

Cultural epidemiology of TB with reference to gender in Bangladesh, India and Malawi

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SUMMARY

SETTING: TB control programmes in Bangladesh, India and Malawi.

OBJECTIVE: To identify and compare socio-cultural features of tuberculosis (TB) and the distribution of TB-related experiences, meanings and behaviours with reference to gender across cultures in three high-endemic low-income countries.

DESIGN: Approximately 100 patients at three sites were interviewed with in-depth semi-structured Explanatory Model Interview Catalogue (EMIC) interviews inquiring about patterns of distress, perceived causes and help-seeking behaviours in the context of illness narratives.

RESULTS: Female patients reported more diverse symptoms and men more frequently focused on financial concerns. Most patients reported psychological and emotional distress. Men emphasised smoking and drinking

alcohol as causes of TB, and women in Malawi reported sexual causes associated with HIV/AIDS. In Bangladesh, exaggerated concerns about the risk of spread despite treatment contributed to social isolation of women. Public health services were preferred in Malawi, and private doctors in India and Bangladesh.

CONCLUSION: Cross-site analysis of these studies has identified features of TB that influence the burden of disease and are likely to affect timely help seeking and adherence to treatment. Health systems benefit from sex-disaggregated epidemiological data complemented by cultural epidemiological study, which together clarify the role of gender and contribute to the knowledge base for TB control at various levels.

KEY WORDS: tuberculosis; gender; cultural epidemiology; TB control; DOTS treatment

IT IS WIDELY ACKNOWLEDGED that socio-cultural factors influence many health outcomes,^{1,2} particularly for tuberculosis (TB).^{3–5} Gender roles, socially constructed in various settings, may affect access to TB services,^{6–9} detection,^{10–13} treatment adherence¹⁴ and outcome.¹⁵ As the success of TB control programmes is largely determined by patients' ability to self-identify symptoms of TB, seek appropriate care and maintain a rigorous course of treatment, attention to the socio-cultural and gender-specific features of TB are matters of practical significance. Clarifying patients' illness-related experiences, meanings and behaviours may help to explain the socio-cultural and gender-specific determinants of symptom recognition, timely and appropriate help seeking, diagnosis, treatment adherence and cure.

This study employed cultural epidemiological methods to investigate patients' TB illness-related experiences, meanings and behaviours across cultures and with reference to gender in Bangladesh, India and Malawi. The current research is one component of a larger multi-methods study concerned with gender and TB, and operational features of TB control programmes.

Cross-cultural comparisons aim to identify both cross-cutting and distinctive features of local TB-related experience, meaning and behaviour, and how these may contribute to the gender sensitivity of TB control. The cross-site analysis of the cultural epidemiological studies reported here examines and compares the distribution of patterns of distress, perceived causes and help seeking with particular reference to gender, based on research completed at the three study sites.

METHODS

Cultural epidemiological studies investigate the distribution of locally valid representations of illness-related experience, meaning and behaviour. A semi-structured Explanatory Model Interview Catalogue (EMIC) interview, a basic tool for such study, has been developed with inputs of the investigators at the project sites. These interviews query categories of illness experience, meaning and behaviour, and complementary narratives. For these studies of TB and gender, prior ethnographic research informed the selection of appropriate categories of illness experience (patterns

of distress), meaning (perceived causes), help seeking, stigma and other features of illness.

Study sites

The three study sites provide relevant examples from low-income countries with high burdens of TB and well-functioning TB control programmes. The Bangladesh Rural Advancement Committee (BRAC) site in Bangladesh operated exclusively in rural clinics. The sites selected in Malawi and India were both urban. In Bangladesh, the study was conducted in 10 rural subdistricts (*upazilas*) of the BRAC TB control programme, covering a population of approximately 2.5 million people. Operating as a non-governmental organisation (NGO) in partnership with the Bangladesh National TB Control Programme (NTP), BRAC has health centres, like those of this study, in designated regions of the country. BRAC-trained female volunteers work as community health workers, known as *shastho shebikas*.

Chennai, India's fourth largest city, with a population of 4.2 million, was the site of the India study, where the Tuberculosis Research Centre conducted the study in the TB units of 10 health centres, five of which also included family welfare clinics providing maternal and child health (MCH) services. TB control in government-run facilities has followed the guidelines of the Revised National Tuberculosis Control Programme (RNTCP) since 1999. Treatment is given three times a week and is observed in the clinics. Private care plays an important role in help seeking.

