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TB CARE II

STUDY REPORT

Reducing TB Delays: Evaluating the Frequency and Causes of Delays in Bangladesh and Swaziland

JULY 2012

This study was produced by TB CARE II-University Research Co, LLC (URC) for review by the United States Agency for International Development (USAID) and was authored by Maria Insua; Samson Haumba; Fatema Zannat; Refiloe Matji and Alisha Smith-Arthur.

This study was made possible by the support of the American people through the United States Agency for International Development (USAID). TB CARE II, is funded by United States Agency for International Development (USAID) under Cooperative Agreement Number AID-OAA-A-10-00021. The project team includes prime recipient, University Research Co., LLC (URC), and sub-recipient organizations Jhpiego, Partners in Health, Project HOPE along with the Canadian Lung Association; Clinical and Laboratory Standards Institute; Dartmouth Medical School: The Section of Infectious Disease and International Health; Euro Health Group; and The New Jersey Medical School Global Tuberculosis Institute.

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DISCLAIMER

The views expressed in this publication do not necessarily reflect the views of the United States Agency for International Development or the United States Government.

Acknowledgements: The authors thank the United States Agency for International Development (USAID) TB CARE II Project for funding this assessment and giving URC the opportunity to implement it. The authors appreciate the important contributions of many individuals to the assessment, design, implementation, and/or report preparations, including by the National Tuberculosis Program staff in Swaziland including Mr. Themba Dlamini, Mr. Sandile Ginindza, Ms. Sibongile Mndzebele, Mr. Thabo Hlope that were instrumental in the design and support of the assessment conducted in health facilities in Swaziland. Special thanks to the URC's field personnel in Swaziland. We thank Mrs. Lindiwe L.P. Mkhathshwa and Mrs. Janet Ongole who worked tirelessly to support the data collection and analysis of the assessments conducted. In Bangladesh we are grateful for the support of the NTP MBDC director, Dr. Md. Ashaque Husain who provided leadership and facilitated the study activities conducted in the districts. Special thanks to our colleagues from WHO and the civil surgeons at the district level, and Upazilla Health and Family Planning officers (UHFPO) at the sub-district level who volunteered their time and expertise to provide valuable input on the TB delay assessment. Also special thanks to the URC personnel who become deeply involved in the training of data collectors, ensuring quality of the data collected and ongoing support to the study activities. Special mention to Dr. Paul Daru for his unconditional support during the length of the study. We also extend our gratitude to the URC headquarters team Dr Neeraj Kak, Silvia Holschneider, Nina Blustein who provided clear guidance, innumerable reviews and extensive support during the study length.

Recommended Citation: Insua M, Haumba S, Zannat F, Matji R, Smith-Arthur A. 2012. Reducing TB Delays: Evaluating the Frequency and Causes of Delays .Technical Report. Published by the USAID TB CARE II Project.

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Acronym List

ACSM	Advocacy, communication and social mobilization
AFB	Acid-fast bacillus
ARV	Antiretroviral therapy
DOTS	Directly Observed Treatment Short course
DST	Drug susceptibility testing
EPTB	Extrapulmonary Tuberculosis
GFATM	Global Fund to Fight AIDS, Tuberculosis and Malaria
HCW	Health care worker
HIV	Human immunodeficiency virus
MDR-TB	Multi-drug resistant tuberculosis
MOH	Ministry of Health
NGO	Nongovernmental organization
NTP	National TB Control Program
SD	Standard deviation
SS	Sputum smear
TB	Tuberculosis
UHC	Upazila health complex
URC	University Research Co., LLC
USAID	United States Agency for International Development
WB	World Bank
WHO	World Health Organization

Executive Summary

An effective tuberculosis (TB) control program requires early diagnosis and immediate initiation into treatment to reduce transmission. The implementation of the World Health Organization (WHO) Direct Observed Treatment-Short course (DOTS) strategy has contributed to significant gains, including achievement of an overall 87% treatment success rate among new cases of smear-positive TB and identification of 65% of the estimated global number of incident cases. More efforts are needed, however, to rapidly identify the remaining TB cases to reduce TB transmission and lessen the impact on communities. Estimates suggest that an untreated smear-positive patient can infect, on average, 10 contacts annually (1). Delay in TB diagnosis leads to a more advanced disease state at presentation, with poor response to treatment allowing more transmission. For these reasons, understanding and identifying the causes of delays in diagnosis and treatment initiation are critical to strengthening TB control programs.

Passive case finding approaches, prevalent in many TB programs, perpetuate delays by failing both 1) to ensure that the health system systematically brings in TB suspects and 2) to engage people in understanding their TB risk. Most-vulnerable populations for TB are frequently omitted from main TB programs, as they don't seek care from quality providers and disproportionately experience a delay in receiving TB diagnosis/ treatment. As countries have moved toward designing interventions to close these gaps, a significant portion of the research has focused on issues within the organization of health services that cause delays once a patient seeks care. These issues include weaknesses in diagnostic networks and lack of coordination and referrals between TB services and other health programs. While such research is critical, a better understanding is also needed of why patients fail to promptly recognize their symptoms as possibly TB-related and seek appropriate care. To that end, TB CARE II conducted a study, reported here, in two TB high-burden countries, Bangladesh and Swaziland, to identify, measure, and explain the causes of patient delays in obtaining a TB diagnosis.

The study found in both countries that patient-caused TB delay was two to three times greater than the health system-caused delay. The main factor contributing to patient delay was patients' unawareness of the severity of the symptoms due to 1) not having well-defined symptoms at the presentation of the disease or 2) a lack of knowledge of TB symptoms (which were often attributed to other diseases). Other factors that caused delay were specific to the country context, such as the distance to the facility and the cost associated with transportation, fear of being diagnosed with TB, and the stigma that might follow such diagnosis. The last played a major role in Swaziland, which has a high TB/HIV co-infection rate. Patients' preferences for the provider they initially sought care from also affected the number of days it took to receive a TB diagnosis. In terms of health system delays in Bangladesh, TB diagnosis was provided in six days in government facilities and in 42 days if the patient first went to a private provider. Patients reported being satisfied with services in government facilities – 80% of patients in Bangladesh and 90% in Swaziland.

Based on study results, we provide a set of general recommendations (country specific included in the annexes) for TB program managers and health service providers to support efforts to reduce the factors influencing patient delays in accessing TB services.

Introduction

The World Health Organization's (WHO's) Direct Observed Therapy-Short course (DOTS) strategy, provides a critical framework for increasing TB treatment success and emphasizes passive case finding. In such case, patients may delay in seeking care for their symptoms increasing TB transmission in the community.

Most TB transmissions occur between the appearance of coughing and a few weeks after the initiation of treatment. Estimates suggest that an untreated, smear-positive patient can infect, on average, 10 contacts annually and more than 20 during the course of the disease (1). A delay in TB diagnosis may lead to a more advanced disease state at presentation, with an increased bacillary load. Late-stage presentation may contribute to a poor response to treatment, resulting in more severe morbidity while increasing the risk of transmission. It is important to identify the causes of such delays to efficiently take steps to make TB control programs more effective (3).

Active case finding shifts the emphasis to empower front-line health care workers, patients, and communities to be more assertive in recognizing TB symptoms and seeking appropriate care and treatment. Recent studies from high-burden TB countries demonstrate that improving case finding may save 10 times as many lives as DOTS alone (4). We conducted a literature review to evidence what the research community has found as the main causes of patients delaying seeking care for their TB symptoms and found great variability regarding the methodology used to define and measure TB delays. To unify the different criteria we designed a framework for evaluating delays in TB diagnosis and treatment. We also followed the same framework for the discussion of the study's findings and to provide recommendations for reducing TB delays.

Understanding the causes that contribute to patients' delays in TB diagnosis and treatment initiation is critical to strengthening TB control programs. At the same time, it is important to recognize that delays occurring in the health service delivery system (i.e., related to weakness in diagnostic networks, lack of coordination and referrals between services, and others) also play a significant role in delaying TB diagnoses and treatment. These delays deserve critical attention; however, this report focuses primarily on the under-scrutinized factors that contribute to patient-related delays.

Background

The TB CARE II Project is a global TB control project designed to provide technical guidance to TB programs in high-burden countries to help them address barriers to building effective TB control systems. In 2011, TB CARE II, which is funded by the U.S. Agency for International Development (USAID) and led by University Research Co., LLC (URC), began working with National TB Control Programs (NTPs) in South Asia (Bangladesh) and sub-Saharan Africa (Swaziland) to develop methods to evaluate the frequency and causes of delays in TB diagnosis. The work was organized around the following steps:

- I. Review existing knowledge;
 - Develop a framework for analysis, and
 - Conduct a desk review of current studies on factors influencing patients' delays in TB diagnosis and treatment;
- II. Develop the assessment methodology, including a set of tools to collect data on TB patient delays from the perspective of those patients, DOTS community leaders, health providers, and TB district managers;
- III. Conduct field assessments in two high-burden TB countries, Bangladesh and Swaziland, to identify specific factors causing delay;
- IV. Develop recommendations for TB program managers to reduce TB patient delays based on country study findings.

Our literature review (Figure 1) was conducted in databases from PubMed, the National Center for Biotechnology Information, Cochrane, WHO, the World Bank, and others. We used the following search terms to identify relevant articles: "TB patient delay," "TB diagnosis delay," "Time delay to TB treatment," "TB perception," "TB stigma," "lay population TB treatment preferences," "gender perspective for TB access," "TB and poverty," and "TB awareness."

The review focused on relevant articles from two geographical areas, Southern Africa and Southeast Asia.

Figure 1. Literature Research Criteria



Framework for analysis

Various frameworks have been used to analyze factors that cause TB delays, and these frameworks define and measure delay differently. Some studies consider the total TB delay as a measure of the time elapsed from the time the patient presents with TB symptoms to the initiation of TB treatment. Others disaggregate this measure into two phases: "patient delay" (i.e., the time from the onset of symptoms until the patient seeks care), and "health system delay," (i.e., the time from when the patient approaches the health system until he/she is diagnosed and put on treatment).

Other studies distinguish between the types of health services patients initially seek to set a cutoff between patient and health system delays(6)(10). For example, one can consider a health system delay as starting as soon as a patient contacts any type of health service, whether formal or informal. Alternatively, one can restrict the definition of a health system delay as starting when the first contact is made with a formal health service provider. Additionally, some studies present results of delays as mean values (6), while others use median values (12-14) (25) to reduce the impact caused by outliers, i.e., patients with extensive delays, which may be several years or more.

