminated, excluded and isolated in their home, communities and workplaces (see Campbell et al., 2006; Campbell et al., 2005; Castro & Farmer, 2005; Gilbert & Walker, 2010; Herek et al., 1998; Mbonu et al., 2009; Parker & Aggleton, 2003; Sontag, 1991; Squire, 2007; UNAIDS, 2005). They are labeled as outcasts, contagious and immoral as a result of the socially taboo circumstances through which the virus is
transmitted (e.g., sexual practices, drug use), its high prevalence in socially marginalized communities, and its strong association with death and dying (Farmer, 1996; Gilmore & Somerville, 1994; Nyblade et al., 2003; Parker & Aggleton, 2003).

Social scientists furthermore believe HIV stigma is a tool to reify inequalities against individuals possessing attributes that are already considered undesirable in the broader social hierarchy, such as sex workers, drug users, men who have sex with men, the poor, and women. People often project their fears around HIV upon these other groups and cast blame upon others that are already socially devalued because of their race, religion, gender, sexual orientation, and/or class. This devaluation of the other, or the “othering” (Campbell et al., 2005: p 808) of HIV risk causes particular (socially marginalized) individuals to experience a higher degree of HIV-associated stigma and discrimination (Joffe, 1997; Link & Phelan, 2006; Parker & Aggleton, 2003; Petros et al., 2006).

Tuberculosis, a much older infection, also invokes stigma and discrimination. Historically, people with TB were isolated and demonized due to fear of their infectivity (see Courtwright & Turner, 2010; Packard, 1989; Westaway & Wolmarans, 1994) but the distribution of curative and affordable chemotherapy between the 1960s and 1970s diminished the stigma associated with TB in many parts of the world (Sontag, 1991). The subsequent advent of the HIV pandemic and global resurgence of TB, however, renewed fears and suspicions against TB patients (Farmer, 1997; Godfrey-Faussett & Ayles, 2003; Johansson et al., 2000; Nnoaham et al., 2006). Researchers theorize, as with HIV, that stigma surrounding TB also reasserts existing prejudices on groups that are at greatest risk for infection, including people living in impoverished, overcrowded areas and/or immigrants from TB-endemic, and generally poorer, countries. Thus, stigma associated with TB is also experienced to a greater extent within socially marginalized populations (Courtwright & Turner, 2010; Farmer, 1996; Farmer, 1997; Gandy & Zumla, 2002).

Stigma associated with HIV or TB has significant negative consequences on the uptake and effectiveness of clinical and operational interventions that target their control. It is associated with the low uptake of HIV testing and TB-related services as discussed earlier, and with poor adherence and retention in HIV care (see Mbonu et al., 2009; Nyblade et al., 2003; Sayles et al., 2007; Skinner & Mfecane, 2004) and TB treatment (see Courtwright & Turner, 2010; Edginton et al., 2002; Liefooghe et al., 1997). Studies conducted with coinfected patients also point to its potential role in the utilization of and adherence to TB/HIV care.
**Stigma in relation to TB/HIV coinfection**

Stigma associated with coinfection may be greater than that associated with TB alone. Quantitative studies from Ethiopia, South Africa and Hong Kong quantitatively compared disease related stigmas and found that TB, TB/HIV patients and general community members all bore higher levels of stigma against HIV and TB/HIV coinfection compared to TB alone. Socio-demographic variables such as age, income, marital status, or clinical factors such as CD4 counts and WHO stage (for coinfected patients) did not correlate with people’s perceptions of stigma in either of these studies (Deribew et al., 2010a; Levin et al., 2006; Mak et al., 2006). However, stigmas were perceived higher by those who were depressed and among women (Deribew et al., 2010a), which speaks to some of the findings presented earlier on the barriers to TB and HIV testing (Chileshe & Bond, 2010; Daftary et al., 2007; Kanyerere & Aase, 2005; Ngamvithayapong et al., 2000; Njozing et al., 2010).

A few researchers have moved beyond measuring or comparing stigmas to examining how and why stigma in the context of TB/HIV coinfection is socially produced and experienced. A comparative mixed-methods study showed that stigma against TB was highest in India compared to Bangladesh or Malawi, but that its social drivers differed across the continents. Whereas TB stigma in Southeast Asia was tied to its negative impact on marital prospects, especially among women, TB stigma in Malawi was significantly linked to its strong association with HIV (Somma et al., 2008). Qualitative studies examining delayed health seeking among TB patients, that were introduced earlier, also showed that in high HIV prevalence settings, discriminatory attitudes once reserved for HIV are being transferred against individuals presenting with TB (Kanyerere & Aase, 2005; Mavhu et al., 2010; Ngamvithayapong et al., 2000). Some of these studies and others (including the one I was involved with) showed that a perceived similarity in TB and HIV symptoms, such as weight loss and fatigue, perpetuated stigma against TB (Bond & Nyblade, 2006; Daftary et al., 2007; Gebrekristos et al., 2009; Ngamvithayapong et al., 2000; Nnoaham et al., 2006), and created a double stigma related to TB and HIV (Bond & Nyblade, 2006; Daftary et al., 2007; Nnoaham et al., 2006).

In Thailand, one study drew on the work of Scambler (1998) and found HIV-negative individuals with TB were most stigmatized and fearful of being discriminated due to TB’s association with HIV (Ngamvithayapong et al., 2000). Researchers accordingly note that communities affected by TB and HIV have come to distinguish between old or normal TB and new HIV-associated TB in ascribing stigmas about the disease (Bond, 2010; Ngamvithayapong et al., 2000). In Zambia, scientists drew on the works of Goffman (1963) and Parker & Aggleton (2003), and theorized that TB/HIV stigma is
socially constructed through three compounded pathways: “new” TB is associated with greater
deviance and culpability; fears of TB transmission are now heightened on account of its association
with HIV, and may be legitimate considering the greater risk of TB in immunocompromised persons;
and, TB patients are thus under continued moral pressure to disclose that they have TB and face the
double stigma of TB and HIV, in order to protect the greater public good (Bond & Nyblade, 2006).
The authors concluded that, “a new disease stigma has unfolded – namely TB-HIV stigma” (p 453),
which needs to be further explored and disentangled across contexts.

Managing multiple stigmas

The prevalence of double or multiple stigmas is recorded among individuals affected by overlapping
illnesses or with personal characteristics that form the basis of routine social stigmatization. For
example, multiple stigmas are documented along the lines of mental illness and race (Gary, 2005),
mental illness and old age (Liu et al., 2008), and mental illness and cancer (Holland, 2003). Multiple
stigmas are also identified among HIV-positive persons in the context of their minority ethnicity
(Lopez et al., 2010), race, sexual orientation (Bogart et al., 2010; Grossman, 1991; Kowalewski,
1988), and/or gender (Mawar et al., 2005). Studies with HIV patients show that their multiple
stigmas result in a greater social burden of illness, for which reason they may delay accessing
medical attention and suffer worse adherence to prescribed treatments (Bogart et al., 2010; Gary,
2005; Grossman, 1991; Mawar et al., 2005).

A key question is: How do affected individuals manage their stigma or multiple stigmas? In his
original analysis, Goffman (1963) described how people cope with stigma based on the visibility or
conspicuity of their undesirable attributes. In the case of less visible attributes, such as mental
illness, individuals may deflect stigma by “passing” (p 73) as normal or simply hiding their condition
when possible. People with asymptomatic HIV infection routinely ‘pass’ as normal when they
conceal their HIV status. Nondisclosure may be considered the most common stigma management
strategy against HIV (see Gilbert & Walker, 2010; Maman et al., 2001; Norman et al., 2005; Ssali et
al., 2010; Wouters et al., 2009). Due to its link with HIV, nondisclosure of TB is also becoming
common (Bond & Nyblade, 2006; Daftary et al., 2007; Ngamvithayapong et al., 2000). However, the
emergence of visible TB or HIV symptoms precludes patients from keeping their condition secret
and eventually prompts them to disclose (Bond & Nyblade, 2006; Kalichman, 1995; Serovich, 2001).
When it comes to hiding more visible attributes, Goffman (1963) introduced the phenomenon of “covering” (p 102), whereby individuals deflect attention away from an obvious stigmatizing attribute, such as facial deformity, by drawing attention to something more socially acceptable, such as dark glasses or heavy make-up. While some social undesirability is still apparent, it is no longer overt. According to Goffman (1963), “what will conceal a stigma from unknowing persons may also ease matters for those in the know” (p 102) and therefore, ‘covering’ may ease the burden of stigma among people possessing more visible undesirable traits. The phenomenon of covering was used to explain how individuals mitigated the visibility of negative social symptoms such as illiteracy (Beder, 1991), non-marriage (Hatch, 1999), and homelessness (Roschelle & Kaufman, 2004), that are sometimes difficult to hide, by pretending they were literate, married and lived in a home, respectively. By minimizing the patency of their undesirable attributes, they were easier able to blend into particular social environments and appear to be ‘normal’.

Relatively few empiric studies have researched how persons with multiple undesirable attributes (visible or less visible) cope with or manage their overlapping stigmas. For example, a quantitative study with HIV-positive women from diverse ethnic minorities in the US found that women were better able to cope with the perceived stress of their HIV status when they perceived a greater sense of ethnic identity (Lopez et al., 2010). In qualitative work, gay men were found to 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 common association with AIDS (Kowalewski, 1988). The management of dual stigmas associated with two diseases, as compared to dual stigmas associated with a disease and socio-demographic characteristic, is even less understood. In the qualitative study that I was involved with, we used theories conceived by Goffman (1963) to show that coinfected patients used TB as a ‘cover’ to hide their illness with HIV. By pretending they had TB, patients evaded the stigma associated with the dominant undesirable attribute of HIV (Daftary et al., 2007). Qualitative studies from Thailand and Haiti also observed how patients and their families disclosed that illness and/or death were a result of TB compared to HIV, in order to protect themselves from the stigma associated with AIDS (Coreil et al., 2010; Ngamvithayapong et al., 2000). (Actions such as these contribute to the misclassification of some AIDS deaths, as was highlighted earlier.)

Only one study, from South Africa, examining patients’ experiences adhering to TB and HIV treatment, touched upon how the current public health shift to integrate TB/HIV care may ease or
challenge patients’ experiences with stigma (Gebrekristos et al., 2009). Similar to earlier studies, interviewed patients felt more comfortable speaking to their families and loved ones about TB. However, the authors additionally found that patients’ ability to access TB and HIV treatment in a concurrent manner helped them create a safer social space whereby they could disclose their illness with TB and hide their illness with HIV. By doing so, patients resisted the stigma associated with HIV.

There is a need for additional in-depth research in this direction, to understand how the integration of TB and HIV services may not only serve as a clinical or operational vehicle for disease control, but also have critical social relevance for the day-to-day lives of affected patients. Exploratory studies are needed to understand whether and how collective care may mitigate or enhance the burden of stigma among people affected by both infections, particularly from patients’ own perspectives.

**Decisional frameworks for TB/HIV care**

Studies highlighting some of the social challenges to TB/HIV care demonstrate that patients’ decisions for TB and HIV services, such as HIV or TB testing and adherence to concurrent treatment, vary across contexts and are affected by numerous overlapping issues such as the financial costs of available services and psychosocial stresses of accessing those services (e.g., social support, stigma). Save for gender, these issues are inadequately reflective of the impact of socio-demographic characteristics such as age and education, or clinical factors such as disease stage, on patients’ decisions. How and why or what factors prompt patients to act in particular ways with regards to their health and wellbeing, that is, their decisional frameworks, relate to the broader social contexts of coinfection and are relevant considerations for the success of integrated TB/HIV care.

Models of individual health behaviour have been applied to understand and predict patients’ decisions around TB or HIV control such as the uptake of TB screening (Poss, 2001), safe sexual practices (Hacker et al., 2005), HIV testing (de Paoli et al., 2004; Dorr et al., 1999; Kakoko et al., 2006), and HIV treatment including ART (Andersen et al., 2000; Anthony et al., 2007). Commonly applied models include the Health Belief Model (HBM) and Theory of Reasoned Action (TRA). The HBM assumes health decisions or behaviours are guided by individuals’ perceived susceptibility to and perceived severity of a problem, as well as perceived barriers to adopting healthy behaviours. The TRA postulates that an individual’s intent to perform a healthy behaviour is the closest marker for their action, contingent on subjective norms and attitudes for performing that action (Glanz et al., 2002). The Andersen Behavioural Model incorporates greater context into modeling individual
behaviour, such as characteristics of the health system (tied to operational constraints, discussed earlier) and outcomes of healthcare utilization (i.e., clinical cure) (Andersen & Newman, 1973; Andersen, 1995). While behavioural models have not been used to study patients’ health decisions in the context of TB/HIV care, they reflect the basis of many TB and HIV interventions that focus on educating patients on healthy behaviours such as HIV testing and ART uptake, with the assumption that the clinical benefits of such behaviours will guide ‘healthy’ decision-making (for example, see Day et al., 2003; Dinh et al., 2005; Jerene et al., 2007; Kalichman & Simbayi, 2003; Mabunda, 2006; Migliori et al., 1996; Wiktor et al., 2004; Zachariah et al., 2003). However, these frameworks for understanding how patients form health-related decisions for conditions such as TB and HIV, as well as TB/HIV coinfection, may be inapplicable for several reasons that are discussed below.

First, these behavioural models conceptualize decision-making as a volitional and cognitive construct that is inherently rational. Critics state that these models fail to adequately consider the impact of emotional, sociocultural and normative factors in individual decision-making (Glanz et al., 2002). These issues may be highly relevant in the case of TB or HIV, where subjective constructs of fear, stigma, access to resources and gender inequalities may influence an individual’s decision or ability to act in ‘healthy’ ways. Sociocultural norms, for instance, are pervasive in patients’ decisions to visit traditional healers (Janzen, 1978; Moshabela et al., 2010). People at risk for TB (Edginton et al., 2002), STI’s, HIV (Jerene et al., 2007; Mayhew, 1996), and cancer (Madjar et al., 2007) are known to reject medically sound choices in light of their experiences, values and beliefs. Counseling and education are shown to be unsuccessful in convincing patients to participate in HIV testing, despite free access to ART (Day et al., 2003; Kalichman & Simbayi, 2003; Mabunda, 2006).

Second, individuals’ intentions may not accurately predict their subsequent behaviours. A small quantitative study from South Africa found that the majority (92%) of surveyed TB patients said they would be willing to attend a dual TB and HIV treatment centre. Yet, unwillingness was significantly associated with greater perceived stigma around HIV and coinfection (Levin et al., 2006). This was the only study that explored patients’ opinion on the TB/HIV integration process, but it stopped short on examining their expressed willingness rather than actual utilization of co-located TB/HIV care. Other studies underscore how patients’ intent to participate in HIV-based services does not guarantee their eventual participation in such care (Dinh et al., 2005; Jerene et al., 2007; Sullivan et al., 2004). In Tanzania, for example, although 73% of TB patients expressed willingness to be tested for HIV, only 42% actually tested and 20% did not return for their test results (Jerene et al., 2007).
Third, while these models may predict and help understand decision-making for conditions that require a relatively greater degree of individual action, such as exercising or smoking (though some would argue these too, depend on extrinsic issues), they are likely inadequate in the context of illnesses tied to pervasive social and economic disparities, such as TB and HIV (Andersen et al., 2000; Glanz et al., 2002; Steele et al., 2001; Wutoh et al., 2005). The mitigation of health risks likely requires a more cohesive response that involves multiple social actors (such as the media and government) and that addresses broader social issues (such as economic and gender inequalities) rather than the adoption of healthy decisions (e.g., condom use) on the part of individual patients alone (Macq et al., 2007; Nwoye, 2004; Papa et al., 2001; Rifat et al., 2008; Shaikh & Hatcher, 2005).

Finally, behavioural models generally adopt a universal logic to what is rational, and assume ‘healthy’ decisions are those that result in positive clinical outcomes. This narrow purview neglects the social consequences of patients’ health decisions. For example, while HIV or TB disclosure can prevent further transmission of disease and enable access to treatment, it also exposes patients to deleterious social effects such as stigma, isolation and physical violence. These effects are tied to general sociocultural norms (e.g., HIV represents sexual transgression and/or death) (Fitzgerald et al., 2010; Skinner & Mfecane, 2004). In understanding HIV disclosure decisions, studies contend that the social, rather than clinical, consequences of disclosure likely mediate how disclosure is enacted; that is, when the social rewards of disclosing, such as family or partner support, outweigh the perceived social costs, such as stigma and rejection (Black & Miles, 2002; Serovich, 2001; Serovich et al., 2008). Furthermore, the targets of disclosure may channel disclosure decisions. For instance, people with HIV may disclose to their family in exchange for their support, to friends to explain the change in physical appearance, and to partners to prevent HIV transmission (Ssali et al., 2010). Traditional behavioural models are unable to capture these multiple influences on decision-making.

Social science theorists have critiqued how individual decision-making in healthcare is routinely based on a medical information model that assumes individuals form decisions based on utilitarian, cognitive and instrumental choice. They argue that health-related decisions are more likely a product of complex social processes that are embedded in, and shaped by, individuals’ broader contexts and their interpretations of those contexts (Buetow, 2007; Garvin, 2001; Mykhalovskiy, 2008; Waisbord, 2007). What may appear to be irrational from the perspective of policymakers or healthcare providers may be understood as “subjectively rational” (Buetow, 2007: p 592) from the perspective of affected patients. In the context of TB, social scientist Waisbord (2007) calls attention
to the “social rationality” (p 2131) or social circumstances and structures that shape patients’ health decisions for TB, such as stigma, gender inequality, economic instability, belief in traditional medicines, and mistrust in medical authorities. Studies with HIV-affected communities similarly emphasize the role of wider social influences on patients’ decisions related to HIV care (for example, see Doull et al., 2006; Geng et al., 2010; Mugisha et al., 2004; Visser et al., 2008).

How and why patients form particular health decisions will likely guide their utilization, adherence and retention in healthcare for TB and HIV. The processes underlying their decisional frameworks are thus of critical relevance to the effectiveness of integrated care. However, except for the one quantitative study that measured patients’ intentions to use co-located TB and HIV services (Levin et al., 2006), no studies have as yet examined how patients’ health decisions are shaped and enacted in the context of integrated care, particular in relation to the overlapping social burden and social stigma attached to TB and HIV.

**Summation**

A comprehensive critical review of the literature on TB/HIV coinfection and related healthcare brings forth three salient points. First, the global scale and impact of TB/HIV coinfection has escalated over the past decade contributing to notorious rates of morbidity and mortality that are disproportionately felt in sub-Saharan Africa. South Africa is, by a significant margin, the most heavily affected country.

Second, healthcare for TB and HIV is moving towards an integrated approach in response to the global burden of coinfection. The WHO’s recommendations for integration are aimed at achieving clinical efficacy and program efficiency. Vertical TB and HIV programs in heavily affected regions are thus being encouraged to collaborate more closely, and broader organizational frameworks for integration may be applied to this process. However, whether or how the distinct approaches to TB and HIV control may affect collaborative efforts has not been empirically examined.

Third, the delivery of healthcare for TB/HIV coinfection is confronted by several overlapping challenges that may be delineated at the clinical, operational and social level (see Figure 2.6). From a biomedical perspective, extensive clinical work has been directed towards disease-specific issues of coinfection and more recently, towards operational constraints to TB/HIV care that are faced at the health system level. The social challenges of coinfection or patient-centred issues around TB/HIV
care are less understood. Save for a recent ethnography from Zambia, the majority of research in this area has tapped into one or two predetermined elements of healthcare such as economic and social barriers to service utilization or acceptability and adherence to treatment, without meaningful insight into the perspectives of affected patients (Chileshe & Bond, 2010).

**Figure 2.6: Overlapping challenges to TB/HIV healthcare delivery**

Although some researchers indicate that a new and double stigma of TB/HIV is unfolding (Bond & Nyblade, 2006), very few studies have tapped into the social pathways by which it is constructed and responded to. This leads to questions such as: how is stigma related to coinfection different from that related to TB or HIV; how is it produced across affected social contexts; what does it mean to a person infected with both; and, how do they resist the stigma associated with their condition? Further, only one study has investigated how the integration of TB/HIV care may fit in with patients’ social needs in relation to their experiences with TB/HIV stigma and stigma management (Gebrekristos et al., 2009).

A closer examination of the social contexts of coinfection, which interact with healthcare delivery for TB and HIV, is needed to further unravel how these healthcare contexts influence patients’ health decisions and their subsequent participation in (integrated) care. A study of the social contexts of coinfection, particularly from the perspective of affected patients, would complement the clinical and technical frameworks upon which such care is based. Inclusion of these social contexts may help guide the implementation and overall effectiveness of integrated programs.
Chapter 3

Methods

Research need

A critical review of the literature demonstrates that the social contexts of TB/HIV coinfection and social challenges of TB/HIV healthcare are poorly understood.

Part of this gap may be a result of the largely biomedical focus on TB/HIV disease control that has focused on the clinical and programmatic aspects of service integration, with little attention to how affected patients actually experience or respond to the process. The basis upon which TB/HIV care is framed rests on the assumption that knowledge or medical rationality will guide individual health decisions. That is, so long as services improve patients’ clinical health and are made accessible and affordable, those coinfected will naturally utilize them. While these are important considerations, other more social (and structural) elements may mediate and challenge how patients form decisions in relation to their health and wellbeing, particularly for social illnesses such as TB and HIV. The inadequate uptake of clinically sound and logistically feasible interventions for TB/HIV care to date urges further study around these broader issues that underlie and shape their success.

An understanding of patients’ perspectives – including their perceptions of illness and healthcare, experiences managing two (stigmatized) infections under various dimensions or models of (integrated) care, and navigation between (distinctly organized) health programs – will lend insight to social challenges of TB/HIV care and help understand the frameworks within which individual health decisions are formed. In response to the escalating burden of coinfection, there is a research and practice imperative to examine these patient-specific social elements of illness, towards developing theories that may shed light on their challenges and decisions in relation to TB/HIV care.

A contextualized study of patients’ experiences with TB/HIV coinfection and related healthcare is thus needed to complement ongoing clinical and operational research in the field, and inform an effective, sustained and comprehensive response against the co-epidemic.
Research objectives

The overall aim of this study is to examine the social contexts of TB/HIV illness from the perspective of coinfected patients as they access and utilize healthcare for their dual infections. The specific study objectives are guided by critical gaps identified in the existing literature, and target patient perspectives on TB/HIV coinfection and related healthcare.

Objective 1

To characterize the illness experiences of individuals dually infected with TB and HIV

This objective investigates the perceptions and understandings of illness that are constructed and interpreted by individuals most intimately affected by TB and HIV, that is, coinfected patients. Questions stemming from this objective are:

- How do patients coinfected with TB and HIV think about their illness and their dual diagnoses?
- How do they understand TB in relation to HIV, and vice versa?
- How do they characterize their experiences being diagnosed with TB and HIV?
- How are patients’ perceptions and characterizations shaped by their social contexts?
- How are patients’ perceptions and characterizations linked to their decisions or actions related to their health?

Objective 2

To characterize their experiences with healthcare related to TB and HIV

This objective specifically examines the experiences of coinfected patients, and their interpretations of the same, as they access and receive medical care for TB and HIV. Questions arising from this objective are:

- How do coinfected patients utilize and participate in healthcare services for their dual illness?
- How do they characterize their experiences with healthcare for TB and HIV?
- How do they coordinate care for TB and HIV?
- How are patients’ experiences and characterizations shaped by their healthcare environments?
- How are patients’ experiences and characterizations linked to the sociostructural contexts of which they are a part?
Process

While the basis of these objectives was developed prior to research implementation, my theoretical framework and study design (discussed further ahead) enabled me to continuously hone them in response to ideas that emerged during data collection and analysis.

I had initially conceptualized the primary study objective as follows: “to identify and analyze patient factors associated with the integration of healthcare services for TB/HIV coinfection”. My adopted theoretical stance (constructivism-interpretivism, which encouraged the interpretation of multiple meanings to individual experience), qualitative study design (which prompted me to move away from identifying associations to interpreting the meanings underlying characterizations of human experience), and emergence of subjective themes during data collection and analysis (themes that I found were irreducible to “factors”) enabled me to refine the study objectives to their present state.

I was also initially interested in comparing patients’ experiences based on their diagnostic histories (e.g., comparisons based on their first diagnosis), and their exposure to different models of TB/HIV care (e.g., less versus better integration of care). As I drew on my theoretical stance during research implementation, I felt that a salient feature of understanding individual experience was to highlight rather than dilute that which was individual. I noted how limiting the categories of “first diagnosis” and “models of healthcare” could be in enabling an in-depth examination of my research goals. These categories reflected my presumption (and preconception) of the meaning of a “first diagnosis” or “model of healthcare”. Trying to fit a person’s experience into these predetermined categories neglected the nuances of the lived reality of their diagnoses, illness and related care.

Several patient participants, for instance, discovered their HIV status only when they developed symptoms of TB. Others were experiencing their second or third episode of TB and were diagnosed with HIV some time in the interim. Some had known their HIV status for several years but kept it to themselves and did not access medical care until they became ill with TB; their reasons for doing so became important findings of their own accord. I realized I needed to emphasize the subjectivity of patients’ illness experiences and foreground these anomalies as the socially constructed truth if I wanted to retain the integrity of my research goals, and gather an in-depth perspective on the experience of dual illness and dual care. Similarly, comparing experiences based on different models of coordinated care led me to categorize participants under one of two preconceived levels of service delivery, integrated and non-integrated, when the boundaries between these levels were
actually fluid. During my literature review and data analysis, I realized integrated care itself was a concept laden with multiple meanings. To cast a preconceived definition of integration precluded problematizing the concept towards understanding patients’ characterizations of TB and HIV care. While the study sites did allow for some comparison of healthcare experiences that were based around relatively more and relatively less integrated models, I refrained from strict comparisons because individual participants characterized their healthcare in different ways than the literature suggests. Further, even within relatively integrated clinics, the literature’s conceptualization of integrated care was not necessarily realized (these ideas are further elaborated in Chapters 4 and 7).

**Study design**

Research studies are typically designed around quantitative or qualitative frameworks, each guided by specific ontological and epistemological schools of thought. Quantitative research is governed by positivist and post-positivist knowledge claims that aim to uncover the causes of particular outcomes. They are primarily deductive, in that they use data to prove or disprove theory. They optimally measure the clinical impact of disease and more objective measures of health (Creswell, 2003).

The majority of research in the field of TB/HIV coinfection, that was reviewed in the preceding chapter, applies a quantitative approach to measure and trace trends in the epidemic growth of TB/HIV (e.g., incidence and prevalence studies) and its impact in relationship to specific epidemiological variables (e.g., gender or socioeconomic status). These studies identify important indicators to evaluate operational deficits (e.g., funding or data gaps), service development (e.g., co-treatment algorithms), and service utilization (e.g., VCT). Several studies addressing the social challenges of coinfection also utilize quantitative approaches to link patients’ socio-demographic (e.g., age, education or gender) or clinical characteristics (e.g., CD4 counts, WHO stage) to health outcomes (e.g., adherence, quality of life, mental health or stigma) (see Burapat et al., 2009; Deribew et al., 2010a; Deribew et al., 2010b; Deribew et al., 2009; Levin et al., 2006; Mak et al., 2006; Sadoh & Oviawe, 2007; Zachariah et al., 2006; Sardar et al., 2010; Shin et al., 2008). These studies collectively help answer the ‘what’ and ‘where’ types of research questions (e.g., what factors are associated with adherence and/or stigma). However, due to their objective measurement of predetermined categories, they do not reveal the subjective elements underlying these quantified measures, that is, how these issues are socially generated and socially relevant.
Qualitative approaches to research are based on socially constructed knowledge claims governed by an aim to examine human experience, belief, action, culture, and organization. They examine a complexity of views arising from historical and social perspectives, rather than focusing on predetermined notions. They are primarily inductive and exploratory, in that they use data to help generate theory (Creswell, 2003; Patton, 2002). Relatively fewer studies in the field of TB/HIV coinfection employ a qualitative methodological framework. They tap into the social pathways by which quantified associations such as stigma and adherence to care are generated and shaped (see Chileshe & Bond, 2010; Daftary et al., 2007; Gebrekrístos et al., 2009; Gebremariam et al., 2010; Naidoo et al., 2009; Ngamvithayapong et al., 2000; Nyblade et al., 2003). These studies help answer the ‘how’ and ‘why’ types of research questions (e.g., how is TB/HIV stigma constructed or why are individuals less adherent), and further connect them to broader sociostructural contexts and norms (e.g., inequality, gender roles). By lending insight to these social pathways, they help direct quantitative studies and complement quantitative findings to develop more comprehensive and context-sensitive responses for disease control.

A qualitative approach

The literature review identified a need to understand patients’ experiences with TB/HIV coinfection and related care. The study objectives were thus driven by this need to tap into patients’ perspectives in relation to their social and structural contexts. Reducing their voice to preconceived categories (e.g., support or adherence) through more objective or quantitative study designs could preclude the development of unanticipated and unexplored themes or capture of the subjective manifestations of such themes (e.g., ways and forms of support, disclosure or stigma), which may influence how such experiences are interpreted by individual patients. A qualitative approach instead, allows responding to the study objectives in a manner by which I may interpret the meanings individuals attach to their health and illness, and their experiences with care through their own voices and in their own terms. Thus, based on the identified research need to examine the social contexts of TB/HIV coinfection and tap into patients’ perspectives on illness and healthcare, a qualitative approach was considered ideal for further study.

Theoretical framework

Following from the nature of the study objectives and design, I applied a sociomedical approach to research conceptualization, implementation and analysis. That is, research was centered on
understanding dimensions of illness that are tied to individual experiences in relation to broader contexts within their social worlds. With this sociomedical frame of reference, I drew on the theoretical tenets of constructivism-interpretivism (Denzin & Lincoln, 2000; Patton, 2002).

Constructivism-interpretivism (CI), borne of relativist ontology, holds that reality or what is commonly understood to represent the truth within an individual’s characterization of particular phenomena is constructed by the person experiencing those phenomena. According to CI, reality is framed within an individual’s mind rather than an external objective entity. In other words, reality is what a person perceives to be true (Denzin & Lincoln, 2000; Patton, 2002). Further, reality is shaped by the social milieu within which individuals exist. That is, constructions of reality are not made in isolation but against a backdrop of people’s historical and sociocultural contexts (recall definitions of social contexts and social structures were introduced in Chapter 2) (Denzin & Lincoln, 2000).

Constructivism-interpretivism seeks to understand people’s perceptions and interpretations of their reality, as this may allow for an understanding of the motivations underlying their (health) actions and behaviours (Prasad, 2005). The point of constructivist research is to discover “what research participants define as real and where their definitions of reality take them” (Denzin & Lincoln, 2000: p 523). The individual is thus the expert source of information for that reality or truth, and truth becomes a subjective and relative notion that is not separate from other conscious or unconscious aspects of that individual’s social world (Patton, 2002).

In this study, I sought to understand how TB/HIV coinfection and related healthcare is experienced from the perspective of coinfected individuals. Through the lens of CI, I examined how patients constructed meanings around TB and HIV, based on their experiences and interactions, and how their interpretations of those meanings, shaped by their broader social (and structural) contexts, enabled them to form particular health decisions in relation to TB/HIV care.

Analytic framework

Following from the broader theoretical framework of CI, my analysis was informed by the general principles of constructivist grounded theory, as put forth by sociologists such as Kathy Charmaz (in Denzin & Lincoln, 2000).

In grounded theory (GT), findings emerge directly from the study data through constant comparisons across and between different portions of data, enabling the capture of underlying or
latent patterns (Glaser & Strauss, 1967). Compared to hypothesis testing or applying preconceived notions in advance of data collection and analysis, the goal is to bracket all presumptions and generate theoretical notions strictly from within the dataset (Denzin & Lincoln, 2000).

Constructivist GT is a modification to pure GT, allowing for the subjectivity in data analysis that is introduced during data collection. Constructivist GT acknowledges that, during qualitative inquiry, such as interviewing, theoretical notions are generated through an interactive dialogue between a researcher and research participant. Participants express their perspectives in their own terms and through their own voice and the researcher interprets the meanings attached to these expressions. There is a conscious understanding that research interpretations are co-constructed through such interactive dialogue (Denzin & Lincoln, 2000).

As a result of this co-construction, constructivists such as Charmaz (in Denzin & Lincoln, 2000) debate imposing the relatively objective analytic technique of GT methodology on qualitative data that they perceive to be inherently subjective. Pure grounded theorists such as Glaser (2002), however, argue that constructivists are exploiting the subjectivity of data as a means to avoid confronting researchers’ biases in the collection and interpretation of that data (i.e., of that interactive dialogue). Glaser posits that researcher biases must be acknowledged and completely bracketed at the study outset, so as to allow the unbiased emergence of qualitative themes during study implementation and analysis (Glaser, 2002). Charmaz contends that while researchers’ biases should be checked, it is unnatural that absolutely no sub-conscious presumptions seep through. Constructive grounded theorists thus propose that critical reflexivity is the framework, or analytic tool, by which the subjective challenge of applying GT methodology in its purest form may be mitigated (Denzin & Lincoln, 2000).

Critical reflexivity compels qualitative researchers to check their assumptions, and also compels them to acknowledge where they may have failed. Drawing on this tenet of constructivist GT, I believed critical reflexivity was a necessary practice for this study, particularly in the current age of overwhelming access to information and inability to escape from many conscious and subconscious social (and academic) messages (e.g., via the Internet, publications, media). I thus built a continuous “self-consciousness” (Denzin & Lincoln, 2000: p 523) into my analytic interpretations. These reflections, or my critical self-consciousness of events that emerged during study implementation, and their potential influence on the study findings are shared towards the end of this chapter.
Abduction

Constructivist GT is primarily inductive in process (i.e., data generates theory). However, it does comprise a degree of deductive inference (i.e., validation of theory from data) through its emphasis on abduction (Seale et al., 2004).

Abduction, or abductive inference, is the process of relating findings to theory and vice versa, to generate meaningful interpretations. While the essential task of GT is to focus on what emerges from the study data, abductive inference enables the analysis of emerging phenomena through some theoretical frame of reference (Seale et al., 2004). For instance, the emergence of a theme on disclosure was not altogether novel. Abduction, however, allowed me to re-contextualize (and re-conceptualize) disclosure within the boundaries of this study. It helped me identify and refine the ways in which disclosure may be understood as a social phenomenon in relation to TB/HIV and to other (preceding) literary work, maintaining a critical reflexive stance during the iterative process.

Analytic influences

Following from this notion of abductive reasoning, my analytic interpretations were influenced by the works of (i) Goffman (1959; 1963) and more contemporary scholars who drew on his writings, based on their scholarship on disease related stigma, and (ii) Eakin & MacEachen (1998), based on their scholarship on the interplay between social interactions and social structures.

As introduced during the literature review, Goffman (1959; 1963), during his work in psychiatric institutions in the 1950s, conceptualized how human stigma is constructed and managed. He noted how relative distinctions between individual attributes allow “normal” (1963: p 5) people to stigmatize those possessing certain undesirable attributes. He noted how stigmatization compels individuals to manipulate how others perceive them (i.e., construct an identity) through careful public performances or self-presentations. Individuals continuously present themselves in ways that enable them to be socially accepted, that is, to avoid being stigmatized. According to Goffman (1963), visible attributes such as race or physical disability are inherently “discredited” (p 4) or stigmatized, causing individuals to avoid interactions and occasions where such obvious deformities may be exposed. Attributes such as mental illness or sexual orientation, on the other hand, are “discreditable” (p 4). They have the potential to cause an individual to be discredited (or stigmatized), but their less visible nature allows individuals to manage the stigma associated with those attributes through conscious (non)disclosure of their discreditable identity, and careful
presentations of a more acceptable self (Goffman, 1959; Goffman, 1963). Several themes around the construction of illness identities and patients’ (stigmatizing) experiences with TB and HIV emerged from the study data that I examined using Goffman’s theoretical frame of reference. His ideology was helpful to understand how stigmas related to TB and HIV were constructed, interrelated and responded to by coinfected patients. I drew on his conceptualization of particular stigma management strategies, such as “covering” (1963: p 102) and “passing” (p 73), when examining coinfected patients’ decisions towards disclosure. These concepts are further discussed in Chapter 5, and re-emerge in Chapters 6 and 7 of the thesis.

Contemporary interpretive scholars who were influenced by Goffman’s work further informed my analysis. Link & Phelan (2001; 2006) conceptualize stigma as a product of labeling particular attributes as social difference (e.g., sexual preference or skin colour), negatively stereotyping that difference as undesirable (e.g., dirty or immoral), and exercising power differentials to allow dominant social groups to discriminate against others they perceive to be socially different (e.g., via discrimination, segregation). Parker & Aggleton (2003) also deconstruct stigma as a highly social process tied to existing hegemonies of power and social exclusion. They argue that stigma allows dominant groups to reify existing social inequalities in relation to class, gender or race. Both sets of authors highlight that stigma is less an attribute owned by an individual as compared to one that others, or society in general, designate to that individual and thus, conceive of stigma as a social (not individual) phenomenon. They have also applied their framework to study how HIV-related stigma is socially produced and reproduced (Ling & Phelan, 2001; Link & Phelan, 2006; Parker & Aggleton, 2003). Consequently, their scholarship was considered particularly helpful to understand how patients’ experiences with the stigma of TB and HIV were tied to their broader socio-structural realities as explicated in Chapter 6, in particular, as well as Chapter 7 of this thesis.

Finally, I drew on the theoretical insights of Eakin & MacEachen (1998). Through their study of social relations and interactions in small workplaces, they noted how individuals’ health experiences are based on their subjective (constructivist) interpretations of those experiences, which in turn, are tied to broader social relations and structures. Individuals’ interpretations of experience may thus serve as “metaphors for and behavioural manifestations of wider social conflicts and contradictions” (Eakin & MacEachen, 1998: p 912). This framework helped me analyze the ways by which coinfected patients attributed meanings to their infections (in Chapter 5) and participation in healthcare (in Chapter 7). Patients’ interpretations of those meanings were embedded in and shaped by social
norms around TB and HIV, the lived reality of their (impoverished and gendered) lives, and the social paradigms within which TB and HIV care were set. Patients’ narratives were also considered to reflect broader social structures, and Eakin & MacEachen’s scholarship was helpful in analyzing how illness experiences with TB and HIV are inextricably linked to patients’ broader social circumstances (Chapter 6), and their interactions within particular programs in the healthcare system (Chapter 7).

Collaborative arrangements for research

The study was undertaken as part of my doctoral degree at the University of Toronto’s Dalla Lana School of Public Health, Toronto, Canada, under the supervision of a doctoral committee (comprising Dr. Liviana Calzavara, primary supervisor; Dr. I.D. Rusen; and, Dr. Ping-Chun Hsiung), and in collaboration with an international host institution, the Centre for the AIDS Programme of Research in South Africa (CAPRISA). CAPRISA is a UNAIDS-partnered research institute based at the Nelson R. Mandela School of Medicine, University of KwaZulu-Natal (UKZN), Durban. Since its inception in 2003, CAPRISA has spearheaded research projects aimed at mitigating the clinical impact of HIV and HIV-related opportunistic infections, in particular, TB. The qualitative design of this study complimented ongoing projects at CAPRISA that were situated in biomedical and quantitative epidemiological frameworks. Our collaborative commitment further followed from previously successful research undertaken during my Masters’ degree (Daftary et al., 2007). During fieldwork, I worked closely with CAPRISA’s Deputy Director, Dr. Nesri Padayatchi.

Definitions

Several concepts warrant explanation in the context of this study. They are tabulated in Table 3.1.

Table 3.1: Definitions in the context of this study

<table>
<thead>
<tr>
<th>Concept</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Host institute</td>
<td>Centre for the AIDS Programme of Research in South Africa (CAPRISA).</td>
</tr>
<tr>
<td>Patient</td>
<td>An adult accessing some form of healthcare. In this study, patients were interchangeably referred to as ‘patients’, ‘participants’ or ‘patient participants’.</td>
</tr>
<tr>
<td>Healthcare</td>
<td>An adult involved in some form of healthcare provision. Examples include doctors or</td>
</tr>
</tbody>
</table>

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7 Information on research based at CAPRISA is available at http://www.caprisa.org
8 Dr. Padayatchi was named the principal investigator on all South African ethics submissions, as was a condition of approval for research conducted at CAPRISA, UKZN.
worker (HCW) physicians, nurses, nurse-aides, clinic managers, and counselors.

Key-informant In this study, key-informants were HCWs and included doctors, nurses and site managers.

| Integrated vs. non-integrated care | The literature review drew attention to various dimensions of integrated healthcare. In the context of the study method, specifically with respect to site selection and description, integrated and non-integrated care were also considered to be relative and non-binding constructs (e.g., co-location did not equate to co-treatment).

*Integrated care* implied patients received TB and HIV care at co-located clinics (Site 3, discussed ahead). While proximity may have allowed for greater communication and coordination, either infection was managed by two clinical teams that were separated by opaque, physical boundaries. This coincides with the WHO’s (2010b) idea of partial integration, or Contandriopoulos’ (2003) definition of functional integration.

*Non-integrated care* implied patients received TB and HIV care at two distal locations, managed by two clinical teams (Sites 1 and 2). It follows that the lack of proximity may have contributed to less communication and coordination between TB and HIV programs. |

Setting

South Africa is the hardest hit country in terms of the distribution and impact of TB/HIV coinfection, as discussed in the literature review, and was thus a fitting venue for this study.

The public health sector

The Health Systems Trust (HST), South Africa reports the majority of South Africans are uninsured and live at or beneath the poverty line. The national unemployment rate is 23% (HST, 2011). Both TB and HIV disproportionately affect economically disadvantaged segments of the population who are believed to access publicly funded facilities to fulfill most of their medical needs (Moshabela et al., 2010). Recommendations for TB/HIV care are also aimed at the public health sector, which serves 84% of the country’s nearly 50 million people. In order to capture the illness experiences of this majority, the study was set in the public health sector.

KwaZulu-Natal

Within South Africa, this research was conducted in the highest-burden province of KwaZulu-Natal (KZN). Demographic information on KZN is included in Appendix C.

Burden of TB/HIV coinfection

KwaZulu-Natal is situated at the geographic epicenter of the national TB/HIV epidemic. It has an annual TB incidence of about 1,066 per 100,000 population (equal to about 123,000 new cases per
year) and an adult HIV prevalence of 26% (equal to about 1.6 million persons), both of which are well above the national average (Day & Gray, 2010; Padayatchi et al., 2010). HIV prevalence among the province’s newly diagnosed TB cases is estimated to range between 65% and 80% (Grimwood et al., 2006; Hausler, 2005).

**TB/HIV healthcare**

Both TB and HIV may be tested and diagnosed through the private as well as public sector. However, once diagnosed, TB treatment must be administered and monitored under the National TB Control Program (NTCP), via DOTS, in the public sector (NTCP, 2004). Work-based DOTS falls within this mandate, where treatment is monitored in the public sector but medication is provided to employment sites and administered at work, as a means to encourage adherence and reduce absenteeism (WHO/ILO, 2003). HIV treatment, on the other hand, may be administered and monitored in the public or private sector but its prohibitive costs, limited coverage via private insurance schemes, and availability at no cost through the national rollout encourages most patients to access ART through the public sector (DOH, 2004). The medical diagnosis of TB and HIV (including all investigative tests) and treatment of eligible patients (including TB chemotherapy and ART) in the public sector are free of charge for all South African residents (HST, 2005; NTCP, 2004).

The KZN Department of Health comprises 11 public health districts, which include 75 provincial hospitals. These, in turn, are affiliated with about 700 primary healthcare clinics, community health centres and/or mobile clinics (KZN Health, 2011; HST, 2011). Approximately 91% of these public health facilities offer some services related to TB control, ranging from screening, diagnostic confirmation, treatment evaluation, and DOTS collection (HST, 2011). However, only 74% of TB cases are successfully detected in KZN and cure rates are the lowest in the country, at 53%. Poor TB outcomes have been linked to overburdened health infrastructures and clinical complications such as those introduced by the province’s high rate of HIV infection (Padayatchi et al., 2010).

The proportion of provincial clinics providing HIV testing and ART services is less clear (HST, 2011). National reports state 96% of government run primary healthcare centres now offer HIV testing, but the proportion of adults testing is not known. In KZN, only 39% of the 297,000 eligible patients with HIV are placed on ART (Padayatchi et al., 2010). It is estimated that the proportion of coinfected patients accessing concurrent TB treatment and ART is similarly low. Thus, not only is the burden of
TB and HIV disease in KZN the highest in the country, healthcare indicators for both infections are also among the poorest (Padayatchi et al., 2010).

**Sites**

The study was conducted at three public health clinics in KZN. The sites are situated in the two most populated cities, Durban (eThekwini district) and Pietermaritzburg (uMgungundlovu district), which enabled recruitment from the widest pool of patients. Socio-demographic information on both cities is included in Appendix C. The rationale and process for site selection are described below.

**Site selection**

**Rationale**

Sites were selected based on the potential to recruit patients who were dually infected with TB and HIV, and the diverse range of services they provided in relation to TB and HIV healthcare.

Based on the study’s qualitative design, a relatively small sample size was needed (sampling is discussed ahead), and following from the high rate of TB/HIV coinfection in KZN (65-80%), an adequate pool of coinfected patients was expected at any TB or HIV clinic province-wide. (This assumption was confirmed during field observations, as is discussed in Chapter 4.)

As the study objectives were inspired by the lack of insight on patients’ experiences with TB/HIV and healthcare in the context of the current shift to integrate TB and HIV services, inclusion of a site offering some integration of care was prioritized. However, considering the paucity of such clinics in the country, and a need to produce findings that would lend insight to the experience of a majority of patients infected with TB and HIV (i.e., who access care at non-integrated clinics), inclusion of two additional sites delivering primarily just TB or HIV services was also considered necessary. Selection of relatively integrated and less integrated clinics would also allow for some qualitative comparisons between patients’ experiences with diverse forms of TB and HIV care.

**Process: integrated site**

Across KZN (and South Africa), HIV testing and TB screening are commonly co-located within primary healthcare centres. However, once diagnosed with either infection, patients access separate facilities for TB and HIV treatment. Very few of the hundreds of such facilities provide TB and HIV care in a co-located or physically integrated manner. One such clinic is the eThekwini TB/HIV clinic in
Durban (Abdool Karim et al., 2009; Friedland et al., 2007), which is also closely affiliated with the host institution. The integration of TB/HIV care at this clinic, potential to recruit coinfected patients accessing integrated care, and host affiliation formed the basis of its selection as a study site (Site 3).

**Process: non-integrated sites**

The Prince Cyril Zulu Communicable Disease Centre is one of the largest TB clinics in Durban. It is also co-located with the eThekwini TB/HIV clinic (Site 3) in that they share space in the same physical building. While some HIV coinfected TB patients attend the eThekwini TB/HIV clinic for HIV care, the majority of TB patients access other HIV facilities based on their place of residence and saturation of patient intake at any one HIV facility. The delivery of TB services at this TB clinic, and potential to recruit coinfected patients accessing non-integrated forms of TB and HIV care formed the basis of its selection as a study site (Site 1). (Clarity on the recruitment of patients at Site 1 is offered ahead.)

Since Sites 1 and 3 are both located in the high-density district of eThekwini, a site in another populated district (uMgungundlovu) was sought to broaden the impact and transferability of study findings (discussed in Chapter 9). An urban facility was also sought to maintain some similarity between sites delivering non-integrated care. However, researching HIV-positive persons in the South African (and global) context is considered to be a highly sensitive task due to the vulnerability of affected populations, and site collaborations depend substantially on building researcher integrity and trust. During early discussions with the host institution, I learned that a high-volume hospital that ran an HIV clinic in Pietermaritzburg shared an affiliation with the Canada Africa Prevention Trials Network or CAPTN\(^9\). The host institution also had some research contacts at this hospital. These points of shared interest were considered important. The delivery of HIV services at this HIV clinic, potential to recruit coinfected patients accessing non-integrated TB and HIV care, and their anticipated interest to collaborate formed the basis of its selection as a study site (Site 2).

All three sites were approached for their interest in the study through introductions made with the host institution and all sites agreed to participate. No other sites were approached for this study.

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\(^{9}\) CAPTN is a Canadian-funded African-operated HIV/AIDS research organization. While CAPTN did not fund this project, the study is included as one of its research activities. More information is available at http://captn.yolasite.com/captn.php
Site descriptions

Site descriptions (see Table 3.2) are based on early collaborative discussions held at each site prior to research implementation. Additional descriptive information on each site was gathered during the study and is elaborated in Chapter 4.

All sites attend to patients on an ambulatory or outpatient basis. Corresponding to the provincial socio-demographic make-up, most patients are of African race and with low income. Many are unemployed (exact number not known). Those employed are generally engaged in manual labour, or in retail, domestic or informal work (e.g., street vending). A minority of patients work in the industrial sector (particularly at Site 1, due to the NTCP mandating all TB treatment be administered via the public sector). Most patients reside in semi-urban townships in and around the cities.