In Malawi, the study was conducted in the urban capital, Lilongwe. TB diagnosis and treatment in Malawi is integrated with other district health activities. In addition to the public health system, free TB diagnosis and treatment is offered through a network of non-profit mission health facilities that provide 40% of Malawi's health care services. In urban areas, a small number of private-for-profit health facilities are also associated with the NTP. Other private allopathic practitioners provide care for TB outside the context of the NTP in Malawi.

Instrument

EMIC interviews were created in a project-development workshop, where investigators from each research site represented site-specific interests in questions of the interview and categories for coding. The instrument was informed by ethnographic knowledge from prior studies. Open-ended questions are followed by questions probing locally relevant categories. The respondent's narrative elaborates and explains coded categories and their context. This EMIC interview for cultural epidemiological assessment of TB-related patterns of distress considered a full range of problems associated with the experience of having TB, including not only somatic symptoms but also relevant features of emotional, psychological and social distress. Perceived

causes encompass locally held beliefs regarding the common causes of TB, which may include, but are not limited to, biomedical causal explanations. Categories of help seeking include the range of possible actions a patient might take when ill, including home therapies, spiritual healers and visits to pharmacies, family assistance, private doctors and government clinics, etc.

Design

After the instrument was translated and pilot tested for this study, approximately 100 patients from each site were interviewed in the local language. Patients in the clinical samples at each of the three sites were selected to achieve a nearly equal balance of men and women, and representation of patients who had recently started treatment (2–4 weeks) or had already been in treatment over a longer period (4–5 months) at the time of the interview.

A sample size calculation was based on a 2-sample *t*-test.¹⁶ A sample of 50 men and 50 women makes it possible to detect a difference of 25% from a 50% frequency with 80% power and 95% confidence (2-tailed test). This calculation was applicable to variables to compare men and women at each site.

Data analysis

Categorical and numeric data from the EMIC interviews were double entered and cleaned using Epi Info (Centers for Disease Control and Prevention, Atlanta, GA, USA, version 6.04d). Analysis and comparison of men and women at each site, and respondents across sites, evaluates the prominence of reported categories by taking into account the frequency of respondents reporting the category. The prominence also considers the fraction reporting a category spontaneously, rather than only in response to category-specific probes. Patients were asked to identify the most troubling pattern of distress, the most important perceived cause and first help seeking; these responses contribute further to the prominence of categories to facilitate comparative analysis.

The cross-site analyses and sex-wise comparisons at each site were performed using SAS (Statistical Analysis Software Institute, Cary, NC, USA). A non-parametric statistic, the Kruskal-Wallis test, was used to compare responses specified by the ranked prominence of cultural epidemiological variables (patterns of distress, perceived cause and help seeking)—based on whether categories were reported spontaneously, after probes (less prominence) or were identified as the most salient category (most prominence). Summary variables were compared using the χ^2 or Fisher's exact tests. Individual variables were analysed as such and were grouped thematically for analysis based on overarching shared conceptual features (e.g., physical or social distress, environmental or traditional causes, various traditional health care providers).

Narrative data were captured during the interview by a data collector, translated and transcribed in English. The qualitative features of site-specific or gender-specific findings were analysed and managed with MAXqda software (Verbi Software, Marburg, Germany) for qualitative data. This software enables access to selected text records and specified coded text segments that are based on the topics and framework of the interview. Qualitative phenomenological analysis of illness narratives elaborated the meaning and substructures of categorical codes and explained the nature of relationships identified from quantitative analysis.

RESULTS

Sample characteristics

Among the patients interviewed with the EMIC, most were married, and were mainly Muslim in Bangladesh, Hindu in India and Christian Protestant in Malawi. The majority of women in Bangladesh and India identified themselves as housewives, but women in Malawi were typically employed in trade or business. Men in urban India and Malawi were most commonly employed as either skilled or unskilled labourers, and in rural Bangladesh, most men identified themselves as farmers.

Identification, seriousness and curability of TB

At all sites, few patients had identified their condition as TB prior to a diagnosis. Women at all sites more

frequently regarded their condition as potentially fatal. Overall, TB was considered serious by 67.6% of patients in Bangladesh, 67.0% in Malawi and only 29.1% in India. At the time of the interview, nearly all patients at the three sites said they thought the disease was curable.

