SPECIAL SECTION

Gender and socio-cultural determinants of TB-related stigma in Bangladesh, India, Malawi and Colombia

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── S U M M A R Y

SETTING: Tuberculosis (TB) control programmes in
Bangladesh, India, Malawi and Colombia.
OBJECTIVE: Assess indicators of TB-related stigma and
socio-cultural and gender-related features of illness associated with stigma.
DESIGN: Semi-structured Explanatory Model Interview
Catalogue (EMIC) interviews were administered to 100
or more patients at each site, assessing categories of distress, perceived causes and help seeking. Indicators of
self-perceived stigma were analysed individually and in a
validated index, which was compared across sites and
between men and women at each site. Cultural epidemiological explanatory variables for stigma and interactions
with female sex were analysed at each site. Qualitative
illness narratives were examined to explain the role and
context of explanatory variables.

RESULTS: The overall stigma index was highest in India,
lowest in Malawi and greater for women in Bangladesh.
In India and Malawi, women were more likely to be concerned about impact on marital prospects. Associations
with HIV/AIDS were linked to TB stigma in Malawi,
where sexual contact as a perceived cause was more associated with stigma for men and less for women.
CONCLUSION: Stigma both influences and indicates the
effectiveness of TB control. Cultural epidemiological
methods clarify cross-cutting and local features of stigma
and gender for TB control.
KEY WORDS: tuberculosis; stigma; gender; DOTS treatment; cultural epidemiology

WITH approximately one third of the world infected,
tuberculosis (TB) is a leading global cause of morbidity and mortality.[1] Because TB control relies on passive
case finding and an effective alliance with patients and
communities for adherence to a relatively long course
of treatment, socio-cultural factors that influence illness behaviour are particularly important. Among
them, public health has been concerned with contexts
of poverty and, more recently, questions of stigma and
gender.[2,3] Although the details and nature of its magnitude, determinants and effects have been difficult to
assess, TB-related stigma is a matter of practical concern because it contributes to suffering as a component
of the so-called hidden burden of disease,[4] and it
may interfere with treatment and control. Stigma may
lead someone with TB to hide symptoms, avoid or
delay seeking care, hide a diagnosis or default from
treatment.[5-8] Health professionals thus have a practical
interest in alleviating the impact of stigma and intervening to counter these effects, which not only affect
individual patients but also promote further spread
and drug resistance.

Social stigma may persist despite effective treatment,
and it may be experienced as overt social exclusion
(enacted stigma) or anticipation of it (felt stigma).[9]
Research from high-burden areas has shown that TB
patients face various levels of isolation and rejection
from families and communities, including fear of or
actual job loss,[5,10] divorce or spoiled marriage prospects,[11] and isolation at home that forbids sharing
food, utensils or sleeping space.[12-14] Stigma studies
have considered the cultural ideas about TB associated with socially unacceptable lifestyles and behaviour with particular reference to sexual behaviour,[15]
'dirtiness and promiscuity',[16] alcohol, smoking[14] and
'sins'.[11] Although TB stigma is widespread, manifestations, associations and implications may vary in different settings.

The occurrence and nature of stigma are also likely
to reflect local gender roles. Several studies show that
TB-related stigma is worse for female patients than it
is for males,[17] potentially resulting in divorce or separation. These factors and other aspects of gender-based
vulnerability, such as limited mobility and financial

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dependency, may discourage women with TB from seeking care because they fear the effects of public disclosure of the diagnosis. It is not clear how pervasive and powerful such gender-based features of TB stigma actually are, although the answer to such questions is clearly important for TB control, which depends on passive case finding and hence illness behaviour.

Cultural epidemiology offers an approach to assessing various aspects of stigma, considering their prominence quantitatively and the nature of stigma, context and impact qualitatively. Cultural epidemiology is the study of locally valid representations of illness, specified by variables, descriptions and narratives accounting for the experience of illness, its meaning and related help-seeking behaviours.[18] Employing this approach, the current study examined locally relevant features of TB-related stigma in Bangladesh, India, Malawi and Colombia, and their socio-cultural determinants in three of these sites. It considered how various categories of distress, perceived causes and prior help seeking affect the magnitude and nature of patient-reported stigma and how gender modified the effect of such variables.

