REPORT SERIES No. 3

Social, Economic and Behavioural (SEB) Research

Gender and tuberculosis: Cross-site analysis and implications of a multi-country study in Bangladesh, India, Malawi, and Colombia

Cross-Site Analysis
Mitchell G. Weiss
Christian Auer
Daryl B. Somma
Abdallah Abouihia

Field site investigators
Julia Kemp
M. Shaheed Jawahar
Fazlul Karim
N.L. Arias

UNICEF/UNDP/World Bank/WHO
Special Programme for Research & Training in Tropical Diseases (TDR)

Gender and tuberculosis: Cross-site analysis and implications of a multi-country study in Bangladesh, India, Malawi, and Colombia

Cross-Site Analysis

Mitchell G. Weiss, MD, Ph.D.[1]
Christian Auer, Ph.D.[2]
Daryl B. Somma, MPH[3]
Abdallah Abouihia, MSc[4]

Field site investigators

Julia Kemp, Ph.D.[5]
M. Shaheed Jawahar, MD,[6]
Fazlul Karim, MPH[7]
N.L. Arias, MSc[8]

[1] Professor and Head, Department of Public Health and Epidemiology, Swiss Tropical Institute, Basel, Switzerland

[2] Post-Doctoral Fellow, Department of Public Health and Epidemiology, Swiss Tropical Institute, Basel, Switzerland

[3] Research Assistant, Department of Public Health and Epidemiology, Swiss Tropical Institute, Basel, Switzerland

[4] Research Assistant, Department of Public Health and Epidemiology, Swiss Tropical Institute, Basel, Switzerland

[5] Coordinator, Equi-TB Knowledge Programme, Lilongwe, Malawi; and Liverpool School of Tropical Medicine, United Kingdom

[6] Deputy Director, Tuberculosis Research Centre, Chennai, India

[7] Senior Research Fellow, BRAC Research and Evaluation Division, BRAC Centre, Dhaka, Bangladesh

[8] Scientist, Centro Internacional de Entrenamiento e Investigaciones Medicas, Cali, Colombia

This monograph is an outcome of TDR Projects A00360 (Principal Investigator N.L. Arias), A00361 (Principal Investigator M.S. Jawahar), A00362 (Principal Investigator J.R. Kemp) and A00362 (Principal Investigator A.M.R. Chowdhury)

TDR/SDR/SEB/RP/06.1

Design and cover: Lisa Schwarb
Layout: Jocelyne Bruyère
Cover picture: WHO/TBP/Gary Hampton

Table of contents

LIST OF TABLES

ABBREVIATIONS AND ACRONYMS

AIDS	Acquired immunodeficiency syndrome
BRAC	Bangladesh Rural Advancement Committee
DOTS	Directly observed treatment, short course
EMIC	Locally adapted interview for cultural epidemiology, also known as Explanatory Model Interview Catalogue
FGD	Focus group discussion
GSI	TDR Task Force on Gender Sensitive Interventions
HIV	Human immunodeficiency virus
MCH	Maternal and child health services
NGO	Nongovernmental organization
NTP	National Tuberculosis Control Programme
RNTCP	Revised National Tuberculosis Control Programme (India)
STB	WHO Stop TB Department
TB	Tuberculosis (pulmonary)
TDR	UNICEF/UNDP/World Bank/WHO Special Programme for Research and Training in Tropical Diseases (TDR)
UNDP	United Nations Development Programme
WHO	World Health Organization

ABSTRACT

Although more men than women are diagnosed with pulmonary tuberculosis (TB), more than half a million women die each year from this disease. The higher proportion of male cases consistently reported by TB programmes may accurately reflect a greater prevalence among men, or it may be an artifact of persisting geographic, socioeconomic, cultural, and health service-related barriers that disproportionately affect timely diagnosis and treatment in women. Despite notable achievements in expanding and implementing directly-observed treatment, short course (DOTS) programmes over the past decade, evidence indicates that gender-related barriers and questions about their magnitude and nature persist. Gender differentials can occur at different levels of TB control, as they affect patients' ability to access appropriate care, undergo examination, submit sputum for microscopic testing, and to initiate and complete treatment. The possible influence of gender on TB and TB control needs to be considered (Somma et al., 2005). The WHO/TDR-sponsored research presented in this report addressed practical questions about the role of gender in TB and TB control in four low- to middle-income countries of Asia (Bangladesh and India), Africa (Malawi), and South America (Colombia).

Objectives

The objectives of the multi-country study were as follows:

- to document sex differences in key aspects of TB control;
- to identify gender-specific barriers to early case detection, appropriate treatment, adherence, and cure;
- to compare and contrast findings from studies in Asia, Africa, and South America; and
- to recommend policy and interventions for enhancing the gender sensitivity of TB control programmes.

Methods

A multi-methods approach guided plans for six components of the research at all four sites:

- A situational analysis of health-services infrastructure and TB control programmes was undertaken at the outset.
- Focus group discussions examined community views of vulnerability to acquiring TB, signs, symptoms, and the social impact of TB, perceived causes, and both common and appropriate help seeking.
- Data from patient registers in local TB control programmes were examined to clarify the sex ratios of patients with respiratory symptoms, sputum submissions, smear positivity for TB, treatment initiation, and treatment outcome.
- Patient-provider interactions were observed during collection of sputum and at initiation of treatment.
- TB outpatients were surveyed to identify any gender differences in patient and provider delay to diagnosis and treatment.

- For the cultural epidemiological component, an in-depth, semi-structured locally adapted interview for cultural epidemiology, also known as Explanatory Model Interview Catalogue (EMIC) interview was conducted with male and female patients to describe and compare the distribution of categories of TB-related illness experience, perceived causes, and help-seeking behaviour. Determinants of TB-related stigma and of delay from awareness of symptoms to a diagnosis of TB were analysed with multivariate statistical methods and integrated qualitative analysis of illness narratives.

Results for each component of the study at each site were examined, identifying overall patterns and gender differences, and findings were compared across sites.

Research sites

Functioning DOTS programmes at each site were characterized by the following features: The programme at the site in Bangladesh served a rural community, was operated by a nongovernmental organization (NGO), and included semi-active case finding. The site in India was associated with an urban government-run programme conforming to the guidelines of the Revised National Tuberculosis Control Programme. In Malawi, components of the study were undertaken in rural or urban settings, and the TB control programme in Malawi operated in a setting of hyperendemic HIV/AIDS. The study in Colombia was based in urban clinics, where the programme was undergoing structural changes but was supported by a health insurance system.

Results

Key findings were:

- Case registries showed that fewer female patients with suspected TB were identified in Bangladesh and India; there were approximately equal numbers of men and women in the Malawi registries, and there were more women with suspected TB identified in Colombia.
- Consistent cross-site findings from registry data showed that more women drop out during the course of diagnosis, while men who are diagnosed with TB are less likely to successfully complete treatment.
- Cultural constraints, aggravated by a lack of privacy, that limited women's production of quality diagnostic sputum were specified in focus groups held at two sites (Bangladesh and Colombia). They were also identified in EMIC interviews in Bangladesh and from observations in Malawi.
- Less specific clinical presentations of TB are more common among women (i.e. women have fewer characteristic symptoms, such as blood in sputum).
- Illness caused by TB is a substantial burden upon the emotional and social well-being of people with TB, and the nature of these psychosocial problems is often gender-specific.
- The reported financial impact of illness caused by TB was

considerable, and it was particularly distressing for men who lost income as a result of their illness and for women who lacked access to household resources.

- Stigma associated with having TB was substantial at all sites, and analysis of the determinants of stigma showed that the nature of social disqualification has both common features (such as fear of contagion despite adequate treatment) and locally distinctive features (such as associations with HIV/AIDS in hyperendemic settings). Focus groups at the sites in South Asia emphasized the problems associated with disclosing TB and the difficulties that having TB impose on arranging marriages for women.
- For women, delays in seeking care often resulted from domestic social responsibilities that hinder their accessing limited resources. The reasons for which men delay seeking care typically focused on interference with livelihood activities. Experience in Bangladesh showed that community outreach with semi-active case finding by community health workers may reduce patient delays before first seeking help.
- Provider delay was typically longer for women. The determinants of delay are influenced by gender and may vary across sites. Findings in India showed that seeking help from private practitioners was more likely to delay diagnosis of TB in women. Findings in Bangladesh showed that a system of semi-active case finding that successfully reduces patient delay may still have problems associated with lengthier provider delay.

Implications

Gender-specific and site-specific findings from the four sites have particular practical implications concerning:

- the clinical presentation of TB;
- the social and emotional impact of TB and stigma;
- the organization of health services for TB diagnosis and treatment; and
- minimizing the impact of determinants of delay.

The findings from cross-site analysis of this multi-country study suggest the following implications and recommendations, which constitute key cross-cutting aspects of TB control. They are likely to be relevant in other low- and middle-income countries, and programmes should consider their local relevance.

- Health-care professionals should be trained to consider the possibility of TB in female patients presenting with more atypical symptoms.
- Site studies of TB control programmes are needed to determine the relationship between the prevalence of TB in men and women in communities and that in clinics.
- Clinic policy and clinician practice should be more attentive and responsive to general and gender-specific barriers to obtaining quality diagnostic sputum for smear microscopy. Local conditions should ensure privacy and a well-ventilated space for patients to produce sputum. Programmes should routinely evaluate procedures

for obtaining samples; clinical staff should provide relevant feedback to patients, and a quality-control system should monitor sputum quality in the clinic, with feedback to staff.

- Sex-specific programme monitoring should be incorporated in the routine operations of TB control programmes, documenting and attempting to distinguish sex- and gender-specific clinical presentations of patients with chest symptoms, sputum requests and submissions, diagnoses, treatment initiation, and outcome.
- Health services and DOTS programmes should develop capacities, either directly or through collaboration, to evaluate psychological, emotional, and social aspects of TB illness and to provide locally relevant and gender-sensitive support. Depression and anxiety are general considerations with gender-specific features. For male patients, alcohol and substance abuse should be identified and addressed. Wherever feasible, collaborations with local mental health programmes should be developed or strengthened, enhancing sensitivity to the mental health component of physical health problems.
- Clinical services should minimize the adverse financial impact and disruption of income-generating activities for patients by ensuring local access and convenient clinic hours. The number of visits required for diagnosis of TB and treatment should be kept to a minimum, and patient-friendly DOT options, such as involvement of guardians at home, should be considered.
- Since TB-related stigma is linked to exaggerated fears of contagiousness, health information should make a clear distinction between appropriate public health precautions to minimize spread and unfounded concerns that contribute inappropriately to stigma and the social and emotional impact of TB. Information addressing key aspects of family life and social interactions should be discussed with patients, identifying reasonable and unreasonable precautions to minimize spread.
- Health promotion and information on TB, especially in regions of hyperendemic HIV/AIDS, should clarify the relationship between the two illnesses and their distinctive modes of transmission. Psychological support–where it exists or needs to be developed–should be sensitive to the psychosocial impact of each condition and comorbidity. Liaison between clinical services, continuity of care, and community support should be assured.
- National and local strategies to improve the detection of patients with TB, with particular attention to reducing patient delay for men and provider delay for women, should consider the impact of strategically reorganizing health and community services. Although it is not suggested that simple formulas or uniform recommendations should be applied everywhere, local options for restructuring critical features of health systems from site-specific experience in these studies should be considered. They include planning for

gender-sensitive active or semi-active case finding (Bangladesh). Such restructuring requires evaluation with reference to local settings, health system contexts, experience, and resources.

- Basic epidemiological and cultural epidemiological monitoring with sex-disaggregated data and focused studies undertaken within the programme or by outside investigators should be implemented in TB control programmes. These efforts are needed to identify, counter, and track gender-specific and setting-specific features of TB illness. Assessments should include: (i) patterns of distress in characteristic presentations of TB pertinent to case finding and clinical management; (ii) perceived causes of TB; (iii) the nature, impact, and determinants of social stigma operating in families, communities and health systems; (iv) previous help seeking before coming to a DOTS clinic. Such data should be monitored and analysed with reference to patient and provider delay in identifying cases and starting treatment, and treatment outcomes.

Conclusion

The findings of this multi-country study contribute to a growing body of knowledge and expertise concerned with socioculturally defined gender roles and their implications for TB control programmes. Findings also indicate critical links between the interests of TB control, gender studies, and the sociocultural contexts of poverty, restricted access to needed resources, and interactions between illness and victimization. We applied a multi-methods approach for studying the role of gender, its context, and impact. The cross-site analysis of findings presented in this report identifies implications and suggests specific strategies for improving TB control through gender-sensitive and locally appropriate community action, clinic operations, programme monitoring, and action-oriented research for TB control.

WHO/TBP/Gary Hampton

INTRODUCTION

Global data show that every year more men than women are diagnosed with tuberculosis (TB). In 2002, an estimated 1.6 million people died from TB, that is, 2.8% of global deaths from all causes, the proportion being higher for men (3.5%) than for women (2.0%). Nevertheless, more than half a million women die from TB each year; TB thus accounts for more deaths among women than conditions associated with maternity or breast cancer (1.9% and 1.8% of global deaths) (WHO, 2004a). WHO data on case notifications in 2002 indicate a 74% excess of sputum smear-positive males over females (WHO, 2004b). Reasons for the excess may be that fewer women in the population have active TB, fewer women with TB present to health clinics for treatment, or fewer women with TB who come for clinical care are diagnosed with smear-positive sputum. As these differences are not accounted for by the basic epidemiology of the disease, it is possible that sex differentials in case detection and reporting may in part be attributable to gender-specific barriers and constraints to health service utilization and to diagnosis (Uplekar et al., 2001). TB control programmes need to be informed whether and how the risk of TB varies for men and women, and how gender affects motivation and access to timely health care, diagnosis, and treatment.

This report synthesizes the results of and lessons learned from a four-country study of gender differentials in TB control. The research was motivated by a workshop held in May 1998, organized by the Nordic School of Public Health and co-sponsored by WHO. It concluded that:

- Gender-related differences in access and use of health services exist in many countries.
- Research is needed to identify and address gender-related barriers to utilization of health services for the detection and treatment of TB.
- Gender-sensitive TB control strategies need to be developed to improve case detection and case holding (completion of full course of treatment).

In September 1999, the TDR Task Force on Gender Sensitive Interventions and the WHO Stop TB Department (STB) organized a small meeting of experts who began to develop a protocol to identify gender issues that influence TB control. Following the meeting in September 1999, investigators from well-functioning TB control programmes in low- and middle-income countries were invited to submit proposals to the Task Force on Gender Sensitive Interventions to conduct operational research studies to document sex differences and identify gender issues hindering the efficiency of TB control programmes. Four research sites were selected to participate in the studies. They were the Bangladesh Rural Advancement Committee (BRAC) in Bangladesh, the Tuberculosis Research Centre in India, the EQUI-

TB Knowledge Programme in Malawi, and the Centro Internacional de Entrenamiento e Investigaciones Medicas (CIDEIM) in Colombia. In December 2000, a workshop was held in Geneva with participants from each of these sites to develop a generic research protocol and methodology.

Findings from each of the four country studies have been reported to WHO/TDR and implications considered for TB control programmes at each site. This cross-site report synthesizes findings, extends the analysis, and examines broader implications for gender sensitivity and TB control in other programmes. The primary audience of this report is anticipated to be health researchers, programme planners, and policy-makers responsible for TB control. The report addresses aspects of TB control with reference to a gender-specific barrier framework concerned with the occurrence and basic epidemiology of TB, help seeking and access to health services, diagnosis and initiating treatment, treatment adherence, and treatment outcome.

SOCIOCULTURAL CONTEXT OF GENDER, HEALTH, AND TB

A growing body of experience and evidence shows that gender roles, which are distinct from biologically based sex differences, affect vulnerability and resilience to disease. These gender roles also determine health status, health-seeking behaviour, and access to health care, and their influence should be considered in the formulation and implementation of health policy generally (Vlassoff & Moreno, 2002). Nonspecific effects of gender on health may also result from interactions between gender and contextual variables (such as indicators of poverty or other aspects of socioeconomic status) and features of particular health problems. Interrelationships between gender and TB reflect the combined influences of biological differences, sociocultural contexts and values, and characteristic features of the disease. Practical implications of interactions between gender and TB are elaborated in a review by Somma and colleagues (2004). Study of the complex relationship between sex, gender, and TB requires qualitative and quantitative research methods; a multi-methods approach is needed to address key questions for TB control.

EPIDEMIOLOGY

Tuberculosis is largely associated with men. Although differences between males and females before adolescence are slight, global rates of prevalence of infection after adolescence are higher among males. The risk of progression from infection to active disease increases for women during

their reproductive years, a time when distinctions in both biological sex and gender roles are more significant (Dolin, 1998). The reasons for this difference between females and males are unclear, but it is likely that both physiological sex differences and sociocultural risk factors related to gender roles make women of this age vulnerable to disease.

Standard explanations are not necessarily satisfactory. For example, higher rates of infection for men are often attributed to men having a broader range of social contacts that increases potential exposures. TB is readily transmitted indoors, however, and in many parts of the world, where women are the primary caregivers for children, the sick, and the elderly, the risk of TB infection from staying at home may also be great. Definitive answers are lacking to questions about the biological and sociocultural basis of the preponderance of TB in males. The results of research in Viet Nam has even suggested that rates of TB among women in the general population may be higher than those among men, despite higher rates of TB among men in clinic registers (Thorson et al., 2004).

CASE FINDING AND TREATMENT DELAY

Passive case finding, upon which most TB control programmes rely, requires that the patient actively seeks help at facilities that can diagnose TB reliably. Problems detecting cases in women may result from fewer women consulting appropriate health services and failure of clinicians to aggressively investigate a diagnosis of TB among female patients with chest symptoms (Uplekar et al., 1999; DANTB, 2002a; Thorson et al., 2000). Research carried out two decades ago showed that the percentage of women with TB identified from active community case finding was higher (46%) than the percentage of women (28%) diagnosed among patients seeking treatment in Nepal (Cassels et al., 1982).

The length of time from the point at which a person with TB initially experiences symptoms to when this person first seeks treatment is defined as patient delay, and the length of time from this first help seeking until diagnosis is considered to be provider delay. Research suggests that both the magnitude and nature of patient and provider delay may differ for men and women. Studies may be cited that show either greater delay for women (HealthScope Tanzania, 2003), for men (Hooi, 1994), or no difference (Godfrey-Faussett et al., 2002; Sudha et al., 2003).

Men's delay may be influenced by the inconvenience and cost of missing work to seek health care (Balasubramanian et al., 2004). Women may lack the opportunities and family resources required to access health services, or may be less able to forego family responsibilities at

home or to venture outside for care independently (Godfrey-Faussett et al., 2002). While stigma may contribute to patient delay for both men and women, studies suggest that the latter are particularly vulnerable in societies where marriage and household acceptance are most sensitive to social disqualification based on identified TB, whether in South Asia (Liefooghe et al., 1995), East Asia (Johansson et al., 2000) or Africa (Godfrey-Fausset et al., 2002).

Research more consistently indicates a longer provider delay for women (Long et al., 1999; Needham et al., 2001; Pronyk et al., 2001). Although WHO recommendations clearly specify that all patients with a cough that persists for 3 weeks should be tested for pulmonary TB, clinical practice does not adhere to this policy in the absence of other characteristic symptoms, especially without a productive cough and haemoptysis, and especially among women (Long et al., 2002).

Help seeking from one or many providers that lack the capacity to diagnose TB blurs the distinction between patient and provider delay. Self-treatment and so-called "treatment shopping" (also "doctor shopping") contribute to such delays. Women in some settings, as Thorson et al. (2000) showed in Viet Nam, are more prone to such self-medication and treatment shopping.

Although more a matter of diagnostic sensitivity than patient or provider delay, evidence suggests that women have greater difficulty producing quality sputum for microscopic examination (Begum et al., 2001; WHO, 2002). It is not clear whether this results from physical incapacity, or from embarrassment and shame about producing sputum in the presence of a health worker, or some mixture of physiological and social factors (Uplekar et al., 1999; Murthy et al., 2000; DANTB, 2002b).

CASE HOLDING

Men are more likely than women to default from TB treatment in different settings (Hudelson, 1996). Although this appears to be a gender difference in illness behaviour, some investigators have raised the question of whether it reflects the tenacity of the subset of women who overcome barriers to accessing treatment and receive a diagnosis (Uplekar et al., 1999). For both men and women, however, a paradoxical result of effective treatment, as patients begin to feel better, is increased likelihood of interrupting treatment and default. Insofar as direct observation may be more embarrassing for women, questions arise about the impact of stigma on treatment outcome (Balasubramanian et al., 2000), and the benefits of assigning female observers for female patients (Morankar & Weiss, 2003).

OBJECTIVES

Research in four low- and middle-income countries was undertaken to serve both local and national interests, and to provide an indication of how the role of gender is relevant for TB control in different settings. It was anticipated that the findings would have implications primarily for the programme at the particular site studied, but also for TB control programmes around the world.