Patterns of distress

At all three sites, physical symptoms common to TB were the most prominently reported categories of distress. Women in India and Bangladesh reported multiple vague physical symptoms—including fever, chest pain and breathlessness—with significantly greater prominence than their male counterparts (Table 1). Female patients in both India and Bangladesh reported a higher mean number of categories of physical distress, and significantly more women in Malawi reported ‘other’ symptoms. Bangladeshi women were particularly troubled by cough, which was identified as the most troubling category of distress by 60% of women there (Table 2). Men in both Bangladesh and India were, however, particularly troubled by blood in their sputum. More men in India reported this symptom, and more men in both India and Bangladesh identified it as the most troubling feature of their illness (Tables 1 and 2).

At all sites, the frequency and uniformity with which psychological or emotional distress troubled both male and female patients was particularly striking. Such

Table 1 Patterns of distress: male-female comparison (%)

Categories of distress*	Bangladesh		India		Malawi	
	Male (n = 52)	Female (n = 50)	Male (n = 66)	Female (n = 61)	Male (n = 50)	Female (n = 50)
Physical symptoms	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
Fever	82.7	98.0 [†]	72.7	91.8 [†]	76.0	64.0
Chest pain	50.0	82.0 [†]	40.9	62.3 [†]	82.0	76.0 [†]
Blood in sputum	21.2	16.0	37.9	14.8 [†]	24.0	30.0
Breathlessness	15.4	80.0 [†]	56.1	72.1 [§]	76.0	74.0
Weight loss	3.8	86.0 [†]	68.2	72.1	52.0	78.0
Loss of appetite	48.1	98.0 [†]	78.8	78.7	62.0	64.0
Weakness	59.6	100.0 [†]	78.8	85.2	92.0	72.0 [†]
Side effects of drugs	1.9	2.0	1.5	3.3	58.0	60.0
Other physical symptoms	40.4	28.0	21.2	27.9	8.0	48.0 [†]
Social	13.5	24.0	33.3	24.6	38.0	52.0
Social isolation	1.9	6.0	18.2	11.5	26.0	30.0
Stigma—reduced social status	7.7	16.0	22.7	19.7	28.0	22.0
Marital problems	3.8	8.0	7.6	4.9	8.0	16.0
Financial	63.5	14.0[†]	75.8	37.7[†]	78.0	60.0[§]
Loss of job and wages	15.4	4.0 [†]	69.7	29.5 [†]	32.0	4.0 [†]
Reduced personal or family income	59.6	12.0 [†]	36.4	26.2	74.0	56.0 [§]
Psychological-emotional	96.2	94.0	84.8	88.5	68.0	76.0
Sadness, anxiety or worry	92.3	94.0	80.3	86.9	50.0	48.0
Concern about course of illness	44.2	88.0 [†]	19.7	34.4 [†]	34.0	54.0 [†]
Miscellaneous	7.7	18.0	6.1	8.2	4.0	0.0
Other	7.7	16.0	4.5	1.6	4.0	0.0

* Grouped categories (in bold) computed from responses. Categories reported by less than 5% of respondents omitted from table but included in grouped values.

[†] $P < 0.1$; [‡] $P < 0.01$; [§] $P < 0.05$. Kruskal-Wallis test for male-female comparisons, based on prominence: 2 = spontaneous, 1 = probed response, 0 = not reported. Percentage values include combined spontaneous and probed responses.

Table 2 Most troubling category of distress: male-female comparison (%)

Category of distress*	Bangladesh		India		Malawi	
	Male (n = 52)	Female (n = 50)	Male (n = 66)	Female (n = 61)	Male (n = 50)	Female (n = 50)
Physical symptoms	96.2	98.0	68.2	39.3[†]	46.0	62.0
Cough	32.7	60.0 [†]	31.8	21.3	8.0	20.0
Fever	5.8	10.0	6.1	3.3	0.0	4.0
Chest pain	21.2	18.0	3.0	4.9	8.0	4.0
Blood in sputum	9.6	0.0 [‡]	12.1	0.0 [†]	2.0	4.0
Breathlessness	5.8	4.0	3.0	4.9	22.0	14.0
Weight loss	0.0	0.0	1.5	0.0	0.0	6.0
Weakness	13.5	4.0	6.1	3.3	6.0	4.0
Social	0.0	0.0	7.6	8.2	4.0	2.0
Stigma—reduced social status	0.0	0.0	1.5	6.6	2.0	0.0
Financial	0.0	0.0	9.1	4.9	20.0	16.0
Loss of job and wages	0.0	0.0	9.1	3.3	14.0	10.0
Reduced personal or family income	0.0	0.0	0.0	1.6	6.0	6.0
Psychological-emotional	3.8	2.0	9.1	34.4[†]	26.0	18.0
Sadness, anxiety or worry	0.0	0.0	4.5	13.1	20.0	10.0
Concern about course of illness	3.8	2.0	4.5	21.3 [†]	6.0	8.0