METHODS

Study sites

The four study sites represented low- and lower-middle-income countries with a high burden of TB and well-functioning programmes for TB control. The Bangladesh programme operated exclusively in rural clinics; the sites selected in Malawi, India and Colombia were urban.

In Bangladesh, the study was conducted in 10 rural subdistricts (*upazila*s) of the Bangladesh Rural Advancement Committee (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 site, 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 in 2001 of 4.2 million, was the research site in India. The Tuberculosis Research Centre conducted the study in tuberculosis treatment units of 10 health centres, five of which also included family welfare clinics providing maternal and child health services. Tuberculosis control in India's 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.

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

Cali is the second largest city in Colombia, with a population of 2.2 million people. In response to the difficult conditions of an earlier World Health Organization (WHO) demonstration site for tuberculosis control, 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 obligated by law to provide diagnostic and treatment services for TB control.

Instrument

Semi-structured explanatory model interviews with a common core structure were developed in a project development workshop of investigators from the four sites. These EMIC (Explanatory Model Interview Catalogue) interviews provide a framework for studying cultural epidemiology that is adapted for disease- and site-specific features of illness.[19] EMIC interviews for these studies included an assessment of patient-perceived stigma. Prior ethnographic research informed the construction of questions and categories for coding categories of distress, perceived causes and help seeking. The prominence of coded categories was based on whether responses identifying that category were reported spontaneously in response to an open question or only in response to probing for that category. If a category was identified as most important among all reported categories, this contributed further to its prominence.

Eighteen indicators of stigma were included in the interview, based on local ethnographic and clinical data and experience of previous studies.[11,14] These indicators included aspects of disclosure of the disease, shame, social isolation, relations with others and marriage. Responses to these questions were coded to represent a range of responses from full to no acknowledgement, assigning values of 3 for yes, 2 for possibly, 1 for uncertain and 0 for no, indicating a relative contribution to stigma for that question.

Design

Approximately 100 patients from each site were interviewed in their local language with the EMIC. Patients in the clinical samples at each of the three sites were selected to achieve a nearly equal balance of men and women.

Data analysis

Categorical and numeric data from the EMIC interviews were double-entered and cleaned using Epi Info

(version 6.04d, Centers for Disease Control and Prevention, Atlanta, GA, USA), and cross-site statistical analysis used SAS (Statistical Analysis Software Institute, Cary, NC, USA) software. Questions about different aspects of stigma were analysed individually, and an index was assessed for internal consistency with the Cronbach's alpha statistic. Higher values of Cronbach's alpha approaching a maximum value of 1 indicate greater internal consistency. Analysis of the item to total correlation and analysis of alpha for excluded variables identified items to be dropped from the index. The Kruskal-Wallis and Wilcoxon tests were used to test for differences in the prominence of reported indicators of stigma and an index of stigma, comparing men and women within sites and comparing the samples across sites.

Determinants of stigma, represented by the stigma index, were analysed with reference to demographic variables and the prominence of cultural epidemiological explanatory variables from the EMIC interviews for categories of distress, perceived causes and prior sources of help seeking. Each of the coded variables was examined individually, and they were also analysed as groups, based on common features (e.g., somatic and social for patterns of distress; psychological, environmental, health-injury-illness-related for perceived causes; and so forth). The effects of these grouped variables on stigma were also studied.

In view of our particular interest in gender, we also considered effect modification, assessing interactions between sex and each variable, examining female sex with reference to male sex as a baseline. This enabled us to identify gender-related differences in the effect of explanatory variables. A crude analysis identified the role of explanatory variables and their interactions with sex. Explanatory variables with $P < 0.3$ were analysed in a multivariate model to adjust for confounding. A normal transformation of the stigma index was made to fulfil conditions for linear regression. The multivariate model used forward selection and an entry value of $P < 0.15$.