The research objectives, formulated in a workshop representing the interests of WHO/TDR and each of the four study sites, were as follows:

- to document sex differences in key aspects of TB control;
- to identify gender-specific barriers to early case detection, appropriate treatment, adherence, and cure;
- to compare and contrast findings from study sites in different regions;
- to recommend policy and interventions for enhancing the gender sensitivity of TB programmes on the basis of findings from the country studies and cross-site comparison.

WHO/TDR/Crump

RESEARCH SITES AND METHODS

Four sites with a functioning directly-observed treatment, short course (DOTS) TB control programme collaborated in these studies. Three were in low-income countries (Bangladesh, India, and Malawi) and one was in a lower middle-income country (Colombia). All sites had a multidisciplinary research capacity. The programme in Bangladesh operated exclusively in rural clinics, the programme in Malawi operated in urban and rural sites, and the study sites in India and Colombia were exclusively urban.

BANGLADESH

In Bangladesh, the study was conducted in 10 rural subdistricts (upazilas) covered by the BRAC TB control programme, and including a population of approximately 2.5 million people. Operating as a nongovernmental organization (NGO) in partnership with the Bangladesh National Tuberculosis Control Programme (NTP), BRAC has health centres in designated regions of the country. BRAC-trained female volunteers working as community health workers, known as shastho shebikas, constitute a key element of rural operations. BRAC maintains sputum-smear laboratories at each health centre, where people with a 3-week cough may report directly on their own initiative or may be referred by the shastho shebikas through semi-active case finding in monthly home visits. Patients with persistent symptoms but negative results by sputum smear are referred to the government subdistrict health complexes or district hospitals for appropriate follow-up and treatment.

The shebikas typically initiate treatment for new cases of TB, and directly observe patients taking their treatment during the first 2–3 months. Subsequently, patients collect drugs once per week from the shebikas' homes. Patients in re-treatment are observed over the full course, and the shebikas also administer streptomycin injections in the re-treatment regimen for treatment failure, relapse, or other reasons.

Patients beginning treatment are requested to deposit Tk. 200 (US$ 4), the equivalent of about 4 days' wages, and to sign a bond guaranteeing that treatment will be completed. After completing the full course, the shebikas receive Tk. 125 as compensation for their time, and patients receive the rest of the deposit. Patients who are unable to pay are not required to deposit the bond.

INDIA

Chennai, India's fourth largest city, with a population of 4.2 million, was the site of the India study. The Tuberculosis Research Centre conducted the research in tuberculosis units of 10 health centres, 5 of which also included family welfare clinics providing maternal and child

health (MCH) care services. Tuberculosis control in government-run facilities has followed the guidelines of the Revised National Tuberculosis Control Programme (RNTCP) since 1999, administered by the Corporation of Chennai. Based on a comprehensive DOTS strategy, treatment of patients with TB is given three times per week and under observation. A box of drugs is earmarked for each patient starting treatment to ensure the availability of a full supply, and patients are not charged for TB diagnostic and treatment services.

In the complex mixture of health-service options of the urban health system, other governmental, NGO, and private services are also available. Services from private practitioners typically do not conform to the principles of the RNTCP. The diagnosis of pulmonary TB is more likely to be based on chest X-ray than on sputum smear, and a wide variety of regimens are prescribed, often requiring patients to purchase drugs from pharmacies. More than half of patients initially seek help from private practitioners, and many who begin treatment in private practice may switch to the free government services.

MALAWI

The Malawi study was conducted by the EQUI-TB Knowledge Programme (a collaboration between the National TB Programme, the Liverpool School of Tropical Medicine, and the University of Malawi) in six districts with a population of 2.5 million persons, located in three administrative regions of the country. About 19% of the study population were in urban Lilongwe, where the community focus groups and cultural epidemiological components of the study were based exclusively. In Malawi, the diagnosis and treatment of TB is integrated with other district health activities, which provide services free of charge, and general health workers routinely provide patient care. In addition to the public health system, free diagnosis and treatment of TB is offered through a network of nonprofit missionary health facilities that provide 30% of Malawi's health-care services. A small number of private, for-profit health facilities are also associated with the TB control programme, but mostly in urban areas. Other private allopathic practitioners provide care for TB patients outside the context of the National Tuberculosis Programme (NTP) in Malawi. Grocery shops are a common first source of care for people with symptoms of cough. Traditional healers have been identified as popular providers of health care, but more commonly in rural than in urban areas. TB control is implemented as a national DOTS programme by the Ministry of Health through the NTP. The programme is managed vertically at the national level, but it is integrated into district level services through local DOTS programmes.

COLOMBIA

Cali is the second largest city in Colombia, and it has a population of 2.2 million people. As a lower middle-income rather than a low-income country, Colombia is expected to have more resources for health infrastructure than countries of the other research sites. Violence is an especially serious public health problem. In response to a variety of difficult conditions encountered at an earlier WHO demonstration site for the DOTS strategy, the former vertical TB programme has been integrated into health care units. These clinics are expected to become self-sustaining by selling services and through a health insurance scheme in a newly emerging health market. Both public and private health-care units are obliged by law to provide diagnostic and treatment services for TB control. The private sector, however, does not follow DOTS guidelines for diagnosis, and practitioners refer most patients in need of treatment for TB to the public sector.

Undertaken by the Centro Internacional de Entrenamiento e Investigaciones Medicas (CIDEIM), this study was conducted in municipal health clinics that also provide general health and MCH services.

STUDY DESIGN

A multi-method design was developed to examine local policy with regard to TB and sociocultural contexts of TB control at the four study sites (Table 1). The components of the four studies were:

- Situation analysis of TB and relevant policy for TB control.
- Community study, relying mainly on focus group discussions. These considered vulnerability, symptoms, causes, treatment, and the social impact of TB.
- Case registry data of each TB programme. These registries were examined to identify the ratio of female:male patients presenting with chest symptoms, and at various stages of the diagnostic and treatment process.
- Structured observations from TB clinics. Comparisons of male and female patients were made with reference to sputum production, treatment initiation, and overall interactions with clinic staff.
- Structured outpatient survey, examining sex differences in patient and provider delay.
- Cultural epidemiology of TB, assessing TB-illness-related experience, meaning, and behaviour.

Table 1. Samples sizes of the five study components

Five components of the study	Bangladesh	India	Malawi	Colombia
FGDs with non-affected lay people[a]	11	16	6	9
TB registry data:				
a) TB suspects	1200	1200	1887	622
b) Patients who submitted sputum	1200	2151	3488	333
c) Sm+ patients registered for treatment	1071	615	1204	130
d) Patients evaluated for treatment outcome	1200	1146	2760	187
Clinic observations:				
a) Sputum submission	100	100	110	none
b) Treatment initiation	100	60	52	none
Outpatient survey of TB patients	1000	982	547	none
Clinical cultural epidemiology	102	127	100	98

FGD: focus group discussion

[a] Number of participants per FGD ranged from 5-11

PLAN OF MULTI–METHOD STUDIES AT FOUR SITES

Research plans, including interviews and agendas for community study and observations, were prepared collectively by the collaborators during a project development workshop in Geneva in December 2000. Sampling strategies and sample sizes were also agreed at this workshop. Translation and local adjustments were subsequently made at the project sites. A preliminary analysis of data was reviewed and discussed at a workshop in Basel, Switzerland, in January 2003.

Situation assessment

During the situation assessment, site-specific information on population characteristics, characteristics of the health system, and health services at each research site was acquired and analysed. These data were collected from secondary sources, collaboration and consultation with social scientists, and key informants from within the health system and among health-care providers. These key informants, including health-care providers, were selected for their knowledge of issues concerning TB and gender in the local setting, and for their ability and willingness to collaborate with research groups at each site.

Focus group discussions

Focus group discussions examined community contexts, perceptions, and explanations of TB with particular consideration of gender differences specific to TB. Group interviews were conducted with men and women aged 25–50 years from communities of the study sites. A minimum of two focus group discussions per respondent group was conducted at each site.

In India, respondents were further stratified into age groups. In Malawi, 16 additional individual interviews were conducted with key informants selected for their special knowledge of health in the community. They included traditional healers, chiefs, traditional birth attendants, a village health volunteer, and a private medical practitioner.

Group discussions and individual interviews used a topic guide developed at the workshop in December 2000. The topic guide included questions about perceptions of the causes, transmission, and treatment of TB. Group discussions and individual interviews were conducted in the local language by a facilitator and an observer, and were recorded. Interviews were transcribed verbatim.

Data analysis identified themes and subissues based on the interview topic guides. Gender differences were analysed either in terms of differences identified by participants themselves, or in terms of contextual differences in data from women's or men's groups. Additional themes and subissues were added as they arose from the data.

Review of TB programme cases: registry data

Data from outpatient registers were collected prospectively in India and Colombia over a period of 12 consecutive months, and retrospectively in Bangladesh and Malawi. TB programme data were reviewed to compare the female:male ratio of patients with suspected TB and patients from outpatient, laboratory, and treatment registers. Data collection tools were drafted to specify female:male ratios of (i) patients with respiratory symptoms suggesting TB; (ii) TB suspects undergoing sputum microscopy; (iii) TB suspects with positive sputum smear; (iv) patients registered for treatment; and (v) patients with successful treatment. Ratios were computed at each step and also with reference to the previous step. The female:male ratios for the specified age groups were also computed. Treatment outcome comparing men and women at each site was also computed and evaluated with chi-squared and Fisher's exact tests.

Observations of sputum collection and treatment initiation

Patients and providers were observed at two time-points: First, when patients were asked to produce sputum that was then collected for microscopy, and second, when instructions were given to begin treatment. A minimum of 25 women and 25 men were observed in Bangladesh, India, and Malawi. Observers were attentive to differences in waiting times for men and women, and the gender-specific nature of interactions with and instructions to patients, based on a structured agenda. In addition to qualitative notes, some sites used an observational checklist. The research teams used Epi Info for descriptive analysis of these data.

Outpatient survey of patients with TB

An outpatient survey of patients with TB used a short 10-item semi-structured interview comprising questions on lag time from onset of symptoms to the first outside help seeking for symptoms of TB (patient delay), and lag time from first outside help seeking to making a diagnosis of TB (provider delay). Data were collected from patients with newly diagnosed pulmonary TB who were interviewed within the first month of their treatment in selected health facilities. Equal numbers of men and women in a total target sample of 1000 patients were studied at each site. In India, a somewhat longer semi-structured interview schedule also elicited signs and symptoms experienced by patients with TB.

Data were verified with double entry, cleaned, and analysed in Epi Info version 6.04d (Centers for Disease Control, http://www.cdc.gov/epiinfo/Epi6/ei6.htm, accessed 1 November 2005) and in SAS (SAS Institute Inc., http://www.sas.com, accessed 1 November 2005). Patient and provider delay for male and female patients were compared using the Wilcoxon test for nonparametric data.

Clinical cultural epidemiology with semi-structured EMIC interviews

Semi-structured in-depth EMIC interviews (Explanatory Model Interview Catalogue) based on a prior cultural epidemiological study of gender and tuberculosis in Pune, India (Morankar & Deshmukh, 2001; Atre et al., 2004) were adapted for use with collective inputs from each study site. EMIC interviews are instruments for assessing representations of illness from the perspective of affected persons (Weiss, 2001). They differ from instruments for basic epidemiology, which are typically con-

cerned with assessing the presence or absence of disease, risk factors and outcomes of disease.

On the basis of priorities for the study of sociocultural gender and consideration of locally relevant representations of TB illness–e.g. categories of somatic, emotional, and social symptoms constituting patterns of distress related to TB, stigma, perceived causes, and help seeking–a draft interview was constructed during the project development workshop in December 2000. The common structure facilitated cross-site analysis, and subsequent local translation and field testing ensured the local validity of these semi-structured EMIC instruments.

Assessment of patterns of distress considered a wide range of problems that patients associate with the illness. Self-perceived and/or enacted stigma was assessed with reference to various indicators of social disqualification targeting the patient because of having TB. Perceived causes specify meaning through ideas of causality, clarifying how patients explain the occurrence of the illness in accounts that may reflect multiple and sometimes conflicting ideas about its cause. Help-seeking categories consider a full range of sources of help for the illness, including self-help, family and community helpers, spiritual healers, medical services, etc. The EMIC also included an assessment of stigma to investigate self-perceived social distress.

Many of the variables in datasets from EMIC interviews distinguish spontaneously reported responses from those elicited after prompting for categories named by the interviewer. The response style (spontaneous or probed) and prominence of these cultural epidemiological variables were analysed.

EMIC interviews were administered in the local language to a minimum of 100 patients currently in treatment at each site. They were stratified in four groups based on sex and whether they had recently started treatment (2-4 weeks) or had been in treatment over a longer period (4-5 months) at the time of the interview.

Analysis of EMIC data

Categorical and numeric data from EMIC interviews were verified by double entry, and cleaned using Epi Info software (version 6.04d), and the cross-site analysis used SAS software for quantitative analysis. Descriptive analysis of frequencies compared the responses made by men and women. Variables for which responses specified a prominence used the Cochran–Armitage test for trend or Wilcoxon statistical tests.

Summary variables for the single most troubling category of distress, most important perceived cause, and first help seeking were compared for men and women using the chi-squared exact test. Response variables were analysed as coded in the interview and also reconfigured in groups that specified broader categories (e.g. fever, cough etc., grouped under the broader heading of physical symptoms among grouped categories of distress).

Computation of the prominence of patterns of distress, perceived causes, and help-seeking response variables facilitated correlational and multivariate analysis. The prominence for each category was based on how it was reported (spontaneously, probed, not at all) and whether it was identified in a summary query as most troubling for patterns of distress, most important for perceived causes, or first for help seeking. The values of these prominence variables ranged from a minimum of 0 (i.e. not reported) to 5 (i.e. identified spontaneously, contributing 2, and in response to the summary query, contributing 3). Prominence was computed for both individual variables and grouped variables.

Indicators of stigma were assessed on a four-point scale, ranging from 0 to 3, with higher values specifying more stigma. The means of these responses were calculated to summarize the dimension of stigma indicated by that variable. The coherence of these variables as an overall index was assessed with the Cronbach alpha statistic. Variables validated in this way were summed for analysis collectively as an index for overall stigma. Determinants of stigma were analysed with reference to other demographic and cultural epidemiological variables from the EMIC interviews. In view of our particular interest in gender, we also analysed interactions between sex and each variable, with reference to males as baseline for this analysis. Variables and their interactions with sex for consideration in a multivariate analysis were identified by a linear regression based on the stigma index (using a normal transformation) as the dependent variable. Independent variables with a relationship to the stigma index with a P value of ≤ 0.20 were considered in the multivariate model. A stepwise regression retained variables with a P value of < 0.15.

Delay from awareness of symptoms to a diagnosis of TB was compared in men and women at each site. The determinants of delay with reference to cultural epidemiological explanatory variables used a similar multivariate approach as that for the analysis of stigma. Cross-site comparisons of stigma, delay, and the prominence of reported categories of patterns of distress and perceived causes used the Kruskal-Wallis nonparametric statistical test. Multiple comparisons identified differences among the sites using the Tukey test with ANOVA (analysis of variance) for a rank transformation of variable values.

Integrated qualitative analysis

Narrative data were translated and transcribed in English at three sites and in Spanish in Colombia. They were managed and analysed with MAXqda software (Kuchartz, 2001) to facilitate access to thematically coded segments from selected records specified with reference to values of any interview variables from the EMIC (or other data sources). This approach enabled an integrated analysis of quantitative and qualitative data.

WHO/HPR/TDR/Crump

RESULTS

FOCUS GROUPS: COMMUNITY PERCEPTIONS OF TB AND HEALTH SERVICES

The number and type of focus group discussions completed at all sites is presented in Table 1. Discussants at all sites were well aware of TB and had some ideas about gender differences, although local ideas about the disease differed across all sites. Most people acknowledged the availability of treatment, but they also had particular ideas about why people should or should not get treatment from the public health sector. Focus groups in Bangladesh and Colombia acknowledged social barriers that inhibited women from producing quality sputum.

Community-identified signs and symptoms of TB

TB was commonly considered to be a problem with the lungs or chest, and coughing was identified as the most characteristic symptom. In Bangladesh, Malawi, and Colombia, forms of TB affecting other parts of the body were also acknowledged. In some areas, cough was described in greater detail with reference to its frequency and persistence, or whether it was associated with production of sputum. Women were more likely to associate TB with a wider range of symptoms, particularly loss of appetite and weight loss in Colombia. References to blood in sputum as a symptom of TB for men were notable in accounts in India. Indian women more frequently emphasized weight loss, persistent cough, and a yellowish and foul-smelling phlegm.

Respondents in Malawi identified a so-called "new TB," that had emerged only in recent years. It was associated with HIV/AIDS, and the characteristic signs and symptoms reflected an intermingling with symptoms of AIDS, especially weight loss, diarrhoea, and changes in hair texture.

Social impact of TB

At all sites, focus group accounts indicated that some degree of stigma was associated with TB. In Bangladesh and Colombia, coughing up sputum for any reason, including diagnosis, was regarded as socially unacceptable for women. Bangladeshi women feared making noise when they coughed, so that their neighbours might hear them and find out they had TB. In both Bangladesh and India, where arranging marriages is a social priority, the negative impact on women's ability to marry, or even to remain in their husband's family household was a well-recognized issue. In Malawi, TB-related stigma was closely associated with

rejection based on widespread assumptions that patients with TB also have HIV/AIDS. Respondents suggested that most people would consequently be reluctant to advise testing for TB. Some respondents also suggested that health-care workers' main interest in diagnosing TB was to identify people with HIV/AIDS.

Causes of and susceptibility to TB

Variations on different aspects of transmission were reported at all sites. In Colombia and Malawi, discussants identified airborne exposure; in Bangladesh, personal contact with a patient with TB was emphasized; and in India and Bangladesh, stepping on the sputum of a patient was identified as a cause of TB. All sites except Malawi explicitly identified contact with the clothing or other possessions of someone with TB as a source of contamination and spread of TB; respondents also mentioned exposure from sharing a meal or sleeping space in the same dwelling. Certain foods were identified with risk of acquiring TB, such as beef and milk from cows; in Malawi, a particular kind of fish was identified. Sexual contact was identified as a cause in India, Colombia and Malawi, but with a somewhat different meaning at each site. In Colombia, respondents specified sexual contact with an infected person, but in India and Malawi respondents distinctly referred to illicit sexual contact. This meant extramarital sex in India and promiscuous sexual activity in Malawi, in both cases referring to sexual activity in violation of socially acceptable behaviour.

In Colombia, poor nutrition and a weak immune system were identified as causes of TB. Participants in focus group discussions in Bangladesh also mentioned poor nutrition and its association with household gender inequities. Women explained that food is unequally distributed in many families, which results in women typically eating only what is left after everyone else in the household has finished their meal. Bangladeshi men's groups identified lack of good food, and they also referred to hard work, smoking, and chewing betel.

Discussants in Malawi and Colombia identified smoking and drinking, which are behaviours more frequently found in men, as factors making them more vulnerable to TB. Other factors, however, reportedly explained the increased vulnerability of women, e.g. exposure to smoke from cooking fires (India), overwork or childbearing (Malawi), or exposure to the disease while caring for others with TB at several sites. Respondents in India commonly mentioned that TB would cause problems with pregnancy and breastfeeding. Men's groups there expressed concern about passing TB to a fetus during pregnancy, but women's groups were more concerned with effects of anti-TB drugs on the fetus.

Care seeking and treatment for TB

Respondents at all sites indicated that treatment for TB was available from public health services, and that TB is curable. Focus group participants, however, also indicated some reluctance to use these public health services. In India, respondents indicated a preference for consulting private practitioners; in Colombia, the public health system was dismissed as inferior to services available to people with health insurance that made it possible to consult private practitioners. In Malawi, various alternatives to the public clinics were preferred for less severe symptoms.

In Malawi, HIV/AIDS has had a substantial impact on ideas about TB. Discussants agreed that TB itself is curable, but that the new form of TB associated with HIV/AIDS could not be fully cured. Because this was widely known, respondents suggested that such patients were less likely to seek care. In Colombia, patients felt that men were more reluctant to seek care when ill because doing so would publicly acknowledge personal or physical weakness and thereby jeopardize machismo. As a result, Colombian respondents felt that women were better able to cope with the symptoms of the disease, because it represented less of a threat to their public image. Paradoxically, however, their ability to cope well when ill was also considered a possible reason for women delaying seeking treatment.

REVIEW OF REGISTRY DATA FROM TB PROGRAMMES

At all four sites, the female:male ratio among patients in the clinic registers decreased at each of the three steps of the clinical process, from symptomatic presentation with suspected TB, to submission of diagnostic sputum, to obtaining a positive result for sputum (Table 2). The relative attrition of women, however, ceased with the next step, that is, smear-positive patients beginning treatment.

At the study sites in Bangladesh and India, fewer women than men were identified as TB suspects but not in Malawi and Colombia. The ratio of women was highest in Colombia. In Bangladesh and Malawi, the female:male ratio for TB suspects from registry data varied markedly between the various clinics. The female:male ratio in the Bangladeshi clinics in the 10 subdistricts ranged from 0.48 to 1.45. In Malawi, the female:male ratios across districts ranged from 0.75 in urban Lilongwe to 1.55.