* Grouped categories (in bold) computed from responses. Categories reported by less than 5% of respondents omitted from table but included in grouped values.

[†] $P < 0.01$; [‡] $P < 0.1$. Fisher's exact test for male-female comparisons.

NA = not assessed at indicated site.

symptoms were reported by 95.1% of patients in Bangladesh, 86.6% of patients in India and 72.0% of patients in Malawi (Table 1). Although more female than male patients at all three sites reported worry about the course of their illness, the frequency varied considerably, from 34.4% of women in India to 88.0% in Bangladesh. Indian women who identified this concern, however, were most likely to identify it as the most troubling feature of their distress (21.3%).

In their illness narratives, women from all sites expressed fear that if their TB could not be cured with the treatment they were receiving, their children would become orphans. A Bangladeshi woman explained, 'I was scared I would die. I was afraid for my child. I felt bad, thinking what would happen to him, and who would take care of him.' In Malawi, women expressed fear of not being cured and not having enough money or food to support and nourish themselves and their families throughout the course of their illness.

Women's sadness and anxiety often overshadowed their physical symptoms; an Indian woman told her interviewer, 'I don't feel anything from my physical symptoms, only the sadness, which makes me feel more dull.' For some Indian patients, distress was so severe that they considered suicide, as illustrated in the following account:

Since I have been suffering from this illness, I could not go for work. I have lost income also. This made me have negative thoughts about life. I don't want to live. Many times I thought of committing suicide.

In South Asia, TB-related stigma and social discrimination were particularly troubling for women because they threatened their ability to marry or put them at risk of divorce.

The basis for rejection from their families and communities was rooted in exaggerated ideas about transmission and risk even with treatment. A Bangladeshi woman explained the nature of the devastating social impact:

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 that 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.

For men at all three sites, the reported social impact typically focused on financial problems resulting from their TB. They worried about losing their jobs and income. Somatic symptoms were distressing not only in themselves, but also because they prevented some men from working for long periods. Inconvenient clinic hours contributed to their distress, because it forced them to choose between treatment and work. Even effective treatment could be a problem, as an Indian man explained: 'Now I am getting better, but I am still not able to go to work regularly because I have to come for treatment.' Experience in Malawi showed that some men were concerned not only about missing work while in treatment but also about having no job to return to: 'I was dismissed from work when I fell sick although I explained to my employer that I was on TB treatment. He said that he had replaced me with someone else.'

Perceived causes

The variety of perceived causes—contamination and contact, food, smoking, exposure through the air and

Table 3 Perceived causes: male-female comparison (%)

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 or 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 [†]
Hereditary	0.0	30.0[†]	15.2	8.2	22.0	26.0
Hereditary	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 [‡]
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 [‡]
Trad, cultural, mag-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 [‡]

* Grouped categories (in bold) computed from responses and indicated in uppercase and bold. Categories reported by less than 5% of respondents omitted from table but included in grouped values.

[†] $P < 0.01$; [‡] $P < 0.05$; [§] $P < 0.1$. Kruskal-Wallis test for male-female comparisons, based on prominence: 2 = spontaneous, 1 = probed response, 0 = not reported. Percentage values include combined spontaneous and probed responses.

NA = not assessed at indicated site.

others—is summarised in Table 3. Ingestion-related causes were more frequently reported by men at all sites, and were different from the accounts of women. Men referred to smoking, drinking alcohol (except in Islamic Bangladesh) and drug abuse. Women, on the other hand, referred to contaminated or unclean food or water, eating or drinking outside the home or drinking too much cold water.

Accounts of perceived causes among women in Bangladesh linked contamination and contact with exaggerated notions of their own dangerousness to others. The focus on this aspect of the meaning of TB, based on exaggerated ideas about risk, even from treated patients, contributed to stigma:

I was afraid to think that my mother, brother and sister might get this TB disease from me. It seemed to me that if they would come close to me, eat with

me and sit close to me, then they would get it too. They also thought that they would get this disease from me.