Narrative data were transcribed during the interview by a data collector and translated into English at all sites except Colombia (Spanish only). A phenomenological qualitative data analytic approach was used to explain the role of significant explanatory variables and to clarify the narrative context. Thematically distinct portions of the narrative concerning particular aspects of stigma and its determinants were coded, and access to them for the sample or subsets of the sample (based on more, less or particular features of stigma) facilitated efforts to relate the quantitative and qualitative interests of the study. MAXqda, a software program for qualitative data management and analysis (Verbi Software, Marburg, Germany), was used to code these narrative data with reference to EMIC interview items. Selection variables were imported from the quantitative data set to select records

of particular interest, based on demographic or response criteria.

RESULTS

Sample characteristics

The majority of patients studied were Muslim in Bangladesh, Hindu in India, Christian Protestant in Malawi and Catholic in Colombia. Most in Bangladesh, India and Malawi were married. In Colombia, patients were typically cohabiting with a partner or had never been married. A majority of women in Bangladesh, India and Colombia identified themselves as housewives, but women in Malawi were typically employed in trade or business. Men in urban India, Malawi and Colombia were most commonly employed as either skilled or unskilled labourers, and in rural Bangladesh, most men identified themselves as farmers. The majority of patients in Bangladesh had not received any formal education, the majority of patients in Colombia had attended formal education for 5 years, and the majority in India and Malawi reported 6 to 10 years of education.

Assessment of stigma

The local index of stigma across sites is presented in the figure. The internal consistency of the item-adjusted index was good in India (Cronbach's alpha 0.85) and Bangladesh (0.77), and acceptable in Malawi (0.63) and Colombia (0.65). Item 2 ('disclosure to confidant') was dropped in the two South Asian sites based on the analysis of Cronbach's alpha. Item 18 ('presumed other health problem,' referring to HIV/AIDS) was not assessed in the local adaptation of the interview
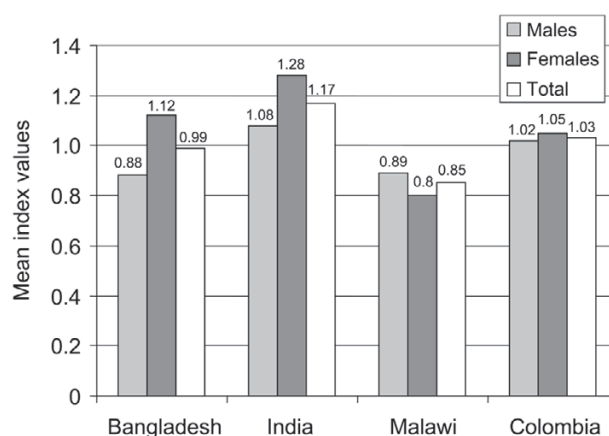

Figure Stigma index at each site by sex. Note: Item-adjusted stigma index validated by testing internal consistency with Cronbach's alpha (0.77 for Bangladesh, 0.85 for India, 0.63 for Malawi and 0.65 for Colombia). Wilcoxon test for male-female comparison: Bangladesh ($P = 0.04$), India ($P = 0.11$), Malawi ($P = 0.24$) and Colombia ($P = 0.76$), based on the mean of the item total, adjusted for the number of items at each site. Cross-site comparison based on Tukey test with ANOVA ($P < 0.01$), indicating differences between index in India and Malawi only. ANOVA = analysis of variance.

in India. Comparisons were based on the value of the index adjusted for the number of items, so they were comparable. India had the highest item-adjusted stigma index (1.17), and Malawi the lowest (0.85). Although the difference between India and Malawi was significant, neither of them differed significantly from the index in the other two sites (0.99 for Bangladesh and 1.03 for Colombia). Female patients in Bangladesh had a significantly higher stigma index ($P = 0.04$), and in India, the male-female difference was suggestive but not significant ($P = 0.11$).

