Challenges to the Success of HIV and Tuberculosis Care and Treatment in the Public Health Sector in South Africa

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The escalating human immunodeficiency virus (HIV) and tuberculosis (TB) epidemics have had a significant impact on public health services in resource-limited settings. The province of KwaZulu-Natal in South Africa is estimated to have one of the greatest TB/HIV coinfection burdens on the African continent, coupled with historically low TB treatment success rates. In May 2004, the South African government began providing antiretroviral therapy (ART) for HIV-infected individuals within the public sector. As in many counties, this HIV treatment program was established in parallel with an existing TB treatment service. In 2005, the Integration of TB in Education and Care for HIV/AIDS (iTEACH) Program was launched in KwaZulu-Natal at Edendale Hospital. The goal of iTEACH was to identify barriers to effective treatment and develop support interventions to enable rapid expansion of access to ART and improve ART and TB treatment outcomes within the district served by this facility. In the present article, we discuss challenges to the delivery of TB and HIV care by these separate treatment programs, as well as opportunities to improve both TB treatment and ART outcomes through lessons learned during ART scale-up in the context of the HIV and TB coepidemics.

In March 2006, the South African Department of Health (DOH) declared that tuberculosis (TB) was “a crisis in the country” and released a national crisis management plan for TB [1], aiming to reduce the country’s TB burden. According to the latest case finding and treatment outcome data, 25 of 53 health districts in South Africa have TB cure rates of <50% [1], despite a long-standing program of directly observed treatment, short course (DOTS), that is operative in all districts. Nine of these 25 health districts are located in KwaZulu-Natal. KwaZulu-Natal, South Africa’s second most populous province, has the greatest number of individuals with TB/HIV coinfection and the highest rate of TB treatment default (23%). Overall, the TB cure rate (32%) and smear conversion rate (49%) in KwaZulu-Natal are also the lowest nationwide [1]. Not surprisingly, KwaZulu-Natal has high rates of multidrug-resistant TB, and recent media attention has been given to an “outbreak” of extensively drug-resistant TB [2]. Despite being a curable infection, TB remains the primary cause of HIV-related death [3], making the need to improve TB treatment outcomes an urgent priority.

HIV infection is the other major health challenge in the public sector in KwaZulu-Natal. For example, at Edendale Hospital, where care at the district and regional level is provided to ~1 million Zulu-speaking people living in impoverished peri-urban and rural settings, up to 50% of patients admitted to the hospital and 60% of women presenting for antenatal care are...
confirmed to be HIV positive. Since the launch of the antiretroviral therapy (ART) program in May 2004, the Edendale ART clinic has initiated ART for just <3000 patients, which is <10% of patients who qualify for treatment. Treatment default rates have been low in this and similar ART programs in other resource-limited settings, in striking contrast to the high rates of TB treatment default. In this article, we compare the TB and ART programs at a representative government hospital in KwaZulu-Natal, and we present what we perceive to be major challenges to treatment success and offer programmatic recommendations for interventions to enhance outcomes for both treatment programs.

ESTABLISHMENT OF A PROGRAM TO ASSESS AND INTEGRATE HIV AND TB CARE

In August 2005, the Integration of TB in Education and Care for HIV/AIDS (iTEACH) program was launched at Edendale Hospital to improve delivery of HIV and TB care, with funding from private philanthropy. The goals of iTEACH include: (1) assessment of existing HIV and TB services through observation and participation in delivery of care, (2) identification of challenges to successful delivery of care, (3) provision of integrated TB/HIV training programs and tools to patients and health care providers at all levels, and (4) implementation of a community awareness and mobilization campaign. The team consisted of 1 physician trained in the United States and living full time in KwaZulu-Natal, with all other iTEACH staff being South African and fluent in the most common local languages—Zulu, Xhosa, and Sesotho. Most of the iTEACH team resides in the surrounding townships, which helped to address local challenges and establish support interventions relevant to the community. Core iTEACH staff had previously worked with the South African DOH at both the national and provincial levels during the drafting of the 2003 Operational Plan for Comprehensive HIV and AIDS Care, Management, and Treatment [4].

The iTEACH team assessed the HIV and TB services provided at Edendale Hospital and its referral facilities. The review included evaluation of training in patient ART adherence, the hospital-based ART clinic, inpatient medical wards, DOTS services, and links between the HIV and TB programs and traditional medicine and community-based treatment service. In addition to encouraging open dialogue, structured questions regarding specific treatment and support barriers were asked of health care staff at all levels, traditional healers, patients, and community members.

BARRIERS TO TB AND HIV CARE AND TREATMENT

Initial review of these parallel programs revealed barriers to optimal care of both HIV-infected and *Mycobacterium tuberculosis*-infected patients. These barriers are discussed below.