In India and Malawi, more women than men identified psychological stressors as causes of their TB: about a third of women in India and fewer at the other sites (Table 3).

In Malawi, where HIV/AIDS is prevalent, both male and female patients reported sexual causes more than at the other two sites. One woman explained why. 'I think because a person who is found with AIDS is also often being found with TB.' Women in Malawi were more likely to attribute TB to sexual contact than men, and typically found it compelling. About one in three women who referred to this cause identified it as the most important (Table 4). They commonly referred to their husband's infidelity, rather than their own ex-

Table 4 Most important perceived cause: male-female comparison (%)

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
Prescribed medicine	NA	NA	0.0	0.0	0.0	0.0
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
Neglect of prior illness	0.0	0.0	NA	NA	0.0	0.0
Hereditary	0.0	6.0	4.5	3.3	0.0	6.0
Hereditary	0.0	6.0	4.5	3.3	0.0	6.0
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
Germes or infection	0.0	2.0	3.0	6.6	0.0	0.0
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
Punishment—prior deed	0.0	0.0	0.0	1.6	NA	NA
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

* Grouped categories (in bold) computed from responses and indicated in uppercase and bold. Categories reported by less than 5% of respondents omitted from table but included in grouped values.

[†] $P < 0.01$; [‡] $P < 0.1$; [§] $P < 0.05$. Fisher's exact test for male-female comparisons.

NA = not assessed at indicated site.

tramarital contacts. Women were troubled by that, and some had confronted their husbands about it:

I do not know what started the problem. It may be because of my husband; he is a driver, and maybe where he was going, he was with other women. I just stay at home and I have never done such a thing, and this is my thirteenth year in marriage. I tell him that maybe this problem is because of him.

Help seeking

Patients' prior help seeking before coming to the TB treatment clinic where they were interviewed indicates a role for gender differences, local preferences for providers and regional differences in the organisation of health services (Tables 5 and 6). In Bangladesh, women were more likely than men to have used home remedies and self-medication, and there was also high use of such care in Malawi, without sex differences.

In India, private allopathic doctors were the most frequently used source of help for symptomatic TB; this preference was most prominent among women. Women were also more likely to use them first (Table 6). Patients' narratives indicated that although many preferred to seek help from private doctors because

they were convenient, familiar and trustworthy, these services were expensive. Patients reported that they had to take out loans and incur considerable debt. Nevertheless, many of these private doctors had not diagnosed and treated TB. The following account of an Indian woman indicates the frustration of such an experience:

I first went to a private doctor. I was given tablets and injections for fever and expectoration. I mortgaged my jewels and even had to borrow from others to meet that expenditure. That doctor told me that it was only an ordinary fever.

Women studied at the BRAC clinic in Bangladesh reported similar experiences, shopping for care or using private services until they ran out of money. One woman retraced a tortuous trail of help seeking:

At first, I went to a traditional healer. Then I went to a village doctor, but he did not give me any medicine. He told me to go to another doctor. Last of all, I went to BRAC, and TB was found after the cough test. Then they started treatment. People from my home thought that I was caught by some evil spirit. That is why they took me to that healer.

Both male and female patients explained they did

Table 5 Help seeking: male-female comparison (%)

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 & 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 & 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 & 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
Magico-traditional 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 [†]
Other TB clinic	7.7	14.0	51.5	41.0	NA	NA
Others	0.0	0.0	0.0	0.0	0.0	0.0

* Grouped categories (in bold) computed from responses. Categories reported by less than 5% of respondents omitted from table but included in grouped values.

[†] $P < 0.01$; [‡] $P < 0.1$; [§] $P < 0.05$. Kruskal-Wallis test for male-female comparisons, based on prominence: 2 = spontaneous, 1 = probed response, 0 = not reported. Percentage values include combined spontaneous and probed responses.

NA = not assessed at indicated site; NGO = non-governmental organisation; RMP = rural medical practitioner.

not seek care at first from the BRAC clinic because it was too far from home, and the road to get there was often difficult to pass. Patients commonly said that treatment would have been easier had the *shebikas* delivered medicines to their homes. Still others, particularly female patients, reported that travel to the

clinic was costly and they often needed to arrange for their husbands or brothers to come with them, which meant that these men would lose wages or would have to take time out from farming.