For this study, we adopted the following definitions of TB delays:

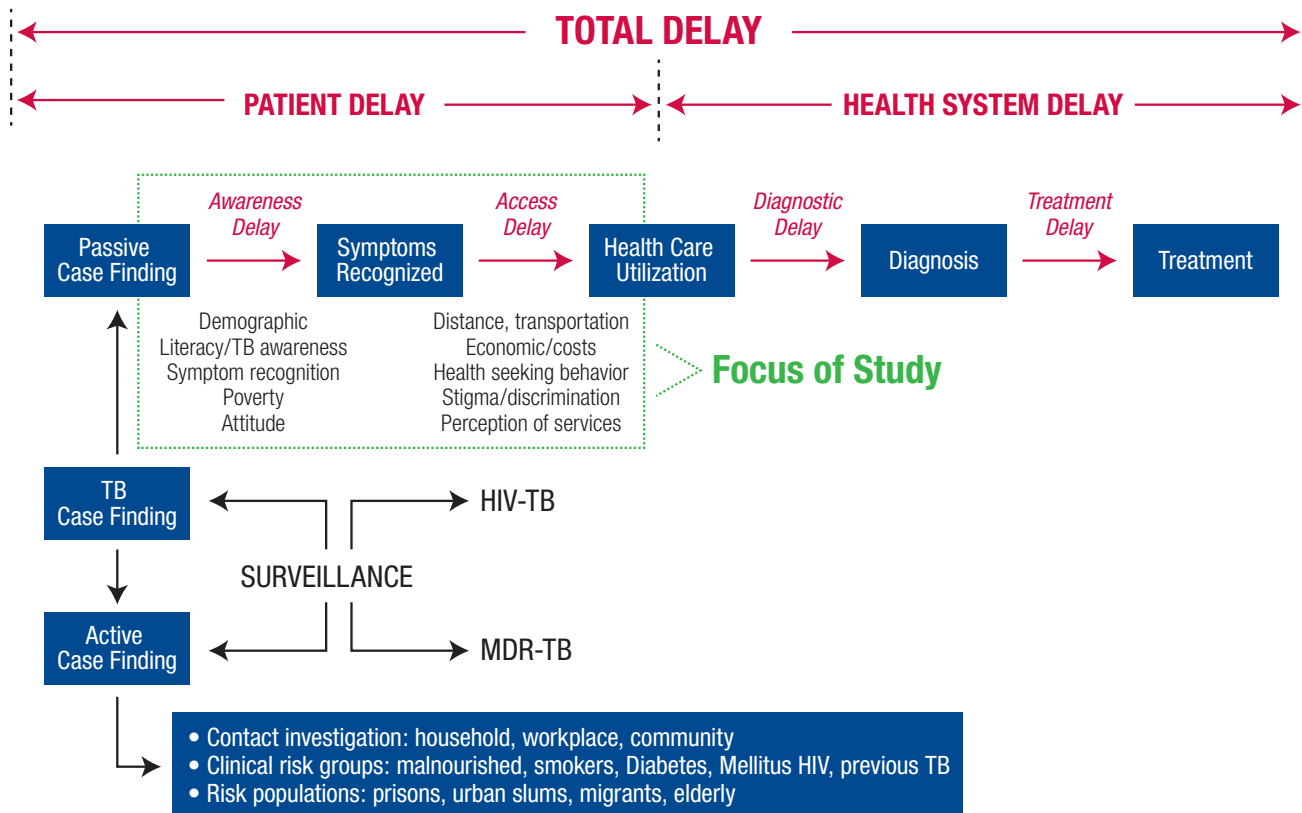
- *TB total delay* is the time between the onset of TB symptoms and the patient's receiving appropriate TB treatment.
- *TB patient delay* is the time between the onset of symptoms and the first contact with any health care service (formal or informal). Patient delay has two phases: 1) awareness delay is the time between the onset of the symptoms and the recognition of those symptoms as a disease that needs health care, and 2) access delay is the time from symptoms recognition to the first contact with a health care system(formal or informal).
- *TB health system delay* is the time between the first care-seeking behavior and receiving TB treatment. It also has two phases: 1) diagnostic delay is the interval between a patient's arriving at any type of provider (public, private, traditional healers) and the patient's receiving a TB diagnosis, and 2) treatment delay is the interval between TB diagnosis and initiation of anti-TB drugs (5).

The disagreement in definitions used to calculate delays makes comparisons and evaluations of improvements difficult. After the literature review we designed a framework for analysis (Figure 2) that includes those factors shown in research studies as playing a contributing role in increasing TB patients' delays in recognizing their symptoms and accessing health care.

Findings from the literature review

In general, the reviewed studies lacked consensus regarding the relative importance of different factors' contributing to patient delays. A review by Storla et al. (6) of 58 studies and conducted worldwide concluded that countries varied greatly in terms of causes of delays, and no pattern emerged for TB delays in different world regions. Even several studies conducted in a single country provided different results regarding the causes of TB delay, perhaps due in part to the overall lack of consistency among researchers in defining the measurement intervals. Some studies presented the results of delays in

Figure 2. Framework for evaluating delays in TB diagnosis and treatment



absolute numbers of days, while others excluded as reasonable a certain number of days or weeks: delay occurred only when that number was exceeded. For example, the 2008 Global TB Control Report (7) proposes that the total time from the presentation of TB symptoms to diagnosis should not exceed three–four weeks for most smear-positive TB patients. Nevertheless, this standard has not been met even in developed countries (USA, Japan, and Australia, among others) (6).

A review study by Sreeramareddy et al. (3) compared high- and low-income countries and found that, as expected, the delay was higher in low-income countries (185 days versus 25 days in high-income countries). Patient delays were twice as long as health system delays in both types of countries.

Patient awareness delay

Factors contributing to delays from a lack of patient awareness are inherent to the patient and include demographic characteristics (age, gender, and marital status), literacy and poverty, individual health status (other diseases, HIV, diabetes, etc), personal knowledge, and attitude toward TB (Box 1).

Demographic factors: Age and gender distribution of TB patients are considered indicators of the progress of TB epidemic control. A shift in the mean population age toward older groups suggests a decreased transmission of TB bacilli, resulting in the older population's being diagnosed, as the infection occurred many years earlier. If we consider that the prevalence of TB infection in both sexes is similar, a lower proportion of TB disease diagnosed in females may indicate that they have more barriers to TB diagnostic services, such as the need of permission from their husband or relatives (8) resulting in a longer time to be diagnosed, leading to a more advanced status of their TB disease. We also found a critical gap in the studies reviewed: a lack of analyses of the causes of TB delays in children, which requires further attention.

Literacy and poverty: The longstanding association between poverty and TB is well documented: TB is frequently labeled “a disease of poverty.” Most studies reviewed supported this association and frequently cited socioeconomic factors related to prolonged delay, including educational level (illiteracy) linked to low awareness and knowledge of TB (1) (6).

Box 1. Delay and demographic factors

A study review (6) found that old age was a risk factor for increased TB diagnostic delay in developed and developing countries. Other studies pointed to gender as a risk factor: Females were consistently found to present greater delays than males (6) (8) (9) (17) (19) (20) (21) (22) (23) (24). TB was diagnosed more frequently in males in the Middle East/ North Africa region (Egypt, Iraq, Syria, Somalia, and Yemen), with a male:female ratio ranging from 1.4 in Yemen to 2.5 in Somalia(1). By contrast, slightly more cases were reported in females in Iran and Pakistan with a male:female ratio of 0.98 males for each female. Several studies in India (21), Puerto Rico, Alaska, Canada, and Norway have shown that women of reproductive age are at higher risk from TB delay than men of the same age (20).

Delays related to gender

Married women in India (21) (41) reported abandonment, isolation within the household, and a lack of proper care from family members, especially rejection from in-laws. The same study found that to avoid rejection by their husbands/family members due to a possible TB diagnosis, women in Bangladesh and Malawi (21) have sometimes sought care for TB from antenatal services.

Patients' low education levels and lack of knowledge of TB symptoms was attributed to 90% of TB patient delay in Tanzania (9) (mean total delay of 185 days), with only 15% of the patients visiting a health facility within 30 days of onset of symptoms. A study in South Africa (10) found that 41% of patients thought they would get better on their own, and 13% said they were too weak, scared, or depressed to seek care.

TB symptom awareness: TB symptoms can be very unspecific in the disease's initial stages. Several studies have shown that more than half of TB patients had fever, weakness, or shortness of breath and that patients often attributed those symptoms to other diseases, such as malaria or viral infections (6) (10) (11).

Those studies also found that patients may be predisposed to identify possible causes other than TB for their illness. For example, chronic cough or other concomitant respiratory diseases, alcoholism, smoking, and substance abuse were risk factors for increased delay in TB diagnosis (1)(6). Even when patients were aware of their symptoms they didn't perceive them as severe to seek medical attention (12) (13). There was no agreement in the literature regarding HIV's being a risk factor for TB delay. Some studies found HIV to be a risk factor for increased delay in diagnosis, while others concluded the opposite (10).

Patient access delay

Patient delay is also impacted by factors influencing access to health care, such as geographic location, gender issues, costs, and health-seeking behavior patterns.

Geographic factors: Health facility's accessibility was a significant predictor of delay in many countries. As expected, a broad difference was noted between distance to a health center and length of delay in rural versus urban settings. Patients living in rural communities were often found to be at a disadvantage compared to those in urban areas, where more TB diagnostic facilities are located (1).

Box 2. Rural versus urban delay

In Gambia, the median delay was substantially longer in rural than in urban areas (12 weeks versus eight) (11). In Ghana (42), South Africa (12), Tanzania (9), Somalia, Syria, Yemen (1), Pakistan (27), and Ethiopia (37) patient delay was also strongly associated with living in rural settings and long distances to health facilities.

Some nomadic groups such as shepherds have the highest delays, exceeding two years in some reported cases. One study (14) found that the median patient delay for shepherds in the Horn of Africa were 60 days and around 20% of the patients had delays that exceeded 120 days (and 50% of them had pulmonary TB with high sputum grade). This long patient delay appears to be associated both with the distance to health care facility and lack of patient knowledge of

the disease. Currently an estimated 50–100 million shepherds live in the developing world, with 60% of them in sub-Saharan Africa. In the Horn of Africa, shepherds constitute 70% of general population in Somalia, 33% in Eritrea, 20% in Kenya and Djibouti, 12% in Ethiopia and 60% of rural populations in Sudan. Therefore, regional TB control programs need to consider the exceptional circumstances of nomadic groups.

Costs: Despite the free provision of TB diagnosis and treatment services in many places, the out-of-pocket expenses patients incurred – such as transportation, food, fees for registration, and laboratory tests results – often create an excessive economic burden (15). Expenses increase with the number of visits required to obtain the TB diagnosis (often more than three visits) (8) (16) and with the loss of income (indirect costs) due to low productivity or loss of employment.

Box 3. Delays related to costs

The TB Control Assistance Program (CAP/USAID) partnership developed a tool to help TB control programs assess barriers (<http://www.tbcta.org/Library/>). A pilot study of the tool in two Kenyan districts (40) showed that the median direct costs from the onset of TB symptoms to diagnosis at a public health facility were US\$13 per patient.

Besides increased costs due to the disease, studies (1) also found that TB patients present a higher rate of unemployment than that found in the general population. In general, more than a quarter of patients with TB reported being in debt. A study in Somalia (1) found that 74% of TB patients were unemployed, compared to 12% in the rest of the population.

Stigma: Our literature review highlighted stigma among the most critical factors affecting increased delays. In countries with a high HIV burden and HIV/TB co-infection, the stigma associated with HIV is usually transferred to a TB patient (perhaps due to assumptions regarding co-infection), resulting in delays in seeking TB diagnosis for fear of also being diagnosed with HIV (17).

Most authors identify the perceived contagiousness of TB as a leading cause of stigmatization and isolation from community activities. In some areas, perceptions

that TB infection reflects a divine punishment for a moral or personal failing have also been cited as causes of TB-associated stigma (1) (18).

TB-associated stigma especially affects women's health-seeking behaviors. Females consistently had been found to present higher delay than males (6) (8) (9) (15) (17) (19) (20) (21) (22) (23) (24) (25). A comparative study in Bangladesh, India, and Malawi(21) found that females only sought care when symptoms became so severe that it compromised their ability to work or maintain the household.

Health-seeking behavior: Stigma and discrimination also influence a patient's choices in seeking care. Once a patient decides to seek care, delays may occur due to his/ her preferences for certain types of health services that may not be able to offer a prompt and accurate diagnosis. Our review found that women were more likely to seek help through self-remedies and/ or traditional or informal healers in part to avoid TB-associated stigma and also because they had fewer resources to travel long distances. This pattern was associated with longer diagnostic delay (>90 days) for female patients compared to males in India and Malawi (21), Malaysia (8), Vietnam (22), Bangladesh (26), Nepal (24), and the Philippines (23).

Box 4. Delays due to stigma

A multi-country review (38) reported stigma as a main cause for TB diagnostic delay in 33% of studies conducted in Asia/Pacific Islands, 28% in Africa/ Middle East regions, compared to 17% multiregional, 9% North America, 8% Latin/ South America and 4% in Europe/ Russia.

Some studies have indicated that men will delay seeking care due to a variety of reasons including opportunity cost and fear of losing employment, which may affect their role and status as a primary bread winner as well as potentially impacting their family's welfare (22).