The comparison of stigma indicators across the

Table 1   Indicators of tuberculosis-related stigma: cross-site comparison (mean)

Indicators of stigma	Bangladesh (n = 102)	India (n = 127)	Malawi (n = 100)	Colombia (n = 98)	Multiple comparison*
1 Desire to keep others from knowing	1.41	2.16	1.10	1.82†	M B C I
2 Did not disclose to confidant‡	0.35	0.17	1.06	0.77†	I B C M
3 Think less of yourself	1.48	1.71	0.81	0.36†	C M B I
4 Shamed or embarrassed	1.24	1.61	0.48	1.13†	M C B I
5 Others would think less of you	1.24	1.91	0.75	1.11†	M C B I
6 Adverse effect on others	0.31	0.71	0.43	0.42§	B C M I
7 Others have avoided you	0.72	0.79	0.95	0.87	B I C M
8 Others refuse to visit	0.55	0.72	0.43	1.18†	M B I C
9 Others think less of the patient's family	1.18	1.28	0.68	1.08§	M C B I
10 Problems for your children	0.79	1.26	1.25	1.72†	B M I C
11 Problem getting married despite cure	1.70	1.71	1.36	0.71†	C M B I
12 Did not expect support from spouse	0.38	0.74	0.46	0.34†	C B M I
13 Partner refuses sex due to tuberculosis	1.37	0.67	0.93	1.03§	I M C B
14 Other problem in marriage (after cure)	0.59	0.65	1.04	0.69†	B I C M
15 Problem for relative to marry	0.85	1.08	0.44	0.95†	M B C I
16 Asked to stay away from work, groups	0.28	0.20	0.74	0.85†	I B M C
17 Decided to stay away from work, groups	1.90	1.60	0.99	1.72†	M I C B
18 Presumed other health problems¶	1.00	—	1.45	1.83†	I B M C

*Country with the lowest score on left.
†$P < 0.01$, Kruskal-Wallis test. Kruskal-Wallis test for comparison of prominence across sites, based on 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.
‡Item 2 excluded from stigma index for Bangladesh and India, based on Cronbach's alpha analysis.
§$P < 0.05$; Kruskal-Wallis test.
¶Item not included for assessment in the interview of the study in India.
M = Malawi; B = Bangladesh; C = Colombia; I = India.

sites is presented in Table 1. All of the indicators of stigma were reported with significant differences across the sites, with one exception. Patients were consistent across sites in the view that others in their community had avoided them as a result of TB (item 7).

Gender-specific features of stigma

Comparison of men and women for reported indicators of stigma at each site are presented in Table 2. In Bangladesh and to a lesser degree in India, impaired self-esteem, shame/embarrassment and perceived low regard of others were likely to be reported by women (items 3, 4, 5). Concern about social isolation was also more frequently reported by women in Bangladesh but not at the other sites. For women with low self-esteem and concern about social isolation in the South Asian sites, these feelings were often related to the experience of having been actively isolated because of their disease, or forced to move away from their homes.

> I do not know why Allah has given me this disease. I cannot go to any social happenings. My dignity is less because I have moved to my mother's place from my husband's home. People from my husband's family stay away from me. My pride and dignity have been decreased a lot because of my disease. (woman in Bangladesh)

The social effects for some were unresponsive to treatment or cure. An Indian woman explained, 'If I did tell others that I have TB, I would be branded as a TB patient for life. I am therefore scared to tell anyone that I have TB.' Such fear of the social impact contributed to feelings of shame, depression and diminished self-esteem. 'My pride and self-respect have been reduced because of the way I have been treated at home,' an Indian female patient explained.

Work-related aspects of stigma were frequently reported, and they were more likely to be an issue for men, except in Colombia, where more women said they had decided to stay away from work and groups (item 17). Narratives indicated diversity in these accounts. For example, a man in India focused on felt stigma and self-exclusion: 'When I cough loudly, especially in front of others, I feel so embarrassed and feel a nuisance. I therefore stay away from work or other social groups.' Men in Malawi more typically discussed enacted stigma and being denied the chance to work: 'I was asked to stay away from work. I have been dismissed from work due to the illness. I would not be allowed to continue working with my employers after I finish the treatment.'

In Malawi, ideas about how TB spreads and its association with HIV/AIDS influenced social perceptions of people with TB. Symptoms were more likely to be linked with HIV/AIDS for men (item 18). 'To other people, when they know that you have TB, they think that you have AIDS, and they stigmatise you.'