Table 3.2: Description of the study sites

<table>
<thead>
<tr>
<th>Site description</th>
<th>Site 1</th>
<th>Site 2</th>
<th>Site 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Location</td>
<td>Durban</td>
<td>Pietermaritzburg</td>
<td>Durban</td>
</tr>
<tr>
<td>Type of healthcare facility</td>
<td>TB clinic</td>
<td>HIV clinic</td>
<td>HIV clinic co-located with TB clinic</td>
</tr>
<tr>
<td></td>
<td>Ambulatory</td>
<td>Ambulatory</td>
<td>Ambulatory</td>
</tr>
<tr>
<td></td>
<td>Public sector</td>
<td>Public sector</td>
<td>Public sector</td>
</tr>
<tr>
<td>Services primarily offered</td>
<td>TB diagnosis, treatment and monitoring (DOTS)</td>
<td>HIV treatment and monitoring Basic TB screening</td>
<td>HIV diagnosis, treatment and monitoring Basic TB screening and TB treatment monitoring</td>
</tr>
<tr>
<td>Services referred out</td>
<td>HIV testing and treatment</td>
<td>TB confirmation and treatment</td>
<td>TB confirmation and treatment</td>
</tr>
<tr>
<td>Relative integration of TB/HIV care</td>
<td>Non-integrated Separate clinical teams Separate medical charts Separate physical spaces</td>
<td>Non-integrated Separate clinical teams Separate medical charts Separate physical spaces</td>
<td>Integrated Separate clinical teams Separate medical charts with shared medical information Shared physical space</td>
</tr>
</tbody>
</table>

10 South Africa's population is divided into four racial groups: African (also termed, black), mixed (coloured), Asian (Indian), and white, comprising 79.4%, 8.9%, 2.6%, and 9.2% of the total population, respectively. In 2008, HIV prevalence was recorded at 13.6%, 1.7%, 0.3% and 0.3%, respectively, across the four racial groups (Day & Gray, 2010; HST, 2011). Corresponding data on TB and other HIV indicators are no longer published, as racial categorization of health statistics was greatly reduced post-democratization in 1994, but the epidemiological distribution and impact of TB and HIV is disproportionately imposed in the majority black-African community (Van Rensberg et al., 2005).
Sites 1 and 2 are similar to many other TB and HIV clinics in the province in terms of their patient intake and health service provision. They primarily cater to the delivery of just TB or HIV services, respectively, with referrals out for diagnosis, confirmation and treatment of patients’ coinfections.

In contrast, as stated earlier, Site 3 is a relatively unique healthcare facility. Although it is situated within the public sector, it is distinctive in three ways. First, it delivers HIV care specifically to patients diagnosed with TB who are (or were) receiving TB treatment at just one co-located TB clinic. Thus, while Site 3 continues to deliver HIV care for patients who have completed TB treatment, all Site 3 patients are (or at one point, were) TB/HIV coinfected, and both TB and HIV care are (or were) provided at co-located facilities. Second, Site 3 has full access to all medical information related to a coinfected patient’s TB care through pro-integration efforts established with the TB clinic. Doctors at Site 3 are able to access and monitor medical information on HIV and TB infections for the coinfected patients they treat, allowing for greater sharing of medical information and coordination of medical care. Third, Site 3 began as a research facility (around 2003) to specifically study the clinical co-treatment of TB and HIV. While its current mandate goes beyond research to the provision of general HIV treatment and HIV (and TB) support, it retains some technical resources (e.g., computers) that other clinics in the public sector may fall short of. As a result of these distinctions, Site 3 may not be comparable to most other HIV clinics in KZN. However, its inclusion allowed for an in-depth examination of coinfected patients’ experiences with a dimension of integrated TB/HIV care (i.e., co-location) that is being widely promoted by the WHO (WHO, 2010b). It thus enabled tapping into patients’ perspectives at a critical period in TB/HIV healthcare reform.

**Clarity on recruitment at Sites 1 and 3**

A total of 40 patients coinfected with TB and HIV and 8 key-informant HCWs participated in this study; details on their sampling and recruitment are discussed further ahead. At this point, co-location of the TB/HIV clinic (Site 3) with the TB clinic (Site 1) merits some clarification on the patient recruitment process at these sites. All patients attending Site 3 for HIV care are (or were) coinfected, and access (or had accessed) Site 1 for TB care. However, the reverse does not apply; the majority of coinfected patients attending Site 1 for TB care access other, external clinics for HIV care (referral mechanisms are discussed in Chapter 4). In order to avoid recruitment overlap in the study, all patient participants recruited from Site 1 excluded those who accessed HIV care from Site 3.
Conflict of interest

The host institution is involved with the operation of Site 3. However, there was no conflict of interest in conducting this study. Their involvement did not influence the study findings or analysis.

Data collection

Sources

Directed by the study’s theoretical underpinnings, data were collected via 3 sources (see Table 3.3):

1. In-depth, semi-structured, private, face-to-face, audio-recorded interviews with 40 adult patients coinfected with TB and HIV
2. In-depth, semi-structured, private, face-to-face, audio-recorded interviews with 8 HCWs (key-informants) providing TB and/or HIV care
3. Non-participant, ethnographic field observations at health facilities providing TB and/or HIV care

Patient interviews were the primary data source for this study. Key-informant interviews and site observations were secondary data sources. Interviews and observations were carried out concurrently, between February and July 2009 (see Appendix D for a timeline of research activities).

Table 3.3: Data sources: patient and key-informant interviews, and site observations

<table>
<thead>
<tr>
<th>Data sources</th>
<th>Total</th>
<th>Site 1</th>
<th>Site 2</th>
<th>Site 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interviews</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Patient interviews*</td>
<td>40</td>
<td>14</td>
<td>13</td>
<td>13</td>
</tr>
<tr>
<td>Women</td>
<td>24</td>
<td>8</td>
<td>9</td>
<td>7</td>
</tr>
<tr>
<td>Men</td>
<td>16</td>
<td>6</td>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td>2. Key-informant interviews</td>
<td>8</td>
<td>3</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3. Site observations</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
</tbody>
</table>

* Primary data source

Interviews

Interviews were conducted with 48 participants: 40 TB/HIV coinfected patients, and 8 HCWs providing TB and/or HIV care. All participants were interviewed face-to-face, on one occasion only, in private and on-site. Interviews were audio-recorded.
Rationale

The study’s theoretical framework guided how data were collected in response to the research objectives. Constructivism-interpretivism holds that reality or meanings attributed to individual experiences are socially constructed and interpreted by individuals experiencing those phenomena (Prasad, 2005). What it means for a person to be ill or to heal is thus inextricably related to the social context within which that person is a part. However, these meanings are generally subconscious or hidden; that is, in their day-to-day actions, people may not consciously think about the history, culture or social structures within which their interpretations are shaped (Gadamer, 1960). A dynamic interaction between a researcher and the individual may facilitate the account of his or her lived experience, and the subjective (conscious and subconscious) meanings attached to his or her characterization of those experiences. In-depth interviews offer an ideal method to analyze such subjective meanings, where the individual is the expert source of information for those meanings (Patton, 2002; Ponterotto, 2005; Seale et al., 2004).

Interviews thus allowed for the production of an interactive dialogue with study participants, through which they could narrate and actively interpret their experiences, and the meanings they accorded to those experiences.

Interview design

The interview design was based on the study’s qualitative approach (Hsiung & Raddon, 2002; Mack et al., 2005; Patton, 2002; Seale et al., 2004). Questions were open-ended, designed to evoke exploratory themes and thick descriptions of participants’ experiences in relation to their social contexts. Participants were considered the expert sources of data and the interviewer led as little as possible, to allow a naturalistic flow of thoughts and expressions.

A semi-structured interview guide was designed and piloted (discussed ahead) to help steer the interview towards unearthing participants’ experiences in the context of illness and healthcare. The wording and suitability of questions was clarified with the host institution to ensure they were posed in a culturally sensitive manner. They progressed from general to more specific in nature, as the interviewer established a stronger rapport with each participant. However, the sequence and wording of questions changed from interview to interview depending on the types of responses received, which depended on participants’ unique social circumstances.
Participants were encouraged to express their thoughts freely, and talk about their understandings of illness, medical experiences and social circumstances in their own terms. Patients were asked questions that tapped into their perspectives on TB and HIV, experiences with learning about their diagnoses, feelings related to these diagnoses, how they spoke about their illness to people within their social networks, their experiences in their home and communities, and their experiences accessing healthcare or other forms of support in relation to their illness. Healthcare workers were asked to share their thoughts about HIV and TB based on their day-to-day experiences providing care, and their perspectives on TB- and HIV-related activities. Probes, or follow-up questions were commonly used to ascertain the meaning of participants’ accounts, clarify a point, open new themes for discussion, or encourage further elaboration (Denzin & Lincoln, 2000; Ruben & Ruben, 2004).

Each interview was shaped by the reality of participants’ diverse and unique sets of circumstances. The first few interviews prompted new questions for inclusion in subsequent interviews. For example, several participants emphasized the importance of food and access to a disability grant leading these issues to be probed further in subsequent interviews. As well, disclosure took on a dynamic and evolutionary temperament of its own, depending on the covert or overt circumstances within which it occurred. Questions were adjusted or added to reflect this reality, and to probe further into how disclosure and trust were maintained or reiterated in participants’ social relations. The continuous and dynamic discovery of new and unanticipated foci was encouraged with qualitative interviewing and, I believe, strengthened the richness of data collected during the study. The interview guides for patients and HCWs are detailed in Appendix E (key modifications are highlighted with asterisks). However, the guide was largely used as a ‘fallback’ in the field, as interviewers became proficient at asking questions based on interviewee responses and individual circumstances rather than following a structured format.

Language

An approximately equal mix of patients preferring to speak in isiZulu and English, the main languages of KZN, was expected at the study outset. While people living in urban areas have a greater tendency to speak English, residents of semi-urban and rural communities more commonly speak isiZulu. The rate of multilingualism is high, and between 45% and 65% of people whose first language is isiZulu are able to speak and comprehend English (Census, 2001; Broeder et al., 2002). Based on patients’ stated language preference, 13 patient interviews were conducted in isiZulu and 27 in English. All 8 key-informant interviews with HCWs were conducted in English.
Interviewers

Interviews were conducted by one of two interviewers, Zanele and myself (Amrita). Zanele was a bilingual research assistant I hired to conduct interviews in isiZulu. We spent several weeks discussing the research purpose and I trained her in the fundamentally open and informal nature of qualitative interviewing prior to data collection. The quality of data attained via in-depth interviews was understood to depend largely on the quality of interactive dialogue between the interviewer and participant (Patton, 2002). An interpreter or translator could inhibit this dynamic and compromise the quality of data collected (Kapborg & Bertero, 2002). Therefore, only one interviewer was present at each interview. Zanele conducted all isiZulu interviews and I conducted all English interviews.

Pilot interviews

Following from recommendations on qualitative interviewing (Patton, 2002), a pilot interview was held between each interviewer and one patient prior to the recruitment stage, in order to design and test interview questions, hone interviewing skills, and receive feedback that could be applied to subsequent study interviews. Two adult patients participated in the pilot interview: one woman at Site 1 (in isiZulu) and one man at Site 3 (in English). Pilot interviews were conducted subsequent to receipt of patients’ written, informed consent and the interviewer’s confirmation that the interview would be used for training purposes only. Data from pilot interviews were not included in the study analysis. Pilot interviews were not conducted with HCWs.

Patient participants

Rationale

The study objectives were centered on tapping into the experience and perspectives of individuals infected with TB and HIV as they accessed and received healthcare for their dual infections. Coinfected patients were thus considered a primary source for this information.

Sampling

The goal of qualitative research is to capture diversity in experiences, rather than achieving a homogeneous sample. Consequently, a heterogeneous sample was targeted using the principles of maximum variation, as one strategy of purposive sampling (Patton, 2002; Seale et al., 2004). Purposive sampling encourages “detecting cases within extreme situations as for certain characteristics or cases within a wide range of situations in order to maximize variation, that is, to
have all the possible situations” (Seale et al., 2004: p 418). Maximum variation sampling allows for the capture of detailed descriptions of all aspects of the social phenomena or cases under study (i.e., experiences with TB and HIV and related care) as a means to document the uniqueness of particular cases and instances; and, also to allow for the capture of important shared or latent patterns that may “cut across cases” in spite of their heterogeneity (Patton, 2002: p 232).

Early sampling efforts targeted maximum variations of characteristics commonly expected to affect patients’ illness experiences, such as gender, time since diagnosis and stage in treatment. Patients’ education level, occupation, WHO HIV stage and CD4 counts were not purposively sampled based on the lack of their relevance in prior studies. HIV and TB are shown to have the greatest impact on people belonging to the economically productive and reproductive age group (Dorrington et al., 2006), and for this reason, interviews were restricted to patients between 18 and 50 years old. Following the higher prevalence of HIV in women compared to men in South Africa (21.2% in women v. 15.4% in men, aged 15-49 years) (Dorrington et al., 2006), a greater number of women were sampled (24 women, 16 men). This maximized the impact and transferability of study findings.

As interviewing progressed, sampling became more purposive in response to emerging themes (Patton, 2002). An early goal during research planning had been to recruit patients diagnosed with HIV in the past year and their first case of pulmonary TB in the past 2 months (to encourage the analysis of recent events, and minimize recall bias). However, these criteria became restricting and unnecessary when I observed the reality of patients’ medical and social circumstances. For example, it became apparent during the interviews that some patients were aware of their HIV-positive status many years prior, but had decided to ignore their test result or avoid accessing care until they became symptomatic with TB (their reasons for doing so were multifarious, and are discussed in Chapters 5 and 6). In addition, several patients were experiencing their second or third episode of TB, and a few were diagnosed with glandular or abdominal TB. Recurrent or EPTB is not atypical in HIV patients (Sterling et al., 2010; WHO, 2010b). To omit any of these cases would have precluded capturing the breadth and depth of illness experiences associated with coinfection. The inclusion criteria thus remained broad (see Table 3.4), and patients who would allow for greater comparative and negative-case analyses were sought for exploration of emerging theoretical concepts.

Another goal of this study was to understand coinfected patients’ experiences accessing and receiving healthcare for TB and HIV. The selection of three sites that provided relatively different
types of TB and/or HIV care (see Table 3.2) could allow for some qualitative comparisons. Thus the sampling strategy targeted the recruitment of approximately equal numbers of patients at each site, to allow for possible comparisons between their experiences with TB/HIV care.

Finally, while a specific or ideal sample size is generally not recommended for qualitative analysis (Patton, 2002), a large sample that would increase statistical power and allow for quantitative associations was not considered as necessary. Thus, a feasible sample size was sought based on the available time and resources. Prior field experiences and discussions with study collaborators suggested that I recruit 30 to 40 patients.

**Table 3.4: Boundaries of the patient sample**

<table>
<thead>
<tr>
<th>Patient inclusion criteria</th>
<th>Patient exclusion criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>◆ Adults between 18-50 years of age</td>
<td>◆ Diagnosed with multi or extensively drug-resistant TB</td>
</tr>
<tr>
<td>◆ Known HIV-positive</td>
<td></td>
</tr>
<tr>
<td>◆ Diagnosed with TB</td>
<td></td>
</tr>
<tr>
<td>◆ Receiving TB and/or HIV care at a study site</td>
<td></td>
</tr>
</tbody>
</table>

While the exact prevalence of HIV coinfection with multi or extensively drug-resistant TB (M/XDR-TB) is not known, it is generally high in outbreak investigations as HIV-positive persons are likely to manifest primary TB disease more rapidly compared to persons without HIV. Coinfection with M/XDR-TB is associated with greater mortality compared to drug susceptible TB. Patients endure longer treatments and more severe medical complications (Andrews et al., 2007; Wells et al., 2007). In South Africa, 1.8% of newly diagnosed TB cases and 6.7% of retreatment cases are estimated to be M/XDR-TB; the rate of HIV coinfection or additional risk, if any, is not clear (WHO, 2010a). Patients with M/XDR-TB are typically managed in more specialized TB hospitals that were not among the three sites included in this study. An examination of their experiences is beyond the scope of this thesis, and warrants a separate study. Therefore, all patients with M/XDR-TB were excluded from this study sample.

**Recruitment**

Recruitment was carried out between February and July 2009 on a site-alternating schedule concurrent with site observations. Patients attending the clinics for their routine clinical care were actively recruited from the outpatient waiting area as they waited their turn in the clinic queue.
Based on early discussions with site staff, patients were known to typically wait several hours for their appointments, allowing for sufficient opportunity to conduct an interview.

Nurses and doctors at each site helped identify potential recruits by matching study inclusion criteria (see Table 3.4) with appointment logs reviewed ahead of time. At Site 1, only doctors were privy to the HIV status of patients; thus they alone assisted with study recruitment. On the day of recruitment, doctors and/or nurses identified the eligible patients and either referred them to speak with the interviewer (Zanele or myself), or indicated when the interviewer could approach the patient for study participation in a manner that would cause minimal disruption to the clinic flow or the patients’ place in the clinic queue. The interviewer accordingly approached patients, stating she was an interviewer assisting with research and was interested in interviewing the patient in private while she or he waited in queue. Patients who expressed an interest to participate were then escorted to a pre-arranged room on site to discuss the study details and consent process. All participating patients’ places in queue were maintained with the assistance of site staff.

Patient recruitment ended once 40 patients had successfully completed an interview. Preliminary analyses of the interviews (discussed ahead) also demonstrated some repetition, or saturation (Patton, 2002), of emerging qualitative themes.

**Consent**

Patient consent forms were designed in close collaboration with the host institution and worded in language that was considered culturally and socially appropriate for study recruits. English forms were translated to isiZulu and translated back to English for accuracy as per local ethics protocols (see Appendix F for English versions of consent forms). The forms introduced participants to the study purpose and process; specifically, that we were interested in learning about their thoughts, feelings and experiences with their illness and healthcare by asking them to participate in an interview. Patients were assured that their participation in the interview was voluntary and that they could decline to answer any question or end the interview at any point without providing a reason. Patients were also assured that their decision to participate and individual responses would not affect their current or future medical care, and that all data from the interviews would be anonymized, securely stored and kept private and confidential. Their responses would not be shared with site staff and other patients. While patients needed to sign the consent form, their name or
identification were not otherwise recorded or verified. All patient participants provided their written, informed consent prior to commencement of the interview.

**Compensation**

Patient participants were remunerated ZAR 50 (about $7) at the end of their interview. The amount was decided in collaboration with the host institution, in accordance with local recommendations for compensating interview participants in South Africa. It is equivalent to about two hours’ wage for a manual labourer in KZN, believed to equitably compensate a person for his or her time spent in the interview, offset indirect medical costs such as transport, food or childcare, and minimize coercion to participate. Light refreshments were also provided during the interviews.

**Final patient sample**

Forty-four patients were approached for the study. Three men declined to participate. The remaining 41 patients expressed an interest to participate and all consented to be interviewed. One interview ended early and was excluded from analysis. Of those who consented, 39 were interviewed on the day of recruitment. Two patients, a woman from Site 2 and a man from Site 3, were interviewed a few days later, as they stated they were busy on the day of recruitment.

**Table 3.5: Patient Interview characteristics**

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>Site 1</th>
<th>Site 2</th>
<th>Site 3</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total</td>
<td>F</td>
<td>M</td>
<td>F</td>
</tr>
<tr>
<td><strong>Number</strong></td>
<td>40</td>
<td>24</td>
<td>16</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td>(60%)</td>
<td>(60%)</td>
<td>(40%)</td>
<td>(57%)</td>
</tr>
<tr>
<td><strong>Duration (minutes)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Average</strong></td>
<td>41</td>
<td>40</td>
<td>41</td>
<td>38</td>
</tr>
<tr>
<td><strong>Language</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>English</td>
<td>27</td>
<td>16</td>
<td>11</td>
<td>11</td>
</tr>
<tr>
<td>(68%)</td>
<td>(79%)</td>
<td>(79%)</td>
<td>(79%)</td>
<td>(79%)</td>
</tr>
<tr>
<td>isiZulu</td>
<td>13</td>
<td>8</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>(32%)</td>
<td>(21%)</td>
<td>(21%)</td>
<td>(21%)</td>
<td>(21%)</td>
</tr>
</tbody>
</table>

The final patient sample comprised 40 patients (24 women and 16 men) approximately equally divided across the three sites (see Table 3.5): 14 patients (8 women, 6 men) at Site 1, 13 patients (9
women, 4 men) at Site 2, and 13 patients (7 women, 6 men) at Site 3. Thirteen interviews were conducted in isiZulu and 27 in English. The average duration of each interview was 41 minutes, ranging between 15 and 73 minutes long. Socio-demographic and clinical characteristics of patient participants are presented in greater detail in Chapter 4.

**Refusals to participate**

Three patients: 2 men from Site 1 and 1 man from Site 3 declined to participate. Although a reason for refusal was not required, each said they were short of time. The patient from Site 3 specified he had to be at work as quickly as possible. One of the patients from Site 1 did not elaborate further on his time constraint, and the other said he needed to return to his wife as she was waiting outside.

**Exclusion from analysis**

A consenting participant from Site 1 ended his interview with me early. He was accompanied to the clinic by his sister and had asked her to wait outside while we spoke. Ten minutes into our interview, she interrupted us, stating they had to return home immediately. Up to this point, I believed the interview had proceeded well. We had discussed his treatment and were moving on to his clinic experiences. However, the interruption and sudden departure left me no opportunity to confirm the patient’s permission to analyze the recorded interview segment. Thus it was excluded from analysis.

**Exclusion from audio recording**

One patient from Site 3 requested I not audio-record our interview. The patient was from another part of Africa. He said he was a legal resident and wanted to share his experiences but did not want to risk repercussions having his voice linked to any type of research, despite my clarification that the recording and all data would be kept confidential and anonymous. The interview lasted 35 minutes and was rich in information. With the patient’s permission, I made short notes as we spoke, followed by more detailed notes as soon as the interview ended.

**Inclusion of a spouse**

While gathering consent, patients were provided with the opportunity to have someone accompany them during the interview if they desired. This was a routine part of local ethics protocol, intended to help participants feel comfortable with the interview process. Two male participants requested their accompanying spouse join them in the interview room after they consented to participate. In both cases, I emphasized that my questions were directed at the patient alone.
The first case involved a patient from Site 2. His wife joined us about 12 minutes into the interview. I had asked him questions about his family and home but despite having consented to participate, he was fairly uncommunicative and quiet. The patient mentioned his wife had accompanied him to the clinic, and at the time, I wondered if he might open up with someone familiar present. I asked him whether he would like to have her join us. He responded affirmatively. Thereafter, he often looked to his wife to recollect events in relation to my questions. As a result, she interjected and elaborated on his short responses despite my posing and gesturing every question to the patient alone. While insight to their marital dynamic was interesting, it deviated from my objective. About 5 minutes after the patient’s wife joined us, I realized she could inadvertently become a participant herself. Not wanting to risk any ethical dilemmas, I wrapped up the interview and thanked them both for their time. The entire interview lasted 19 minutes, and was the second shortest in the study.

The second case involved a patient at Site 3 (also the unrecorded interview), who asked that his wife join us right from the beginning. She did not speak during the interview except to clarify a date at the patient’s request. My personal reflections on experiences with patient recruitment and the interviews are shared at the end of this chapter. They are informed by my critically reflexive stance.

Key-informants

Rationale

All key-informants in this study were HCWs at one of the study sites. Interviews with key-informants helped contextualize the characterizations of illness and healthcare experiences voiced by patient participants, and linked them to the clinical, organizational and structural backgrounds to which patients were exposed in the healthcare system. Key-informant interviews also allowed for some inclusion of the provider’s perspective on coinfection and the site-specific delivery of TB and HIV care. They drew attention to the manner in which policies were applied or challenged during day-to-day operations. While these were not explicitly part of the research objectives, key-informant interviews were critical in bringing context to the study.

The sampling and recruitment of key-informants were based on field observations at each site. Further detail on observations as a data source is provided after this section on key-informants.
Sampling

At the study outset, I planned to interview approximately equal numbers of HCWs at each site to have a similar representation of their perspectives on patients’ experiences. Since HCW perspectives were sought to contextualize patient experiences (and not their own), 2-3 key-informants per site were considered to be sufficient. The early recruitment goal was to capture the impressions of at least one HCW involved in either an administrative or managerial role and at least one other HCW involved with direct patient care for TB and/or HIV, at each site.

Two critical field observations affected the final recruitment process. First, it was clear that of all professional, allied and lay HCWs, doctors and at times, nurses and site managers, were most involved in organizing or providing HIV-related care within TB clinics and TB-related care within HIV clinics. It became apparent that contextual information on coinfected patients’ experiences with TB/HIV care would be best ascertained by interviewing these staff members. Each site had about 3 doctors and between 3 to 12 nurses per working day (discussed in Chapter 4). Second, most HCWs, especially doctors and nurses, were involved in some site administration or management concurrent with their provider role. My goal to recruit two distinct types of HCWs became less relevant.

My observations thus helped identify a purposive sample of key-informants that were observed to participate in a diverse range of roles related to the provision of services for TB and/or HIV. I identified 7 HCWs (4 doctors and 3 nurses) whom I observed were heavily involved with direct service provision through their continuous contact with patients in the waiting areas (and assumed contact with patients that they escorted to their consulting rooms). I believed their high level of patient contact would lead to greater elaboration of the interactional context of patients’ experiences. Within this group of 7, I identified 4 HCWs whom I believed were involved with site management or administration activities through their official job titles or observed involvement with the delegation and supervision of tasks. I believed their overlapping roles would lend greater context to the structural or health system level influences on patients’ experiences. In line with the original recruitment goal, I also approached 1 HCW who I observed had minimal to no involvement with direct patient care. Three of the 7 HCWs (mentioned in the beginning of this paragraph) had minimal to no involvement with site management. This information is tabulated in Table 3.6.
Recruitment

Key-informants were recruited and interviewed between April and July 2009, following six weeks of field observations and towards the latter half of the patient interview stage. They were approached by me during regular work hours for their interest to participate in an interview. A time that was convenient to the HCW was arranged, and interviews were held either in their office or another private room on site after receiving their consent.

Consent

Key-informant consent forms were designed in close collaboration with the host institution and worded in English language considered to be culturally and socially appropriate for HCWs (see Appendix F). The forms introduced HCWs to the study purpose and process; specifically, that I was interested in learning about HCWs’ experiences treating patients by asking them to participate in an interview. Key-informants were assured that their participation was voluntary and that they could decline to answer any question or end the interview at any point without providing a reason. They were also assured that their decision to participate and individual responses would not affect their current or future employment, and that all interview data would be anonymized, securely stored, and kept private and confidential. Their responses would not be shared with staff, employers or patients. While all key-informants signed the consent form, I did not otherwise verify their name or identity. All key-informants provided their written, informed consent prior to their interview.

Compensation

Based on the host institution’s suggestion and in accordance with customary practice for HCWs’ participation in research interviews, key-informants were not offered monetary compensation. Their interviews were held during work hours. Light refreshments were provided during the interviews.

Final key-informant sample

Eight HCWs were actively approached for an interview, and all consented to participate in the study. The final key-informant sample comprised 4 doctors, 3 nurses and 1 manager, approximately equally divided across the three sites (see Table 3.6): 3 HCWs at Site 1, 2 HCWs at Site 2, and 3 HCWs at Site 3. The average duration of HCWs’ interviews was 65 minutes, ranging between 38 and 102 minutes. Additional detail on key-informants is omitted to protect their identities and anonymity.
### Table 3.6: Key-informant sample and interview characteristics

<table>
<thead>
<tr>
<th>Key-informants</th>
<th>Total</th>
<th>Site 1</th>
<th>Site 2</th>
<th>Site 3</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Number</strong></td>
<td>8</td>
<td>3</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td><strong>Type of work</strong>&lt;sup&gt;a&lt;/sup&gt;</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Doctor</td>
<td>4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nurse</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Manager</td>
<td>1 + 4&lt;sup&gt;b&lt;/sup&gt;</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Interview duration</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Range (minutes)</td>
<td>38-102</td>
<td>60-66</td>
<td>43-75</td>
<td>38-102</td>
</tr>
<tr>
<td>Average (minutes)</td>
<td>65</td>
<td>63</td>
<td>59</td>
<td>71</td>
</tr>
</tbody>
</table>

<sup>a</sup> Due to their small number, key-informants are not distinguished by site or gender to protect their confidentiality and anonymity.

<sup>b</sup> Four key-informants shared overlapping roles with direct patient care provision and site management.

### Field observations

#### Rationale

Field observations (Mack et al., 2005; Patton, 2002) helped ascertain a first-hand or insider’s perspective on the physical and social environment that study protagonists, the patients, and HCWs were exposed to while participating in TB and/or HIV care. Observations allowed for a witnessed account of the social contexts in which patients attended clinics and accessed services, insight to their interactions with and between clinic staff and each other, and norms and actions practiced within the clinic environment that could affect their overall experiences with illness and care. Observations also allowed me to form a closeness with study sites towards more sensitive and reflexive analyses. They helped inform my line of questioning during interviews, including questions pertaining to waiting times, interactions between people in the clinic queue, relations between patients and HCWs, and the social dynamic between and within clinics. My observations further helped interpret what I learned during interviews (see Appendix F for the field observation guide).

#### Process

Field observations were carried out during regular working hours in the waiting areas of all sites for 3 days a week on average, between February and July 2009. Observations were not conducted outside of the public waiting area; provider consultation rooms were not accessed. They commenced after ethics approvals were received from all sites, and were performed concurrent with study interviews. The most extensive observations were drawn in the first few weeks prior to
or during low patient recruitment; thereafter, observations were less detailed. Handwritten notes documented during direct observations were subsequently elaborated in private. The names of individuals observed or whom I shared casual conversations with were excluded from all field notes.

Within the first two weeks of observations I introduced myself to all staff (e.g., doctors, nurses, counselors, receptionists, other allied HCWs, and cleaners) as a research student collecting qualitative data on the overall experience of TB/HIV for coinfected patients. I also stated I worked as a HCW (pharmacist) in Canada. I explained the study goals and established my presence on site as an observer. In order to mitigate any suspicion around my presence, and impose as little intrusion on their time and space as possible, I clarified the study was not aimed to evaluate or assess how the site operated, but to understand patients’ perspectives regarding their illness and healthcare.

I shared casual conversations with staff over a range of topics from a piece of news to some aspect of their workday. For the most part, our conversations remained non-specific. In two instances, discussions with a HCW began to get more specific and detailed. In line with the ethics of conducting field observations (Mack et al., 2005), I interjected our conversation and requested their participation in an in-depth interview to which they each consented. Critical reflections on my experience as a field observer are discussed at the end of this chapter.

**Analysis**

Qualitative analysis is a highly fluid process involving non-linear movements back and forth between field notes, transcripts, personal thoughts, and emerging ideas. Microsoft Word® computer software was used for all analytic steps.

**Transcription and translation**

Transcription and translation were conducted concurrently with data collection and continued after the interviews were completed. The two interviewers independently transcribed each interview in its original language, Zanele in isiZulu and I in English. We used a common transcription guide (see Appendix H) to help maintain consistency in our transcription styles. Following this, we translated the isiZulu interviews together, so as to gather both the literal as well as the metaphorical meanings of statements. I also shared transcripts of the English patient interviews with Zanele to benefit from her nuanced understanding of local norms and references, towards an enhanced interpretation of
their subjective meanings. My critical reflections on the translation process and interpreting accounts in isiZulu and English patient interviews are discussed at the end of this chapter.

To help enhance internal validity and mitigate general translation biases, two transcripts were randomly selected and translated by a bilingual speaker who was not involved with other aspects of the study. The independent translations had no major differences when compared to the originals.

Elaborated field notes were also transcribed in English.

**Coding and conceptualizing**

Preliminary analysis of the early interviews, while data collection was ongoing, provided a means to adapt questions to the lived reality of participants’ experiences, refine probes within the interview guide, and to help note when an adequate sample size was reached. While some transcription, translation, and discussions of the nature of Zanele’s and my interviews were done parallel to data collection, more detailed line-by-line coding of transcribed interviews and field notes were performed at the end of the interview stage. The data were used to substantiate an understanding of how persons with TB and HIV experience and make sense of their dual diagnosis, and manage it in the social context of existing health structures and various forms of service delivery.

Initial substantive coding involved assigning portions of interview transcripts and field notes under broad sets of codes (Fassinger, 2005; Seale, 2004). While the identification of most codes arose directly from the data sources (e.g., perceptions of the self: “doing bad things”), some were informed by the literature review and study objectives (e.g., disclosure, experiences with ART). Thereafter, selective coding was applied within the extant dataset (Fassinger, 2005; Seale et al., 2004). Codes deemed critical during substantive coding were discriminately re-applied to transcripts to allow for active development of concepts, or theoretical notions, which in turn responded to the study objectives (e.g., seeking varied dimensions and enactments of disclosure, ART experiences, and self-perceptions). This enabled comparisons between different experiences within individual narratives, and across narratives to allow the identification of latent patterns. The accounts of participants’ exposure to different social and medical circumstances, and perceptions of their health or experiences with healthcare delivery were compared in relation to the broader contexts of those circumstances (e.g., towards understanding the different contexts of integrated TB/HIV care). Comparisons were also made within each account to understand how particular circumstances and
events might influence a diverse set of actions and behaviours for the same individual. Characterizations of experience were interpreted as dynamically interconnected rather than static events within their life course. The positivist ‘unit of analysis’ moved away from a focus on comparing individuals to that of comparing experiences or events.

**Interest in ‘outliers’**

When developing the study objectives, I was encouraged to highlight rather than dilute what was *individual* about participants’ experiences. Consequently, during analysis, events or experiences that contributed to a set of themes were set apart from those deviating from established patterns. In other words, negative cases or characterizations at the periphery of the ‘norm’ were equally drawn out and analyzed. Why was it that most patients appeared to have certain common experiences but one patient experienced something sharply contrasting? What led to this markedly different construction of events, and interpretation of the same? I paid attention to unexpected themes or surprise cases and even non-themes or the lack of an expected theme. For instance, commuting times are cited in the literature as being problematic for low-income patients, but the study illustrated some unexpected manifestations of this theme (discussed in Chapter 7). Discovery of these findings and further analyses of them was recursive, involving moving back and forth between different levels of coding and conceptualization. This encouraged a dynamic flow between facets of patient and key-informant interviews and field observations, that is, a *triangulation* of data.

**Triangulation**

Triangulation may be defined as the application of different methodologies to study the same phenomenon, through the use of various methods, data sources or theoretical perspectives. Triangulation may be treated as a tool to validate data emerging from different sources, as is critical when seeking a singular truth within positivist research paradigms. On the other hand, as with this study, it may be used as an interpretive tool for constructivist-driven research “to reveal varied dimensions of a phenomenon, not in the expectation that different data sources will confirm one another” (Murphy et al., 1998: p 183). In this study, triangulation between data sources (interviews and observations) helped capture a more complete, holistic, and contextual depiction of patients’ experiences with illness and care. Triangulation enriched data interpretations and helped uncover unexpected themes that were not apparent through every source. For example, several participants shared their difficulties coordinating healthcare for TB and HIV even at the relatively integrated
study site. Observations at this site enhanced my analyses of their experiences as I witnessed how lengthy waiting queues for each program precluded a fuller integration of care (discussed in Chapter 7). I reiterate, here, that patient interviews were the primary source of data for this thesis.

**Ethical considerations**

**Institutional approvals**

Permission to implement research was sought from South African and Canadian institutions (see Table 3.7). Applications were concurrently submitted to and received from international, provincial and local ethics committees between October 2008 and February 2009. Data collection commenced subsequent to receipt of all ethics approvals. Ethics boards at the University of Toronto, Canada and UKZN, South Africa re-certified the study in 2009 and 2010, respectively, in support of this analysis.

**Table 3.7: Institutional ethics approvals**

<table>
<thead>
<tr>
<th>Institution or site</th>
<th>Level</th>
<th>Approval received</th>
</tr>
</thead>
<tbody>
<tr>
<td>UKZN Biomedical Research Ethics Committee</td>
<td>Local (institutional)</td>
<td>Feb 2009, 2010, 2011</td>
</tr>
<tr>
<td>KZN Department of Health</td>
<td>Local (provincial)</td>
<td>Mar 2009</td>
</tr>
<tr>
<td>eThekwini Municipality Health Unit</td>
<td>Local (site)</td>
<td>Feb 2009</td>
</tr>
<tr>
<td>Grey’s Hospital</td>
<td>Local (site)</td>
<td>Feb 2009</td>
</tr>
<tr>
<td>CAPRISA Scientific Review Committee</td>
<td>Local (site/collaborator)</td>
<td>Jan 2009</td>
</tr>
</tbody>
</table>

**Mitigating potential risks**

The study involved no clinical procedures and posed no physical risk to participants. The process was transparent and clearly explicated at each site during ethics review prior to commencement of field observations, and to HCWs and patients when seeking their consent to participate in interviews.

Consent and compensation procedures for study participants were discussed earlier in this chapter. Before each interview began, the interviewer made a conscious effort to sit with recruits for a few minutes in silence after discussing the consent form, to ensure they had adequate opportunity to request further information or clarification.
It was anticipated that the study could pose some emotional risk to patients as interview questions invoked discussion of sensitive subject matter pertaining to experiences with HIV and TB. Many questions were of a personal nature and interviewers, Zanele and I, strove to mitigate the potential for psychological or emotional harm in several ways. We were trained to act and ask questions in a culturally and socially appropriate way. Zanele was from South Africa and had worked in the public sector for a number of years. She was well versed in the local vernacular. I have travelled to South Africa on several occasions and conducted research in the area since 2005. We had both learned to recognize signs of emotional uneasiness among interviewees. Often, we changed the sequencing or wording of questions if we sensed it caused participants discomfort or embarrassment. During the course of each interview, we repeatedly checked in with participants to see how they felt and to ensure they were comfortable. All patients were offered referral to a counselor once the interview ended, in case the interview triggered emotional stress for them, or if they wanted to be linked to a support group. We offered them the option of using a pseudonym, confirmed their willingness to be audio-recorded, and their preference to have anyone else present during the interview.

Two male patients from Site 3 expressed interest in learning about support groups at the end of their interview, and Zanele referred them to an outreach counselor for follow-up. One woman from Site 2 spoke about having difficulties in her relationship with her boyfriend. Towards the end of our interview she asked for my advice on the matter. I discussed how I was not the best person to advise her and, with her permission, introduced her to the counselor on-site for follow-up. As stated earlier, one patient requested I not audio-record the interview, and two patients requested their spouse accompany them; my reflections on these events is discussed at the end of the chapter.

**Data handling**

During fieldwork, two digital audio-recorders were used to record interviews and field notes. Zanele and I kept the recorders on our person, and transferred audio files to my computer at the end of each day, deleting the original file from the digital device. The computer was password-protected accessible only by myself. I carried it with me or stored it in a locked cabinet at my private residence in Durban. Audio-recordings and corresponding transcripts and notes were marked with unique identifiers to protect participants’ identities. Patient identifiers included a number between 1 and 40, the study site, and their gender. Key-informant identifiers included a number between 41 and 48 and the recruitment site. A duplicate copy of electronic files was stored on a password-protected
USB key to ensure against the loss of collected data. The USB key, along with hard copy documents related to the study, such as handwritten field notes and signed participant consent forms, was stored in a locked desk at the host institution and accessible by Dr. Padayatchi and myself.

Upon completion of fieldwork, I brought back to Canada my computer, hard copy study documents, and scanned versions of the signed consent forms, all of which are securely stored. The USB key with duplicate files and original consent forms (as per local protocol) remain securely stored at the host institution, accessible by Dr. Padayatchi alone. Five years post data collection, in 2014, all identifying markers will be removed (de-linked) from all electronic and hard copies of transcripts and field notes. Consent forms (original and scanned versions) and digital recordings will also be destroyed.

**Reflecting on the research process**

Following from my analytic framework of constructivist GT, I incorporated a degree of critical reflexivity or self-consciousness into research implementation. Rather than practicing reflexivity as an after-thought, I tried to build it into my day-to-day implementation of research activities, so as to be continuously aware of my social position and presumptions during field observations and participant recruitment, the interviews and analysis, and finally, while writing this thesis.

I had discussed this idea of being continually conscious of who we are and how we might sub-consciously portray ourselves to others with Zanele during her training. Accordingly, we repeatedly shared ‘confessionals’ with each other during the interview stage, and during our independent transcription and joint translation process. I drew on Zanele’s experiences during the research process, to the extent shared with me, which thus influenced and became part of my own critical reflections, particularly with respect to the interview dynamic and the different perspectives we may have brought to the collection and interpretation of study data.

**Observing in the field**

Site observations were intended to be non-participant (Gold, 1958), in that I did not contribute to, assist or impede routine site activities. Rather, I assumed the role of a discreet observer. However, my presence could have inadvertently affected the behaviours of people working and attending the clinic. I tried to mitigate these effects by emphasizing that the study was focused on patients rather than the site per se, or on individual HCWs’ actions. I also visited each site regularly over six months with the aim of making my presence seem less conspicuous and my role seem less intrusive over
time. Observing over this extended period allowed me to gradually blend into the clinic environments. I believe it helped me establish a good rapport with staff at each site. I shared many informal conversations during their coffee breaks or when something exciting was broadcast on the news. The province was a hub of political activity at the time of the study, with ongoing elections or strikes presenting me with ample opportunity to initiate a dialogue. As the study progressed, I believe my continued presence enhanced my legitimacy and credibility in the field.

I had lived in Canada for over a decade at the time of data collection (I grew up in India), and I was conscious about my position as an overseas researcher (from dual backgrounds) based on my reading of literature that describes the challenges of conducting international research (CAHR, 2008). But there is a substantial East Indian populace in South Africa and I ended up passing off as a ‘local’ on several occasions, that is, until I spoke, at which point my accent gave me away as a foreigner. Several workers at all sites showed their surprise that I was not South African and further, that I was an “Indian from India”. I thought this may inhibit their openness with me (staff were a mix of South African races) but it ended up piquing their interest in my study. There also appeared to be an immediate comfort in complaining about the bureaucracy of their work and the social constraints of their day-to-day lives, due to a perceived shared understanding of our experiences with such things; we both came from relatively under-resourced parts of the world and this prompted many informal exchanges. In this way, I came to enjoy a good degree of comfort and openness at the sites.

I also informed site staff that I worked as a pharmacist. They were aware that Zanele, who assisted me with the interviews, worked as an HIV counselor. I had not wished to misrepresent either of us in an environment where I would spend much time recruiting participants, observing, and conducting interviews. I believe this transparency encouraged staff to more willingly engage with us, on the basis of our perceived shared reality. The extended duration of my key-informant interviews (65 minutes, on average) affirms that, at least in part, this openness helped create a positive rapport. The staff’s tremendous assistance during patient recruitment, and our many casual and frank conversations were likely a result of the transparency I shared on my identity and the study purpose. The HCWs I approached also all enthusiastically accepted my request for an interview.

**The interviewer-interviewee dynamic**

Aside from our dynamic with site staff, I reflected on how my (and Zanele’s) demeanor may have contributed to our experiences during patient recruitment and interviewing. I thought about how
we presented ourselves in the field, the manifestation of gender and social differences between the participants we interviewed, and the potential impact of such events on the study outcomes.

**Our identities as interviewers**

In contrast to how we presented ourselves to HCWs, I felt it was important to refrain from introducing Zanele or myself as healthcare providers to patient participants. The host institution also recommended this idea. Instead, we portrayed ourselves as “interviewers helping with research” to patient recruits and consenting participants. I believe this mitigated the risk of us being perceived as people who could cast judgment on patients’ health actions or influence their medical care. Some of our interview questions were also designed to provoke discussions of patients’ experiences in the health system, positive and/or negative. I wanted to ensure patients were comfortable sharing praise or criticism in this regard, rather than restricting themselves to socially desirable responses. Patients’ telling narratives, that are highlighted in Chapter 7, affirm that this openness was likely created in our interviews and that our provider roles probably did not emerge or negatively impact the quality of data collected. Foregrounding our role as interviewers rather than providers may have also minimized the perceived power differential between us, which I discuss further below.

**Our gender and social position**

Qualitative researchers have pointed to the creation of an inadvertent power dynamic during interview-based research between an interviewer and the interviewed. Feminist theorists, in particular, have analyzed power imbalances and the role of gender, class, ethnicity and race in the context of interviewing, to find that the quality of an interviewer-interviewee dialogue may rely to some degree on the (perceived) social similarity (or dissimilarity) between the two (Best, 2003; Brown, 2001; Oakley, 1981). I believed that this social distance may be more relevant in the gendered and racially charged society of South Africa, where much research is carried out under a relatively impersonal rubric of quantitative assessments that warrant the researcher is almost always one arm’s length removed from the researched. For example, in randomized controlled trials, principal investigators are often at a physical distance (i.e., blinded) from their research subjects.

That patients declining to participate in the study were all men, and that the interviewers were women, prompted me to deliberate on the potential impact of gender and/or perceived social distance on study recruitment. It is possible that the men who declined to participate felt less
comfortable sharing their thoughts and experiences with a woman. They may have agreed to participate if a male interviewer approached them. Research shows men may be more willing to discuss their health with other men, rather than with women (Brown, 2001). However, I also explored two other potential reasons for their disinclination to participate. First, perhaps these men viewed us as researchers and persons of authority, despite our attempts to downplay that role, and mistrusted people in those positions, as has been found in other research and healthcare contexts (Scharff et al., 2010). Second, it is possible that the two men from Site 1 who declined to participate were less willing to discuss issues related to their HIV status at a TB clinic, and more so if accompanied by family to whom they had not yet disclosed. Indeed, coinfected patients’ reluctance to share HIV-related issues at non-HIV clinics was an important finding that is discussed in Chapter 7.

Similarly, I considered the nature of the two very short interviews with male participants, one from Site 1 (the shortest study interview, 15 minutes) and one from Site 2 (the second-shortest interview, 19 minutes). Both men had consented to participate but were generally uncommunicative. I wondered if my social position was a factor in their elusiveness, if I had posed questions in an unsuitable way, or if they were simply less talkative people. I realized all of these issues could have played a role. In the first case (at Site 1), the participant ended the interview before I had a chance to ask all my questions. He said he was in a hurry and needed to return to work. His request may have been prompted by a telephone call he had just received on his cellular device but it also coincided with the point in the interview when I began asking questions about his experience with HIV testing and ART. It is possible he was uncomfortable discussing his HIV status at a TB clinic (which was as an important finding), or more simply with me, as a result of our perceived social differences, his mistrust in my intentions with the details of his HIV illness, or a poor interview style.

I was prompted to review and reflect on my interviewing technique. I replayed the audio recording of the interview to critique my tone and manner of speaking. Up to this point, I had not had a patient respond evasively about his HIV treatment at this site and I did not believe I was asking questions in a manner that may have inadvertently upset the participant. I felt my questions had been open and relatively general. Nonetheless, despite this being my final interview at the TB site, I was especially cautious and slow in bringing up the topic of HIV during following interviews.

In the second case (at Site 2), as well, I considered whether the participant was less open as a result of our perceived social distance. Or perhaps he was still early in his treatment (just one month into ART) and not ready to have open discussions about his illness and experience with HIV or TB care. I
also reviewed my line of questioning. I realized I had been deterred by his monosyllable responses, and had begun to ask very closed-ended questions. This further encouraged “yes” and “no” types of responses from him. I had been caught off guard, and found it difficult to escape this cycle of closed-ended probing instead of inquiring about something more general. I was more cognizant of avoiding such a situation in the future, and made sure I always had at least one open-ended question in the back of my mind during subsequent interviews (e.g., Tell me a little bit about your family, or child, or partner – I found most participants shared a liking, or dislike, for at least one of these parties and would provide a fairly rich response to which I could probe and use to proceed with the interview).

Following from these reflections, I deliberated over why this same man (at Site 2, with whom I shared the second-shortest interview), and another man from Site 3 had requested their spouse join us during the interview. I wondered if they acted to affirm the transparency and trust of their marital relationship to me, at a time when these relations may have been in question; in both these cases, participants said they were sero-discordant with their wives. Inclusion of their wives in the interview room may also have assuaged a sense of suspicion or guilt that may come with speaking privately with another person at the clinic, who was not obviously a doctor or a nurse. With these thoughts in mind, I went back to my analysis and coding of their interviews to see whether I had been sub-consciously impressed by the support their spouses appeared to share with them. I was more cognizant of these issues in subsequent interviews.

**Proactive self-cognizance**

At the study outset, I had anticipated some of these issues would manifest and affect the ways in which data were collected (and analyzed). I attempted to mitigate them through a proactive self-cognizance. For example, Zanele and I approached patients using informal mannerisms. We dressed casually but conservatively. We offered refreshments at the beginning of each interview to show that we were conscious of and appreciated patients’ time. The presence of just one interviewer in the room, a conversational-style interview format, and our portrayal to patients as “interviewers helping with research” was aimed to minimize our perceived authority, power or social distance, and build a comfortable rapport. I also completed an introductory course in conversational isiZulu, to pick up phrases or greetings that could help me initiate conversation with patient recruits.

Although female participants are found to be more talkative and open than male counterparts and research shows this disparity may be more apparent when the interviewer is female (Best, 2003;
Brown, 2001; Oakley, 1981), a review of this study’s interviews demonstrated that men and women spoke for a similar duration on average (40 to 41 minutes, see Table 3.5). And although the shortest interview (15 minutes) was carried out with a man, so was the longest (73 minutes). Thus, while the interviewer’s gender may have played some role in patients’ refusal to participate or the quality of a few short interviews, I do not believe it negatively impacted the overall quality of data collected.