Compared with the sex ratio for patients with suspected TB, even fewer women submitted sputum for diagnostic microscopy in all four

Table 2. Female:male ratios in clinic TB registers

	Bangladesh		India		Malawi		Colombia	
	F:M	Previous step[a]	F:M	Previous step[a]	F:M	Previous step[a]	F:M	Previous step[a]
TB suspects	0.81		0.71		1.09		2.26	
Sputum submitted	0.52	0.64***	0.61	0.86***	1.06	0.97	1.19	0.53***
Smear-positive	0.38	0.73**	0.29	0.48***	0.94	0.89**	0.38[b]	0.32**
Smear-posit. treatment	0.41	1.08	0.29	1.00	0.96	1.02	0.73	1.92

*P< .10, **P < .05, ***P < .01. Poisson regression for comparison of ratios from the previous step.

Data from chronic cough register, laboratory register, and treatment register.

[a] Female:male ratio with reference to ratio in total at previous step.

[b] Sample size was very small: 3 females and 8 males.

sites; among those who did submit sputum, fewer women were found to be positive. The ratio of female:male patients making sputum submissions was markedly lower among older patients than younger ones in Bangladesh and India.

At all four sites, the female:male ratio for smear-positive patients was no different from that for those starting treatment. For smear-negative patients starting treatment, however, female:male ratios were higher than those for smear-positive patients in Bangladesh and India, but were no different in Malawi and Colombia. Consequently, treating smear-negative patients in South Asia may better meet the needs of female patients not diagnosed by sputum testing.

Treatment success rates were higher for women than men in Bangladesh, India, and Malawi. They were low overall in Colombia, less than 60% for both sexes and with no significant difference between them (Table 3).

Table 3. Treatment outcomes based on treatment registers (%)

Diagnostic status and treatment outcome	Bangladesh		India		Malawi		Colombia	
	Male n = 850	Female n = 350	Male n = 836	Female n = 310	Male n = 1413	Female n = 1347	Male n = 111	Female n = 76
Smear positive	89.6	88.3	57.1	44.5***	43.5	43.7	NA	
Treatment success[a]	87.6	92.0**	86.1	91.9***	60.7	66.0***	55.9	59.2
Treatment failure	0.9	0.6	1.3	0.3	0.6	0.7	NA	
Died	8.8	5.7*	2.4	3.5	24.1	21.4*	9.0	3.9
Defaulted	2.2	1.1	9.4	3.5***	4.7	3.4*	30.6	22.4
Transferred-out	0.4	0.6	0.7	0.6	4.5[b]	4.0[b]	4.5	14.5**

NA: not available.

[a] "Cure" and "treatment completed" combined.

[b] In addition, treatment outcome was unknown for 5.5% of the male and 4.5% of the female patients (P = 0.3).

*P < .10, **P < .05, ***P < .01, Pearson chi-square.

CLINIC OBSERVATIONS

Clinic observations of interactions between patients and providers were conducted when patients were asked to give sputum for diagnostic microscopy and when instructions were given at the start of treatment. This component of the research was omitted in Colombia; and in India, fewer indicators, especially for submitting sputum, were systematically observed.

Sputum collection

Patients were observed in clinics at three sites when they were asked to produce a diagnostic sputum sample during the consultation: 50 male and 50 female patients in Bangladesh, 57 males and 43 females in India, and 61 males and 49 females in Malawi. In Malawi, observers noted that not all patients received adequate instructions about how to produce a satisfactory sample. Clinicians' instructions of various kinds were given to most patients in Bangladesh. Observations did not identify gender differences in India concerning the quality of instructions or other aspects of patient-provider interactions.

At each of the three sites, observers found that patients were somewhat anxious and worried about producing sputum. Such discomfort was more frequently identified among women (39%) than men (15%, P = 0.004) only in Malawi, and no gender differences were observed at the other sites.

Observers noted other gender-relevant features of clinic presentation and behaviour in the DOTS clinics. In Bangladesh, female patients (66%) were more likely to be accompanied by a caretaker than were men (40%, P = 0.01). Waiting time and duration of clinic visits, however, were about the same for men and women. Waiting time in Malawi, however, was shorter for men (median, 25 minutes) than for women (median, 33.5 minutes, P < 0.001). Queue jumping in Malawi was observed in about one-third of patients, but no differences distinguished male and female patients in this regard.

Bangladesh was the only site where patients had the option to receive smear-positive results of diagnostic testing of sputum at home. This option was more frequently offered to female (62%) than to male (38%) patients (P = 0.02).

Patient–provider interaction during treatment initiation

Observation of interactions between clinicians and patients at the start of treatment focused on the content and style of communications regarding information and instructions about taking tablets, their side-effects, and consideration of how to prevent the spread of TB. The most notable difference across sites was the smaller number of people in Bangladesh who were observed to be uneasy as they were instructed at the start of treatment (9%); the report from India indicated anxious discomfort at this point among nearly all patients.

Patients in Bangladesh were frequently accompanied by family or a neighbour when they came to the clinic. Female clinicians gave direct instructions to nearly all male patients (90%), but to only 33% of female patients–more often instructions were directed to a guardian. Few patients (10%) appeared to be uncomfortable during the interaction. Any discomfort that was observed among patients appeared to result from their concerns about taking the prescribed drugs or symptomatic weakness from TB. An observer noted:

The patient seemed to be very weak. She just maintained a bewildered gaze fixed on the provider. However, she took two tablets and waited for awhile. On the provider's further request, she again started to take the tablets. It seemed the tablets were bitter to swallow.

Observers noted that some providers gave inappropriate advice. One clinician advised a woman to keep a handkerchief over her mouth for a full 2 months. Providers explained side-effects to a majority of patients, but not all; they also advised men not to smoke and emphasized the importance of nutritious foods.

Observations in the Indian clinics found that most of these consultations lasted 5–10 minutes. Consultations were longer than 15 minutes for 30% of female and 20% of male patients. Details of the treatment regimen, such as the number of tablets to be taken, were not explained to many patients (80% of men and 63% of women) during the observed interaction, and explanations of side-effects were also omitted for 43% of male and 53% of female patients. Although the clinicians' interactions with patients were generally polite, they did not provide health educational materials. Women (77%) were more likely than men (67%) to be given some advice about preventing the spread of their condition, which was a serious concern for many patients.

Observations in Malawi also showed that nearly half of the patients were not instructed about the dosage and frequency of their medicines, and observers found instructions emphasizing the importance of completing the full course were given to only 31%. Most of the information given to patients focused on abstaining from drinking alcohol and smoking (63%) and limiting hard work and strenuous physical activity (59%). For most patients (55%), health-care providers also emphasized the importance of nutritious foods. Despite the recognized comorbidity of HIV/AIDS and TB, the topic was infrequently considered; the question of testing and voluntary counselling was discussed with only two patients (4%).

OUTPATIENT SURVEY OF TB PATIENTS

Data from outpatient surveys were available from the studies in Bangladesh, India, and Malawi. Men sampled at each of these sites were significantly older than women (41.8 versus 33.6 years in Bangladesh, 40.2 versus 32.1 years in India, and 36.9 versus 31.8 years in Malawi, $P < 0.001$ for each). In Bangladesh, all patients were smear-positive, but the percentage in India was 52% (58% of men and 46% of women, $P < 0.001$), and in Malawi approximately half were smear-positive. Data for various intervals of delay are summarized in Table 4.

Table 4. Help seeking and diagnosis delay (mean no. of days), from outpatient survey[a]

Interval of delay	Bangladesh		India		Malawi[b]	
	Male n = 500	Female n = 500	Male n = 492[c]	Female n = 490[c]	Male n = 290	Female n = 257
Symptom onset to first help seeking	14.1	14.4	57.2	48.1***	28.3	26.7
Symptom onset to PHC facility	48.8	51.9**	67.8	66.3	32.9	34.5
Symptom onset to sputum examination facility	52.0	53.3	71.7	72.7	50.8	56.3
Symptom onset to sputum examination	58.5	61.2**	NA	NA	58.1	64.6
First help seeking to PHC facility	34.7	37.5*	9.7	18.2***	4.7	8.0*
First help seeking to sputum examination	44.4	46.8*	13.5	24.7***	30.2	38.8*
PHC facility to sputum examination	9.7	9.3	3.9	6.5	26.5	32.1

NA: not available; PHC, primary health centre.
*P < 0.10, **P < 0.05, ***P < 0.01; T-test.
[a] Comparable data unavailable from Colombia.
[b] Small variations from expected values of the sums of mean scores result from rare deviations in the diagnostic protocol or missing data.
[c] Not 500, since for 18 patients, the available data did not permit calculation of lag times.

Rural Bangladesh, with its shebikas interacting with their communities in a system of semi-active case finding, had the shortest mean lag time from awareness of symptoms to first seeking help–about 2 weeks. Delays reported in Malawi and India were longer–about 1 month and nearly 2 months respectively. The system in Bangladesh was least efficient in advancing patients from that first point of contact to the facility where they were diagnosed by sputum-smear testing. This delay was uniformly longer for women than for men at the three sites. Once patients reached a primary health-care facility, subsequent delay to microscopy was relatively short in both Bangladesh and India (about 1 week), but about 1 month in Malawi. There were no differences in that interval for men and women at any of the sites. These findings indicate that the features of each system were associated with particular strengths and weaknesses concerning patient delay and two aspects of provider delay (referral to TB control clinic and delay before sputum testing after reaching that clinic) at each site.

Associated symptoms among outpatients were also studied in the sample in India. Although characteristic symptoms of cough and blood in sputum were as frequent among men as among women, nonspecific symptoms–including fever, weight loss, chest pain, loss of appetite, and breathlessness–were more frequently reported by women.

CLINICAL CULTURAL EPIDEMIOLOGY

Sample characteristics

Approximately 100 patients were interviewed with EMIC interviews at each of the four sites; half were men and half were women. Patients were also equally divided between those in treatment for 2–4 weeks or 4–5 months. Actual sample sizes ranged from 98 in Colombia to 127 in India. In Bangladesh and India, respondents were predominantly Muslim and Hindu respectively, while they were mainly Christian Protestant in Malawi and Catholic in Colombia. The majority of patients at all sites were married, except in Colombia where cohabitation was more common. The most frequently reported occupation for women was housewife, except in Malawi, where more than twice as many women specified trade or business. Men at the three urban sites were identified as either skilled or unskilled labourers, and in rural Bangladesh most men were farmers (Table 5).

Table 5. Sample characteristics of patients studied with EMIC interviews

Demographic variable (%)	Bangladesh		India		Malawi		Colombia	
	Male n = 52	Female n = 50	Male n = 66	Female n = 61	Male n = 50	Female n = 50	Male n = 50	Female n = 48
Religion								
Muslim	88.5	86.0	7.6	13.1	12.0	8.0	0.0	0.0
Hindu	11.5	14.0	81.8	77.0	0.0	0.0	0.0	0.0
Christian	0.0	0.0	10.6	9.8	82.0	92.0	100[a]	100[a]
Other	0.0	0.0	0.0	0.0	6.0	0.0	0.0	0.0
Marital status								
Never married	3.8	12.0	27.3	26.2	32.0	14.0	40.0	27.1
Married	94.2	72.0	69.7	59.0	34.0	46.0	6.0	16.7
Cohabiting	0.0	0.0	0.0	0.0	0.0	0.0	32.0	27.1
Separated/divorced/widowed	2.0	16.0	3.0	14.8	10.0	18.0	18.0	29.2
Remarried	0.0	0.0	0.0	0.0	24.0	22.0	4.0	0.0

[a] 74% of the men and 69% of the women were Catholic, 20% of the men and 25% of the women were Protestant/Evangelical, and 6% each belonged to other Christian groups.

Table 5. Sample characteristics of patients studied with EMIC interviews (Continued)

Demographic variable (%)	Bangladesh		India		Malawi		Colombia	
	Male n = 52	Female n = 50	Male n = 66	Female n = 61	Male n = 50	Female n = 50	Male n = 50	Female n = 48
Occupation								
Student	2.0	8.0	0.0	0.0	0.0	0.0	10.0	6.3
Housewife	0.0	68.0	0.0	39.3	0.0	20.0	0.0	52.1
Unskilled labour	8.0	6.0	19.7	11.5	16.0	2.0	48.0	22.9
Skilled labour	10.0	0.0	45.5	14.8	28.0	2.0	10.0	6.3
Trade/business	19.0	2.0	7.6	9.8	22.0	44.0	12.0	4.2
Farmer	29.0	0.0	0.0	0.0	6.0	8.0	2.0	0.0
Other	19.0	0.0	22.7	6.6	16.0	18.0	8.0	6.1
None	13.0	16.0	4.5	18.0	12.0	6.0	10.0	2.1
Education								
No formal education	48.1	60.0	4.5	4.9	6.0	14.0	8.0	8.3
Up to 5 years	40.4	18.0	21.2	27.9	14.0	18.0	38.0	39.6
6–10 years	11.5	22.0	45.5	36.1	52.0	52.0	32.0	37.5
More than 10 years	0.0	0.0	15.2[b]	8.2[b]	28.0	16.0	22.0	14.6

[b] No data were available regarding level of education for 13.6% of the men and 23% of the women.

Identification, seriousness, and curability of TB

At all sites, few patients had identified their condition as TB before they were diagnosed at a clinic. Women at all sites, except in Colombia, more frequently acknowledged the seriousness and potentially fatal character of their TB, and this difference was clearest in Bangladesh and Malawi. The perceived seriousness overall varied across sites: it was considered serious in Bangladesh by 67.6% of patients, in Malawi by 67.0%, in Colombia by 48.0%, and in India by only 29.1% of patients. At the time of the interview, nearly all patients said that they thought their condition was curable.

Patterns of distress

The prominence of reported categories of distress varied across sites for many variables, with some exceptions (blood in sputum, breathlessness, and marital problems) (Appendix Table 1). At all four sites, physical symptoms were the most prominently reported categories of distress. Patients identified a vague constellation of physical ailments that are common to TB, including cough, fever, weakness, loss of appetite, weight loss, chest pain, and breathlessness. The prominence of psychological and emotional categories of distress, however, was striking, and they were reported by a large majority of patients at all sites (95.1% of all patients in Bangladesh, 86.6% in India, 72.0% in Malawi, and 84.7% in Colombia). On the basis of spontaneous and probed responses, sadness, anxiety, and worry was the second most prominently ranked symptom in Bangladesh and India, and third most prominently ranked for the pooled sample of four sites, after cough and fever. Financial concerns and other social problems associated with TB were also frequently reported across sites.

Although blood in sputum is widely associated with TB, this symptom was not reported as consistently as others. Because of its association with TB, the absence of blood in sputum was interpreted by some patients as evidence that their condition was not TB. A Bangladeshi woman explained, "I thought this disease was not TB, because a TB patient gets blood with the cough. But I have never had blood with my cough." Similarly, a Bangladeshi man concluded that his condition was TB after he experienced this symptom: "When blood came out with the cough, I understood that I probably have got TB. In my childhood, I had learned from my father that if blood came out with the cough, then it is TB." Similar accounts came from other sites. In Malawi a man explained, "I knew it was TB only one week after I began coughing. Coughing up blood signalled to me that I was suffering from TB." That par-

ticular symptom also generated intense worry about the seriousness of the condition, which may motivate appropriate help seeking. A Bangladeshi man reported, "At first, I got cough and fever...One day, blood came out with the cough. Then I got very scared, and I came to BRAC for treatment." Patients in India and Malawi related similar narratives.

Table 6. Most troubling category of distress: cross-site comparison (%)

Most troubling category of distress	Bangladesh n = 102	India n = 127	Malawi n = 100	Colombia n = 98
Physical symptoms	**97.1**	**54.3**	**54.0**	**78.6*****
Cough	46.1	26.8	14.0	27.6***
Fever	7.8	4.7	2.0	10.2*
Chest pain	19.6	3.9	6.0	9.2***
Blood in sputum	4.9	6.3	3.0	11.2*
Breathlessness	4.9	3.9	18.0	8.2***
Weight loss	0.0	0.8	3.0	7.1***
Loss of appetite	2.9	0.0	0.0	2.0*
Weakness	8.8	4.7	5.0	2.0
Side-effects of drugs	2.0	0.0	2.0	0.0
Other physical symptoms	0.0	3.1	1.0	1.0
Social	**0.0**	**7.9**	**3.0**	**4.1****
Social isolation	0.0	3.1	0.0	2.0
Stigma – reduced social status	0.0	3.9	1.0	1.0*
Marital problems	0.0	0.8	2.0	1.0
Financial problems	**0.0**	**7.1**	**18.0**	**1.0*****
Loss of job and wages	0.0	6.3	12.0	1.0***
Reduced personal or family income	0.0	0.8	6.0	0.0***
Psychological-Emotional	**2.9**	**21.3**	**22.0**	**14.3*****
Sadness, anxiety, or worry	0.0	12.6	7.0	0.0***
Concern about course of illness	2.9	8.7	15.0	14.3**

$^{*}P < 0.1$, $^{**}P < 0.05$, $^{***}P < 0.01$; exact chi-squared test for differences across sites.
Grouped categories computed from responses and indicated in bold type.

The majority of patients at all sites identified somatic symptoms as most troubling (Table 6), especially in Bangladesh (97.1%) and Colombia (78.6%). A substantial proportion, however, identified emotional and social categories of distress as most troubling in India (29.1%) and Malawi (25.0%). In Malawi, these concerns were explained as resulting from economic hardship; job loss (12.0%) and reduced income (6.0%) were also reported as separate categories more frequently in Malawi than at other sites. A man in Malawi said, "What troubles me the most is the inability to do heavy work, which I need to make enough money for food and other essential needs." The financial impact of TB was also emphasized in South Asia. An illustrative narrative from a Bangladeshi man explained, "I cannot work because of my disease. We are facing a financial crisis to run the family." Another elaborated on the devastating impact of financial crisis: "My life is collapsed completely. I am the only earning member in our family. I have been forced to send my wife to work in the rice mill. I feel bad for that."

Gender-specific features

Although both women and men at all four sites were burdened by the physical symptoms associated with TB, women presented to the clinic with a greater diversity of nonspecific physical symptoms (Appendix Table 2). Women in Bangladesh and Colombia spontaneously identified a significantly higher mean number of categories of distress than men did (8.4 for women in Bangladesh versus 5.4 for men, $P < 0.001$; 5.1 for women in Colombia versus 3.8 for men, $P = 0.01$). Women in Bangladesh, India, and Colombia reported fever more frequently than did men; in Malawi, where malaria-induced fevers are common, there was no significant difference between men and women reporting fever. More women than men in Bangladesh and Columbia were concerned about weakness from their TB, but in Malawi, where narratives indicated this symptom fuelled fears of job loss, men were more concerned than women about weakness. Women in Bangladesh and in India were more troubled by breathlessness than men.

In Bangladesh, social concerns about somatic symptoms, mainly coughing–identified by 60% of women as most troubling–also produced psychosocial distress. Women there reported that they thought they must suppress their cough to avoid disclosing that they had TB. They also explained that the severity of their coughing produced vomiting (perhaps from swallowing phlegm), urinary incontinence, and that it made them cry.

In India, blood in sputum was more frequently reported by men (37.9%) than women (14.8%, $P < 0.05$), and for 12.1% of men it

Table 7. Most troubling category of distress: comparison between males and females (%)

Most troubling category of distress	Bangladesh		India		Malawi		Colombia	
	Male n = 52	Female n = 50	Male n = 66	Female n = 61	Male n = 50	Female n = 50	Male n = 50	Female n = 48
Physical symptoms	**96.2**	**98.0**	**68.2**	**39.3*****	**46.0**	**62.0**	**78.0**	**79.2**
Cough	32.7	60.0***	31.8	21.3	8.0	20.0	24.0	31.3
Fever	5.8	10.0	6.1	3.3	0.0	4.0	14.0	6.3
Chest pain	21.2	18.0	3.0	4.9	8.0	4.0	6.0	12.5
Blood in sputum	9.6	0.0*	12.1	0.0***	2.0	4.0	10.0	12.5
Breathlessness	5.8	4.0	3.0	4.9	22.0	14.0	12.0	4.2
Weight loss	0.0	0.0	1.5	0.0	0.0	6.0	6.0	8.3
Weakness	13.5	4.0	6.1	3.3	6.0	4.0	2.0	2.1
Social	**0.0**	**0.0**	**7.6**	**8.2**	**4.0**	**2.0**	**4.0**	**4.2**
Stigma - reduced social status	0.0	0.0	1.5	6.6	2.0	0.0	0.0	2.1
Financial	**0.0**	**0.0**	**9.1**	**4.9**	**20.0**	**16.0**	**0.0**	**2.1**
Loss of job and wages	0.0	0.0	9.1	3.3	14.0	10.0	0.0	2.1
Reduced income	0.0	0.0	0.0	1.6	6.0	6.0	0.0	0.0
Psychological - Emotional	**3.8**	**2.0**	**9.1**	**34.4*****	**26.0**	**18.0**	**16.0**	**12.5**
Sadness, anxiety or worry	0.0	0.0	4.5	13.1	20.0	10.0	0.0	0.0
Concern about course of illness	3.8	2.0	4.5	21.3***	6.0	8.0	16.0	12.5

*P < 0.1; **P < 0.05; ***P < 0.01; Fisher's exact test for comparisons between men and women.
Grouped categories computed from responses and indicated in bold type. Categories reported by less than 5% of respondents were omitted from the table but were included in grouped variables.

was the most troubling symptom (but not for any women, $P < 0.01$). In Bangladesh 9.6% of men identified it as most troubling (and no women, $P < 0.10$) (Table 7). A Bangladeshi man said, "When blood came out with the cough, then I felt very bad. I was afraid to see the blood with the cough and I thought that I would die soon. I thought that I had caught a disease that would lead me to death."

