Social Assessment Influences Design of the India Tuberculosis Control Project

The government of India is implementing a new strategy to arrest the spread of tuberculosis (TB) in the country. The World Bank-funded Tuberculosis Control Project, one part of this endeavor, used social assessment (SA) as an "umbrella" approach to collect and analyze the socioeconomic data needed for project preparation and design; create an innovative strategy for stakeholder involvement in project planning and activities, including a tribal peoples' action plan; and develop appropriate social indicators for the project.

India's Struggle to Control TB

The burden of TB in India is staggering. More than 1.2 million cases are reported every year, and the annual mortality rate is around 500,000, nearly one-fifth of annual TB deaths worldwide. Estimates indicate that up to 50 percent of India's population is infected with TB, of which approximately 10 percent will develop the disease. Without appropriate intervention, cumulative TB deaths during this decade could be as high as 5 million.

In 1992 the government of India initiated a rigorous evaluation of its thirty-five-year-old National Tuberculosis Control Program. Based on its findings, the government and the World Bank, with technical support from the World Health Organization (WHO), prepared the Tuberculosis Control Project to revise the program's strategy. The project was designed on the basis of fifteen pilot projects, financed by an advance from the Project Preparation Facility, that tested a new strategy for TB control. The updated approach encourages directly observed treatment—that is, TB patients take prescribed drugs in the presence of a health care worker or other trained person who observes and records the treatment—and it focuses on infectious patients to prevent further transmission of the disease.

SA Designed to Meet Several Project Planning Needs

The greatest obstacle to overcoming TB is that patients do not complete their treatment. Project planners knew that to address noncompliant behavior they would have to comprehend the underlying influences on the behavior, such as people's understanding of the disease and the relationship between patients and service providers. The Bank team recommended SA as way to conduct the necessary social analysis and to formulate a key component of the TB Control Project: a comprehensive strategy for information, education, and communication (IEC). The SA's social analysis objectives were to:

- Identify symptomatic patients in selected households and obtain information about their perceptions and interpretations of their symptoms, their knowledge about the causes and transmission methods of and cure for TB, and their health seeking behavior.
- Identify individuals who have been treated for TB to determine the type and duration of treatment prescribed, their experience with health providers, and their current health status.
- Assess the distribution, capacity, and accessibility of health facilities in the

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study areas and obtain information about health personnel’s knowledge of, attitudes toward, and perceptions of TB and TB patients.
- Determine the extent of patients’ use of public health care facilities, traditional healers, and other health care providers
- Determine why some patients failed to complete their course of treatment.

The main process objective of the SA was to involve key stakeholder groups, especially tribal populations for whom the Bank requires a specific plan of action, in the design and implementation of the IEC strategy (see box 1) and to build and use local capacity to carry out the SA. The final objective of the SA was to use the data collected to develop appropriate social indicators for the project.

SA Methods

The SA team focused on two different population groups, urban slum dwellers and rural tribal populations, and hired two research organizations to organize data collection and analysis. FEMCONSULT, a Dutch organization, worked with Indian researchers to undertake an in-depth exploration of TB-related issues among slum dwellers in Bangalore, Hyderabad, Jaipur, Lucknow, and Pune. At the same time, the Foundation for Research and Development of Underprivileged Groups, an Indian organization with experience working in tribal areas, examined the sociocultural factors related to TB among tribal populations in selected districts of Bihar, Gujarat, Himachal Pradesh, and West Bengal. Each of the research teams combined both qualitative and quantitative data collection methods (see the table on page 3); however, the main focus of the research was on qualitative data to uncover the reasons for patient and provider behavior.

Findings

The two studies found that in both urban slum and tribal contexts, poverty, patient perceptions about providers, and the stigma attached to TB are the three factors with the greatest impact on beliefs and practices in connection with TB. Ineffective communication between service providers and patients was also found to discourage people from seeking treatment for TB.

Poverty

Among both slum dwellers and tribal populations, the main reasons why many patients do not complete their treatment are related to poverty, namely:

- Lack of funds to pay for transportation, leading patients to rely on the closest source of treatment, even though it may be expensive or ineffective
- Lack of funds to pay for medicine, leading to the interruption of treatment
- Inability to sustain the costs of treatment by private practitioners
- Inability to sustain the loss of income associated with having to take time to collect medicine, and in the tribal areas,
the inability to sustain the loss of income of those who have to accompany women to collect their medicine. 

- Inability to sustain treatment following migration in search of work 

- Inaccessibility of primary health centers in rural areas, especially during bad weather and nonwork hours. 

The SA found that those who do not abandon their treatment either have enough money to complete the course or, if they do not have money, they have access to a competent nongovernmental organization (NGO) or local government facility that provides free treatment. 