Some patients in Bangladesh said they could not afford the deposit charged by the BRAC. Although

Table 6 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 & 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
Local herbal healer	1.9	8.0	0.0	0.0	NA	NA
Government & NGO health services	9.6	8.0	28.8	19.7	46.0	46.0
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
Private doctors & 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 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
Magico-traditional healers	0.0	0.0	0.0	0.0	6.0	14.0
Traditional healer	NA	NA	NA	NA	6.0	10.0
Other TB clinic	0.0	0.0	6.1	4.9	NA	NA
Study clinic	5.8	6.0	7.6	4.9	30.0	26.0

* Grouped categories (in bold) computed from responses. Categories reported by less than 5% of respondents omitted from table but included in grouped values.

[†] $P < 0.05$.

[‡] $P < 0.1$. Fisher's exact test for male-female comparisons.

NA = not assessed at indicated site; NGO = non-governmental organisation; RMP = rural medical practitioner.

the fee is waived for the ultra-poor, many patients did not want to admit they needed the waiver, and some preferred to take a loan. One such patient advised:

My suggestion is that if they would provide free treatment without taking 200 *taka*, then it would be very helpful for poor people like me. I had to take a loan with interest to pay 200 *taka*. How can a poor person like me manage 200 *taka* at a time?

DISCUSSION

Findings from this cross-site analysis of multi-country studies indicate social and cultural factors that operate in the context of the gender-specific barrier framework, which has been proposed to guide research accounting for the role of gender in TB control.^{4,17} That framework, which was a motivating consideration from the outset in planning these studies, suggests that socio-cultural features of gender help to explain how men and women with TB proceed along a course with selective gender differentials in experiencing and interpreting symptoms, which affects their efforts to find relief and successfully engage in treatment. The cultural epidemiological approach, using EMIC interviews for this research, elicited patterns of categorical responses that are further clarified by relating them to characteristic narrative contexts. The research thereby helps to explain the role of gender in the cultural epidemiology of TB and indicates an approach to analysing gender and other socio-cultural determinants of gender differentials in TB control.

Limitations

These studies were undertaken to examine site-specific socio-cultural and gender-related features of TB at designated treatment sites. Although sample sizes were moderate, they were adequate for gender comparisons within sites and analysis across sites. Clinical samples were selected to represent the patient population of the well-functioning TB control programmes at the study sites, but they were not intended to represent a profile of TB for the entire country or even the community where the treatment sites are located. Differences within countries and communities may vary according to the socio-economic status of the clinical populations, urban/rural differences and whether and where a person with TB presents for treatment. Among our three study sites, one was rural and two were urban.

Because the studies were based at diverse TB clinic sites, the question of how to generalise findings must be considered carefully. The countries of these studies are diverse, and the local clinics serve not only a segment of society but also the subset of people with TB who reach these clinics for treatment. The findings are clearly relevant for the patient population of these clinics, and they may also have broader relevance. The research clarifies programme-relevant social and

cultural dimensions of gender, and it also indicates an approach that may be usefully adapted for other programmes. The broader interests of a community study of the cultural epidemiology of TB, however, would require a design with broader scope, also considering untreated persons with TB.

Implications for control

Several findings from this study provide relevant information with implications for TB control programmes.

1) *Female patients may present to health centres with atypical symptoms for TB*

Female patients eventually diagnosed with TB reported a higher mean number of categories of physical distress, reflecting a wider range of symptoms less specific for TB. Furthermore, female patients were less likely to report characteristic symptoms of TB, such as blood in their sputum. Other investigators in South and South-East Asia have also noted that female TB patients were less likely to experience blood in their sputum.^{18,19} As health staff may be less able to identify TB among patients presenting with atypical symptomatology, documenting local patterns of distress associated with TB benefits clinical management and ensures the relevance of training for clinical health staff and their sensitivity to local presentations of TB.

2) *Psychological and emotional distress among TB patients is substantial*

Our findings show that both male and female patients experience considerable psychological and emotional distress associated with TB, and that the nature of this suffering is often gender-specific. The World Health Organization (WHO) estimates that up to 46% of TB patients suffer from major depression.²⁰ References to suicide at our study sites indicate the severity of these patients' distress. Such findings support the priority of mental health as an integral feature of general health, an aspect of the WHO definition of health that is particularly relevant for tuberculosis.²¹ Appreciation of this interaction should guide clinical management, staff training and organisation of TB services and support networks.