Strict application of ART program guidelines. National guidelines dictate that all patients initiating ART must undergo rigorous adherence training and demonstrate treatment literacy. The training at Edendale lasts ∼9 h and is delivered over the course of 3 days, with a recommendation that patients bring a treatment supporter, or “buddy.” From September 2005 to April 2006, strict application of the training requirement, irrespective of clinical status, resulted in attendance by patients who were too ill to gain meaningful benefit. Those too weak to walk or sit were brought to training by wheelchair or were carried, and, in extreme cases, patients were placed on foam pads on the floor, where they spent each of the 3 sessions. It was not uncommon to find patients who were coughing, diaphoretic, complaining of headache or fever, or going back and forth to the bathroom because of diarrhea or vomiting. Training facilitators had no medical training and were not equipped to manage groups that included patients with acute illness.

Requirement of a “treatment buddy” to accompany the patient to a doctor’s appointment. The ART clinic at Edendale, like other treatment rollout sites, requires that patients bring a treatment buddy to their first doctor’s appointment to demonstrate adequate support and to diminish the risk of patients defaulting on treatment. For some patients, arriving without a treatment buddy resulted in postponement of treatment initiation. This requirement made no provision for unemployed patients living a significant distance from the hospital, who were forced to borrow money (up to R52 [approximately US $8]) for their own transport fees per round-trip and who were unable to pay additional fees for a treatment buddy. If denied treatment, they were forced to borrow additional money, within a short period, for another visit.

Communications barriers among providers and between providers and patients. At Edendale, most patients speak Zulu and are not fluent in English. However, at their first ART clinic visit after training, some doctors assessed treatment readiness by using a “knowledge checklist” administered to the patients in English. Patients who were unable to demonstrate treatment literacy were often deemed to be not ready for ART initiation and were referred back to the HIV counselors for further preparation. One striking finding was the lack of communication between counselors and doctors. Counselors did not express their concerns to the doctor about assessing treatment readiness in English, and the doctors did not give feedback to counselors regarding knowledge gaps and how patients might be better prepared.

Counselors providing ART adherence training. HIV counselors at government facilities such as Edendale receive training to provide one-on-one voluntary counseling and testing and ongoing HIV counseling to patients. Once the ART rollout began, HIV counselors were given the task of delivering group adherence training, which is the cornerstone of treatment prep-
aration for patients. At Edendale, the quality of training was variable; given that counselors were not selected because of skill or an interest in training, and given that they received no special preparation as trainers, this was understandable.

**HIV expertise at the inpatient medical service.** ART management at Edendale and other hospitals at the regional level is restricted to an outpatient specialty service, with no ART initiation occurring on the wards. Doctors and nurses working on the inpatient wards were generally well equipped to manage HIV-associated opportunistic infections and to deliver palliative care, but they lacked basic knowledge of ART. Attitudes toward ART among staff members were sometimes negative, particularly when provider exposure to ART was limited to caring for patients with serious drug-related adverse effects, including immune reconstitution syndrome, Stevens-Johnson syndrome, pancreatitis, hepatitis, and lactic acidosis. Because there was limited experience with ART among the nurses, it was common for doses of ART to be given late or even be missed for patients who were admitted while receiving ART. Nurses did express an interest in receiving training in HIV basics, ART, and TB/HIV coinfection. However, the scheduling of in-service training is complicated by staff shortages and competing clinical demands.

**HIV/AIDS burnout among health care providers.** Despite high rates of HIV infection among health care workers at Edendale, including professional staff, stigma regarding HIV infection was pervasive. Many health care workers avoided HIV testing, fearing that their HIV infection status would not remain confidential. Gossip about colleagues with recurrent illness and absenteeism was common, contributing further to staff seeking care late and, too commonly, to death among colleagues too fearful to seek treatment. Many were looking after sick family members at home, although, at work, they seemed to be somewhat distanced from HIV-infected patients, as if they did not come from the same community or, potentially, from one’s own family. With chronic human-resource shortages and with wards filled to capacity with patients in the advanced and end stages of AIDS, staff burnout was pervasive.

**Limited patient preparation for TB treatment.** Although formal, government-mandated adherence training exists for the ART program in South Africa, preparation of patients to start receiving TB treatment is comparatively minimal and nonstandardized. Unfortunately, the burden of TB and the consequences of delaying treatment initiation prevent replication of the comprehensive ART adherence training model. For patients who start receiving TB treatment during hospitalization, the process of discharge and transfer to community clinics to complete their 6-month course of TB treatment posed significant risks for treatment default. Important procedures, including filling of forms for TB case notification, case registration, transfer forms, and patient treatment cards, as well as provision of TB treatment training for patients, were not performed in the wards. Rather, at discharge, patients were instructed to go to a TB office located near the front gate of the hospital to complete these procedures. For patients who bypassed the TB office, case registration was missed and treatment default went unchecked, because clinics would receive no record that the patient was expected.

