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# 6 From Cough to Cure Strategic Approaches to an Age-old Disease

## The Challenge

More than 20 years ago the Academy conducted its first campaign against the stigma of illness.<sup>1</sup> The scenario should be familiar:

Research showed that *fear of ostracism* was the primary reason young men at highest risk for the disease did not seek treatment even when their symptoms were debilitating. Those being treated said the greatest burden of their illness was rejection by family and community. They felt themselves to be a danger to loved ones and were overwhelmed by emotional isolation and guilt. Many healthy people attributed the disease to “aberrant” behavior. Sixty percent of those interviewed felt that if they became infected they would be rejected by their families.

The country was Honduras. The disease was tuberculosis. AED conducted a campaign to change both attitudes and behaviors. Results were published in *Medical Anthropology*.<sup>2</sup> (See box on the next page.)

*Stigma* is now a target of many public health campaigns because of its insidious role in the HIV/AIDS pandemic. But HIV/AIDS has also brought about a global resurgence of tuberculosis,

<sup>1</sup> HEALTHCOM I, funded by the U.S. Agency for International Development.

<sup>2</sup> Jose Ignacio Mata. (2005) *Integrating the client's perspective in planning a tuberculosis education and treatment program in Honduras*. *Medical Anthropology*. Volume 9, Number 1. P. 57-67



including multi-drug resistant strains. One-third of HIV/AIDS-positive people are co-infected with TB.<sup>3</sup> In sub-Saharan Africa, the TB infection rate is increasing at about 10 percent annually. Nearly three million people die of tuberculosis every year.

TB, like virtually all other health emergencies, however, has been overshadowed by HIV/AIDS in terms of both political will and funding. And while researchers have investigated the social and individual determinants of behaviors among myriad

### *Understanding and Undermining the Stigma of TB*

In 1983 AED worked with the Ministry of Health in Honduras, with funding from USAID, to investigate the reasons for low rates of both careseeking and appropriate treatment for TB. Researchers interviewed patients, their families, the general public, and health providers. They uncovered several key issues.

Most people thought TB was incurable. They also did not understand that a person being treated is no longer contagious. Patients didn't understand the importance of completing treatment and often stopped going to the health center when their symptoms improved—partly to avoid their neighbors' suspicions. At the same time, health workers often failed to recognize the key sign of TB: a cough lasting more than 15 days. They also "lost" many new cases because they could not explain to patients how to provide a sputum sample, or motivate them to return for results.

AED helped the Ministry conduct a campaign for several audiences focusing on three issues: 1) when to seek treatment; 2) how to treat the illness and support the patient (including facts about transmission); and 3) how to take a sputum sample. After just two months into the campaign, which relied primarily on radio, 75 percent of patients interviewed recalled key messages, as did 61 percent of their families and 45 percent of the general public. Between 50-60 percent of auxiliary nurses also remembered critical information.

An evaluation in two health regions showed that exposure to the campaign was strongly related to both correct knowledge about TB and likelihood of practicing specific positive behaviors. More than 90 percent of those who heard the messages understood that TB can be cured if it is treated early. Accepting this simple concept was critical to both prompt careseeking and diagnosis, and to overcoming *fears about TB* as well as *fear of people* infected with it.

groups at risk for HIV/AIDS, tuberculosis is still being fought primarily via a "medical model." The social stigma surrounding TB—increasingly complex due to its link in the public's mind to HIV/AIDS—is just one of the factors to be tackled.

## The Client's Perspective

Over 180 countries now conduct public health programs called DOTS – or "directly observed treatment, short-course." Patients receive their medications *under observation* for a full six to nine months, increasing the chances they will be cured. Around 82 percent of patients who enroll in DOTS are treated successfully.<sup>4</sup>

At the same time, only about 50 percent of TB cases worldwide are actually detected.<sup>5</sup> Even within areas served by DOTS, detection has been constant at about 52 percent for the last ten years.

Providing drugs and good public health services are essential, but clearly not enough. National programs must understand why some people with symptoms do not seek care, and why others drop out. They must understand the *client's perspective*.

The Stop TB Partnership<sup>6</sup> and others have asked the Academy to help incorporate systematic social and behavior change strategies into TB control efforts. In 2004, AED began working to provide an overall framework, tools, and training programs to *change the basic model* on which national TB communication programs are built.

## Examining Key Determinants

The first step was to find out what countries have already learned about barriers to careseeking and successful treatment. Do programs face common problems? Are key obstacles related to knowledge? To the logistics of treatment? To family or social factors? How have programs tried to confront these barriers?

<sup>3</sup> *The Global Burden of Tuberculosis*. USAID. [www.usaid.gov/our\\_work/global\\_health/id/tuberculosis/burden.html](http://www.usaid.gov/our_work/global_health/id/tuberculosis/burden.html).

<sup>4</sup> *World Health Organization*. 2005. *Global Tuberculosis control: Surveillance, Planning, Financing*. Geneva: WHO

<sup>5</sup> *Ibid*. Data are for 2003. This falls short of the goal set by the World Health Organization for 2005 of 70 percent case detection. WHO's target for treatment success in 2005 was 85 percent of smear-positive cases (which compares more favorably with the current rate of 82 percent).