Recognising the potential impact of the emotional component of TB illness on suffering, help seeking and treatment adherence, clinical care should include an assessment and capacity for non-specialist support and counselling, or referral when indicated. Even where referral services may be lacking, support networks and patient groups may benefit from solidarity among current and recovered patients in treatment programmes.²²

3) *The financial burden of TB and help seeking*

The financial impact of seeking TB care contributes to the undefined burden of disease, with consequences

for patients, their families and communities. Financial burdens associated with TB disease result from help-seeking expenses, additional nutritional requirements, opportunity costs related to lost productivity and wages lost due to absences. The financial impact of TB has been recognised in other studies in Bangladesh,²³ India²⁴ and Malawi.²⁵ Men in our samples were particularly troubled by financial distress and loss of work and wages resulting from seeking care for TB, which, as shown by Balasubramanian et al.,⁶ limits men's access to health services and their adherence to a full course of treatment.²⁶

The opening hours of clinics should therefore be extended to accommodate wage earners. Enhancing health systems to provide treatment for TB in the workplace will also improve treatment adherence and outcomes for working patients. For poor rural patients, the burden of financial deposits must be weighed against programme needs and alternative approaches to motivating commitment to treatment. Programmes should carefully monitor the impact of control strategies in the changing socio-economic contexts of their service areas.

4) Gender- and site-specific ideas about the spread of TB may motivate help seeking or contribute to stigma, particularly exaggerated perceptions of risk

Patients in our study reported gender-specific behaviours associated with perceived causes of TB, including smoking for men and perceived causes related to food and water for women. As patients' beliefs about what causes TB influence help-seeking behaviour, clarifying modes of transmission and perceived risk in the community may help to shorten patient delay.

Stigma is often a product of exaggerated notions of contagiousness. Community awareness and patient education help to mitigate the isolation and rejection of TB patients and encourage TB suspects to seek initial care. As reported elsewhere in South Asian studies,²⁷ investigators in our multi-site studies found that TB patients, particularly women in India and Bangladesh, were frequently avoided, isolated or divorced because family and community residents feared being contaminated and placed at risk for TB from casual contact with them.

Health care providers should ensure that patients and their families understand the benefits of treatment and the duration of infectiousness after the start of treatment. Support to patients from community members, recovered patients and others may also facilitate destigmatisation of TB and promote awareness of its transmission, course and cure.

In areas where the dual TB-HIV/AIDS epidemic is substantial, integrated TB and HIV control strategies should recognise and address the related interests of the two conditions, and be attentive to professional and local vantage points. Both conditions require a

balance of efforts to support patients and correct unfounded, exaggerated ideas about their dangerousness and risks they pose to others. These priorities co-exist, however, with programme strategies based on rational approaches to preventing the spread of these conditions.

5) Effective collaboration with private practitioners is needed in areas where they are preferred

Our findings show that patients in the South Asian sites, especially women, prefer private practitioners when seeking help for symptoms of TB, and they often consult these doctors first. Our findings are consistent with a broad range of experiences in South Asia,^{3,7} which acknowledge the appeal of private services.^{8,27,28} The differences between private services in India and Bangladesh, however, also highlight the diverse nature and heterogeneity of public-private mixes. Research to explain how they work, opportunities for effectively building alliances within health systems, and other strategies for working between public and private sectors in both rural and urban settings have appropriately become an increasing priority of global TB control.^{29,30}

CONCLUSION

The findings from this study have identified features of TB and local profiles of illness-related experience, meaning and behaviour for patients treated in TB control programmes in Bangladesh, India and Malawi. The findings demonstrate gender-based vulnerabilities of men and women that require attention in local and national programmes. Our cross-site analysis of these studies has identified cross-cutting and culture-specific features of TB that influence the burden of the disease and are likely to affect timely help seeking and adherence to treatment. The approach has also guided the study of the determinants of stigma and delayed diagnosis.^{31,32} Health systems benefit from classical sex-disaggregated epidemiological data complemented by cultural epidemiological study, which together clarify the role of gender and contribute to the knowledge base of TB control programmes at various levels.