Psychosocial distress

Fears and worries are recurring themes in patients' narratives; they often feared isolation and death, and women were especially afraid of leaving their children as orphans. An Indian woman reported, "I felt sad about my condition. I worried about who would take care of my children."

The psychological and emotional distress of Indian women was often extreme, overshadowing physical symptoms. "I don't feel anything from my physical symptoms," one woman explained. "Only the sadness, which makes me feel more dull." The intensity of these symptoms interfered with women's ability to care for their children, further contributing to a sense of worthlessness and in turn to greater sadness. The emotional impact of illness caused by TB in Bangladesh and India affected a few women and men strongly enough that they mentioned concerns about suicide:

Since I have been suffering from this illness, I cannot go to work. And so I have also lost income. This made me think negatively about my life; I don't want to live. Many times I also thought of committing suicide.

A few women at these sites also indicated that their husbands or in-laws would like them to commit suicide.

Stigma, social discrimination, and family rejection contributed substantially to such intense emotional impact and psychosocial distress from TB for women. The disease raised questions about divorce and spoiled opportunities for marriage. Women are particularly vulnerable to these effects, especially in the South Asian cultures of the Bangladesh and India sites, where arranged marriages and concerns about acceptance or rejection from joint families remain important features of social life and well-being for many. A Bangladeshi woman reported the following account:

When I became sick, my mother-in-law and husband told me that they would not keep me there. They said I had to go to my father's home. They told me that I had a dangerous disease, so it was impossible to

keep me at home. My husband informed me he would marry again. My sister-in-law always kept a distance from me; she even told her children not to come close to me.

Social stigma and rejection of children in the family, compromising their ability to marry, were also concerns for men. A Bangladeshi man explained, "This disease will affect my children. If I try to arrange marriages for my daughters, then others will say that it is not nice to marry a girl whose father is a TB patient. Even after I get cured, it will be difficult to arrange marriages."

Much of this stigma was fuelled by inappropriate family concerns about contagion, which suggested a lack of confidence in the effectiveness of treatment. The narrative of an Indian woman illustrates this point:

I felt so sad and worried because of this disease. I have been alienated from others and neglected by my husband and mother too. Even though treatment is available for TB, nobody is there to console me or to show concern towards me. Everybody treats me like a patient with a dangerous disease, which made me feel so hurt.

Exaggerated social concerns about the dangerousness of infected persons, despite treatment, were especially burdensome for women. These social concerns about the persisting danger of TB patients appear to have been complemented by patients' personal concerns about the course of illness. Such concerns coexisted with conflicting responses to questioning that demonstrated that nearly all patients regarded the condition as curable. Findings across sites indicated greater concerns among women about the course of illness, particularly in Bangladesh (88.0% compared with 44.2% reported by men, $P < 0.01$) and in Malawi (54.0% of women and 34.0% of men, $P = 0.06$). Although the difference between the 34.4% of women and 19.7% of men reporting this concern was not significant in India, the percentage identifying it as the most significant problem clearly was (21.3% of women and 4.5% of men, $P < 0.01$).

Consequently, it appears that much of the emotional distress reported by South-Asian women is rooted in concerns about social and family rejection, and ambivalence about the course and curability of their illness. The psychosocial impact on men in Malawi and South Asia, however, was often related to concerns about the financial impact of the disease affecting a man's ability to pursue livelihood occupations. Other factors also seem to have played a role in Colombia. Findings suggest that more women (85.4%) than men (78.0%) in Colombia report experiencing sadness, anxiety, or worry ($P = 0.06$). Women more frequently reported this symptom spontaneously (50.0%) and men more frequently

in response to the interviewer's probe (48.0%). Reluctance to reveal emotional symptoms, regarded as a sign of weakness, suggest that for men, the social issues contributing to psychosocial distress may result from threats to male machismo, and that they are based to a lesser degree on concerns about financial and socioeconomic jeopardy than they are at the other sites.

Stigma

Stigma related to TB here refers to disqualification from full social acceptance, the result of a process that identifies a person with his or her TB, a medical problem that may also be dangerous to others. The process ignores that person's human qualities, which might otherwise motivate compassion and support. Such stigma may be socially enacted, self-perceived, or anticipated by people with a stigmatized condition. In the previous section in which patterns of distress were reported, various examples and aspects of stigma were presented with particular attention to how they engendered psychosocial and emotional distress. The EMIC interviews examined stigma as a form of social distress, assessing it with reference to indicators of TB-related stigma, formulated from local experience with TB and from ethnographic data.

The character of TB-related stigma is strongly influenced by exaggerated concerns about the risk of spreading the disease to others. The assessment of stigma is complicated by the need to distinguish potentially conflicting interests—public health interests in reducing transmission and stigma-mitigating interests in correcting exaggerated and mistaken ideas about the spread of TB. Concerns about transmission influenced other aspects of stigma, including disclosure to others. A Bangladeshi woman explained:

I do not tell anybody about my disease. If I tell, they may think they may also get this disease from me. My self-respect has decreased somewhat because this disease of mine is communicable. That is why I am careful to stay by myself. If others come to know, they will not come close to me and will not associate with me.

Findings based on assessment of these indicators of stigma are presented in Appendix Table 3. This table presents a cross-site comparison of the stigma index, and of each of the indicators that comprise the index. For items in which differences between the sites were identified, a graphical representation of findings from multiple comparisons shows which sites differed.

India had the highest item-adjusted stigma index and Malawi the lowest. Although the difference between India and Malawi was statistically

significant, neither differed significantly from the other two sites. Although one indicator–item 7, "Others have avoided you"–was a consistent feature of stigma, with no differences across sites, other indicators differed across sites, indicating how the features of stigma vary locally. Even though the overall stigma index was highest for India, several variables made a small contribution to the stigma index in India compared with their role at other sites. These included item 13, "Partner refuses sex due to TB," and item 16, "Asked to stay away from work or groups." Similarly, even though the Malawi site had the lowest overall index of stigma, responses to item 14 ("Other problems in marriage after cure") were most prominent compared with the three other sites. Such findings specify local, site-specific features of stigma.

Some of these cross-site differences reflected other aspects of their sociocultural contexts. For example, it was notable that item 11, "Problem getting married despite cure," figured significantly less prominently for Colombia than any of the other sites. This was consistent with the sociodemographic profile at that site, where fewest respondents were married and many were cohabiting (see Table 5). Consequently, "difficulty marrying" may have reflected the normative social status, rather than a matter of concern and a stigmatizing feature of TB. Nevertheless, internal consistency with other items of the index, based on analysis with Cronbach's alpha, suggested that it was a valid indicator of stigma, even though it was reported less frequently.

Gender-specific contributions to stigma

Analysis of gender differences in stigma identified Bangladesh as the only site where there was a significant difference between men and women for the overall stigma index ($P = 0.04$), indicating more self-reported stigma for women. In India, similar findings were suggestive but not significant ($P = 0.11$). Consistent with these comparisons of the stigma index, analysis in Bangladesh identified six items that are more prominent for women compared with two items that are more prominent for men, which shows gender differences in the character of stigma at that site (Appendix Table 4). Although exaggerated and incorrect ideas about the spread of TB were a consistent feature of TB-related stigma in narrative accounts at all sites, in Bangladesh more women reported that others had avoided them, and had refused to visit. Male–female differences in the site-specific prominence of other indicators of stigma elaborated such site-specific gender-based features of stigma. For example, item 16: more women were asked to stay away from work or groups in Bangladesh, and more men in India and Malawi.

The nature of the stigma reported by TB patients at the Malawi site was distinctive; the association of TB with HIV/AIDS influenced social perceptions of TB, and this association had different social implications for men and women. Although there was no significant difference between men and women in the overall stigma index in Malawi, five indicators there contributed more to stigma for men. Only item 11, "Problem getting married despite cure," was more of an issue for women. As one woman explained, men considered women with TB to be dangerous:

It is difficult because people say anyone with TB has AIDS. So a person can come and ask for your hand in marriage, but when he realizes that you had suffered from this disease, he might pull back.

Presumed male promiscuity, associated directly with HIV/AIDS and indirectly with TB, was a distinctive feature of stigma in Malawi. Some men discussed the social impact of these presumed associations between TB and HIV/AIDS: "To other people, when they know that you have TB, they think that you have AIDS, and they stigmatize you." Another explained, "Most people say that if you have TB, then you have AIDS. Then people with TB are not supposed to be in contact with other people."

Qualitative accounts of the predominant male concern that the social impact of their condition would affect their children, item 10, reflected concerns about children suffering from criticism directed at their father for having this disease. This social vulnerability of children, rather than concern about their risk of infection (which was also a factor in Malawi, as it was at other sites) suggested links to social concerns associated with HIV/AIDS-related stigma. These also appeared to promote "adverse social perceptions of the family," another concern (item 9) reported more frequently by men in Malawi.

Determinants of stigma

A multivariate analysis was used to examine how the cultural epidemiological profile of variables specifying the prominence of categories of TB-related experience, meaning, and behaviour may explain self-reported stigma. This analysis examined each determinant of the overall index of stigma at each site as a dependent variable. Because of our particular interest in the question of how gender influences social response, we examined not only sociodemographic and explanatory variables from the study with the EMIC interview (patterns of distress, perceived causes, and help seeking), but also interactions of these variables with sex (female compared with male), proceeding first with a bivariate analysis and then a multivariate analysis of variables that merited further con-

sideration. This analysis was completed for three sites (excluding Colombia, for which data were unavailable), first for variables as coded in the interview and second for grouped variables. A summary of these findings for all three sites is presented for the variables as coded in Appendix Table 5, and for the grouped variables in Appendix Table 6.

Findings showed that self-reported stigma lessened with increasing age in Bangladesh and India. Other sociodemographic explanatory variables identified in the analysis of grouped cultural epidemiological variables included less stigma for married persons in India and more stigma for jobless people in Malawi. Being Muslim in India was marginally associated with less stigma.

With respect to variables specifying illness experience, weakness was associated with greater stigma in Bangladesh, but "other physical symptoms" were associated with reduced stigma in India, perhaps deflecting the focus of attention to nonspecific health problems, rather than stigmatized TB. Social and emotional problems were positively associated with stigma at the three sites. Reduced income, a particular concern in Malawi, was also associated with stigma there. Analysis of interaction terms showed that in Malawi the loss of job and income was more stigmatizing for women than for men. In Malawi, the attribution of TB to sexual behaviour was associated with stigma for men only. In India, climate–that is, a condition over which individuals have no control, and for which they cannot be held responsible–was associated with less self-reported stigma for men. In Malawi, where malaria is endemic, fever was associated with less stigma.

Analysis of variables that were grouped because they specified related concepts helped to identify determinants that were less clear from study of the larger number of variables as coded in the interview. These showed that social and emotional factors contributed more clearly to stigma in India and Bangladesh. Findings also showed a relationship between use of government clinics in India and more stigma, but use of private services and magico-religious healers was associated with less stigma. The positive association between more stigma and prominent prior use of government clinics appears to result from efforts of clinic staff to promote treatment adherence. Several patients referred to the embarrassment caused by the policy of clinic staff making home visits if patients miss a clinic visit: "They told me that they would come to my home and enquire about my absence, making it known to everybody in the community."

Such findings raise questions about whether health-related stigma, which is usually considered problematic, may in some contexts con-

tribute to better treatment outcome. Private practice is less likely to discomfort patients with follow-up for defaulters, and this may explain the association with less stigma. Since such follow-up in government clinics motivates treatment adherence, however, this association suggests that stigma is not uniformly problematic, and that the patient's concerns about drawing the attention of family and community to the condition may even facilitate treatment.

Perceived causes

Many of the most commonly reported perceived causes of TB indicated local ideas about the nature of transmission of TB at each site. The meaning of the illness was intimately bound with the question of how it was passed from one person to another, and concerns about the practical implications of this. Contamination and contact were the most frequently reported perceived causes across the three sites, followed by food, smoking, and airborne exposure. Findings for perceived causes reported in Bangladesh, India, and Malawi are reported in Appendix Table 7; data are not available for Colombia. Concerns about risk included exposure and transmission from personal contact with infected persons, from contaminated foods, and from smoking or environmental substances that passed through the air.

Another nonspecific aspect of spread referred to factors that increase vulnerability to the agent that transmits TB and diminish the capacity to resist the disease when exposed. Physical exertion and heavy work, alcohol, and the debilitating effects of a prior illness all had such effects, and these were identified as causes of TB. Smoking as a reported perceived cause operates both as an agent of transmission through contaminants in the inhaled smoke, and as a habit that enhances vulnerability. References to food as a cause at all three sites indicated a mixture of concerns about transmission factors and vulnerability factors. Patients in Malawi identified concerns about infection from eating contaminated or suspect meat:

Most of the meat that we eat is from cattle that are stolen and slaughtered without supervision and certification by veterinary officers. I may have consumed beef from one of these infected animals. In addition, the exotic white chicken that we eat can cause the illness. I believe we eat them while the medicines that they are given are still in their body, which brings problems to our body.

In rural communities, food production is central to livelihood and daily work. In Bangladesh, food was identified as the most frequently reported

perceived cause of TB, reported by 31.4% of respondents. In India, however, it was third most frequently reported perceived cause (26.8%), after smoking and alcohol. In Malawi, patients reported food as a perceived cause more often than at the other sites (32.0%), but they were also concerned about other causes, and food was the sixth most frequently reported cause after "cannot say," airborne exposure, contamination and contact, smoking, and alcohol.

Working too hard without time or access to nutritious food was elaborated as a cause both in urban India and in rural Bangladesh. An Indian man in Chennai explained: "I had to work hard to get orders, and I used to reach home late at night. By then the food would not be fresh and wholesome. Many times I had taken only the leftover rice and I used to skip breakfast too." A farmer in Bangladesh linked concerns about food with weakness and overexertion: "I am a farmer. I need to stay in the sun all day long. I work in the dust. I cannot eat in time. I cannot eat good food because I am a poor person. That is why I have got this health problem."

In Malawi, misgivings about speaking forthrightly about some concerns appeared to have influenced styles of response. Contamination and contact, the most prominent category reported across the three sites, was especially prominent in Malawi. It is notable, however, that it did not occur as frequently in spontaneous responses (26.0%) as it did in response to questions directly probing that category. In Malawi, 28.0% of patients identified this category in probed responses, compared with 4.7% in India and 4.9% in Bangladesh.

In Malawi, most respondents also began their answer with "don't know" or "cannot say." This may have reflected reluctance to discuss the role of HIV/AIDS as a prior illness and possible cause. Although 54.0% of respondents acknowledged contamination and contact, fewer specified sexual contact (16.0%), and of these fewer were spontaneous responses (6.0%) than probed responses (10.0%). Although the association with HIV/AIDS was widely considered in discussions of social perceptions of TB, only 11.0% of patients in Malawi reported prior illness as a cause of their TB, compared with 17.7% of patients in Bangladesh, where consideration of particular prior illnesses did not refer to HIV/AIDS. In Malawi, these findings show that it was easier for people to acknowledge the impact of HIV/AIDS in the community generally, but more difficult to acknowledge its personal impact when asked directly.

Most important perceived cause

Patients' narratives often referred to more than one category of perceived cause, and patients were also asked to identify the single most

Table 8. Most important perceived cause of TB: cross-site comparison (%)

Most important perceived cause	Bangladesh n = 102	India n = 127	Malawi n = 100
Ingestion	**37.3**	**30.7**	**25.0**
Food	11.8	7.1	5.0
Alcohol	0.0	9.4	5.0***
Smoking	17.6	10.2	14.0
Health, illness, or injury	**26.5**	**7.9**	**7.0*****
Physical exertion, work	13.7	2.4	5.0***
Prior illness	8.8	2.4	1.0***
Psychological-Emotional	**1.0**	**7.9**	**0.0*****
Mental-emotional stress	1.0	7.9	0.0***
Environmental	**16.7**	**18.1**	**27.0**
Contamination - contact	14.7	7.9	16.0
Airborne exposure	1.0	4.7	9.0**
Traditional, cultural, magico-religious	**4.9**	**10.2**	**6.0**
Sexual	**1.0**	**1.6**	**5.0**
Sexual contact	1.0	1.6	5.0
Miscellaneous	**9.8**	**19.7**	**27.0*****
Other	8.8	12.6	4.0**
Cannot say, no idea	1.0	7.1	23.0***

*P < 0.1, **P < 0.05, ***P < 0.01. Exact chi-squared test for differences across sites.
Categories with a frequency of less than 5% are not shown.
Grouped categories computed from responses and indicated in bold type.

important category among these (Table 8). With an emphasis on both transmission and vulnerability, smoking was identified as the most important perceived cause across sites, being reported with a mean frequency across sites of 14.0%, and most frequently in Bangladesh (17.6%). Physical exertion and work, which was reported third most frequently in Bangladesh as most important perceived cause (13.7%) was reported infrequently at the other sites. In India, smoking was reported second most frequently (10.2%) after an amorphous category of "other" (12.6%). Although smoking was specified more frequently in Malawi than in India, it was the most frequently reported category of most important perceived causes after "other" (23.0%) and contamination and contact (16.0%).

Gender and perceived causes

Differences in the profile of perceived causes reported by men and women were striking and clearly identifiable at all sites (Appendix Table 8, and Table 9). Ingestion, which was the most frequently reported group of categories in India and Bangladesh, and second most frequently reported in Malawi, provides a good example. This grouped category was reported more frequently by men at all sites, mainly with reference to ingestion of abused substances. These include smoking, drugs (not Malawi), and alcohol (not Bangladesh, where only one man in this Muslim country identified alcohol as a cause). Some accounts, like the following from a man in Malawi, elaborated the context of substance abuse with reference to other risk factors, thereby clarifying local views of the balance of transmission factors and vulnerability factors:

Three things may have caused my illness. As a minibus driver, windows in some of the buses cannot be opened for ventilation. Even in buses that have windows some passengers may like to close the windows, maybe because they are feeling cold. If someone has TB, it could easily spread. However, I strongly believe that it is the smoking and alcohol that caused my illness.

Ingestion as a category reported by women was different in character from men's reports; it was clearly not with reference to substance abuse. In India, about one-third of the women considered bad water to have been the cause of their TB. Reports referred to various ways in which water might be responsible, including exposure to contaminated water from cleaning toilets, drinking unboiled and unclean water, taking water from different places outside the house, or drinking too much cold water.

In Bangladesh, several factors classed under the group heading of health, illness, and injury were more frequently reported by women. These included blood problems and constitutional weakness, which were also both reported by more women in Malawi. Pregnancy and childbirth was a distinguishing feature of women's perceived causes in the three sites. Heredity was reported by 30.0% of women and no men in Bangladesh. The women spoke of having people with TB in the family whom they cared for and that it was more a matter of exposure than genetics. The narratives indicated that they attributed the illness to taking care of, and sometimes eating with, relatives or neighbours who had TB: "My father and my grandfather had this disease. I nursed my father and I got it from him at that time." Another woman explained, "My paternal uncle had this disease. A neighbour of mine who lives close to our home had TB too... I went to their homes when they had TB, and I ate food from their hands. I think that I got this TB then."

Table 9. Most important perceived cause of TB: comparison between males and females (%)

Perceived causes	Bangladesh		India		Malawi	
	Male n = 52	Female n = 50	Male n = 66	Female n = 61	Male n = 50	Female n = 50
Ingestion	**53.8**	**20.0*** **	**42.4**	**18.0*** **	**42.0**	**8.0*** **
Food	9.6	14.0	3.0	11.5*	8.0	2.0
Water	1.9	6.0	0.0	4.9	0.0	0.0
Alcohol	0.0	0.0	18.2	0.0***	10.0	0.0*
Smoking	34.6	0.0***	18.2	1.6***	24.0	4.0***
Drug abuse	7.7	0.0	3.0	0.0	0.0	2.0
Health - Illness - Injury	**19.2**	**34.0**	**4.5**	**11.5**	**4.0**	**10.0**
Injury, accident, surgery	0.0	6.0	0.0	0.0	0.0	0.0
Physical exertion, work	19.2	8.0	1.5	3.3	2.0	8.0
Prior illness	0.0	18.0***	0.0	4.9	2.0	0.0
Heredity	**0.0**	**6.0**	**4.5**	**3.3**	**0.0**	**6.0**
Heredity	0.0	6.0	4.5	3.3	0.0	6.0

*P < 0.1, **P < 0.05, ***P < 0.01. Fisher's exact test for male-female comparisons.
Grouped categories were computed from responses and indicated in bold type. Categories reported by less than 5% of respondents were omitted from the table but were included in grouped values.