Effects of TB-related stigma on marriage (items 11, 14, 15) were reported by fewest respondents in Colombia and were most frequently reported by women in India, whose livelihood is most likely to depend on the family's ability to successfully arrange a marriage. In India, women were more concerned about the adverse impact of their TB on a relative's ability to marry, but in Colombia this was more likely to be a concern of men rather than women (item 15).

Table 2   Indicators of tuberculosis-related stigma: comparison between men and women (%)

	Bangladesh (n = 102)		India (n = 127)		Malawi (n = 100)		Colombia (n = 98)	
Indicators of stigma	Male	Female	Male	Female	Male	Female	Male	Female
1 Desire to keep others from knowing	40.4	56.0	66.7	78.7	36.0	38.0	58.0	66.7
2 Disclosure to confidant*†	17.3	6.0	7.6	3.3	28.0	42.0	32.0	18.8
3 Think less of yourself	42.3	62.0‡	54.5	65.6	22.0	34.0	6.0	16.7
4 Shamed or embarrassed	26.9	60.0§	48.5	63.9¶	16.0	22.0	32.0	45.8
5 Others would think less of you	36.5	46.0	57.6	75.4¶	26.0	24.0	44.0	33.3
6 Adverse effect on others	7.7	10.0	21.2	23.0	8.0	6.0	12.0	16.7
7 Others have avoided you	19.2	34.0‡	36.4	24.6¶	34.0	24.0	28.0	33.3
8 Others refuse to visit	9.6	30.0‡	24.2	23.0	10.0	18.0	40.0	43.8
9 Others think less of the patient's family	38.5	42.0	40.9	50.8	28.0	14.0¶	38.0	35.4
10 Problems for your children	19.2	32.0	40.9	41.0	54.0	28.0‡	64.0	56.3
11 Problem getting married despite cure	59.6	52.0	42.4	70.5§	34.0	58.0‡	24.0	27.1
12 Support from spouse expected†	7.7	16.0	28.8	27.9	20.0	14.0	2.0	16.7‡
13 Partner refuses sex due to TB	53.8	38.0¶	18.2	16.4	26.0	30.0	38.0	31.3
14 Other problem in marriage (after cure)	0.0	40.0§	24.2	16.4	26.0	40.0	26.0	25.0
15 Problem for relative to marry	30.8	26.0	28.8	42.6‡	14.0	16.0	48.0	18.8§
16 Asked to stay away from work, groups	5.8	16.0‡	10.6	3.3‡	36.0	14.0‡	30.0	27.1
17 Decided to stay away from work, groups	80.8	54.0‡	54.5	52.5	52.0	18.0§	48.0	68.8‡
18 Presumed other health problems#	23.1	34.0	NA	NA	60.0	40.0‡	60.0	66.7

* Item 2 excluded from stigma index for Bangladesh and India, based on Cronbach's alpha analysis.
† 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.
‡ $P < 0.05$; § $P < 0.01$; ¶ $P < 0.10$; 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.
# Item not included for assessment in the interview of the study in India.
NA = not assessed.

Determinants based on multivariate analysis

To identify demographic and cultural epidemiological explanatory variables (patterns of distress, perceived causes and help seeking) for the stigma index at each site, adjusted for confounding, a multivariate analysis was performed. This analysis examined determinants of the stigma index at each site as a dependent variable. To facilitate a gender analysis, we also examined the interactions of these variables with sex. Summaries of findings for crude and adjusted analysis of variables, based on prominence of reported categories, are presented in Tables 3 and 4. EMIC data for Colombia were unavailable for comparison and were not included in the multivariate analysis.

Among demographic variables, never having been married was associated with greater stigma in India and Malawi, but increasing age in Bangladesh and being employed in Malawi were less associated with stigma. Unskilled women labourers were likely to report more stigma, however, than men.