A preference for private providers, including homeopaths and traditional healers, was reported in multiple studies. Such preference was due to proximity to the patients' residence, patients' trust, and patient

Box 5. Delays related to informal healers

In Ethiopia half of TB patients delayed seeking health care at a public health facility to get treatment from informal sources (i.e., the Orthodox Church) (36) (39), doubling the time required for a TB diagnosis (median 31 days, compared to 15 days for those who went first to a health facility). In Bangladesh (26) 70% of females and 32% of males received treatment from various traditional healers before attending a health center. In Malawi (21) 40% of TB patients sought treatment from healers before seeking care in a health facility. A South African (10) study reported that 15% of patients used a home remedy, and 14% visited a traditional healer before going to a health facility. Another study in South Africa (12) cited a preference for traditional healers as contributing to diagnostic delays, along with distance to health facilities and limited awareness of TB disease. In Botswana (30) (43), traditional medicine was used to "cure" the cause or "tswana" of disease while the symptoms were treated with conventional medicine.

dissatisfaction with government care despite lower cost or beliefs that low cost service are inadequate resulting in reluctance to seek care from public services (1) (27).

Health system delays

Once a patient enters a health system for TB diagnosis and treatment, delays are caused by such factors as engaging in a "vicious cycle of visits" to health providers who fail to perform a TB diagnostic test (6) (15) (28) (29). Patients exhibited preferences for seeking care from a range of different sources, which may not result in a prompt and accurate diagnosis. The sources included:

- Primary-level government health posts, which had limited diagnostic facilities and poorly trained personnel;
- Private practitioners with low TB awareness; and
- Unqualified drug vendors and traditional practitioners/ healers.

A health provider's delay does not necessarily reflect a lack in training or skills but instead may signal a lack of effective diagnostic tools and follow-up routines to identify TB in patients with chronic cough. Concomitant infections such as HIV add to the difficulty in determining a diagnosis, as they present with more sputum negative TB, and difficult to interpret X-rays.

Multiple consultations: Repeated consultations at the same level, undergoing repeated courses of nonspecific antibiotics (6), and failure to perform sputum microscopy, particularly among private practitioners and rural government institutions, were among the factors identified that contributed to low rates of TB diagnosis, increasing health system delays (10) (11) (30).

Box 6. Health system delays

In Ghana (42), the time that lapsed to obtain a TB diagnosis once a patient had a consultation was eight weeks, double the four weeks that patients delayed after recognizing their symptoms and before seeking care. Limited knowledge was evidenced among personnel in government health posts for screening and diagnosing TB.

Study Design, Protocol, and Tools to Assess TB Delay

Findings from the literature review confirmed the need for additional information on the relative importance of the factors contributing to TB patient delay. Consequently, the USAID TB CARE II project designed and performed a cross-sectional study in Swaziland and Bangladesh to gain knowledge about the causes influencing TB delay and the strategies being implemented to reduce those delays. These countries were selected due to their high TB burden and perceptions among relevant actors that TB patient delays significantly hindered TB control efforts. By including one country in Southeast Asia and one in Africa, we could illustrate and compare different factors that may contribute to patient delays in these regions.

Study aim and objectives

Aim: Inform the development of an integrated set of recommendations for TB program managers and service providers regarding the appropriateness of different strategies for reducing the factors contributing to patients' delays in accessing TB diagnostic and treatment services.

Objectives:

- Determine the causes of TB patient delays in study countries: Bangladesh and Swaziland,
- Recommend methods and tools for evaluation of TB diagnostic delays,
- Analyze the impact of factors contributing to patient delays in accessing and routinely using TB services,
- Assess strategies applied by each country's NTP to reduce patient delays, and
- Develop recommendations for TB program and service providers regarding strategies for reducing patient delays in accessing TB services.

Tools for fact-finding visits

Four types of questionnaire were designed and pilot tested in each country, that can be accessed at <http://tbcare2.org>:

- The NTP Manager Questionnaire was administered to district-level personnel in the NTP;
- The Health Provider Questionnaire was administered to public, private, and informal health care providers actively screening, and providing TB care;
- The TB Community Leader Questionnaire was administered to the provider or manager of an active TB community organization (i.e., community TB DOTS supporters, TB advocacy organization); and
- The TB Patient Questionnaire was administered to patients on active treatment for TB regardless of the treatment phase (initiation or continuation).

Methodology

A research protocol was designed, presented to, and approved by both the Ministry of Health (MOH) Scientific and Ethical Review Committees in the respective countries and also by the URC Institutional Review Board. Informed consent was obtained from each participant before the interview and confidentiality was assured. Sampling was done randomly through numbers generated by Excel to ensure representation of the various patient categories. We included in the sample new or returning patients receiving TB treatment.

Teams of data collectors and field supervisors were selected and trained on ethical consent, interview techniques, and the use of data collection formats.

Patients sampled: We randomly interviewed 80 patients in Bangladesh (69% males, 31% females) at upazila health complexes (UHCs), where government TB services are provided; no children were included in this sample. Of these 80 patients, 89% were married, and 65% had at least primary or secondary education level. In addition, 45% were not working or were

working at home (e.g., housewife). Most of the sample population (89%) lived in rural areas (Table 1).

We interviewed 409 patients in Swaziland, (47% males, 53% females), and 4% of the sample were children eight to 14 years old (whose parents gave consent). Of the total, 85% had at least a primary education, and 54% were unemployed or working at home (housewives). Most were urban residents (74%), and 45% were married or cohabitating.

Providers sampled: In Bangladesh we interviewed three categories of service provider: providers at the

public facility (UHC), private providers (medical school graduates), and service providers at the pharmacy outlet/village doctor. We decided to increase the number of health providers interviewed to include not only government providers but also trained private providers and those in the informal health sector, such as Bangladesh's village doctors (traditional healers who have received some [inconsistent] training from nongovernmental organizations (NGOs) or pharmaceutical companies to support health programs in the community). Village doctors often run the village drug outlets.

Table 1. Sampling distribution

Swaziland	Region	Study site	Patients	HCWs	NTP regional coordinator	System audit	TB community leaders
	Manzini	Mankayane Hospital	20	1	2	0	2
		TB Center	38	1		6	
		Raleigh Fitkin Memorial	43	1		6	
	Hhohho	Mbabane Government Hospital	36	1	2	6	2
		Mkhuzweni Health Centre	31	1		0	
		Pigg's Peak Hospital	36	2		5	
	Shiselweni	Matsanjani Health Centre	15	1	2	0	2
		Nhlangano Health Centre	47	1		4	
		Hlatikulu Government Hospital	37	1		5	
Lubombo	Good Shepherd Hospital	62	2	1	7	2	
	Sithobela Health Centre	21	1		4		
	Cabrini Ministries	15	0		0		
	Ubombo Sugar	8	1		0		
Total: 438			409	14	7	43	8

Bangladesh	District	Upazila health unit	Patients	Practitioners: government, private, pharmacists/village doctor	NTP manager	TB community leaders
	Barisal	Muladi	10	7	1	1
		Bakergonj	10			1
	Faridpur	Alfadanga	10	7	1	1
		Char Bhadrasan	10			1
	Joypurhat	Joypurhat Sadar	10	7	1	1
		Kalai	10			1
	Khulna	Batiaghata	10	7	1	1
		Terokhada	10			1
	Total: 120			80	28	4

Note: HCW stands for health care worker.

In Swaziland, health care workers were drawn from 13 health facilities including nine government hospitals and health centers, two mission (faith-based) hospitals, and two private health facilities (one private for profit and one work place/ industry clinic). Health workers were doctors, nurses, lab technicians, and pharmacists.

TB community leaders: In Bangladesh, the interviewed TB community leaders were the NGO managers responsible for coordinating TB services delivery at the community level. In Swaziland, interviewed community leaders represented four organizations: Cabrini Ministries, The AIDS Information and Support Centre, Adventist Development and Relief Agency, and Caritas. Three of these organizations coordinate and provide TB treatment, care, and support to TB patients in their respective communities, and one runs a health facility that provides TB screening, diagnosis, and treatment to TB patients.

Regional NTP manager: In Bangladesh responsibility for coordinating the NTP at the regional/district level resides with the Civil Surgeon, who in addition to leading NTP activities also manages other health activities in the district. In Swaziland, the study interviewed seven NTP Regional Coordinators, two from each of three regions and one from a fourth region. These coordinators are primarily nurse practitioners and are responsible for coordinating TB activities in their region.

Health systems audit: In Swaziland a health systems audit was conducted at the NTP's request to provide unbiased examination and evaluation of the health system parameters related to TB diagnosis and treatment and to compare the results with those obtained through patient interviews. Although this assessment did not fall within the primary objectives of TB CARE II, the project and the NTP agreed to undertake this examination, which provided useful information for the study overall. The health system audit considered the following health systems parameters:

1. Diagnostic delay: date of first visit and date of diagnosis by sputum, X-ray, and clinical assessment;
2. Turnaround time (TAT) for the sputum sample, that is, the date of sputum delivery to the laboratory and date of results; and
3. Treatment initiation delay, that is, the date of diagnosis results to the date of TB treatment initiation.

The auditors reviewed four types of recording and reporting tools in each facility: TB suspects register, TB lab register, TB patient cards, and TB treatment register. From the lab register we obtained information regarding the patient's date of sputum delivery to a lab, date of sputum examination, date when the sputum result was analyzed, and date the sputum result was issued to the health care center. From the TB suspect register, we obtained information regarding each patient's sex, age, date of the first visit, date of sputum request form sent to the lab, and date a treatment card was issued. The TB patient's card provided the date for the prescription of TB drugs, date of dispensing of drugs, and date of initiation of treatment. The TB treatment registers provided the date of treatment initiation.

Eight health facilities (Hlatikhulu, Nhlanguano, Good Shepherd, Sithobela Health Care, Piggs Peak Hospital, Mbabane Government Hospital, Raleigh Fitkin Memorial, and the TB Centre) were selected from four regions for the health systems audit. Two health facilities were chosen per region and 40 records (roughly 10% of the total sample of 409 interviewed patients) were selected randomly from the facilities and regions.

Data analysis

Data from the patient questionnaires was analyzed using SPSS® software version 17.0 and Excel software. Chi-square test and student t-test were used for variable comparison and association analysis. Generalized linear regression models were used to assess significance of associations and to control for confounding effects. Level of significance was determined at 95% (P value <0.05).

Study limitations

As with most studies of this nature, a key limitation in the Bangladesh study relates to the sample size. Other limitations include: Purposeful selection of the regions/districts, thus the sample may not have represented the causes of TB delays throughout the country; women were interviewed in the presence of their husband/companion due to cultural/social norms, and they may not have responded freely to all questions (especially those regarding stigma and gender issues). Since exit interviews were held in

health facilities, interviewed patients may have felt observed, which may have affected their responses. TB providers in government facilities in Bangladesh usually have a morning public practice and an afternoon private practice, so we expect a level of overlap among the two groups of providers.

In Swaziland the HIV status of the TB patients interviewed were not considered for the analysis of delay, nevertheless 36% of TB patients said they were treated for HIV/AIDS-related symptoms before being tested for TB. HIV status may have played a role influencing TB patient services utilization In Swaziland. Incomplete data from the TB and lab registers could also limit interpretation of the data from the health systems audit.

Moreover, since the studies conducted to assess TB delays were cross-sectional, a cause-effect relationship cannot be established.

Study Results From Bangladesh and Swaziland

The databases obtained from interviews with patients, community TB leaders, TB program managers, and service providers were cleaned to reconcile data entry errors and analyzed to provide information on three major types of TB delays (patient, diagnostic, and treatment).

Total delay

Swaziland was found to have an overall longer total TB delay period, with 102 days from onset of symptoms to the initiation of treatment, compared to 77 days in Bangladesh. In both countries, TB patient delay times were higher than TB health system delays, almost threefold in Bangladesh and double in Swaziland (Figure 3).