Having said that, other social differences extrinsic to the issue of gender may have inadvertently affected how data were collected. Regular discussions between Zanele and myself and applying a critical stance to how research tasks were conducted helped build a degree of self-consciousness into the study process. As we shared our experiences and reflections during some of these events just described, Zanele and I were more aware of our social positioning as the study progressed.

**Emic and etic perspectives**

The inclusion of Zanele, a local South African person, as an interviewer, helped balance the types of data collected and the ways in which they were analyzed. The differences between us as interviewers, and their potential impact on the interviews and interpretations are discussed below.

**Differences between interviewers**

Between Zanele and myself, we successfully completed 40 patient interviews. Nearly all patients were African, most of Zulu ethnicity. The 27 patients I interviewed were adequately conversant but by and large, they were native isiZulu speakers with English as their second language. Both Zanele and I remarked at how patients’ language choice appeared to stem from their inclination to be interviewed by the person who initially approached them for study participation, rather than a well-thought out decision to communicate in their first tongue. We did not objectively measure this, but Zanele noted how some patients could have also expressed themselves well in English (especially when they were not of Zulu ethnicity). I felt some of my interviews might have been richer in isiZulu.

Our interviews were markedly different in several ways. First, Zanele’s interviews were much longer, about 50 minutes on average, whereas mine were about 35 minutes on average. Second, patients were more expressive with her and thus the quality of data was often richer. As discussed earlier, research has shown that participants may develop a better rapport with interviewers of the same (perceived) social class or ethnicity (Best, 2003). Canadian researchers have also encountered difficulties conducting research abroad as a result of their inherent lack of knowledge or
understanding about local norms (CAHR, 2008). While I had conducted interview-based research in South Africa before this study, and drew on lessons learned from those experiences, I was still a relative outsider in the context of patient interviews. Zanele, on the other hand, is a Zulu woman in her 40s, and resides in one of Durban’s semi-urban townships. She was more of an insider and clearly shared an understanding with Zulu participants different from what I experienced. There was a certain assumed level of trust and commonality and patients appeared to open up to her more expressively, and using more descriptive words and metaphors that would not easily translate to English. For example, many of her interviewees shared more detailed accounts of their experiences with stigma or social subordination within their home and neighbourhoods. Certain aspects of local culture and action could be discussed in the safety of their shared realities.

However, other aspects of Zulu or South African culture may have been omitted or assumed as known. While some underlying meanings may have been missed during my interviews, others were explained to me through participants’ own words. For instance, although the topic of direct illness disclosures within participants’ social networks was probed during both our interviews, the notion of general community-based silencing of HIV (discussed in Chapter 5) was more apparent in my interviews. That HIV may be a hushed topic of conversation was more obvious to Zanele who lived amidst this reality, and less likely probed or recounted during her interviews. Zanele also commented that on various occasions, my closeness in age to some women participants could have enabled them to open up with me in more casual and nonchalant ways. This was probably the case in at least one situation, where a participant described her relationship with her boyfriend in a manner akin to how women share their personal experiences in the context of a close friendship.

**Interpretative translations of isiZulu and English data**

Following from the study’s constructivist stance, no singular truth was presumed in our interviews, and thus there could be no singular translation (Lapadat, 2000). Qualitative researchers postulate that when different people are involved in the collection (or co-construction) of data, the interpretation of that data is shaped by the social underpinnings of those people. When different cultures and languages are involved, ontological problems of constructing similarities and differences between datasets or arriving at a consensus between what each person may be thinking needs to be acknowledged and continuously contemplated (Patton, 2002).
Zanele brought an inherently insider or “emic” perspective (Patton, 2002: p 267) to her interviews. That is, her position as someone belonging to the same broader society or culture of study participants allowed her to better understand the meanings of their responses, and this consciously and sub-consciously influenced her translation and interpretation of the study data. I shared and reviewed all the patient interviews with Zanele, both English and isiZulu, so that her insider perspective would broaden my outsider or “etic” (p 267) outlook; that is, my position as an observer outside of the broader society or culture of the study. My constructivist framework also problematized those meanings Zanele considered to be immutable or took for granted (e.g., silencing of HIV, discussed earlier).

Two examples help portray our collaborative interpretive process, and how Zanele challenged that which I misunderstood to be ‘normal’. A woman that Zanele interviewed quoted her dying sister-in-law whom she had cared for, without ever being told what illness she suffered from, and despite the women never having gotten along. The participant said, in isiZulu, “There is a word she said by the time we are going for the last, she said, ‘I have left you the will, the will which you cannot survive with’”. Zanele explained to me that, akin to English, the isiZulu word for “will” (as in, will power or intention) is the same as “will” (as in, inheritance). The participant’s sister-in-law knew she was dying from HIV and recognized the participant suffered from this same illness. Other portions of the interview confirmed that the sister-in-law did not believe she had transmitted (“left”) the virus to the participant. Rather, it was her way of telling the participant to acknowledge that she was close to death herself, but in a somewhat spiteful, not helpful, way. In retrospect, Zanele’s inference may be considered completely logical, but it was just as easy for me to pass over this statement as one that was relatively uninteresting. Similarly, another patient whom I interviewed described, in English, that her partner was receiving “tablets for time”. I would have likely considered her statement to be benign, analytically speaking. However, Zanele pointed out that this was a common way for people to speak about ART, as it offered patients additional time (to live) but was not perceived to be curative (discussed in Chapter 5).

In these ways, Zanele and I reached a shared interpretive translation or consensus in our analysis of the interview data. I believe this consolidated effort allowed us to capture a wider range of experiences and narratives, as well as an enhanced mix of less assumed and presumed expressions, compared to what either one of us may have accomplished independently. Reviewing all patient interviews with Zanele helped clarify several concepts and uncover latent meanings to the
metaphors and phrases commonly used in isiZulu, Zulu culture and broader South African pop culture. Zanele’s insight enhanced my own beyond mere translation towards a more refined and likely, in many cases, a more precise interpretation and analysis. Following from this, I embarked on the more detailed tasks of coding, conceptualizing, triangulating, and writing.
Chapter 4

Descriptive findings

This chapter provides a description of patient participant and study site characteristics that were qualitatively assessed to be the most relevant for understanding patients’ experiences with TB/HIV coinfection and related healthcare. I first describe patients’ relevant socio-demographic and clinical characteristics, based on their self-report. Thereafter, I present important site characteristics based on my field observations and key-informant interviews. These descriptive findings provide context for the more analytic findings that follow in Chapters 5, 6, and 7.

Characteristics of patient participants

Process

It is important to note that while this chapter is presented early in the thesis, to provide the reader with a general description of the patient sample, it was written at the very end of the analysis to help contextualize qualitative themes presented in Chapters 5, 6 and 7. Aside from some characteristics that were considered important during sampling (e.g., gender, treatment stage, number per site), other characteristics presented in this chapter were not collected in a deliberate or predetermined manner (e.g., relationships, employment, type of TB). Rather, they are presented herein because they emerged as relevant for the overall understanding and contextualization of patients’ experiences with their illness and healthcare. In all, they reflect the purposively diverse sample that was intended for this study. Explicit information about any one participant is not provided to protect their identity and maintain anonymity.

Intended use of numeric descriptors

Numeric descriptors are rounded to the nearest whole number. Descriptors are an objective tally of data that was collected via open-ended interviews, that is, in a subjective manner. Following from this less structured format of data inquiry, not all descriptive characteristics were collected or naturally arose out of every patient interview. They were neither validated nor verified through medical record examination, as per the limits of the study ethics protocol and the study’s theoretical stance to examine patients’ subjective interpretations or perceptions of their health experiences.
rather than an objective truth of that experience or of their health and healthcare. Further, patients were recruited using maximum variation, non-random sampling. Accordingly, these descriptors are meant to be used to contextualize the study sample, but not to deduce statistical probabilities or associations.

**Socio-demographic characteristics**

The final patient sample (N=40) comprised 24 women (60%) and 16 men (40%). The exact age of three patients was unknown, but confirmed by referring staff to be within the range stipulated by the study inclusion criteria (i.e., 18 to 50 years of age). Remaining patients ranged between 21 and 47 years in age, 34 years on average. Thirty-eight participants were visibly identified to be of African race, and two were of mixed race. Socio-demographic characteristics are summarized in Table 4.1.

**Partners**

Twenty-five patients (63%), a higher proportion of who were men, said they were involved in a relationship at the time of interview. The nature of these relationships varied between monogamous, marital or in the process of lobolo payment. Six patients (2 women, 4 men) were married and cohabitated with their partner. The remaining 19 (10 women, 9 men) stated they had a boyfriend, girlfriend or fiancé, of whom 6 (2 women, 4 men) cohabitated. Cohabitation may have indicated a stronger relationship, but in at least two interviews, patients described sharing little trust in their cohabitating partners’ fidelity or support. Some said they were involved in a relationship but kept sexual activities to a minimum or on temporary hold as a result of their illness. Several women were involved with men who had or were believed to have other girlfriends. All of these patients were classified collectively as married, engaged, and/or in a relationship. The diverse character and experiences of their relationships is further discussed in Chapters 5 and 6.

**Children**

Thirty patients (75%) had one or more of their own children, including 15 with multiple children. At times, children were spread out over several households. A few participants parented the child/ren of their deceased or debilitated siblings, or stepchild/ren from their spouses’ prior relationships. Tabulated figures represent the number of participants with one or more of their own children.

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11 South African lobolo is a traditional custom that is often loosely translated to ‘bride price’. It constitutes specified money or assets paid by a man to a woman’s family towards her hand in marriage. While lobolo payment is in process, which often takes years, partners continue to be referred to as boyfriends, girlfriends or fiancés (South Africa, 1988).
Most participants lived together with their children intermittently based on available resources, support networks, relationship with the child’s other parent (an ex-spouse), and participants’ own capacity to serve as caregiver while on treatment. About half the patients with children (10 women, 6 men) lived with and looked after at least one of their own children, either alone or together with a spouse or family. In remaining cases, at least one or more of the children lived separately with another parent, neighbor, and/or other family member such as a grandparent, cousin or sibling. Children of two participants were older and lived on their own. The financial and emotional burden of participants’ having to care for their children and themselves is discussed in Chapters 5 and 6.

**Employment**

Nineteen patients (48%), a higher proportion of who were men, were employed at the time of interview. Most worked temporarily or in the informal sector. Women worked as street or retail venders, domestic workers, cleaners, or assisted in their partner’s or family’s business. Men performed contract work such as gardening, painting and tiling, or drove taxis; one patient said he sold “dhaka” or marijuana. Two patients (1 woman, 1 man) were self-employed and ran small businesses. Seven patients (3 women, 4 men) worked in the formal sector in hospitals, the police or security services, or offices.

The employment history of one patient was unknown. Twenty patients (50%), a higher proportion of who were women, were unemployed at the time of interview. Twelve of those unemployed had been employed prior to diagnosis, and had left paid work as a result of their illness or related treatment. They had mostly worked in the informal sector and were unable to continue or access sick leave upon developing the physically debilitating symptoms of TB and/or HIV. A few participants stated they had received, were receiving or were applying for a disability grant from the government but this information was not collected during all interviews. The impact of work commitments and unemployment on patients’ experiences with healthcare is discussed in Chapter 6.

**Habitation**

Most participants lived in townships and informal settlement areas in and around Durban and Pietermaritzberg. Many changed residence during the course of their illness, sometimes more than once, based on their access to income and related resources, employment, relationship with their family, and/or partner support. Loss of paid work was a common reason why several participants returned to live with their parents, siblings or extended families at one point or another.
Eighteen participants (13 women, 5 men), lived with extended family (that is, family other than just a partner or child); 12 (4 women, 8 men) lived with their partner with/out their children; 6 (5 women, 1 man) lived with just a younger sibling and/or young child; 3 (1 woman, 2 men) lived alone; and 2 women lived with their friends. One woman lived with her fiancé and her mother. Those who lived alone accessed some support from a relative or partner for childcare, food and/or connection to temporary work. Overall, women more often lived with their family (including their children) whereas men more often lived with their partner. The nature of participants’ relationships with the people they resided with and its impact on their access and adherence to care are discussed in Chapters 5, 6, and 7.
Table 4.1: Summary of self-reported socio-demographic characteristics of patient participants

<table>
<thead>
<tr>
<th>Patient characteristics</th>
<th>All Sites</th>
<th>Site 1</th>
<th>Site 2</th>
<th>Site 3</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total</td>
<td>F</td>
<td>M</td>
<td>Total</td>
</tr>
<tr>
<td>Number</td>
<td>40</td>
<td>24 (60%)</td>
<td>16 (40%)</td>
<td>14</td>
</tr>
<tr>
<td>Age^a (years)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Average</td>
<td>34</td>
<td>33</td>
<td>34</td>
<td>35</td>
</tr>
<tr>
<td>Relation status</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married/engaged/sexual relation</td>
<td>25 (63%)</td>
<td>12 (50%)</td>
<td>13 (81%)</td>
<td>8</td>
</tr>
<tr>
<td>Single</td>
<td>15 (37%)</td>
<td>12 (50%)</td>
<td>3 (19%)</td>
<td>6</td>
</tr>
<tr>
<td>Children</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>With ≥1 child</td>
<td>30 (75%)</td>
<td>16 (67%)</td>
<td>14 (88%)</td>
<td>12</td>
</tr>
<tr>
<td>Employment status^b</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>19 (48%)</td>
<td>8 (33%)</td>
<td>11 (69%)</td>
<td>9</td>
</tr>
<tr>
<td>Unemployed (UE)</td>
<td>20 (50%)</td>
<td>16 (67%)</td>
<td>4 (25%)</td>
<td>4</td>
</tr>
<tr>
<td>UE due to illness (% of total UE)</td>
<td>12 (60%)</td>
<td>10 (63%)</td>
<td>2 (50%)</td>
<td>3</td>
</tr>
</tbody>
</table>

F: female; M: male; UE: unemployed

a: The exact age of 3 participants (1 woman each from Sites 1, 2 and 3) was not known.
b: The employment status of 1 participant (1 man from Site 1) was not known.
Clinical characteristics

During study recruitment, site staff identified eligible coinfected patients. They also assisted with recruiting patients at various stages in their TB or HIV treatment (e.g., at the start of treatment, on treatment for several months), and with different types of TB (e.g., EPTB). However, data presented below is based on self-reported information derived from patient interviews alone. Patients’ clinical characteristics are summarized in Table 4.3.

Types of tuberculosis

Twenty-eight patients (70%) had pulmonary TB including 7 patients experiencing their second or third episode of TB. Another 12 patients (30%) had EPTB, of which 5 were a repeat lifetime episode. Overall, 19 cases (48%) were believed to be more clinically complex, that is, either a repeat episode and/or EPTB that mandated a longer treatment period and was associated with a greater degree of morbidity compared to a first episode of pulmonary TB (WHO, 2009a). The social contexts of the various types of TB and impact on patients’ decisions for care are discussed in Chapters 5 and 6.

Diagnostic history

All patients were coinfected and diagnosed with TB and HIV at the time of interview. Twenty-two participants (55%) were considered as being diagnosed with TB and HIV ‘together’. They tested for HIV and were diagnosed as HIV-positive upon development of symptoms related to TB, during pulmonary and/or extra-pulmonary symptom investigation. In most cases, HIV test results had been immediately available whereas TB was diagnosed a few days or weeks later. Patients stated that, on occasion, TB confirmation took several months and in one case, almost a full year (this may relate to the relative ease of diagnosing HIV, via rapid HIV testing, compared to TB). Four patients were diagnosed with HIV during a prior TB episode. All patients diagnosed with HIV during a TB diagnostic work-up, quick or lengthy, current or prior, were included in this category.

Three participants (8%) were considered to have a first diagnosis of ‘TB’. They specifically stated they delayed VCT and discovery of their HIV status 1 month to 1 year after being notified about their current episode of TB. However, this figure should be considered imprecise. There may have been additional participants who could be viewed as having had a first diagnosis of TB if they delayed HIV testing, did not get tested, or tested negative for HIV during a prior episode of TB. Based on the interview design, participants were not asked to recall these events in an objective, chronological
format. (This ambiguity with defining a ‘first diagnosis’ also contributed to re-defining the study objectives, as discussed in Chapter 3).

Fourteen patients (35%) were considered to have a first diagnosis of ‘HIV’ since they developed TB after being notified they were infected with HIV. They knew of their HIV-positive status between 9 months and 9 years prior to the interview. The time between their HIV and TB diagnoses ranged between 9 months to just over 8 years.

The time since HIV diagnosis was unclear for one patient who was experiencing his second episode of pulmonary TB. While the objective history of which diagnosis followed the other was less relevant to this study’s findings, patients’ characterization of their diagnostic histories emerged as relevant for their decisions around disclosure and access to or retention in healthcare in Chapters 5 and 6, and their decisions to access care at particular healthcare facilities as discussed in Chapter 7.

**Treatment**

**TB treatment**

Thirty-eight patients said they were on TB treatment from 0 up to 10 months on the day of interview. Patients with pulmonary TB stated they anticipated being on treatment for about 6 months, and those with EPTB or a repeat episode of TB stated they expected to be on treatment for longer, from 9 up to 18 months. Of the two patients not on TB treatment, one said he was asked to discontinue all medications that same day due to the development of a treatment complication and one said she had completed TB treatment a week earlier.

**HIV treatment (ART)**

Thirty-one patients said they were on ART from 1 week up to 5 years on the day of interview. Nine patients stated they were not on ART: 2 were temporarily off ART (1 due to a clinical complication and 1 due to an adherence issue), and 7 said they had never commenced ART due to high CD4 counts or other clinical, logistic and personal reasons that are discussed in Chapters 6 and 7. Patients’ experiences with or initiation of CPT or IPT were not discussed during the interviews.

**Co-treatment of TB and HIV**

At the time of interviews (February to July 2009), the South African National TB Guidelines from 2008 were in effect at all sites and guided the clinical co-treatment of TB and HIV coinfection. They
were based on WHO clinical staging for HIV/AIDS and immunological staging with CD4 counts, and are summarized in Table 4.2 (copied from NTCP, 2008). The degree of dissemination or application of these guidelines was not measured in this study but field observations and key-informant interviews indicated that HCWs were aware of them, even if they did not necessarily agree or adhere to them. Patient interviews also demonstrated that many of them had some knowledge of these guidelines. Their perceptions and decisions in the context of these guidelines emerged during qualitative analysis, and are discussed in Chapters 6 and 7.

Table 4.2: Guidelines for the treatment of TB and HIV coinfection, South Africa, 2008

| WHO clinical staging for HIV/AIDS | PTB → WHO Stage 3 → ART not required  
|                                  | PTB + any other WHO Stage 4 illness or EPTB → WHO Stage 4 → ART required |
| Immunological staging with CD4 counts | CD4 > 350 → Repeat CD4 every year → ART not required  
|                                  | CD4 200 – 350 → Repeat CD4 every 6 months → ART not required  
|                                  | CD4 < 200 → ART evaluation required  
|                                  | CD4 < 50 → ART required (urgent) |
| Summation | WHO Stage 3 and CD4 > 200 → ART not required → Reassess after TB treatment  
| | WHO Stage 4 or CD4 < 200 → ART required  
| | Already on ART → Start TB treatment + continue ART* |

Table adapted from the South African National TB Control Programme Guidelines 2008 (NTCP, 2008: p 75-8).  
EPTB: extra-pulmonary TB; PTB: pulmonary TB. * Modify drug regimens to minimize drug interactions and/or toxicities.

As patients’ clinical characteristics were not validated through chart review, this study cannot attest to the proportion of patients who received timely co-treatment, particularly with regards to ART initiation. Thus, a general synopsis of patients’ description of their TB/HIV treatments is provided:

Eleven patients stated they began TB therapy while already on ART: 4 diagnosed with HIV during a previous TB episode, 1 whose EPTB (diagnosis and treatment) took several months longer to confirm than HIV, and 6 who developed their first episode of TB after they were diagnosed with HIV.

Regardless of the timeline of TB and HIV diagnoses, another 16 patients previously not on ART stated they began ART within 2 months of initiating TB treatment: 7 who began dual TB and HIV therapy on the same day, 6 who began ART within 1 month of TB treatment initiation, and 3 who began ART within 1 to 2 months of TB treatment initiation. (Of these 16 patients: 7 were newly diagnosed with HIV and began ART within a few days of their HIV diagnosis and/or CD4 count result, and 9 began ART between 2 months and 2 years after receiving a positive HIV test result, including 1

12 This coincides with the current WHO and South African guidelines for TB/HIV co-treatment, and is discussed ahead.
patient who began ART 3 years prior to the interview but stopped treatment a year later until this, first lifetime, episode of TB.)

Another 5 patients stated they commenced ART 3 to 6 months after initiating TB treatment, though they had been diagnosed with HIV between 8 months and 9 years ago. Finally, another 7 patients receiving TB therapy stated they had not commenced ART at the time of interview. They were diagnosed with HIV between 2 months and 5 years prior to the interview, and were already on TB treatment for over 2 to 6 months. Experiences with co-treatment are discussed in Chapters 6 and 7.

Comment on TB/HIV co-treatment

Since the time of interviews, the South African guidelines (DOH, 2010) have expanded to more closely reflect the current WHO recommendations (WHO, 2010b) that were described in the literature review; that is, to commence ART in all newly diagnosed TB (and EPTB) patients within 8 weeks (2 months) of TB treatment initiation, and to commence TB treatment immediately and continue ART for patients already on ART (with drug modifications to minimize interactions and/or toxicities). If one were to use these broader criteria for co-treatment (i.e., that are less tied to patients’ CD4 counts or WHO HIV stage) to assess the proportion of patient participants that received timely access to dual treatment, their narratives reveal that 27 (68%, including 16 women and 11 men) were treated for both infections in a timely manner. In other words, 27 patients received TB treatment while already on ART or they received ART within 2 months of TB treatment initiation. This includes 10 (72%), 7 (54%) and 10 (77%) patients from study sites 1, 2 and 3, respectively. However, 12 patients (30%, including 9 women and 3 men) were not treated for TB and HIV in a timely manner; that is, they received ART after 2 months of TB treatment initiation (or had not begun ART despite 2 months having passed since TB treatment initiation). This includes 3 (21%), 6 (46%) and 3 (23%) patients from study sites 1, 2 and 3, respectively. Whether or how treatment for TB and HIV was delayed or timely was unclear from 1 patient’s interview.

Granted that the current guidelines were not in place at the time of the study, and drawing inferences about the timeliness of co-treatment for study participants is inherently invalid. But this exercise helps demonstrate a few interesting points. First, not all patients from the physically integrated Site 3 received what is currently considered to be timely co-treatment for TB and HIV. Second, several patients from the physically non-integrated Sites 1 and 2 were co-treated in line with current recommendations. Thus, the study highlights that (i) co-location may not automatically
imply timely co-treatment, and (ii) physical non-integration may not always imply a lack of treatment integration.

Furthermore, analysis of self-reported diagnostic and treatment histories demonstrates that while several patients may have received timely co-treatment with respect to their coinfection, they perceived they had experienced substantial delays with ART in relation to their HIV diagnosis; this theme emerges in Chapters 6 and 7. The time between patients’ reported time of HIV diagnosis and ART initiation (regardless of TB) ranged between 0 and 9 years. Thus, integrated care or co-treatment may not necessarily imply the timely treatment of HIV infection in general.

I re-iterate that associations between dual diagnoses and treatment initiation, and the proportions of patients receiving what is currently considered to be integrated or timely treatment for coinfection in terms of TB and HIV co-treatment may not be statistically evaluated in this study, neither overall nor between the three sites. The clinical and technical reasons or constraints for co-treatment, which were discussed in the literature review, were also not investigated. However, patients’ perceptions and experiences with their dual diagnoses and access to dual (or timely) treatments were analyzed, and what patients characterized as pertinent for their health and wellbeing were explored. These are discussed in Chapters 6 and 7, which are more analytic and interpretive.
<table>
<thead>
<tr>
<th>Patient characteristics</th>
<th>All Sites</th>
<th>Gender</th>
<th>Site 1 TB Clinic</th>
<th>Site 2 HIV Clinic</th>
<th>Site 3 TB/HIV Clinic</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total</td>
<td>F</td>
<td>M</td>
<td>Total</td>
<td>F</td>
</tr>
<tr>
<td>Number</td>
<td>40</td>
<td>24 (60%)</td>
<td>16 (40%)</td>
<td>14</td>
<td>8 (57%)</td>
</tr>
<tr>
<td>Type of TB</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pulmonary TB</td>
<td>28 (70%)</td>
<td>18 (75%)</td>
<td>10 (62%)</td>
<td>8 (57%)</td>
<td>5 (62%)</td>
</tr>
<tr>
<td>Extra-pulmonary TB</td>
<td>12 (30%)</td>
<td>6 (25%)</td>
<td>6 (38%)</td>
<td>6 (43%)</td>
<td>3 (38%)</td>
</tr>
<tr>
<td>Lifetime episodes of TB</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>First episode</td>
<td>28 (70%)</td>
<td>19 (79%)</td>
<td>9 (56%)</td>
<td>10 (71%)</td>
<td>7 (88%)</td>
</tr>
<tr>
<td>Recurrent episode</td>
<td>12 (30%)</td>
<td>5 (21%)</td>
<td>7 (44%)</td>
<td>4 (29%)</td>
<td>1 (12%)</td>
</tr>
<tr>
<td>‘First’ diagnosisa</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>TB</td>
<td>3 (8%)</td>
<td>1 (4%)</td>
<td>2 (12%)</td>
<td>1 (7%)</td>
<td>1 (12%)</td>
</tr>
<tr>
<td>HIV</td>
<td>14 (35%)</td>
<td>11 (46%)</td>
<td>3 (19%)</td>
<td>6 (43%)</td>
<td>3 (38%)</td>
</tr>
<tr>
<td>Togetherb</td>
<td>22 (55%)</td>
<td>12 (50%)</td>
<td>10 (63%)</td>
<td>6 (43%)</td>
<td>4 (50%)</td>
</tr>
<tr>
<td>Co-treatmentc</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>On ART ≤2m of TBtx</td>
<td>27 (68%)</td>
<td>15</td>
<td>12</td>
<td>10 (71%)</td>
<td>6</td>
</tr>
<tr>
<td>Not/on ART &gt;2m of TBtx</td>
<td>12 (30%)</td>
<td>9</td>
<td>3</td>
<td>3 (22%)</td>
<td>2</td>
</tr>
<tr>
<td>Temporarily off ART</td>
<td>2 (5%)</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>HIV test to ART (years)d</td>
<td>0-9</td>
<td>0-4</td>
<td>0-6</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

ART: antiretroviral treatment; F: female; M: male; m: months; TBtx: tuberculosis treatment initiation.

a: ‘First’ diagnosis is an estimate of patients’ first diagnosis. The diagnostic history of 1 patient (1 man from Site 1) was not clear.
b: Four patients (1 woman from Site 2, and 1 woman and 2 men from Site 3) were diagnosed with HIV during a previous TB episode.
c: The time of ART initiation was not clear for 1 patient (1 man from Site 1).
d: Denotes the time between the HIV test and ART initiation. Seven patients (1 woman and 1 man from Site 1, and 4 women and 1 man from Site 2) had not started ART at the time of interview.
Characteristics of the study sites

Site characteristics are based on the study’s secondary data sources: field observations conducted during regular work hours in the outpatient waiting areas, and key-informant interviews. Site characteristics elaborate on basic descriptions that were provided in Chapter 3 and Table 3.2, and lend social and physical context to patients’ experiences with TB and HIV healthcare in Chapter 7.

Site 1

Physical description

Site 1 was a large ambulatory clinic specializing in TB diagnosis and treatment. It was located in the downtown, urban core of Durban. A prominent sign displaying the clinic name was advertised at the building entrance. There were a few posters on display encouraging viewers to access medical care for TB symptoms, and two posters for HIV testing. At one corner was a large container dispensing free male condoms. The bustle of downtown was visible and audible from the clinic’s primary waiting area. This area was large and spacious with a reception desk at one end, and five entryways to doctors’ and nurses’ offices, laboratories, diagnostic rooms, and the DOTS collection room. It comfortably held 200 patients, in four distinct queues: sputum collection, radiography, DOTS, and doctor or nurse appointments. Secondary waiting areas were located within four entryways, excluding the DOTS room, and were meant to move patients closer to their appointments. These waiting areas collectively held another 40 patients. Since recent renovations, all patient records were maintained electronically; there were no paper records except for the DOTS collection log.

Staffing

At any given time, Site 1 was staffed by 3 to 4 doctors, 6 nurses also known as professional nurses, a nurse manager, and 6 to 8 nurse aides, a janitorial crew and receptionist. Five staff members worked on site management and administration, some with overlapping healthcare roles.

Patient population

Site 1 was by far the busiest of the three sites, recording approximately 11,000 patient-visits a month, including about 5,000 DOTS-related visits with nurses or nurse aides, about 2,500 doctor visits from new patients or TB suspects, and about 3,500 repeat visits for evaluation and monitoring with either a nurse and/or doctor. The number of visits was far greater than the number of actual
registered patients, as DOTS-related visits and some diagnostic visits were repeated every week. Doctor visits and evaluation/monitoring visits were repeated once every 1 to 3 months, depending on the patients’ progress. There were about 1,850 active patients on TB treatment at the time of the study. Site management recorded the proportion of women and men attending Site 1 at approximately 43% and 57%, respectively. The racial demographic of attending patients was also monitored at about 95% African, 3% Asian, 2% mixed, and less than 1% white. Each year, 6-8,000 new cases of TB were diagnosed, of which 10% were extra-pulmonary cases.

**Site 2**

**Physical description**

Site 2 was a specialized HIV clinic set within a larger hospital compound at the outskirts of the city of Pietermaritzburg, up on a hill and distant from the urban core. The satellite clinic related to this facility was a few kilometres away. While the main clinic initiated and followed patients on ART, the satellite clinic monitored patients with known HIV infection but not yet on ART, usually due to their higher CD4 counts. Both were smaller and quieter than Site 1, and in poorer physical condition.

The main clinic was housed in the same building as the hospital’s occupational health and safety division, which was marked at the building entrance. I was advised this was meant to avoid drawing attention to its role in HIV care. There was a narrow waiting area accommodating 70 patients with a combined reception and nursing station at one end. The glass entrance door served as the only window. Four doctors’ offices, 2 nurses’ offices and a counselor’s room branched off from the waiting room, with a pharmacy at one end. I was informed free condoms were kept in the men’s washroom and counselor’s room. During observations, I did not see any in the women’s washroom.

The satellite clinic was housed in the same building as the local Red Cross chapter that was marked at the building entrance and I was told, also served to avoid drawing attention to the facility’s role in HIV care. Its waiting area was relatively more spacious with several large windows and a reception desk, but the clinic was older than the main clinic. One doctor’s office branched off from the waiting room. There was no private nurse consulting area but a storage room was occasionally used to counsel or attend to patients. At Site 2, all patient records were maintained on paper charts.
Staffing

The main clinic hired 4 rotating doctors resulting in a maximum of 2 or 3 doctors on any given day who helped with managerial work. It also staffed 2 nurses, a nurse manager, 4 nurse aides, a counselor, a dietitian who visited every other day, 2 nursing students, and 2 site administrators. The pharmacy was staffed separately. The satellite clinic staffed a doctor, a nurse and a counselor who all partook in site administration and management. Both clinics had a receptionist and janitors.

Patient population

Site 2 was much smaller than Site 1, recording about 1,500 patient-visits a month. The number of active patients was recorded at 1,050, the majority of whom attended the clinic no more than once a month. The main clinic logged about 800 monthly visits, including 500 doctor appointments and 300 visits related to (monthly) ART collection and/or blood monitoring with a nurse. The satellite clinic logged another 700 patient-visits a month, almost all of which were doctor appointments. The number of active patients here was much higher, at 4,000, but represented patients who were only seen every 3 to 6 months because they were diagnosed as clinically-well HIV patients (i.e., had higher CD4 counts and were still being monitored for ART initiation). Site 2 recorded the proportion of female and male patients at about 70% and 30%, respectively.

Site 3

Physical description

Site 3 was a specialized clinic located in the downtown, urban core of Durban. Site 3 was essentially an HIV clinic physically connected to a TB clinic13 by a long doorway but also had its own public entrance. Neither entrance was specifically marked with the clinic name and I was informed this was purposeful, to avoid attention. The HIV clinic was airy with many open windows. Despite being downtown, it was quiet due to its inner location within the building. There were several posters on display publicizing VCT, common TB symptoms, ART regimens, and adherence messages. Bowls of male and female condoms were placed atop several counters. The more apparent display of posters and condoms could be related to its original establishment as a research facility; Site 3 may continue to benefit from resources invested in its initial operation. The primary waiting area at the reception held 30 patients. The secondary inner waiting area was divided into two rooms connected by a

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13 As described in Chapter 3, the TB clinic that was physically integrated with Site 3 was Site 1. Patients recruited from Site 3 attended Site 1 for TB care. Patients recruited from Site 1 did not attend Site 3 for HIV care.
broad passage, and held another 100 patients. The secondary area branched out into 4 doctors’ offices, 2 nurses’ offices, 3 counseling rooms, and a pharmacy. This area held four distinct queues for nurses, doctors, ART collection, and counseling. Patient records were maintained both electronically and on paper charts.

**Staffing**

Site 3 had 3 doctors, 12 nurses including 2 nurse managers, 7 counselors, 1 community outreach worker who doubled as a social worker, 3 site managers, 4 other members involved with site administration, 2 receptionists, and cleaning staff. The pharmacy was separately staffed.

**Patient population**

Site 3 also recorded about 1,500 patient-visits a month, of which 75-80% were doctor visits. The number of visits corresponded closely to the number of registered patients, as most patients attended the clinic no more than once a month. About 900 patients were currently receiving ART. Site 3 recorded the proportion of attending women and men at 52% and 48%, respectively.

**Other site characteristics**

**Ratio of doctors to patients**

The ratio of doctors to patients on a regular workday was approximately 1:25 at all sites.

**Patient referrals from Sites 1 to co-located Site 3**

Due to the voluntary nature of HIV testing, all doctor referrals for HIV testing were understood to be ‘suggestions’ in practice. While an in-depth understanding of HIV testing or referral was not a study objective, this concept emerged during field observations and helped understand how patients came to be seen at Site 3, as compared to another (less integrated) HIV clinic.

Healthcare workers at the TB clinic, Site 1, stated they could only suggest to TB patients that they visit a primary healthcare or specialized HIV clinic for HIV testing, but not initiate a formal referral (due to the voluntariness of VCT). How such suggestions were made was discretionary. Providers generally tried to avoid saturating any one clinic with an overwhelming number of VCT referrals, so usually suggested more than just one clinic or randomly suggested one clinic over another. Often, they suggested clinics that were closer to a patient’s home. Site 3 also sent HIV counselors to Site 1 for active recruitment of VCT clients. Eventually, following the voluntary nature of HIV testing,
patients decided where or whether they wanted to test. Subsequent to suggestions for HIV testing, TB providers did not typically make referrals for HIV treatment; the onus for such referrals lay with the site at which patients were diagnosed with HIV (i.e., at the VCT site).

At the time of the study, if a TB patient from Site 1 did test for HIV at Site 3, and received an HIV-positive result, they were presented with two options based on their CD4 level. Patients with CD4 counts above 200 were requested to return to Site 3 after 6 months for re-evaluation for ART (based on 2008 guidelines presented in Table 4.2). Patients with lower CD4 counts were given the option to initiate ART at Site 3 or be transferred or referred to another HIV clinic that may be closer to their place of residence or work. While Site 3 could (and on occasion, would) accept patients referred from other TB or primary healthcare clinic or even walk-ins, in practice, virtually all Site 3 clients were originally patients of Site 1. Once coinfected patients completed their TB treatment (i.e., ended the co-treatment phase of TB/HIV care), I was informed that they were to be gradually moved to another HIV clinic to allow for other coinfected patients to be treated at Site 3. This was consistent with Site 3’s specific mandate to treat TB/HIV coinfection. In practice, however, I was told patients often continued to access care at Site 3 for several years after they had been treated for TB due to operational difficulties with transferring ART collection and an oversaturation of several other HIV clinics in the area. Patients’ desire to maintain continuity of care at their HIV clinic was also a related issue that is discussed in Chapter 7.

Waiting times

Patients were seen on an outpatient basis. Clinic doors opened to patients by 7 a.m. and closed around 4 p.m. concurrent with the work hours of nurses. Doctors arrived between 8 and 9 a.m. by which time patients began to have their blood work or other tests performed. Patients usually waited outside clinic doors hours in advance of the official opening to hold a place in the queue.

Patients were given clinic appointment days rather than specific times for attendance. They registered with the receptionist before sitting in the waiting areas. Registration routinely ended around 8 a.m. at all sites after which patients were requested to come on another day, unless there was an emergency. Site 1 was the busiest clinic and applied their registration cut-off time most rigidly compared to Sites 2 and 3, where latecomers were often admitted.
Waiting times at all sites varied between 1 to 5 hours, sometimes longer, depending on the clinic queue and types and/or number of healthcare tasks arranged for a patient on a particular appointment day. Patients appeared to adhere to an unwritten rule of holding each other’s place in queue regardless of whether someone had to use the washroom, draw blood work, or be weighed by a nurse/aide in the interim. Site staff monitored the queue though an appointment log. Once inside the doctor’s office, patients were usually attended to between 15 to 30 minutes. TB-DOTS collections at Site 1 was the only queue that proceeded quickly; patients generally waited no more than 10 to 15 minutes on a weekly (on occasion, biweekly or monthly) basis to be supervised by a nurse/aide for their daily dose of treatment and dispensed sufficient doses until their next visit.

Patients at Sites 1 and 2 were called out by their names to be seen by a nurse or doctor. At Site 1, a microphone was used for this purpose due to the large waiting area, leaving little privacy for those whose names were called out. At Site 3, patients were called out by their medical chart numbers.

**Interactions**

Social interactions at all sites varied from day to day but a few patterns became apparent over the course of the study. The early morning routine at Sites 2 and 3 included communal singing and a prayer among HCWs and patients already waiting in queue, after which the day’s work began. Thereafter, there was much conversing between staff and patients at Sites 2 and 3. Occasionally, patients spoke with one another. In relation to the greater numbers of counselors at Site 3, patients were often observed speaking with or being educated by counselors as they waited in the clinic queue on issues such as adherence and treatment. At Site 2, patients were referred to the counselor’s room after they completed their medical appointments. Both Sites 2 and 3 appeared to have greater staff diversity, with inclusion of allied health workers such as counselors, social and outreach workers, and dietitians.

Site 1 was markedly different from Sites 2 and 3. The sense of shared community and activity at Sites 2 and 3 – both HIV clinics – was less apparent with Site 1 being much larger, more crowded, and with a substantially higher patient intake. There was little conversation between HCWs and patients in the queue unless patients were called for their appointment. Staff, in general, were less visible in the waiting area and stayed behind office doors. Patients, too, seldom spoke with one another. There were no counselors at Site 1, but on occasion, a counselor from the adjoining HIV
clinic (Site 3) dropped in to speak with patients about VCT. As one key-informant stated, TB clinics had less of a “multi-disciplinary approach” to healthcare.

By mid-day, all sites offered tea and bread to patients waiting in the queue, a routine that appeared to be more consistently and generously applied at Sites 1 and 3. Sites 2 and 3 quieted down by noon, Site 1 slightly later by 2 p.m. They were all usually empty of patients by 4 p.m.

Integration of TB and HIV healthcare

Integration of care at each site was observed based on WHO principles that were presented in Chapter 2 (Table 2.2), but was not assessed quantitatively as per the study methodology and objectives. Site staff were not evaluated on the degree to which they practiced integration of TB and HIV care. Rather, field observations and key-informant interviews provided insight on how TB and HIV services were coordinated at the three sites. Details are summarized in Table 4.4. More interpretive qualitative themes around healthcare integration, drawn from patient (and further from key-informant) interviews are discussed in Chapter 7.

TB and HIV service provision

As stated in Chapter 3 (Table 3.2), Sites 1 and 2 served as TB and HIV clinics, respectively, with referrals out for related coinfections. Site 1, a TB clinic, did not offer any HIV testing or treatment on site but referred patients to HIV clinics (including Site 3) for these services. Site 2, an HIV clinic, performed basic TB screening for all new patients and all patients about to initiate ART, but no TB confirmation or treatment evaluation. Site 3, an HIV clinic co-located with a TB clinic, also performed basic TB screening for all new patients and all patients about to initiate ART, but no TB confirmation or treatment evaluation. They referred all suspected TB cases to the co-located TB clinic (Site 1).

Communication and coordination between TB and HIV programs

Site 1 appeared to have limited contact with HIV programs regarding the coordination of care for their TB patients’ HIV coinfection. There was no formal referral system or medical information sharing system between the HIV programs their clients attended. Instead, where possible, Site 1 relied on telephone calls and referral letters, sometimes facsimiles, to communicate with these other programs. The special contact between Site 1 and 3 is discussed ahead.
Site 2 also appeared to have limited contact with TB programs regarding the coordination of care for their HIV patients’ TB coinfection. There was no formal referral system or medical information sharing system with TB programs. Akin to Site 1, where possible, Site 2 relied on telephones, referral letters and facsimiles to communicate with these other programs.

Site 3 had the greatest degree of contact with the one (i.e., primary) TB program it referred patients to (i.e., Site 1). However, this contact was unidirectional. Site 3 had full electronic access to its coinfected patients’ TB confirmation and treatment progress through arrangements made with the TB clinic, but the reverse was not established (Site 1 had no direct access to its coinfected patients’ HIV profile, as this was tied to the confidentiality of patients’ HIV status and is discussed in Chapter 7). Further, Site 3 could not alter any information on the TB profile of its coinfect ed patients; only modify their own HIV charts. In short, from the perspective of Site 3 (the HIV clinic), they shared a formal medical information sharing system with the TB program their clients attended. On occasion, Site 3 doctors walked across the building to communicate with TB doctors regarding their patient’s infection (subject to the patients’ consent). They also relied on telephone calls and referral letters. However, from the perspective of Site 1 (the TB clinic), this information sharing did not lend them insight into their coinfectioned patients’ HIV status or treatment progress (i.e., unidirectional sharing of patients’ medical information).

**TB/HIV data recording**

Sites 1 and 2 recorded some information on their patients’ coinfections within patients’ medical charts. At Site 1, this information was stored electronically, whereas at Site 2 it was maintained in hard copy. However, charts (electronic or hard copy) were not accessed during this study.

Outside of patient charts, Site 1 attempted to maintain fairly detailed records of all their approximately 1,850 active patients’ HIV status, whether it was known, and if known, the result, ART status and name of patients’ HIV/ART clinic. At the time of the study, the HIV status was unknown for 53% of patients attending Site 1, and the HIV treatment or clinic information was unknown for 40% of patients whose HIV status was known to be positive.

Outside of patient charts, Site 2 maintained a less detailed record of their patients’ history with TB. The main clinic had a TB suspect register to document all patients who were screened for TB at some point, and who were considered suspects and/or referred for TB confirmation. However, staff
complained that the register was poorly maintained. The satellite clinic recorded patients’ TB information, when known, within their medical charts.

Site 3 maintained a detailed record of their patients’ history with TB, on account of full access to their coinfected patients’ TB profile. At the time of the study, about 80% of all patients were receiving concurrent TB treatment (at the co-located clinic, Site 1) and ART (at Site 3).

**TB infection control**

Site 1, as stated earlier, was recently renovated. It appeared to have the most effective environmental infection control measures in place. It was equipped with pressure controlled waiting areas and consultation rooms, air filtration systems, and ultraviolet light dissemination from high windows to neutralize TB bacilli. Sites 2 and 3 relied on open windows and fans for ventilation and environmental infection control, but window space at Site 2 was limited and often kept closed.

In terms of personal protection measures, Site 3 appeared to be the most disciplined in its practice. All patients were provided a facemask at the reception desk prior to entering the secondary waiting area and adjoining offices. (Again, this may be related to its origins as a resource-rich research facility, but may also have been a result of its specialized focus on TB/HIV healthcare that encourages a greater degree of adherence to WHO’s infection control recommendations.) Patients wore facemasks until their departure from the clinic. Most staff also wore a facemask for infection control. However, facemasks were seldom worn or apparently available at Sites 1 and 2.

This chapter thus offers important descriptive information on patient participants and study sites, and helps bring social, demographic, clinical and physical context to the more interpretive analyses that are presented in the following chapters.
Table 4.4: Description of integrated TB/HIV healthcare services at study sites

<table>
<thead>
<tr>
<th>Site</th>
<th>TB and HIV service provision</th>
<th>Communication / coordination between programs</th>
<th>TB/HIV data and data recording</th>
<th>TB infection control</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 TB</td>
<td>Full TB service provision. VCT referred out for newly diagnosed TB patients with unknown HIV status. Continued referral for patients with unknown HIV status, subject to doctors’ discretion. CD4 and ART referred out for known HIV-positive TB patients. No on-site VCT, CD4 or ART. Some CPT.</td>
<td>VCT and CD4 result not accessible (even if TB clinic initiated HIV referral). HIV data gathered via direct communication with patients, followed by referral letters and/or telephone calls.</td>
<td>Known HIV data recorded on patients’ electronic TB profile (accessible by doctors). At the time of study, 1,850 active TB cases: 13% known HIV-positive at presentation, 42% actively referred for VCT, 5% refused VCT. Overall, 38% known HIV-positive, 9% known HIV-negative, 53% with unknown HIV status. Of known HIV-positive TB patients, 60% have their HIV clinic and/or ART status recorded on their TB profile.</td>
<td>High ceilings, large windows for ultraviolet-light entry, pressure-controlled rooms, air filtration. No facemasks.</td>
</tr>
<tr>
<td>clinic</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 HIV</td>
<td>Full HIV service provision (no ART at satellite clinic). TB symptom screening of all new patients, and all patients about to start ART. No subsequent screening unless patient presents with symptoms. Sputum microscopy for all TB suspects (then referred out). No on-site radiography, cultures, TB-DOTS, IPT. Initial TB treatment prescribed for some TB patients awaiting TB clinic appointment.</td>
<td>Sputum microscopy results relayed back to HIV clinic only if HIV clinic initiated referral. Further TB data gathered via direct communication with patients, followed by referral letters and/or telephone calls.</td>
<td>When known, TB data recorded on patients’ HIV chart (accessible by doctors and nurses). At the main clinic only: Sputum microscopy test and results recorded on a TB suspect register at the main clinic only. In 2008, 104 TB suspects ordered sputum microscopy: 67 negative, 14 positive, 23 results unknown.</td>
<td>Few windows, usually kept close (hilly area, cooler climate). No facemasks.</td>
</tr>
<tr>
<td>clinic</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 TB / HIV</td>
<td>Full HIV service provision. All patients referred or actively recruited from co-located TB clinic (i.e., all patients are/were TB suspects or confirmed TB cases). TB symptom screening of all new patients and all patients about to start ART. Subsequent TB screening subject to doctors’ discretion and if patients present with symptoms. Sputum microscopy for all TB suspects (then referred to co-located TB clinic). Radiography, cultures, TB-DOTS, IPT at co-located TB clinic. Initial TB treatment dispensed for some TB patients awaiting TB clinic appointment.</td>
<td>Electronic TB profile accessible online from co-located TB clinic. Full access to sputum microscopy, culture sensitivity, DOTS/treatment and adherence. HIV doctor may not alter or add information on the electronic TB profile. TB clinic is co-located: subject to doctors’ discretion, they walk back/forth to address medical issues on specific patients. Further communication about TB care via direct communication with patients, followed by referral letters and/or telephone calls.</td>
<td>All TB data accessible and recorded from patients’ electronic TB profile to their HIV chart. At the time of study: 850 TB suspects/cases tested for HIV per month for past 6 months: 46% HIV-positive, 2-5% refused VCT. 900 patients currently on ART, 80% on concurrent ART and TB treatment. Additional TB/HIV data maintained but not accessible during field observations/key-informant interviews.</td>
<td>Many windows, always kept open. Rigid use of facemasks for all incoming patients and most HCWs.</td>
</tr>
</tbody>
</table>
Chapter 5

Living with TB and HIV: identity, stigma and disclosure

While the preceding chapter summarized key descriptive characteristics of patient participants and study sites, subsequent chapters adopt a more interpretive stance to the presentation and analysis of qualitative themes emergent from the study’s data sources. I draw primarily on narratives from patient interviews. On occasion, I include key-informant accounts and notes from field observations to provide additional context to patients’ experiences with their illness and healthcare.

A primary study objective was to characterize the illness experiences of individuals dually infected with TB and HIV. This chapter responds to research questions stemming from this objective to develop insight on how coinfected patients may think about their dual diagnoses, how they understand their illness with TB in relation to HIV and vice versa, how their characterizations may be shaped by their social environment and finally, how these may be linked to particular health-related actions. I first present themes that emerged directly from the interviews, such as perceptions of illness and the self, experiences with stigma related to TB and HIV, processes and decisions around illness disclosure, and the social milieu within which these perceptions and decisions were set. I then critically discuss the empiric findings, and situate them in the broader literature base.

I first share the ways in which participant narratives are presented in Chapters 5, 6, and 7.