Acknowledgements

The research on which this cross-site analysis is based was supported by the Special Programme for Research and Training in Tropical Diseases (TDR) at the WHO. P Hudelson initiated the multi-country study of gender and tuberculosis control through the TDR Task Force on Gender-Sensitive Interventions. Plans for collaborative study were developed in workshops in September 1999 and December 2000. In addition to researchers from the study sites, facilitators at these workshops who contributed substantially to the design and development of these studies include M Uplekar, M Borgdorff, and N H Long. J Sommerfeld facilitated arrangements for the research and cross-site analysis in his capacity as manager of the TDR Steering Committee for Social, Economic and Behavioural Research, which has overseen the study portfolio since the TDR Task Force on Gender-Sensitive Interventions ended in 1999.

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RÉSUMÉ

CONTEXTE : Programmes de lutte contre la tuberculose (TB) au Bangladesh, en Inde et au Malawi.

OBJECTIF : Identifier et comparer les caractéristiques socioculturelles de la TB et la répartition des expériences liées à la TB, leur signification et les comportements par rapport au sexe au sein des cultures de trois pays à faibles revenus et à haute prévalence.

SCHÉMA : On a interviewé environ 100 patients dans

trois sites différents en utilisant une interview semi-structurée approfondie (EMIC), recherchant les types de détresse, la perception de leurs causes et les comportements de recherche d'aide dans le contexte des récits de maladie.

RÉSULTATS : Les patientes tuberculeuses de sexe féminin ont signalé des symptômes plus variés, alors que les hommes signalaient plus fréquemment des soucis finan-

ciers liés à la maladie. La plupart des patients ont signalé une détresse psychologique et émotionnelle. Les hommes ont souligné le rôle du tabagisme et de l'alcoolisme comme sources de la TB, alors qu'au Malawi les femmes ont signalé une origine sexuelle en mettant en relation la TB et le VIH/SIDA. Au Bangladesh, les soucis abusifs au sujet du risque de contamination malgré le traitement ont contribué à un isolement social des femmes atteintes de TB. Au Malawi, la préférence va aux services de santé publique, alors qu'en Inde et au Bangladesh, elle va aux médecins privés.

CONCLUSION : Une analyse inter-sites de ces études a influencé des caractéristiques de la TB qui influencent le fardeau de la maladie et sont susceptibles d'influencer défavorablement un recours aux soins en temps utile et l'adhésion au traitement. Les services de santé peuvent bénéficier de données épidémiologiques classiques dissociées en fonction du sexe, complétées par une étude épidémiologique culturelle : ensemble, elles clarifient le rôle du sexe et contribuent à la base de données utile à la lutte antituberculeuse à divers niveaux.

RESUMEN

MARCO DE REFERENCIA : Los programas de control de la tuberculosis (TB) en Bangladesh, India y Malawi.

OBJETIVO : Definir y comparar las características socio-culturales de la TB y la distribución de las experiencias relativos a la enfermedad, y su significación comportamientos en función del género, entre las culturas de tres países de bajos ingresos los con una alta endemia de TB. **MÉTODO :** Se estudiaron cerca de 100 pacientes en cada uno de los tres centros mediante una entrevista en profundidad semiestructurada (EMIC) sobre los tipos de preocupaciones, la percepción de las causas de la TB y los comportamientos de búsqueda de ayuda en el contexto de las narrativas sobre la enfermedad.

RESULTADOS : Las mujeres con TB informaron síntomas más diversos y los hombres refirieron con mayor frecuencia preocupaciones económicas relacionadas con la enfermedad. La mayoría de los pacientes comunicó trastornos psicológicos y emocionales. Los hombres hicieron énfasis en el tabaquismo y el consumo de alcohol como

causas de la enfermedad y las mujeres de Malawi describieron causas de tipo sexual, relacionando la TB con la infección por el VIH/SIDA. En Bangladesh, las preocupaciones desproporcionadas sobre el riesgo de transmisión pese al tratamiento, contribuyeron al aislamiento social de las mujeres con TB. En Malawi, se acudió de preferencia a los servicios de salud pública y en India y Bangladesh a los médicos del sector privado.

CONCLUSIÓN : El análisis cruzado de los resultados de estos estudios identificó las características que influyen sobre la carga de morbilidad por TB y que pueden impedir la búsqueda oportuna de atención de salud y el cumplimiento terapéutico. Los datos epidemiológicos discriminados según el sexo, aunados a los datos del estudio cultural aportan información útil a los sistemas de salud y contribuyen a elucidar la función del género y a enriquecer la base de conocimientos para el control de la TB en diferentes niveles.