Table 9. Most important perceived cause of TB: comparison between males and females (%) (Continued)

Perceived causes	Bangladesh		India		Malawi	
	Male n = 52	Female n = 50	Male n = 66	Female n = 61	Male n = 50	Female n = 50
Psychological - Emotional	**1.9**	**0.0**	**3.0**	**13.1****	**0.0**	**0.0**
Mental-emotional stress	1.9	0.0	3.0	13.1**	0.0	0.0
Environmental	**9.6**	**24.0***	**16.7**	**19.7**	**24.0**	**30.0**
Contamination - contact	9.6	20.0	7.6	8.2	8.0	24.0*
Airborne exposure	0.0	2.0	6.1	3.3	14.0	4.0
Traditional, Cultural, Magico-Religious	**3.8**	**6.0**	**7.6**	**13.1**	**2.0**	**10.0**
Fate, God, stars [karma]	0.0	2.0	1.5	6.6	0.0	4.0
Sexual	**0.0**	**2.0**	**0.0**	**3.3**	**0.0**	**10.0***
Sexual contact	0.0	2.0	0.0	3.3	0.0	10.0*
Miscellaneous	**11.5**	**8.0**	**21.2**	**18.0**	**28.0**	**26.0**
Other	9.6	8.0	15.2	9.8	2.0	6.0
Cannot say, no idea	1.9	0.0	6.1	8.2	26.0	20.0

*P < 0.1; **P < 0.05; ***P < 0.01. Fisher's exact test for male–female comparisons.

Grouped categories were computed from responses and indicated in bold type. Categories reported by less than 5% of respondents were omitted from the table but were included in grouped values.

An exaggerated focus on food as a means of transmitting TB was an important feature of many women's accounts. As family caretakers and cooks, this view within the community and households contributed to their social vulnerability and questions about the dangers they posed as family cooks and providers, despite effective treatment. Exaggerated ideas about the transmission of TB may contribute to stigma and suffering, as illustrated by the following narrative of a Bangladeshi woman:

Everybody, except my parents thought that they might get this disease from me. My sisters-in-law did not come to me. They were afraid that they would get this disease. But they and their children took care of my youngest child. If they hadn't, then my old mother could not have done it all. I think they can get this disease from me because we eat together. I think like this because people have said that TB is a communicable disease. Therefore, I do not want to associate with the others, because it is so bad. If someone else gets this disease, then he or she will suffer like me.

Women in both India (32.8%) and Malawi (14.0%) identified mental and emotional stress as a cause more often than men. A substantial percentage of women in India identified this as the most important cause of their TB (13.1%). Accounts like the following were commonly given by these women: "It is due only to mental and emotional stress that I am having this infection." Such accounts also reflected a sense of helplessness that was a feature of their life: "I am having so many problems in my family, and I used to worry about my kids. This should be a reason for my illness."

Sexual contact reported as a cause indicated another kind of helplessness and inability to avoid recognized risks. Many women in Malawi attributed their condition to sexual contact (28.0%), explaining that they were infected by their husbands:

You know, some men are not able to tell their wives in a loving manner that "I did this thing," or that there is such a problem. Some even go to the hospital and are found with a disease, but they fail to tell their wives. And when the problem happens to you, they say, "Well, [this] problem has gotten to her also."

Few men in Malawi (4.0%) identified sexual contact as a cause. At the three sites, women identified traditional astrological and religious causes more than men. This difference was also especially pronounced in Malawi.

Help seeking

Self-help

Patients at all sites commonly relied initially on informal self-help to treat their symptoms (Appendix Table 9). In Bangladesh and Malawi,

they typically used self-care, home remedies, or consulted family. In India, fewer reported using self-help and more patients said that they had gone to a druggist or pharmacist for advice. Bangladeshi patients also reported consulting pharmacies. Women were more likely than men in Malawi to consult health workers, and more likely to use informal sources and pharmacies in Bangladesh. Nonspecific help that patients typically received at the outset included advice regarding nutritious foods, taking more rest, and engaging either in more or less exercise.

Outside help

Sources of help outside the home that were used before patients came for treatment to the study clinic are also reported in Appendix Table 9. Half of the patients in Bangladesh reported using rural doctors with very limited or no formal credentials. Some patients had access to private allopathic doctors (35.3%), and some made their way to an urban government hospital (17.6%). Most Indian patients made use of private allopathic doctors (62.2%), especially women (70.5%); a substantial number had also used urban government hospitals (44.1%) and TB clinics (46.5%). Despite their expense, and often despite their failure to prescribe treatment conforming to accepted standards of care for TB, private doctors were the most appealing category of health-care provider for many patients in the India sample. "I went because it is very close to my home and moreover, he is our family doctor." Powerful interventions, whether or not they conformed to accepted standards of TB treatment, were also appealing:

I went to a private doctor first, and I was given drips. We always go to him for everybody in the family...He prescribed tablets for three days. I was given glucose (drips), tablets and injections. I was not given these tablets [anti-TB drugs received at the government clinic]; the tablets were different. I pawned my earrings with the moneylender and raised a loan [in order to go there].

In Malawi, patients made use of a wide range of types of health-care provider. The most common was the urban government hospital (67.0%), which was used by more women (82.0%). Unlike Bangladesh and India, in Malawi private hospitals (29.0%) and an NGO clinic (27.0%) were used more frequently than were private practitioners, who were rarely used. Malawi was also the only site where the use of traditional healers (12.0%) and religious leaders (8.0%) was reported, and these traditional and magico-religious sources of help were used more by women.

Seeking treatment from various types of health-care providers, so-called "treatment shopping," was common at all sites. In Bangladesh and Malawi,

Table 10. First outside help seeking: male-female comparison (%)

Clinic or health-care provider	Bangladesh		India		Malawi	
	Male n = 52	Female n = 50	Male n = 66	Female n = 61	Male n = 50	Female n = 50
Informal and self-medication	**15.4**	**34.0****	**1.5**	**0.0**	**2.0**	**2.0**
Druggist/pharmacist for advice	11.5	26.0*	1.5	0.0	0.0	0.0
Health worker	1.9	0.0	0.0	0.0	2.0	2.0
Local herbal healer	1.9	8.0	0.0	0.0	NA	NA
Government and NGO health services	**9.6**	**8.0**	**28.8**	**19.7**	**46.0**	**46.0**
Primary health centre or sub-centre	0.0	2.0	4.5	1.6	2.0	10.0
Rural government hospital	0.0	2.0	1.5	0.0	6.0	2.0
Urban government hospital	7.7	4.0	22.7	18.0	28.0	20.0
NGO health clinic-hospital	1.9	0.0	0.0	0.0	10.0	14.0

NA: not assessed at indicated site; NGO, nongovernmental organization; RMP, registered medical practitioner.

*P < 0.1, **P < 0.05, ***P < 0.01. Fisher's exact test for male–female comparisons.

Grouped categories were computed from responses and indicated in bold type. Categories reported by less than 5% of respondents were omitted from the table but were included in grouped values.

Table 10. First outside help seeking: male-female comparison (continued)

Clinic or health-care provider	Bangladesh		India		Malawi	
	Male n = 52	Female n = 50	Male n = 66	Female n = 61	Male n = 50	Female n = 50
Private Doctors and Facilities	**69.2**	**52.0**	**56.1**	**70.5**	**14.0**	**12.0**
Private practitioner - allopathy	17.3	8.0	47.0	63.9*	2.0	0.0
Private doctor specialist	0.0	2.0	4.5	1.6	0.0	0.0
Private doctor - homeopathy	3.8	2.0	1.5	0.0	NA	NA
Private hospital	1.9	0.0	3.0	4.9	12.0	12.0
Unqualified doctor (RMP, etc.)	46.2	40.0	0.0	0.0	NA	NA
Traditional or Magico-Religious Healers	**0.0**	**0.0**	**0.0**	**0.0**	**6.0**	**14.0**
Traditional healer	NA	NA	NA	NA	6.0	10.0
Other	**0.0**	**0.0**	**6.1**	**4.9**	**0.0**	**0.0**
This clinic (study clinic)	5.8	6.0	7.6	4.9	30.0	26.0
Other TB clinic	0.0	0.0	6.1	4.9	NA	NA

NA: not assessed at indicated site; NGO, nongovernmental organization; RMP, registered medical practitioner.
*P < 0.1, **P < 0.05, ***P < 0.01. Fisher's exact test for male–female comparisons.
Grouped categories were computed from responses and indicated in bold type. Categories reported by less than 5% of respondents were omitted from the table but were included in grouped values.

treatment shopping was more prominent for women than men. The profile of first help seeking was notable for use of private facilities and use of druggists and pharmacists in Bangladesh; use of private clinics and governmental health services in India; and use of government health facilities, including the urban study clinic, in Malawi (Table 10). In Bangladesh, more women initially consulted pharmacies, and in India more women initially went for help to private allopathic doctors.

Delay to diagnosis

The delay from patients' first awareness of symptoms to diagnosis of TB was analysed and compared among the four sites (Table 11). The median delay before diagnosis was shortest in Malawi (33.5 days) and longest in Colombia (82 days). The differences in the overall delay across the four sites were significant (P = 0.03).

Table 11. Delay to diagnosis of TB: cross-site comparison

Delay (days)	Bangladesh n = 102	India n = 127	Malawi n = 100	Colombia n = 98
Mean	67.9	98.4	136.4	120.2
Median	60	74	33.5	82
Minimum	1	3	3	1
Maximum	335	730	2555	1275
Standard deviation	49.0	90.5	350.2	176.7
Mean rank score	204.7	233.1	188.2	225.3

P < 0.03, Kruskal-Wallis test for cross-site comparison. Values for time delay were transformed to rank scores, and tied ranks were assigned a mean score. Tukey test of differences between site-specific ranks with ANOVA was used to identify which sites differed from each of the others. The only statistically significant difference among mean rank scores was between India (highest) and Malawi (lowest).

Analysis of this delay before diagnosis also compared men and women at each site; findings are presented in Table 12. The delay before diagnosis for women (90 days) was longer than for men (44 days, P = 0.01) in Colombia. The delay was also longer for women than men in Malawi (median, 55.5 days and 30 days respectively, P = 0.09). Differences between men and women in India were not significant, and there was no indication of any difference in delay before diagnosis for men and women at the Bangladesh study site.

Table 12. Delay to diagnosis of TB: comparison between males and females

Delay (in days)	Bangladesh		India		Malawi		Colombia	
	Male n = 52	Female n = 50	Male n = 66	Female n = 61	Male n = 50	Female n = 50	Male n = 50	Female n = 48
Mean	64.3	71.6	92.8	104.5	78.2	194.6	89.8	151.9
Median	61	60	67	93	30	55.5	44.0	90
Minimum	1	21	3	7	3	4	1	7
Maximum	187	335	365	730	1095	2555	730.0	1275
Standard deviation	35.0	60.4	80.0	101.0	158.2	464.6	125.9	214.2
P value[a]	0.83		0.32		0.09		0.01	

[a] Wilcoxon test.

Multivariate analysis of sociodemographic and sociocultural determinants of delay before diagnosis, from first awareness of symptoms to diagnosis of TB, was completed at three sites. This analysis also examined interactions with sex (female compared with male) (Appendix Table 10). In Bangladesh, greater age and symptoms of cough were variables in the model associated with longer delay. Being never married, marital problems, and traditional humoral perceived causes of TB were associated with an increased delay for women compared with men.

The analysis in India suggested that education, vague physical symptoms, sexual contact, and prior use of a healing temple for help with TB illness were associated with longer delay to diagnosis. Factors associated with reduced delay in India included cough, blood in sputum, and concern about the course of illness. The significance of the interaction variable for female sex showed an increased delay for women using a private doctor compared with men.

The analysis for Malawi suggested that being a housewife, job loss, drug abuse, and use of NGO health clinics were associated with longer delay. Interaction variables in the model indicated that concern about the course of illness led to increased delay for women compared with men, and never having been married was associated with reduced delay for women compared with men.

Findings for the second analysis, based on grouped variables (patterns of distress, perceived causes, and help seeking) are summarized in Appendix Table 11. Findings showed that physical symptoms reduced diagnosis delay in Malawi. Female patients with TB in Malawi who reported both psychological and emotional symptoms and prior use of government or NGO health-care services more prominently experienced a longer diagnostic delay than did male patients also reporting these categories.

DOTS clinic experience and social support

Patients discussed the various factors that affected the quality of their experience at and access to the DOTS clinics, and the support they received (or did not receive) from family and in-laws (Appendix Table 12). In Bangladesh, more women were likely to report problems associated with attending the clinic and with inadequate social support. Problems for women attending the clinic focused on domestic responsibilities and the inconvenience of the distance they had to travel to the clinics. Most patients in Bangladesh, especially women, reported that costs related to the use of the BRAC clinic were a strain for their fami-

lies. In their narratives, many women also reported that they needed to arrange for someone to accompany them to the clinic. The women had higher average travel costs and longer average time to reach health services than men, and they had more difficulty getting the money they needed. "My husband does not provide for any expenses." Although the initial deposit fee in Bangladesh is partially refundable, some patients had to borrow money at interest to pay it. "There is always crisis in our family," a woman explained. "To manage the expenses for this disease adds to the crisis. My mother is working very hard to pay the loan back." Even though BRAC does not require the deposit from people who cannot afford to pay it, some are reluctant to take that exemption.

Among working women in India, wages were frequently cut; one woman from India reported, "I need to take permission of two hours whenever I come here for treatment. My wages for two hours would be cut down." Another Indian woman reported, "My income has been cut since I need to come here once in a week to collect medicines." Several women in India reported having to make sacrifices associated with decreased finances, such as preparing less or lower quality food, having lost jobs entirely, or if they were self-employed, being unable to meet earnings they had previously attained. Narratives indicated that employers withholding wages was less likely to be a problem for men.

Producing sputum was reportedly difficult for a range of 23.1% to 37.7% of men and women at the various sites, except in Bangladesh where it was difficult for the vast majority of women (84%). This reflected a cultural taboo discouraging women from coughing deeply and spitting to produce sputum, particularly in the presence of others. This culturally defined reticence was also reflected in the narratives of Indian women. "When I was asked to collect sputum in the container for the test I felt very bad. I had to spit into the container in front of others." Another Indian woman reported, "I felt it difficult to produce sputum because everyone was looking at me, and I had to cough out sputum and collect sputum in the container." In addition to social discomfort, somatic symptoms contributed to difficulties producing sputum. A Bangladeshi woman reported, "I felt pain in the ribs while coughing up the sputum. I felt pain in the throat. It seemed to me that I would die."

Unlike the other sites, more men in Malawi (34%) were concerned about the financial burden of treatment than women (14%, $P = 0.06$), or than men at other sites. Although treatment at the clinic is provided free of charge, this burden was related to direct costs, such as transport, and the opportunity costs of reduced earnings due to time lost from work. Patients treated in Malawi were especially concerned with

the availability of an adequate supply of TB medicines. Although many patients said that this was also a problem in the TB clinics, some thought the drugs were more likely to be available there, and this motivated them to come there for treatment. A woman aged 30 years explained, "I knew that the supply of medicine here is adequate and free. And so I felt that I better come here rather than sticking to the private hospital, where I would have to buy the medicine myself...In addition, the supply at the private hospital is unreliable."

WHO/TBP/Gary Hampton

DISCUSSION

Findings from this multi-country study are particularly relevant to the various factors that affect (i) timely, efficient, and gender-equitable case finding; (ii) locally variable and gender-specific clinical presentations of TB; (iii) recognition of the substantial impact of the psychosocial and emotional component of illness caused by TB; (iv) the social response of families, communities, and health systems to TB, based on the complementary public health interests of treatment and minimizing spread, and mitigating TB-related stigma; and (v) case holding to minimize treatment default and promote effective treatment and cure.

KEY FINDINGS

The following points represent key findings from the cross-site analysis of these four studies:

1. *Fewer women are represented in case registries in the steps from presentation to diagnosis, and fewer men successfully complete treatment.*

Results from cross-site study of registry data showed that fewer women are routinely identified as having suspected TB, fewer women submit sputum for diagnosis, and fewer are found to be smear-positive in the course of case finding. Men, however, are less likely to complete treatment after diagnosis. The high and outlying ratio of females:males with suspected TB in Colombia raises questions about the epidemiology of TB among females in the population. The lack of clinic registers in Colombia necessitated alternative techniques of data collection that may have introduced bias. It is possible that in the course of interviewing patients, researchers were more sensitive to the possibility of TB among women. It is unclear whether health-care providers are systematically less suspicious of TB among female respiratory patients because of gender biases or differential symptomology, or if they are correctly estimating the proportion of female patients with TB among all consulting respiratory patients. Questions remain about the extent to which a lower proportion of women at various stages of case finding may reflect sex differences in the basic epidemiology of TB, or gender-specific barriers to access and case identification. Although distinguishing the impact of sex and gender has been recognized as an important question for the field (Borgdorff et al., 2000; Thorson et al., 2004), an attempt to resolve the issue was beyond the scope of the multi-country study, which did not include active community case finding.

Other research highlights the barriers to health care for men. Balasubramanian and colleagues (2004) found a higher proportion of

men with TB in study communities than in TB clinics. Their study in rural Thiruvallur, adjacent to Chennai, examined the prevalence of TB in the community and in the clinic. Active community case finding included a door-to-door survey, symptom screening, mass miniature radiography, and sputum examination; findings showed that 7.2% of men and 3.3% of women ($P < 0.001$) had respiratory symptoms that had lasted for more than 3 weeks. Self-referred clinic patients indicated a case-finding gap of 2.2% for men and 1.1% for women, and a male:female ratio of smear positivity of 6.5 in the community sample and 4.1 in the clinic. Such studies are needed in other settings to determine how widespread the problem of "missing men" actually is. In any event, as indicated by the problems completing treatment experienced by men that were identified in our multi-country study, gender-sensitive TB control needs to focus not only on women's health, but also on men's.

Furthermore, spread of the disease results not only from failure or delay in diagnosing TB in women and men (the focus of most studies on gender and TB to date), but also from patients failing to complete treatment. Findings at the four sites, consistent with the literature, show that patient default is predominantly an issue for men. Consequently, while the historical emphasis of health and gender studies has focused on needs for the support of women, more attention is required with regard to complementary gender-specific needs to improve the adherence and completion of treatment of men with TB. Gender-specific support for men should include attention to problems of alcohol and other substance abuse, and other specific concerns of male patients identified in this study.

2. Difficulty obtaining quality diagnostic sputum from women

Cultural constraints and physical incapacity limit women's ability to produce high-quality diagnostic sputum. This problem was noted during discussions in focus groups at two sites and from observations in Malawi; it was confirmed by EMIC interview data in Bangladesh. According to observations made in Malawi, evaluation and feedback to patients concerning the quality of sputum are inadequate. Data from India and Bangladesh suggest that providing an adequate (private and well-ventilated) place to produce diagnostic sputum may be of particular benefit to women.

The findings also suggest, however, that better means of diagnostic assessment are also needed. Further study of diagnostic adjuvants is warranted. For example, evidence suggests that bronchodilators may facilitate the production of sputum and improve the sensitivity of smear microscopy. If further testing ultimately demonstrates their effectiveness, they are likely to be particularly important for diagnosing TB in

women (Murthy et al., 2000; Al Zahrani et al., 2001; Bell et al., 2003). The limitations of smear microscopy highlighted by our gender-oriented studies, however, may also ultimately be regarded as demonstrating the need for improved diagnostic methods to replace sputum microscopy, which is currently the best available approach.

3. Local and gender-specific features of TB symptomatology

Less specific clinical presentations of TB are more common among women, and they have fewer characteristic symptoms, such as blood in sputum. Patterns of distress reported in EMIC interviews were notable for the occurrence of women with TB who were experiencing a wider range of symptoms that were less clearly indicative of the diagnosis.

This finding has already been acknowledged at least four decades ago in South Asia (Banerji & Anderson, 1963), and it has been noted in other settings, including a recent qualitative study of providers in Viet Nam (Johansson & Winkvist, 2002). It remains an issue that is likely to contribute to under-diagnosis and provider delay in diagnosing cases of TB among women. Our finding indicates the need to locally document patterns of distress associated with TB and to ensure that these are recognized in clinic management and training of personnel. Recognition of disease symptomatology should be complemented by appreciation of illness-related patterns of distress.

4. Psychosocial and emotional burden of TB illness

Illness caused by TB places a substantial burden upon the patient's emotional and social well-being, and the nature of these psychosocial problems is often gender specific. Our findings support efforts to clarify the links and relationships between general health and mental health. This issue is more relevant for clinical management and control of TB than is usually acknowledged in control programme training, policy, and practice. According to some estimates, up to 46% of patients with TB suffer from major depression (WHO, 2003). We found that nearly one-third of the women in the Indian EMIC study sample reported psychological and emotional distress among the causes of their TB. Two men and one woman in India emphasized the degree of their distress by mentioning thoughts of suicide. One woman each in India and Bangladesh said that their husbands had encouraged them to commit suicide, and others referred to fears regarding their in-laws' homicidal response to their being diagnosed with TB.