Re-presenting participant narratives

In order to protect patient participants’ identities, excerpts included in this thesis are linked to their gender (M: male, F: female) and site (1, 2 or 3), except when the study site may compromise their anonymity or implicate an individual patient. This latter consideration is most apparent in Chapter 7 when patients relay their experiences at specific types of healthcare facilities (including those outside of the study sites). Patients’ ages have been omitted for several reasons. First, on occasion, due to the relatively small number of patients recruited at each site, it may be possible to link several narratives together and identify the ‘story’ of a few individual patients if their gender, age, and site were to be included. This could compromise their anonymity. Second, the age range for study participants was relatively small based on the sampling strategy to recruit persons between 18
and 50 years of age; most patients were between the ages of 21 and 47 years, and on average 34 years old (see Table 4.1). Third, age did not emerge as an important ‘descriptor’ in this study’s qualitative analysis, and aligns with the general lack of correlation between age and common social constructs that have been analyzed through prior quantitative work presented in Chapter 2.\textsuperscript{14}

Excerpts from key-informant interviews are identified as being spoken by a HCW, but considering the small number of HCWs interviewed, any additional information such as their gender or site could compromise their anonymity, and are thus excluded.

Some words that were emphasized by participants themselves, that is, stated loudly or emphatically, are underlined to provide readers with greater tone and context of spoken statements. Words that were paraphrased by the translator due to language and/or grammar, or to protect participant anonymity, are included within [square brackets]. Non-verbal gestures are included within (round brackets).

\section*{Analytic findings}

\subsection*{Illness perceptions: “TB is 6 months, ARV until I’m dying”\textsuperscript{15}}

How patient participants perceived or understood their illness was a central finding of this study. Though co-infected, HIV and TB were regarded by patients as distinct infections and discussed with distinct tones and attitudinal expressions. Differences between TB and HIV were expressed as a function of people’s vulnerability to either infection, and their prospects for remediation or cure. Perceptions of TB were often described in contrast to HIV.

From the interview excerpts shared below, I analyzed how TB was understood to be a markedly normal infection. Tuberculosis was “just” TB, a function of everyday life; it’s “how we live”, a part of every individual’s environment. Participants’ accounts illustrated how they and their communities shared the belief that no one was truly invulnerable to developing TB and further, those infected were not at fault for having contracted it.

[I said] it’s just TB… he just said, ‘Hey, relax brother, it’s the available sickness in the world’… At home, I told them that I was suffering from TB… they just said, ‘Hey, we must really be careful. It’s life of this world because that’s how we live’. (M, site 3)

\textsuperscript{14} Where possible, the author may oblige interested readers on the ages of patients associated with a few excerpts.
\textsuperscript{15} (F, site 1)
In contrast to TB that was perceived to be “usual” and readily “available”, HIV was considered a more selective affliction infecting people on the basis of their personal character, which could render them more or less vulnerable to contracting the virus. Ironically, HIV was also perceived as more contagious or transmissible.\(^\text{16}\)

They take it [TB] a usual thing because they say it’s usual, it’s in everyone. It means it’s a thing which doesn’t select... [HIV] there it’s difficult for them to take easy. They tell themselves that as you have HIV-positive, you are the thing which will leave the world. You’ll infect them. (F, site 1)

Tuberculosis was perceived as an interim setback to patients’ routine lives. It could be reversed and managed with treatment. Participants believed that so long as prescribed medical regimens were followed, individuals infected with TB were likely to recover within a defined period of time.

It [i.e., TB] was natural because I knew it’s going to be finished some time if I keep on taking the treatment. (F, site 1)

HIV however, was branded as an illness that “finished” people. Although they acknowledged that HIV could be treated, patients conceived of it as incurable and representative of a permanent fixture in their lives.

If they can say I’ve got this disease [i.e., HIV] because they say it finishes people, I am also going to go as well... TB, sister, I just told myself that it’s a curable thing. I’m going to be right as long as I will follow regulations, how to eat treatment. (F, site 1)

**Perceptions of the self: “I was doing bad things, loving”**

Compared to TB, patient participants internalized their attitudes around HIV, which affected their own self-perceptions. An HIV-positive diagnosis invoked shame and blame. Participants worried that they would be gossiped about, or viewed as “disgusting” by their communities. Their seropositivity also perpetuated sorrow and fear related to the permanency of their HIV status and its association with death and dying.

I was taking it [i.e., HIV] as if it’s something which kills. Scared, I was scared that if I can have this disease, I will go in this world or they will find me disgusting. People won’t like you because they’ll know that you’ve got this disease, because of course you are going to leave the world. I was just telling myself that for my whole life. (F, site 1)

\(^{16}\) It is ironic that patients perceived HIV to be more contagious than TB, despite the reverse being true: TB is airborne and more easily contracted than HIV that, in the context of the study setting, is contracted primarily via sexual contact.
Associations between people’s moral character and their HIV status emanated from several narratives, but perceptions differed by gender. Women, in particular, expressed shame, guilt, and self-blame at their predicament compared to men. Although some realized their partners were not monogamous, they held themselves responsible for contracting HIV. And while upset about their partners’ infidelities, any sense of anger and disappointment was directed inward.

Nothing worried me that much because it of course means I get this through my mistakes at that thing. I got this through my mistakes... I was doing bad things, loving, you see that thing. (F, site 1)

I was madly in love with somebody. Trusted him so much... We went unprotected knowing that he’s mine and I’m his. Why not, you know? And that’s how it happened... I had everything going for me, and I just threw it all away... No one in the member of the family has had it, you know. And here I am with it... I was scared, that’s how I could put it. Scared. Miserable. Mad at myself that, how can I be so clumsy, how could I put my trust in somebody that’s like this? (F, site 2)

The exemption from self-blame by some men, and the attribution of guilt to their partners was exemplified in the following excerpt. The patient blamed his girlfriend and believed that she knew her status long before he did, but deliberately kept the information secret. He held her guilty and responsible for his prognosis, but he also kept “quiet” about his own HIV test result.

So you feel when you goes sees the person, because eh, how come she don’t like to go take a blood test. Listen, if a person don’t like to take blood, she is guilty of something... Even her as well, she has got her privacy... I won’t leave her, I will carry on go with her, because if I’ve got it, even she must have it... Same like a baby, sharing a bond with a baby, now sharing a bond, same thing. Sharing... [When I disclosed] she was, she just feeling normal but quiet, as her name is [partner’s name], know the [partner’s name] is a snakes. They only keep quiet. Don’t tell that’s what. That’s another thing, I just keep quiet. I just tell her as long as she knows now because she knows if I got it, definitely. (M, site 3)

**Linking TB and HIV: “TB is AIDS’ neighbor”**

Though HIV and TB were regarded as distinct infections, they were simultaneously perceived to share a close link. Patients described how conversations related to TB often led to explicit thoughts of HIV. Tuberculosis was understood to be a sign signaling one’s HIV-positive status or the onset of AIDS. In several instances, it consequently signaled death.

In our township once we have the TB, means people think that once you got the TB, that means you are HIV. They tell their selves that. (M, site 1)

There they laugh at each other in the rurals... If you ever say you have TB, they become your doctors. It’s them who will say, ‘Yes, of course, TB is AIDS’ neighbor. It means she has got AIDS’, you see? (F, site 3)
Not only did participants suggest how assumptions around AIDS were widely prevalent in their general community, these assumptions further emanated as part of participants’ own conscious thinking. One patient replayed his thoughts when he discovered he had developed TB. His words succinctly represent how these two illnesses have come to be understood as part and parcel of one another by those who are most intimately affected by both.

I can see that I suffer even from TB, things I did not suffer from. I realized that it means I have [this] sickness. (M, site 1)

This sentiment may have been distilled through the healthcare system, as was apparent from the following excerpt taken from an interview with a HCW:

Remember that TB and HIV is a brother and a sister. One of the two is a male and the other one, could be a female. So, and for true that’s how I look at it, no matter what. If a person is saying, ‘I am TB positive, I’ve got TB’. ‘Did you check for HIV?’ ‘No’. ‘Please do’. Even in the community, that is a big itch. That is a motivation that we should remember that please, once there is TB, don’t say you wasted because of TB. Check the brother. Go for another. (HCW)

These accounts sensitized me to patients’ dual consternation with TB and HIV, and their construction of a dual illness identity, which is examined further in the discussion.

**Shifting perceptions of self: “the person with TB is with HIV and she is dying”**

Within individual patient narratives, perceptions of TB altered as TB became indicative of HIV. Simultaneous to regarding it as distinct from HIV, popular associations between TB and HIV rendered TB to be incurable and fatal. Patients’ self-perceptions accordingly kept shifting.

For TB, they think the person with TB is with HIV and she is dying. We mustn’t come close to her. [HIV] same thing, and she’s dying... They pointing and pointing, they talking about that person. Sometimes even that person sees them, then this person reports to me, she’ll say they are, ‘I’m hungry but I won’t come to eat at your home, because they are saying only the people who are sick who come at your home’. (F, site 3)

Some participants rejected community-based assumptions tying TB to AIDS. They held on to the fact that TB was not always connected to an underlying HIV diagnosis. They were keen to distinguish HIV from TB, to direct how others perceived them, as well as how they perceived themselves.

Like a lot of people are very ignorant about it because lots of people say, ‘Oh, TB turns into AIDS’, which I think is... they don’t really understand or know that they’re talking about. (F, site 2)
The righteousness of individuals was reiterated in characterizing the link between TB and AIDS. According to one participant, whether a person’s TB was indicative of his or her HIV status depended on what that person had done in his or her life, implying people’s HIV status was a function of their own (incorrect or immoral) behaviour or action. He emphasized how TB was not automatically suggestive of AIDS. Although aware of his seropositivity, he attempted to reconcile his own actions, or what he “did” in his life, by drawing attention to people who were infected with “only” TB:

This is the story that I like to talk about. There is TB, once the person, hey you got TB, no, you got AIDS too! Many say, they say, ‘You got TB, you got AIDS’. But it’s not true. If you’ve got TB you’ve got TB. If you’ve TB, you’ve got TB and AIDS some times. All depends on what you did in your life to have both at the same time. But most only got TB, if you TB, then there is something, HIV, yeah, they call I don’t what some counselors or some nurses or doctors tell certain patients, ‘If you have TB you must have AIDS’. It’s not true. Say like me, because I meet people say, ‘Yeah [patient’s name] you got AIDS’. I say, ‘No it’s not true’. Although I know I do have but I know my friend got TB, but hasn’t got [HIV]. (M, site 3)

The visibility of thinness: “other one left this world being like a stick for matches”¹⁷

Alongside the psychosocial stresses of fear, blame, guilt, and shame, participants distressed about the effect the illness wore on their bodies. Weight loss was a critical and common symptom of both TB and HIV, and in this setting, representative of a fatal illness. Thinness identified participants as being ill and infectious, and many worried about justifying their physical condition to inquisitive members within their community.

They knows. Neighbors know me. I am thin, I am 46. Now size, I am now, now 40. I was big. They told me, ‘[Name], are you sick?’ I never explained what I got. (F, site 2)

The visibility of disease produced by thinness created a platform to perpetuate gossip and discrimination against those who had lost weight. Be it a consequence of TB or HIV, thinness reinforced transparency of participants’ HIV status and of their proximity to death.

Sometimes you’ll sit in this chair and the person will say, ‘Who was sitting on it, did you see her? She’s thin and maybe she has the rash. Can you see her how she is structured now? Maybe she’ll infect you with this disease she has’. (F, site 1)

You can see if someone is getting thin, until he dies then you can say, eh, he has HIV. (M, site 1)

¹⁷ (M, site 3)
The visibility of EPTB: “if you have got glands, everybody knows what’s going on”

Nineteen patients were infected with disseminated or EPTB, and/or were experiencing a repeat episode of TB. Patients perceived these more severe forms of TB to be more intimately tied to HIV, and often compared their perceptions of recurrent or EPTB to pulmonary or “regular” TB.

For some, recurring episodes of TB or slow recovery despite having started chemotherapy prompted an HIV test to find out what else was going on or “why” they had developed TB to begin with.

This is the third time... I feel very, very disappointed because I done the treatment clearly. I take the tablets accordingly. I don’t know, that’s why I decided to go to [clinic] to check my blood ‘cause of this. Every time I getting TB, every time I’m thinner, so I decided to get my blood and every thing. That’s why I found that it’s TB plus HIV. (F, site 3)

You know, I was, I had taken my TB treatment and I was still not coming alright... I’m taking my tablets everyday but I don’t feel better... You know when I’m sick, you want to know why you are sick. So I just accept everything, it was easy... maybe I’ve got this. So I must check. I was, I was ready to know that I am positive. (F, site 1)

The unmasking of HIV by more visible forms of TB distressed patients. Glandular TB, also referred to as “glands TB” or simply “glands”, attacked the body’s lymph nodes causing them to swell out from beneath the skin. In many cases, enlarged nodular protrusions were clearly noticeable on the face and neck of affected patients.

You sometimes have those feelings that maybe, as you see this one scared to talk about this, maybe she has glands. You’ll say, oh, so and so, you know what, as she has glands, its because she’s been started by this HIV, you see that. Other person will be scared if she see herself developing things... I heard that if you have this and having rash and having abscesses like that, but the person would not be aware. (F, site 1)

One woman reflected at length on her second experience with TB. Six years prior, she was treated for pulmonary TB, and diagnosed with HIV at that time. She now developed glandular TB for which she was receiving chemotherapy. During our interview, I noticed her neck was enlarged. She said her symptoms had been much worse some months ago, prior to commencing TB treatment. From her perspective, “lungs TB” or pulmonary TB had been easier to cope with; it allowed her to be less visible. In contrast, the swelling associated with glandular TB immediately exposed her. It made her conspicuous in public, and she believed the association between TB and HIV was all the more obvious. The overt physical symptom betrayed the privacy of her HIV status.

If you’ve got a lungs TB, I think its better because you, nobody knows what’s going on in your, you’re sick... Glands TB you’re so ill and embarrassed because everybody knows what’s
going on because some other peoples, if they see you, you’ve got a glands, they think you got HIV because HIV is a confidential disease, you can’t tell anybody. So if you, if you have got glands, everybody knows what’s going on... Oh, so, it was so difficult to me, it was so difficult to go to see people other places because I was so, feel so sorry that time. I was using a scarf that time. (F, site 1)

However, not all cases of EPTB were perceived to compound visibility and public contempt. One participant, diagnosed with TB of the spine, expressed his relief at not having incessant coughing episodes that could have made his illness more obvious and invited a greater degree of negative attention, compared to what he experienced in his current state. In these ways, EPTB offered coinfected patients a relatively higher or lower degree of public visibility.

They are taking like, but for example, say, if I have TB, they don’t have TB. Like if I’m coughing, they just ignoring looking like this, like maybe you gonna spitted on him then. Sometimes I say its better because sometimes I am not coughing, since I am working with people. (M, site 1)

**Silencing HIV: “they don’t see it so close, they see it so far”**

Participants described a general aura of silence around the subject of HIV and AIDS. Despite its high prevalence and regard as a “present” infection, HIV was not straightforwardly discussed in public, let alone within more private settings such as patients’ homes. I got the distinct impression that for some participants, talk of their illness had become the allegorical ‘elephant in the room’ – it existed, everyone was aware it existed, yet no one was prepared to talk about it.

The news about being sick, they don’t talk about it, you just see that the person is sick. (F, site 2)

It’s that one is complaining about that she is sick, then another one is complaining... they are dying, shame. Most of the time... they are going to the clinics, but you don’t ask the person. (F, site 2)

Evading the topic of HIV/AIDS was tied to fears about having to face the possibility that it was imminent within participants’ communities. People could no longer deny nor ignore the threat of infection; HIV was now prevalent in their own social worlds.

I can say that they take it [HIV] as a present disease but they don’t see it so close, they see it so far... There are not so many people talking about it but its there. (M, site 1)

Even, you will find somebody sick, if you sitting, why don’t you go and making a check up, go? They don’t want to hear about this, going tell me, tell me that I got AIDS all this time... (M, site 1)
Feeling discriminated: “they looking at you with the mind not with the eyes”

While conversations around HIV were often hushed, participants reflected that the times when it was discussed were in openly prejudicial ways. Consequently, participants were afraid of being judged and victimized as a result of their ill health. Their characterizations of discrimination were closely tied to their perceptions of HIV (and TB).

Now you know the people, maybe the people don’t like. They looking at you with the mind not with the eyes. With the mind they looking at you. Now you, I mean the person is sick and people around you, you feel the same. That’s the people that’s thinking about you. You feel good but more you feeling, how can I put it, you feel shit, so to say. You not yourself that time, because you’re like, you go home, you feel like demolish. (M, site 3)

Several participants spoke about their experiences with overt discrimination, within their home and workplace, due to the perceived contagious nature of their condition.

What can I say, my mother is a talking person, she’s talking naturally. She talks with children and we can all hear. So that even others cannot be infected, so that they cannot use things I’m using. My thing to be my things only, to be specifically mine. Hey, maybe towel, maybe not to touch it, my toothbrush, everything like that. (M, site 1)

This perpetuated a sense of shame, blame, and disempowerment, and inclined many to hide their illness from others especially at their places of work.

Sometimes in the [workplace] you know, the clients, they used to talk about HIV, like if they are ignoring if they are talking about HIV, sometimes I just feel uncomfortable... because they are not talking nice. It’s like they are talking about some thing, I don’t know... They think, they are ignoring, its just HIV. So like my clients, I am scared to tell my clients because maybe if I am touching them, they won’t feel comfortable like... if I have HIV. (F, site 1)

Accounts of feeling excluded or negatively differentiated were typically characterized within the context of being HIV-positive. But a few participants shared how they felt rejected specifically on account of their illness with TB, due to its perceived contagiousness.

Even TB, I can say they’ve got that stigma, you see because the most of them, they are telling themselves that TB its easy to infect. (F, site 2)

For one participant, this rejection was particularly upsetting as it left him feeling “guilty” when he believed such guilt was undeserved. It tied to the attributes of culpability and self-reproach that participants held for HIV but perceived to be unjustified when speaking about TB.

My brother, its just that he’s very stubborn. Now if they see that, it’s just that even him, he has, that’s why I don’t want to stay with him. You see now, if they, they realize maybe that he just say, eh, he looked after his children, maybe it might happen that some other time
doing this, maybe I don’t know whether but infect them [i.e., his children] with TB so that’s why I’m not staying with him. Yeah, that is what makes you sometimes you feel guilty while you are not guilty at that time, you see. (M, site 2)

Disclosure and support

Virtually all participants disclosed their TB illness to close relatives and sexual partners, and often to co-workers and friends. Sharing an HIV status, however, varied greatly across the sample with critically different experiences between men and women.

HIV disclosure: “my problem is one, my friend is me”

Compared to men, many female patients were single and no longer with the boyfriends that they believed had infected them, as a result of either a break up or at times, death. For these reasons, they did not go through a process of disclosure with those men. In some cases, those boyfriends had disclosed their HIV status at an earlier point in time, but in less direct ways.

I don’t want any man next to me ‘cause I know like, how it work, how can I get the HIV. ‘Cause in 2005, I was having a boyfriend, and he come and pay lobolo and everything and he never tell me that he’s married. Then when I found out, I was like why did you not tell me. He says he was scared of telling me he is married. Then I just tell him it’s over from now. Then he send me the messages, go and check your HIV, what, what, what, what, what. Then I didn’t go to check until I get sick. Then when I go and check, I find out oh, that’s why he send me the messages... but he never told me the direct things. He go and find out. Then I just there, cause I wasn’t sick by that time. When I was sick, I was, oh, that man sent me the message then I go and check it. (F, site 3)

I showed him my results that I was negative and he said he was negative, he said, ‘Of course I am negative’, he said, ‘But I don’t like what you are doing, because next time you’ll be disappointed’. (F, site 2)

Women involved in a relationship during discovery of their HIV status decided to disclose this information to their sexual partners in several ways. At times, they disclosed less directly to avoid their partners’ anticipated rejection and betrayal. In the case below, her partner eventually left her.

I told him after some time. But I didn’t tell him what I had. I said, ‘Everyone supposed to know himself, to go and check’, and him, he went to check. He came back and told me, and I also told him that I am HIV-positive. (F, site 2)

Rejection reverberated in the stories of most women who had disclosed to partners subsequent to HIV notification, and then indicated that no subsequent support was received. In many cases, their partners abandoned them soon after disclosure. Many of these men already had other primary girlfriends to whom they returned.
For now I don’t know if we are still carry on or what is happening because when I was sick, he just neglected me. It means I felt so bad about that. It means, I told him that that made me felt bad but neglecting me, not taking care of me when I was sick. For now he abandoned me. I don’t know if he abandoned me or we are separated, I don’t know. (F, site 3)

In other cases, women were not abandoned outright after HIV disclosure but only when they insisted their partners have protected sexual intercourse or get tested for HIV. A perceived inability to discuss HIV openly, and their partners’ refusal against VCT left them feeling distressed and helpless. A few women said they did not know how to negotiate or sustain condom use when their partners were unwilling. For some, rejected insistences on safe sexual practices pushed them to confront their partners with an ultimatum towards self-protection. However, such confrontations often ended up being the breaking point of their relationship, leaving them further upset.

The time we came back from the hospital, he was asking me, over the phone, ‘What’s wrong, did you take the test?’ I said, ‘Yes’. He was asking me, ‘What, what, what was it?’ ‘I’m negative’. By the time I came back I told him, ‘I’m positive’. Then I think he also had to go and do a test. He just refused to go and take the test, he refused even to use a condom, then I just ask him that its between two choices, use a condom or its either I just or I will just dump you, because I can’t do the thing because just for your sake, I have to do it myself. You take it or leave it, its up to you. But now we are still separated because he refuse to do the things that I am asking. He don’t want to go to the hospital, he says he is not sick, he doesn’t have HIV. (F, site 1)

The few women who enjoyed the support of their partners after sharing their VCT result appeared to be in more stable, longer-term relationships including marriage. They did not experience a breakup post disclosure. Their partners appeared to be financially secure and emotionally available, and except in one case, also conceded to test for HIV. One woman disclosed to a new boyfriend simultaneous with his own disclosure to her, after which they supported one another during their treatments.

I told him first because, you know, when you like somebody, and you know that they, they sometimes gonna ask for, like, ‘Why we protecting? Why we protecting all the time?’ you know, and then you tell them, ‘No, you protecting because of this’. ‘How, you’ve got this? I’ve also got it’, you know, because I’m sure, at that time, we were a bit tipsy, but not drunk. Yeah we weren’t that drunk, but sometimes, I mean, sometimes when you’re drunk you can say things that are meant to be said, but in a sense of just talking, casually. (F, site 2)

Most women in new relationships did not disclose to their new boyfriends, discouraged by the negative reactions of previous partners including their loss of support, and confronting their partners’ infidelities. That many women financially depended on their new partners further discouraged them from introducing their status and upsetting the relationship. These women
typically portrayed their illness with TB or pregnancy prevention as justifications for using condoms or avoiding sex, but worried about how long these excuses would last.

Even now we are still together the only thing is I haven’t disclosed to him that I’m HIV, such that we haven’t been together since I was HIV diagnosed... he comes and we chat, its nice, but because I’m sick. I’m sick, I told him. 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. That’s my problem because he is the only one... I still want the way of telling him. (F, site 3)

In the case of several women, between one and three years went by during which time they were afraid or uncomfortable or had been denied the emotional space to speak about their HIV infection with loved ones. On occasion, a negative outcome from a very early disclosure to their partner discouraged them from sharing their status with anyone else. As a result of being shut out by boyfriends, many women typically resorted to confiding in their families or friends.

I done the HIV test in 2007 but I didn’t believe it yes, at [hospital]. So, that’s why I am struggle now taking it. To be sure that it’s here, that I am doing exactly what am I supposed to do, yes. It’s the second time... at that time I didn’t tell anybody except my boyfriend. Only my boyfriend... He’s a person who don’t want to believe anything like this. He don’t want to talk. Nothing about HIV and AIDS. If you start talking about it, then he just leave. So I decided to talk with my friend now. Now. After this one... That’s one it stress to me. It given me, it giving me a losing off the weight because I didn’t talk to anybody about this. (F, site 3)

Most women, regardless of whether or not they disclosed to their current or past boyfriends, did disclose to someone in their family, usually a sibling and/or parent, and/or on occasion, an aunt or grandparent with whom they lived. Several women who had had negative experiences with past boyfriends and/or had not disclosed to new boyfriends considered HIV to be a “family thing” that need not be shared with others. They were especially grateful for their sisters’ support, which was often greater than that anticipated or offered from a parent or other relative.

We [i.e., my sisters and I] don’t tell mother because she is that person who is drinking. Maybe sometimes if there is a query in the house, she will insult about that thing. She will say, ‘You went and became a bitch then you came back with your sickness you’ll infect us’. Maybe sometimes she will isolate because by the time when my brother was dead, she was able to tell people while we said this must be the secret... to be a family thing. (F, site 1)

But despite having disclosed, many women expressed feeling isolated from relatives who accepted their presence in the home but showed no interest in discussing their illness any further. From these patients’ perspectives, their illness had accrued a level of tolerance but no commensurate emotional support. Feeling muted and sometimes discriminated by their family, they sought comfort among others who were HIV-infected. A perceived loss of power to speak openly within their closest social
networks prompted them to seek outlets outside of the home. Extended networks grew into informal peer support groups and helped alleviate their sense of isolation and quiet despair.

I told them that I am sick, but they don’t want to discuss with me, yeah they don’t want to talk about this. Even on the TV, there is a Soul City; they don’t want to watch the Soul City with me, because they feel shame with me, so every time when these things started, they just leave… so I don’t want to bother them. If I want to open my heart, I cross my road and talk to my neighbor. And I find that there’s three or four neighbors who’s taking ARV’s, I am sharing with them… So if I am having a problem, I am going to the neighbors, I am asking her, oh what’s this problem now? And they give me the solution. (F, site 3)

Compared to women in this study, men were more mistrustful and weary about sharing their HIV status with multiple people. They expressed preference to share their status with a partner compared to a relative. Often, they disclosed to a close friend before discussing HIV with their immediate family due to a perceived lack of confidence and dependability.

My problem is one. My friend is me, and my girlfriend only. Even my family, I don’t trust my family. There is some thing that I can talk to my family, there is something I won’t to talk to my family. That’s because maybe tomorrow you can get a conflict, they are going to say like that, you see. So my friend is me, and my girlfriend then. I trust myself, I trust my girlfriend… So I don’t trust anybody except her only and myself for. (M, site 1)

Men with girlfriends or wives all disclosed to their partners, and virtually all went on to receive their support and care. At clinics, men were often accompanied by women, but the reverse was seldom observed to be the case. These men described how their spouses frequently reminded them to take their tablets, indicating a degree of support and compassion that was rarely voiced during interviews with women. Many male participants said they had tested for HIV after their partners disclosed to them and encouraged them to go for VCT. In only one case did a male patient speak of his girlfriend having left him, for another man, after he fell ill with HIV but before he explicitly shared his VCT result. He expressed resentment at her betrayal but satisfaction that he was now with another woman to whom he had disclosed, and who supported him during treatment.

The gendered characterizations of HIV disclosure speak to the different attributes and perceptions of shame and self-blame held with regards to an HIV status by the men and women of this study. Accordingly, they shared different concerns about HIV disclosure. In deciding disclosure, women typically worried about being blamed and judged for contracting the virus.

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18 At the time of the study, Soul City was a popular South African television program that candidly explored current health issues including HIV and TB, as part of a broader South African health promotion movement.
I was having that, that it might happen that I’ve got this from him of course. I talked to his parents, I went to tell his mother that if something happens, they must not blame me ‘cause when I told him that its like this, and like this, he was just a person who is not sad. It means its something he knows. (F, site 2)

Men, on the other hand, did not want to be ridiculed, disrespected or be associated with death. Both men and women feared being ostracized by their communities, but it appeared that women’s fears were tied to their sense of morality and wrongdoing, whereas men’s concerns were tied to public shaming, and a loss of respect and social status.

If she doesn’t know about it, she will be left like that. I will keep quiet. I just, if the person will know, hey, maybe she’ll end up making a joke about me... a person is between death. (M, site3)

I am telling the really friend. Other one they’re laughing. Even HIV, I telling some friend. Eh, my friend, you must go to test. You must know your status. You can laugh for me, but you don’t know what’s going on. They laughing, they laughing. I say okay. Other friend he was laughing. They was telling another friend, ‘Eh, don’t share the cold drink, the HIV’. (M, site 3)

Fore grounding tuberculosis: “she only knows I’m suffering from TB”

Based on narratives around disclosure experiences, it was apparent that both men and women spoke about TB more often, with more people, and more readily than about HIV.

I told her about TB, and I’m just standing in that... With TB, you can even tell that I’m eating tablets for TB. These one, you just need to close your mouth. Tell only your family. (F, site 2)

TB is quite easy to talk about, because it’s curable. Yeah, that’s why people are not scared to talk about it. (F, site 2)

Participants’ selective disclosure of TB over HIV was tied to their contrasting perceptions of either infection. A diagnosis of TB was understood to invoke less judgment, and as being more socially acceptable than HIV. The permanence and moral retrospection associated with HIV was dreaded compared to the curability and normalness of TB. When sharing their health status with others, coinfect ed patients naturally foregrounded their illness with TB.

You know, it’s not easy to tell anybody about HIV, because some of them, they just take you like, I don’t know, they just don’t want you to come near them, some of them. But some of them are right, see. But when you got TB, they always say, no you’re gonna be okay as long as you taking the treatment. (F, site 1)
To the point that their social networks regarded them as having TB, patients felt protected and looked after. They did not want to risk giving up the security of this support and sympathy by exposing their HIV status.

I only told my family and my step mom, about my TB not about my HIV. Because you know sometimes, women are fighting in the family, and the person can tell you that oh, you gonna die soon, you’ve got HIV, all those things... The only person that knows is only him [i.e., partner], it’s only him. (F, site 1)

I don’t think about I’m gonna tell my mum I’m taking this now. Because TB, people don’t worry about TB because TB they know that, that you have to get tablets, it’s finished. But HIV, you must know that, you must know, I think you know, once you get HIV, people start to run away from you. That’s what makes us scared to tell that much. Yeah... even my boss, I’m telling about TB. But this TB I can tell, not something that people can look you like, ok shhh, maybe. (M, site 1)

Although most accounts revealed how disclosure of TB was easier than HIV, a few patients realized that disclosing their TB status could invoke associations and thoughts about HIV. As a result, several participants remained cautious about disclosing either illness and avoided discussions of HIV and TB, particularly among people they felt less secure around such as their neighbors and extended family.

People they know I was hospitalized and asking so and so. I say the doctors picked up the TB, I don’t mind. But I know that other people they are shy, other people they don’t like that. That’s what I picked up from the hospital, that there are other people they seems to be unhappy to tell other people that they are suffered by TB. Upon I’m asking, upon I’m finding out it was that no, I wasn’t telling you I’m having a TB. You might tend to think of other things as well, hmm, yeah. (M, site 1)

Others rejected or ignored the perceived assumptive associations between TB and HIV, and emphasized that they were infected with just TB.

I don’t hide my TB thing, because I’ve got lots of friends, and I talk about the TB, and stuff... it is easier because its something that’s around. And yes, people say its something connected to this thing. I don’t care what they think, but I actually tell them, you know, ‘I’m taking these tablets and, it’s just something that you take every morning, and it’s quite easy to take’. (F, site 2)
Discussion

Important theoretical ideas arose from the characterizations of illness experience presented in this chapter, of which patients’ illness perceptions, identity constructions, stigma, and stigma-management via selective, gendered disclosures were overarching themes. Patients spoke about their illness with TB and HIV, and how they believed they, as infected individuals, were perceived in the context of their social environment (and, consequently or therein perceived themselves). This prompted consideration of patients’ experience with dual illness as inextricable from continuous mediation with their perceptions, constructions, experiences and management of stigmas associated with HIV and/or TB.

My interpretations drew heavily on Goffman’s (1959; 1963) and other contemporary scholars’ theorizations of stigma (Link & Phelan 2001; Link & Phelan, 2006; Parker & Aggleton 2003) that were introduced in Chapter 3, where stigma may be understood as a socially constructed phenomenon; as a process rather than a static event; and, where individuals naturally aspire to gain social acceptance and resist stigmatization through constructing positive self-identities and presenting desirable impressions of themselves. Illness disclosure, in relation to self-presentation, was thus a critical element of participants’ experiences living with TB and HIV. My analysis also drew on the work of Ellen & MacEachen (1998), as patients’ interpretations of their illness and consequent interactions within their social networks, particularly disclosure or discussions about their condition, were due to and additionally reflected in broader social (and prejudicial) norms about TB and HIV.

Construction of a dual identity

Disparate identities

Participants’ accounts were laden with contrasting perceptions of TB and HIV, based on two social constructs. First, the culpability or guiltiness of contracting HIV was set apart from the blamelessness or innocence of developing TB. Tuberculosis was considered a “natural”, “usual” and readily “available” sickness that could affect people indiscriminately; individuals were not held conscionably responsible for having TB. Conversely, an HIV status reflected an individual’s moral integrity and conscious action, tied to sexual transgression. It rendered them morally susceptible, and fit to be judged. Second, the permanence of HIV was set apart from the temporary or impermanent course of TB. While TB was considered curable through short-term treatment, HIV was deemed irreversible and deadly. Though ART was available, participants knew it did not cure. In
this way, socially dichotomous identities associated with TB and HIV were typecast, and stereotyped, through constructs I term moral susceptibility and (im)permanence.

The study showed that while TB and HIV were both regarded as infectious and transmissible, the negative consequences of these perceptions were unequally applied and experienced. Despite TB being more easily transmissible, HIV was the more dreaded as it challenged participants’ moral character and was deeply associated with death and dying. Coinfection provoked the construction of dual TB and HIV identities that were distinctly tied to attributes that were socially constructed as desirable and undesirable, respectively, and invoked disparate degrees of social stigma: a positive self-identity associated with TB that was morally upright, blameless and temporary; and a negative self-identity associated with HIV that was immoral, culpable, discreditable, and permanent.

The paradox of coinfection

Mediating participants’ dichotomous identities was the inextricable link between TB and HIV in this study setting. While TB and HIV were regarded as having distinct social attributes, they were parabolic in that those who developed TB were instinctively assumed to have HIV. Negative social desirability, labeling and stigma that were typically reserved for people with HIV were transferred to individuals with TB. The identity associated with TB had become undesirable, discreditable, and stigmatized just as HIV. Coinfection thus introduced a paradox in participants’ dual identities.

Not only was TB symbolic, it was also symptomatic of AIDS. Tuberculosis invited the onset of physical symptoms such as weight loss that also caused HIV illness to become more visible. With this visibility, TB transformed HIV from being considered “discreditable” or hidden, in Goffman’s terms (1963: p 3, italics added), to one that was irrevocably discredited or apparent, allowing coinfected persons to be exposed and consequently stigmatized. This transformation was sometimes stronger in the case of glandular TB, one form of EPTB, where physical bodily changes were more telling of HIV. It was sometimes weaker with other forms of EPTB, such as spinal TB, where the absence of respiratory symptoms enabled concealment of TB, and of HIV. Patients’ social undesirability thus became more or less visible, and patients with extra-pulmonary disease enjoyed novel experiences with stigma, as compared to other forms of TB. In all cases, coinfection gave impetus to the construction of an overlapping stigma of TB and HIV.
Disentangling TB/HIV stigma:

Researchers Bond & Nyblade (2006) state that in the context of high HIV prevalence, “TB stigma can no longer be thought of, or addressed, separately from HIV stigma” (p 453). They encourage further study into disentangling the double stigma of TB and HIV. Findings from this chapter unravel some of these concepts towards developing greater understanding of how TB/HIV stigma is a result of dichotomous but interconnected social constructions of disease and identity.

Persons with HIV have long been associated with sexual promiscuity, immorality, and death (see Campbell et al., 2005; Castro & Farmer, 2005; Mbonu et al., 2009; Parker & Aggleton, 2003; Petros et al., 2006). Tuberculosis has also invoked stereotypes of dirtiness and social transgression (see Johansson et al., 2000; Liefooghe et al., 1997; Packard, 1989). However, the accounts of dually infected patients in this study showed how negative attributes of TB were largely restricted to assumptions about HIV; patients were judged and labeled with a social difference on account of HIV (or associations and assumptions about HIV), rather than TB. This is not to say TB was perceived as completely socially benign. The infectious character of TB was used to justify the social exclusion of some patients (though a connection to HIV may have been implicit). But for the most part and more intensively, HIV was the driving factor behind patients’ experiences with stigma and discrimination.

While other studies have found communities affected by TB and HIV to distinguish between older, more socially acceptable forms of TB and newer, HIV-associated TB (Bond & Nyblade, 2006; Ngamvithayapong et al., 2000), this study showed that from the perspective of coinfected patients, their identities and invoked stigmas around TB were completely subsumed by those of HIV/AIDS. In a setting where nearly four of every five TB patients were estimated to be HIV coinfected, older forms (and perceptions) of TB were less relevant. This finding substantiates a recent literature review that found stigma related to TB has declined within low HIV prevalence communities but resurged in high-burden settings, due to the strong (perceived, social and physiological) interrelations between the two infections (Courtwright & Turner, 2010).

The theoretical application and role of unequal identity constructions on the experience of TB/HIV stigma is a novel finding of this research. Patient narratives highlighted that disparities in the attribution of TB and HIV stigma may be better understood through the social constructs of moral susceptibility and (im)permanence, and linking such constructs to patients’ discredited and discreditable identities associated with HIV and TB, respectively. In this way, this study clarifies the
social pathways by which the double stigma of TB/HIV is produced, as was first identified in prior qualitative work (Bond & Nyblade, 2006; Daftary et al., 2007; Ngamvithayapong et al., 2000; Nnoaham et al., 2006). It also lends insight as to why stigma against HIV may be greater than that against TB, as was found through prior quantitative research. (Levin et al., 2006; Mak et al., 2006).

Finally, study patients’ narratives show that stigma associated with more (and less) visible forms of EPTB such as glandular TB may be particularly complex compared to the stigma tied to more common forms of pulmonary TB. While qualitative researchers have pointed to the stigma associated with sudden weight loss that is often attributed to HIV (Gebrekristos et al., 2009), and visible body shape changes such as lipodystrophy that are produced by HIV therapy (Park-Wyllie et al., 2007; Persson, 2005), little is documented about the greater social stress perpetuated by some of these more physically conspicuous forms of TB/HIV disease.

**Negotiated disclosure**

From the perspective of study patients, TB marked them with HIV/AIDS. Perceived links between TB and HIV rendered identities associated with TB to also become undesirable and stigmatized. Coinfected individuals thus experienced a unique form of stigmatization that was compounded by their dual diagnosis. Not only did they have HIV, the primary stigmatizing attribute, they also developed TB, which revealed their HIV status, reinforced the stigma of having HIV, and consequently perpetuated and renewed stigma against TB. Further, their identity associated with TB became equal (in terms of its undesirability) to that of HIV, prompting patients to segregate this double stigma by distinguishing and highlighting the differences between each infection and identity. For them, HIV was clearly perceived as the least desirable identity and invoked a dominant degree of discrimination.

**Deflecting the stigma of HIV**

Goffman and others have theorized that individuals possessing discreditable (or stigmatizing) attributes avoid being discredited, or resist stigma, by manipulating the information they share with others. Through negotiated disclosures, individuals may present themselves in socially favourable ways to retain social desirability and inclusion (Goffman, 1959; Goffman, 1963; Hatch, 1999; Roschelle & Kaufman, 2004). Coinfected patients in this study altered the information they shared with others, or their illness identities, to help mitigate the stigma associated with their dual infections through unique stigma management strategies.
First, despite strong public associations that TB equals HIV, patients maintained clear boundaries between these identities in order to protect themselves from the double stigma of TB/HIV. It was important for them to highlight the identities and associated stigma of TB and HIV were not one and the same. Several participants fought public perceptions linking TB to HIV to reject assumptive labeling, negative stereotyping, and stigmatization that were usually reserved for people with HIV. In this way, some patients perpetuated a new form of HIV ‘othering’. By symbolically separating themselves from people with HIV, they attempted to preserve their own normalcy (associated with TB), and deflected the greater stigma of HIV.

Second, and in relation to the first point, as their dual identities became symbolically defined (at least from their own perspective), patients rejected their identity associated with HIV by adopting the less stigmatizing identity tied to TB. Virtually all participants disclosed TB more quickly, more often, and more easily compared to HIV as a means to protect them selves from being surely discredited. Outright ‘passing’, or the ability to conceal their illness and present as normal, was no longer possible with the onset of physical TB (especially some EPTB) symptoms. ‘Covering’ the dominant stigma of AIDS with the lesser stigma associated with TB was their only means to resist discrimination, that is, to remain discreditable but not discredited. While their identity was still associated with some undesirability, it was no longer as apparent and undesirable as the identity associated with HIV/AIDS.

**Re-conceptualizing HIV othering and covering**

The notion of HIV ‘othering’ has routinely been applied as a tool to protect self-stigmatization and reify prejudice against social groups on account of their perceived subordinate race, gender, religion or social status, and thus perceived greater vulnerability to HIV (Campbell et al., 2005; Joffe, 1997; Petros et al., 2006). In the current study, TB patients were considered to comprise a social group that served as easy targets of HIV-based stigmatization. Distancing themselves from the TB-HIV stereotype through HIV othering became a necessary strategy of stigma management for those who were dually infected. Patients’ emphasis on their TB status allow them to align with the more acceptable social group of people affected by TB, separate themselves from the HIV ‘other’, and deflect, at least in part, the stigma associated with their coinfections. This study thus extends the application of HIV othering to public reactions against the stereotyping of illnesses that overlap with HIV, as compared to stereotyped socio-demographic traits that have been shown in prior research (Petros et al., 2006; Campbell et al., 2005).
The selective or negotiated disclosure of TB over HIV by coinfected patients was first documented in research emerging from Thailand (Ngamvithayapong et al., 2000) and re-emerged during work I was involved with in South Africa (Daftary et al., 2007). It has since been documented in several qualitative studies with coinfected patients as well as their families (Chileshe & Bond, 2010; Corell et al., 2010; Gebrekristos et al., 2009), and was echoed by study participants in the current work. This study’s findings support the social act of ‘covering’ in the context of coinfection, which was conceptualized during (our) earlier work. The study further refines the rationale behind such stigma management strategies, in that patients’ inability to ‘pass’ as normal may compel them to foreground a more acceptable excuse for their symptoms, and avoid the dominant stigma of HIV. Findings also highlight the impact of extant sociocultural norms around disclosure decisions, which have been postulated by researchers studying HIV disclosure (Fitzgerald et al., 2010; Skinner & Mfecane, 2004). Prevailing norms that TB is a more acceptable illness compared to HIV guided study patients’ decisions to emphasize their diagnosis of TB over that of HIV.

Several patients avoided disclosing their illness with TB as well, not just HIV. The stress of disclosing TB has been examined by researchers in Zambia from the perspective of its juxtaposition between individual exposure to stigma (particularly in communities that associate TB with HIV), and patients’ duty to serve the public good (by preventing TB transmission in immunocompromised communities) (Bond & Nyblade, 2006). In the current study, patients did not appear to perceive public health pressures to publicize the infectiousness of their illness (with TB). Rather, the few patients who declined to disclose even their TB status did so to protect themselves against an automatic social diagnosis of AIDS. Patients who described being discriminated against on account of their infection with TB indicated that for the most part, such acts were heavily laden with public assumptions around HIV. This substantiates earlier theoretical ideas emergent from this study that, in this high HIV prevalence setting, stigmas around TB were entirely attributed to its association with HIV.

Deciding HIV disclosure

Silence over stigma

Patient narratives demonstrate that silencing of the HIV epidemic is still at large in South Africa. Though HIV prevention and safe sexual practices were emphasized in media representations, via education-entertainment messaging (e.g., Soul City) that has been termed youth ‘edutainment’ (Papa et al., 2001; Squire, 2007), participants spoke of a general hushing of HIV-based conversations,
which prevented them from speaking about their illness in open and transparent ways. While TB was disclosed more readily and openly, the process of HIV disclosure was more selective and deliberate, and silence was often selected over the anticipation of stigma, perceived lack of support, and related fears of being abandoned and losing access to basic resources. Similar fears about HIV disclosure have been documented with TB patients in Zambia, South Africa, and Thailand (Chileshe & Bond, 2010; Daftary et al., 2007; Gebrekristos et al., 2009). However, these studies focused on TB patients’ constraints with respect to disclosure rather than the factors that facilitated HIV disclosure.

**Facilitators of HIV disclosure**

HIV disclosure is routinely encouraged, particularly to sexual partners, as a means to prevent further viral transmission. Disclosure is also considered crucial to access medical and social support, and build empowerment (UNAIDS, 2007; UNAIDS, 2001; UNAIDS/WHO, 2004; WHO, 2002a). But HIV disclosure can be stressful. It facilitates the enactment of stigmatizing acts such as discrimination, rejection, exclusion, and a loss of hope and confidence that may further be internalized through social constructions of the disease and the diseased self (Link & Phelan, 2006; Norman et al., 2005). Disclosure may thus undermine people’s self-identity and further deepen their experiences with stigma. How, then, do individuals with HIV decide how, when, and to whom they disclose their status? According to disease progression theories on HIV disclosure, symptomatic progression of HIV illness may prompt patients to disclose their status, as they are no longer able to keep it secret (Kalichman, 1995; Serovich, 2001).

For coinfected patients in this study, ‘passing’ or altogether concealing the fact that they were ill was no longer an option once the symptoms of TB set in. Hospitalizations, doctor appointments, weight loss, and physical debilitation mandated that patients with advanced disease explain their condition to the people they lived or worked with. However, distinct from the documented experiences of singly infected HIV patients (Kalichman, 1995; Serovich, 2001), the majority of coinfected patients could maintain a degree of invisibility through their selective disclosure of TB over HIV. Disease progression thus did not mandate they disclose HIV.

HIV disclosures in this study, instead, were decided on the basis of perceived trust in the targets or recipients of that information, need to ease the emotional burden of an HIV diagnosis in exchange for support, empathy and care, and desire to protect one’s own health going forward. Save for disease progression theories, facilitators of disclosure thus mimicked those postulated by many
other HIV-based researchers, in that patients tended to weigh the perceived social risks and benefits of disclosure when forming such decisions (Black & Miles, 2002; Kalichman, 1995; Serovich, 2001; Serovich et al., 2008; Ssali et al., 2010). Social norms around gender further influenced how and to whom they shared their status in this regard.

**Gendered disclosure of HIV**

**Fears against disclosure**

Social barriers of HIV disclosure varied between male and female participants. Women worried about being judged and abandoned, and the consequent loss of financial and emotional support. Men worried about being ridiculed and insulted, and the consequent loss of self-respect and social worth. While women appeared to be weighted by shame, blame, and despair, men appeared to be most debilitated by their disrupted sense of pride and self-esteem. Fears of disclosure tied to their gendered self-perceptions as HIV-positive persons – women tended to hold themselves to blame for their HIV status, and internalized the guilt and shame associated with having HIV, and men further tended to place blame upon their female companions.

HIV risk perceptions and HIV disclosure in the African context is considered to be a highly gendered phenomena, shaped by socially constructed roles and expectations for men and women (Lynch et al., 2010; Maman et al., 2001; Maman et al., 2003; Ragnarsson et al., 2010; Visser et al., 2008). Studies show that men and women’s reasons, contexts, and targets of disclosure can vary widely. Women more often fear violence and financial repercussions, while men more often worry about being exposed as unfaithful (Black & Miles, 2002; Deribe et al., 2009; Maman et al., 2001; Medley et al., 2004). Though violence was not voiced by women in the current study, loss of financial and social support were critical reasons why they refused to disclose their status to the people they depended upon, including new partners who supported their livelihood. Men in this study seemed less concerned about having their infidelities exposed but were more susceptible to the toll HIV bore on their sense of self-control and esteem. Other studies within the general population (Fitzgerald et al., 2010; Lynch et al., 2010), as well as with TB coinfected persons (Chileshe & Bond, 2010; Mavhu et al., 2010), demonstrate how the threat of HIV, viewed as vulnerability to death, may threaten the strongly gendered expectations of men in relation to their family or work, and their identity as indomitable heads of the household. The added burden of having TB may have heightened their perceived fears. The current study thus substantiates gender-based fears around HIV disclosure.
Partner reactions

Studies show that not only do men and women have different fears around HIV disclosure, they also enjoy different levels of support subsequent to disclosure. Negative outcomes are more commonly found among women compared men (Frye et al., 2007; Gielen et al., 1997; Medley et al., 2004). In the current study as well, disclosure prompted differential changes in the subsequent levels of partner support among men and women participants. Men who disclosed their status almost unanimously retained a degree of practical and emotional support from their wives or girlfriends. The outcomes of disclosure for women were markedly different.

Although intimate partner violence, abandonment, and emotional abuse are measured to be higher for women, the frequencies of positive outcomes are believed to outweigh negative ones. Women’s actual experiences post disclosure may thus belie many of their original worries (Medley et al., 2004). For women in this study, however, many of their original fears were indeed fulfilled. Most were rejected by their partners, either immediately following disclosure or in the short term when they insisted on safer sexual practices. In several cases, their boyfriends returned to other relationships they were concurrently involved with. The minority of women who enjoyed the support of their spouses were in long-term relationships or married, a finding that is in line with that of a meta-review examining HIV disclosure by women (Medley et al., 2004).