**TB diagnosis and adherence to TB program guidelines.** With the majority of hospital beds occupied by patients with advanced AIDS, and with the high frequency of TB coinfection, smear-negative TB presents a significant diagnostic challenge. For TB microscopy results, the turnaround time from the hospital laboratory has recently improved in the context of the TB crisis, with microscopy results now available within 24–48 h. However, requests for TB diagnostic testing, including microscopy, and, particularly, for culture and drug-susceptibility tests, were sporadic, indicating that doctors lacked uniform knowledge and application of diagnostic protocols. When doctors did request culture and drug-susceptibility testing, the sputum specimen was sent out to a large tertiary care facility without logging of the specimen in the hospital laboratory or performance of microscopy. This resulted in delayed reporting of microscopy results and encouraged the practice of doctors initiating TB treatment on the basis of clinical assessment alone. For busy staff on patient wards, phoning an outside laboratory for results was not feasible, and computers and the Internet were not readily available to obtain results online. A lack of dedicated TB wards, with the resultant admission of patients with suspected cases of TB on multiple wards throughout the hospital, posed the additional challenge of training large numbers of staff members regarding TB policies, as well as an inability to provide proper isolation and infection-control measures to prevent occupational and nosocomial infection.

**Failure of DOTS in the face of human-resource shortages.** The standard for TB treatment recommended by the World Health Organization is DOTS, with health care workers or volunteers observing patients taking their medication. The South African DOH reports 100% DOTS coverage in the country, although this did not translate into 100% of patients receiving DOTS support. Five health facilities (4 primary health clinics and 1 TB specialty hospital) were assessed within the catchment area, with all facilities found to have DOTS supporters or their equivalent. The local TB hospital reported having 22 volunteer DOTS supporters who were managed by a nongovernmental organization and 2 “tracers” who were responsible for patient follow-up and tracking. One clinic utilized volunteer community health workers in lieu of formal DOTS supporters, providing both general health and TB support. The other 3 clinics had 20–30 volunteer DOTS supporters. Three sites said that they did not know the percentage of patients with TB who received DOTS support. Two sites estimated that they were able to link ~10% of patients with a DOTS supporter, selecting only
patients perceived to be at increased risk for treatment default. These same sites reported that patients matched with a DOTS supporter “almost always” completed their treatment unless they relocated out of the catchment area. No information was available for the ~90% who were not provided DOTS support. Staff at all sites said that they needed further TB training, and they expressed interest in HIV care and ART training.

**Separation from traditional healers.** Although national guidelines endorse incorporation of traditional healers into the government ART rollout [4], Edendale was not unique in lacking a formal role for traditional healers in the ART and TB programs. It is known that the majority of South Africans both trust and receive care from traditional healers; therefore, potentially powerful allies in HIV and TB care were not being utilized. This separation contributed to a common belief that patients must choose between ART and traditional cultural practices.

**Need for HIV and TB support services.** TB is said to be a disease of the poor, yet little is being done by government programs to address high rates of unemployment, lack of food security, and other challenges faced by those living in poverty. The government recently started providing heavy food parcels to patients infected with TB or HIV; the food parcels are not only difficult for debilitated patients to carry, but they do not represent a sustainable intervention. Lack of attention to such crucial issues as poverty was shown to fuel desperate behavior among patients interviewed, including intentional nonadherence to TB treatment and ART and voluntary sacrifice of health to retain disability grants. Throughout the communities surrounding Edendale, multiple nongovernmental organization–driven support programs existed, but they were being accessed by only a small percentage of patients. No database of existing support services was available to facilitate referrals, and no linkage or networking between services was present to optimize limited resources and manpower.

**RECOMMENDATIONS AND INTERVENTIONS**

Assessment of TB and HIV services led to a number of recommendations and interventions that we believe will improve treatment outcomes for both programs.

**Stabilization and treatment before ART adherence training.** Because acutely ill patients are unlikely to benefit from sitting through adherence training, we recommended that the hospital’s ART clinic institute a policy of referring all patients with active illness or debility for treatment and stabilization before training. Delays in ART can be avoided if a treatment buddy attends training on behalf of the patient, is able to demonstrate treatment literacy, and agrees to provide close treatment support until the patient is stable enough to attend adherence training.

**Incorporate TB and individualize adherence training.** Treatment literacy training is mandatory for all patients starting ART and thus represents an ideal opportunity to incorporate TB education, because many patients starting ART are coinfected with *M. tuberculosis*. At Edendale, ART training now includes a segment on TB and TB/HIV coinfection and cotreatment. Additionally, psychosocial issues are explored, and referrals to social workers are made as a part of the training. Closer interaction between the clinic and training staff now allows updates and policy changes to be incorporated into patient training.