Although we did not evaluate the diagnostic criteria for major depression or other mood disorders, it was clear from our findings that the

emotional burden of TB is pervasive and serious, and that this aspect of illness requires attention in the clinical management of TB. Other investigators have acknowledged this point in the literature, but have focused on multidrug-resistant TB (Shin et al., 2004; Vega et al., 2004). Findings from the multi-country study highlight the issue more generally for TB control. Apart from the suffering it contributes, the question of whether and how much psychosocial and emotional morbidities influence help seeking, treatment adherence, and default also remains a matter that requires further study. The impact of alcohol and substance abuse among men requires particular attention in this regard. The broad-based impact of TB illustrates the need for clinic and community programmes to acknowledge the interrelationship of "physical, mental, and social well-being" specified in the definition of health in the preamble to the constitution of the World Health Organization (WHO, 1948).

5. Financial burden of TB and help seeking

The financial burden of TB results from wage earners who cannot work, from the expenses required for help seeking and treatment, and from the financial impact arising from other aspects of TB illness affecting caretakers and dependent persons in a household. The financial impact was particularly distressing for men responsible for their family's livelihood and who had lost income as a result of their illness, and for women without access to household resources to pay for health care.

Our findings are consistent with those of other studies documenting the substantial financial burden of TB in Bangladesh (Croft & Croft, 1998), India (Rajeswari et al., 1999), and Malawi (Pocock et al., 1996). The financial burden contributes to other problems, imposing a so-called "undefined burden" affecting patients, their families and communities (WHO, 2001). The impact of this aspect of TB is particularly hard for the poor, and highlights related aspects of public health interests in TB, gender, and poverty.

6. Stigma related to TB: impact, features, and determinants

Stigma was substantial at all sites, and analysis of illness narratives showed that the nature of social disqualification has common disease-specific features, in particular, exaggerated fears of contagion. Locally distinctive features of stigma were also notable, such as associations with HIV/AIDS in hyperendemic settings, represented by findings in Malawi. In contrast to findings in Colombia, focus groups at the South-Asian sites emphasized the problems associated with disclosing TB and

the difficulties that disclosure imposes on arranging marriages for women in cultures where this is a high social priority,

In practice, strategies for TB control must typically balance complementary interests; the transmission of TB from people who are actively infectious must be minimized, while exaggerated fears of contagion that fail to acknowledge the effectiveness of successful treatment must be corrected, because this promotes stigma. Patients require a clear explanation about the contagiousness of their disease, what they should do to minimize spread to others, and when in the course of treatment they are no longer infectious. The complementary interests of minimizing both transmission and stigma require mutual accommodation.

Several studies have previously suggested that stigma has adverse effects on TB treatment adherence, default, and cure (Balasubramanian et al., 2000; Thomas, 2002). Reflection on the balance of programme interests in promoting responsibility and treatment adherence with interventions that counter blame and stigma has led some investigators to question the DOTS strategies, partly on the basis of concerns about stigma and social distress for participating patients. In assessments of stigma, including that carried out by us, however, it may be difficult to distinguish problems of stigma from critical social responses that promote responsible behaviour. The report of a National Institute of Mental Health (NIMH) (*National Institute of Mental Health*, 1996) workshop on AIDS and stigma cautioned that public health practice must recognize and balance the interests of disease control that arise from competing notions of responsibility and blame. Findings from research at the site in India highlight an analogous point concerning TB. Home visits, which our multivariate analysis suggests may explain a positive association between use of government clinics and stigma, may nevertheless be justified because they promote responsible treatment adherence and reduce default. The prominence of prior use of private practitioners was associated with less stigma, but narratives, like findings of other studies (Uplekar & Rangan, 1993), indicated problems with the quality of TB treatment received.

Further study and consideration of the interrelationships between health policy options, blame, responsibility, ethics, and outcomes are warranted. Experience in these multi-country studies has contributed substantially to methods for assessing stigma, relating both quantitative measures and complementary qualitative assessments required to study complex interrelationships that are relevant to policy. Other researchers have used a summary index of stigma since 1991 to study stigma and HIV/AIDS (Herek, 2002), and more recent cultural epidemio-

logical studies have integrated quantitative and qualitative methods for study of the determinants of stigma targeting persons with mental health problems (Raguram et al., 2004). In our multi-country studies, this approach made it possible to compare stigma systematically across sites. The approach may also be applied for comparisons over time at a single site with reference to the effects of health system interventions, broader social policies, and other social changes. Developing capacities to assess and monitor the level, determinants, and impact of stigma is likely to benefit not only other TB control programmes but also other aspects of health policy and planning.

7. Site- and gender-specific features of patient delay

Although data were not available for a detailed analysis of the cultural epidemiological determinants of patient delay, illness narratives and outpatient data indicated some characteristic features. Women generally identified more barriers to outside help seeking, and they often delayed seeking care because of domestic and social responsibilities that hindered their ability to access limited available resources. Reasons for men reporting such inconvenience typically focused on interference with livelihood activities. Responses from women in Chennai, however, showed that as women working at paying jobs becomes a more common feature of urban societies, women's concerns about the convenience of access to health services are more likely to resemble men's patterns of response. Such women, typically working as skilled or unskilled labourers at this site, spoke about the problem of losing income from their jobs when they took time off to go for treatment.

Experience in Bangladesh showed that community outreach with semi-active case finding may reduce the time to first help. This was especially remarkable because at the rural site the distances required to reach help might well have been expected to create longer delays to first help. In Malawi, concerns about clinic supplies of medicines reduced patients' confidence in and commitment to poorly equipped facilities, especially when it seemed that a better alternative might be available.

8. Site- and gender-specific features of diagnosis delay

Evidence from the three sites providing outpatient data suggested that provider delay was typically longer for women at each of those sites. The determinants of delay are influenced by gender and may vary across sites. Multivariate analysis of grouped variables from EMIC interview showed that increased diagnosis delay was explained by an interaction between being female and social symptoms of distress in Bangladesh

and with psychological-emotional symptoms in Malawi. That is, a prominent psychosocial component affecting women delayed case finding, compared with effects of these symptoms on men. Treatment shopping, which is more of an issue for women than men, appears to contribute to diagnosis delay, and analysis of its determinants and effects may clarify an important feature of illness behaviour.

The prominence in patient accounts of blood in sputum, regarded as a characteristic symptom of TB in the general population and by clinicians, was found to reduce the time from first awareness of symptoms to diagnosis of TB in India. Patients' narratives showed that it was also a marker of illness severity independent of associations with TB. As prominence of "other physical symptoms" was associated with increased diagnosis delay in India, the interests of TB control are appropriately concerned with reducing such delay for clinical presentations that do not conform to a restrictive textbook clinical profile, especially for women.

We have presented and compared our findings after analysis of diagnosis delay on the basis of the available data. It would also be useful to consider particular features of patient delay and provider delay, in order to evaluate and guide TB control. Each type of delay reflects the influence of different factors and programme needs for improvement. In Bangladesh, for example, patient delays to first seeking help were shortest, and provider delays for referral up to a level of the health system where a diagnosis could be made were longest. Thus, the system with shebika semi-active community case-finding works well in some respects and poorly in others. Additional efforts are needed to improve the process of referral for diagnosis. Focused study of the determinants of these particular aspects of delay would benefit programmes by identifying relevant issues that require attention to improve programme effectiveness.

Data from patients specifying the time from first awareness of symptoms to first seeking help (patient delay) and from first seeking help to diagnosis (provider delay) may then be used as dependent variables for analysis of determinants, as we have done in the present studies of diagnosis delay. Other relevant programme outcomes, not considered in the present studies, may also be studied in that way (e.g. adherence, default, cure, and death).

IMPLICATIONS

Our cross-site analysis of gender and TB at these four sites aimed to relate site-specific findings to the broader interests of other TB control

programmes in low- and middle-income countries. The research was designed to investigate the local epidemiology, gender, and sociocultural aspects of TB. Although it was intended that the methods, interests, and approach for studying local conditions of practical significance would be relevant to the interests of other programmes, it was not expected that findings would be uniform across sites or universally applicable in other settings without careful consideration of context.

On the basis of the findings discussed above and considerations for generalizing findings from these studies, implications mainly concern the clinical presentation of TB, the social and emotional impact of TB and stigma, the organization of health services for the diagnosis and treatment of TB, and ways to minimize diagnosis delay. These points have been formulated to enhance the gender sensitivity and overall effectiveness of TB control in other low- and middle-income countries:

- Health-care professionals should be trained to consider the possibility of TB in female patients presenting with more atypical symptoms.

- Control programme site studies are needed to relate the prevalence and sex ratios of men and women with TB in communities and clinics.

- Clinic policy and clinician practice should endeavour to identify general and gender-specific barriers to obtaining quality diagnostic sputum for smear microscopy. Local conditions should ensure privacy and a well-ventilated space for patients to produce sputum. Programmes should routinely evaluate procedures for obtaining samples; clinical staff should provide relevant feedback to patients, and a quality control system should monitor sputum quality in the clinic with feedback to staff.

- Sex-specific programme monitoring should be incorporated in the routine operations of TB control programmes, documenting and attempting to distinguish sex- and gender-specific clinic presentations of patients with chest symptoms, sputum requests and submissions, diagnoses, treatment initiation, and outcome.

- Health services and DOTS programmes should develop capacities, either directly or through collaboration, to evaluate psychological, emotional, and social aspects of TB illness and provide locally relevant and gender-sensitive support. Depression and anxiety are general considerations with gender-specific features. For male patients, alcohol and substance abuse should be identified and addressed. Wherever feasible, collaborations with local mental health pro-

grammes should be developed or strengthened, enhancing sensitivity to the mental health component of physical health problems.

- Clinic services should be organized to minimize adverse financial impact and disruption of income-generating activities for patients by ensuring local access and convenient clinic hours. The number of visits required for diagnosis and treatment of TB should be kept to a minimum, and patient-friendly DOT options, such as the feasibility of involvement of guardians at home, should be considered.

- Since TB-related stigma is linked to exaggerated fears of contagion, health information should clearly distinguish appropriate public health precautions to minimize spread from unfounded concerns that contribute inappropriately to stigma and the social and emotional impact of TB. Points of information addressing key aspects of family life and social interactions should be discussed with patients, identifying reasonable and unreasonable precautions to minimize spread.

- Health promotion and information on TB, especially in regions of hyperendemic HIV/AIDS, should clarify the relationship between the two illnesses and their distinctive modes of transmission. Psychological support should be sensitive to the psychosocial impact of each condition and comorbidity. Liaison between clinical services, continuity of care, and community support should be assured.

- National and local strategies to improve detection of patients with TB, with particular attention to reducing patient delay for men and provider delay for women, should consider the impact of strategically reorganizing health and community services. Although it is not suggested that simple formulas or uniform recommendations should be applied everywhere, local options for restructuring critical features of health systems as suggested by site-specific experience in these studies should be considered. They include planning for gender-sensitive active or semi-active case finding (Bangladesh). Such restructuring requires evaluation with reference to local settings, health system contexts, experience, and resources.

- Basic epidemiological and cultural epidemiological monitoring with sex-disaggregated data and focused studies undertaken within the programme or by outside investigators should be implemented in TB control programmes. These efforts are needed to identify, counter, and track gender-specific and setting-specific features of TB illness. Assessments should include: (i) patterns of distress in characteristic presentations of TB pertinent to case finding and clinical management; (ii) perceived causes of TB; (iii) the nature, impact, and deter-

minants of social stigma operating in families, communities, and health systems; and (iv) previous help seeking before coming to a DOTS clinic. Such data should be monitored and analysed with reference to patient and provider delay in identifying cases and starting treatment, and treatment outcomes.

WHO/TBP/DR

CONCLUSION

The cross-site analysis presented in this report has summarized experience in a multi-methods study of gender and TB in four countries. The study was motivated and undertaken in response to open questions about the role of gender in explaining known sex differences in the epidemiology of TB, and to ensure that control programmes are sensitive to gender issues in the course of their routine operations. Experience in this multi-country study contributes to a growing body of knowledge and expertise on identifying and responding to socioculturally defined gender roles and their impact on TB control programmes. The research developed and applied a multi-methods approach for studying the role of gender.

The cross-site analyses of findings presented and discussed in this report have practical implications for improving gender sensitivity and the overall effectiveness of TB control. Findings also highlight critical links between the interests of TB control, gender studies, and the sociocultural contexts of poverty, restricted access to needed resources, and interactions between illness and victimization. Implications are primarily concerned with gender-sensitive and locally appropriate community action, clinic operations, programme monitoring, and action-oriented research for TB control.

WHO/TBP/Davenport

ACKNOWLEDGEMENTS

Patricia Hudelson initially formulated and developed plans for this multi-country study of gender and tuberculosis control through the UNICEF-UNDP-World Bank-WHO Special Programme for Research and Training in Tropical Diseases (TDR) Task Force on Gender Sensitive Interventions (GSI). Plans for collaborative study were developed in workshops in September 1999 and December 2000. Facilitators at these workshops who contributed substantially to the design and development of these studies, in addition to researchers from the study sites, included Mukund Uplekar, Martien Borgdorff, and N.H. Long. Contributions of Penelope Vounatsou and Dominic Gosoniu to the statistical analysis are gratefully acknowledged.

The inputs and efforts of researchers and research staff at each of the study sites is much appreciated. Although not all of them can be named here, several must be acknowledged. At the Bangladesh Rural Advancement Committee (BRAC) site in Bangladesh, these included: M. Akramul Islam, Programme Manager; A. Mushtaque R. Chowdhury, Deputy Executive Director, BRAC; Insana Begum, Anthropologist, BRAC Health Programme; Faruque Ahmed, Director, BRAC Health Programme; Aminul Alam, Deputy Executive Director, BRAC; and Imran Matin, Director, BRAC Research and Evaluation Division. In India, we are grateful to S. Ganapathy, Beena E. Thomas, V. Kumaraswami, Josephine Arokiaselvi, S. Sivasubramanian, S. Alwyn, G. Sangeetha, and Gopinathan of the research team, and K. Karunakaran, Health Officer-in-Charge, Chennai Corporation, for granting permission to carry out the study. In Malawi, we would like to thank Ireen Makwiza, Lifah Sanudi, Nellie Kawazi, Bertha Nhlema, Emily Salima, and G.N. Makhalira as particularly notable representatives of their large research team. Ernesto Jaramillo initially led the development of the project at the Colombia site, and after joining WHO in Geneva, continued to support the study at that site. Graciela Abouchaar, Dyego Cordoba, Joas Benitez, and Cesar Moreira were key members of the research team.

Steven Wayling, Manager of the Research Training Grants for the Research Capacity Strengthening Team at TDR, supported a workshop in July 2002 for training in the study methods. Johannes Sommerfeld, Manager of the Steering Committee on Social, Economic, and Behavioural Research at TDR, supported another analysis workshop for investigators at the Swiss Tropical Institute in January 2003. Support of Johannes Sommerfeld made it possible to undertake and complete these studies, and to produce this report.

REFERENCES

Al Zahrani K, Al Jahdali H, Poirier L, Rene P, Menzies D (2001). Yield of smear, culture and amplification tests from repeated sputum induction for the diagnosis of pulmonary tuberculosis. *International Journal of Tuberculosis and Lung Disease*, 5(9):855–860.

Atre SR, Kudale AM, Morankar SN, Rangan SG, Weiss MG (2004). Cultural concepts of tuberculosis and gender among the general population without TB in rural *Maharashtra, India. Tropical Medicine & International Health*, 9(11):1228–1238.

Balasubramanian VN, Oommen K, Samuel R (2000). DOT or not? Direct observation of anti-tuberculosis treatment and patient outcomes, Kerala State, India. *International Journal of Tuberculosis and Lung Disease*, 4(5):409–413.

Balasubramanian R, Garg R, Santha T, Gopi PG, Subramani R, Chandrasekaran V, Thomas A, Rajeswari R, Anandakrishnan S, Perumal M, Niruparani C, Sudha G, Jaggarajamma K, Frieden TR, Narayanan PR (2004). Gender disparities in tuberculosis: report from a rural DOTS programme in south India. *International Journal of Tuberculosis and Lung Disease*, 8(3):323–332.

Banerji D and Andersen S (1963). A sociological study of awareness of symptoms among persons with pulmonary tuberculosis. *Bulletin of the World Health Organization*, 29:665–683.

Begum V, de Colombani P, Das Gupta S, Salim MAH, Hussain H, Pietroni M, Rahman S, Pahan D, Borgdorff MW (2001). Tuberculosis and patient gender in Bangladesh: sex differences in diagnosis and treatment outcome. *International Journal of Tuberculosis and Lung Disease*, 5(7): 604–610.

Bell D, Leckie V, McKendrick M (2003). The role of induced sputum in the diagnosis of pulmonary tuberculosis. *Journal of Infection*, 47(4): 317–321.

Borgdorff MW, Nagelkerke NJD, Dye C, Nunn P (2000). Gender and tuberculosis: a comparison of prevalence surveys with notification data to explore sex differences in case detection. *International Journal of Tuberculosis and Lung Disease*, 4(2):123–132.

Cassels A, Heineman E, LeClerq S, Gurung PK, Rahut CB (1982). Tuberculosis case-finding in Eastern Nepal. *Tubercle*, 63(3):175–185.

Croft RA, Croft RP (1998). Expenditure and loss of income incurred by tuberculosis patients before reaching effective treatment in Bangladesh. *International Journal of Tuberculosis and Lung Disease*, 2(3):252–254.

DANTB (2002a). Effectiveness of two gender sensitization strategies in RNTCP. New Delhi, New Concept Information Systems (http://www.dantb.org/publictn.html, accessed 19 March 2006).

DANTB (2002b). Low utilization of TB services by women: study in six districts of Orissa. New Delhi, New Concept Information Systems (http://www.dantb.org/publictn.html, accessed 19 March 2006).

Dolin P (1998). Tuberculosis epidemiology from a gender perspective. In: Diwan VK, Thorson A, Winkvist A, eds. *Gender and tuberculosis*, Göteborg, Nordic School of Public Health, pp. 20–40.

Godfrey-Faussett P, Kaunda H, Kamanga J, van Beers S, van Cleeff M, Kumwenda-Phiri R (2002). Why do patients with a cough delay seeking care at Lusaka urban health centres? A health systems research approach. *International Journal of Tuberculosis and Lung Disease*, 6(9):796–805.

HealthScope Tanzania (2003). Factors affecting diagnosis and treatment of tuberculosis among men and women in Tanzania: study report. HealthScope Tanzania, National Tuberculosis and Leprosy Programme. February 2003.

Herek GM, Capitanio JP, Widaman KF (2002). HIV-related stigma and knowledge in the United States: prevalence and trends, 1991–1999. *American Journal of Public Health*, 92:371–377.

Hooi LN (1994). Case-finding for pulmonary tuberculosis in Penang. *Medical Journal of Malaysia*, 49(3):223–230.

Hudelson P (1996). Gender differentials in tuberculosis: the role of socio-economic and cultural factors. *Tubercle and Lung Disease*, 77:391–400.

Johansson E, Long NH, Diwan VK, Winkvist A (2000). Gender and tuberculosis control: perspectives on health seeking behaviour among men and women in Vietnam. *Health Policy*, 52:33–51.

Johansson E, Winkvist A (2002). Trust and transparencz in human encounters in tuberculosis control: lessons learned from Vietnam. *Qualitative Health Research*, 12:473-491.

Kuchartz U (2001). *MAX qualitative data analysis: introduction*. Translated by: John Poppe. Consult Sozialforschung GmbH, Berlin.

Liefooghe R, Michiels N, Habib S, Moran MB, De Muynck A (1995). Perception and social consequences of tuberculosis: focus group study of tuberculosis patients in Sialkot, Pakistan. *Social Science & Medicine*, 41(12):1685–1692.

Long NH, Johansson E, Lönnroth K, Eriksson B, Winkvist A, Diwan VK (1999). Longer delays in tuberculosis diagnosis among women in Vietnam. *International Journal of Tuberculosis and Lung Disease*, 3(5):388–393.

Long NH, Diwan VK, Winkvist A (2002). Difference in symptoms suggesting pulmonary tuberculosis among men and women. *Journal of Clinical Epidemiology*, 55(2):115–120.

Morankar S, Deshmukh D (2001). Socio-cultural aspects of tuberculosis among women: implications for delivery of services. Pune and Mumbai, India, Foundation for Research in Community Health.

Morankar S, Weiss MG (2003). Impact of gender on illness experience and behaviour: implications for tuberculosis control in rural Maharashtra. *Health Administrator*, 15(1–2):149–155.

Murthy KRJ, Yazdani A, Lakshmi KA (2000). Use of oral salbutamol in improving quality sputum microscopy in the DOTS strategy. *International Journal of Tuberculosis and Lung Disease*, 4(12):1191–1192.

National Institute of Mental Health (1996). AIDS and Stigma: A Conceptual Framework and Research Agenda. Final Report from a Research Workshop, 12–13 April 1996 (http://psychology.ucdavis.edu/rainbow/html/stigma98.pdf, accessed 28 August 2004).

Needham DM, Foster SD, Tomlinson G, Godfrey-Faussett P (2001). Socio-economic, gender and health services factors affecting diagnostic delay for tuberculosis patients in urban Zambia. *Tropical Medicine & International Health*, 6(4):256–259.