The outcomes of partner disclosures affected how participants decided subsequent disclosures. For women, negative experiences during early disclosures prompted them to hide their HIV status in future relationships, and foreground disclosure of their illness with TB. Most women did not disclose HIV to new boyfriends as they anticipated little support; their fears had already been realized in the past. Several women also perceived continued disclosure to be unnecessary so long as sexual activity was protected or avoided; however, safe sexual practices were not always sustained. The influence of early experiences on future disclosure decisions is poorly documented, particularly in the case of HIV coinfections. (Men’s decisions on subsequent disclosures are discussed at the end of the chapter.)

Reaching out

Based on dissimilar anticipated and experienced reactions from their partners, men and women sought support from dissimilar groups of people. Both enacted disclosure in an outward loop, starting from the people they were sexually involved with during the time of HIV notification. In the
case of most women, partner rejection moved them to disclose in exchange for support with their extended network. They continually weighed the social risks and benefits of disclosure (akin to theories of HIV disclosure discussed earlier). They disclosed to people they believed would respond least negatively, in terms of rejection and loss of access to resources, financial or otherwise. New partners were thus left in the dark, and family members, particularly sisters, became their closest confidantes. However, while some relatives tolerated their HIV status, many women were still left with a sense of isolation and despair within their homes. A general silencing of what Squire (2007) has termed “HIV talk” (p 5), prevented the emotional relief of discussing their illness openly. Consequently, when they felt stifled by their families and spouses, many women proactively ventured outside of their closest circles of confidence. They sought out and disclosed to their peers – other HIV-positive persons – with whom they would not be labeled with a social difference, feel discredited or stigmatized.

A lack of social support has been correlated with non-adherence (Shin et al., 2008), a poorer quality of life, higher perceptions of stigma, and poor mental health among coinfected patients (Deribew et al., 2010b). These quantitative correlations, however, failed to capture the distinctions between various forms of support and the impact of such distinctions on patients’ decisions to disclose, seek care, or access additional support. For women in the current study, tolerance of their illness by their families was unequivocally different from their ability to access any meaningful form of mental or emotional solace. It was this perceived gap in social support that led them to reach out to their peers. The study findings thus enhance our understanding of the social construct of support, by extending it beyond the sources of support (e.g., family or partner) to the perceived level or worth of such support (e.g., tolerance or acceptance compared to emotional comfort or relief).

**Peer support**

The value, comfort, and security in similitude found in peer groups has been documented among people living with not just HIV, but also mental health illnesses, cancer, and other chronic conditions (Swendeman et al., 2009). Peer support capitalizes on shared experiences and is believed to instill social inclusion, intimacy, and a sense of belonging where people are otherwise outcast and isolated (Coniglio et al., 2010; Witmer et al., 1995). The positive consequences of disclosure to peer groups in this study were two-fold: first, patients were able to access social support and comfort and second, they were able to shed a potential social cost (i.e., discrimination) because of a shared status with
their peer group. Common experiences reduced the likelihood of patients being stigmatized or rejected by others who were just like them.

Women more often reached out to their peer groups substantiating prior research that shows they are more likely to seek social support through disclosure despite their greater experiences with stigma and discrimination, and to build a stronger network of support against the negative effects HIV may have on their emotional health and wellbeing (Deribe et al., 2009; Gielen et al., 1997; Simbayi et al., 2007). Patients’ narratives demonstrated that their decisions to reach out were further prompted by an absence of emotional support and/or safety within their homes.

**Keeping it in**

In the case of most male participants, partner support obviated their need to disclose any further, or to bond with their peer group. As well, the perceived social cost of loss of respect and self-worth mitigated their willingness to disclose to extended family or friends, particularly when such relationships were already mistrusted. The few men who felt discriminated by the people they were closest to post disclosure tended to clamp up and revert to themselves for emotional support, to protect their remaining sense of self-worth and credibility. This substantiates prior research that has documented men’s preference to deal with their illness independently. However, far from implying that men may need less support compared to women, their perceived desire to cope on their own may perpetuate their greater internalization of stigma in the long run (Maman et al., 2003; Simbayi et al., 2007).

In these ways, gender roles appeared to influence how and why men and women shared their HIV status with others along different general patterns. The discussion also hints at the influence of access to resources on patients’ negotiated disclosures of TB and HIV, particularly from the perspectives of women. These are elaborated in the next chapter that ties patients’ experiences with stigma and disclosure to their need for material support, rather than just social or emotional support, and to broader socio-structural inequalities.
Chapter 6

Living with TB and HIV: cues, constraints and inequalities

This chapter further responds to the primary study objective of characterizing the illness experiences of coinfected patients, by embedding those experiences in their broader social and structural realities.

While Chapter 5 considered how disclosure decisions were shaped by the social construction of illness identities and the dual stigmatization of TB/HIV, this chapter extends the boundaries of patients’ social contexts of illness to consider how competing social, structural, and medical constraints further constitute and mediate their health experiences overall. Together with disclosure, patients’ participation, adherence, and retention in healthcare may be a function of their attuning a balance between various social and structural mediators.

I first present themes that emerged directly from participant interviews and field observations, including the ways in which patients’ lived realities were continually bound by extrinsic forces such as their access to economic and other resources, limits within the health system, and the consequent perpetuation (or mitigation) of stigma and powerlessness. I then critically discuss these empiric findings, and situate them within the broader literature base.

Analytic findings

Economic constraints: “I’ve got no food”

Sustained and, at times, urgent access to food and money was an imminent concern for patient participants. Many did not have a steady or independent income source and were unemployed prior to becoming ill. They typically returned to their family homes or moved in with siblings or extended relatives, as they lacked the means to support themselves. Some lived off a portion of their parents’ old-age pensions or siblings’ salaries. In some cases, no family member earned an income or received a government subsidy, and participants from these families had an especially difficult experience juggling their healthcare with basic life necessities.

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. No food, that's my problem. If my grant is alright, I don’t mind, I buy the food. (F, site 1)

Most patients who were employed prior to their diagnosis had to stop work for a period of time on account of their illness. They reached a point where they could no longer access care or adhere to treatment without some flexibility in time, with or without their employer’s support. For many, the discontinuation was permanent, either because they were physically unable to continue working or because their employment was terminated.

Access to grants: “you got to be I think dead before you’ll get a disability grant”

Disability grants, applied for at patients’ HIV clinics and approved by district surgeons within the Department of Social Services, were a common resource for temporary financial aid for patients with limited or no access to earned income. The topic of grants was regularly cited during interviews with patients and HCWs, most often in reference to the difficulties experienced with accessing them. Eligibility was understood to be a function of one’s HIV status particularly with respect to a low CD4 level. Having TB was insufficient grounds for approval, and ART as well as TB treatment could raise CD4 counts above the eligibility threshold. The strict approval criteria left some patients feeling powerless and others resentful of the governing system of social assistance.

The times 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 because this young one, never get it... this pension, they didn’t give me, they said my CD4 count, as it was saying 249, I won’t be able to get the one for TB... They said, ‘No, we won’t be able to’. Hey, they didn’t do it for me. (F, site 2)

That story about CD4 count for getting a grant is rubbish... I think the government must work in to, they must work in to the government, because many people can’t use medication without eating. They must, if you use medication, you must have a good work. 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. That is the thing that I must have to look on. It doesn’t matter what your CD4 count, the grant is only there to help you for your treatment your medication or whatever. That is what the grant is to be now to for me now, for us. My grant close, I don’t wanna go back, ‘cause I know I’m not gonna qualify. (M, site 3)

Grant ineligibility and consequent financial difficulties appeared to worsen patients’ overall burden of disease. It left them with insufficient food to tolerate drug regimens, and at times, insufficient money for transportation. Several women described begging at bus stops to reach their clinic or walking for several hours despite physical disability, as they could no longer afford the bus fare. Health workers echoed these constraints when narrating their experiences with coinfected patients:
There’s one chap here I saw, he’s last worked in 19, no 2002. He got a 6 months grant, it’s been stopped now. His sister phones me, says ‘Please you must stop coming here ’cause I can’t give him bus fare to come here because I’ve lost my job so he must be transferred out to the local clinic’. (HCW)

Healthcare workers, too, balked that grant eligibility was based on clinical indicators that belied their patients’ complex social circumstances, and that grant approval varied across districts. They felt CD4 counts were an insufficient measure of how difficult it might be for patients to access basic resources. Quoting one HCW, a patient had to be “dead” to be approved for a disability grant.

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, and I phoned the guy, I actually knew him, I said this guy really deserves a grant. I ask, I tell them, get a wheelchair or carry them into the room, I said, because they might believe you then. (HCW)

The (lengthy) narrative below from another HCW taps into the convoluted social cycle of grant eligibility and distribution, and its relation to the infrastructure of the governing authority in terms of competency, access, and resource prioritization. The HCW worried about the government’s apathetic focus on medical indicators and disconnect from the social realities of many patients’ lives.

We have quite a lot of patients whose grants are turned down... by somebody who is paid by the government to do grants, and I suspect to turn down, to keep the numbers down. Part of the problem is that the criteria for grants are purely medical. And I often see, for instance, a woman whose sisters have died of HIV and is looking after maybe six or eight children, and she’s the only caregiver. Now we find that she’s got HIV, and she’s got a low CD4 count and she needs antiretrovirals. But she hasn’t got the funds to travel all the way to [hospital] once a month to fetch her antiretrovirals. So I try and get her a grant. Now, she may well be well enough to keep down a light job. But there aren’t any light jobs. So I will write the thing saying she qualifies for a grant. But the guy, the other doctor, doesn’t look at the social issues... He’s not supposed to. He’s supposed to only look at whether the person is medically incapable of work. And he will often turn down the grant. Now the result of that of course is that she doesn’t go for antiretrovirals. So then she returns later, maybe 6 months later. Now she’s incapable of working. Now she gets her grant. But the trouble is she’s deteriorated seriously and we get her on to antiretrovirals and she may or may not survive. So those children are at huge risk because of that kind of monocular vision. I can see why the department of welfare keeps this. I mean, the problem is that we’ve now got a population in South Africa where 25% are HIV positive, and large numbers of people who are now no longer able to work because of HIV and large numbers of children who are at risk because of the death of their parents. And the numbers, numbers game is so enormous that the national fiscus kind of gets overwhelmed, so they try and put in these barriers, but they often counterproductive. They actually create a problem rather than solving the problem. (HCW)
Grant unavailability and the subsequent lack of resources may also have negatively affected some patients’ adherence, and compromised their clinical outcomes. Healthcare workers described dealing with patients who had stopped or altered their treatment in order to maintain a CD4 count below the grant eligibility threshold.

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, something that, which is becoming more of a problem... you know with HIV grant, they have the grant which is meant to be temporary for a year and then normally when their CD4 count is above 200, its stopped. Its 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)

Patients as caregivers: “it’s my heart who is working”

In addition to difficulties associated with taking care of their health, several patients were primary caregivers to their families, including young children, spouses, parents, and at times, an ill or aged relative. Participants commiserated on the difficulties with accessing sufficient food and money to look after themselves and their dependents, people with whom they lived and to whom they were expected to send money. Disparate gender roles and expectations within patients’ homes and families were also apparent. Men were typically the financial providers, and they usually enjoyed the support of a wife, girlfriend, mother, or neighbor when looking after a child. In contrast, women tended to be responsible for providing direct care as well as financial support. They were expected (and appeared to expect it of themselves) to help with domestic chores, tend to older relatives, younger siblings, their own children, and the children of deceased relatives. They more intently described putting aside their own health problems to ensure their families were taken care of. They pushed themselves to continue work and earn enough money for the wellbeing of their children.

I went for testing, doctor said that my sputums were negative and my picture was negative so I told myself that it means I don’t have a problem. I stayed, I continued at work. Then by November, I realize that hey, 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, Site 2)

Experiences at work: “when you feel sick they think you’re lying”

Patients who were employed experienced mixed levels of support from their employers, subsequent to developing symptoms of TB and HIV. In a few cases, patients felt their employers’ lack of support may have perpetuated delays with their diagnosis and treatment of TB.
I worked there for a very long time, and what made me leave the place, it’s when you know when you’re sick, when you feel sick, they think that you’re lying. They don’t let you go to the doctor. That’s why I discovered my TB late. (F, site 3)

Many women working in temporary jobs were let go once their employers discovered they were sick with TB. The underlying association with HIV/AIDS was apparent and consequently, some participants left work without disclosing either infection.

People cannot accept person with these diseases because they scared that she might infect others. Most of the time where I worked, its restaurants, and there no any other job I can able to do because that’s where I worked the most and having experience for there. Because they will say, ‘Firstly, it’s the restaurants, you’ll be carrying food for the customers’, you see that... Such that where I was working, they knew that I have this thing such that they asked me to go. (F, site 1)

I couldn’t tell them [i.e., employers]. They were gonna 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, you see? (F, site 3)

Women and men who worked in the industrial or formal business sector, on the other hand, tended to receive some support in terms of time off work and/or sick pay subsequent to disclosing they had TB. Compensation was generally provided during the intensive phase of TB therapy, which lasted 2 to 3 weeks. Two male participants went on to receive work-based DOTS for the remainder of their treatment course.

**Negotiating support: “they took me so good but I didn’t tell them about the other thing”**

As a result of financial instability, grant ineligibility, compromised access to food and shelter, mixed levels of support from employers, and the burden of finding as well as providing care for their families, many patients negotiated disclosure of their illness with caution and forethought. While they had needed to disclose that they were ill in order to gain some social and financial assistance, the degree of information they shared was balanced against the risk of losing that assistance.

Below is the case of one woman whose partner left her and their son when she fell ill. She was let go by her employer, and could neither afford nor was physically able to care for her child. She sought help from her extended family but worried it would end if they discovered she suffered from HIV.

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
Similarly, patients who received employer support post TB disclosure were careful not to share more than their TB infection at work. They feared information about their HIV status would result in termination of whatever support they had managed to earn thus far.

I didn’t tell her [i.e., employer], I just said that I am suffering from TB, what else was I supposed to say? I didn’t say about any other thing… I told them that it’s said that I’m suffering from TB… Hey, 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, site 2)

The potential negative consequences of being known to have HIV within the workplace were recounted by HCWs. They understood some coinfected patients used TB as an “excuse” to stave off the (greater) discrimination associated with HIV. Letters to patients’ employers requesting sick leave were carefully worded, without direct reference to HIV. In many cases, omission of any reference to HIV illness was at the explicit request of their patients.

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 here so, and 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 here? What can I tell him?’ and that’s been quite a issue... they’ve lost their excuse. Sometimes we’ve actually written letters just to say that this patient requires essential treatment. This is they’re, they need to come every month here... I just say, enough said, essential treatment. (HCW)

Only two of the women who were employed at the time of HIV notification disclosed their HIV status to employers and received some degree of support in terms of compensation and/or time. In both cases, participants described having shared a positive and long-standing relationship with their employers prior to their illness. One was a domestic worker and had been afforded time off and some financial aid. The other worked in a salon; her boss had helped pay rent while she was hospitalized, and gave her time off during the first few weeks of TB therapy. She also enjoyed some flexibility in hours in order to adhere to appointments at her HIV clinic.

**Access to concurrent ART: “most of them die whilst on the waiting list”**

Several coinfected patients believed they had experienced or were currently experiencing delays with access to ART. Delays reflected overlapping clinical and health system constraints, discussed below, together with challenges experienced at the social or personal level, discussed further ahead.
Just as CD4 counts were tied to grant eligibility, they were additionally a criterion for ART eligibility. As was introduced in Chapter 4, under the national rollout scheme at the time of the study, persons diagnosed with HIV needed their CD4 counts to drop below 200 in order to be considered eligible for ART. Tuberculosis was insufficient ground for eligibility. This worried many patient participants, as they had witnessed or known of other infected persons who succumbed to illness because they had failed to meet this clinical threshold.

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. You know if I can count the nearest clinics, the nearest to our homes, the one they are talking about, they don’t give the treatment soon. It can take even 18 months, still attending up until she dies. You see there is another child from [town], she died without them giving treatment at that place. And I’m the one who brought that one, my heart was sore, I didn’t sleep. Every time when she was sick, the family called me, when she was sick they will call me. We brought her to [clinic], they checked her and she went to [clinic], I don’t know what’s happening with the CD count... out of ten people only two were they saying the CD4 is going down, all others are right [i.e., only 2/10 will qualify for ART]... but you can see that this person is finished. (F, site 3)

Others, who were denied ART at the time of HIV notification due to their higher CD4 counts, were told to return to their HIV clinic for semi-annual examinations and re-evaluation for ART. Many of these patients indicated that their ineligibility for ART and apparent physical wellbeing had pushed them to discontinue accessing care, until they fell ill with more debilitating symptoms related to TB.

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 337, but I just forget about that up until its now, when I’m coming back. (F, site 2)

Healthcare workers, too, expressed frustration with ART eligibility criteria particularly for TB patients, who they believed needed urgent attention regardless of the stringent clinical indicators.

It’s a vertical structure, it is very, they’re very strict and I mean, there have been many patients that are with CD4 counts of above 200 that I would think should have – for instance, we have patients who are now developing their third attack of TB but now if they’re anti, if their CD4 count is still about 200, they don’t go onto antiretrovirals. (HCW)

They further complained that long waiting lists due to oversaturation of the national rollout program, a lack of policy dissemination, and misinformed colleagues further compounded delays with co-treatment, and contributed to their patients’ poor experiences with TB and HIV healthcare.

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 gonna kill you if you take it whilst when you
on ARVs. So, oh, park the ARVs, take the TB treatment'. Patients get confused, they get sick,
they fall, they get, they fall into liver failure and they die. (HCW)

Perceived delays with access to ART were essentially a mixed bag of challenges that manifested and
intersected at the medical, operational, and social level. One woman, cited below, was diagnosed
with HIV years prior to the interview. Since then, she had experienced very challenging
circumstances including a pregnancy followed by a miscarriage, trials with traditional remedies,19
rejection from her spouse, abandonment from her parents, and the recent death of her only
supportive relative. The medical complication introduced by TB coinfection, operational delays with
clinic referrals, and her HIV clinic’s subsequent decision to avoid co-treatment despite her low CD4
count, were just additional obstacles mitigating her ability to start ART and receive adequate care.

They [VCT clinic] did a letter because of course, my CD was low. I must go that [HIV clinic]. It
[i.e., CD4 count] was 161. I must go there. They then asked and I told them of course I have
started the class at [hospital clinic]. I then went there. 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. I then
waited... They told me to wait 3 months or 4 months, they will see how is my blood then
they will let me start, maybe sometimes when they will start me, when I have just started it,
then they will interact too much. It’s better maybe, if there are few months left to finish. (F,
site 1)

Saying no to ART: “I just want to finished these ones for TB first”

Following from themes arising from the preceding narrative, several patients shared their personal
reasons for discontinuing or deferring the initiation of ART.

Some patients who discovered that they were HIV-positive during their TB diagnostic workup,
wanted to hold off initiating HIV treatment while being treated for TB. One participant, cited below,
hoped TB chemotherapy would restore his health to a point where he no longer needed additional
treatment. His girlfriend, who was also HIV-positive and had encouraged him to be tested in the first
place, recently left him. He was exhausted and stressed trying to support his larger family, and had
lost “amandla” or the physical and mental strength to deal with ART at the time of the interview.

It [i.e., CD4 count] said 1... 144... They said I am supposed to use tablets, the ARVs. I am
supposed to go to my nearest clinic using it... 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 [i.e., amandla, in original, isiZulu]. I just said maybe, if I have picked up [i.e., got well],

19 Patients’ experiences with traditional remedies are further discussed in Chapter 7.
must be that I have to check on June as well that I will be right to use the ARVs. If still something happens I will just use them. (M, site 1)

Based on interactions with patients at their current and previous places of practice, HCWs cited fear, mistrust or disbelief in the efficacy of ART as an influence on their patients’ decisions to delay or refuse ART. They tied patients’ attitudes to the history and politics of ART availability in South Africa.

HIV is [a] problematic thing, because of history I think of this country, it being that ARVs are not good for you, that they’re toxic, and even now some of patients have been absolutely scared to start. I mean they sort of want to start, but they, actually, ‘I’m very scared, I’m very scared’. And you have to sort of try to work them through this message that ARVs are toxic. (HCW)

In the case of one patient, his apparent physical recovery from several months of ART prompted him to discontinue ART (despite its timely prescription), and stop attending his HIV clinic. The physical deterioration associated with TB later prompted him to re-connect with medical care.

In 200[X], I make a CD4. I found my CD4 is also 94. I was supposed to start ARVs. So I get a counselling, all that stuff, so I don’t know use it, starts to use it. 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, because I got a pain in my back... when I am sleeping, I’m sweating... 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 all in the chest and spine... So I found out that I got a problem. So when I am speaking to the doctor I saw that, 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, uh-uh, I was went, I was going with a job at [town] so I didn’t remember to make the, all different stuff so they believe me (M, site 1)

Fears to adhere: “I just said no, its quits, let me go back to my life”

At the time of interview, most study participants were receiving ART and TB chemotherapy. Some used telephone alarms or the broadcast of a popular television show as a reminder to aid adherence. Those who enjoyed some support from their partner and/or family were also reminded by them to take their daily medication doses. Adherence cues, however, were not always accompanied by full disclosure. Patients stated that their relatives (including young children) would offer them helpful reminders without fully knowing what exactly the tablets were being used to treat. Very often, participants had only disclosed they were being treated for TB.

Others described hiding their medication, or delaying or skipping a dose of treatment to avoid being labeled as a sick person, or being questioned about their health. They believed that within the context of their communities, illness equaled AIDS, as a function of TB or otherwise.
I hide ARVs. I hide them because I just lock my suitcase and lock them... its because of course we don’t use other person dresses, you see that. I just took out my tablets and wrap them with tissue... I will put them in my breast knowing that if it’s for me to drink them, she 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, site 1)

I never took it yesterday. You know I’m a very shy person... Now, house is always full. Now, its 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, but sometimes I do it, no, my friends now blocking me. I can say no, I can pop it. My thing. 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... That’s the reason where I forget to use my ARVs sometimes, then I cover up in the morning... For now when there’s people, they are smoking there its not easy but no man, I say, it is my place I have to eat. They’ve got their place. I didn’t ask them to come smoke here... That’s the reason where I forget to use my ARVs sometimes, then I cover up in the morning. (M, site 3)

The desire to remain secretive was strong for many patients both in their homes and in public. Not only did this impact adherence to prescribed regimens, it further influenced their decisions to attend clinics or access medical support. This was particularly true among women diagnosed with HIV several months or years prior to developing TB, and who had been ineligible for ART at the time. Just as the fear of being identified as ill with HIV impeded some patients’ adherence to treatment, it also impacted some patients’ (particularly women’s) retention in HIV care.

Below is an account from a woman who discovered that she was HIV-positive as an adolescent. At that time, she was unprepared to deal with her diagnosis and had avoided confronting this “truth” she intensely feared. The social consequences of being identified at an HIV clinic, where her identity could be stigmatized prompted her early decision to “quit” care. That she had felt and looked physically well further cinched her health decision.

When I first check, they said I must go to the clinic... it was like a couple of months, and I just said, you know what? I’m feeling well so what, why am I coming here? Because people are gonna see me. I was still young. Why am I coming? I was about, maybe 16 or, you know. And I’m saying, people are gonna 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... I was still at school... just 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, site 2)

Fears around HIV disclosure had prompted several women to hide their HIV status from others even years after being diagnosed (discussed in Chapter 5). As a result, they had avoided accessing any
form of medical care. Unable to confide in loved ones, they cocooned themselves in secrecy and avoided dealing with their HIV infection until the more acute symptoms of TB arose.

Some of them admitted how they might have compromised their health by refraining from attending an HIV clinic, due to their continual worry and fear of how others would perceive them.

I was afraid that people will see me turning and coming here... and that if I don’t come, I’m killing myself, just by being afraid of people. (F, site 2)

However, for some participants, particularly those with glandular manifestations of EPTB, the stigma associated with the physicality of their illness encouraged their adherence to treatment. Obvious symptoms and the related fear of being persistently associated with HIV motivated them to continue accessing their clinics. They realized that compliance would not only assure quicker recovery, it could confer quicker invisibility against the label of AIDS.

I wanted this thing, this thing to be finished, yeah, to be finished [points to enlarged neck, from glandular TB]. Because everybody, if you are... they are looking at you, so, eh I was so embarrassed. People are looking at you. So that’s why what make me not forget to take this tablet. (F, site 1)

Feeling alive: I’ve forgotten about death

Within most interviews, patient participants described feeling bereft of hope when they first came to know they had HIV, often in conjunction with a TB diagnosis. As described earlier, a few patients had been afraid to start ART at first. Concurrent TB therapy and a general lack of trust in conventional HIV medicines may have contributed to their hesitation, together with delays manifested within the health system. Mostly, however, they had felt stripped of confidence, hope, and power (“amandla”) as a result of the shame and death associated with their illness. When asked about their participation with clinic and community based support groups or their interest in doing so, most participants said they were not interested or did not have the time. They felt uncomfortable speaking out.

Me, I don’t like to talk. I just came and sit down and read the paper when I am bored. Sometimes I, we heard some ladies talking about one topic but me, I don’t feel comfortable. (F, site 1)

However, several patients described how seeing other patients getting better and looking well on HIV medication encouraged them to attend their HIV clinic and to seek treatment for HIV.
People, they are afraid of talking about this thing... but the only lady who is confessing at the work, only lady who was saw me that time I was sick, she said, ‘Don’t be afraid. I myself am taking ARV, just go to there and take the ARVs, you will be right’. So I was very confident I was coming here with that confidence of that, there’s many people who are taking the ARVs. So why am I one who is afraid? Because all these people are right. They are not sick, they are beautiful than me. Why am I afraid of taking this? That’s why I am coming with it, I am coming it here. (F, site 3)

I was just hearing on the TV and on the radio about the ARVs. Since I am here to meet my friend, my neighbor, and I saw her taking it. That’s why I getting the confidence to take it, because I saw my neighbor is healthy, she is very beautiful and I ask her, ‘Why, how do you manage to take the ARVs because I am afraid of it’. She say, ‘It is just a tablet like any other tablet like panadol’. She just say, ‘Drink it, like nothing else’. So I say I will try it, and I try it again and I try it. (F, site 3)

Many participants, who were on ART for several months, some for years, described how relieved and hopeful they now felt compared to when they first accessed care. The physical improvements from treatment translated to a sense of emotional wellbeing. It enabled them to shed fears related to death and dying, and promoted hopefulness towards their future.

I used to say, if a person is talking then they will say, ‘Hey just leave me, can’t you see that I’m about to die?’... Its better now, I’ve forgotten about death. I’ve just forgotten but I don’t know what made me to forget (laughing), I liked it so much. If you visit me, I would say, ‘Hey, just leave me I’m about to die’. Now, I’ve forgotten as I’m eating these tablets. I completely forgotten about the issue of dying. (F, site 2)

For many, ART was a lifesaver, both corporally and mentally. One patient described ART as “gold”. The success of his treatment allowed him to feel positive about himself, and overcome the shame and silence associated with his illness.

HIV, I can’t follow it, it’s all over, it’s in the air. I can’t say it [i.e., ARVs] can heal you, but it can make you live a little bit longer, than what you supposed to live without using treatment or medication. It’s, it is a benefit, I can say it helps you a lot, you feel more positive in your own life because of this ARVs... I think ARVs that’s, that is a gold, that’s a gold for people... There is a couple of people [I disclosed to] because how come, I’ve just decided, no, man, this thing is not something to hide. This thing is all over. There is no shame about it. You feel the shame because maybe, maybe this person who talking, she haven’t got it... They believe if you got this thing, you, if you say you sick, you feeling weak... But as you get thing is, right medication, treatment like ARV’s, there is a big difference. You feel, no, you did nothing wrong. This thing is out of your blood. You feel like that to be honest, you feel like there is nothing in you. (M, site 3)

Patients living with HIV for longer periods of time slowly came to realize they were not losing the battle against AIDS. Though it was still a permanent fixture in their lives, it was not the death sentence they once perceived it to be. It eased their fear of dying, and of being perceived in a
negative social light. They began to feel more confident and started to accept their identity associated with HIV.

I’m no longer nervous. It’s at the beginning when I was afraid. Now I don’t have a problem because I just say I’m from the clinic. I direct them that not this one down [i.e., clinic down the road], I say this one up [i.e., the HIV clinic up the road]. They know that this one here, what is it for. (F, site 2)

I was thinking that I will become sick, same like other people with it. Maybe I will sleep on bed. Maybe I won’t reach certain year. But I was alive, proceeded with this life. I realized that if I take care of myself, I will be able to carry on with my life... Now I believe. I can see that ok, oh right, I’m HIV, I accept with my heart. It’s not the same as before that hey, I’m really sick. (M, site 1)
Discussion

Review of the findings demonstrates how social, medical, and structural forces shape the experience of TB/HIV for coinfected patients, and the potential and real impact of such forces on their decisions and ability to access and adhere to healthcare. The findings further contextualize the lived experience of coinfection, and link their health-related actions to this broader social context. My interpretations drew on the work of Eakin & MacEachen (1998), Link & Phelan (2001; 2006), and Parker & Aggleton (2003). I also continued to analyze the social construction and reproduction of TB/HIV stigma as it was an overarching theme across participant narratives.

Aside from coping with physical symptoms, coinfected patients simultaneously dealt with impoverishment, life responsibilities, difficulties in accessing support, and the (stigmatizing) social symbolism of their illness, phenomena that were often beyond their direct control and which intercepted with broader issues of socioeconomic and gender inequality. Patients were also exposed to positive influences that inspired hopefulness and strength to take action. These subjective constructs collectively mediated their health-related decisions, such as disclosure, adherence to, and retention in medical care.

Impact of competing constraints

Economic hardship

Loss of employment and ineligibility for government subsidies brought the threat of food insecurity and economic deprivation to the forefront for most patient participants. The physical symptoms of TB/HIV disabled many from being unable to undertake paid work, and the generally high rates of unemployment resulted in pervasive impoverishment. Despite this, patients continued having to provide for their families and children. The higher financial burden of dual treatment (due to indirect medical costs and job loss), and constraints posed by having to juggle multiple responsibilities has similarly been found in prior quantitative and qualitative work with coinfected patients (Chileshe & Bond, 2010; Sadoh & Oviawe, 2007).

Patients in this study also experienced frustration and distress with respect to government subsidies that were only accessible on the basis of firm clinical markers. These markers belied the dual morbidity of their illness and the day-to-day responsibilities that they were unable to escape from. A recent survey from South Africa found that people living with HIV were routinely denied access to
government subsidies due to its stringent allocation based on a CD4 level below 200, which the authors assessed was an unreliable indicator of an individual’s functional ability (Phaswana-Mafuya et al., 2009). Studies additionally show that patients’ quality of life with coinfection is unrelated to their CD4 count or HIV stage, but rather directly tied to their access to material support or income (Deribe et al., 2009). Job loss and poor access to grants, despite being debilitated by not just HIV but also TB, likely left coinfected patients in a doubly precarious socioeconomic position.

As a result of having little or no income, many patients were continually reliant on others for access to resources such as work, food, childcare, and even transport to their clinic appointments. Their physical symptoms left them unable to completely ‘pass’ as normal but they were compelled to present themselves in ways that invoked the least degree of social undesirability, so that they could gain access to resources. The preemptive disclosure of TB over HIV was again apparent to the people whom they depended on for some form of material support. It helped patients deflect the greater negative symbolism of HIV, as was discussed in Chapter 5. Some patients worried about what would happen once they completed their TB treatment, when their ‘cover’ would essentially be lost, and they might have to relinquish the support they had managed to earn thus far. Several patients commented on how their employers and families had given them much-needed support with work and childcare on account of their illness with TB, but firmly believed that such support would end if those supporters were to ever discover that they also suffered from HIV. Researchers studying theories of HIV disclosure have recognized that one reason why patients may eventually disclose their HIV status is to access material resources (Serovich et al., 2008; Shaikh & Hatcher, 2005). The necessary selective degree of information sharing in exchange for access to essential resources that was analyzed in the current study refines how such theory may be applied in the context of HIV coinfections.

**Gender inequality**

The backdrop of gender inequality in patients’ experiences with illness in relation to their access to resources and ability to adhere to treatment was pervasive in study participants’ accounts. Higher levels of unemployment, poverty, and dependency on others are known to drive a disproportionate loss of control among women with TB or HIV, compared to men (Johansson et al., 2000; Lekas et al., 2006; Maman et al., 2001; Sanou et al., 2004; Voeten et al., 2004). These disparities are found to be critical determinants of women’s health seeking (Hunter, 2007; Krishnan et al., 2008; Tarimo et al., 2009). Although women may be more conscientious about their treatment due to a desire to stay
healthy for their children, their obligation to fulfill competing family responsibilities is, paradoxically, also found to be a critical impediment to their retention in HIV care (Geng et al., 2010).

In the current study, the disproportionate effect of poverty and dependency, and the higher burden of social responsibility and accompanying stress were decidedly higher among women participants. They were at a disadvantage in terms of their socioeconomic status and social capital, more often jobless and without a partner, and as a result, often with greater need for material support. The burden of fending for their extended families and children generally fell on their shoulders. As a result of these stresses, they had to balance access to material resources and childcare, disclosure of their illness, and decisions to retain care more carefully and fearfully. The study builds on earlier research that show how women’s subordinate social position may leave them with little power or agency to prioritize their health over meeting other obligations in their home (Chileshe & Bond, 2010).

Both economic adversity and gender inequalities point to the broader social inequalities in which patients’ lived experiences with illness were set. These social and structural hardships contributed to the perpetuation of TB/HIV stigma, which is discussed further ahead in the chapter. Challenges identified at the health system level also reinforced the ways in which health decisions were made. These issues are discussed below.

**Health system constraints**

The financial hardship of illness experiences with TB/HIV, and extant gender inequalities, was compounded by health systems constraints that inhibited patients’ timely access to TB and HIV treatment. Rigid policies guiding the prescription of ART excluded many patients from early initiation based on their higher CD4 counts. National guidelines at the time of the study did not guarantee ART for all TB patients, a fact that disheartened several patients and HCWs alike. Difficulties with diagnosing atypical TB may have provoked delays with TB treatment, and poorly trained HCWs may have further delayed ART in potentially eligible patients (i.e., patients with CD4 counts below 200). Such deficiencies within high-burden countries are reported in the literature, and were discussed in Chapter 2. What is less known is that health system constraints may compound patients’ decisions to default from HIV-related care.
Ethnographic work from rural Zambia revealed how severe financial hardship and persistent lack of food crippled the families of coinfected patients. Delays in accessing ART due to health system deficiencies merged with patients’ economic instability and disabled them from attending HIV clinics, and maintaining adherence to care (Chileshe & Bond, 2010). Findings from this study corroborate that work, and extend insight to the intersection of these economic and health system constraints. In the current study as well, the unavailability of ART catalyzed some patients’ inclination to delay or avoid subsequent HIV care, particularly in light of their other social responsibilities.

Reports from South Africa point to escalating rates of patient attrition from HIV programs (Padayatchi et al., 2010). Findings from the current study lend insight as to why such attrition may occur, that is, as a result of their poor access to ART against a backdrop of socioeconomic hardship. Findings additionally highlight how attrition may be further catalyzed when patients feel physically well. This connection between patients’ perceived wellbeing, experiences with stigma, and health-related decision-making is discussed further throughout this discussion.

A recent quantitative review found that, in lower income settings, the risk of attrition from HIV programs to be significantly higher among HIV patients with higher CD4 counts who were ineligible for immediate ART compared to persons with lower CD4 counts. The review further showed that surveyed ‘defaulters’ cited stigma as their primary reason for non-retention (Geng et al., 2010). Here too, while patient participants’ CD4 levels were not measured, their experiences being denied ART compounded their perceptions of HIV stigma. This perpetuation of stigma played a crucial role in their health decisions, as is discussed further below.

**Stigma**

Stigma related to TB/HIV underscored many patients’ actions in relation to their illness and healthcare. The fear of being discriminated against or labeled with TB and/or AIDS resulted in job insecurity for several patients, greater dependency, and an accompanying loss of social status. It affected how they disclosed their illness to family members whom they depended on for food or shelter or childcare. Among women, it also affected how they shared their illness with new boyfriends, as was discussed in Chapter 5. Patients persistently strove to maintain equilibrium between stigma and access, between access and support, between support and disclosure, and between disclosure and stigma.
The impact of stigma on study patients’ health decisions for TB and HIV was profound. The threat of being exposed and identified as an HIV patient had discouraged several patients from accessing HIV care at their clinics despite knowing that they were HIV-positive. The lack of support in their closest relationships compelled them to internalize the stigma and abstain from accessing any form of medical care (sometimes for years) until they became ill with TB. While weighing the costs of delayed health-seeking for TB symptoms against the fear of discovering one’s HIV status has been documented (Kanyerere & Aase, 2005; Mavhu et al., 2010; Ngamvithayapong et al., 2000), the current study illustrates how such fears continue to discourage patients from accessing medical care even after they become aware of their coinfected state. Similar to the review introduced earlier (Geng et al., 2010), this study also shows that while stigma may drive patients to default from HIV care, it is reinforced by their poor access to material support and clinical resources such as ART.

For patients who were on dual treatment, the fear of being discriminated against and abandoned prompted them to conceal their medicines at home, and may have compromised their adherence to both TB and HIV treatment. Indeed, patients reported skipping doses to avoid being labeled with HIV. The study thus supports findings from prior research, where coinfected patients’ adherence to TB and HIV treatment were compromised on account of perceived stigmas (Gebremariam et al., 2010; Naidoo et al., 2009), and when they experienced a concurrent lack of social and material support (Shin et al., 2008). The stress of having to conceal one’s medication, and thus one’s HIV diagnosis, has similarly been found to aggravate experiences with stigma and adversely affect the quality of life of HIV-positive patients in other settings (Parke-Wyllie et al., 2007).

A quantitative study from India, however, found stigma to be an insignificant contributor to coinfected patients’ adherence to TB treatment. But surveyed patients were not on ART (Sardar et al., 2010), and the association of TB with HIV in that geographic context may also be less strong (Somma et al., 2008). The current study, instead, highlights two critical points. First, it shows that in this high HIV prevalence setting, stigma likely does influence patients’ adherence to TB/HIV treatment and care. Second, findings show that when considering adherence to both TB treatment and ART, the consequences of stigma on either treatment may vary widely; the stigma of accessing HIV-based treatment and care was perceived to be far worse. While several patients described discontinuing attendance from their HIV clinics, they did not generally report similar actions against TB care. The study thus urges distinctions in understanding how stigma related to TB and HIV may have unequal effects on coinfected patients’ adherence to TB therapy compared to ART or to other
types of HIV care. Furthermore, several patients pretended they were taking TB medication believing it to be less stigmatizing compared to ART (following their selective disclosure of illness with TB over HIV). This adds to findings from the only other qualitative study on experiences with integrated treatment, where coinfected patients stated that their TB treatment forged a safe space within which they could conceal the fact that they were also being treated for HIV (Gebrekristos et al., 2009). In the current study as well, TB treatment allowed the ‘covering’ up of ART and the corresponding stigma of HIV.

**Inequality and the perpetuation of stigma**

The convergence of economic, medical, and structural constraints that was apparent in this study reflected the inherent social disparity and inequality underlying patients’ lived experience with TB and HIV. It aggravated their susceptibility to the effects of stigma, and rendered their health decisions to be inevitably socially informed.

Financial instability made women more reliant on others, and diminished their sense of power and confidence. Unequal gender roles, discussed earlier, imposed upon them a greater social burden and responsibility. Gender disparities have been found to trigger women’s greater susceptibility to the effects of stigma, an unwillingness to disclose illness, and to access necessary medical care for TB and for HIV (Courtwright & Turner, 2010; Medley et al., 2004; Somma et al., 2008; Ssali et al., 2010), all of which were also evident in the current context of coinfection. Women participants’ unequal gender roles within the home, workplace, and in their sexual relationships reduced their ability to resist the stigma of TB and HIV. They were consequently less able to discuss their illness openly to the people they depended on. Stigma, particularly in relation to HIV, also prompted them to give up accessing HIV care, particularly when other financial and health system constraints such as CD4 levels were not in their favour. Findings from this study thus corroborate earlier studies that emphasize women’s greater social burden of illness and poorer access to support and care.

While individual instances of discrimination, or the fear of discrimination, and loss of support were the more proximal determinants of patients’ health-related actions vis-à-vis disclosure and adherence to care (such as skipping a dose of medicine or concealing one’s HIV status from their employer), these proximal issues were embedded in much broader social structures of gender inequality, class, and power. Such inequalities synergistically diminished patient participants’
capacity to escape the cycle of fear, shame, and blame. Patients’ interactions with their family, employers, and spouses were a product of these social and structural forces.

As a means to resist discrimination and a further loss of status, patients continually balanced their clinical need for medical attention against their social need to save public face. They balanced their dependency on others with selective disclosure and the need for social acceptance. Even when access to care was granted by the health system, participation was weighed against the social consequences of accessing such care. Just as patients had weighed the social pros and cons of disclosing illness (in Chapter 5), they calculated the costs of accessing and adhering to care. Stigma pervaded their health decisions, and variables such as weight loss, physical debilitation, and CD4 counts served as catalysts, at times pretexts, for decisions intended to resist the maximum degree of stigma: that is, to either reject participation in healthcare to avoid the stigma associated with accessing such care (i.e., be identified at the clinic), or to seek participation in healthcare to remove the stigma associated with a visible illness (i.e., weight loss). For instance, although the visibility of symptoms motivated some patients with EPTB to adhere to care, adherence was governed by their desire to recover a ‘normal’ bodily appearance, reflecting the gross perpetuation of TB/HIV stigma even within those health decisions. While the influence of stigma on health decisions related to TB and HIV testing are better understood (Daftary et al., 2007; Edginton et al., 2002; Kanyerere & Aase, 2005; Ngamvithayapong et al., 2000; Njozing et al., 2010; Obermeyer & Osborn, 2007; Yi et al., 2009), its omnipresence in the decision-making of patients known to be coinfected despite being offered access to care has not been documented, and was highlighted in the current study.

Social scientists allude to the social epidemiology of TB and HIV by noting that they affect the most poor and marginalized segments of society (Farmer, 1996; Gandy & Zumla, 2002; Parker & Aggleton, 2003). In the words of medical anthropologist Farmer (1997), “those least likely to comply are those least able to comply” (p 353) as a result of the systematic and disproportionate impact of structural phenomena such as sexism, classism, and racism on not just the risk or emergence of (preventable) diseases but also the ability of people to access and receive treatment (Farmer, 1996; Farmer, 1997). The ethnographic case study from Zambia, mentioned earlier, is one of the only studies to have examined how the absence of financial support, poor access to food and other basic resources, difficulty of illness disclosures, and health system inefficiencies all barred access to dual care for households affected with TB and HIV. In that study, stigma was cited as yet another social constraint to care (Chileshe & Bond, 2010).
The current study instead shows that rather than being just one more ‘variable’ in patients’ decision-making, stigma is an over- and under-arching theme, the manifestation of which overlaps with preexisting structural inequalities. Poor access to basic resources, unemployment, and poverty diminished patients’ power, and honed susceptibility to the effects of stigma from the very outset. Stigma surrounding HIV (and in this context, TB/HIV) allowed for a re-enactment of what social scientists have termed structural and symbolic violence (Campbell et al., 2005; Link & Phelan, 2001; Parker & Aggleton, 2003) against an already marginalized and disempowered populace.

While stigma was not measured, negotiating disclosure of TB and HIV illness introduced an added complexity to patients’ experiences with stigma (as was discussed in Chapter 5, and appears in this chapter) that is poorly acknowledged to date. TB/HIV stigma, found to be greater than that associated with just TB (Levin et al., 2006; Mak et al., 2006), reinforced social inequalities and mediated coinfected patients’ decisions for self-care. The current study thus extends the application of existing theories of stigma put forth by scholars such as Parker & Aggleton (2003) and Link & Phelan (2001; 2006), by identifying its social construction, perpetuation and possibly, duplication, in communities affected by not one, but two overlapping (and socially undesirable) epidemics.

**Positive reinforcement**

Alongside the plethora of competing constraints on patients’ access to and utilization of healthcare, they were also exposed to positive reinforcements that encouraged them to make health-promoting decisions.

**Symptom relief**

Patients who did commence ART and TB treatment felt positive about its beneficial effects including symptom management and weight gain. Patients with glandular TB (who are also more likely to be coinfected with HIV) were further motivated to adhere in order to reduce the physicality of their illness. Tangible improvements in health and symptom improvement thus served as positive cues for their adherence and retention, actions that are widely predicted by most models of healthcare utilization (Glanz et al., 2002).

However, for some patients, an improvement in health, paradoxically, also encouraged attrition or treatment interruption. Symptom relief is found to deter treatment adherence among people with chronic or longer-term illnesses including depression (Demyttenaere & Haddad, 2000), hypertension.
(Kjellgren et al., 1995), TB (Courtright & Turner, 2010; Naidoo et al., 2009), and HIV (Assefa et al., 2010). ‘Feeling better’ was also found to be significantly correlated with treatment non-adherence in a quantitative study conducted with coinfected patients (Sardar et al., 2010). Findings from the current study substantiate this correlation but additionally identify how disease related stigma played a mediating role in patients’ decisions to discontinue care. The physical visibility of TB/HIV was continually weighed against the associated symbolic visibility, or stigma, of continuing to access care. This overarching influence of stigma, in the context of adherence and physical improvement, is less widely understood, and was discussed earlier in the chapter.

**Chance encounters**

An unwillingness to access TB and/or HIV services because of the implicit assumption and stigma of AIDS, as was seen in this study, is documented in other qualitative studies analyzing delayed TB diagnoses and non-adherence in Thailand, Malawi, and South Africa (Bond & Nyblade, 2006; Kanyerere & Aase, 2005; Mavhu et al., 2010; Naidoo et al., 2009; Ngamvithayapong et al., 2000). However, the point at which patients’ decisions may be overturned has not been explored. In the current study, encouragement from other patients and witnessing how “beautiful” their peers looked (tied to perceptions of symptom relief, which were discussed earlier) appeared to build confidence for some participants to start and stay on ART. This human connection represented a turning point in the trajectory of patients’ health decisions, where their symbolic fears were overcome.

The positive influence of shared intimacy and shared experience, that is usually engendered within formal peer groups (Coniglio et al., 2010), was thus re-enacted at a more informal level of chance encounters within study patients’ communities and at HIV clinics. Considering the negativity associated with thinness, the perception of good health and beauty that was recast by weight gain created a sense of hope and empowerment, which helped patients overcome their fear of death and of being stigmatized. HIV-positive facilitators have been used as role models to build patient empowerment and confidence to access and adhere to HIV care (Watt et al., 2010). The current study supports the basis of such interventions, as a social connection with healthy-looking peers inspired study patients’ to get better themselves, and set aside their fears of being identified and discredited at their HIV clinic.
However, the study highlights the value of using less formal role models for instilling retention in HIV care. Study patients’ decisions were catalyzed through mentors within their communities. Mentors were not methodically selected or imposed by the clinic, but rather, they were informally sought and confided in. The nature of these ‘chance’ connections was an important study finding. Thus far, informal mentorship has only been applied in the context of at-risk youth and/or student populations (Cunic et al., 2000; Kogan & Brody, 2010; Stanton-Salazar & Spina, 2008). Within poor communities, informal mentorships between adults and children, that have not been pre-arranged or planned, are customary in response to trying social circumstances (Stanton-Salazar & Spina, 2008). By contrast, in the realm of TB and HIV care, mentor and/or role-model interventions employed to boost infection prevention and treatment adherence are routinely provided in a deliberate, intervention style that requires some initial level of patient willingness to participate (Coniglio et al., 2010; Dhand, 2006; King et al., 2008; Macq et al., 2007). Such pre-arranged peer programs have been criticized because they risk “disempowering and freezing clients in dependent roles” (Dhand, 2006: p 2684). In the current study, participants’ narratives demonstrated how early experiences with HIV may be so distressful and despairing that some patients may lack the will and hope to plan and connect with their peers, despite that early connection being critical to assist them with continuing to access care. When this bond was established in a more natural way, the established rapport and counsel was more intimately understood and appreciated. Compared to formal role models, the higher value accorded to informal mentors who appear “serendipitously” (Stanton-Salazar & Spina, 2008: p 237) in the lives of people in most need of mentorship, has been linked to their ability to form an emotional bond that is considered to be more “real” and a source of “actual support” (p 234). Study findings thus point to the relevance of such specific dimensions of social support in the case of communities that are affected by socially debilitating illnesses.