Patient delay

We found that 60% of patients in Bangladesh and 51% in Swaziland waited more than a month before seeking medical care for their symptoms. The mean patient delay in Bangladesh was 57.2 days (median 30 days), and in Swaziland it was 65.6 days (median 46.4 days): (Figure 4).

Diagnostic delay (health system delay)

In Bangladesh, the mean time between first approaching the health facility and receiving the TB diagnosis was 17.8 days (SD 42.6) and a median of 3 days. Several outliers were reported, including three patients with nine-, seven-, and six-month delays. Another nine patients waited more than a month to receive results.

In Swaziland we obtained a mean 31.4 days (95% CI: 13.3-49.5) for diagnostic delay with a median of 12 days. The median in both countries may convey more meaning in this result since we observed so many outliers in our sample.

Figure 3. TB patient delay and TB health system delay (TB diagnostic + TB treatment) in Bangladesh and Swaziland

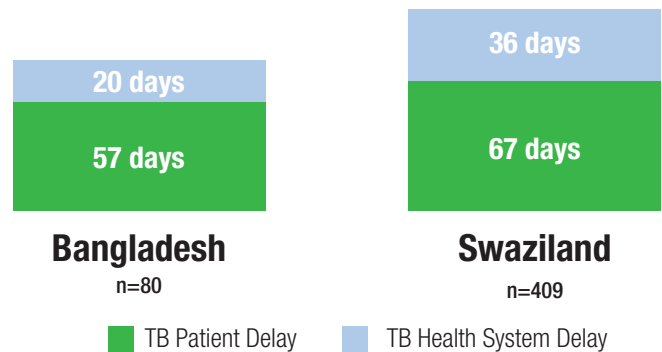
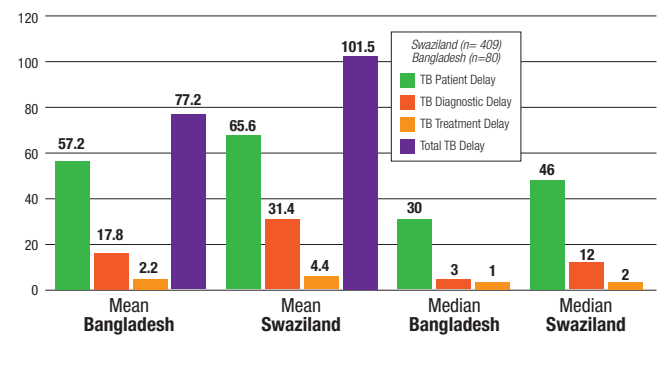


Figure 4. TB delay categories (patient, diagnostic, and treatment) in Swaziland and Bangladesh



Treatment delay (health system delay)

In Bangladesh, after diagnosis 96% of patients were initiated on TB treatment in two days (mean 2.2 days, SD 4.3). Only one patient had a week interval before treatment initiation, and two experienced a month delay.

In Swaziland, 25% of patients were initiated on treatment the same day they were informed that they had TB, and 36.4% were started on treatment the following day. The mean period from diagnosis to treatment was 4.4 days (95% CI: 2.5-6.4), and the median was two days.

Causes of patient delay

Symptoms recognition

The study asked patients to recall the symptoms they presented to the clinic at their initial visit, such as cough for more than two–three weeks, fever, weight loss, sweats, tiredness, dizziness, bloody sputum, and chest pain. While in Bangladesh, 88% of TB patients said they presented with cough, only 63% did so in Swaziland. Sputum with blood, which is usually recognized as a sign of TB, was reported by only 10% of patients in Bangladesh and less than 5% in Swaziland (Figure 5).

Once aware of their symptoms, patients delayed seeking clinical attention. We asked them what made them delay once they had symptoms, and most said that they perceived the TB symptoms to be mild. In Bangladesh, 90% of patients and in Swaziland 59% said that they were not aware of the severity of the symptoms and that they did not feel initially that they needed medical assistance (Figure 6).

Figure 5. Initial symptoms reported by TB patients that led them to seek health care

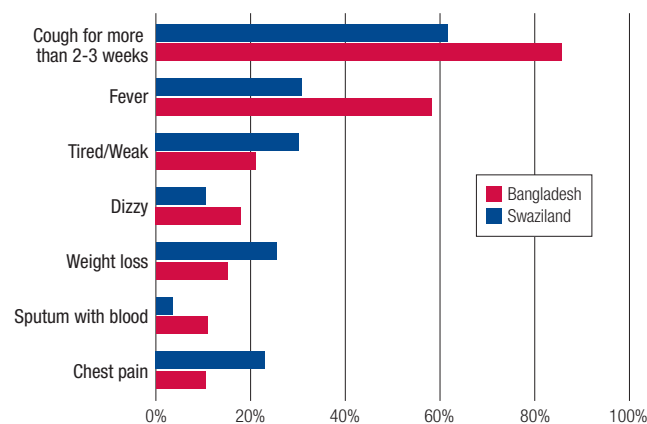
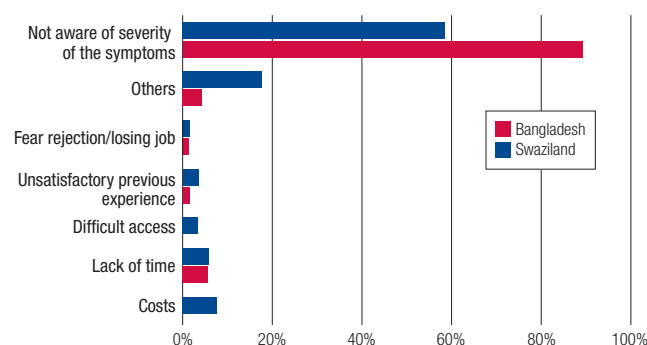


Figure 6. Patients' explanations for not seeking care for their TB symptoms



We did not analyze the HIV status of patients sampled in Swaziland, but a significant number were likely infected with HIV, since the current estimated co-infection rate for TB/HIV in that country is 80% (31). Concomitant HIV/AIDS may explain the insidious and non-specific symptomatology that more patients had in Swaziland and which sometimes manifested only as a slow wasting with minimal inflammatory reaction.

District NTP managers in Bangladesh identified the lack of patients' knowledge and their failure to promptly identify their symptoms and seek adequate treatment as the major factor in TB delay. In Swaziland, the regional TB coordinators identified a lack of easy access to TB services as a major contributor to TB delay. Other factors identified included lack of awareness of TB symptoms, fear of stigma or job/ wage loss, lack of economic resources, and preference for traditional medicine/healers.

TB knowledge

Since we conducted exit interviews with patients already diagnosed with TB and during their treatment phase, we expected that they had received counseling and education on TB symptoms and treatment. The TB knowledge measured by the patient exit interviews is therefore considered a proxy for the measure of the effectiveness of TB counseling and education the health facilities provided.

In Bangladesh, 71% of TB patients interviewed knew that TB is an infectious disease transmitted by germs in the air and the same percentage also thought TB was a serious disease. Most patients (90%) knew that TB is diagnosed through sputum examination and X-ray and recognized cough and fever as the symptoms most frequently associated with the disease. All patients also knew that TB can be cured when adequate treatment is provided and that some types of TB (multi-drug resistant [MDR] TB) may require a longer treatment time to achieve a cure.

In Swaziland, a similar percentage (72%) of patients reported that they knew TB was an infectious disease transmitted by germs; (65% of respondents knew the germs were transmitted through the air; and 80% considered it a serious disease. Some knew it was manifested by cough (83%), fever (44%), and weight loss (38%). Also, 16% still held misperceptions about the causes of disease, including HIV, witchcraft, alcohol, dust and smoking, drinking cold water, lack of eating a balanced diet, inherited, and not dressing warmly.

Seventy-three percent of TB patients interviewed in Swaziland knew that the disease was diagnosed through sputum analysis, and 65% knew it was also diagnosed with X-rays. Most of the respondents also knew that TB can be cured with treatment (96%), and more than half (60%) knew that some cases require longer treatment to be cured.

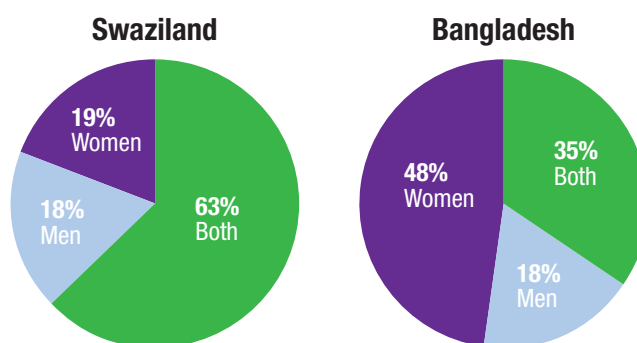
Perception of TB infection

Half of TB patients as well as TB community leaders interviewed in Bangladesh thought that TB was more frequent in females than in males, in spite of the finding among our sample that three times as many male patients received TB treatment as females. Analyzing the responses disaggregated by sex, we found that 48% of the sample perceived women to be more likely to get infected with TB, as compared to only 18% perceiving men to be more likely to be infected. More research should explore the reasons for this skewed perception and possible gender-related stigma associated with it (Figure 7).

Half the female respondents also perceived TB disease as having a negative impact on their ability to become pregnant and have healthy children and on their marriage or marriage prospects.

In Swaziland, when asked who is more likely to get TB, 63% of respondents felt that men and women were equally likely; 19% said women were more likely; and 17% said men were more likely. We therefore did not find that perception of being infected with TB was influenced by gender in Swaziland.

Figure 7. Perception of who is more likely to become infected with TB



Stigma and discrimination

In Bangladesh, most respondents (93%) had disclosed their disease to family and community members, and 25% said their relationships changed after doing so; 28% acknowledged suffering discrimination after revealing their illness. Asked which sex experienced more frequent discrimination, 69% of males and 48% of females failed to respond. TB community leaders replied that women were more likely to experience discrimination in the community as they are not taken seriously due to their impoverished status, lack of decision-making power (they need their husband's permission to access health care), and lack of education.

We disaggregated the calculations of TB delay by participants' sex to assess the role of gender in TB patient delays (Table 2). We found five male outliers in our sample with extremely long delays in seeking care

Table 2. TB delays in days disaggregated by sex, Bangladesh

		Mean (\pm sd)	Median	Min	Max
TB patient delay: Time from TB symptoms recognition to health care consultation (p=0.21)					
Male	3 outliers removed* (n=52)	54.5 (\pm 108.0)	30	1	720
Female	Total sample (n=25)	40.8 (\pm 38.6)	28	7	180
TB diagnostic delay: Time from health care consultation to TB diagnosis (p=0.47)					
Male	3 outliers removed* (n=52)	10.0 (\pm 13.1)	3	1	60
Female	Total sample (n=25)	9.8 (\pm 10.6)	3	1	30
TB treatment delay: Time from TB diagnosis to TB treatment (p=0.11)					
Male	Total sample (n=55)	1.6 (\pm 1.1)	1	1	8
Female	Total sample (n=25)	3.5 (\pm 7.4)	1	1	28

* Male outliers: Three patients were identified as having excessive patient delays (6, 6, and 12 months) and diagnostic delays (6, 7, and 9 months). These patients were removed from the sample before calculations were made.

(patient delay) for their symptoms with 6, 6, 12, 12, and 24 months' delay; three of them also reported longer-than-usual delays in receiving a TB diagnosis (6, 7, and 9 months). We removed these last three to calculate TB delays in males. We found no specific characteristic to explain their long delays: all three individuals lived in rural area within 2.5–7 km of the health facility, were 55–60 years old, and married; two were working. Differences in patient delay, diagnostic delay and treatment delay among females and males in Bangladesh were not statistically significant, probably due to the small sample.

In Swaziland, 77% of patients reported that there was no discrimination against people with TB in their communities and that there is no difference in discrimination between women and men. Only 13% said that their relationships with friends and family had changed after their TB diagnosis. Of them, 65% said that they suffered from discrimination, rejection, and isolation from friends and family members, while 35% said that their relationships actually improved because they received more support from their family. Of employed respondents, 93% said they were not afraid of losing their jobs after learning their TB status, and 7% said that they were afraid.