Female sex was itself positively associated with stigma in Bangladesh. Most women who reported higher levels of stigma said they were unable to meet responsibilities for their household work. They required the assistance of family and neighbours, which led to family stress. Many women reported that their husbands had rejected them and sent them to their natal homes. One woman said, 'My husband behaved badly with me because of my sickness; he told me to go to my father's home and expected that if I would die, then I could die there.' Many Bangladeshi women also reported that their husbands had physically or verbally assaulted them, or refused to bear any expenses associated with treatment. One woman, who had not disclosed to her husband that she had TB, explained,

> When my husband came to know that I had this disease, he beat me very badly with a stick. I was hospitalised for seven days after that. My husband told to me to take back all the dowries that were paid to him to marry me, and mentioned that he would marry again. My father in-law told everybody about it.

Table 3 Crude analysis of variables and interactions with female sex associated with stigma

| | Bangladesh | | | | India | | | | Malawi | | | |
| | Main variable | | Interaction | | Main variable | | Interaction | | Main variable | | Interaction | |
Explanatory variables	Estimate	P value	Estimate	P value	Estimate	P value	Estimate	P value	Estimate	P value	Estimate	P value
Demographics												
Never married	0.92	0.19	−0.27	0.74	0.57	0.03	−0.21	0.58	0.39	0.19	0.22	0.65
Married	−0.69	0.23	1.05	0.11	−0.59	0.02	0.47	0.20	0.07	0.82	−0.44	0.29
Unemployed	−0.50	0.21	0.03	0.96	1.12	0.05	−1.35	0.04	0.51	0.23	0.67	0.35
Other occupation	0.27	0.44	0.00		−0.63	0.03	1.11	0.06	0.31	0.41	−0.75	0.15
Age	−0.03	0.00	0.00	0.89	−0.02	0.13	0.01	0.44	0.01	0.71	−0.01	0.65
Patterns of distress												
Fever	0.22	0.07	−0.16	0.40	0.08	0.44	−0.09	0.62	0.11	0.57	−0.51	0.04
Weight loss	−0.82	0.02	0.69	0.08	0.23	0.08	−0.10	0.64	0.02	0.87	0.09	0.67
Loss of appetite	0.11	0.33	−0.68	0.01	0.10	0.54	0.11	0.65	0.11	0.59	0.03	0.91
Weakness	0.18	0.03	−0.20	0.41	−0.02	0.83	0.28	0.09	0.04	0.80	0.06	0.79
Side effects of drugs									0.29	0.16	−0.57	0.03
Other physical symptoms	0.01	0.97	0.09	0.70	−0.22	0.03	0.03	0.87	−0.92	0.02	0.93	0.02
Social isolation					0.38	0.00	−0.18	0.32	0.33	0.13	0.38	0.24
Stigma—reduced social status	0.45	0.07	0.08	0.79	0.56	0.00	−0.33	0.03	0.16	0.43	0.61	0.12
Marital problems	0.36	0.41	0.03	0.95	0.54	0.00	0.07	0.83	−0.21	0.46	0.22	0.54
Loss of job and wages	0.07	0.73	0.15	0.72	−0.01	0.92	0.20	0.16	−0.06	0.57	0.48	0.01
Reduced income	0.28	0.05	−0.44	0.10	0.26	0.05	−0.12	0.49	0.28	0.03	−0.08	0.67
Sadness, anxiety or worry	−0.11	0.65	0.25	0.48	0.37	0.00	−0.34	0.01	0.16	0.16	0.09	0.55
Concern about course of illness	-0.02	0.88	−0.16	0.45	0.27	0.01	−0.20	0.12	0.01	0.94	0.01	0.97
Perceived causes												
Food	0.04	0.61	−0.09	0.46	0.28	0.02	−0.13	0.33	0.06	0.59	0.07	0.76
Contamination/contact	−0.03	0.72	0.17	0.13	0.11	0.21	−0.03	0.80	0.15	0.16	−0.27	0.04
Fate/God/stars/[Karma]					0.40	0.02	−0.32	0.11	−0.17	0.87	0.16	0.87
Sexual contact					−0.03	0.94	0.10	0.83	0.70	0.05	−0.65	0.08
Help seeking												
Home remedies, self-care	−0.01	0.95	0.09	0.69	−0.26	0.21	0.24	0.40	0.11	0.49	0.47	0.04
Druggist/pharmacy for advice	0.16	0.06	−0.04	0.67	0.34	0.01	−0.24	0.20				
Urban government hospital	−0.08	0.37	0.16	0.33	0.17	0.01	−0.08	0.39	0.08	0.23	−0.17	0.13
Private practitioner—allopathy	−0.07	0.35	0.02	0.88	−0.13	0.01	0.06	0.45				
Private doctor specialist					−0.06	0.58	0.47	0.03				
Private hospital	−0.31	0.06	0.66	0.09	−0.34	0.01	0.47	0.01	−0.02	0.80	0.03	0.81
Healing temple, dargah					−1.12	0.03	1.01	0.19				
This clinic	−0.39	0.05	0.40	0.14	0.11	0.46	−0.20	0.41	−0.09	0.38	−0.09	0.54
Female sex*	0.19	0.06			0.14	0.12			−0.15	0.13		