Pocock D, Khare A, Harries AD (1996). Case holding for tuberculosis in Africa: the patients' perspective. *Lancet*, 347(9010):1258.

Pronyk RM, Makhubele MB, Hargreaves JR, Tollman SM, Hausler HP

(2001). Assessing health seeking behaviour among tuberculosis patients in rural South Africa. *International Journal of Tuberculosis and Lung Disease*, 5(7):619–627.

Raguram R, Raghu TM, Vounatsou P, Weiss MG (2004). Schizophrenia and the cultural epidemiology of stigma in Bangalore, India. *Journal of Nervous and Mental Disease*, 192:734–744.

Rajeswari R, Balasubramanian R, Muniyandi M, Geetharamani S, Thresa X, Venkatesan P (1999). Socio-economic impact of tuberculosis on patients and family in India. *International Journal of Tuberculosis and Lung Disease*, 3(10):869–877.

Shin S, Furina J, Bayonab J, Matec K, Kim JY, Farmer P (2004). Community-based treatment of multidrug-resistant tuberculosis in Lima, Peru: 7 years of experience. *Social Science & Medicine*, 59:1529–1539.

Somma DB, Auer C, Abouihia A, Weiss MG (2005). *Gender and tuberculosis research: status of the field and implications for research*. Geneva, World Health Organization (Department of Gender and Women's Health).

Sudha G, Nirupa C, Rajasakthivel M, Sivasusbramanian S, Sundaram V, Bhatt S, Subramaniam K, Thiruvalluvan E, Mathew R, Renu G, Santha T (2003). Factors influencing the care seeking behaviour of chest symptomatics: a community based study involving rural and urban population in Tamil Nadu, South India. *Tropical Medicine & International Health*, 8(4):336–341.

Thomas C (2002). A literature review of the problems of delayed presentation for treatment and non-completion of treatment for tuberculosis in less developed countries and ways of addressing these problems using particular implementations of the DOTS strategy. *Journal of Management in Medicine*, 16(4–5):371–400.

Thorson A, Hoa NP, Long NH (2000). Health-seeking behaviour of individuals with a cough of more than 3 weeks. *Lancet*, 356:1823–1824.

Thorson A, Hoa NP, Long NH, Allebeck P, Diwan VK (2004). Do women with tuberculosis have a lower likelihood of getting diagnosed? Prevalence and case detection of sputum smear positive pulmonary TB, a population based study from Vietnam. *Journal of Clinical Epidemiology*, 57:398–402.

Uplekar M, Rangan S (1993). Private doctors and tuberculosis control in India. *Tubercle and Lung Disease*, 75:332–337.

Uplekar M, Rangan S, Ogden J (1999). *Gender and tuberculosis control: towards a strategy for research and action*. Geneva, World Health Organization (WHO/CDS/TB/2000.280).

Uplekar MW, Rangan S, Weiss MG, Ogden J, Borgdorff MW, Hudelson P (2001). Attention to gender issues in tuberculosis control. *International Journal of Tuberculosis and Lung Disease*, 5(3):220–224.

Vega P, Sweetland A, Acha J, Castillo H, Guerra D, Smith Fawzi MC, Shin S (2004). Psychiatric issues in the management of patients with multidrug-resistant tuberculosis. *International Journal of Tuberculosis and Lung Disease*, 8(6):749–759.

Vlassoff C, Moreno CG (2002). Placing gender at the centre of health programming: challenges and limitations. *Social Science & Medicine*, 54:1713–1723.

Weiss MG (2001). Cultural epidemiology: an introduction and overview. *Anthropology and Medicine*, 8(1):5–29.

WHO (1948). *Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19–22 June, 1946*; signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organization, No. 2, p. 100) and entered into force on 7 April 1948 (http://www.who.int/about/definition/en/, accessed 25 August 2003).

WHO (2001). Mental health problems: the undefined and hidden burden. Fact Sheet No. 218, revised November 2001 (http://www.who.int/mediacentre/factsheets/fs218/en/print.html, accessed 5 August 2004).

WHO (2002). Gender and tuberculosis. Geneva, World Health Organization (Department of Gender and Women's Health) http://www.who.int/gender/other_health/en/genderTB.pdf, accessed 28 August 2003).

WHO (2003). *The world health report 2003: shaping the future*. Geneva, World Health Organization.

WHO (2004a). *The world health report 2004: changing history*. Geneva, World Health Organization.

WHO (2004b). *Global tuberculosis control: surveillance, planning, financing*. Geneva, World Health Organization (WHO/HTM/TB/2004.331).

APPENDIX: ADDITIONAL DATA TABLES

Appendix Table 1. Patterns of distress: cross-site comparison (Part 1)

Categories of distress	Bangladesh n = 102			India n = 127			Malawi n = 100			Colombia n = 98			Multiple comparisons[a]	
	Spon %	Probe %	Mean	Spon %	Probe %	Mean	Spon %	Probe %	Mean	Spon %	Probe %	Mean		
Cough	90.2	3.9	1.84	89.8	4.7	1.84	72.0	12.0	1.56	73.5	21.4	1.68	***	M C I B
Fever	85.3	4.9	1.75	70.9	11.0	1.53	26.0	44.0	0.96	51.0	34.7	1.37	***	M C I B
Chest pain	55.9	9.8	1.22	26.8	24.4	0.78	31.0	48.0	1.10	11.2	52.0	0.74	***	C I M B
Blood in sputum	13.7	4.9	0.32	18.1	8.7	0.45	9.0	18.0	0.36	14.3	23.5	0.52	*	B M I C
Breathlessness	34.3	12.7	0.81	29.1	34.6	0.93	35.0	40.0	1.10	18.4	52.0	0.89	*	B C I M
Weight loss	36.3	7.8	0.80	29.1	40.9	0.99	28.0	37.0	0.93	25.5	63.3	1.14	**	B M I C
Loss of appetite	60.8	11.8	1.33	34.6	44.1	1.13	12.0	51.0	0.75	24.5	56.1	1.05	***	M C I B
Weakness	69.6	9.8	1.49	53.5	28.3	1.35	42.0	40.0	1.24	42.9	48.0	1.34	**	M C I B
Side-effects of drugs	1.0	1.0	0.03	0.0	2.4	0.02	12.0	47.0	0.71	2.0	28.6	0.33	***	I B C M
Other physical symptoms	21.6	12.7	0.56	19.7	4.7	0.44	21.0	7.0	0.49	33.7	22.4	0.90	***	I M B C
Social isolation	2.0	2.0	0.06	12.6	2.4	0.28	6.0	22.0	0.34	22.4	15.3	0.60	***	B I M C

Appendix Table 1. Patterns of distress: cross-site comparison (Part 2)

Categories of distress	Bangladesh n = 102			India n = 127			Malawi n = 100			Colombia n = 98			Multiple comparisons[a]	
	Spon %	Probe %	Mean	Spon %	Probe %	Mean	Spon %	Probe %	Mean	Spon %	Probe %	Mean		
Stigma - reduced social status	10.8	1.0	0.23	14.2	7.1	0.35	0.0	25.0	0.25	5.1	27.6	0.38	**	B M I C
Marital problem	3.9	2.0	0.10	3.9	2.4	0.10	3.0	9.0	0.15	1.0	5.1	0.07		C B I M
Loss of job and wages	7.8	2.0	0.18	45.7	4.7	0.96	15.0	3.0	0.33	30.6	20.4	0.82	***	B M C I
Reduced personal or family income	34.4	2.0	0.71	28.3	3.1	0.60	44.0	21.0	1.09	28.6	31.6	0.89	***	I B C M
Sadness	85.3	7.8	1.78	74.8	8.7	1.58	45.0	4.0	0.94	39.8	41.8	1.21	***	M C I B
Concern about course of illness	61.8	3.9	1.27	18.1	8.7	0.45	5.0	39.0	0.49	17.3	55.1	0.90	***	I M C B
Other	10.8	1.0	0.23	2.4	0.8	0.06	1.0	1.0	0.03	1.0	7.1	0.09	***	M I C B

Spon, spontaneous response; Probe, probed response.

*P < 0.1, **P < 0.05, ***P < 0.01, Kruskal Wallis test. Site comparisons for each category are based on the mean prominence of responses, calculated from values of "2" for spontaneous, "1" for probed, and "0" for not reported.

[a]For categories with P < 0.05, analysis of differences between individual sites used the Tukey Test with ANOVA for ranked scores. Country with the lowest score on the left.

Appendix Table 2. Patterns of distress: comparison between males and females (%) (Part 1)

Categories of distress	Bangladesh		India		Malawi		Colombia	
	Male n = 52	Female n = 50	Male n = 66	Female n = 61	Male n = 50	Female n = 50	Male n = 50	Female n = 48
Physical Symptoms	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0****
Cough	92.3	96.0	97.0	91.8	84.0	84.0	96.0	93.8
Fever	82.7	98.0***	72.7	91.8**	76.0	64.0	78.0	93.8**
Chest pain	50.0	82.0***	40.9	62.3***	82.0	76.0*	56.0	70.8
Blood in sputum	21.2	16.0	37.9	14.8**	24.0	30.0	40.0	35.4
Breathlessness	15.4	80.0***	56.1	72.1**	76.0	74.0	68.0	72.9
Weight loss	3.8	86.0***	68.2	72.1	52.0	78.0	86.0	91.7*
Loss of appetite	48.1	98.0***	78.8	78.7	62.0	64.0	74.0	87.5
Weakness	59.6	100.0***	78.8	85.2	92.0	72.0***	86.0	95.8***
Side-effects of drugs	1.9	2.0	1.5	3.3	58.0	60.0	32.0	29.2
Other physical symptoms	40.4	28.0	21.2	27.9	8.0	48.0***	48.0	64.6
Social	**13.5**	**24.0**	**33.3**	**24.6**	**38.0**	**52.0**	**44.0**	**45.8**
Social isolation	1.9	6.0	18.2	11.5	26.0	30.0	34.0	41.7
Stigma - reduced social status	7.7	16.0	22.7	19.7	28.0	22.0	32.0	33.3
Marital problems	3.8	8.0	7.6	4.9	8.0	16.0	4.0	8.3

Appendix Table 2. Patterns of distress: comparison between males and females (%) (Part 2)

Categories of distress	Bangladesh		India		Malawi		Colombia	
	Male n = 52	Female n = 50	Male n = 66	Female n = 61	Male n = 50	Female n = 50	Male n = 50	Female n = 48
Financial	**63.5**	**14.0*****	**75.8**	**37.7*****	**78.0**	**60.0****	**60.0**	**62.5**
Loss of job and wages	15.4	4.0*	69.7	29.5***	32.0	4.0***	48.0	54.2
Reduced personal or family income	59.6	12.0***	36.4	26.2	74.0	56.0**	58.0	62.5
Psychological-Emotional	**96.2**	**94.0**	**84.8**	**88.5**	**68.0**	**76.0**	**82.0**	**87.5**
Sadness, anxiety, or worry	92.3	94.0	80.3	86.9	50.0	48.0	78.0	85.4*
Concern about course of illness	44.2	88.0***	19.7	34.4	34.0	54.0*	66.0	79.2
Miscellaneous	**7.7**	**18.0***	**6.1**	**8.2**	**4.0**	**0.0**	**8.0**	**10.4**
Other	7.7	16.0	4.5	1.6	4.0	0.0	6.0	10.4

$^{*}P < 0.1$, $^{**}P < 0.05$, $^{***}P < 0.01$. Cochran–Armitage test for trend for male–female comparisons, based on prominence: 2 = spontaneous, 1 = probed response, 0 = not reported.

Percentage values include combined spontaneous and probed responses. Grouped categories computed from responses and indicated in bold type. Categories reported by less than 5% of respondents were omitted from the table but were included in grouped variables.

Appendix Table 3. Indicators of TB-related stigma and stigma index: cross-site comparison (Part 1)

Indicators of stigma	Bangladesh n = 102				India n = 127				Malawi n = 100				Colombia n = 98				Multiple comparisons[e]	
	% Identified			Mean	% Identified			Mean	% Identified			Mean	% Identified			Mean		
	Yes	Pos	Unc		Yes	Pos	Unc		Yes	Pos	Unc		Yes	Pos	Unc			
1. Desire to keep others from knowing	44.1	3.9	1.0	1.41	70.1	2.4	0.8	2.16	34.0	3.0	2.0	1.10	57.1	5.1	0.0	1.82	***	M B C I
2. Disclosure to confidant (reverse coded) [a, b]	11.8	0.0	0.0	0.35	4.7	0.8	1.6	0.17	35.0	0.0	1.0	1.06	25.5	0.0	0.0	0.77	***	I B C M
3. Think less of yourself	40.2	11.8	3.9	1.48	51.2	8.7	0.0	1.71	23.0	5.0	2.0	0.81	10.2	1.0	3.1	0.36	***	C M B I
4. Shamed or embarrassed	36.3	6.9	1.0	1.24	48.0	7.9	0.8	1.61	9.0	10.0	1.0	0.48	35.7	3.1	0.0	1.13	***	M C B I
5. Others would think less of you	33.3	7.8	7.8	1.24	56.7	9.4	2.4	1.91	14.0	11.0	11.0	0.75	28.6	10.2	5.1	1.11	***	M C B I
6. Adverse effect on others	4.9	3.9	8.8	0.31	18.1	3.9	8.7	0.71	3.0	4.0	26.0	0.43	8.2	6.1	5.1	0.42	**	B C M I
7. Others have avoided you	16.7	9.8	2.0	0.72	14.2	16.5	3.1	0.79	24.0	5.0	13.0	0.95	25.5	5.1	0.0	0.87		B I C M
8. Others refuse to visit	12.7	6.9	2.9	0.55	15.7	7.9	8.7	0.72	5.0	9.0	10.0	0.43	30.6	11.2	4.1	1.18	***	M B I C
9. Others think less of your family	31.4	8.8	5.9	1.18	33.1	12.6	3.1	1.28	11.0	10.0	15.0	0.68	30.6	6.1	4.1	1.08	**	M C B I
10. Problems for your children	20.6	4.9	7.8	0.79	32.3	8.7	11.8	1.26	31.0	10.0	12.0	1.25	51.0	9.2	1.0	1.72	***	B M I C
11. Problem getting married despite cure	51.0	4.9	6.9	1.70	47.2	8.7	11.8	1.71	36.0	10.0	8.0	1.36	16.3	9.2	4.1	0.71	***	C M B I

Appendix Table 3. Indicators of TB-related stigma and stigma index: cross-site comparison (Part 2)

Indicators of stigma	Bangladesh n = 102				India n = 127				Malawi n = 100				Colombia n = 98				Multiple comparisons[e]				
	% Identified			Mean	% Identified			Mean	% Identified			Mean	% Identified			Mean					
	Yes	Pos	Unc		Yes	Pos	Unc		Yes	Pos	Unc		Yes	Pos	Unc						
12. Support from spouse expected (reverse coded)[b]	10.8	1.0	3.9	0.38	9.4	18.9	7.9	0.74	6.0	11.0	6.0	0.46	8.2	1.0	7.1	0.34	***	C	B	M	I
13. Partner refuses sex due to TB	45.1	1.0	0.0	1.37	8.7	8.7	23.6	0.67	22.0	6.0	15.0	0.93	29.6	5.1	4.1	1.03	**	I	M	C	B
14. Other problem in marriage (after cure)	15.7	3.9	3.9	0.59	10.2	10.2	13.4	0.65	21.0	12.0	17.0	1.04	16.3	9.2	2.0	0.69	***	B	I	C	M
15. Problem for relative to marry	19.6	8.8	8.8	0.85	27.6	7.9	9.4	1.08	10.0	5.0	4.0	0.44	18.4	15.3	9.2	0.95	***	M	B	C	I
16. Asked to stay away from work, groups	6.9	3.9	0.0	0.28	4.7	2.4	0.8	0.20	23.0	2.0	1.0	0.74	27.6	1.0	0.0	0.85	***	I	B	M	C
17. Decided to stay away from work, groups	54.9	12.7	0.0	1.90	51.2	2.4	1.6	1.60	29.0	6.0	0.0	0.99	56.1	2.0	0.0	1.72	***	M	I	C	B
18. Presumed other health problems[c]	24.5	3.9	18.6	1.00	No data available				37.0	13.0	8.0	1.45	55.1	8.2	1.0	1.83	***	I	B	M	C
19. Stigma index[d]				0.99				1.17				0.85				1.03	***	M	B	C	I

Pos: possibly, **Unc:** uncertain. *P < 0.1, **P < 0.05, ***P < 0.01. Kruskal-Wallis test.

Kruskal-Wallis test for comparison of prominence across sites, based on responses of yes (3), possibly (2), uncertain (1), and no (0) for responses to each item indicating stigma, and mean of the item total for the index, adjusted for the number of items of each sites.

[a] Item 2 excluded from stigma index for Bangladesh and India, based on Cronbach's alpha analysis.

[b] Items 2 and 12 presented as reverse coded, so that a "yes" response in the table indicates no disclosure/support and more stigma, as for other items.

[c] Item not included for assessment in the interview of the study in India.

[d] Item-adjusted stigma index validated by testing internal consistency with Cronbach's alpha (0.77 for Bangladesh, 0.85 for India, 0.63 for Malawi, and 0.65 for Colombia).

[e] Country with the lowest score on left.

Appendix Table 4. Indicators of TB-related stigma and stigma index: comparison between males and females (Part 1)

Indicators of stigma	Bangladesh n = 102				India n = 127				Malawi n = 100				Colombia n = 98			
	% Identified		Mean		% Identified		Mean		% Identified		Mean		% Identified		Mean	
	M	F	M	F	M	F	M	F	M	F	M	F	M	F	M	F
1. Desire to keep others from knowing	40.4	56.0	1.17	1.66	66.7	78.7	1.97	2.36	36.0	38.0	1.12	1.08	58.0	66.7	1.68	1.96
2. Disclosure to confidant (reverse coded) [a,b]	17.3	6.0	0.52	0.18	7.6	3.3	0.24	0.10	28.0	42.0	0.84	1.28	32.0	18.8	0.96	0.56
3. Think less of yourself	42.3	62.0	1.17	1.80**	54.5	65.6	1.61	1.82	22.0	34.0	0.64	0.98	6.0	16.7	0.20	0.5
4. Shamed or embarrassed	26.9	60.0	0.77	1.72***	48.5	63.9	1.38	1.85*	16.0	22.0	0.46	0.50	32.0	45.8	0.92	1.35
5. Others would think less of you	36.5	46.0	1.15	1.32	57.6	75.4	1.70	2.15*	26.0	24.0	0.84	0.66	44.0	33.3	1.26	0.96
6. Adverse effect on others	7.7	10.0	0.29	0.34	21.2	23.0	0.64	0.79	8.0	6.0	0.42	0.44	12.0	16.7	0.38	0.46
7. Others have avoided you	19.2	34.0	0.48	0.96**	36.4	24.6	0.97	0.59*	34.0	24.0	1.14	0.76	28.0	33.3	0.78	0.96
8. Others refuse to visit	9.6	30.0	0.29	0.82**	24.2	23.0	0.71	0.72	10.0	18.0	0.36	0.50	40.0	43.8	1.16	1.21
9. Others think less of your family	38.5	42.0	1.17	1.18	40.9	50.8	1.11	1.46	28.0	14.0	0.88	0.48*	38.0	35.4	1.12	1.04
10. Problems for your children	19.2	32.0	0.65	0.94	40.9	41.0	1.20	1.33	54.0	28.0	1.56	0.94**	64.0	56.3	1.86	1.58
11. Problem getting married despite cure	59.6	52.0	1.85	1.54	42.4	70.5	1.26	2.20***	34.0	58.0	1.04	1.68**	24.0	27.1	0.66	0.77
12. Support from spouse expected (reverse coded) [b]	7.7	16.0	0.23	0.54	28.8	27.9	0.74	0.74	20.0	14.0	0.50	0.42	2.0	16.7	0.12	0.56**
13. Partner refuses sex due to TB	53.8	38.0	1.62	1.12*	18.2	16.4	0.61	0.74	26.0	30.0	0.92	0.94	38.0	31.3	1.10	0.96

Appendix Table 4. Indicators of TB-related stigma and stigma index: comparison between males and females (Part 2)

Indicators of stigma	Bangladesh n = 102				India n = 127				Malawi n = 100				Colombia n = 98			
	% Identified		Mean		% Identified		Mean		% Identified		Mean		% Identified		Mean	
	M	F	M	F	M	F	M	F	M	F	M	F	M	F	M	F
14. Other problem in marriage (after cure)	0.0	40.0	0.04	1.16***	24.2	16.4	0.67	0.62	26.0	40.0	0.84	1.24	26.0	25.0	0.68	0.71
15. Problem for relative to marry	30.8	26.0	0.88	0.82	28.8	42.6	0.83	1.34**	14.0	16.0	0.42	0.46	48.0	18.8	1.30	0.58***
16. Asked to stay away from work, groups	5.8	16.0	0.12	0.46**	10.6	3.3	0.32	0.07**	36.0	14.0	1.06	0.42**	30.0	27.1	0.90	0.79
17. Decided to stay away from work, groups	80.8	54.0	2.25	1.54**	54.5	52.5	1.61	1.59	52.0	18.0	1.48	0.50***	48.0	68.8	1.42	2.04**
18. Presumed other health problems[c]	23.1	34.0	0.88	1.12	NA	NA	-	-	60.0	40.0	1.76	1.14**	60.0	66.7	1.78	1.88
Stigma index[d]			0.88	1.12**			1.08	1.28			0.89	0.80			1.02	1.05

F: female; **M:** male; **NA:** not assessed.