Thus, notwithstanding the numerous socio-structural constraints that interfered with patients’ health decisions, symptom relief and informal mentoring were both appeared to positively influence patients’ retention in HIV care. Additional themes related to patients’ particular experiences with TB and HIV healthcare vis-à-vis TB and HIV programs are discussed in the following chapter.
Chapter 7

Coordinating healthcare for TB and HIV: pluralism, fragmentation and integration

The study was centered on two primary objectives: to characterize the illness experiences of patients infected with TB and HIV, and to characterize their experiences with healthcare for coinfection. Chapter 5 developed insights on how coinfected patients construct dual identities related to their infections and negotiate illness disclosure in response to the dual stigmatization of TB and HIV. Chapter 6 situated their (stigmatized) experiences with illness within broader socio-structural realities. This chapter analyzes patients’ experiences with illness vis-à-vis their interactions in the healthcare system, both generally and specifically in relation to TB and HIV programs.

I first present themes that emerged directly from participant interviews and field observations, including how patients utilized and coordinated healthcare for their infections, their navigation and patterns of disclosure across varied programs, experiences and perspectives on TB and HIV programs, and related decisions towards integrated TB and HIV healthcare. I then critically discuss these empiric findings, and situate them in the broader literature base.

Analytic findings

Multiple points of care

Coinfected patients attended various clinics and were treated by an array of healthcare providers during the course of their illness prior to TB and HIV diagnosis and during treatment. These included but were not limited to the three study sites.

Local primary healthcare centres

Patients accessed local primary healthcare clinics that were decentralized under the provincial government and located near their homes. These clinics offered the convenience of proximity with easy access to basic medical care for relatively uncomplicated conditions such as fever, headache or stomachache. When patients suspected they suffered from a more serious illness or feared they may have HIV (illness was often associated with HIV, as was discussed in Chapter 5), they accessed
care from larger institutions situated further away from their homes. Participants did this on account of several reasons. They said their local clinics were usually staffed by nurses alone, with intermittent visits from a doctor. The clinics lacked the technical tools to diagnose serious infections such as TB, and patients indicated they had been referred out on several occasions due to an inability to have their condition accurately assessed. Patients further complained about routinely confronting medical and drug supply shortages.

Nowadays there is no medicine. Doctor write me to go the pharmacy to gave me, but at [local clinic] no medicine. Sometimes when I go to the clinic, [local clinic] there is no medicine and then I go back home and I wait, I wait. (F, site 2)

Some patients also worried they might be identified attending clinics near their home, leaving them exposed to neighborhood gossip.

I don’t want to go to [local clinic], because [local clinic], people there talking too much, you see... Hey, talking say, maybe they told the other people, hey, see, this one, maybe he got the TB, you see... the other one, think you got TB, maybe you’ve got AIDS, so... they’re talking... they read that if you sick, all the people now have got sick. (M, site 2)

For the most part, patients tended to use their local clinics for early medical inquiries prior to being diagnosed with TB and/or HIV and then later, after TB confirmation, to collect weekly TB treatment doses under the DOTS program or be treated for intermittent conditions, as discussed ahead.

**Private practitioners**

At some point during the course of their illness, most patients indicated they had accessed a private medical doctor, generally because their local clinic had failed to confirm a diagnosis or “find TB”. Patients perceived the quality of care at private clinics to be of a higher standard than at publicly funded counterparts. They believed private clinics offered more security and privacy, and were willing to pay out-of-pocket premiums despite the additional economic hardship. But despite patients’ inclination to seek private care, many acknowledged their private doctors had also been ill equipped to make a sound diagnosis, particularly when they presented with extra-pulmonary or atypical symptoms of TB. These patients went on to be referred to provincial hospitals or specialized TB centres such as Site 1 for differential diagnostic workup.

Several patients continued to seek the care of private practitioners for intermittent issues that arose after TB and HIV diagnosis and treatment initiation. This was despite them collecting treatment through the public sector as a result of constant cross-referrals by their TB and HIV programs, and
patients’ inclination to access private care from providers they believed were more efficient and effective than at their local clinics. Patients’ utilization of private clinics is re-visited further ahead.

**Work-based health programs and insurance**

A minority of patients employed in the industrial or formal work sector accessed work-based health programs and/or employer-sponsored health insurance for early TB symptom evaluation. Here as well, TB diagnosis was often confirmed in collaboration with hospitals or specialized TB centres such as Site 1. Tuberculosis treatment was then collected and administered via the public sector (e.g., at a TB clinic or a local primary healthcare centre), as insurance policies deferred to the national DOTS program once a diagnosis of TB was confirmed. Two patients received work-based DOTS.

Patients with access did not get tested for HIV at work-based health programs, fearing breaches in confidentiality, discrimination, and consequent loss of employment. Instead, they used their health insurance to see private doctors outside of the workplace for VCT and ART. In some cases, related expenses for doctor consultations were covered through employer-sponsored insurance packages, but patients perceived less risk of HIV disclosure to employers and co-workers when accessing care in the private sector. In some cases, although HIV was initially evaluated at a private clinic, ongoing consultations and ART were accessed through the national rollout in the public sector. These decisions appeared to be based on eligible patients’ specific insurance schemes. Only two patients\(^{20}\) accessed ART via the private sector with the aid of work-based insurance, while receiving TB treatment in the public sector.

**Traditional healers**

Several patients indicated they had utilized the services of a traditional Zulu healer or ‘sangoma’ at some point during their illness. They sought traditional methods during the manifestation of early, undiagnosed symptoms, or soon after TB confirmation or HIV diagnosis but prior to the initiation of conventional medical treatment. The former situation commonly arose when patients experienced delays with TB diagnosis (e.g., due to atypical symptoms), and the latter situation commonly arose when they were denied immediate access to ART post HIV notification. Common Zulu treatments involving ingestion of herbal tonics or cutting techniques to “let the disease out” were then attempted in hopes of a cure or, minimally, some symptom relief.

\(^{20}\) Not equal to the two patients accessing work-based DOTS.
One participant narrated her experience with alternative treatment. She was ineligible for ART due to a high CD4 count when first diagnosed with HIV. She continued to be denied ART during and after her first bout with TB. She recalled her mounting frustration with her ineligibility and fears around dying that prompted her to skip several follow-up appointments with her HIV clinic. She subsequently reverted to traditional medicines or *muti*. Although she felt better at first and experienced a parallel jump in CD4 counts, her condition eventually deteriorated, and the costs of *muti* began to add up. It was only once she was prescribed ART that she said she abandoned Zulu treatment and felt optimistic about her prospects for conventional medical care.

You know some of us, they taking the ARVs, and some of us are taking the Zulu medication... When I finished my TB treatment last year, in October, I took the Zulu medication for like 3 months. I saw a difference ‘cause I was gaining weight and I was recovering more, but then it was costing me. So when I come back to this clinic, they, they were so surprised because my CD4 count was up. They asked me why and then I told them why. Then they said that I must stop taking the Zulu medication if I want to take the ARVs... I’m not taking the medication anymore. (F, site 3)

In most cases, patients’ experimentation with traditional medicines was initiated on the insistence of older relatives and stopped when their condition deteriorated, upon realizing the futility of the practices and/or beginning conventional therapy.

What made me not to have much courage not to use it [anymore], its because I was telling myself that I will come there and be the same like that sister saying, even myself, I’m negative. When I came there still, my CD is low. It didn’t go up like this sister who she said they said don’t have any anything any more. It was saying 161. (F, site 1)

Two patients admitted using traditional remedies at the time of interview; their practices appeared to be relatively benign: one woman on TB treatment and ART routinely sprinkled “holy” water around her home, and one man who was not yet on ART consumed aloe juice every day.

**Hospitals**

In addition to primary healthcare centres, private clinics, work-based programs, and traditional healers, patients also accessed larger hospitals at the district or provincial level for several reasons: of their own volition for a perceived emergency, via a clinic referral for TB confirmation needing specialized diagnostic equipment, for surgical therapy that was common in cases of EPTB, to draw CD4 counts subsequent to VCT, or for emerging complications related to coinfection that could not be treated on an outpatient basis.
Finally, participants attended more specialized HIV and TB clinics, which were either standalone facilities such as study Sites 1 or 3, or attached to larger hospitals such as Site 2.

**TB clinics**

Many patients described being shuffled across multiple healthcare facilities before their TB diagnosis was confirmed. As discussed earlier, this was often a result of their exhibiting atypical symptoms that could not be easily or directly linked to TB, and thus requiring multiple referrals and diagnostic tests, as well as their own decisions to gain additional opinions to “find TB” (e.g., private doctors) or be rid of their symptoms (e.g., traditional healers). This study’s focus is on the experience of TB-related healthcare at an ambulatory clinic in the public sector, so the following is a general synopsis of such care in the context of observations and interviews with patients and HCWs at study Site 1, and at TB clinics patients described having attended during interviews at Site 2.

Once diagnosed, patients were examined about once a month by a doctor at their TB clinic during the first 2 to 3 months of treatment (i.e., the intensive phase), and then 6 to 9 months later at the end of treatment. When treatment was prescribed for longer periods, as was common in the case of recurrent or EPTB, doctors attended to patients more regularly, about every 1 to 2 months. Two patients received work-based DOTS. The remaining patients adhered to weekly (less commonly, biweekly or monthly) DOTS at either the same clinic where a TB doctor evaluated them or at a primary healthcare centre near their home (where treatment was dispensed by nurses/aides but not necessarily evaluated by a doctor). Streptomycin injections were administered daily for the first 8 weeks to patients diagnosed with recurrent TB. Unanticipated issues during DOTS collections were dealt with via referral to a professional or senior nurse, who then triaged patients for doctor review.

A description of HIV-related service provision at Site 1 was presented in Chapter 4 (see Table 4.4). Tuberculosis doctors typically suggested VCT to all new TB patients or TB suspects but subsequent follow-ups were based on individual doctors’ discretion. Referrals for VCT were not offered during DOTS collections. One HCW surmised it was unfeasible due to a general lack of privacy in the collection queue, and the high workload of DOTS which precluded setting aside adequate time for HIV counseling. During patient interviews, several patients indicated that, on occasion, their TB doctor did ask about their HIV status and HIV related care, but actual rates of provider-initiated HIV testing or ART referrals were not measured nor evaluated for this study. None of the participants on ART were prescribed or clinically monitored for ART at their TB clinics.
HIV clinics

Many patients described being counseled, tested and diagnosed with HIV at various facilities, such as a VCT clinic or hospital, sometimes more than once. In some cases, they were counseled and tested for HIV as they were being evaluated for TB-related symptoms (as was described in Chapter 4); indeed, it was often these symptoms that had prompted them to access medical care in the first place. Some patients recalled that they went for an HIV test at a clinic located far from any other healthcare facility they attended in order to avoid being identified. A few patients indicated they had repeated HIV testing at several clinics to confirm the result was accurate. As highlighted in Chapter 6, a few participants knew their HIV status for several years prior to developing TB, but had stopped attending their HIV clinic for follow-up appointments. Their illness with TB and/or their TB doctors had specifically encouraged them to re-connect with HIV-related care. The study’s focus was on the experience of HIV-related healthcare at ambulatory clinics in the public sector, so the following is a general synopsis of such care in the context of observations and interviews with patients and HCWs at study Sites 2 and 3, and at other HIV clinics patients described having attended during interviews from Site 1.

Once an HIV diagnosis was made, patients with high CD4 counts (i.e., above 200) were usually placed on CPT and requested to return to their HIV clinic every 6 months for follow-up and repeat evaluation for ART. It was at this point that many patients described having detoured from conventional modes of care to try traditional remedies (as was described earlier in this chapter), or altogether shelved their HIV diagnosis because of the associated stigma, particularly if they felt physically well (as was analyzed in Chapter 6). When CD4 counts dropped (i.e., below 200), the HIV doctor stepped in to make a clinical decision on ART initiation. Patients already on ART prior to TB diagnosis, continued ART during TB treatment. A doctor examined all patients on ART approximately every week for the first month, then every month for 6 months, until they were stable. Thereafter, nurses checked patients monthly (coincident with ART collections), and a doctor examined them every 1 to 6 months, depending on the patient’s medical history or if a complication arose.

All patients on ART said they collected ART on a monthly basis from their HIV clinic; their doses were self-administered. Patients receiving ART through the national rollout scheme had attended adherence support lessons before initiating treatment. Lessons, which were held at the clinic, lasted about 3 days and included discussions on HIV treatment, side effects, adherence, and issues pertaining to stigma and disclosure. Patients were encouraged to recruit a person they trusted to
accompany them to their adherence lessons who could provide ongoing support during treatment. While HCWs stated a support partner was encouraged but not required, many patients considered it to be mandatory. Some patients who had not yet initiated ART worried about being denied ART after having waited so long already, if they could not (disclose to and) recruit such a partner.

I used to talk, just that, God, if you are sick and has taken blood, knowing yourself that you are HIV positive, to start the tablet. I just tell myself that by thinking... when you go to the hospital, to the doctor, you’ll find out that other one is very sick, and not able to learn. There is no one who will learn for her (i.e., adherence partner), her life will be finished like that. (F, site 2)

A description of TB-related service provision at Sites 2 and 3 was presented in Chapter 4 (see Table 4.4). HIV doctors typically screened all new patients and all patients about to commence ART for clinical TB symptoms. Suspects were referred for further investigation. Subsequent screening was based on individual doctors’ discretion. One HCW surmised mandatory TB screening for all HIV patients was unfeasible due to their lack of resources, more so for complicated, atypical diagnoses. Several other HCWs said they counted on their patients to complain about symptoms that could be related to TB such as weight loss, cough, fever, and night sweats. Patients indicated that when known, their HIV doctors did subsequently ask about their progress with TB treatment during monthly consultations. However, actual rates of TB screening or treatment referrals were not measured or evaluated in this study.

Commuting and waiting: “I don’t know why maybe I can’t take two things here”

Patients recalled their experiences commuting to various healthcare clinics and waiting in queues as they accessed medical care for TB and HIV. They commuted via public transport, using shared taxis or ‘coombies’, or walked when they ran out of money.

Patients who did not live or work near their TB clinic described this commute to be long, but indicated relief that they only endured it every 2 or 3 months, sometimes less often, to be evaluated by their TB doctor. Commutes to the HIV clinic were also considered long for many patients, and conducted at least once a month for ART collection and/or doctor visits. Objective measures of transport and commute were not collected but the contexts underlying a few particularly inconvenient commutes that were introduced during patient interviews merit mention. They tie to changes in residence and the concurrent lack of coordination between health programs to accommodate patients’ mobility.
A few patients initiated ART at a particular clinic or hospital but had since moved away to live with a family member or partner when they no longer worked or were able to support themselves. Some patients, as they became well, developed new relationships or broke up from older ones, and moved repeatedly to live closer to their workplace or with a new partner or caregiver. These changes in residence affected patients’ transport routines. While some requested and successfully transferred their records to more conveniently situated clinics, others experienced severe delays, especially in relation to the transfer of ART collection.

The patient cited below experienced several delays with clinic transfers as she moved away from her family’s home, where she stayed during the early days of coinfection, back to the city to resume work. She anticipated running out of ART before her appointment at the new clinic but was told to return to her old clinic if this occurred. That clinic was located several hours away, mandating she take additional time off from work. She felt neither clinic wanted to claim her as a patient during this time of transfer and she worried about compromising her adherence to ART. She expressed a desire to collect TB and HIV medications at one location, to avoid the double commute and further misunderstanding across her HIV clinics, and between her HIV and TB clinic.

I was in [Town A, rural, remote area] before, and I was better, then I came here. They said, I said they must transfer me here because I can’t go and take my tablets in [Town A]. Then I came here, they do it. Then this morning they said I must come here to take my tablets here. And I ask them about the ARVs. They said they can’t do it for me. I must go to [city clinic]... Then I asked them again to do me the tablet, they said I must go to [city clinic]... I’m not living there. My house is at [Town B, semi-urban area]... But now, my tablets are gonna getting finished... They say if my tablets gets finished before I see the doctor, I have to go back to [Town A]... I don’t know what I’m going to do this month... I don’t know why maybe I can’t take two things here. (F, study site)

The difficulties with commuting and other reasons underlying patients’ preferences for integrated or co-located TB and HIV care, including some patients’ desire to maintain longer commutes, are discussed further ahead in this chapter.

Subsequent to their commute from home, patients said they endured long waiting lines (usually 3 to 4 hours and at times as long as 6 to 7 hours) to be examined by a doctor at their TB and HIV clinics, including but not restricted to the three study sites. At both TB and HIV clinics, patients passed this time being triaged and examined by nurses and other health professionals, often in multiple queues, before being seen by a doctor. At the TB clinic, they usually received chest radiographs or provided sputum samples for laboratory examination. At the HIV clinic, they spoke with a counselor, and had
their weight and other clinical symptoms examined. Treatment collection for HIV (and for TB, for those patients who collected DOTS at the same site where they were examined by their TB doctor) was always done at the very end, based on decisions made during doctor consultations. The physical ambience and observed social dynamic at TB and HIV study sites were recounted in Chapter 4.

In analyzing patients’ experiences commuting and waiting for TB and HIV care, only DOTS collections were perceived to be quick and efficient, as was also observed at Site 1. Most patients collected DOTS from local primary healthcare clinics that were within walking distance or a short coombie-ride from their residence or place of work. Still others collected DOTS from their TB clinic itself, especially if they lived or worked nearby. Work-based DOTS mandated no additional commute. Weekly commuting times as well as waiting times for DOTS collections were generally perceived to be low, even if inconvenient.

For patients who were employed, all non-DOTS related clinic appointments mandated they take at least half a day, if not a full day, off from work. DOTS-collections, though usually quick, also entailed a late start to the workday for some patients. Two patients disclosed and received the support of their employers to access medical care for HIV. Several other patients working in the formal sector received time off for their TB clinic appointments, conditional on submitting a note from the clinic doctor. The nature and level of illness disclosure to employers was discussed in Chapter 6.

**Being passed along: “go to your local clinic, that’s where you’re supposed to start”**

A recurring theme in patients’ characterizations of healthcare, once diagnosed with TB and HIV, related to their experiences being passed along from clinic to clinic for medical issues that emerged during TB and HIV treatment, for which their TB and HIV clinics referred them out.

In [the HIV clinic] where I am going, they are just doing of the HIV/AIDS that’s all. That’s all. So if I’ve got any problem, if it’s about my TB I have to come here. If it’s anything, anything else, I have to go to the local clinic... When I’ve got, maybe, sometimes, you know when I have taken my ARV’s I got cramp, cramps all over and I told the doctor. He made me the letter to take it to the local clinic, and he said, ‘You, if you got something, maybe some pills, you must go there’. (F, site 1)

Staff at TB and HIV study sites reiterated their preference and perceived mandate to attend to strictly TB or HIV related problems.

You see, the problem with this tertiary level ARV rollout. You can’t go and get all the mundane things, they’ll freak out. But if the patient comes in here and he’s got a sore, the
doctors will treat it. If he’s got flu the doctors will treat it. If he’s got abdomen pain, the doctors will treat it and send them up to [referral]... they will treat it. But they won’t have someone coming from home, bypassing their clinic at home, saying, ‘I’ve got a sore leg’. They’ll say, ‘Go to your local clinic, that’s where you supposed to start off’. (HCW)

Referrals were generally made out to the other infectious disease program, local primary healthcare clinics, or to district or provincial hospitals. Several patients described their frustration and discontent going back and forth between these facilities, where they endured long commutes and waits, some having to request additional time off work.

Look, the thing here, I got pain here on my back. If here, I am coughing, you feel pain here. Just, I said, if I come here to the doctor’s, doctors said I will treat chest, your TB only. If you got pain here, go to the doctor, other doctor or, or you can go to the chemist and buy the pills... I am not better. Sometimes I think cold water is right! (F, site 1)

Due to their prior negative experiences at local clinics and positive perceptions of private clinics, these patients reverted to private care for intermittent issues that were not treated within TB or HIV programs. Both patients and HCWs commented that oftentimes patients themselves served as the only link between the various providers they accessed – in the public and private sector – through the passage of referral notes or direct communication with patients. Communication across various health programs was perceived as time-consuming, unhelpful, and uninformative.

It does become a bit of a problem because often you don’t have any contact details of the exact doctor, and if you’d phone one of these public institutes often 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. So often if there’s an issue, the only other option is for us to write a referral back... so then the patient will take that letter back to wherever they’re receiving the [medicine], which I’ve done here... so there’s a delay again because the patient will wait to get an appointment there, and then may or may not decide to come back with note, their response to us. [I communicate] through the patient, which is not very reliable. And then I think, 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 often they wouldn’t come back specifically... so there’s another delay in that. (HCW)

Poor coordination and communication between programs, and between patients and providers, fueled delays in the diagnosis and resolution of clinical complications. It set the stage for fragmented TB and HIV care.

Co-treatment: “they sort of get lost in the follow-up”

While many patients received concurrent treatment for TB and HIV, some experienced significant delays with the initiation of ART. Delays with TB treatment were also reported by some patients and
tied to diagnostic difficulties with atypical symptoms and poor employer support to access required medical care. Additional reasons for ART delays included patients’ ineligibility due to high CD4 counts and their personal preferences to defer or refuse ART, as were discussed in Chapter 6.

Patients described being confused at the mixed messages received within TB and HIV programs, as well as at other facilities they were referred out to. They voiced how contrasting messages from various clinics may have hampered their ability to receive timely co-treatment for both infections.

Like they told me I mustn’t worry, it [TB] can be cured. But then at the clinic, I was very angry because I had had myself tested there for HIV at the clinic, and they said I mustn’t worry about the HIV, I must worry about the TB. And then I told them here at the hospital, they said no, that’s nonsense, they should have done it too, together. (F, study site)

Patients, as well as TB- and HIV-based HCWs encountered instances when ART was delayed until after the completion of TB treatment. Drawing from some HCWs’ experiences working at TB clinics at the time of interview or in the past, newly diagnosed coinfected patients who were not placed on ART during TB treatment (e.g., within 2 months) ran the risk of being completely lost to follow-up. In these HCWs’ experiences, once TB treatment ended, physical recovery could leave patients with little incentive to continue accessing medical care.

The guidelines are not very clear but obviously you know, when you’ve picked up TB first, then you delay the ARVs depending on what their CD4 count is... but sad to say, 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 immuno-compromised, and they sort of get lost in the follow-up in the system... Often you’d find they are referred to us, and they don’t have any follow up with the ARV clinic. So unless we refer them back, a lot of them are not going back. (HCW)

Often, because they may be feeling better after their TB treatment, they feel it’s not necessary to even go back and so, they probably would only go back if there was another acute illness or they were deteriorating further. (HCW)

HIV disclosure at TB clinics: “even they can ask me, I can say I don’t have it”

Just as disclosure within social networks in the home and workplace was a salient feature of how participants experienced their dual illness and characterized their illness identities, disclosure re-emerged as an important aspect of coordinating care for TB and HIV infections.

The information patients shared with their providers varied across the different clinics they attended to receive TB, HIV, and other forms of healthcare. Across all these environments, the
deliberate nondisclosure of their HIV status was more evident in contrast to TB. Patients tended to disclose HIV across clinics only when specifically and/or repeatedly asked by doctors, and HCWs appeared to be aware of patients’ general reluctance to disclose.

None of them, ok very few, not none, very few patients offer that information voluntarily. Like you have to go into it, and often even when you 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)

Patients’ decisions to disclose their HIV status to TB doctors were based on whether they felt it was necessary for their overall care, as demonstrated in the first interview excerpt below, or their perceived trust in the confidentiality and attitude of HCWs, as is apparent in the second excerpt.

I told them, I told everybody because I don’t want them to give me my advice of taking the tablets, different advices. I want to match it whether it’s same or not. I am going to tell my TB doctors and my [HIV clinic] doctor that what time am I supposed to take TB treatment and am I going to mix it, or am I going to just give me an allowance of what time, you know. So they give me exactly the same time. (F, site 3)

I’m going to the [TB clinic]. Every Thursday, every Thursday I am taking the medication at [TB] clinic... We are not waiting to see the doctor. You go to take, collect the medication at that, you going home... even they can ask me, I can say I don’t have it [i.e., HIV and/or ART] because they are talking too much. (M, study site)

At times, a family member to whom they had not disclosed accompanied patients to their TB doctor appointments. HIV disclosure in these situations was additionally problematic due to a lack of privacy. Sometimes, disclosure was inconsistent; patients would disclose at one point in their TB care but refuse during another appointment or with another HCW.

I had one patient for example... the family member had walked in and then at the same time we were asking about the status so, they didn’t knock just sort of walked in, and so she told me she was negative. And then, she sort of came to me pretending to look at my x-ray and sort of whispered in my ear that she was positive. So, with probing eventually, most of them eventually will disclose but I still also found some group of patients, even though, like, if I look at the previous notes, I see that they’re positive, their CD4 counts, but I’ll always ask again, have you been tested? I don’t just go straight to, no, where, or even ask where they’ve been tested. Yeah and sometimes they’ll say no, they haven’t been tested despite us already having a result. (HCW)

HIV-based HCWs emphasized that information flow between HIV and TB clinical teams was often unidirectional because patients were more likely to share their TB status to all providers but keep their HIV status from some. Consequently, HIV doctors understood they had access to their patients’ full clinical picture but their TB counterparts may only be privy to TB-specific issues. The imperative
to protect patients’ privacy and maintain confidentiality of their patients’ HIV status precluded some doctors from promoting full disclosure across clinic environments. This was apparent even at the relatively integrated study site.

We can access their notes but they can’t access our notes... I’m not sure they know that all the patients, 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)

At other times, TB clinicians were aware of patients’ HIV status but were under specific obligation to keep this information confidential from other clinical teams involved in their patients’ overall care. In particular, patients did not want to share their HIV status with doctors at their workplace.

I had a patient today who was referred from his work sort-of doctor, and he is HIV positive. He’s had TB previously so he was referred back to screen again. So in that sort of case, when I was writing a referral back, he didn’t want me to mention the HIV status because he had now, he had told them about TB but not the HIV. So now it becomes difficult because I mean, in a case where they may not want to disclose certain information to, then you can’t really get anything further. Or for example, if you’re writing a referral letter, I mean if you haven’t disclosed to your family, then you may be scared that that letter may fall into, or [be] seen. I had another patient who was seen at [clinic] but came to me the next day for a letter because at the [clinic] letter had a stamp, I think it mentioned something about HIV so he didn’t want to take that back to work. So he wanted me to write a separate thing which didn’t show the HIV, so I say it’s those sort of things that makes it difficult. (HCW)

Inconsistent patterns of HIV disclosure and inconsistent access to HIV-related health information across facilities impinged on the coordination of TB and HIV care for coinfected patients. Some of this related to health professionals’ adherence to patient confidentiality and privacy, and some of it was related to miscommunication or non-communication between programs. It was also related to patients’ decisions to conceal their coinfections (especially HIV), which were tied to interpretations of their experiences within TB and HIV clinics, as is discussed below.

**TB vs. HIV clinics: “they ask you questions and they show that they care”**

When patients were asked about the different clinics they accessed for TB and HIV care, they often distinguished and compared their experiences in the various settings.

Several patients complained about the lack of individual attention experienced at TB clinics and larger hospitals that they were referred to during the course of their illness (e.g., for VCT) as is apparent within the first and second excerpts, respectively, cited below. The poor quality of services perceived at these facilities further motivated them to seek care elsewhere where possible, including at private clinics.
Sometimes they don’t care. I can stay there waiting, waiting, they don’t ask you what, what you’re here for, what. Then later, they come and said ok, those you need help. You know what they are doing about other, you see. Maybe that makes people to start talking big, now I won’t go back. Staying there for a long time, they won’t take care of us, they say. That’s the thing... if they’re working, they won’t do their own thing. Check the phone, water, phone someone, before they come to you. (M, study site)

After the [HIV+ test, I had to go for the CD4 and stuff like that. That’s when they referred me. If you go for the test at another place and then they send you to another place for CD4. I went there, yeah I went there and the service, they are not good to the patients. See a young lady there, the way she talks to speak to the elder lady sitting, lady there, she is sick and stuff like that, and their attitude towards those people, (clicks tongue) and I am very sensitive in that, that kind of a person. Yeah, that’s what drive me away. (M, study site)

In contrast to these rushed and impersonal interactions, most patients perceived the quality of care to be more personalized and efficient at clinics where they accessed HIV care and/or ART. They appreciated the extra attention they received in these environments where they felt staff went beyond what was expected to make them feel comfortable and cared for.

You know at the [TB] clinic, there is a long queue compared to [HIV clinic] queue. And things at [TB] clinic, they go slow compared to [HIV clinic]... the sisters at the [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?’ (F, study site)

[TB] side it takes some time because there are many people... there is no one who will go around and say, and you get lost and sometimes sitting in a wrong place. 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... you’ll be taken by the sister and she will put you there... There is no way you’ll go and ask people if it’s the right queue, you are not worried about that... There is care [HIV] side. There is a difference, its not the same as [TB] side. [TB] side it’s like a government hospital, just a hospital you see? [HIV] side, its as if we are paying money, that way they take care of us. (F, study site)

Some participants recognized staff from their own communities and neighborhoods. While initially fearful of being exposed or recognized, they came to appreciate the comfort of a familiar face.

At first I was, because the counselor that’s here is, like, someone in our community. And first I just said, no, you know what, okay, I’m afraid but it’s not only me that he sees. So I just went straight to him... I was, like, and he was counting my medication, and like, oh he never said anything, you know. I was scared at first but, and then I got used to it. (F, site 2)

Other participants further realized that some staff shared the same HIV status as they did (although HCWs commented that staff disclosure to patients was not typical within the workplace). Patients appreciated the empathy afforded during counseling sessions, and with the ongoing delivery of HIV services, which fostered optimism for their own health and wellbeing.
[HIV clinic], no, most of the staff they are in a same status as us. They understand what you are going through... during the counseling, they taught us about the HIV virus and how it can be managed, and that it can be manageable and stuff like that. It’s not a death sentence. They told us and what it does to your body, and taking ARVs will do what to your body. Before you go for a testing. By the time you go for a testing, you already know. So there is no reason to be scared, hey, if I do the test, if I am positive, I’m dead or thing like that. You go there, you have a positive attitude. (M, site 3)

The expressed comfort in similitude associate with being with others in similar circumstances emerged as a critical point of relevance in patients’ characterizations of healthcare for HIV.

Safety in similitude: “now we are all in the same situation”

Many participants described their first few experiences at the HIV clinic as fearsome and embarrassing, stemming from an initial sense of hopelessness that was described in Chapter 6. They worried about being recognized and being judged. Patients’ comfort and appreciation towards the quality of care in HIV clinics was borne with time, and appeared to grow as they began to see the benefits of treatment among their peer-groups, and as they themselves began ART and experienced a relief in symptoms. Participants recalled feeling more and more comfortable about their visibility within HIV clinics because of their shared situation.

Even if he can see me in that place, I think I don’t care because they came just to do the same thing I came to do, and if I’m hiding from that person, its not going to give me nothing. (F, site 1)

You can see even yourself that we are seeing each other where. They said there is somebody who asked and said, ‘Why are you here? Are you sick?’ Hey, I never asked a person I know here because I can see where she is. What else can I say? Is it that we are both. (F, site 2)

Being in this common space gradually mitigated their fear and guilt, and lifted their burden of stigma. They felt as if they had nothing to hide. If people were to start gossiping about someone they recognized, they would also be instigating gossip about themselves.

I see my neighbors [at HIV clinic]... they can’t ask me the questions because even them, they got, so it’s not easy. Every, each and every person, if you found the person there, you know this person have this disease... you can’t say anything. You can’t go and gossip to another person. ‘They, this person is’... they can ask you, how can you, how do you know this thing, how? (M, site 1)

Otherwise I don’t mind if somebody recognize me, because, he or she is gonna go and talk, but at the end of the day, how did you see me there? (F, site 2)
While this sense of appeasement and security first stemmed from a defensive stance to rule out the possibility of being gossiped about and discriminated within their peer-groups, patients described how they came to slowly appreciate and enjoy the comfort of being at their HIV clinics. The clinic became a safe space to foreground their HIV identity and for some, to speak more openly and confidently about their condition, especially as they spent long hours together waiting for their doctors’ appointments.

You feel at ease there, but it’s for the first time, you feel quiet. Hey, what is this person gonna think of me, how is everything... you feel like you like out of order, is that how you feel for the first time if you come around people [with] the same thing... but when you sitting every time, how, I’m like this... People know, know you got it... You don’t have to tell a lie that time. I say, ‘No, don’t worry, we know you got it, don’t you worry’. (M, site 3)

People like that its only people who know, it’s only here at the clinic that take place... Those who got, I can say mostly here by [HIV clinic], because there is no privacy, as you’re here at [HIV clinic], you know you got this, you got TB like that, but you had AIDS you must be here [HIV clinic]. That’s why I say, ‘No, no nothing to hide’. We open with each other here... All of us talk, if something happen we talk. ‘Hey, this tablet make you hey, dizzy like this’, like this, there now we are all in the same situation. (M, site 3)

In contrast, patients recounted a need to maintain a veil of secrecy at their TB clinics, especially considering the popular associations between TB and HIV. At the TB clinic, no one knew who was coinfected with HIV. Patients described avoiding discussions around their health, at times even casual talk of any kind.

There [TB clinic]? I go and take the tablets only. Here, I stay and talk with the people. (M, site 2)

Depending if I know them but it, generally like, if we sick people, you talk. But its like, ‘So, you come to take your medication?’ and like, ‘Yeah, I come to take my medication’... and, like, it depends, I’m the person, like, if they’re gonna carry on and then you carry on talking... [TB clinic] I just stick to TB. And over here [HIV clinic], I mean, we talk, we talk here... everything... even TB. I mean, its quite easy... TB is just something that’s general and you can talk about it... and if we all, like, HIV positive, so what must I be afraid of? We just talk. (F, site 2)

It was clearly easier for coinfected patients to discuss a less stigmatized topic (i.e., TB) at their HIV clinic, as opposed to a more stigmatized topic (i.e., HIV) within the boundaries of their TB clinic.

Preferences for TB and HIV healthcare

Prompted by their characterizations of experiences shared at the various clinics they accessed, patients were probed around their preferences for TB and HIV care, and/or their preference for a
specific point of care while they were being treated for both infections. Understanding their perspectives mandated some assessment of an objective intention around their health, but the analysis focused on how and why, rather than just what, preferences and decisions were formed.

Co-located care not equal to coordinated care: “If it happens in one day, it’s better”

Patient participants recruited from the relatively integrated study Site 3 stated they enjoyed the convenience of receiving TB and HIV care at proximally located clinics. Co-location, however, did not guarantee TB and HIV service coordination with regards to their money or time. Many of them were still given separate appointment dates for either side, both for doctor consultations and for DOTS collections. While they appreciated coordination of TB and HIV care with regards to its physical location, they additionally wanted coordination of care with respect to TB and HIV doctors’ appointments. At the very least, they hoped to be examined by their HIV doctor (once a month, at Site 3) on the same day of the week that they collected TB-DOTS treatments (once a week, at the co-located TB clinic, Site 1). However, only a few patients said they had deliberately requested this latter option; most others did not consider it was something they could ask of the clinic.

I am not okay, I want the same date. If my 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, and you know. (F, site 3)

The only thing I would like to have, you know when you have to go for a TB, to see a, to take my treatment on this side, maybe if it happens in one day, its better ‘cause sometimes I come here on Monday, then on Tuesday I go for my TB treatment. (F, site 3)

A few patients at Site 3 picked up on at least one reason precluding concurrent appointment dates for TB and HIV care. They realized, based on experience, that even if clinic appointments were to be held on the same day, they would still need to wait in two queues for examination by two clinical teams. Outside of weekly DOTS collections, doctors’ queues at either clinic tended to be long, and the likelihood of being seen on the same day by their TB and HIV doctor was perceived as low, despite co-location. Neither clinic attended to patients with specific consideration of the other clinic’s appointment schedule (and this was confirmed during key-informant interviews). So, even if granted appointments at both clinics on the same day, patients realized they would be unable to complete any one appointment in time to adhere to the other. Patients highlighted this drawback

21 Recall that for most study participants, HIV doctor/nurse appointments and HIV treatment was scheduled every month, TB doctor appointments were arranged every 1 to 3 months, and TB-DOTS treatment was collected every week.
with the co-located model of integration, and thus stated they preferred to retain distinct appointment days for TB and HIV care.

The dates coincide in the same day. I also see that it’s better... not to coincide. Because the problem that side when you’ll come here, it will be the same day, while even that side it’s full, and even this side it’s full... Yeah, it can help if it can coincide but [only] if it’s going to happen [i.e., work]. (M, site 3)

The onus to maintain separate dates for TB and HIV doctors’ appointments was greater still for those patients who had to commute to clinics that were not co-located, that is, patients recruited from the relatively non-integrated Sites 1 and 2. For at least one participant, coinciding dates at distally located clinics may have partly contributed to his delayed commencement of ART.

I have started [ART] on the 6th... I was supposed to go on January 15 [HIV clinic] then I had an appointment for [TB clinic] as well. They were together, both. Then I came [TB clinic]. I was unable to go [HIV clinic]... The date coincided. Then they postponed to come and take this month... because it was the first time for me to come [TB clinic], it was my first appointment to see the doctor... I went there the following day and they gave me the 19th. I went back on the 19th then the doctor asked me, she made the 6th when I had to start the ARVs... Them, they shouted at me that I didn’t come on the 15th. I explained to them that my date coincided with the one for [TB clinic]... Then they made the date for the 19th. (F, study site)

Commute vs. confidentiality: “people are talking... so that is why I’m going to different places”

Most other patients attending non-integrated Sites 1 and 2 said they would like the opportunity to access TB and HIV services at the same clinic and on the same day, to save time and money associated with dual appointments. This was also evident from some patients’ accounts of their difficulties with long commutes and clinic transfers, which were presented earlier in this chapter. However, these patients had not been exposed to the problems encountered by some of their peers (at Site 3), who were unable to keep TB and HIV appointments on the same day despite the clinics’ proximity.

In contrast, several patients from Sites 1 and 2 explicated their desire to retain separate clinics for TB and HIV care. Protecting themselves against inadvertent HIV disclosure was a prominent feature of their decision. Upon probing, patients indicated they particularly did not wish to receive any HIV-related care at their TB clinic, as it would expose their HIV status within an environment where they felt less trustful and less comfortable. Worried about being identified, labeled and gossiped about, especially at (TB) clinics where they already felt rushed and unattended, patients preferred going to “different places” for TB and HIV healthcare.
I’m okay because it’s different place. People are talking. People are talking, serious. So, 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, I don’t like to talk, even the doctors, they are right, yeah. (M, study site)

The importance these patients attributed to protecting the privacy of their HIV status exceeded practical issues of time and cost, and they continued to attend clinics farther away from home to avoid being recognized by people in their communities. This was particularly true for participants who lived in areas outside of city centres, where TB and HIV clinics tended to be smaller, and could magnify their visibility and identification.

For example, the participant cited below began ART near his grandmother’s home, located 4 hours away from the study site, but soon moved back to the city to resume work. Although he had to take time off work for his HIV appointments and travel a long and expensive commute, he did not want to initiate a transfer in his HIV care. For patients like him, the longer commute was acceptable as it helped ensure greater confidentiality of their HIV status.

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

Popular negative associations between TB and HIV provoked patients to access care for coinfection in ways that were not the most logistically convenient options available to them. Healthcare workers, too, noted that many of their patients might prefer co-located TB and HIV care based on inward acceptance of their HIV status, and willingness to disclose HIV to their family and employers, rather than just the more practical issues related to a double commute. However, HCWs did not relate patients’ decisions for care to patients’ experiences at individual TB and HIV programs.

I think with those patients who would want to keep it separate, it’s probably those patients who haven’t disclosed, haven’t really come to terms with their status and are not open with it. And for those sort of patients, they’d probably feel more comfortable keeping it separate. But I think in the majority, I think patients who are on TB and HIV treatment would probably prefer to have it together because just in terms of... it makes it easier for them logistically, in terms of money. A lot of patients complain but when you have defaulters, a lot of them will say they didn’t have money for the bus fare, or the transport, whatever, and just in terms of if you think they have to spend the whole day here, missing a day of work, gonna go for the TB treatment, the HIV treatment it’s the same thing. A lot of, some employers are not as understanding especially if you haven’t disclosed that you’re HIV positive and you need to go for that treatment. So a lot of sick days off, a lot of money in terms of... and also in terms of when you have questions about your ARVs, I suppose in terms of them answering, they
would probably feel, they would probably have less sort of hassle in terms of having to send them back and forth to get information if it was all [together]. (HCW)

**Permanency and preference for HIV clinics: “I won’t change my doctor for this thing”**

Patient participants who were diagnosed with HIV long before they developed TB considered the anticipated temporary nature of TB to be insufficient grounds for altering their primary point of care, which they considered to be their HIV clinic. They already shared a longer relationship with their HIV doctor and/or they expected to have a “permanent” relationship going forward.

I only come [to TB clinic] for [TB] treatment for, you know, I can’t change my [HIV] doctor for this thing [i.e., TB] because he’s the one who knows me now... I only want my [HIV] doctor, Dr. [X] who knows me. So because that other one is gonna ask what is wrong with me, blah, blah, blah. That’s right, I start again, I telling, what is wrong with me, what’s happening with me, but Dr. [X] he knows because when he opens my files, he knows, say, ok, Mrs. [Y], yes. (F, study site)

This participant echoed the views of several others in rejecting integration of TB and HIV services at the point of TB service delivery. When diagnosed with TB, she tried aggressively, but was ultimately unable to access TB treatment from her HIV clinic, since TB treatments had to be administered via the national DOTS program through TB or primary healthcare clinics. Her preference for integrated care was otherwise clear: if she could not receive TB care from her HIV clinician, with whom she shared a strong and continuous relationship, she would rather have the two infections treated separately. In a similar vein, due to negative experiences with TB-DOTS collections at their local primary healthcare centres, stemming from the paucity of medical supplies, absence of medical expertise, and having to wait in duplicate clinic queues; and, positive experiences with HIV service delivery, stemming from greater trust in medical expertise, and the perceived quality and privacy of care, several coinfected patients expressed a desire to be examined for TB and HIV at their HIV clinic.

I was just wishing, it was my wish, no they are helping us, if they can help us that if everything can be here, even the TB treatment we can find it here, because we do have a doctor here. (F, site 2)
Discussion

Findings from this chapter lend insight to TB/HIV coinfected patients’ experiences accessing and receiving medical care for their dual infections. My interpretations drew primarily on the work of Eakin & MacEachen (1998). They also extended theories discussed in preceding chapters to consider the social contexts of patients’ health decision-making and service utilization in relation to their interactions in the health system and broader social and structural norms related to TB, HIV, and dual TB and HIV service delivery. In engaging with various models or forms of TB and HIV care, coinfected patients navigated through the health system in interesting and unanticipated ways. Their narratives reflected how and why they adopted particular (pluralistic) health behaviours, and formed decisions towards integrated and non-integrated forms of TB/HIV care, based on the structure and social dynamic inherent within various programs, which in turn, were reproduced during their direct experiences with care. A comprehensive understanding of patients’ health-related decision-making demands situating them within this broader social and structural context.

Medical pluralism

Patient participants accessed a host of healthcare providers and facilities during the course of their illness prior to diagnosis and subsequent to commencing treatment for TB and HIV. Medical pluralism, that is, when people perceive, understand, and treat illness in multiple and diverse ways (Janzen, 1978; Moshabela et al., 2010; Ross, 2008) was a central aspect of study patients’ experience with TB and HIV care. Pluralistic health seeking behaviours are believed to be shaped by existing sociocultural norms around disease and health, and have been tied to the perceived quality, accessibility, and cost of healthcare services for HIV and TB (Janzen, 1978; Kanyerere & Aase, 2005; Moshabela et al., 2010; Ross, 2008). They may involve parties in the private, public, and complementary health sectors (Moshabela et al., 2010; Shaikh & Hatcher, 2005; Skordis-Worrall et al., 2010). Accordingly, patient participants accessed local primary healthcare centres as well as work-based health programs due to their ease of access and affordability. National TB and HIV programs likely expect and count on this behaviour to initiate the early diagnosis and treatment of infections through referral to TB-DOTS and HIV programs, respectively. However, participants also accessed a variety of other healthcare providers such as private doctors and traditional healers, which is not well understood in the case of overlapping infections.
Some degree and version of medical pluralism need not be problematized. For instance, many people access multiple medical opinions about the treatment of chronic and sometimes fatal conditions such as cancer; second opinions are even valued in this regard (Brimo et al., 2010; Richards, 2010). Therapeutic supplementation with some herbal remedies has improved the quality of life of individuals affected by illnesses including cancer (Walji et al., 2007) and HIV (Palmer, 2008). However, shuffling between multiple providers, the use of the private sector, and of traditional medicines in place of or alongside conventional therapy may interfere with optimal clinical outcomes. They may increase the risk of delayed diagnoses, sub-optimal or unsound treatment, drug or herb toxicity and interactions, under-reporting of related adverse events, and other unanticipated clinical complications (Edginton et al., 2002; Hatchett et al., 2004; Kanyerere & Aase, 2005; Ladenheim et al., 2008; Needham et al., 2001; Plummer et al., 2006; Rajeswari et al., 2002; Walji et al., 2010; WHO, 2008b). In studies with coinfected patients, use of traditional medicines was found to be significantly associated with their poor adherence to TB treatment (Sardar et al., 2010).

**Traditional medicine**

The practice of traditional and faith healing is commonplace in Africa (Moshabela et al., 2010; Ross, 2008), and in other parts of the industrialized and developing world (WHO, 2008b). Trust in local healing systems often reflects deeply entrenched health beliefs and norms that cannot be swayed by the imposition of conventional allopathic sources of care (Waisbord, 2007). Patients with TB or HIV are known to access ritualistic and traditional healers in hopes of diagnosis, symptom relief or cure, or to attain equilibrium between the spiritual determinants of disease, and are sometimes accessed in concurrence with biomedical recourse (Moshabela et al., 2010; Plummer et al., 2006; Ross, 2008; Schneider & Palmer, 2002; Skordis-Worrall et al., 2010). In this study too, sociocultural norms around healing, the presence of undiagnosed symptoms, as well as family advice or pressures encouraged patients to seek traditional remedies.

The added influence of ART unavailability and ART initiation on coinfected patients’ health-seeking behaviours vis-à-vis medical pluralism and their use of complementary and alternate medicines may not yet be fully appreciated. In the current study, ART denial or ineligibility instigated some patients to try traditional remedies, whereas confirmation of a TB and HIV diagnosis and subsequent prescription of treatment, particularly ART, encouraged most to discontinue those practices. The findings substantiate those of a qualitative project in South Africa, which showed that HIV-positive patients’ experimentation with alternate remedies and their utilization of private healthcare
declined following their initiation of ART (Moshabela et al., 2010). The unavailability of ART, as an extension of the perceived failure of the conventional (public) health sector, further pushed patients in the current study to revert to alternate healing practices as well. This may have contributed to delays with the timely initiation and/or integration of TB and HIV treatment when patients were eventually eligible for publicly funded ART. At least a few participants stopped attending their HIV clinics for CD4 count monitoring and re-evaluation for ART eligibility because they had decided to use traditional remedies instead. This pluralistic behaviour has been poorly documented among coinfected patients, and was missing in the more in-depth ethnographic accounts of patients’ experiences with coinfection that was recently conducted in a similarly high-burden setting in Zambia (Chileshe & Bond, 2010).

**Private clinics**

In South Africa, while primary healthcare clinics are the most common points of initial access to medical care (Moshabela et al., 2010), up to one-third of people without health insurance also or instead seek private care (Skordis-Worrall et al., 2010). Patients’ willingness to pay out-of-pocket on health expenditures in the private sector, despite the availability of publicly funded services and personal financial instability, is tied to their perceived failure of and disillusionment with the public health system (Gibson, 2001; Wilson & Perumal, 2003). Individuals affected with TB or HIV often believe private facilities provide higher quality and more individualized service, and greater efficiency and flexibility with respect to diagnostic testing and treatment (Lonnroth et al., 2001; Needham et al., 2001). In this study, many participants reverted to private doctors when their local clinics could not “find” or confirm a TB diagnosis, in light of atypical symptoms, and clinics’ shortage of technical resources, medical supplies and expertise. Even when citing satisfaction at a public clinic, participants stated it in surprise, as it was what they would typically expect in the private sector. A higher perceived quality of care was a key reason for coinfected patients’ pluralistic behaviour, and is consistent with evidence from studies held with patients affected by just TB or HIV.

A recent study analyzing medical pluralism in the context of TB in South Africa (Skordis-Worrall et al., 2010), found private doctors were perceived to be “confidential” (p 176) doctors, not merely by portraying greater confidentiality within their clinics but additionally, by being located in areas that were less visible or obvious to onlookers. This desire for privacy to counter stigma associated with TB, as a result of its implicit association with HIV, has also been documented as a reason to avoid
seeking medical attention for undiagnosed TB (Bond & Nyblade, 2006; Ngamvithayapong et al., 2000; Burapat et al., 2009). Patients in this study echoed such sentiments when they moved away from work-based and local health programs to private practitioners for the confirmation and treatment of coinfection. The continued use of private practitioners by coinfected patients is not yet acknowledged, particularly in the context of complicating the delivery of concurrent medical care.

Furthermore, the utilization of private medical care continued for many study participants, not just from a greater sense of privacy, trust, and efficiency in those services but also as a result of them being perpetually referred out by TB and HIV programs for matters that fell outside of those programs’ direct purview. This reflected problems related to the vertical delivery of TB and HIV care that are as yet inadequately acknowledged, and discussed further below.