Critical gender-related findings included that prohibitions against women's control of their own activities and family finances were significant factors in their inability to earn or have access to money to comply with treatment regimens. Similarly, women's tendency to wait longer than men before adopting a "sick role" and seeking help leads to severe TB cases and higher mortality among women.

**Service Providers**

The three main types of TB service providers are government, NGO, and private practitioners. Most people with symptoms of TB first seek out private practitioners because they are conveniently located, but also because patients

- Believe that they will treat them more respectfully and with more understanding than other health providers 

- Perceive the free medicines government clinics provide to be inferior to those available from private practitioners or pharmacies

- Value the greater privacy afforded by private providers.

Relatively few NGOs in India care for TB patients. However, the SA found that people in urban areas tend to value the NGOs more highly than they value government health providers and to view NGO physicians as more caring and dedicated.

Public services are the most commonly sought among tribal populations, for whom NGOs or private services are not readily available.

Although popular among TB patients because of privacy and convenience, especially in urban areas, private service providers had no system for patient follow-up; did not ensure that patients had the money or means to purchase the necessary treatment; and recommended more than sixty different types of treatment, only a couple of which are considered effective by WHO standards. As a result, many patients who first visit private physicians end up seeking treatment in the government sector, usually when the disease is well advanced and more difficult to treat. The SA also found that, despite patients' preferences for private treatment, government facilities that offered directly observed therapy cured more people and had the largest number of compliant patients.

**Stigma and Secrecy**

The SA found that the stigma associated with TB also prevents patients from seeking treatment, and then from completing it. The stigma was higher among slum dwellers than among tribal populations, and within the urban population, it has an inverse correlation with level of education. In areas where stigma was least severe, it affected only females in certain categories, such as unmarried girls and newly married women without children. Women suffer the worst consequences of the TB stigma. Where it is strongest, young women with TB are unlikely to marry, and those already married are sometimes expelled from their homes.

The diagnosis of TB brings such shame to patients in some areas, that even health practitioners will keep the diagnosis secret.
from TB sufferers. Fearing the impact of the news on the patient, the practitioners sometimes wrongly inform them that they have another ailment, such as asthma. Consequently, these patients do not complete their treatment. The general culture of secrecy leads to erroneous beliefs, such as that TB is spread through food, clothing, and heredity, and thus that TB patients and their belongings should be physically isolated.

**Communication**

The most effective form of communication about TB has been word of mouth through compliant and cured TB patients who spread information about TB and treatment facilities to their families and neighbors. This helps other infected people seek treatment initially; however, they are most likely to complete treatment if they receive information and support from health providers, such as through directly observed therapy. A significant finding for the tribal populations in this regard is that most physicians who are newly posted to serve them neither speak the local language nor understand the culture in which they are working.

Similarly, a major factor deterring patients from using government facilities is that they do not like the way service providers treat them. Patients commonly reported that providers blame and scold them for noncompliance instead of explaining the implications of interrupting treatment and finding ways to help them take their medicine regularly.

**Impacts of the SA**

The SA helped the project team
- better understand the major obstacles to patient compliance with treatment regimens,
- identify the main problems associated with the provision of services by private and public practitioners,
- uncover the key hindrances to effective communication between patients and providers.

With this information the project team was able to prepare a more focussed communications strategy, a new approach

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**Box 2. SA Produces Social Indicators for the India TB Project**

The basic indicator of project effectiveness is the percentage of patients cured. However, other process-related social indicators include the following:

**Economic**

- Minimum cost of transportation to treatment centers (should be affordable to patients and symptomatic people)
- Minimum lost wages in coming to treatment center (cost should be within comfortable economic limits for patients and their families)

**Programmatic**

- Treatment and diagnostic sites readily accessible to patients in catchment area
- All drugs continuously available at treatment center
- Convenience of patient flow within and between facilities
- Time spent by patient in diagnostic facility, treatment facility, in transportation between facilities
- Patient information-obvious and comprehensible to illiterate patients (oral or pictorial)
- Explanation provided and patients understand how to take medicines and duration of treatment
- Explanation provided and patients understand that feeling well is not correlated with being cured
- Information is repeated about how and how long to take medicine (number of times, occasions, and health providers)
- Patients agree that doctor has thoroughly examined them
- Patients agree that doctor is interested in how they feel and in their recovery
- Patients have confidence in doctors’ authority
- All health care staff display a modicum of respect for patients

**Social**

- Reduction of TB stigma
- Patients report neighbors and relatives still willing to converse with them and visit them
- Increase in initial visits to TB treatment centers
- Decline in percentage of false names and addresses given to treatment centers
- Increase in percentage of TB patients reporting that doctors have informed them that they have TB

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To involving private physicians in TB control, and a more appropriate way to measure project effectiveness and outcomes (see box 2).