Most patients in Swaziland (91%) favored disclosing their TB status and even more (95%) had done so. Asked how they felt when they learned they had TB, 47% said they accepted the diagnosis, 12% were scared, 24% got depressed, and 17% were in disbelief and denial.

However, TB community leaders reported that there was discrimination and stigma against TB patients in Swaziland, in part due to the high association between TB and multi-drug resistant (MDR) TB with HIV. Reasons given for not disclosing TB diagnosis were: fear of rejection and isolation, wanting to protect their family, fear of discrimination, and fear of losing their jobs.

In Bangladesh, 60% of females interviewed said that they needed permission from their husbands to access the health services. This information was confirmed by the community DOTS managers. A gender barrier was not observed in Swaziland, where 85% of females said they did not need permission to access health services.

Access and transportation

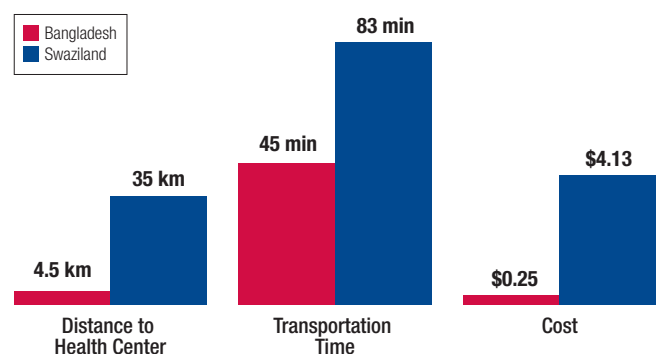
Most patients (89%) interviewed in Bangladesh lived in rural settings. More than half (60%) said they lacked easy access to the health facility closest to their

households. Out-of-pocket costs for transportation to facilities were reported to be approximately US\$ 0.25 (19 takas) per trip. The average walking distance from a patient's home to the health facility was 4.5 km, which required around an hour of travel time. (Providers reported that the average TB patient traveled 3.5 hours to reach the facility). Patients reported that they were not required to pay for TB services and lab tests done in government facilities, and most were satisfied with the service hours at facilities (Figure 8).

Since half the patients in Bangladesh initially sought care from private providers, we analyzed whether they did so because such providers were more accessible. We found, however, that most patients used transportation (public or the patient's) when visiting a pharmacy or private facility (70% and 77%, respectively); whereas only 40% used transportation when visiting a government facility. In addition, more patients (40%) walked to the government (NTP) facility where services were free, and fewer walked to private providers (24%) and pharmacies (30%). These findings and the relative affordability of public transportation do not support the hypothesis that transportation plays a major role in patients' health-seeking behavior. Other factors, such as office hours, greater trust in private providers, or perceptions of better services at nongovernment facilities may be playing a role.

In Swaziland, 73% of patients sampled lived in urban settings. Public transportation (buses) were used by 42% to reach a facility, requiring on average 83 minutes (range: 3–300 minutes) to travel an average distance of 35 km. Twenty-one percent walked an

Figure 8. Transportation to the government (NTP) health center



average of 2.5 km to reach a facility. The average amount paid for each round trip to a government facility was US\$ 4.10 (E 32.00), a significant economic burden. One female patient said “I have to sell two chickens every time I go to the TB clinic” (Figure 8).

While important, distance barriers seem to be secondary in Swaziland to a patient’s perceived quality of a facility’s services. We found that 55% of patients, in spite of having government facilities closer to their households, were receiving TB services at a more-distant facility. It is not clear from the responses whether this seeking behavior was due just to patients’ perceptions of the quality of and/or trust in the services or because TB services were not provided at the closer health facility. Most (80%) respondents said they did not have to pay for primary diagnostic services at public facilities, although they were required to pay for x-rays and any extra lab tests required to obtain extra-pulmonary TB (EPTB) diagnosis. Costs were subsidized at the government facility, and patients were usually required to pay an average US \$3.80 (E 24.00) for health services. In private hospital/clinics the cost for services are much more expensive, and those patients who are unable to pay go untreated.

Health-seeking behavior

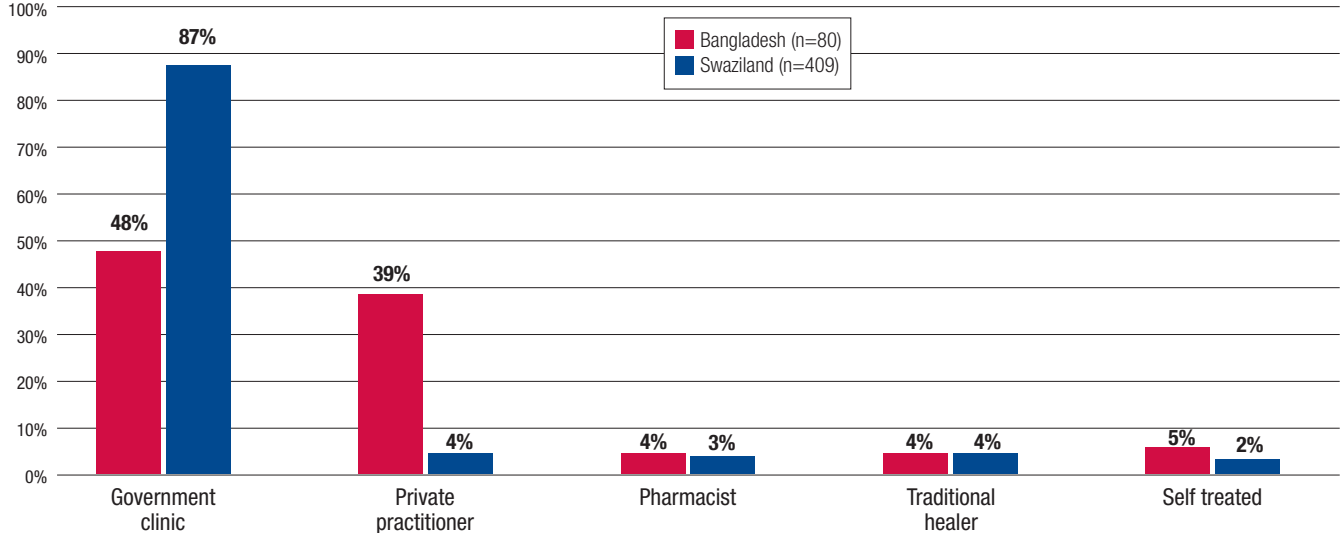
All practitioners from government facilities in both countries said that they had been trained by the NTP and that they diagnose TB by detecting TB mycobacteria in sputum. Providers in NTP-trained facilities reported that

they treated patients following the WHO-recommended DOTS strategy (supervision of treatment with standard drug regimens for at least six–nine months) and that they follow up on patients’ response to treatment. Nevertheless, not all private physicians had been trained yet, despite country efforts.

Approximately half (48%) of TB patients in Bangladesh initially sought care for their symptoms in government facilities (51% males, 44% females); 39% visited trained private providers (40% males, 32% females), 8% private pharmacists/healers (4% males, 20% females); and 5% self-treated (Figure 9). Duplicative services are common among patients in Bangladesh: a third of patients interviewed said that besides treatment at the health facility, they were also being treated by other public practitioners, traditional healers/ pharmacist, and/or private practitioners.

Distance to the government health clinic and the cost of transportation influenced 23% of patients’ initial decision on the type of care they sought in Bangladesh. As to the convenience of facility hours, government facilities were open eight hours a day, six days per week, and closed on Fridays. Private providers have a competitive advantage, being open in the evening in addition to the regular work schedule. In Bangladesh it is common that a provider attending patients at the government facility in the morning will provide private services in the evening. The so-called “village doctors” in Bangladesh are informally trained practitioners who provide clinical services and run the local pharmacy, usually from their

Figure 9. Health-seeking behavior after recognition of first TB symptoms



own home. Twenty-five percent of patients said they attended the government facility because they had previously used its services and 22% because the facility was recommended by a relative/friend.

Most patients in Swaziland (87%) initially went to a government health facility when they felt sick. The reasons they gave for doing so was that it was closer (48%); they trusted the providers more (22%); and they received better care (18%). Distance to the facility is of concern in Swaziland, as transportation is expensive, but we found that patients were willing to travel farther to attend other government facilities where service quality was considered superior. Private services were not affordable to poor patients. Regardless of their TB treatment in a government facility, 37% of patients also received treatment from a traditional healer, as disease was perceived as having a “soul” component that needed traditional medicine or “witchcraft” healing.

We investigated TB delay by the type of provider visited in Bangladesh (Figure 10). Surprisingly, we found that the patient delay for patients who went to a trained private provider was 78% longer than for those who sought care from a government provider (81 days versus 45 days, respectively). We had expected a shorter period for seeking care from private providers, as patients mentioned the convenience and flexibility of private providers’ hours. Patients sought care from untrained private providers within 30 days, much earlier than with any other provider.

Once patients approached public provider services, they were diagnosed with TB within six days, compared to 42 days for trained private providers and 15 days

for untrained providers/village doctors. Village doctors usually referred patients to the government facilities for diagnosis, which explains the shorter TB diagnostic time observed compared to private providers.

Patient’s satisfaction

Most patients (86%) in Bangladesh said they were highly or somewhat satisfied with the service received in the government TB facility, and half of them all (54%) said that they received better service at the facility than they had expected. Most patients said that providers responded to their questions with respect and that they found the government facility work schedule and waiting times acceptable. Besides initial consultation with other providers, at the time of the survey most (79%) patients said they preferred to be treated in government facilities.

Swaziland’s findings were similar, with 88% of respondents reporting they were satisfied with the services received and very satisfied (92%) with DOTS providers’ services. More than half (59%) of patients said they received better service than expected, and most were also satisfied with the clinic schedule (86%) and the waiting time there (69%).

Causes of diagnostic delay

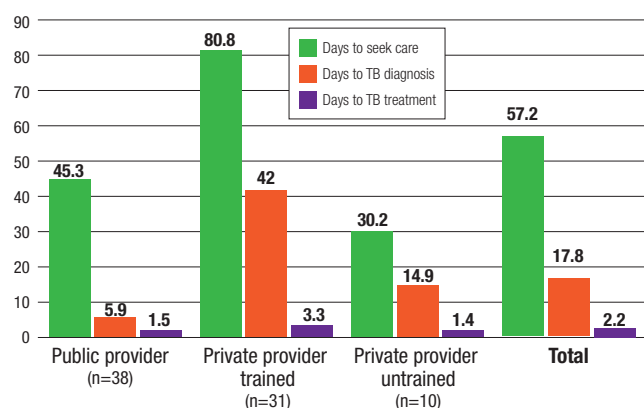
Provider diagnostic capacity

Training

In Bangladesh all providers in government facilities said they had received training in TB. Most private providers (88%) as well as village doctors/pharmacists (83%) said they had received TB training during 2011. Training was provided by NTP with funds from the Global Fund to Fight AIDS, Tuberculosis, and Malaria (GFATM). Training focused on TB service delivery, case detection, and referral to the appropriate facilities. Funding was provided at the district/upazila level to strengthen links between private providers and NTP.

In Swaziland TB health care workers had received routine training on TB, TB/HIV, and MDR-TB with funding from the Global Fund and TB partners. NTP coordinators said that TB training was also provided at the regional level and at health facilities (peer-training) as frequently as needed. In two of four regions interviewed, the training was also provided to private providers and pharmacists. Personnel interviewed from government and private (faith-based) health facilities said they had been trained in TB management.

Figure 10. TB delays disaggregated by type of provider first contacted, Bangladesh



Compliance with diagnostic TB guidelines

In Bangladesh, 87% of government providers, 62% of trained private providers, and 83% of pharmacists/village doctors said they had the Essential Drug List available for consultation. All government facilities said they had the guidelines for infection prevention and control available, and 87% said they also had guidelines for treatment of TB and MDR-TB.