**Vertical care equals fragmented care**

The vertical nature of TB and HIV programs required coinfected patients to continue accessing multiple providers even when they were inclined to let go of their pluralistic health-seeking tendencies. Study patients were continually referred back and forth between various clinics within the health system during diagnostic workup (referrals were often tedious with atypical TB symptoms), and during intermittent issues that arose subsequent to treatment initiation. A specialized or vertical focus on healthcare was maintained despite the decentralization of services such as DOTS and VCT. Not only were patients referred by HIV clinics back to their TB programs for TB specific complaints and vice versa, they were also referred out of either specialized program back to the hospitals or the primary healthcare sector from where they were originally referred (i.e., when emerging issues did not directly relate to TB or HIV). This created a situation of continuous cross-referrals. The dissatisfaction expressed within patients’ narratives indicate how they may have been ‘dumped’ or ‘disposed’ by (and between) TB, HIV, and primary healthcare clinics, validating Dartington’s (1979) critique of poorly integrated systems of healthcare.

Verticalization and the resultant system of cross-referrals, and jettison of patients between TB and HIV programs, led to several interrelated consequences that cyclically produced a fragmented experience with healthcare. These issues may impinge on optimal patient care and are reflective of the critical, broader frameworks of health service delivery. However, to date they have not been reported or addressed in the organization and delivery of TB/HIV care:
The specialization of services within individual programs created a system of medical information sharing that relied heavily, at times entirely, on the patient. As the task of coordinating appointments and medical care for TB and HIV fell into the hands of coinfected patients – the sole common thread between disparate health programs – they often bore the sole responsibility of disclosing relevant information across the many programs they accessed.

While HIV disclosure decisions have been widely problematized in the context of patients’ partners, families, and friends, disclosure to doctors is often assumed once patients are connected to the health system. Little is understood about their subsequent nondisclosure to providers. Two small (and dated) studies with dental providers estimated that between 13% and 26% of HIV-positive persons may hide their serostatus within healthcare settings (McCarthy et al., 1995; Terry et al., 1994). Patients in the current study, encased within vertical systems of TB and HIV care, were able to negotiate disclosure of their HIV status within the health system based on the perceived outputs of such disclosures. In some cases, nondisclosure was less intentional based on the lack of investigative questions from patients’ various providers. Indeed, patients and HCWs both reported how doctors did not always actively probe for TB symptoms in HIV programs or follow-up on VCT results in TB programs, on account of structural and professional constraints (e.g., relying on patients to report complaints, or having inadequate time, resources, or training to monitor co-morbid infections). In other cases, nondisclosure was intentional. Several patients kept their HIV status from TB doctors when they believed it was not necessary for TB treatment, and particularly when they lacked trust in the confidentiality of providers at TB and other non-HIV clinics they accessed or were referred to. The social risk-benefit balance for HIV disclosure was re-enacted. Patients’ illness identities and dual stigmatization from their social worlds outside of the health system thus penetrated, often detrimentally, their lived experience within the healthcare arena as they negotiated HIV disclosure at clinics that did not offer them HIV-related care.

HIV-based providers, too, were restricted regarding the amount of information they could divulge to other members of patients’ healthcare team, due to the ethical (and legal) repercussions of nonconsensual disclosure. While co-located TB and HIV programs did allow for a greater exchange of medical information for patients attending study Site 3, the exchange was demonstrably one-sided to the advantage of the HIV clinical team. Medical confidentiality and patients’ right to privacy precluded the open exchange of HIV-related data across clinics, while allowing full disclosure of TB-related data due to it being a publicly notifiable, as opposed to a privately guarded, medical
condition. Nondisclosure on the part of patients and HCWs relates back to the stigma and discrimination associated with HIV/AIDS.

As coinfected patients were shuffled between various facilities, they were also subjected to mixed messages with regards to their dual treatments due to miscommunication and misinformation between programs, and between providers and patients. This was fueled, to some extent, by HIV nondisclosure. Poorly coordinated or non-integrated care (together with the intersection of ART ineligibility, HIV stigma, and physical recovery post TB treatment, which were discussed in Chapter 6) may have been an additional factor in attrition from HIV care, as was evident in the accounts of study patients who were diagnosed with HIV several years prior to their initiation of ART.

Health policy analysts point to the disadvantages of producing a workforce with diminished technical competence in any one area when integrating specialized services into the primary healthcare sector (Criel et al., 1997; Criel et al., 2004). The current study shows that the reverse may also be true. HIV and TB professionals may have become so specialized in their expertise around just HIV or TB issues, respectively, that they may no longer feel comfortable dealing with non-specialized health problems. This may have exacerbated their propensity to refer or ‘dump’ coinfected patients out of their own specialized programs, and into the primary healthcare sector. Furthermore, although breakdowns in referral-systems are documented in other clinical spheres (Abate & Enquisaelassie, 2010; Brandt et al., 2008; Flynn et al., 2010), and form the basis for the WHO’s promotion of integrated TB/HIV care in the first place (WHO, 2010b), the added social challenges to TB and HIV service integration with regards to patients’ concealment of their HIV status and medical confidentiality within the health system were highlighted by this study.

While specialized attention was valued within TB and HIV programs, patients were unable to get all their health needs fulfilled at these facilities. Constant referrals left them disenchanted, including one participant who facetiously commented it might be in his best interest to “drink cold water” instead of being passed on from one clinic to the next. Referred out once again, patients selectively accessed those providers whom they perceived would provide a higher quality of care. In this way, vertical care for TB and HIV fueled patients’ pluralistic tendencies, and fed back into the cycle of medical pluralism. Patients opted to visit private clinics rather than endure long waits at seemingly inefficient primary healthcare clinics, when they could or would not be treated for intermittent issues within specialized TB and HIV programs. The vertical structure of TB and HIV programs thus
perpetuated a fragmented experience with healthcare, which was further bound by the stigma of having HIV and patients’ predisposition to access alternate forms of care. In this way, the study expands an understanding of how patients’ health actions, routinely considered as being made at the individual or micro level, or informed by cultural norms, are also a product of broader structural and health system constraints.

**Contrasting cultures of care**

In addition to patients’ pluralistic health behaviours, in relation to their navigation through vertical systems of care, this study draws attention to the distinct experiences patients enjoyed at TB and HIV clinics. Patients’ attitudes towards and experiences within clinic environments are found to influence their uptake of and adherence to HIV and other STI related health services (Lindberg et al., 2006; Meredith et al., 1997; Rowe et al., 2005; Skordis-Worrall et al., 2010). However, no studies have analyzed how TB and HIV program environments may be understood and responded to from the perspective of coinfected patients who concurrently access services from such programs. While a qualitative study from Ethiopia showed that poor communication between coinfected patients and HCWs contributed to patients’ non-adherence to co-treatment, the study did not compare or contrast patients’ experiences with HCWs at TB and HIV clinics (Gebremariam et al., 2010).

In the current study, patients’ experiences at TB and HIV clinics, not unrelated to the operational aspects of individual programs, were clearly shaped by the distinct approaches of healthcare delivery instilled within each program. While the underlying paradigms of healthcare espoused by TB and HIV programs was examined during the advent of the AIDS epidemic (Bayer et al., 1993; Gittler, 1994; Hansell, 1993; Selwyn, 1993), only a few authors have since alluded to the contrasting disease control strategies of a standardized TB approach and individualized HIV approach to care in the context of service integration (Coetzee et al., 2004; Friedland, 2004; Wang et al., 2007). For instance, higher treatment adherence rates in HIV programs, compared to TB programs, have been hypothesized to be a function of their greater attention to treatment literacy (Abdool Karim et al., 2009; Lawn & Wood, 2007).

In this study, coinfected patients attending both proximal and distally located TB and HIV clinics compared and contrasted their experiences with TB and HIV care in similar ways. Patients believed that their HIV clinics offered more personal, individualized attention, with a higher standard of care. They felt less inhibited among their peer-groups, that is, patients and possibly staff, who they
believed were HIV-positive just like them. Patients felt they had nothing more to hide or “lie” about, and were able to gradually open up and feel secure within the boundaries of their HIV clinics. At these clinics, they perceived a greater continuity of care going forward, as they understood HIV was a lifelong, irreversible illness. Interview narratives also mirrored the holistic, patient-centered, and multi-disciplinary approach (and staffing) associated with HIV control that was documented during field observations.

In contrast, experiences at TB clinics were perceived to be impersonal and rushed, with little individual interaction between staff and patients. Patients attending TB clinics did not perceive other patients to be the (stigmatized) “same”; not each one was HIV-positive. Instead, the imperative to extricate oneself from popular assumptions around TB and HIV was strong, and patients refrained from any discussion around their health that could inadvertently expose them as being HIV-positive.

Coinfected patients’ distinct experiences at TB and HIV clinics were thus marked by a perceptible friendliness and compassion enjoyed within HIV clinics, as compared to a lack of the same within TB clinics, and a sense of solidarity and security among other HIV-positive persons, compared to a sense of uneasiness and inadvertent exposure among persons who may be infected with “just TB”. Patients’ own perceptions and experiences with the stigma of HIV and/or TB thus became fortified through the disparate cultures or paradigms of healthcare exuded within the TB and HIV clinics they attended. These disparate cultures were further reflected in the physical facility and social interactions observed at each site (described in Chapter 4), and in characterizations of interactions between patients and providers that were recounted during participant interviews. The culture of TB and HIV care is understood as being shaped by decades of infectious disease epidemiology, advocacy, activism, and political history (Bayer et al., 1993; Gittler, 1994; Raviglione & Pio, 2002; Selwyn, 1993). The current study represents one of the first instances in which the impact of disparate program cultures on patients’ experiences and decisions for healthcare was considered empirically.

**Deciding integrated care**

This study also represents one of the first attempts at understanding coinfected patients’ actual experiences and perspectives on integrated healthcare during a critical shift in the public health planning and delivery of TB and HIV services.
The convenience of accessing TB and HIV services at one physical location was both welcomed and appreciated by study participants who attended the co-located study site. However, although co-location allowed for improved communication and coordination of care from the perspective of HCWs (or individual programs), it did not automatically enhance coordination of care from the perspective of all coinfected patients. HIV and TB services continued to be delivered by separate programs and separate clinical teams. Many patients were still required to commute to the co-located study site on separate days for HIV and TB care (including, for many patients, DOTS collections), not merely because of poorly coordinated appointment dates between TB and HIV programs, but also because of the inherent unfeasibility of being examined by two clinical teams on the same day given the long waiting times at each end. As a result, double commutes persisted, and precluded any real savings with regards to patients’ time or funds. The study findings thus refute cost-savings assumptions for TB/HIV integration that are ubiquitously touted by program planners (Cerda et al., 2011). Actual reductions in patient costs depend heavily on the specific design of an integrated program, and the ability for patients to be treated for both infections at the same place and on the same day.

Coinfected patients attending distally located clinics expressed a desire to access TB and HIV services at proximal or co-located sites, to save on time and costs associated with dual treatment. However, the study showed that patients’ acceptance towards integration was specifically set in the context of HIV programs. This is where they felt most comfortable and inconspicuous, and this is where they perceived a greater continuity of care going forward, particularly patients who were diagnosed with HIV long before developing TB. In contrast, within TB programs, patients worried about being identified and labeled as having HIV/AIDS. Even patients attending the co-located clinic conveyed their preference to access healthcare services at the “HIV side”, despite the proximity of the “TB side”, as a result of the greater compassion and safety in similitude that they enjoyed with HIV-based care. The greater attention to patient privacy and building of a sense of community instilled within the culture of HIV programs was also recorded during field observations. This important aspect of patients’ decision-making for dual TB/HIV care remains unexplored, to date, and reflects the greater trust, confidence, and security that patients may experience within their HIV clinic environments, compared to facilities providing TB care.

While many study patients invited the opportunity or already enjoyed having access to TB and HIV care at proximally situated clinics, some participants favoured accessing care from separate facilities
that mandated longer commutes. They preferred going to “different places” for TB and HIV care because of a perceived mistrust in the quality of care offered by their TB clinic, which related to their preference towards HIV clinics as was discussed earlier. They also preferred to travel farther away for HIV services because it was “better than close to home”, where they may be identified by others and thereby stigmatized. Patients thus took deliberate steps to ensure the separation or non-integration of TB and HIV care in order to avoid disclosure of their HIV status, and from their perspective, to retain a higher degree of social desirability. They traded practical convenience for confidentiality of their serostatus, and retention of a non-stigmatized illness identity. In other words, their decisions or preferences for integrated care were based on the social consequences of such decisions, rather than just their medical implications or monetary costs.

One study from South Africa surveyed TB patients’ acceptability towards integrated services beyond the issue of HIV testing (Levin et al., 2006). Fear of stigma and being labeled as having HIV were found to be the primary deterrents regarding integration. Though most surveyed patients expressed willingness to attend a physically integrated clinic, their actual utilization was never measured. The current study calls attention to social and structural mediators, such as stigma and program cultures, that can render patients’ expressed intentions as moot, and challenge their ability to form ‘practical’ or ‘correct’ health decisions when the actual time to enact such decisions arise.

**Social rationality of health decisions**

The expressed satisfaction with and preference for co-located TB and HIV services on the part of many study participants satisfies the current assumption of many interventions that have been designed to integrate TB and HIV care. That is, to manage TB and HIV under one (or proximal) roof as a means to deliver services in a manner that is clinically and logistically efficient for patients and for programs. This assumption, that is pervasive within the dominant discourse around TB/HIV care, is based on a logic model that reckons individuals form health decisions based on correct knowledge and a desire for clinical cure or symptom relief (Boudon, 2003; Buetow, 2007; Garvin, 2001; Mykhalovskiy, 2008; Waisbord, 2007). Some studies with TB patients show that access to and the apparent success of HIV treatment may improve their willingness to undergo VCT (Chimzizi et al., 2004; Loveday et al., 2007). Similarly, clinic proximity and low transportation costs have been associated with the improved uptake of ART by the general population and by TB patients (Geng et al., 2010; Zachariah et al., 2006).
However, that some patients in the current study opted against the most clinically or logistically sound choice for TB and HIV care, that is, co-located care, reflects how other non-biomedical and non-technical issues may underlie their health decisions. The experiences of stigma reflected in their narratives suggest that these patients may indeed be at greatest risk for the social impact of coinfection and thus, may be in most need of a socially-responsive remedial intervention. How patients weigh clinical or practical options against those which lend them the least social cost may further be a function of them accepting and owning their illness, their progress with treatment, and interactions or experiences enjoyed within TB and HIV programs.

The social costs of accessing physically integrated clinics, and being labeled as HIV-positive, particularly within (some TB) programs that fell short of patients’ expectations for confidentiality and quality of care, subsumed the health benefits of clinically- and operationally-sound interventions. These social costs were further embedded in interrelated structural constraints, such as economic, gender, and power inequalities that were discussed in Chapter 6. The most practical health decisions were shadowed by these sociostructural constraints, and the study shows how apparently irrational health decisions may indeed be socially rational from the perspective of coinfected patients. Decisions against attending co-located programs were a function of patients’ broader social contexts (and inequalities) rather than their medical or practical need to access care.

The study thus substantiates theories of ‘social rationality’, or the social processes underlying people’s health decisions, that have been postulated by social science researchers (Buetow, 2007; Garvin, 2001), and applied to understand decision-making in the context of TB (Waisbord, 2007) and HIV (Mykhalovskiy, 2008). Findings highlight how identities associated with TB/HIV coinfection, and the social consequences of utilizing related health programs may impact the ways in which patients decide and navigate dual care. While patients’ experiences were marked by sociocultural norms and structural constraints around health seeking and service utilization, they were further bound by the stigma associated with coinfection, and the disparate paradigms of TB versus HIV service delivery. While proximal or physically integrated clinics were considered to be advantageous with regards to patient costs and the programmatic coordination of care, they also heightened some patients’ social burden of disease due to inadvertent HIV disclosure and related stigmatization. Patients’ social rationale for particular forms of TB and HIV care is thus a critical consideration for healthcare integration. The study findings have critical policy and practice implications for TB and HIV healthcare that are discussed in the final chapter.
Chapter 8

Synthesis of findings: study contributions

This study, based in South Africa, was centered on two main objectives: (i) to characterize the illness experience of individuals infected with TB and HIV, and (ii) to characterize their experiences with healthcare for their dual infections. While these objectives were considered and analyzed individually, there is inherent interplay and connection in their conceptualization and corresponding interpretation of findings. Observations presented in Chapter 4 further contextualize these interpretations.

This chapter synthesizes and summarizes the study’s main qualitative findings and interpretations to highlight critical theoretical contributions (irrespective of which chapter they first appeared within). Many of the findings substantiate prior work in the area and some are novel to the discourse around coinfection and integrated care. Qualitative findings that are original to this study are highlighted in Appendix I.

Dual stigmas and negotiated disclosures

- Coinfection with TB and HIV is associated with a unique form of social stigmatization that affects the ways in which affected individuals experience, understand, and disclose their illness.

In this study, patients constructed dichotomous identities associated with TB and HIV through social constructs of moral susceptibility and (im)permanence. Each identity was associated with a disparate degree of social stigma as a product of labeling, negative stereotyping, loss of status, and discrimination. HIV was the least desirable identity and invoked the greatest stigma.

The confluence of the TB and HIV epidemics rendered TB symbolic and symptomatic of HIV, and enhanced the visibility of AIDS. Coinfection thus introduced a paradox to patients’ separate identity constructions and produced a unique, overlapping form of double stigmatization. It facilitated emergence of new forms of stigma against TB, and further aggravated existing stigma against HIV. It also conferred different degrees of visibility and stigmatization against particular forms of EPTB.
Coinfected patients managed this dual stigma through novel forms of information sharing and impression management that relied on segregating their TB and HIV illness identities. Patients deflected the dominant stigma associated with HIV through concurrent processes of HIV ‘othering’ (Joffe, 1997), that is, their symbolic distancing from persons affected by HIV, and ‘covering’ (Goffman, 1963), that is, their selective disclosure of illness (and identity associated) with TB over that of HIV. Findings thus contribute to the scholarship of disease related stigma, and extend theories of stigma management that were first postulated by researchers such as Goffman.

Reproduction of sociostructural inequalities

- Patients’ (stigmatized) experiences with TB and HIV may be understood as a product and reinforcement of extant sociostructural inequalities

Alongside the clinical complications of TB and HIV, coinfected patients struggled with access to basic resources such as food and shelter, and juggled competing life responsibilities such as providing for their children and families. Most were or became unemployed during the course of their illness. Disability grant criteria disregarded patients’ complex social circumstances, and left them continually dependent on their spouses, families, and/or employers. Patients further struggled with access to ART and TB treatment on account of constraints within the health system.

Patients’ experiences with coinfection were thus set within an environment of socioeconomic inequity, which mandated they balance fulfilling their clinical need for medical care, when granted, with these social circumstances, need for material support, and the imperative to resist further loss of status. Decisions to access, retain, and adhere to healthcare (again, when granted) were formed on the basis of selective illness disclosures to spouses, families, and employers that were carefully negotiated in exchange for their acceptance and socioeconomic support. Objective markers of illness such as weight loss, physical debilitation, and CD4 counts often served as pretexts for such decisions, decisions that were influenced by patients’ need to deflect the stigma of coinfection and gain access to essential resources. The production of stigma, and its intersection with social and gendered inequalities (discussed ahead), theorized by scholars such as Link & Phelan (2006) and Parker & Aggleton (2003) in the context of HIV, was reiterated in the context of TB/HIV coinfection.
Genderification of illness experience

- In relation to social norms around gender and gender roles in the study setting, and social inequities identified above, women and men may share different experiences with TB and HIV and be subject to varied manifestations of TB/HIV stigma.

The social impact of coinfection was disproportionately worse among women due to their roles and expectations within the family, responsibility to their children, unequal access to employment and family support, and greater poverty and dependency on others (particularly their sexual partners). Compared to men, women struggled further to balance medical care with access to social support, access that was also negotiated through disclosures they perceived to be the least stigmatizing.

Women and men disclosed their illness with HIV in different ways and for different reasons. While women grappled with the shame, guilt, and loss of financial and social support subsequent to HIV diagnosis and disclosure, men were more worried about their loss of self-esteem or social worth. Men usually retained their partners’ support, and tended to mistrust most other people. Rejected women, on the other hand, reached out to confide in their families. However, quiet tolerance in their homes eventually encouraged them to bond with peers in their community to access a sense of belonging and shared experience that was often denied in their closest relationships.

Stigma and adherence or retention in care

- Stigma against TB and HIV may affect how coinfected patients decide to utilize healthcare services, attend healthcare facilities, and adhere to prescribed treatments.

The visibility of infection that was created by patients’ attendance at clinics, self-administration of medication, and by overt symptoms such as weight-loss or glandular EPTB motivated healthcare retention in confounding ways. For some, the stigma of being identified and labeled discouraged retention in care especially when denied access to ART, and interrupted adherence when granted access to treatment. On the other hand, tangible improvements in physical health, and reduction in stigma through the disappearance of symptoms, usually after the initiation of ART, encouraged them to continue care. However, physical wellbeing also triggered some patients to discontinue care, particularly when they perceived the social costs of treatment were too high.
Interactions with informal peers and role models, and a gradual perceived invisibility at HIV clinics, where everyone was “the same”, mitigated many patients’ experiences with stigma. These positive cues empowered patients to relinquish their fears, and helped reinforce their adherence to care. Thus, alongside social, economic, and health system constraints, stigma remained an overarching theme influencing patients’ decisions for healthcare, albeit often in non-linear ways.

**Pluralistic health seeking**

- Coinfected patients may access a host of healthcare facilities when being diagnosed and treated for TB and HIV for a variety of reasons.

Patients attended local primary healthcare clinics and work-based health programs due to their convenience with regards to affordability and access. However, they distanced themselves from these facilities when they perceived it could threaten their positive self-identity, via disclosure of their HIV (and/or TB) status.

Patients utilized private clinics, as they perceived greater efficiency in diagnosis and treatment, a higher degree of privacy, and trust in the confidentiality of their HIV status at those facilities. Their utilization of complementary or traditional medicines was shaped by existing social norms around healing, but further catalyzed by a lack of expeditious access to HIV and TB treatment, particularly to ART. Thus patients’ medical pluralism was tied to structural and health system constraints. It was also fueled by the fragmented system of TB and HIV care.

**Fragmented healthcare**

- Coinfected patients are exposed to a system of healthcare that is often fragmented and uncoordinated due to the nature of healthcare delivery within TB and HIV programs, and patients’ experiences with the stigma of coinfection.

Patients’ pluralistic health seeking reflected the failure of the public health sector to fulfill their medical and social needs, and was reinforced by the verticalization of TB and HIV care. The highly specialized nature of service delivery that was espoused within TB and HIV programs produced a system of continuous (and often inefficient) cross-referrals, where coinfect ed patients were ‘dumped’ (Dartington, 1979) between various health programs and subjected to poorly coordinated care. This, together with the medical confidentiality around HIV, enabled patients to manipulate the
information (or illness identities) they shared with different providers, and for TB/HIV stigma to continue to infiltrate their health decisions after their entry into the healthcare system.

**Disparate program cultures**

- Coinfected patients may share different experiences at their TB and HIV clinics, which are embedded in and shaped by the distinct cultures of TB and HIV care

Patients had markedly different experiences within TB and HIV programs. Save for DOTS-collections, appointment waiting times for TB and HIV providers were considered long. In general, interactions at TB clinics were perceived to be rushed and impersonal, whereas HIV care was considered to be more attentive and individualized. Attention to patients’ privacy and a multi-disciplinary approach were more apparent with HIV-based care. Patients believed they could be more open at their HIV clinics, among others just like themselves, a sentiment that was generally missing within TB programs. Patients with longstanding diagnoses of HIV felt that they had established a more trustworthy relationship in this (HIV-based) environment, and TB was often conceived of as a temporary setback that did not mandate a change in their primary point of (HIV) care. Notwithstanding the (historical) public health reasons that motivated the development of such program cultures, the distinctions between TB and HIV control impacted patients’ experiences at their TB and HIV clinics, and their subsequent attitudes and decisions for TB/HIV care.

Coinfected patients’ health decisions were a product of the meanings they attached to TB and HIV, and their interpretations of experiences at TB, HIV, and other (e.g., primary) healthcare programs. Patients’ decisions to disclose illness, adhere to or retain care, and access services at particular health facilities all reflected the “wider social conflicts and contradictions” (Eakin & MacEachen, 1998: p 912) of their lived reality, including extant social and gender disparities and the distinct organizational structures (and cultures) of TB and HIV programs. Findings thus enable an extended application of Eakin & MacEachen’s scholarship by highlighting how social (and stigmatizing) interactions experienced by coinfected persons in their community and healthcare environments may be interpreted by individual patients, but are a function of wider social norms around TB and HIV, and of wider (conflicting) social structures within which TB and HIV control are based.
Co-location may not reflect cost-effective or shared patient care

- Co-located clinics may not necessarily relieve coinfected patients’ costs and time for TB and HIV care, or equally enhance information sharing between TB and HIV programs.

Co-location facilitated the diagnosis and treatment of TB and HIV at proximal health facilities. However, few patients were able to access HIV and TB care (including DOTS collection) on the same day, and save on the duplicate costs and time of co-treatment. The difficulty with waiting in two separate (and long) queues to see two distinct clinical teams on the exact same day precluded the expected efficiency of a co-located arrangement. Thus, co-location did not necessarily ease the logistic burden of dual care from the perspective of affected patients.

Adherence to patients’ medical confidentiality on the part of HIV-based HCWs, and HIV non-disclosure at TB and other non-HIV clinics on the part of some coinfected patients precluded an equal degree of (or bi-directional) information sharing between TB and HIV programs. This impinged on the integration or provision of comprehensive TB and HIV care even at co-located facilities.

Social rationale for integrated care

- Patients’ health decisions may appear to be medically irrational at the outset but reflect complex social phenomena related to TB/HIV stigma and the nature of TB and HIV healthcare.

While many coinfected patients enjoyed the practical convenience or expressed a desire to attend proximal or co-located facilities for TB and HIV care, others preferred to access clinics that were located farther away to avoid disclosure of their HIV status. When probed about their inclination to access a single point of care, many patients voiced a preference to attend their HIV clinics, where they felt they had nothing to hide, experienced more personalized care, and anticipated sharing a life-long relationship. Coinfected patients’ accounts call attention to the ‘social rationality’ (Waisbord, 2007) of health decisions that, in this study, eclipsed the practical and clinical benefits of many health decisions. These findings help broaden the current understanding of individual decisional frameworks for health and healthcare.

Summation

In summary, TB/HIV coinfection may expose patients to a double and unequal form of social stigmatization that is embedded in sociostructural and gendered inequalities, and which mediates
their decisions to access, retain, and adhere to medical care. Coinfection may also expose patients to pluralistic and fragmented forms of health service delivery, including double and unequal cultures of TB and HIV care. Patients’ experiences with the double stigma of TB and HIV and with the distinct cultures of TB versus HIV care may influence their decisions for (integrated) TB/HIV healthcare. While physically integrated clinics may enhance the coordination of some medical care, they may not always mitigate the cost and time associated with dual care from the perspective of patients, or enhance medical information sharing for non-HIV programs. Further, they may fuel the untimely disclosure of HIV and subsequent (double) stigmatization for some coinfected patients, and thereby enhance their social burden of disease. These sociostructural and sociomedical contexts of patients’ illness experiences, and the non-biomedical, social rationality of their health decision-making should be considered alongside the clinical and operational issues around healthcare integration.
Chapter 9

Study implications, limitations and recommendations

This final chapter discusses the potential implications of the study for healthcare policy and practice. In concluding the thesis, the chapter also highlights important study characteristics and limitations, and recommends directions for future research.

Study implications

The study demonstrates that the lived experience of TB/HIV coinfection is complex and wide reaching, with important policy and practice implications for TB and HIV healthcare. While findings focus on socially complex phenomena underlying patients’ experiences with illness and care, they also show that despite reviewed operational, clinical and social challenges, many coinfected patients (i) are receiving healthcare for both TB and HIV, and (ii) want to access concurrent care for TB and HIV. The task at hand, now, is to devise ways by which such care may be delivered under a socially informed and socially responsive paradigm. The points below urge address to several issues that represent the key implications of this study. They are likely of interest to key-informants and coinfected patients who participated in the study, health professionals and allied HCWs, clinic and hospital managers, NGOs (e.g., WHO, the International Union Against Tuberculosis and Lung Disease or The Union), government officials in high-burden countries who are responsible for TB/HIV policy and program development, and to social sciences, operational, and clinical researchers. The study implications and planned dissemination are also summarized in Appendices J and K, respectively.

Address to the social stigmatization of TB/HIV coinfection

The study helps characterize and disentangle the stigma of TB/HIV coinfection. It emphasizes how, in the context of high HIV-prevalence settings, stigma around TB is intricately linked to stigma around HIV/AIDS. The nature and impact of this stigma in such settings needs to be acknowledged and addressed in healthcare policy and practice, particularly its ability to influence patients’ decisions for (integrated) TB and HIV care, its capacity to challenge biomedical assumptions of health behavior and healthcare utilization, and its potential to affect how patients with just TB may form decisions to access and adhere to care on account of its implicit connection to AIDS.
The study underscores that stigma in the context of TB and HIV should not be conflated with other sociomedical challenges to healthcare delivery and uptake; rather, it tends to pervade them all. Stigma influences how patients disclose illness to their spouses, families, and social networks, and what they choose to disclose. It influences how they disclose illness within the health system and across a range of health providers. It impacts how and why they decide to access and retain diverse forms of care, within the conventional and traditional sector, at private and public facilities, and across TB and HIV programs. Stigma is also experienced and managed differently across genders.

The influence of stigma is neither linear nor formulaic. On one hand, stigma associated with the visibility of illness may encourage patients to adhere to treatment. On the other hand, stigma associated with the visibility of being identified at a clinic may discourage patients from accessing care. While stigma can preclude patients from discussing their illness openly, shared experiences with stigma also bring them together to ‘profit’ from the intimacy and belonging inculcated by peer support. While HIV stigma may prompt some to discontinue HIV care, it may not parallel attrition from TB care. Health actions for TB thus may not mirror those for HIV and urge distinct examination.

The complex and tangled experience of TB/HIV stigma, as was highlighted in the study, renders it highly circumstantial and context-specific. While it is easier to conceptualize stigma as a variable that can be altered through targeted, individualistic change, a much broader understanding of stigma, and the impact of stigma on patients’ experiences with illness and decisions for disclosure and care is encouraged. TB/HIV stigma, in the context of high-burden and resource-disparate settings, is compounded by impoverishment, gender inequality, diminished access to resources, and a persistent dependency on other, often more dominant, social groups. Stigma may also be perpetuated by uncaring, unequal, or socially unresponsive healthcare environments. Mitigation of stigma thus also warrants broader adjustments in how services are delivered and greater allowances for the influence of complex social circumstances that may aggravate patients’ negative experiences with illness and impede their ability to access or adhere to medical care. In this study, informal peer support and positive role models of beauty equaling health, expeditious connection to ART, financial and emotional support from families and employers, destigmatizing clinic environments, and trust in the privacy of healthcare all appeared to overpower or at least mitigate the stigma associated with TB and HIV. An application of interventions that promote these features within their mandate for disease control, in context-specific ways, may help promote positive self-identities for patients coinfected with TB and HIV, and encourage their sustained utilization of TB and HIV healthcare.
**Address to the specialization of TB and HIV healthcare**

Patient and key-informant accounts attest to the highly vertical nature of TB and HIV programs and the fragmentation of TB/HIV care. Though the study was not intended to evaluate clinic performance, participants spoke about their healthcare experiences at a number of facilities including, but not limited to, the three study sites. Their narratives urge address to the specialized nature of TB and HIV service delivery.

Despite decentralization of many services such as VCT and DOTS, many other critical services remain singularly administered at specialized TB and HIV facilities. Coinfected (and possibly singly infected) patients may actually prefer receiving comprehensive care at these specialized clinics as compared to their local clinics, based on unsatisfactory encounters at primary healthcare centres, poor and multiple cross-referrals, and intersecting experiences with stigma. However, TB and HIV clinics may be unwilling or unable to deliver more integrated care with respect to HIV, TB, and other more general health issues that emerge during the course of coinfection (due to resource constraints and a traditional vertical mindset). Specialized service providers may also feel less competent dealing with more general health concerns, despite they being indicative of clinical complexities or drug interactions that are specific to TB and HIV (e.g., atypical TB symptoms or IRIS).

The implications of these crosscutting issues are multifarious. First, decentralization should not be assumed as representative of integrated or horizontal healthcare delivery. These occur in degrees and contexts, with varied advantages and limitations. For patients with coinfection, referrals from the primary healthcare sector to specialized TB and HIV clinics tend to be routine and constant (possibly related to their synergistic clinical complexity). Decentralized clinics in lower-resource communities may lack the technical and human capacity to resolve emerging issues, and patients recognize this incapacity when forming their own decisions to access care at other locations, or revert to different health sectors. While the decentralization of DOTS to primary healthcare clinics may assist patients’ adherence by bringing healthcare closer to their homes and places of work, it also perpetuates some fragmentation of care related to coinfection. Patients withhold HIV-related issues at DOTS sites on account of poor staff interactions and site constraints (many of which are beyond HCWs’ control), and due to their greater personal visibility and fear of being stigmatized.

Second, co-location of TB and HIV services is one model of integration. Though it may assist clinical teams in coordinating dual care, the model must commensurately respond to the needs of target
populations, that is, patients who want to access dual services on the same day, not just at the same place. In the absence of a fully integrated unit (i.e., one medical record or chart, one clinical team), which likely requires a greater degree of financial and managerial integration, improved coordination of appointments between TB and HIV clinical teams will allow patients to collect TB treatment and ART, and/or be examined by a TB and HIV clinician on the same day.

Third, notwithstanding that most TB and HIV programs function independently, or at best interdependently (likely related to their vertical funding and accountability), they need to expand their medical purview beyond considerations related to just TB and HIV care. This is especially so for HIV programs considering the lifelong trajectory of the disease, and the statute of medical confidentiality that precludes transparent referral of HIV-related care (which also warrants revisiting AIDS exceptionalism and stigmatization within the health system, and may be resolved through the attainment of patients’ consent on a case-by-case basis). This is especially so for programs in lower resource settings, where specialized facilities are often the only ones that have the technical and human resource capacity to provide high quality care for (any) co-morbidity, and where the primary sector may suffer from weak operational capacities for comprehensive care.

Fourth, the study highlights missed opportunities for the concurrent delivery of TB treatment and ART, and expeditious placement of TB patients on ART due to the separation of TB and HIV clinical care. Enhanced collaborative efforts between programs, especially communication, and prompt resetting of clinical thresholds for ART initiation in patients with (any form of) TB are critical study implications. This includes dissemination of the WHO’s (2010b) recent, more inclusive guidelines for co-treatment. The eventual process of integration must of course consider patients’ perspectives alongside the clinical and operational imperative to align TB and HIV care, as is discussed below.

**Address to the cultural differences in TB and HIV care**

The study calls attention to the disparate philosophies of health service delivery that are commonly espoused by strategies of TB and HIV disease control. Patients’ articulated appreciation of and preference towards the caring and compassionate atmosphere created within HIV clinics speaks to the strengths and weaknesses of HIV and TB programs, respectively.

Findings, first and foremost, should serve as a wake-up call to TB policymakers, program planners, and providers that despite them being the pioneers of integrated TB/HIV care, and leading the way
in monitoring the co-epidemic, coinfected patients may want to receive healthcare for coinfection at HIV, not TB, clinics. In their systematic and often, clinically successful quest to standardize TB control, TB programs may have prioritized technical efficiency at the expense of social acceptability. Much research has pushed HIV programs to learn from TB policy and practice, and incorporate the tenets of DOTS into the rollout of ART and other HIV services (Farmer et al., 2001; Sebastian et al., 2006). However, commensurate dialogue around the incorporation of patient-centered approaches to care, routinely advocated by HIV programs, must be generated within TB program planning as well. And while some HIV advocates have invited those engaged in TB control to mobilize treatment literacy, community involvement, and patient empowerment (Achmat, 2006; Harrington, 2010), such concepts need to diffuse from pilot projects into the day-to-day culture of TB control.

Second, patients’ experiences should also serve as a wake-up call to HIV programs that have steadily lagged behind in their efforts to proactively collaborate with TB programs and respond to TB resurgence (Harries et al., 2002; Nunn et al., 2007). Coinfected patients in this study clearly voiced where they want to be treated for coinfection. They clearly stated why they made this choice. It is now up to HIV policymakers and program planners, as well as healthcare professionals, to step up to the task and prioritize TB as a critical force impacting HIV control. HIV patients’ disinclination to disrupt their points of (HIV) care on account of what they perceive to be a temporary coinfection should prompt HIV programs to cater to the broader needs and co-morbidities of people living with HIV. The clinical trajectory of HIV, which aggravates the incidence of TB (and other infections), mandates that HIV care cannot, and should not, reasonably be delivered in a vertical manner with respect to its outreach and scope.

Structural and paradigmatic changes in the delivery of TB/HIV care necessitate channeling additional resources or re-prioritizing the allocation of existing resources (presently skewed in favour of HIV control (Harrington, 2010; Nunn et al., 2007)) to enable TB and HIV programs to cater to the unique needs of patients with, or at risk for, coinfection. Realistic address to the cultural differences of TB and HIV care must consider how to optimally marry the holistic philosophy of HIV care with the focused strategy of TB control in the context of available financial and human assets.

**Address to the social underpinnings of patients’ decision-making**

The study shows that multiple issues mediate patients’ health decision-making, and that the social consequences of their decisions may override the operational or clinical logic of such decisions. The
study also shows that decision-making is not just an individual or cognitive process, but that structural and contextual issues may challenge, or facilitate, how and why patients make particular choices in relation to their health. For instance, some patients may favour a long commute, depending on their experiences with illness and care. The health workforce must realize that in many cases, patients’ algorithms for health-related decisions are simply different from their own, and should not be dismissed as wrong or irrational. Rather, they should be adequately acknowledged and engaged with (see Figure 9.1). Just as attention is drawn to resolving the clinical and logistic complications of TB and HIV care, awareness and advocacy needs to be raised to address and improve the general social conditions of people affected by TB and HIV. For instance, employment policies should be re-visited, and additional recourses made available for patients in lower resource settings who are largely unemployed or work in the informal sector. Eligibility criteria for social assistance should consider non-clinical social indicators of applicants’ health, and their (in)ability to work and care for their families as they balance adherence to TB and to HIV care.

**Figure 9.1: Balancing decisional algorithms: social vs. biomedical rationality**

When patients’ socially motivated decisions are construed as problematic, sociologist Buetow (2007) alerts us that it “denies their personhood; marginalizes them from the dominant discourse and
(re)production of knowledge; leads professionals to attempt to change, rather than respond constructively to, their beliefs and decision not to attend for healthcare; and damages patient-professional relationships” (p 593). By ignoring what makes sense or is socially rational to patients, and by imposing pure biomedical rationality on their health-related decision-making, we may further isolate hard-to-reach populations and further distance ourselves from their social realities. Greater attention to patients’ interests, medical and social, is thus warranted to promote their acceptability, uptake, and adherence to interventions for TB and HIV care.

**Address to patient perspectives towards integrated care**

A key feature of any integrative process in the health system, promoted by health analysts and researchers, is that it must be contextualized to local epidemiological, social, political, economic, and historic contexts, and respond to the specific needs of targeted communities. A one-size-fits-all approach is unlikely to succeed (Atun et al., 2010b; Criel et al., 1997; Criel et al., 2004; Friedland, 2004; Shigayeva et al., 2010; WHO, 2010b). This study demonstrates that future interventions and research around integrated TB/HIV care, or structural changes in the delivery of any healthcare, should adequately consider the patient’s (social) perspective alongside issues specific to the disease and health system. Having token community ‘gatekeepers’ or informants on a program planning committee is probably insufficient. Ongoing process and outcome evaluations of pilot (and wider) projects must re-connect with the societies they operate within to ensure the dominant biomedical or clinical logistic paradigm of healthcare delivery is commensurately aligned with the continuing (and often changing) social needs of the people they attempt to serve.

To date, this study represents one of the few research initiatives focusing on patients’ voices in the scientific assessment and critique of TB and HIV healthcare. Their narratives are telling of important themes that may go unexplored in many categorical program evaluations (successes and failures) of clinical interventions for TB and HIV control such as TB-DOTS, VCT, and ART. By considering patients’ perspectives, we may situate their health decisions within broader social contexts, and modify the paradigms through which we develop and deliver related health services. This will enhance the success (and predicted success) of future interventions by ensuring the paradigms in which they are set consider the clinical *and* social factors of disease and healthcare (see Figure 9.2).
While writing this thesis, I was asked to explicate a ‘bottom line’: To what extent may this study be used to push for an ‘ideal’ system of TB/HIV care? Should coinfected patients’ decision-making prompt the development of integrative efforts that address TB/HIV stigma or prompt opportunities for patients to access care from remote locations that mitigate their current experiences with stigma? Notwithstanding the many potential dimensions and models of TB/HIV integration, enhanced coordination of services appears to be ultimately imperative for reduction in the enormous clinical burden and impact of coinfection. There seem to be too many missed opportunities for co-treatment and follow-up that go unattended within non-integrated programs. Encouraging patients to access care from remote locations will likely exacerbate disease progression, and the overall (clinical and social) morbidity of their illness in the long run. It would also absolve program planners from confronting the issue of stigma associated with TB and HIV, and from re-visiting their different approaches to disease control. Instead, the study urges incorporating patients’ socially based decision algorithms in the future development of (integrated) healthcare interventions that are aimed to mitigate the double impact of TB and HIV.

**Address to the nature of individualized constructs and numeric associations**

Last but not least, the study urges against applying a unidimensional purview on social constructs such as stigma, disclosure, and social support that are commonly used in research related to TB and HIV. For example, the production and impact of stigma, as was highlighted earlier, may follow non-
linear pathways, change over time, and relate to issues at more (macro) social levels as compared to (micro) individual levels. Thus, any assessment of ‘stigma’ should incorporate these multiple levels and conceive of stigma as a social rather than individual-centred phenomenon. Similarly, ‘disclosure’ is also multidimensional. It is not a static event but rather a dynamic process with varied degrees (e.g., TB over HIV) and targets (e.g., spouse or HCW). Disclosure may change over time (e.g., new vs. old partners) and even compound itself (e.g., early disclosure influences future disclosure). Finally, the study shows that the notion of ‘support’ also has varied dimensions, not just in terms of the type of support (e.g., material or social), or the amount of support (e.g., income or grant), but additionally the perceived value or quality of that support (e.g., tolerance, acceptance or solace).

Following from this, the study urges further exploration on the social relevance of numeric associations. For instance, although a higher proportion of male participants had children (see Table 4.1), the social burden of tending to children, and the impact of such burden on decisions to disclose illness and access support was more intensely experienced by women (see Chapters 5 and 6).

**Study characteristics and limitations**

In response to the research objectives, the distinct methodological underpinnings of this study may have limited the resultant findings in several ways. The particularities of these limitations, as well as the steps that were taken to mitigate their potential impact, are discussed below. Note that the impact and resolution of study characteristics relating to some patients’ refusal to participate, short interviews, interviewer-interviewee dynamics, and multiple *emic* and *etic* influences on data translations and interpretations were discussed in Chapter 3.

**Boundaries of the study sample**

The boundaries of the study sample may limit the study findings and impact. First, participants were purposively selected. While this facilitated insight from a more varied group of patients (see Tables 4.1 and 4.3) that may not have been attained through more random samples, findings may not be representative or generalizable to all coinfected patients in South Africa or elsewhere.

Second, participants were recruited from three sites that were selected on the basis of their provision of TB and HIV care, patient population, and interest in collaborating on this research. Sites 1 and 2 were managed within the public sector and derived their operational directives from the province and/or district municipalities. They may be considered to represent many other TB and HIV
clinics in the country. However, the form of co-located care accessible to patients recruited from Site 3 is still uncommon in most of South Africa, and in many high-burden countries. Thus, the site may not be representative of how TB and HIV services are delivered more generally. Identified challenges to the coordination of patient care may also be differently experienced across other programs that attempt to integrate or co-locate TB and HIV services.

Having stated these limitations, the study findings may be fitting or transferable (Murphy et al., 1998) to understanding patients’ experiences with TB/HIV coinfection and decision-making for TB/HIV care in similar settings, such as where (i) attempts to integrate TB and HIV services are underway, (ii) patients face concurrent social co-morbidities in relation to their socioeconomic status and access to comprehensive care, and (iii) public perceptions of TB are closely tied with those of HIV and/or AIDS (i.e., in settings with a high burden of TB and HIV). They may also be transferable to understanding patient perspectives in the context of other HIV-related co-morbidities, and attempts to coordinate the delivery of services between other vertical or less integrated programs in the health system. That the final sample included patients exhibiting a range of clinical characteristics (with regards to their TB infection, diagnostic history and treatment stage), and social circumstances (with regards to their demography, marital/partner status, children, employment status and residence), and who were accessing a range of clinics (not just limited to the three sites) additionally broadens the qualitative applicability (Murphy et al., 1998) of this research.

Lastly, the sample was limited to people who were already accessing healthcare for TB and HIV. The voices of individuals who were not receiving any form of medical care and/or those who may have abandoned conventional medical care were absent. While their inclusion may have extended the limits and explicated scope of the study, it would have allowed for a fuller understanding of the nuances of illness experience among people who are likely the most marginalized and most vulnerable to stigma and structural inequalities. The inclusion of narratives from patients who had confronted difficulties accessing and/or retaining care, or had discontinued medical care for some period of time in their past, lent some insight into these complexities of healthcare utilization.

**Subjectivity of data and data collection**

Data were primarily collected on the basis of patients’ self-report and secondarily, through key-informant interviews and field observations. Interviews were employed because of their suitability to explore individual perceptions, attitudes, beliefs, and motives, for the inclusion of context in the
discussion of sensitive topics, and to encourage the probing of novel and unanticipated themes (that were believed irreducible or unpredictable via other forms of inquiry such as questionnaires) (Barriball & While, 1994; Mack et al., 2005). However, interview responses were not validated through an objective examination of patients’ medical records in relation to their health or health seeking actions. The clinical and/or logistic aspects of why some patients were refused or experienced delays with ART, or were accessing TB and HIV care from particular health facilities, may have contradicted or validated patients’ understanding or expression of these issues. Patients may also have omitted or altered recounting events that cast them in socially undesirable ways, which could detract from their image as ‘good’ patients. The added subjectivity of the relationship between participants and interviewers was discussed in Chapter 3.

These limitations in the subjectivity of data and data collection were mitigated by several methodological considerations. First, interview questions were framed so as to establish a rapport with participants that minimized a sense of judgment or harm upon those interviewed. For example, they generally began with an inquisitive “How?” as compared to a potentially implicative “Why?” (Hsiung & Raddon, 2002). Main questions were also piloted and subsequently revised. Second, probing, as a tool to increase interactive opportunities, and other strategies that could mitigate tension (e.g., controlling the interviewers’ dress code and manner of speaking, discussed in Chapter 3) were believed to reduce the risk of attaining socially desirable responses (Barriball & While, 1994; Patton, 2002). Behaviours commonly considered judgment-worthy or risky (e.g., sexual practices) were not directly probed, as is common with other studies that highlight the problem of social desirability (Okamoto et al., 2002; Tourangeau & Yan, 2007). Though patients were expected to avoid describing their experiences at the study sites in negative ways in order to maintain desirability, several patients at all sites did complain about the problems they had experienced at those as well as at other clinics. Their responses (that were subsequently anonymized) were at least in part, telling of the trust or open rapport created during most interviews.

Finally, and most importantly, as compared to a realist or positivist perspective, the study’s constructivist-interpretivist theoretical stance (Denzin & Lincoln, 2000) allowed for the interpretation of multiple meanings and multiple truths in participants’ illness accounts. The goal was to understand social reality from the perspective of participants, compared to what the dominant discourse around coinfection considered to be the truth in their experience. The primary tenet of this theoretical stance was that these subjective meanings or perceptions of reality underlie
patients’ actions or decisions for care, and this allowed for the subjectivity of the study data and data interpretations.

**Subjectivity of data interpretations**

Qualitative researcher Sandelowski (1993) has cited constructivist grounded theorist Kathy Charmaz in acknowledging that “researchers never enter any project tabula rosa but, rather, with the general perspectives of their discipline; with their own research interests and biographies; and with certain philosophical, theoretical, substantive, and methodological considerations” (p 215). Following from the study approach to data collection, analyses of interview excerpts as well as field observations were similarly subjective, mandating address to the researcher’s biases.

In addition to critical reflections on the research process that I discussed in Chapter 3, the study interpretations may have been tainted by my personal interest in (and prior work) in the substantive area of TB and HIV, including an ongoing sensitization to concepts such as stigma and labeling that are widely cited in the literature. Interpretations may also have differed based on my adopted theoretical stance. The use of constructivist GT (Denzin & Lincoln, 2000), as a deviation from the strictest application of GT, encouraged my persistent ‘self-consciousness’ during the various steps of data collection and interpretation. Abduction, attention to ‘outliers’ or unique circumstances, and ongoing consultation with Zanele’s emic viewpoint enabled weaving the data in the contexts of the current study, rather than forcing a fit between my preconceived ideas and participants’ voices. These applications of reflexive exercise helped keep my assumptions in check, enhanced trustworthiness of the study findings, and credibility of their interpretations (Murphy et al., 1998). Transparency in the analysis, inclusion of relevant quotes, and of accounts that diverged from those most commonly recounted also helped enhance the study’s internal validity.