*P < 0.10, **P < 0.05, ***P < 0.01. Wilcoxon test for male–female comparison of item prominence at each site, based on stigma-indicative responses of yes (3), possibly (2), uncertain (1), and no (0) for each item. For the index, it is based on the mean of the item total, adjusted for the number of items at each site. For categories not assessed, the mean could not be calculated, and this is indicated by "-".

[a] Item 2 excluded from stigma index for Bangladesh and India, based on Cronbach's alpha analysis.

[b] Items 2 and 12 presented as reverse coded, so that a "yes" or "possibly" response indicates no disclosure/support and more stigma, as for other items.

[c] Item not included for assessment in the interview of the study in India.

[d] Adjusted mean for number of items at each site.

Appendix Table 5. Determinants of stigma: gender-based analysis of EMIC variables as coded

Variable	More stigma		Less stigma	
	Variable in model	Females compared with males**	Variable in model	Females compared with males**
Demographic features				
Sex (Female)***	B.05			
Never married	I.01 M.05			
Unskilled labour			M.01	
Trade-business occupation			M.05	
Increasing age			I.05	
Patterns of distress				
Fever			M.01	
Blood in sputum	I.05			
Loss of appetite				B.05
Weakness	B.05		I.05	
Other physical symptoms			I.05	
Social isolation	I.01 M.01			
Reduced social status	B.01 I.01*			I.10
Loss of job and wages		M.01	M.10*	
Reduced personal/ family income	I.15 M.01			
Sadness, anxiety, or worry	I.05 M.05			
Perceived causes				
Food	I.01			
Smoking	M.05			
Physical exertion, work	I.01			
Contamination and contact	I.01			
Climate		I.01	I.05*	
Sexual contact	M.01*			M.01
Help seeking				
Home remedies, self-care, family			I.10	
Druggist/pharmacist for advice	I.05			
Urban government hospital	M.01*			M.01
Private doctors, allopathy			I.01	
Private doctors, specialist			I.15	
Private hospital		B.05 I.01	B.15* I.10*	

Findings are presented for analysis of determinants of stigma in Bangladesh (B), India (I), and Malawi (M). The table summarizes variables retained in multivariate stepwise regression models at each site. More stigma represents a positive coefficient for a variable, and less stigma represents a negative coefficient. Superscripts indicate the upper limit of significance in the multivariate models. Model-adjusted R-square in Bangladesh: 0.33; India: 0.49; Malawi: 0.46. Data were unavailable for comparison from Colombia.
*Variables included in a model that also considered an interaction term for female sex. Effects of the specified variable are for males only. For other variables in this column, without interaction terms in the model, effects are for both males and females.
**Columns based on analysis of interaction of the specified variables with female (compared to male) sex.
***Female sex compared to male; reference for interaction of other variables.

Appendix Table 6. Determinants of stigma: gender-based analysis of grouped EMIC variables

Variable	More stigma		Less stigma	
	Variable in model	Females compared with males**	Variable in model	Females compared with males**
Demographic features				
Sex (Female)***	B.05			
Increasing age			B.01	
Muslim			I.15	
Married			I.05	
No occupation	M.05			
Personal distress				
Physical symptoms			I.15*	
Social	B.01 I.01			
Financial problems	B.05 M.01			
Psychological, emotional	I.05			
Perceived causes				
Health, illness, or injury	I.01			
Help seeking				
Informal and self-medication	M.01			
Government and NGO health services	I.15			
Traditional or faith healers			I.05	

Findings are presented for analysis of determinants of stigma in Bangladesh (B), India (I), and Malawi (M). The table summarizes variables retained in multivariate stepwise regression models at each site. More stigma represents a positive coefficient for a variable, and less stigma represents a negative coefficient. Superscripts indicate the upper limit of significance in the multivariate models. Model-adjusted R-square in Bangladesh: 0.33; India: 0.39; Malawi: 0.20. Data were unavailable for comparison from Colombia.
*Variables included in a model that also considered an interaction term for female sex. Effects of the specified variable are for males only. For other variables in this column, without interaction terms in the model, effects are for both males and females.
**Columns based on analysis of interaction of the specified variables with female (compared to male) sex.
****Female sex compared to male; reference for interaction of other variables.

Appendix Table 7. Perceived causes: cross-site comparison (Part 1)

Perceived causes of TB	Bangladesh n = 102			India n = 127			Malawi n = 100			Multiple comparison[a]			
	Spon %	Probe %	Mean	Spon %	Probe %	Mean	Spon %	Probe %	Mean				
Food	29.4	2.0	0.61	18.1	8.7	0.45	6.0	26.0	0.38		M	I	B
Water	3.90	0.0	0.08	4.7	15.7	0.25	0.0	9.0	0.09	***	B	M	I
Alcohol	1.00	0.0	0.02	20.5	7.1	0.48	13.0	13.0	0.39	***	B	M	I
Smoking	21.6	2.9	0.46	21.3	7.9	0.50	18.0	5.0	0.41		M	B	I
Drug abuse	5.9	2.0	0.14	2.4	1.6	0.06	0.0	11.0	0.11		I	M	B
Prescribed medicine	NA	NA	–	0.0	1.6	0.00	0.0	5.0	0.05		B	I	M
Insect bite	0.0	0.0	0.00	0.0	8.7	0.09	0.0	4.0	0.04	***	B	M	I
Physical exertion, work	26.5	1.0	0.54	6.3	11.0	0.24	4.0	25.0	0.33	**	I	M	B
Blood problems	2.9	1.0	0.07	0.0	12.6	0.13	1.0	11.0	0.13		B	I	M
Prior illness	16.7	1.0	0.34	3.9	3.9	0.12	5.0	6.0	0.16	**	I	M	B
Neglect of prior illness	2.9	0.0	0.06	NA	NA	–	1.0	6.0	0.08		I	B	M
Pregnancy or childbirth	2.9	0.0	0.06	1.6	3.9	0.07	0.0	8.0	0.08		B	I	M
Constitutional weakness	2.9	2.9	0.09	2.4	7.9	0.13	0.0	17.0	0.17	*	B	I	M
Heredity	11.8	2.9	0.26	5.5	6.3	0.17	6.0	18.0	0.30		I	B	M
Mental-emotional stress	3.9	1.0	0.09	9.4	14.2	0.33	0.0	8.0	0.08	***	M	B	I
Sanitation	0.0	0.0	0.00	0.8	18.9	0.20	0.0	13.0	0.13	***	B	M	I
Personal hygiene	1.0	0.0	0.02	2.4	9.4	0.14	0.0	1.0	0.01	***	M	B	I
Germs or infection	15.7	1.0	0.32	11.0	9.4	0.31	1.0	9.0	0.11		M	I	B

Appendix Table 7. Perceived causes: cross-site comparison (Part 2)

Perceived causes of TB	Bangladesh n = 102			India n = 127			Malawi n = 100			Multiple comparison[a]			
	Spon %	Probe %	Mean	Spon %	Probe %	Mean	Spon %	Probe %	Mean				
Contamination - contact	24.5	4.9	0.54	18.9	4.7	0.43	26.0	28.0	0.80	***	I	B	M
Airborne exposure	3.9	1.0	0.09	11.8	13.4	0.37	19.0	43.0	0.81	***	B	I	M
Heat/cold (humoral)	6.9	2.0	0.16	7.9	10.2	0.26	NA	NA	–	*	M	B	I
Climate	3.9	0.0	0.08	0.8	4.7	0.06	3.0	11.0	0.17	**	I	B	M
Punishment - prior deed	0.0	0.0	0.00	5.5	10.2	0.21	NA	NA	–	***	M	B	I
Fate, God, stars [karma]	2.9	2.0	0.08	5.5	11.0	0.22	2.0	18.0	0.22	***	B	I	M
Evil eye, sorcery, etc.	0.0	0.0	0.00	1.6	2.4	0.06	3.0	13.0	0.19	***	B	I	M
Sexual contact	1.0	0.0	0.02	1.6	7.9	0.11	6.0	10.0	0.22	***	B	I	M
Other	19.6	1.0	0.40	16.5	4.7	0.38	3.0	0.0	0.06	***	M	I	B
Cannot say, no idea	1.0	0.0	0.02	7.9	0.8	0.17	41.0	0.0	0.82	***	B	I	M

NA: not assessed; **Probe:** probed response; **Spon:** spontaneous response.

*P < 0.1, ***P < 0.05, ***P < 0.01. Kruskal–Wallis test. Site comparisons for each category are based on the mean prominence of responses, calculated from values "2" for spontaneous, "1" for probed, and "0" for not reported. For categories not assessed, the mean could not be calculated, and this is indicated by "-".

[a]For categories with P < 0 .05, analysis of differences between individual sites by Tukey Test with ANOVA for ranked scores. Country with the lowest score on the left.

Appendix Table 8. Perceived causes: comparison between males and females (%) (Part 1)

Perceived causes	Bangladesh		India		Malawi	
	Male n = 52	Female n = 50	Male n = 66	Female n = 61	Male n = 50	Female n = 50
Ingestion	**76.9**	**40.0*** **	**72.7**	**52.5*** **	**70.0**	**42.0*** **
Food	26.9	36.0	21.2	32.8	38.0	26.0
Water	1.9	6.0	9.1	32.8***	8.0	10.0
Alcohol	1.9	0.0	51.5	1.6***	46.0	6.0***
Smoking	48.1	0.0***	53.0	3.3***	42.0	4.0***
Drug abuse	15.4	0.0***	7.6	0.0**	8.0	14.0
Prescribed medicine	NA	NA	1.5	1.6	6.0	4.0
Health-Illness-Injury	**36.5**	**56.0****	**37.9**	**42.6**	**32.0**	**56.0**
Injury, accident, surgery	1.9	6.0	0.0	0.0	0.0	4.0
Insect bite	0.0	0.0	9.1	8.2	4.0	4.0
Physical exertion, work	32.7	22.0	16.7	18.0	24.0	34.0
Blood problems	0.0	8.0**	13.6	11.5	2.0	22.0**
Prior illness	3.8	32.0***	6.1	9.8	10.0	12.0
Neglect of prior illness	0.0	6.0*	NA	NA	6.0	8.0
Pregnancy or childbirth	0.0	6.0*	1.5	9.8**	0.0	16.0***
Constitutional weakness	0.0	12.0**	10.6	9.8	6.0	28.0***
Heredity	**0.0**	**30.0*** **	**15.2**	**8.2**	**22.0**	**26.0**
Heredity	0.0	30.0***	15.2	8.2	22.0	26.0
Psychological-Emotional	**1.9**	**8.0**	**15.2**	**32.8****	**2.0**	**14.0****
Mental-emotional stress	1.9	8.0	15.2	32.8**	2.0	14.0**

Appendix Table 8. Perceived causes: comparison between males and females (%) (Part 2)

Perceived causes	Bangladesh		India		Malawi	
	Male n = 52	Female n = 50	Male n = 66	Female n = 61	Male n = 50	Female n = 50
Environment	**21.2**	**46.0*** **	**42.4**	**57.4**	**76.0**	**76.0**
Sanitation	0.0	0.0	18.2	21.3	18.0	8.0
Personal hygiene	0.0	2.0	16.7	6.6	0.0	2.0
Germs or infection	5.8	28.0***	18.2	23.0	12.0	8.0
Contamination - contact	19.2	40.0**	19.7	27.9	48.0	60.0*
Airborne exposure	1.9	8.0	22.7	27.9	68.0	56.0**
Traditional cultural, magico-religious	**11.5**	**18.0**	**34.8**	**45.9**	**28.0**	**52.0***
Heat-cold (humoral)	9.6	8.0	15.2	21.3	NA	NA
Climate	1.9	6.0	6.1	4.9	18.0	10.0
Punishment - prior deed	0.0	0.0	13.6	18.0	NA	NA
Fate, God, stars [karma]	0.0	10.0**	10.6	23.0*	2.0	38.0***
Evil eye, sorcery, etc.	0.0	0.0	6.1	1.6	12.0	20.0
Sexual	**0.0**	**2.0**	**4.5**	**14.8**	**4.0**	**28.0*** **
Sexual contact	0.0	2.0	4.5	14.8	4.0	28.0***
Miscellaneous	**26.9**	**16.0**	**33.3**	**23.0**	**34.0**	**52.0***
Other	25.0	16.0	27.3	14.8*	6.0	0.0*
Cannot say, no idea	1.9	0.0	6.1	11.5	30.0	52.0**

NA: not assessed at indicated site.
*P < 0 0.1; **P < 0.05; ***P < 0.01. Cochran–Armitage test for trend for male–female comparisons, based on prominence: 2 = spontaneous, 1 = probed response, 0 = not reported. Percentage values include combined spontaneous and probed responses.
Grouped categories computed from responses and indicated in bold type. Categories reported by less than 5% of respondents were omitted from table but were included in grouped values.

Appendix Table 9. Help seeking: comparison between males and females (%)

Categories of help seeking	Bangladesh		India		Malawi	
	Male n = 52	Female n = 50	Male n = 66	Female n = 61	Male n = 50	Female n = 50
Informal and self-medication	**50.0**	**84.0*** **	**37.9**	**39.4**	**70.0**	**76.0**
Home remedies, self-care, family	36.5	76.0***	13.6	13.1	70.0	74.0
Druggist/pharmacist for advice	15.4	30.0*	28.8	32.8	0.0	6.0*
Health worker	1.9	0.0	1.5	0.0	2.0	18.0**
Local herbal healer	9.6	18.0	0.0	0.0	NA	NA
Government and NGO health services	**34.6**	**24.0**	**53.0**	**44.3**	**62.0**	**90.0*** **
Primary health centre or sub-centre	0.0	6.0*	6.1	1.6	2.0	16.0**
Rural government hospital	0.0	6.0*	4.5	0.0*	6.0	2.0
Urban government hospital	25.0	10.0**	43.9	44.3	52.0	82.0***
NGO health clinic-hospital	13.5	4.0	1.5	0.0	22.0	32.0
Private doctors and facilities	**75.0**	**74.0**	**63.6**	**80.3****	**30.0**	**32.0**
Private practitioner - allopathy	30.8	40.0	54.4	70.5*	2.0	0.0
Private doctor specialist	1.9	4.0	7.6	3.3	2.0	0.0
Private doctor - homeopathy	3.8	14.0*	0.0	0.0	NA	NA
Private hospital	7.7	4.0	6.1	9.8	26.0	32.0
Unqualified doctor (RMP, etc.)	50.0	50.0	0.0	0.0	NA	NA
Traditional or magico-religious healers	**0.0**	**0.0**	**10.6**	**9.8**	**8.0**	**32.0****
Traditional healer	NA	NA	NA	NA	8.0	16.0
Healing temple, dargah	NA	NA	6.1	4.9	0.0	0.0
Religious leader	0.0	0.0	0.0	0.0	0.0	16.0***
Others	**7.7**	**14.0**	**51.5**	**41.0**	**0.0**	**0.0**
TB clinic	7.7	14.0	51.5	41.0	NA	NA

NA: not assessed at indicated site; NGO: nongovernmental organization.
*P < 0.1, **P < 0.05, ***P < 0.01. Cochran–Armitage test for trend for male–female comparisons, based on prominence: 2 = spontaneous, 1 = probed response, 0 = not reported.
Percentage values include combined spontaneous and probed responses.
Grouped categories computed from responses and indicated in bold type. Categories reported by less than 5% of respondents were omitted from the table but were included in grouped values.

Appendix Table 10. Determinants of diagnosis delay: gender-based analysis of EMIC variables as coded

Variable	More delay		Less delay	
	Variable in model	Females compared with males**	Variable in model	Females compared with males**
Demographic features				
Age	B.10			
Education (higher level)	I.10			
Housewife	M.05			
Never married		B.05		M.05
Patterns of distress				
Cough	B.10		I.01	
Blood in sputum			I.05	
Marital problems		B.05		
Loss of job and wages				B.05
Concern about course of illness		M.01	M.15* I.10	
Other physical symptoms	I.15			
Perceived causes				
Food	B.10*			B.01
Drug abuse	M.05			
Heat/cold (humoral)		B.10		
Sexual contact	I.05			
Help seeking				
Private doctor/specialist		I.01		
NGO health clinic–hospital	M.05			
Healing temple, dargah	I.05*			I.05

Findings are presented for analysis of determinants of diagnosis delay in Bangladesh (B), India (I), and Malawi (M). The table summarizes variables retained in multivariate stepwise regression models at each site. More delay represents a positive coefficient for a variable, and less delay represents a negative coefficient. Superscripts indicate the upper limit of significance in the multivariate models. Model-adjusted R-square in Bangladesh: 0.20; India: 0.27; Malawi: 0.25. Data were unavailable for comparison from Colombia.
*Variables included in a model that also considered an interaction term for female sex. Effects of the specified variable are for males only. For other variables in this column, without interaction terms in the model, effects are for both males and females.
**Columns based on analysis of interaction of the specified variables with female (compared to male) sex.

Appendix Table 11. Determinants of diagnosis delay: gender-based analysis of grouped EMIC variables

Variable	More delay		Less delay	
	Variable in model	Females compared with males**	Variable in model	Females compared with males**
Demographic features				
Education (higher level)	I.05			
Female	I.05			
Student		B.10		
Skilled labour	M.10*			M.05
Housewife	M.15			
No occupation	M.15*			M.05
Patterns of distress				
Physical symptoms			M.15*	
Social		B.01	B.05	
Psychological/emotional		M.10		
Perceived causes				
Sexual	I.05*			I.05
Help seeking				
Public health services		M.10		
Traditional or magico-religious healers	I.01*			I.05

Findings are presented for analysis of determinants of diagnosis delay in Bangladesh (B), India (I), and Malawi (M). The table summarizes variables retained in multivariate stepwise regression models at each site. More delay represents a positive coefficient for a variable, and less delay represents a negative coefficient. Superscripts indicate the upper limit of significance in the multivariate models. Model-adjusted R-square in Bangladesh: 0.12; India: 0.28; Malawi: 0.22. Data were unavailable for comparison from Colombia.
*Variables included in a model that also considered an interaction term for female sex. Effects of the specified variable are for males only. For other variables in this column, without interaction terms in the model, effects are for both males and females.
**Columns based on analysis of interaction of the specified variables with female (compared to male) sex.

Appendix Table 12. Patients' experiences in DOTS clinic and social support: comparison of males and females (%)

Indicators of inadequacies experienced by patients	Bangladesh		India		Malawi		Colombia	
	Male n = 52	Female n = 50	Male n = 66	Female n = 61	Male n = 50	Female n = 50	Male n = 50	Female n = 48
Experiences in the clinic								
Difficulty in giving sputum	23.1	84.0***	30.3	37.7	34.0	24.0	26.0	27.1
Inconvenient to go to clinic	5.8	20.0**	6.0	10.5	70.0	30.0***	10.0	10.5
Clinic hours inconvenient	1.9	0.0	6.1	0.0*	28.0	8.0*	4.0	2.1
Long waiting time in the clinic	30.8	56.0***	3.0	3.3	52.0	40.0	20.0	18.7
Some TB drugs not always available	0.0	2.0	1.5	0.0	90.0	98.0	10.0	16.7
Adjustments at home needed to visit clinic	17.3	14.0	22.7	29.5	52.0	76.0**	42.0	66.7**
Costs related to clinic a strain on family	75.0	90.0**	7.6	16.4	34.0	22.0*	14.0	20.9
Coming to clinic was burden for family	26.9	44.0**	12.1	14.8	16.0	10.0	8.0	18.8
Coming to clinic results in lost income	55.7	18.0***	15.2	11.4	26.0	10.0*	22.0	16.7
Social support during the TB episode								
Inadequate support from parental family	26.9	18.0	21.2	19.6	44.0	58.0	2.0	8.3*
Family should have given more support	5.7	26.0***	19.7	29.5	36.0	18.0**	16.0	25.0
Inadequate support from in-laws	53.9	52.0	27.3	41.0*	44.0	52.0	38.0	43.8
In-laws should have given more support	11.5	26.0*	12.1	18.0	22.0	12.0***	2.0	6.2

*P < 0.10, **P < 0.05, and ***P < 0.01. Cochrane–Armitage test for trend analysing the full range of ranked responses. Percentage indicates combined response of "yes" and "possibly" or "somewhat," as alternative to "no" or "uncertain."

Mailing address:
WHO/TDR
World Health Organization
20, Avenue Appia
1211 Geneva 27
Switzerland

Street address:
WHO/TDR
Centre Casai
53, Avenue Louis-Casai
1216 Geneva
Switzerland

Tel: (+41) 22-791-3725
Fax: (+41) 22-791-4854
E-mail: tdr@who.int
Web: www.who.int/tdr