Seventy-three percent of government providers identified TB suspects using symptom screening, and 27% conducted case contact tracing. Ninety-three percent of providers said that they requested sputum microscopy, and 61% also requested an X-ray to make a TB diagnosis. Some (11%) also requested tuberculin skin test.

In Bangladesh, government health facilities assisted a monthly average of 76 TB suspects (SD ±71) compared with five (SD±1) by private providers and four (SD±3) by village doctors/drug vendors (Table 3).

Forty-six percent (6 of 13) of providers interviewed in Swaziland said that they diagnose TB within a day and all providers said they had diagnosed MDR-TB

cases during the previous year, although not all of them treated patients once diagnosed. All providers said they based their diagnosis on sputum smear results, and most (85%) also asked for X-rays. Nurses provided education and counseling on HIV, TB, and MDR-TB for all patients as appropriate. The volume of TB patients seen yearly in each facility is presented in Tables 3 and 4.

Treatment for other diagnoses

In Bangladesh, patients seeking care for their symptoms were treated for other diagnoses before being diagnosed with TB. Forty-three percent of patients reported being treated for other respiratory infections, 23% for malaria, 3% for HIV/AIDS, and 15% for other pathologies. After receiving non-TB treatment for fever and cough, 54% said they did not notice an improvement or their condition worsened, leading them to pursue further treatment, usually at a government health facility.

In Swaziland 36% of TB patients were treated for HIV/AIDS-related symptoms before being tested for TB and 32% for respiratory infection; 31% also received

Table 3. Bangladesh: number of TB patients seen monthly, by health provider category

	Government		Private		Pharmacist/village doctor	
	Mean (±sd)	Median	Mean (±sd)	Median	Mean (±sd)	Median
TB suspects	76(±71)	45	5(±3)	5	4(±3)	3

Table 4. Swaziland: annual patient volume by health provider (2011).

Region	Study site	Patients per year	Type of facility
Manzini	Mankayane Hospital	789	Government
	TB Center	1410	Government
	Raleigh Fitkin Memorial	1229	Mission
Hhohho	Mbabane Government Hospital	861	Government
	Mkhuzweni Health Centre	623	Government
	Pigg's Peak Hospital	717	Government
Shiselweni	Matsanjeni Health Centre	252	Government
	Nhlangano Health Centre	936	Government
	Hlatikulu Government Hospital	636	Government
Lubombo	Good Shepherd Hospital	660	Mission
	Sithobela Health Centre	410	Government
	Cabrini Ministries	99	NGO
	Ubombo Sugar	218	Private industrial

treatment for malaria, asthma, cold, flu, and digestive disorders. Fifty-eight percent of patients received treatment with traditional medicines, and antiretrovirals (ARVs), antibiotics and treatment for allergies, cold, and/or flu. After symptoms failed to improve, further tests were pursued to finally reach the TB diagnosis.

Number of patient visits to receive a TB diagnosis

All patients interviewed in government facilities in Bangladesh received a TB diagnosis at the same facility (UHC). Most (74%) said it required several visits with the same provider in that facility to get the TB diagnosis. Of those, 20% said that they received the TB diagnosis during the following visit to the facility (two visits: one to be tested and one to receive the diagnosis), while 60% required three visits, and the remaining 20% required four or more visits (Figure 12). This suggests that providers may not have requested a sputum sample during the patient’s first visit or that more investigation was needed for patients with a negative sputum test. We didn’t investigate the result of patient’s sputum as positive or negative.

Most patients in Swaziland were seen at the government facilities where only 15% said they had several visits with the same provider. Since at least 64% of patients required more than one visit to obtain a TB diagnosis, this low (15%) percentage may be due to a high rotation/turnover in the facility or because the patient was being treated for another disease. A surprising 36% of TB suspects were diagnosed with

TB during the first visit, although providers said that the average time to obtain the microscopy results in government clinics was three days. These findings suggest that patients were diagnosed on the basis of symptoms or X-rays. Twenty-five percent of patients received a diagnosis in two or three visits, and 39% needed more than four visits (Figure 11). Most (88%) said the initial TB diagnosis was done at a government health facility; 10% in a mission health facility (run by a faith-based organizations); and 2% either in a private or other health center.

Referral

In Bangladesh 31% of interviewed patients said they had been screened by private providers (trained and untrained) and referred to the NTP facility for diagnosis and treatment. Private providers and pharmacists/village doctors who refer TB suspects to the government health facilities usually provide a verbal referral only and do not conduct follow-up of referred patients. There was no documentation on referrals (referral log) for TB suspects, so we assessed the referral mechanism based on the responses given by providers.

Interviewed government providers were the contact person for TB at the UHC and received referrals of TB suspects from other government primary care providers as well as private providers and NGOs working in TB control efforts in the community.

Figure 11. Diagnoses suspected by the provider before TB diagnosis

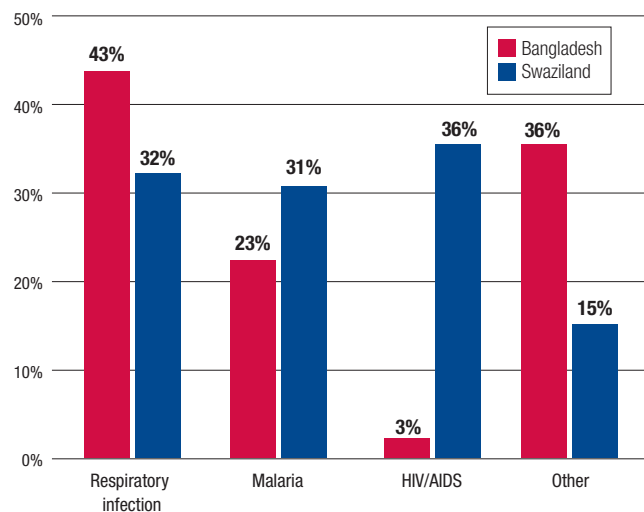
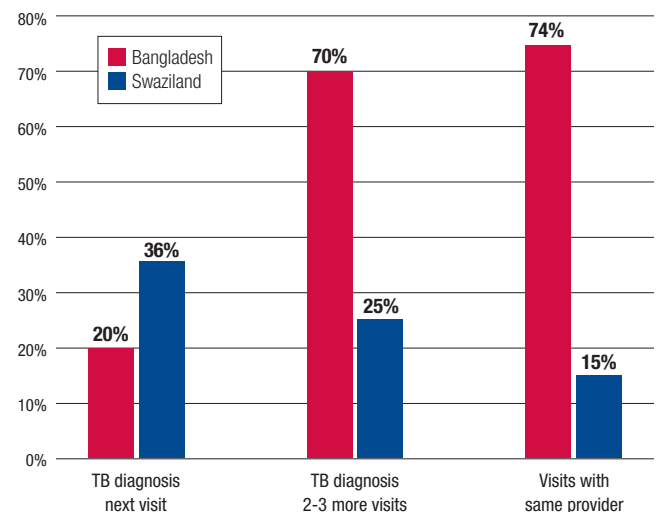


Figure 12. Number of visits to receive a TB diagnosis



Some private providers also received patients from government providers for chest X-rays, fine needle aspiration cytology (FNAC) test and other tests that were not available at the UHC. Most UHCs have X-ray equipment, but they are frequently dysfunctional due to such causes as lack of X-ray film, availability of a radiologist or machines that are out of order.

In Bangladesh, village doctors/pharmacists/shasthya¹ sebika often act as the focal TB person in their communities. They refer TB suspects for diagnosis and initiation of treatment to the NTP-NGO and provide follow-up of TB DOTS. NTP-NGOs also count on these trained community members to provide DOTS.

In Swaziland 15% of patients said they were referred to the facility by other providers, most of them from private or faith-based clinics, to the NTP facilities for TB diagnosis and treatment.

Delay in receiving lab results

In Bangladesh, government providers said that the average time to receive microscopy (acid-fast bacillus or AFB) results was one or two days; for private practitioners it was three or four days, and for pharmacists/village doctors approximately five days. Sputum culture and drug susceptibility testing (DST) were not available in all districts, and providers said it usually took three months to obtain the culture report.

In Swaziland, providers said that the average TAT for sputum results was three days. Most of the seven regional coordinators interviewed reported having had shortages of lab supplies for TB diagnosis in the past year. Such shortages were caused by a lack of reagents (for culture tests and DST), stock-outs, and a shortage of sputum collection bottles. Some sites lack on-site smear microscopy and depend on the national sample transport system, which services each clinic two or three times a week, picking up samples and delivering lab results. In one district the collection was done weekly, in which case specimens were refrigerated.

Specimens were also collected by community health workers from satellite sputum collection spots weekly or monthly, or people were asked to give specimens when they visited the facility. According to the patient questionnaires, 81% of TB patients received sputum

bottles: 73% from the TB clinic and 8% from the antiretroviral therapy (ART) clinics. We found that the clinic lab received more sputum specimens than the number of sputum collection containers provided, which indicates that referrals had been received at the lab from other providers requesting sputum analysis.

Most TB suspects received sputum sample bottles on the day they reported to the facility. Of those who received the bottles, 35% returned a specimen to the lab the next day, 26% did so after two days, 24% after three days, and the remaining 15% after seven days or more. The health audit found that 15% of patients did not obtain sputum bottles at the facility during their first consultation, which could have contributed to diagnostic delay.

The audit also found that 98% of the randomly selected patients' records had sputum collected and that of them 95% received sputum results. Two sputum results were missing. The audit found that 27% of patients had an X-ray taken, but 85% of providers said that they requested an X-ray to diagnose patients.

Causes of treatment delay

In Bangladesh, almost all (92%) patients at government facilities were initiated on TB treatment within a day or two after receiving the TB diagnosis, within three–four days by private providers, and within a day or two by pharmacists/ village doctors.

MDR-TB is treated only at government facilities. Results from AFB culture and DST usually take 61–90 days. Half of government providers and 12% of private providers said they had diagnosed (suspected) MDR-TB cases in the previous year, and four UHCs reported having MDR patients undergoing TB second-line drug treatment.

Only one district manager of the seven interviewed in Swaziland said that his/her district had a TB drug shortage for one month due to delayed shipment of TB drugs from the supplier. Three out of 13 providers said they had been affected by the TB drug shortages during the last year and that this caused delays ranging from one week to two months in initiating patients on TB treatment. In most districts a prescription is required to obtain TB medication, but only two (of seven) district managers said there is a

¹ A *shasthya sebika* is a voluntary community health worker selected from among the village-based women's credit group. Ahmed, S.M. Taking healthcare where the community is: the story of the *Shasthya Sebikas* of BRAC in Bangladesh. *BRAC University Journal* V(1), 2008: 39–48.

regulatory framework enforced for selling TB drugs. Of interviewed providers 54% said they prescribed the TB treatment one day after receiving TB diagnostic results; the remainder said it took two to three days.

TB health system delay (Swaziland health system audit)

In Swaziland, most TB program coordinators (four out of six) felt that TB diagnostic delays were due to providers not screening and referring TB suspects to the appropriate facilities for diagnosis as well as long turnaround times for TB lab test results. The NTP requested that an audit assess the magnitude and causes of health system delays. Data were collected by the NTP, the MOH Strategic Information Department, and a senior monitoring and evaluation specialist from URC.

The audit team thoroughly reviewed the TB suspects register, TB laboratory register, TB patient register, and patient's health cards for 41 TB patients in eight facilities from the four districts participating in the study. The team identified no errors in the data collection methodology or data registry but did find that some facilities had missing data in their registries or had not recorded data accurately. Results from the health system audit are presented in Table 5.

Interventions carried out by the countries to reduce TB delays

Coordination mechanism: Both countries have functional TB management teams at the district level that meet monthly/semi-monthly to discuss their TB infection control program advances. The NTPs in both countries were aware of patient factors as a main contributor to the overall TB delays.