**Lack of causal associations**

Following from the study’s qualitative approach, findings were more inductive and interpretive as compared to deductive or inferential. Causal associations between participants’ characteristics or individual circumstances and their experiences or decisions for care may not be made. While some patterns were identified such as the distinct experiences with disclosure by men and women, their significance must be validated with larger sample sizes and quantitative designs (keeping in mind how some social constructs such as stigma may not always follow a linear path).
Recommendations for future research

The study represents one of the first attempts to elucidate the experience of TB/HIV coinfection and related healthcare from the perspective of individuals most intimately affected by TB and HIV. Findings help chart future research on coinfection including TB and HIV service delivery. The explicated characteristics and limitations of this study help conceptualize how future studies may be designed to refine the theories developed herein, and expand their applicability to other settings.

Three important follow-up studies would supplement the findings of the current study. The first is a qualitative investigation into the challenges faced by those patients who may have been omitted because of their lack of connection to any form of healthcare or discontinuation from care (i.e., defaulters). These individuals likely represent the most vulnerable group of coinfected patients. Their perspective could be helpful in further developing, negating, or revealing new themes related to this study in order to ensure TB and HIV programs are both accessible and desirable to a larger portion of the affected population (including its most disenfranchised). The second is a broad-based quantitative and qualitative comparison of coinfected patients who specifically opt to receive TB and HIV care from distant versus proximal (or co-located) health facilities. Their experience could significantly enhance the design of integrated programs that build around the model of co-location, and help understand patients’ readiness to access such care. The third is a more focused analysis of HCWs’ experiences delivering TB and HIV care in the public and private sector, particularly the operational constraints and social challenges that they may face while managing dual infections, considering they are the primary liaisons between TB/HIV policymakers and TB/HIV patients.

Several novel theoretical notions relevant to patients’ health-related decision-making emerged from this study, such as the double stigmatization of TB and HIV, selective disclosure of TB over HIV, social rationality of health decisions, and unequal environments of TB and HIV care. Some of these may be used in surveillance research to refine pre-existing quantifiable measures (e.g., stigma or disclosure), or to strengthen the validity and applicability of pre-existing instruments used to monitor such measures (e.g., health-related stigma scale developed by Van Brakel, 2006; HIV stigma scale developed by Kalichman et al., 2005; TB/HIV stigma scale developed by Van Rie et al., 2008). They may also be studied in different social and demographic contexts to understand how they affect patients’ decision-making. Weight loss, for instance, appeared to be a critical mediator of patients’ self-perception (self-identity) and experiences with treatment. Health decisions may be traced as a
function of the social meanings attached to such clinical variables. The impact of early ART on newly diagnosed TB patients’ retention in care may similarly be studied, as it appeared to be another key mediator underlying decisions for care (a mediator that also coincides with common assumptions made by the medical community in predicting patients’ utilization of services). A quantitatively significant finding supporting ART as a predictor for TB patients’ retention in care could bolster the policies to commence ART for all TB patients, and improve patients’ adherence overall.

Longitudinal qualitative and quantitative studies would help track and understand how patients’ participation in integrated models of care may change with time, as their beliefs, preferences, social circumstances, stigmas, and consequent decisions may change with clinical progression or symptom control. These studies would draw attention to the experience of patients who eventually recover from TB (i.e., when their ‘cover’ is lost) and/or relapse during their lifetime experience with HIV.

As introduced earlier, the social acceptability and impact of diverse models of TB and HIV healthcare from the perspective of patients with, or at risk for, coinfection should be further investigated or validated. The general perspectives of TB-endemic communities should also be understood, as HIV stigma may discourage individuals from accessing any form of care, integrated or non-integrated, for symptoms that may be indicative of just TB (see Mavhu et al., 2010; Ngamvithayapong et al., 2000). The one study that measured TB patients’ willingness to utilize integrated services was conducted in a high HIV prevalence community, and stigma was cited as the primary reason for patients’ non-acceptance (Levin et al., 2006). The current study shows coinfection and a lack of access to ART may be critical added ‘variables’ in patients’ decisions for TB and HIV care. Quantitative studies that correlate all these variables may help predict patients’ retention patterns, particularly in settings where stigma around TB/HIV is pervasive, and the burden of both infections is high. These research foci would assist in the design of more patient-sensitive responses.

The study calls for further interventional research towards the mitigation of TB/HIV stigma. In particular, the study urges updating philosophies of service delivery within TB and HIV programs, improving access to treatment (ART), and using targeted context-specific interventions (e.g., use of informal role models and/or peers). Many stigma interventions have been designed around educating individual persons and/or affected communities. While counseling and dissemination of information can dispel myths around infection transmission and death, studies show that people’s education-levels and knowledge are not clear predictors of stigmatizing perceptions (Babalola, 2007;
Day et al., 2003; Levin et al., 2006; Nachega et al., 2005). Wider social movements, including paradigmatic shifts in the delivery of healthcare services, are needed to truly effectuate a reduction in the experience and impact of stigma. UNAIDS recently broadcasted the success of pilot projects that enhanced positive perceptions (and reduced stigma) of HIV via community-wide improvements in the quality of life and standard of living involving the provision of general medical (including ART), nutritional, financial, childcare, and educational assistance (UNAIDS, 2005). The social construction and perpetuation of TB/HIV stigma that emerged in the current study points to this need for broader social change to destigmatize not just HIV, but also TB (also see Achmat, 2006; Harrington, 2010). The dissemination of anti-discriminatory sentiments around people living with HIV through positive media representations, and through the involvement of the private sector and religious leaders across sub-Saharan Africa, South-East Asia, and Eastern Europe speaks to this wider movement to reduce HIV stigma and promote ‘positive’ health behaviours (UNAIDS, 2005). Keeping in mind the varied social and epidemiological contexts of coinfection in different communities, similar call-to-action urging TB researchers to incorporate the advocacy efforts of HIV, is suggested by this study.

Finally, there is a research imperative to widen the designs and theoretical perspectives of scientific research work. Qualitative approaches may offer important contributions to understanding socially complex phenomena that underlie quantitative measures relevant to TB and/or HIV care, such as CD4 counts and weight loss. Ethnographic research, and institutional and community-based approaches to understanding the experiences of communities affected by HIV and TB may lend further insight to the social epidemiology of these infections, and encourage a more diverse array of patient-sensitive interventions through which disease control may be achieved. Considering the distinct manifestation of TB/HIV stigma, a Foucauldian or Bourdieusian theoretical stance could further enrich our understanding of stigma in the global context of power and resource allocation. A political economy or historical perspective may similarly invite more applicable theory around the development of TB and HIV disease control, particularly in the context of the ‘developing world’.

**Conclusion**

This thesis has attempted to foreground the perspectives of affected patients in the broader scientific discourse around TB/HIV coinfection and integrated care. It captures qualitative themes around illness experience and decision-making that are less explored, and often assumed to coincide with dominant biomedical perspectives. The study extends our understanding of patients’ health
decision-making, and helps generate a novel theorization of how individuals experience TB/HIV coinfection and decide on TB/HIV care. Refinement and scope of theory on the social contexts of TB/HIV illness will eventually come from further applications and comparisons across different social, geographic, and structural contexts, and through the implementation of further research and analyses.
### Appendix A: The expanded Stop TB strategy

<table>
<thead>
<tr>
<th>Components</th>
<th>Key topics</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Pursue high quality DOTS expansion and enhancement</strong></td>
<td>Political commitment and sustained financing</td>
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<tr>
<td></td>
<td>Early case detection/diagnosis via quality-assured bacteriology</td>
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<td></td>
<td>Standardized treatment with patient supervision and support</td>
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<td></td>
<td>Effective drug supply and management</td>
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<td></td>
<td>Performance and impact monitoring and evaluation</td>
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<tr>
<td><strong>2. Address TB-HIV, MDR-TB and the needs of poor and vulnerable populations</strong></td>
<td>Collaborative TB/HIV activities</td>
</tr>
<tr>
<td></td>
<td>Prevention and treatment of MDR-TB</td>
</tr>
<tr>
<td></td>
<td>TB contacts, and poor and vulnerable population needs</td>
</tr>
<tr>
<td><strong>3. Contribute to health systems strengthening based on primary healthcare</strong></td>
<td>Health policies, human resource development, financing</td>
</tr>
<tr>
<td></td>
<td>supplies, service delivery and information</td>
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<tr>
<td></td>
<td>Infection control in health services, households and congregate settings</td>
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<tr>
<td></td>
<td>Laboratory network upgrades</td>
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<tr>
<td></td>
<td>Practical Approach to Lung Health (PAL)</td>
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<td></td>
<td>Adaptation of approaches from other fields and sectors</td>
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<td></td>
<td>Action on the social determinants of health</td>
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<tr>
<td><strong>4. Engage all care providers</strong></td>
<td>Public, voluntary, corporate and private provider engagement</td>
</tr>
<tr>
<td></td>
<td>via Public-Private Mix (PPM) approaches</td>
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<tr>
<td></td>
<td>International Standards for Tuberculosis Care (ISTC)</td>
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<tr>
<td><strong>5. Empower people with TB and communities through partnership</strong></td>
<td>Advocacy, communication and social mobilization</td>
</tr>
<tr>
<td></td>
<td>Community participation in TB care, prevention and health promotion</td>
</tr>
<tr>
<td></td>
<td>Patient’s Charter for Tuberculosis Care</td>
</tr>
<tr>
<td><strong>6. Enable and promote research</strong></td>
<td>Program based operational research</td>
</tr>
<tr>
<td></td>
<td>New diagnostics, drugs and vaccines related research advocacy and participation</td>
</tr>
</tbody>
</table>

Adapted from the WHO Stop TB Strategy website (WHO, 2011).
Appendix B: WHO model of healthcare delivery for TB and HIV

1. Establish mechanisms for collaboration between TB and HIV/AIDS programs

   i. Set up a **coordinating body** for TB/HIV activities effective at the regional, district and local level, with equal representation of TB and HIV programs, and TB and HIV support groups.

   ii. Conduct **surveillance of HIV prevalence among TB patients**, irrespective of national adult HIV prevalence rate, preferably by HIV counseling and testing of all TB patients, otherwise by sentinel or periodic surveys.

   iii. Carry out **joint TB/HIV planning** including mobilization of technical and human resources; laboratory and health worker capacity building and training; TB/HIV advocacy, communication and social mobilization; community involvement and supportive care; and, operational research on country-specific issues for effective and efficient implementation of healthcare activities.

   iv. Conduct **monitoring and evaluation** of collaborative TB/HIV healthcare activities with agreement by TB and HIV programs on a core set of indicators and data collection tools.

2. Decrease the burden of TB in people living with HIV/AIDS

   i. Establish **intensified TB case-finding** in all HIV testing and counseling settings, among persons living with HIV/AIDS in clinics or hospitals, household contacts, high-risk populations and congregate settings with effective referral to TB diagnostic and treatment facilities.

   ii. Introduce **isoniazid preventive therapy (IPT)** as part of the package of care for all persons living with HIV, when active disease has been excluded.

   iii. Ensure **TB infection control** in healthcare and congregate settings to reduce nosocomial TB transmission.

3. Decrease the burden of HIV in TB patients

   i. Offer and provide **HIV testing and counseling** to all TB patients is setting where adult HIV prevalence exceeds 5%, with effective referral to HIV/AIDS programs.

   ii. Introduce **HIV prevention methods**, targeting sexual, parenteral or vertical transmission, and screen and treat sexually transmitted infections among all clients attending TB clinics, either within TB control programs or with effective referral to HIV, prevention of mother-to-child transmission, and STI facilities.

   iii. Introduce **cotrimoxazole preventive therapy (CPT)** to all eligible TB patients coinfected with HIV.

   iv. Ensure **HIV/AIDS care and support** along with TB support to all TB patients coinfected with HIV, with effective referrals to HIV programs for continuity of care post TB treatment.

   v. Introduce **antiretroviral therapy (ART)** to all TB patients coinfected with HIV, based on country-specific eligibility criteria and drug interactions.

Appendix C: Demography of KwaZulu-Natal province, South Africa

<table>
<thead>
<tr>
<th>Relevant information on study setting</th>
<th>KwaZulu-Natal a</th>
<th>South Africa a</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>General</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total population</td>
<td>10,645,508</td>
<td>49,991,470</td>
</tr>
<tr>
<td>% Poverty</td>
<td>n/a</td>
<td>39</td>
</tr>
<tr>
<td>% Unemployed</td>
<td>30</td>
<td>23</td>
</tr>
<tr>
<td>% Adult mortality: total (female/male)</td>
<td>72 (67/76)</td>
<td>57 (53/61)</td>
</tr>
<tr>
<td><strong>Health</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>% HIV prevalence: 18-50 years/antenatal</td>
<td>26/40</td>
<td>19/29</td>
</tr>
<tr>
<td>Number HIV-positive persons</td>
<td>1,572,457</td>
<td>5,813,089</td>
</tr>
<tr>
<td>% Deaths due to AIDS</td>
<td>58</td>
<td>43</td>
</tr>
<tr>
<td>TB Incidence (per 100,000 population)</td>
<td>1066</td>
<td>971</td>
</tr>
<tr>
<td>Number TB cases (reported)</td>
<td>122,642</td>
<td>405,699</td>
</tr>
<tr>
<td>TB deaths (per 100,000 population)</td>
<td>233</td>
<td>158</td>
</tr>
<tr>
<td><strong>Size</strong></td>
<td></td>
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<tr>
<td>Durban b</td>
<td>2,292 sq km</td>
<td>649 sq km</td>
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<tr>
<td>Pietermaritzburg b</td>
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<tr>
<td><strong>Population</strong></td>
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<tr>
<td>Total</td>
<td>3,090,112</td>
<td>553,212</td>
</tr>
<tr>
<td>18-50 yrs</td>
<td>1,651,930</td>
<td>282,550</td>
</tr>
<tr>
<td><strong>Demography</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Race (% African/Indian/White/Mixed)</td>
<td>68/19/9/3</td>
<td>77/12/8/3</td>
</tr>
<tr>
<td>% Male/Female</td>
<td>48/52</td>
<td>47/53</td>
</tr>
<tr>
<td>% Unemployed</td>
<td>28</td>
<td>31</td>
</tr>
<tr>
<td>% Completed high school</td>
<td>27</td>
<td>24</td>
</tr>
</tbody>
</table>

a: Based on the Global TB Report 2010 (WHO, 2010), South African Health Review 2010 (Day & Gray, 2010; Padayatchi et al., 2010), and Health Statistics, Heath Systems Trust (HST, 2011).
b: Based on Statistics South Africa (Census, 2001).

## Appendix D: Timeline of research activities

<table>
<thead>
<tr>
<th>Research Activities</th>
<th>2008</th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
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<tbody>
<tr>
<td><strong>Month</strong></td>
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<td>JF M AM J JASON D</td>
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<tr>
<td><strong>Planning</strong></td>
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<tr>
<td>Collaborative discussions</td>
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<tr>
<td>Ethics submissions</td>
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<td>Ethics approvals</td>
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<tr>
<td>Ethics recertification</td>
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<tr>
<td><strong>Implementation</strong></td>
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<tr>
<td>Re-location and set-up</td>
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<tr>
<td>Interviewer training</td>
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<tr>
<td>Site introductions</td>
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<tr>
<td>Field observations</td>
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<tr>
<td>Participant recruitment</td>
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<tr>
<td>Interviews</td>
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<tr>
<td><strong>Processing</strong></td>
<td></td>
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<tr>
<td>Transcription, translation</td>
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<tr>
<td>Preliminary analysis</td>
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<tr>
<td>Preliminary dissemination</td>
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<tr>
<td>Comprehensive analysis</td>
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<tr>
<td>Doctoral dissertation</td>
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<tr>
<td>Comprehensive dissemination</td>
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In Canada

In South Africa
Appendix E: Interview guides

Main questions for patient participants

Probes are not actual questions but rather, thoughts, to assist the interview in framing a follow-up question depending on the responses received by participants thus far. Asterisks indicate modifications adopted during fieldwork.

1. How did you become a patient at this clinic?
   Probe: inquire about their specific illnesses; explore previous medical experiences and with accessing health services; link to questions 2 & 3.

2. How did you know you have tuberculosis (or TB)?
   How did you feel when you were told you have TB?
   Probe: inquire on their medical history or process related to TB diagnosis and awareness; what was their awareness of TB prior to diagnosis; how did they take the news?

3. Tell me about how you came to know you had HIV.
   How did you feel when you were told you have HIV?
   Probe: inquire on HIV testing experiences; how did they react to the diagnosis; explore processes of HIV self-awareness. **Which of the two infections were they diagnosed with first? When? Why/How? Try to develop a ‘diagnostic trajectory’**

4. Have you spoken with anyone about your illness?
   What do you tell them?
   What do they say about it to you?
   Probe: inquire on their disclosure experiences; do they disclose TB or HIV or both; to whom, how; what were the social consequences; explore their support systems.

5. What type of healthcare are you receiving for TB?
   What about for HIV?
   Tell me about your experience with care (treatment).
   Probe: inquire on their access and referral to TB and HIV services; is TB and HIV being treated concurrently or sequentially; how do they navigate between TB and HIV programs; what other programs do they access; what difficulties have they experienced: clinical, logistic, social, financial and personal; what relationship do they share with providers; how involved are patients in their own healthcare; are they aware of the treatment options available to them; what is their perception/attitude on co-location of TB and HIV programs, on co-treatment? **When did they begin treatment for TB and/or HIV? How long have they been on treatment? What are their thoughts on it – do they perceive it as delayed? Did they have a choice/say in this? What is their experience at the clinic? What about at other clinics? How long do they have to wait? What do they think about this? Do they use traditional treatments, visit private clinics – what are their current and past experiences? What motivated such help-seeking?**

6. How are you dealing with your illness?
   How do you feel, physically?
   How do you feel, emotionally?
   Probe: how do they describe the impact of their illness; what changes/challenges have they experienced over time; how has their illness impacted work/family/finances?
7. Tell me a little bit about yourself.
   Who do you live with?
   Were you working before you were diagnosed? Tell me about the work you did.
   **Probe:** where are they from; how do they live; what is the social climate at home; what are their responsibilities; what is their main source of income; who do they depend on, for what; who depends on them, for what? **Do they receive a grant?** Have they applied? Have they ever received financial aid? What has been their experience with such programs? Approved/rejected? Why/not?**

8. How has your life changed since you were diagnosed?
   **Probe:** changes with work; do they work; have relationships with family/friends/partner changed; are they debilitated or coping; how do they perceive their future? **Go back to disclosure?** Did disclosure affect their relationship? Did their relationship affect how they disclosed?**

9. Tell me about the expenses you have to meet during your illness?
   How has this affected you?
   How has this affected your treatment?
   **Probe:** what are their indirect medical expenses; describe their commute to the clinic; how do their finances interfere with health decisions; explore their family/spousal support system; how do they balance economic, social and clinical burden of disease? **Ask these questions alongside question 7 where possible**

10. What do you do when you feel tired or unwell?
    At such times, do you speak with anyone in your family or community?
    **Probe:** inquire again on disclosure experiences; what are their social networks; inquire on their thoughts and participation in peer-support groups or other social support resources.

11. Are you aware of someone else diagnosed with TB?
    HIV?
    **Probe:** explore perceptions/attitudes on others living with the same disease; what relationship do they share with other patients or their peers; what did they think of TB and HIV before they became ill; how do they think about these diseases now?

12. Tell me about the type of support you receive:
    At home?
    In your community?
    When you visit the clinic (or pick up your medications)?
    **Probe:** what is their relationship with clinic personnel; what relationships do they share in their community; what social support resources are they exposed to; how open are they about their illness outside of close confidantes; does anyone accompany them to the clinic?

13. Tell me about the type of care you receive at the clinic?
    What are your thoughts on it?
    What would you like done differently?
    **Probe:** describe positive/negative/neutral experiences accessing/with TB and HIV care; what is their attitude/perception of collaborative TB/HIV care; what relationship do they share with providers; what are their personal preferences towards TB and HIV healthcare; how would they prefer their illness be managed?
14. How do you think other people in your community feel or think about TB?
   What about HIV?
   What are your own thoughts about these two illnesses?
   **Probe:** inquire on attitudes/perceptions around dual diagnosis or coinfection; inquire on stigma or discrimination against people living with HIV and/or TB.

15. Have I missed anything or is there something you would like to add?
Main questions for key-informants

Probes are not actual questions but rather, thoughts, to assist the interview in framing a follow-up question depending on the responses received by participants thus far.

1. Tell me about your role at this facility?
   **Probe**: what is their position/role; what do they actually do; what are their defined responsibilities; how long have they worked here; how has their position/role changed?

2. What training have you received in TB (or HIV)?
   - What about HIV/AIDS (or TB)?
   - Have you received any training on healthcare for TB and HIV coinfection?
   - What do you think about the training you have received?
   **Probe**: inquire on their in/formal education/on-the-job training or continuing education; how/when were they trained/by whom; are they satisfied with the training; do they want to have access to further information; do they feel equipped to deal with TB/HIV issues?

3. What is your comment on the situation of TB and HIV in the community?
   **Probe**: explore awareness/attitudes/perceptions on coinfection.

4. What do you know about integrated or collaborative TB/HIV healthcare?
   **Probe**: explore awareness/thoughts/attitudes and their ideas about integrated services

5. What types of collaborative TB/HIV activities do you offer?
   - Where do you receive your directives from?
   - What are your thoughts on the implementation or feasibility of these activities?
   - What support do you receive from higher levels of management?
   **Probe**: exactly what TB/HIV services do they provide; explore managerial hierarchy/ work-directives; inquire on site infrastructure/resources/coordinative capacity; explore support from management regarding financial/training/motivation; what do they perceive as barriers or facilitators for TB and HIV service provision; what are their likes/dislikes on providing added services, not just TB or HIV; explore accountability, motivation/morale/incentives.

6. How do you promote collaborative TB/HIV services?
   - How do you think they are received/adopted by the patients you serve?
   **Probe**: what, if any, are their specific ways of promoting TB/HIV care; inquire on service uptake; how do they perceive patients’ decisions; examples of experiences with patients

7. What are your thoughts on testing TB patients for HIV?
   - What about starting CPT?
   - What about providing concurrent ART and TB chemotherapy?
   - In your experience, what are the pros and cons of such collaboration?

8. What do you think about screening HIV-positive patients for TB?
   - What about commencing IPT?
   - What about providing concurrent ART and TB chemotherapy?
   - In your experience, what are the pros and cons of such collaboration?
   **Probe** for questions 6 & 7: explore their attitudes/perceptions towards service integration; explore burden of work; probe on stigmatizing views; ask for specific examples.
9. How do you coordinate treating patients who may be receiving medical care for another condition (i.e., TB or HIV) from another health facility?
   How do you monitor their progress?
   Does this affect your daily work routine?
   **Probe:** explore programs’ coordinative capacity and referrals; what are the on-ground barriers/facilitators to non-integrated programs; what is their personal experience – is the current level of collaboration making work easier or more difficult?

10. What types of patients do you screen for TB (or HIV)?
    What do you do if a patient refuses to be tested or screened for TB (or HIV)?
    When do you think testing a TB patient for HIV or screening an HIV patient for TB is irrelevant?
    What types of problems are you confronted with when trying to treat patients for both TB and HIV?
    How do you overcome these problems?
    **Probe:** explore personal experiences/examples with patients’ decisions; what is the pattern of delivering specific integrated services; who is the medical decision-maker: patient or provider; what is their perception of the patient most likely to have coinfection; what are their biases; focus on patient-specific problems/resolutions vs. clinical issues.

11. How are collaborative activities monitored at this facility?
    Do you notice a change in how TB/HIV services are being provided over, say, the last 6 months?
    **Probe:** explore referral patterns; what is the current trend in delivering dual care; explore their performance indicators; do they have to meet targets or quotas; again, what are the mechanisms for accountability

12. Can you think of any ways to improve the delivery of health services in relation to TB and HIV infections?
    **Probe:** gather comments on how constraints/barriers may be resolved.

13. Have I missed anything? Is there something you would like to add?
Appendix F: Consent forms

Patient consent forms (English)

CENTRE FOR THE AIDS PROGRAMME OF RESEARCH IN SOUTH AFRICA (CAPRISA)
UNIVERSITY OF KWAZULU NATAL

INFORMED CONSENT FOR PATIENTS

Study title: Integrating health services for TB/HIV co-infection in South Africa: patients’ experiences with their illness and related care

Principal Investigator: Dr. Nesri Padayatchi
Co-investigator: Amrita Daftary
Contact: Telephone: +27(0)31 260 4574, Email: padayatchin@ukzn.ac.za
Funding agencies: International Development Research Centre, Canadian Institutes of Health Research (Canada)

Greeting: I would like to speak with you for a few moments to see if you are interested in participating in an interview with me.

Introduction: My name is __________________________ (Name of Interviewer). I am working at the Centre for the AIDS Programme of Research in South Africa (CAPRISA) and, together with my colleagues, am doing a study of the social aspects of healthcare, particularly around illnesses such as tuberculosis (TB) and human immunodeficiency virus (HIV). Research is just the process to learn the answer to a question. We want to learn about patients’ experiences with their illness so we may provide more sensitive healthcare in the future. This study is not a part of your regular medical service. There will be no treatment or advice offered.

Invitation to participate: We are inviting patients who are enrolled at a number of clinics that provide healthcare services for TB and HIV to participate in this study. I am asking you to participate in a research study because you are a patient enrolled at a clinic that provides health services for TB and HIV.

What is involved in the study: There will be about 48 patients and 8 healthcare workers in this study, from several clinics in KwaZulu-Natal. If you agree to participate, I will interview you privately. No one else will be present when we speak, unless you would like someone to be present. I will ask you some questions about your life and illness so that I can learn from your thoughts and feelings. We will speak for 60-90 minutes. All patients in this study will be asked the same types of questions. After our interview is completed, your participation in the study will have ended. There will be no follow-up since I will not be giving you any treatment or advice.

If you agree, I would like to tape our conversation so that I can remember what we spoke about, using a type of (digital) tape recorder. There will be no physical tapes or cassettes. After the interview, I will transfer the recording directly to a computer. I will store the recording on the computer under a specific number to protect your identity. The original recording will then be deleted from the digital recorder.

Risks: I do not anticipate any risks to your participating in the study. You may find some of the questions to be personal. If any question makes you uncomfortable or you do not wish to respond, you do not have to answer it and you do not have to provide a reason. At any time, you can end the interview. If you would like to speak with a counselor or health practitioner during or after the interview, I can refer you to the appropriate person.

Benefits: There are no direct benefits to your participating in the study. The interview is not intended to provide you with any health-related information. Your participation will help us design better health services in the community. This may benefit other patients in the future.

Alternative: There are no other procedures to this study. The alternative is not to participate.

Participation is voluntary: Taking part in this study is voluntary. If you refuse to participate, you will suffer no penalty or loss of health services that you normally receive. If you choose to be in the study, you may refuse to answer any question or stop your participation at any time without any ill feelings (adverse consequences) or change in your medical care.

Protocol BF147/08
Patient Informed Consent | Version 1.2

Biomedical Research Ethics Committee
Nelson R Mandela School of Medicine
Approved Version
2 FEB 2000
**Reimbursements:** Taking part in the study will take 60-90 minutes. We will offer a payment of R 50.00 as soon as the interview is completed, to compensate for your time and expenses such as transport, food and childcare. If the interview ends early, you will still receive this payment.

**Confidentiality:** Our interview will be kept private and confidential. It will not be shared with your doctors or anyone at the clinic, including managers, nurses, counselors or any other staff or patient. During the interview, you do not need to provide me with your name. If you prefer, you can use a different name during our interview. The recording of our interview will not be associated with your name but will have a number attached to it, in order to protect your identity. The recording will be securely stored in the study office. The study team may check the recording to clarify whether I have interpreted what you have said correctly, but no one will know your name or have access to your identity. Personal information may be disclosed only if required by law.

The Research Ethics Committee may check the study procedures but will not have access to your name or personal identity. If the study findings are published in a paper or speech, they will be combined together with all participants in the study; they will not be associated with your name or identity. If we quote what you say during our interview, it will be kept strictly anonymous and not be associated with your name or identity.

**Contact details of researcher/s:** If you have any questions, concerns or comments, or if would like a copy of our final study report, you may contact Dr. Nesri Padayatchi or Amrita Daftary at telephone: +27 (0) 31 260 4555 or 260 4574, email: padayatchin@ukzn.ac.za.

**Contact details of BREC Administrator or Chair:** If you want to report a problem or complaint, please contact Biomedical Research Ethics, Private Bag X54001, Durban 4000
Telephone: +27 (0) 31 260 4769 / 260 1074
Fax: +27 (0) 31 260 2384
Email: ngwenvap@ukzn.ac.za

**Consent to Participate in Research:*** You have been asked to participate in a research study.

You have been informed about the study by ____________________________, (Name of Interviewer)

You have been informed about the compensation for your time and access to a counselor or health practitioner should you need to see them after the interview.

Your participation in this research is voluntary, and you will not be penalized or lose any health benefits if you refuse to participate or decide to stop.

If you agree to participate, you will be given a signed copy of this document which includes a written summary of the research.

The research study, including the above information, has been described to me orally. I understand what my involvement in the study means and I voluntarily agree to participate.

**PERSONS TO CONTACT. If you:**
- Have questions about this research study; contact Dr. Nesri Padayatchi by calling (031) 260-4555.
- Have questions about your rights as a research subject you may contact the Biomedical Research Office on 031-260 4769 or 260 1074 or 260-4495 if you have questions about your rights as a research subject.

**CONSENT STATEMENT.** "My signature below indicates that I agree to be in this study. I was given a chance to ask questions. I feel that my questions have been answered. I know that being in this study is my choice. I know that after choosing to be in this study, I may withdraw at any time. I have been told that I will receive a signed copy of this consent."

I consent to the audiotaping of my interview:

Printed patient name: ____________________________

Protocol BF147/08
Patient Informed Consent | Version 1.2

Biomedical Research Ethics Committee
Nelson R Mandela School of Medicine
Approved Version 2/3

2 FEB 2009
Printed guardian name (if applicable): ______________________

Signature of patient or guardian: ______________________ Date: __________

Signature of witness: ______________________ Date: __________
(When prospective participant is unable to read)

Signature of interpreter: ______________________ Date: __________

Printed name of person obtaining consent: ______________________

Signature of person obtaining consent: _______________ Date: __________

Signature of principal investigator: ______________________ Date: __________
Key-informant (healthcare worker) consent forms

CENTRE FOR THE AIDS PROGRAMME OF RESEARCH IN SOUTH AFRICA (CAPRISA)
UNIVERSITY OF KWAZULU-NATAL

INFORMED CONSENT FOR HEALTHCARE WORKERS

Study title: Integrating health services for TB/HIV coinfection in South Africa: patients’ experiences with their illness and related care

Principle Investigator: Dr. Nesri Padayatchi
Co-investigator: Amrita Daftary
Contact: Telephone: +27(0)31-260-4574, Email: padayatchin@ukzn.ac.za
Funding agencies: International Development Research Centre, Canadian Institutes of Health Research (Canada)

Greeting: I would like to speak with you for a few moments to see if you are interested in participating in an interview with me.

Introduction: My name is ___________________________ (Name of Interviewer). I am working at the Centre for the AIDS Programme of Research in South Africa (CAPRISA) and, together with my colleagues, am doing a study to research the social aspects of healthcare, particularly around illnesses such as tuberculosis (TB) and human immunodeficiency virus (HIV). In this study we want to learn about patients’ experiences with their illness so we may provide more sensitive healthcare in the future. This study is not a part of your regular work.

Invitation to participate: I am asking you to participate in a research study because you work at a health facility that provides patient services for TB and HIV, and because you are closely involved with the day-to-day functioning of this facility.

What is involved in the study: This study involves interviewing 8 healthcare workers and 40 patients from several clinics in KwaZulu-Natal. If you agree to participate, I will interview you privately. No one else will be present when we speak, unless you should so desire. I will ask you some questions about your work so that I can understand the types of experiences you encounter with patients. We will speak for 60-90 minutes. All healthcare workers in this study will be asked the same types of questions. After the interview is completed, your participation in the study will have ended. There will be no follow-up since I will not be providing you with any service or advice.

If you agree, I would like to tape our conversation so that I can remember what we spoke about, using a digital recorder. There will be no physical tapes or cassettes. After the interview, I will transfer the recording directly to a computer. I will store the recording on the computer under a specific number to protect your identity. The original recording will then be deleted from the digital recorder.

Risks: I do not anticipate any risks to your participation in the study. You may find some of the questions to be personal. If any question makes you uncomfortable, you do not have to answer it and you do not have to provide a reason. At any time, you can end the interview.

Benefits: There are no direct benefits to your participation in the study. The interview is not intended to provide you with any professional or health-related information. Your participation will help us design better health services in the community.

Alternative: There are no other procedures to this study. The alternative is not to participate.

Participation is voluntary: Taking part in this study is voluntary. If you refuse to participate, you will suffer no penalty in your employment or practice. If you choose to be in the study, you may refuse to answer any question or stop your participation at any time without any adverse consequences or change in your work.

Reimbursements: There is no monetary compensation for your participation.

Protocol BF147/08
Healthcare Worker Informed Consent | Version 1.1
Confidentiality: Our interview will be kept private and confidential. It will not be shared with your employers or anyone at the clinic, including managers, physicians, nurses, counselors or any other staff or patient. The computerized recording of our interview will not be associated with your name but will have a number attached to it, in order to protect your identity. If you prefer, you can use a different name during our interview. The recording will be securely stored in the study office. The study team may check the recording to clarify whether I have interpreted what you have said correctly, but no one will know your name or have access to your identity. Personal information may be disclosed only if required by law.

The Research Ethics Committee may check the study procedures but will not have access to your name or personal identity. If the study findings are published in a paper or speech, they will be combined together with all health workers in the study (aggregated); they will not be associated with your name or identity. If we quote what you say during our interview, it will be kept strictly anonymous and not be associated with your name or identity. The study team will not link any response to a specific health worker or a specific type of health worker (e.g., one involved with direct or indirect patient care).

Contact details of researcher/s: If you have any questions, concerns or comments, or if would like a copy of our final study report, you may contact Nesri Padayatchi or Amrita Dafty at telephone: +27 (0) 31 260 4555 or 260 4574, email: padayatchi@ukzn.ac.za.

Contact details of BREC Administrator or Chair: If you want to report a problem or complaint, please contact Biomedical Research Ethics, Private Bag X54001, Durban 4000
Telephone: +27 (0) 31 260 4769 / 260 1074
Fax: +27 (0) 31 260 2384
Email: nguyenyp@ukzn.ac.za

Consent to Participate in Research: You have been asked to participate in a research study.

You have been informed about the study by ____________________________ (Name of Interviewer)

You have been informed about the compensation for your time and access to a counselor or health practitioner should you need to see them after the interview.

Your participation in this research is voluntary, and you will not be penalized or lose any health benefits if you refuse to participate or decide to stop.

If you agree to participate, you will be given a signed copy of this document which includes the participant information sheet which is a written summary of the research.

The research study, including the above information, has been described to me orally. I understand what my involvement in the study means and I voluntarily agree to participate.

PERSONS TO CONTACT. If you:
• Have questions about this research study contact Dr. Nesri Padayatchi by calling (031) 260-4555.
• Have questions about your rights as a research subject you may contact the Biomedical Research Office on 031-260 4769 or 260 1074 or 260-4495 if you have questions about your rights as a research subject.

CONSENT STATEMENT. “My signature below indicates that I agree to be in this study. I was given a chance to ask questions. I feel that my questions have been answered. I know that being in this study is my choice. I know that after choosing to be in this study, I may withdraw at any time. I have been told that I will receive a signed copy of this consent.”

I consent to the audiotaping of my interview: ____________________________

Printed patient name: ____________________________

Printed guardian name (if applicable): ____________________________

Protocol BF147/08
Healthcare Worker Informed Consent | Version 1.1
Signature of patient or guardian: ___________________________ Date: ____________

Signature of witness: ___________________________ Date: ____________
(When prospective participant is unable to read)

Signature of interpreter: ___________________________ Date: ____________

Printed name of person obtaining consent: ___________________________

Signature of person obtaining consent: ___________________________ Date: ____________

Signature of principal investigator: ___________________________ Date: ____________
## Appendix G: Field observation guide

<table>
<thead>
<tr>
<th>What to observe</th>
<th>Examples of what to document/describe</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>The setting</strong></td>
<td>Physical environment, spacing/crowding, type of seating, layout, posters/flyers, ventilation</td>
</tr>
<tr>
<td><strong>The human or social environment</strong></td>
<td>People characteristics (types of persons, gender, ethnicity/race, clothing, physical appearance), frequency and types of interactions between persons (patterns/types of communication, body language), human traffic (numbers, entries/exits, accompanying persons, patient intake/output, waiting times)</td>
</tr>
<tr>
<td><strong>Activities and behaviours</strong></td>
<td>Types of activities (who initiates them and who is involved, what is communicated/done, what are the dynamics of the interaction, what is effect on other activities/people at the site), non-verbal gestures, facial expressions, tone of voice/language, body language, administrative activities (non/integration of TB/HIV care, observe to the extent possible, staff roles, patients’ apparent responses), trends/changes throughout the day/week</td>
</tr>
<tr>
<td><strong>Surprises and non-occurrences</strong></td>
<td>Observations that stand out (people or activities receiving more attention), unexpected activities, expected observations that are not observed, observations that do/not appear congruent with interview responses, absence of staff/resources that are typically present</td>
</tr>
</tbody>
</table>
Appendix H: Transcription guide

The interviewers transcribed interviews in their original language using the following guide.

1. Listen to the recording. Type what you hear using pause/stop/play/rewind.
   - First, listen to about 5 seconds of tape → stop/pause → type quickly.
   - Second, rewind the tape by 5 seconds → correct what you have typed, fill in missing words, add messages in square/round brackets, and space the lines properly, as suggested below.
   - Third, complete transcribing the full interview in 5-second intervals (or whatever suits you)
   - Fourth, correct spelling mistakes in your typed transcript (do not listen to the tape)
   - Fifth, listen to the entire audio recording and read the transcript simultaneously to correct any remaining errors or add extra information, as suggested below.

2. **Stay true** to what is actually said. Do not correct grammar errors or do not try to make the interview sound ‘good’ or ‘correct’. For instance, if a person says ‘gonna’ instead of ‘going to’, transcribe the word as ‘gonna’. However, there is no need to be overly phonetic. For instance, if a person says ‘reeee-a-lyyy’, transcribe the word as ‘really’ underlined (see #9).

3. Start a new person’s speech on a **new line**.
   - Line 1 – Question/statement
   - Line 2 – Answer/response

4. Try to mark a difference between what is spoken by the interviewer and interviewee using *italics* or **bold** or mark each response with A (for Amrita) or P (for patient).

5. Leave a one-line space between new conversations.
   - **Examples:**
     - A: Thank you for coming here. **What is your name?** **Where are you from?**
     - P: You are welcome. **My name is Amrita** **I am from Canada.**

6. Bracket your **own comments or things you want to discuss later using round brackets.** Add non-verbal gestures or any extra details that you recall.
   - **Examples:**
     - (I/he/we laugh) **(points to legs)** **(seems sad)** **(purposely change the topic)**

7. Bracket words spoken that you are **not sure about** using **square brackets** and a question-mark.
   - **Examples:** [Makhandu?] [??] [yesterday?]

8. Use punctuation marks (**full-stops, commas**) as they come naturally in the conversation.

9. **Underline words** that were spoken with extra emphasis or stressed.

10. Use **three full-stops** to mark a pause. Use more full-stops to mark longer pauses.

11. Use a **dash** to indicate an interruption (when one person interrupts another person).
    - **Example:**
      - Where do you **some from**?
      - I come from, I come from... Canada. It is very cold there... ... very **very** cold, you know (laughs). **Oh really! How –**
      - Eh, it can get to minus 35.
Appendix I: Research contributions: novel findings from qualitative analysis of the study data

- TB/HIV stigma is tied to the construction of dual and unequal identities which reflect the moral susceptibility and im/permanence of TB and HIV, and the relative in/visibility of these identities
- Coinfected patients use a novel form of HIV ‘othering’ (and ‘covering’) to symbolically distance themselves from HIV
- Different forms of TB (EPTB) invoke different levels of visibility, HIV symbolism and social stigma
- Outcomes of early HIV disclosure influence how subsequent disclosures are decided, along distinct gender lines
- Social tolerance is not equal to emotional comfort or support, and may further catalyze HIV-positive women to bond with peer groups
- Informal peer support and role models may encourage retention in HIV and/or TB healthcare
- Coinfected patients share distinct experiences within TB and HIV clinics as a result of distinct program cultures
- ‘Dumping’ between programs in the public sector enable coinfected patients to manipulate HIV disclosure in the health system
- Personalized, continuous care, a sense of ‘sameness’, and gradual inconspicuousness at HIV clinics, compared to relatively impersonal care at TB clinics, compel coinfected patients to avoid disclosing HIV or accessing HIV-related care at TB (and other non-HIV) clinics
- Coinfected patients’ decisions for adherence and disclosure are made against a backdrop of doubly precarious socioeconomic inequalities, and health system constraints that perpetuate TB/HIV stigma, and their (particularly women’s) need for material support
- Health decisions are based on resisting the greatest degree of stigma and rendering visible stigmas invisible – TB is used as a ‘cover’ or ‘excuse’ to hide HIV and gain access to resources; and, clinical benefits of care are weighed against the social costs of accessing care.
- Pluralistic behaviours are a product of structural health system constraints such as ART ineligibility, difficulties with TB diagnosis, and vertical or specialized TB and HIV care
- Co-located TB and HIV facilities may not guarantee cost-savings for coinfected patients, or comprehensive information sharing for non-HIV providers due to health system constraints and medical confidentiality around HIV/AIDS
- Health decisions for TB/HIV care are inevitably socially informed: patients’ experiences with TB/HIV stigma, social inequalities, health system constraints, and exposure to disparate cultures of TB and HIV care all influence patients’ decisions for TB and HIV care, and may override the practical and clinical benefits of such decisions
Appendix J: Potential implications of study findings: relevance and recommendations for TB/HIV healthcare policy and practice

<table>
<thead>
<tr>
<th>Main findings</th>
<th>Relevance to TB/HIV healthcare</th>
<th>Recommendations for TB/HIV policy and practice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dual stigmas and negotiated disclosures</td>
<td>▪ TB/HIV stigma is socially constructed, context-specific and often, non-linear</td>
<td>▪ Recognize the broader social dimensions of TB/HIV stigma</td>
</tr>
<tr>
<td>Reproduction of sociostructural inequalities</td>
<td>▪ Patients selectively disclose TB over HIV to protect themselves from stigma and discrimination</td>
<td>▪ Address social and gendered inequalities confronting TB/HIV patients, together with the clinical complications of their infections</td>
</tr>
<tr>
<td>Genderification of experience</td>
<td>▪ Patients may not disclose HIV to (non-HIV) HCWs</td>
<td>▪ Improve government (employer) support for coinfected patients, especially women, through broader (nondiscriminatory) eligibility criteria and inclusion of social indicators of disability</td>
</tr>
<tr>
<td>Stigma and retention in care</td>
<td>▪ Men and women may disclose/hide TB/HIV for different reasons and in different ways</td>
<td>▪ Improve provider trust in healthcare environments, especially at non-HIV clinics in the public sector</td>
</tr>
<tr>
<td></td>
<td>▪ Social burden of TB/HIV may be greater among women</td>
<td>▪ Tailor medical expectations for healthcare to patients’ social circumstances and life responsibilities owed to their families</td>
</tr>
<tr>
<td></td>
<td>▪ Health decisions are balanced against competing life responsibilities and social stigma, and social stigma is perpetuated by these competing constraints</td>
<td>▪ Explore the use of less formal peer support systems and role models to encourage patients’ adherence and retention in care</td>
</tr>
<tr>
<td>Pluralistic health-seeking</td>
<td>▪ Patients access multiple health facilities/providers during the course of their illness with TB and HIV</td>
<td>▪ Improve communication and coordination between TB and HIV programs, including follow-up of referrals</td>
</tr>
<tr>
<td>Fragmented healthcare</td>
<td>▪ TB and HIV care can be vertical and fragmented, despite partial decentralization of services</td>
<td>▪ Improve information-sharing between specialized and primary healthcare facilities (and the private sector and traditional healers)</td>
</tr>
<tr>
<td></td>
<td>▪ Patients’ pluralistic health-seeking is a function of (i) social norms, (ii) social stigma, (iii) deficiencies in the public health sector, and (iv) fragmented and vertical care (constant cross-referrals)</td>
<td>▪ Address medical confidentiality around HIV/AIDS through policy revisions, and through patients’ consent and stigma reduction in the health system in general</td>
</tr>
<tr>
<td></td>
<td>▪ Non-integrated service delivery creates missed opportunities for (concurrent) TB/HIV treatment</td>
<td>▪ In the absence of full integration, expand address to TB care within HIV programs and vice versa</td>
</tr>
<tr>
<td></td>
<td>▪ Co-location is not necessarily indicative of adequate integration</td>
<td>▪ In the absence of an efficient primary healthcare system, expand the scope of general health services for patients attending specialized TB and HIV clinics (with commensurate expansion in human and financial resources)</td>
</tr>
<tr>
<td></td>
<td>▪ Medical confidentiality around HIV may obstruct integration of TB and HIV care</td>
<td>▪ Address operational deficiencies of decentralization and co-location</td>
</tr>
<tr>
<td></td>
<td></td>
<td>▪ Expedite access to ART for all TB patients, regardless of CD4 counts</td>
</tr>
</tbody>
</table>
## Disparate program cultures

<table>
<thead>
<tr>
<th>Social rationality of integrated care</th>
</tr>
</thead>
<tbody>
<tr>
<td>- TB and HIV programs deliver services under distinct, fundamental paradigms of care</td>
</tr>
<tr>
<td>- As a consequence, patients share contrasting perceptions of their TB and HIV programs</td>
</tr>
<tr>
<td>- TB control may be prioritizing disease control at the expense of social acceptability</td>
</tr>
<tr>
<td>- Social acceptability may trump practical convenience in patients’ health-related decision-making</td>
</tr>
<tr>
<td>- Patients may prefer to access TB and HIV services at separate facilities</td>
</tr>
<tr>
<td>- Patients may prefer to access TB and HIV services under the rubric of an HIV program</td>
</tr>
<tr>
<td>- Patients balance their health decisions against the social consequences of those decisions, in addition to the practical benefits, and previous experiences in various programs within the health system</td>
</tr>
</tbody>
</table>

| - Learn from the strengths and weaknesses of individual TB and HIV programs |
| - Delivery more personalized, patient-sensitive healthcare within TB programs; incorporate this tenet into the generic DOTS-mandate |
| - Prioritize TB control within HIV programs; incorporate TB prevention and treatment into HIV treatment and support |
| - Acknowledge and address patients’ preferences for TB/HIV healthcare |
| - Incorporate patients’ social rationality into standard medical decision-making, noting the dynamicity and context-specificity of such rationality |
| - Integrate TB and HIV care according to the social contexts of illness and healthcare within particular social settings |
| - Address the clinical, operational and social considerations to TB/HIV healthcare |
## Appendix K: Planned dissemination of study findings, implications and recommendations

<table>
<thead>
<tr>
<th>Form of dissemination</th>
<th>Target audience (key stakeholders)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Posters</strong> at clinics engaged in the study</td>
<td>All TB/HIV patients (including study participants)</td>
</tr>
<tr>
<td></td>
<td>All TB and HIV staff at the study sites</td>
</tr>
<tr>
<td><strong>One-page summaries of relevant study findings and contributions</strong></td>
<td>All TB/HIV patients (including study participants)</td>
</tr>
<tr>
<td></td>
<td>All TB and HIV staff at the study sites</td>
</tr>
<tr>
<td><strong>Executive summaries (2-4 pages) of relevant study findings, contributions, and recommendations</strong></td>
<td>Study key-informants (healthcare workers and site managers)</td>
</tr>
<tr>
<td></td>
<td>All study site managers and relevant hospital or clinic officials*</td>
</tr>
<tr>
<td></td>
<td>Non-governmental organizations and government officials at the local, provincial and central level*</td>
</tr>
<tr>
<td><strong>Presentations</strong> (oral and poster)</td>
<td>Attendees (policymakers, program planners, healthcare professionals, scientists, community organizations, patients, and health advocates) at relevant conferences and scientific meetings for policy and practice development of TB and HIV healthcare, and health services (integration) in general</td>
</tr>
<tr>
<td><strong>Publications</strong></td>
<td>Readers (policymakers, program planners, healthcare professionals, scientists, community organizations, patients, and health advocates) of medical and social science journals that focus on healthcare practice and health services research</td>
</tr>
</tbody>
</table>

* Includes stakeholders whose permission or collaboration was sought for study implementation, as outlined in Chapter 3 (see Table 3.7).
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