<sup>6</sup> *The Stop TB Partnership*, established in 2000, is a network of donors, governments, and nongovernmental groups and others committed to eliminating TB.





*Women delay treatment longer than men, and are also offered sputum tests less often than men.*



*In Afghanistan, new systems must be found to make services and medicines accessible.*

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dropping out as women. Stigma appears to affect the speed of diagnosis, but not adherence to treatment or likelihood of dropping out.

Insights such as these, though very general, provide countries with hypotheses to test as they plan their own audience research. They also provided AED with the basis for designing a fundamental diagnostic tool. (See figure 6.1.)

## Tools and Training for Country Implementation

The review highlighted six critical signposts on the path every patient must take from the time he or she develops the tell-tale cough of TB to the time s/he can be considered cured. It also revealed an array of common barriers at each of these junctures. Barriers, in turn, tended to fall into four categories—relating to the individual, to his or her social group, to the health system, or to the external environment.

AED’s behavioral team created a simple framework, *From Cough to Cure*, that incorporates these different levels of analysis. They also designed research guidelines to help TB control programs unravel

the individual, social, and system factors affecting both diagnosis and treatment behaviors in their populations.

These tools have provided the basis for a new kind of training approach. Instead of focusing immediately on how to produce posters, pamphlets, and radio programs, TB program managers and their communication counterparts consider how to design interventions that will actually address the reasons behind their clients’ behaviors.

At the invitation of the Pan American Health Organization, AED has conducted capacity building for the national TB programs in 12 Latin American countries.<sup>7</sup> The first workshop took place in Bolivia in 2005. Many of these countries had received grants from the Global Fund for AIDS, TB, and Malaria. A second workshop was held to train consultants who will provide technical assistance to National TB Programs throughout the region. With funding from Stop TB, AED is also working with PATH to create four standardized training modules on applying systematic behavior principles to the design of advocacy, communication, and social mobilization activities.

## Focus on Tanzania, Afghanistan, and Gender

AED’s primary effort has been to give countries the tools they need to carry out their own assessments and strategies. But two countries have also received in-depth technical assistance.

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<sup>7</sup> AED’s ongoing assistance is funded by USAID through the RPM+ Project.

## *The Gender Factor*

In 2001, the Academy carried out a study for USAID in Tanzania to understand whether, and how, gender affects careseeking and treatment of TB.

Researchers interviewed 1,429 new smear-positive TB patients as well as Ministry and health facility staff and community members. They also examined treatment outcomes of more than 2,300 patients and the records of 8,000 new TB “suspects.”

The study revealed that women delay treatment longer than men for several reasons. The many months of treatment that require weekly visits to a health facility put special burdens on women. They may have to ask for transportation money and are often reluctant to use family resources on themselves. Domestic and child care responsibilities may also force them to ask for help from neighbors when they go for treatment. A woman’s illness is always a family and a social issue, rather than a private one.

Women in this study were more apt to seek care first from traditional providers. They took on average 14 weeks to visit a health center; those who believed their symptoms were caused by witchcraft (and therefore consulted traditional healers) took 24 weeks to visit the health center. In many communities, prompt treatment for women may require working with these alternative providers.

At the same time, in Tanzania, fewer women default from treatment than men do. They therefore have a better cure rate than men. Looking only at this statistic, however, can obscure the greater obstacles women face and the importance of special strategies for reaching them.

In Tanzania, the Academy conducted a study for USAID to look specifically at the role gender differences may play in diagnosis and treatment rates.<sup>8</sup> (See box.) Research in three districts with high TB notification rates revealed valuable insights about the “gender factor.” It also confirmed a trend, noted in other countries, of patients receiving critical information from former TB patients, rather than their health providers. Former patients represent a valuable and usually untapped communication channel.

The Academy is also assisting USAID and the National Tuberculosis Institute of Afghanistan to develop a behavior change strategy to improve both detection and treatment completion rates.<sup>9</sup> Afghanistan has the highest burden of TB in the Eastern Mediterranean Region. Even in the 46 percent of districts that are served at least partially by DOTS, case detection is just 23 percent of estimated cases. In a country such as this where the majority of poor people live in remote areas where roads are inaccessible for months of the year, new systems must be found for supplying medicines. Community decision making and community support for these systems, and for TB patients themselves, will be critical to better disease detection and control.

It is too late to reach WHO’s ambitious goal of 70 percent case detection in high burden countries by the close of 2005. But a new understanding of patients’ perspectives, and better sharing of lessons across countries, will help make targets feasible in the decade to come.■

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<sup>8</sup> *The research was funded by USAID through the SARA project and conducted with the National Tuberculosis and Leprosy Programme of the Ministry of Health in Tanzania, together with HealthScope Tanzania. Sub-regional meeting.*

<sup>9</sup> *The Academy is providing assistance through USAID’s REACH Program.*