Advocacy, communication, and social mobilization (ACSM) activities: Although TB managers said they conducted TB communication campaigns, they acknowledged that the campaigns were insufficient in reaching targeted populations and vulnerable groups. In Bangladesh, TB messages were communicated through mass media campaigns, community health care providers, some sporadic activity such as folk songs, and drama plays during market days. Some NGOs working in TB control referred patients to HIV voluntary counseling and testing centers in targeted districts, but this strategy was not widely scaled up. In Swaziland most NTP regional managers interviewed said they had ongoing communication campaigns to improve awareness and knowledge of TB. Some organizations have started a program with three chiefdoms to raise TB awareness among people attending community meetings and also to teach

Table 5. Swaziland health system audit results

Laboratory assessment (n=41)				
Sputum microscopy	98% had sputum examination	5% had missing results		
Microscopy TAT	1 day:78%	2 days :5%	3 days: 12%	Mean 1.5 days
Diagnostic delay assessment				
Time to diagnosis ‡	1 day after sputum collected: 48% (n=19)	2 days after sputum collected: 7% (n=3)	3 days after sputum collected: 15% (n=6)	4 or more days after sputum collected: 23% (n=9)
Treatment delay assessment				
Treatment after sputum results: 63% (n=26)	1 day after sputum results:62% (n=16)	2-3 day after sputum results: 15% (n=4)	More than 3 days: 23% (n=6)	
Treatment before sputum results: 37% (n=15)	X-ray result: 27% (n=4)	Clinical: 73% (n=11)		

‡ Diagnostic delay outliers: 1 patient each with the following diagnostic delays: 196 days, 58 days, and 28 days delays (n=3)

traditional healers about TB and HIV to improve referral of patients to the health centers. All organizations send their community DOTS supporters to be trained by the NTP. In Swaziland all NTP coordinators said that TB messages were communicated to the population in their regions, continuously in health centers and periodically through mass media campaigns.

Populations vulnerable to TB delay were identified in Swaziland as people living in rural areas, people with very low resource levels, and people in prisons. NTP managers said that they are targeting these populations through intensified TB symptom screening, referral mechanisms, and rapid diagnosis through gene Xpert molecular tests. These activities are being carried out under the TB Reach project (Stop TB Partnership).

Health providers in Swaziland said that patient education was provided on treatment adherence (100%), TB and HIV (69%), healthy lifestyle (69%), and TB symptoms recognition (62%).

Patient support mechanisms, such as nutritional support for TB patients, were provided through the World Food Program in half of the regions (according to the NTP regional coordinator interview). Transportation support, initially programmed under the Global Fund, was later discontinued. All TB patients in Swaziland are expected to have a TB treatment supporter, who could be a family member, a neighbor, a community volunteer, or a paid (incentivized) community treatment supporter.

Interventions to strengthened health system in Swaziland: The good results found in Swaziland's health system audit could be attributed to the implementation of several activities conducted during the last five years, such as:

- Training of microscopists on sputum microscopy and institutionalizing quality assurance: The NTP and national laboratory service adopted a system for training 12 microscopists to focus exclusively on sputum microscopy. Adopting this measure reduced the TAT for microscopy from two weeks in 2006 to less than 48 hours by 2009. The audit revealed an even lower TAT of 1.5 days. For quality assurance, a functional, double-blinded smear rechecking system has been institutionalized.

- Increased human resources for microscopy: The Swaziland government, the Global Fund, and URC collaborated to increase the number of government microscopists, improving workload/staff ratios where microscopy is done daily.
- Improved national sample transport system: URC has been funding salaries and providing technical assistance to the National Sample Transport System to manage a network of transportation vehicles. The system is serving 113 clinics countrywide. Vehicles from the system travel to the clinics two–four times a week to collect sputum samples and deliver sputum results. The system has helped increase access to sputum microscopy and contributed to the overall TAT reduction.
- Monitoring TB laboratory data quarterly: Increased monitoring meetings focus on the quality of lab processes, including reviewing laboratory logs to identify sputum microscopy not done or not reported. Since most facilities are implementing strategies to reduce the number of sputum microscopies not done, the baseline of 54% of sputum not tested in 2006 was reduced to less than 20% in most health facilities in 2009.
- Capacity building among clinicians: Extensive training of nurses and doctors has helped improve the number of TB suspects who receive sputum microscopy tests. Nurses are now found to comply more regularly with guidelines in requesting a sputum sample than doctors.

Discussion of Findings and Recommendations

Main findings

The Bangladesh and Swaziland studies revealed that the delays due to patient causes were two to three times longer than those due to health systems causes.

The main factors contributing to TB patient delay in both countries were:

- Patients not seeking timely care because they were unaware of the severity of the symptoms: We found that patients did not initially present a well-defined symptomatology of the key symptoms we consider for the TB screening (cough, fever, and weight loss). In Swaziland 40% of TB patients said that they did not have cough; this could be due to reduced inflammatory reaction secondary to coinfection with HIV.
- Other factors that contributed to delay were more specific to a country context, such as distance to the nearest facility and transportation costs, as well as fear and stigma of being diagnosed with TB, because it was assumed that person with TB was also infected with HIV.
- We were surprised to find that only 4-7% of patients feared losing their jobs due to TB diagnosis, considering that around half of the patients were unemployed at the time of their interview.

Patients' **health-seeking behaviors** influenced the time it took to reach the TB diagnosis but not the time it took to treatment. Since the exit interview was conducted in facilities where patients were diagnosed and initiated treatment, the time to treatment was similar for all of them (except for some outliers). Findings regarding patients' perceptions of health services included:

- Health-seeking behaviors had a direct impact on the number of days it took to receive a TB diagnosis. A TB diagnosis was provided in six days in government facilities and 42 days if the patient first went to a private provider. Reasons for this delay may be due to private providers' lack of awareness of TB diagnostic standards or lack of compliance

with standards. Even though most (88%) private providers said they received NTP TB training in the last year, provider questionnaire responses showed that these providers did not comply with screening guidelines to conduct an immediate sputum examination on each TB suspect but instead treated symptomatic patients with one or more cycles of general antibiotics. After a patient's failure to respond to one or more cycles of antibiotic therapy, he/she was considered a TB suspect and referred to a government facility for diagnosis.

- More than half of TB patients in both countries said they had received better service in the TB facility than they had expected. In addition, 80% of patients in Bangladesh and 90% in Swaziland were satisfied with the government TB services.
- We could not support the hypothesis of patients' preferences for private providers due to easier access and more convenient working hours to explain why half of TB patients in Bangladesh initially sought care from private practitioners. Instead, we found that patients approached government facilities earlier than private providers once they had symptoms, 45 days versus 81 days, respectively ($p < 0.05$).
- Other factors may play an important role in Bangladesh in motivating patients to seek care from private providers, such as greater trust and a perception of receiving better services. We found that 40% of males initially visited a trained private doctor compared to 32% of females. Similar health-seeking behavior was observed among patients receiving services from untrained "village doctors." Patients, especially females, said they felt more comfortable and trusted more the services received from a village doctor than did males.
- Trust in the provider or facility also played an important role in Swaziland. Besides the distance and transportation costs associated with visiting a health facility, patients were willing to travel longer distances to attend other government facilities where service quality was considered superior.

In addition to TB patient-related delays, the health system contributed to the overall TB delay. We did not assess providers' compliance with TB diagnosis standards as this was analyzed in another USAID-TB CARE II study² but we measured other factors influencing health systems delay:

- The number of visits that were required to obtain the TB diagnosis: 90% of TB patients were diagnosed within three or four visits (74% with the same provider) in Bangladesh. Sixty percent of patients interviewed in Swaziland were diagnosed within three or four visits (only 15% with the same provider). The high rotation of health personnel in Swaziland may have contributed to a higher diagnostic delay of 31 days compared to 18 days in Bangladesh.
- Health providers said they received laboratory sputum microscopy results in one day in Bangladesh and three days in Swaziland. Nevertheless, the Swaziland health system audit yielded a mean of 1.5 days turnaround time.
- Initiation of TB treatment after TB diagnosis seems to be almost immediate: within one–two days in Bangladesh and two–three in Swaziland. The Swaziland health system audit revealed that 35% of the patients initiated TB treatment before the sputum results were received, based on their clinical symptoms (two-thirds) and X-ray findings (one-third). Most providers (80–85%) in both countries said they requested X-rays in addition to sputum smears for TB diagnosis.
- An issue observed in both countries was the ability to obtain TB drugs from pharmacies and drug outlets without a medical prescription. These countries have a regulatory framework for TB drugs but are not fully enforcing it.
- TB managers did not report any major stock out regarding distribution of TB drugs. Only one out of seven district managers interviewed in Swaziland said they suffer from one month of stock out of TB drugs due to the distributor issues that affected several patients.

General recommendations to address TB patient delay

Before countries focus on improving their overall TB detection and treatment systems, it is advisable to conduct a baseline assessment to determine the type of delay (patient and/or health system) and what causes influence it in each country. The assessment could be conducted using and adapting the tools (four questionnaires for TB patients, TB providers, TB community leaders, and TB managers) that were designed to conduct the assessment reported here. They can be accessed in the USAID TB CARE II portal: <http://tbcare2.org>.

Interventions to improve symptom recognition and reduce stigma

- *Based on the survey results, a communication and awareness campaign should be designed and tailored to address those factors identified as the cause of delays and reach identified populations (vulnerable or at-risk populations). Since stigma is a deeply rooted social problem, advocacy and behavior change communication campaigns are needed to influence and modify community perceptions and attitudes toward TB infected individuals. Communication and awareness activities should be designed with a patient-centered approach, including patient rights considerations (Patient Rights Charter) to modify patients' health-seeking behaviors and reduce TB delays.*

Interventions to improve patients' access to TB services

- To reduce the economic burden associated with TB diagnosis and the impact of TB on patients' lives, it will be appropriate to identify vulnerable communities and provide them with **economic support** for transportation to TB diagnostic centers. Assistance could include food packages and the possibility to stay overnight if necessary. Strong advocacy with health authorities and providers will also be necessary to **eliminate user fees for diagnosis** in public services. In instances where patients are required to pay for certain services under the NTP, those user fees need to be transparent and well publicized, and a mechanism needs to be put in place to discourage providers from receiving payments under the table. To reduce patients' costs of TB treatment, **treatment also**

2 Assessment of Provider Compliance with TB Evidence-based Standards and Guidelines. Bangladesh. URC. Forthcoming.

needs to be streamlined so that only essential TB medications are included and unnecessary drugs and supplements are avoided.

- Create or scale up **community TB support groups**. These groups, which typically consist of 3-10 individuals with TB, are organized by TB DOTS workers and meet weekly to offer emotional/social support, arrange transportation to clinics, encourage treatment adherence, and monitor treatment side effects. They also encourage TB screening among other at-risk community members.

Interventions to reduce TB health system delays

Scaling-up public-private mix programs that include formal and informal health providers will maximize access of TB suspects to high-quality TB diagnosis and treatment services, particularly in countries where private practitioners and informal practitioners are often the first point of contact in the health system for people with symptoms. The WHO global TB report 2011 (32) shows that non-NTP public and private care providers contributed about 20%–40% of the notified TB cases in 20 countries, including 10 high TB-burden countries.

TB management guidelines need to be developed for informal health care providers including an algorithm for identifying TB suspects and referrals. Education and skills building on TB screening and referral could be achieved through group training, distribution of printed information, jobs aids, or a CD ROM if the necessary supportive structure is in place.

To scale up such initiatives, additional consideration needs to be given to: 1) Incentives for providers, 2) certification and accreditation after appropriate training is received in TB management, 3) regulatory approaches such as mandatory TB case notification for all type of providers, 4) restricting access to anti-TB drugs to collaborating care providers, and 5) a functional monitoring and supervisory system.

If a country's health system allows, its TB program should explore options for the introduction of **health insurance schemes** where TB diagnostic and treatment fees are reimbursed. Promoting cooperation with existing social welfare programs, community funds, micro health insurance, and other innovative community and financing initiatives is also essential.