**Take-home materials in the local language.** ART training is now being supplemented by tools to enhance treatment literacy and adherence. Per patient request, a written summary of key points from each training session is provided in Zulu. The doctor’s knowledge checklist is given to patients along with preparation to enable them to “pass” the doctor assessment. A separate treatment-readiness questionnaire is used to evaluate disclosure and other barriers to adherence. Finally, a treatment planner is given during the final training session. The images and messages used in these tools echo those shown during training, to enhance recognition and information retention. The ART clinic reports improvement in patient literacy and a decrease in treatment default after upgrades in the adherence program.

**Effective TB/HIV reference tools for care providers.** Printed TB guidelines often are not available, and reference books on HIV infection are not ideal for quick reference in busy clinics. At Edendale, we introduced the “ring tool,” which is a set of pocket-sized laminated cards containing information on HIV infection and TB. This tool is easy for providers to use for quick reference and impromptu training while they are seeing patients. The basic set of HIV cards consists of 4 double-sided cards and includes a diagram of the ART operational plan; simple tables with a laboratory test and clinic follow-up schedules; photographs of the ART regimens with relevant details; and a list of all HIV referral facilities in the district, including their telephone/fax numbers and the name of the nurse-in-charge. There are 2 double-sided TB cards with similar user-friendly program and treatment information, which completes the basic TB/HIV reference set. As guidelines change or new drugs are added, individual cards can be quickly updated and replaced. An example is the addition of a card for management of lactic acidosis, which contains a definition of lactic acidosis, a description of at-risk patients, photographs of the recommended alternative ART regimen, and an algorithm for management. The ring tools are currently being used by all services providing HIV care at Edendale Hospital, as well as by staff at
challenges facing patients seeking HIV and TB care. However, maximizing program coordination should reduce some of the services when possible. For coinfected patients living in poverty, for both the TB and ART programs, it is sensible to integrate pervasive and challenges to achieving treatment success overlap in a resource-limited setting. Because resource constraints are it is replete with all the challenges facing a government facility in a resource-limited setting. Because resource constraints are pervasive and challenges to achieving treatment success overlap for both the TB and ART programs, it is sensible to integrate services when possible. For coinfected patients living in poverty, maximizing program coordination should reduce some of the challenges facing patients seeking HIV and TB care. However, precautions must be taken if ART and TB treatment are combined in a single facility, because this would create a high-risk environment for the nosocomial spread of TB among highly susceptible HIV-infected patients.

Unlike ART, TB treatment is widely available, and established infrastructure is in place. Therefore, it should be unacceptable that TB, as a curable disease, continues to claim so many lives. With DOTS as a cornerstone of the TB treatment strategy, and with South Africa reporting 100% coverage, reliance on the DOTS strategy must be reexamined, and additional approaches must be considered in this setting. Limited knowledge, as well as rigid application of guidelines without the ability to adapt to patient challenges, contributes to program failure. A system that is responsive to patient needs may help to restore hope and encourage patients to participate in their own treatment success. When patients are empowered and made responsible for their care, they are less likely to experience treatment default. Lessons from the ART program, particularly the more patient-centered approach, should be replicated in the TB program, where highly structured protocols are currently failing to achieve treatment goals.

The tendency for health providers to view themselves as separate from patients is probably symptomatic of burnout, and it results in care that is devoid of personal commitment and persons who lack motivation to provide the best support possible [5]. Counselors and many health providers in this setting come from the same communities as the patients and are similarly affected and infected with M. tuberculosis and HIV. It is therefore essential for the long-term success of these programs that a system of support be provided for those on the front lines of the government’s ART rollout and TB program.

Treatment and support for patients with HIV infection and TB, particular where there is a high burden of TB/HIV co-infection, require comprehensive systems that integrate services and training, link providers within a facility and throughout the down-referral network, and maximize access to existing support services. As seen in the TB program, the existence of protocols and referral forms is insufficient to prevent default and treatment failure. Human-resource needs must be addressed urgently through aggressive recruitment and appropriate remuneration to provide and maintain staffing for the diverse array of clinics and hospitals providing HIV and TB care. Uniform knowledge of program guidelines is essential. Multidisciplinary care and optimal HIV and TB training programs with incorporation of local cultural beliefs and practices, combined with wide availability of effective training and reference tools, may contribute to ART and TB program success by promoting better service integration, increased health provider knowledge, and improved patient trust and treatment literacy.

DISCUSSION

Edendale Hospital is located in the heart of the area where the HIV and TB coepidemics are occurring in South Africa, and it is replete with all the challenges facing a government facility in a resource-limited setting. Because resource constraints are pervasive and challenges to achieving treatment success overlap for both the TB and ART programs, it is sensible to integrate services when possible. For coinfected patients living in poverty, maximizing program coordination should reduce some of the challenges facing patients seeking HIV and TB care. However,
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