Activities targeting patient related delays need to be closely coordinated with activities targeting improvements in health system capacity (33) to more rapidly and efficiently diagnose and initiate patients into treatment. These may include: 1) facilitating access to health services through more convenient schedule and providing transportation support to poor population; 2) building the capacity of health workers, particularly in primary care settings, to identify and screen TB suspects; 3) improving provider counseling skills to effectively communicate with patients, and build a relationship based in trust and respect; 4) provide patient support through community based services and awareness; 5) ensuring that diagnostic services (smear and/ or culture and molecular tests plus chest X-rays, as appropriate) are provided to all those with signs and symptoms suggestive of TB; 6) identifying the appropriate combination of diagnostic tools to be introduced in the given national programs/ health services and 7) integrating HIV- TB diagnosis and treatment centers.

Activities to reduce TB delays should be patient centered and designed within the collaborative framework of the TB Patient's Right Charter (44). The Charter emphasizes people and TB patients' right to have knowledge of their disease, how it was caused and how it can be diagnosed and cured. Knowledge will empower people and communities to take an active role in recognizing their symptoms, approaching health services, and promoting active participation in supporting TB patients. Patients have the right to be treated with respect and dignity, including the delivery of services without stigma, prejudice, or discrimination. Patients that trust their health provides will seek attention promptly and will adhere to the TB treatment resulting in reduction of TB delays, improved cure rates and a reduction of TB transmission.

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Annex 1

Bangladesh: Recommendations to Reduce TB Patient Delay

The leading cause of TB delays identified by patients, providers, and managers in Bangladesh is patient failure to promptly recognize TB symptoms as a serious disease that requires seeking care from a formal health care setting. To improve patient TB symptom recognition and demand for TB services, the following would be recommended:

ACSM activities

- Messages focused on patients' symptom recognition and availability of TB diagnosis and treatment services in government (NTP) facilities need to be widely distributed, since 90% of TB patients interviewed said that they did not seek immediate care because they were not aware of the severity of the disease or were not aware that TB services could be obtained for free in the public sector. We found that 38% TB patients said they watch TV regularly, 75% listen to the radio, and 50% read the newspaper regularly. Distribution of TB ACSM messages through the mass media is expected to increase awareness in the population.
- Increase gender-based outreach and communication, as the study found that more than twice as many males were being treated as females (55 males versus 25 females). Our sample size is too small to allow us to generalize conclusions, nevertheless similar findings were reported by other studies (26) and in the WHO Global TB control that reports a ratio 2:1 male:female (2005). Women in general have lower education, limited decision making authority (need husband/relative's permission to access health care), and fewer economic resources to pay for health services and transportation, poor nutritional conditions and vulnerability to other health conditions therefore should be considered vulnerable population for TB.
- The study also found that half of interviewed female TB patients had misconceptions associating TB with negative childbearing and pregnancy outcomes. ACSM activities will have a higher and more targeted impact on this population group if they are integrated

with other services, such as antenatal care, reproductive health visits, children's health, and Expanded Program on Immunization (EPI) activities.

Health-seeking behavior

Groups with lower social status and marginalized populations rarely sought to access health services, instead they tend to rely on healers and local paramedics. We found that 20% of females initially sought care from pharmacists/healers, compared to 4% of males. Health-seeking behavior significantly impacted the number of days to achieve a TB diagnosis. We found that patients were diagnosed with TB in six days when they approach government facilities, 42 when they initially sought care from private practitioners, and 15 when they first approached "village doctors"/pharmacists ($p < 0.05$). In addition to the communication and awareness campaign, we recommend:

- Continue training and involving private providers (private doctors, pharmacists, village doctors, healers) in TB screening and prompt and appropriate referral to NTP services. Promote TB pre-service training in medical colleges to reach out to practitioners public and private.
- Strengthen functional referral linkages with a recording system between private practitioners and public health facilities.
- Increase advocacy and involvement of local community leaders, school teachers, religious institutions, and private practitioner associations to improve early referral of patients with pulmonary symptoms and encourage demand for TB services in the community.
- Since at least 20% of females seek initial care for TB symptoms from community pharmacists, regulations guiding TB drugs sales only through authorized prescription from certified providers should be enforced. This measure is expected to encourage patients to seek treatment from accredited providers who are more likely to follow TB treatment guideline, and to increase cure rates and reduce the risk of MDR-TB.

Stigma and discrimination

One-third of the TB patients said that they were discriminated against because of TB; in general respondents (male and females) said that male TB patients suffer more discrimination than females when diagnosed with TB, especially in the work environment. Possible interventions include:

- Conduct advocacy meetings with policy-makers, local chambers of commerce, employers, and workers associations to promote and ensure that TB patient workers' rights are respected.
- Develop and promote TB community support groups to provide a reassuring environment to counter stigma and reduce negative or harmful attitudes towards TB patients among family members and the community. NTP managers said that support groups are functioning in some districts but they will need further support to be scaled up throughout the NTP network.
- Increase community awareness of TB transmission and infection control to encourage positive behavior towards TB patients (lessen fear of transmission).
- Increase platforms for engaging cured TB patients to provide examples of reintegration in social activities and into the work market. They will also motivate TB patients to improve adherence and reduce loss to treatment.

Limited access to quality health services

NTP managers are aware that vulnerable populations such as those living in rural areas, the very poor, women, and children experience increased TB delays; nevertheless, only 37% of managers interviewed said that they are taking any actions to identify and design interventions to improve TB access for vulnerable groups.

- An effort should be made to identify and map populations with difficult access to health services to determine how to better allocate resources and plan strategies to improve access to quality health services. Although prisons and other enclosed communities were not studied, these groups should also be prioritized to improve TB case detection and treatment, including referrals for treatment upon return to the community.

- Develop regular support mechanisms at the community level to overcome possible access barriers in some patients such as costs of transportation and other indirect treatment costs. Community patient support groups should be encouraged to organize small fundraising events to provide and arrange transportation to clinics. Expansion of mobile sputum collection units or periodic community TB screening and sputum collection points might also be considered. The TB program should explore options for social insurance schemes where extra-pulmonary (EPTB) and sputum smear negative diagnostic fees are reimbursed. In instances where patients are required to pay for certain services under NTP, user-fees should be transparent and well publicized, and mechanisms should be enforced to discourage unnecessary out-of-pocket payments.

Health system strengthening

Activities targeting patient delays need to be closely coordinated with activities targeting improvements in health system capacity to more rapidly and efficiently diagnose TB and initiate treatment.

- About half of the government providers said that they do not provide education and counseling on HIV for TB patients. In 2007, the MOH initiated the integration of TB/HIV collaborative services within the National Health Service, but the initiative was implemented in only a few districts and was subsequently discontinued. A major barrier identified was the lack of coordination of activities between NTP and the National AIDS and STD Program.
- Only 37% of government providers said they have a system to evaluate patient satisfaction to address patient needs and complaints. It should be considered community sessions to assess/identify customers' perspectives on the quality of care and assessing patient satisfaction through periodic focus group discussions and running semi-structured questionnaires.

Annex 2

Swaziland: Recommendations to Reduce TB Patient Delay

We found that TB patient delays were the major cause of overall TB delays in Swaziland, as most patients wait an average of two months from the onset of symptoms until seeking care at a health facility. The leading cause of patient delay was the lack of perceived severity of the symptoms to seek medical attention.

ACSM activities

- Focus on TB symptom recognition and awareness of the insidious clinical presentation in the initial stages of TB, especially for patients who are HIV positive. More than half (60%) of TB patients interviewed said that they didn't seek immediate care because they were not aware of the severity of the disease. More than half had no cough, so TB was not suspected. The fact that the co-infection rate for HIV among TB patients is 84% (NTP report, 2009) could explain the insidious and unspecific symptomatology in Swaziland's TB patients that sometimes manifests as merely a slow syndrome with minimal inflammatory reaction.
- TB suspects and communities should receive tailored messages from multiple sources. Since the media has the potential to reach to a wider population, including those who are difficult to reach, an effort should be made to increase information disseminated by radio and TV. In the sample, 65% of TB patients said that they received information about TB before they were diagnosed. Of those, 47% said they received TB information in the health centers, 26% through informal channels such as family or friends, and only 17% through the media. Other sources of TB-related information cited (9%) were community meetings, support groups, other TB patients, the workplace, and school.

Stigma and discrimination

TB community leaders reported discrimination and stigma due to the high association between TB and MDR-TB with HIV, and this made patients choose not to disclose their TB or MDR-TB status to avoid isolation.

- Additional advocacy meetings and coordination strategies between policy-makers, employers, and workers associations (unions) will promote and ensure that TB patients' workers' rights are respected. There is no regulatory framework to protect TB patients from losing their jobs due to absence related to TB treatment. According to the labor laws, an absence from work of 14 days will lead to half paycheck cut or eventual dismissal. Such a policy is suitable for shorter term illnesses than TB in which patients maybe need to refrain from working until infectiousness is halted to avoid transmission in the workplace.
- Expansion of TB community psychosocial groups should be promoted to reduce stigma and isolation. The groups can also organize small fundraising events to provide for patients' needs during treatment, such as childcare, family support if unemployed, etc. Depending on the psychological status of groups' members, such as members with depression, it may be appropriate to provide specialized support from a social assistant or psychologist. The participation of cured patients in the support groups as well as in community social events will help reduce the stigma associated with the disease by providing successful examples of reintegration in social activities and into the workplace.

Limited access to quality health services

According to study respondents, the primary access barrier is the time and cost associated with transportation to health services. Even though 73% of TB patients interviewed live in urban settings, 42% used public transportation to reach the health facilities, spending approximately one hour and a half and paying the equivalent of US\$4.30. Only 21% of patients could walk to a health facility.

- Expand access to services in hard-to-reach or underserved areas through:
 - Mobile clinics: to reach out to those communities far from or with difficult access to the health facilities
 - Community sputum collection points: supported by a sample transportation system
- Address out-of-pocket costs: Unexpected out-of-pocket costs for diagnostic and treatment services (such as EPTB and SS- diagnostic and treatment fees) hinder access to services, especially for the most vulnerable patients. In instances where patients are required to pay for certain services, user-fees should be transparent and well publicized and mechanisms to discourage under the table payments to providers should be enforced. Mechanisms for providing reimbursements for indirect out-of-pocket costs, including transport and social support packages, should also be explored.

Address causes of health system delays

- High rotation of personnel in health facilities: At least 64% of patients required more than one visit to obtain a TB diagnosis, although only 15% of patients said they had repeat visits with the same provider. The NTP should advocate with nurse managers and clinics directors to mitigate the impact of rotations on the TB program. Frequent rotation of nurses within departments, in some cases as often as every 6 months, does not give sufficient time for nurses to master TB control skills and knowledge such as TB suspicion, investigating a TB suspect, diagnostic methods for TB, delivery of health education, and adherence and compliance to treatment.
- Asymptomatic TB: The tremendous burden of HIV/TB in Swaziland makes it difficult to recognize TB in the absence of the classic symptoms such as productive cough. The new protocols recommend TB screening for all adults and adolescents living

with HIV and consider all people with at least one of the following symptoms suspects: current cough, fever, weight loss, or night sweats. Raise awareness among health care workers on the few, unspecific symptoms that a TB patient may have initially. HIV-infected people are especially vulnerable and need to be screened for TB during every clinical consultation (34).

- Supplies and infrastructure: NTP managers reported that almost all of study regions had lab supply shortages in the past year (one district suffered a stock-out for more than a month), and three out of seven districts interviewed lacked a facility to perform microscopy. The procurement mechanism for drugs and diagnostics supplies should be strengthened to ensure that supplies arrive on time and products do not expire on the shelves.
- Data: The health audit found that some inconsistencies in the reporting and recording of data. Workshops should be organized for providers to improve and data recording practices.

USAID TB CARE II PROJECT

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