* Estimate and P value based on simple linear regression.

Table 4   Adjusted analysis of variables and interactions with female sex associated with stigma

	Bangladesh				India				Malawi			
	Main variable		Interaction		Main variable		Interaction		Main variable		Interaction	
Explanatory variables	Estimate	P value	Estimate	P value	Estimate	P value	Estimate	P value	Estimate	P value	Estimate	P value
Demographics												
Never married					0.47	0.00			0.41	0.04		
Unskilled labour									−0.93	0.00	1.44	0.08
Trade or business									−0.48	0.01		
Age	−0.02	0.00										
Patterns of distress												
Fever									−0.30	0.00		
Blood in sputum					0.12	0.02						
Loss of appetite	0.13	0.20	−0.54	0.01								
Weakness	0.14	0.03			−0.15	0.05	0.18	0.17				
Other physical symptoms					−0.15	0.02						
Social isolation					0.21	0.00			0.54	0.00		
Stigma—reduced social status	0.44	0.00			0.28	0.01	−0.20	0.09				
Loss of job and wages					−0.03	0.65	0.13	0.19	−0.16	0.07	0.48	0.00
Reduced income					0.13	0.10			0.27	0.00		
Sadness, anxiety or worry					0.11	0.02			0.15	0.01		
Perceived causes												
Food					0.15	0.00						
Smoking									0.13	0.01	−0.28	0.04
Physical exertion/work					0.30	0.00						
Contamination/contact					0.15	0.00						
Climate					−0.93	0.01	1.11	0.01				
Sexual contact									0.88	0.00	−0.79	0.01
Help seeking												
Druggist/pharmacy for advice					0.18	0.01						
Urban government hospital									0.16	0.00	−0.24	0.00
Private practitioner—allopathy					−0.09	0.00						
Private hospital	−0.20	0.14	0.68	0.04	−0.18	0.08	0.34	0.01				
Female sex	1.07	0.01			−0.08	0.75			0.12	0.73		

Variables from the crude analysis (Table 3) with $P < 0.3$ were considered in this adjusted analysis; forward selection retained variables with entry value $P < 0.15$ in the model. This table shows all variables in the model, some of which did not remain significant.
Adjusted R^2 in Bangladesh (0.37), India (0.58) and Malawi (0.51).

Table 5   Adjusted analysis of grouped variables and interactions with female sex associated with stigma

	Bangladesh				India				Malawi			
	Main variable		Interaction		Main variable		Interaction		Main variable		Interaction	
Explanatory variables	Estimate	P value	Estimate	P value	Estimate	P value	Estimate	P value	Estimate	P value	Estimate	P value
Demographics												
Muslim (for Malawi: Christian)					−0.37	0.13						
Married					−0.38	0.01						
Separated, divorced or widowed	0.35	0.67	−1.15	0.20								
Unemployed									0.71	0.03		
Age	−0.02	0.00										
Patterns of distress												
Somatic					−0.05	0.61	0.06	0.59				
Social	0.47	0.00			0.24	0.00						
Financial problems	0.22	0.02							0.16	0.01		
Psychological—emotional					0.22	0.02	−0.14	0.25				
Other					0.05	0.48						
Perceived causes												
Health, illness or injury					0.14	0.01						
Traditional, cultural, supernatural					0.09	0.23	0.07	0.45				
Help seeking												
Informal									0.25	0.01		
Public doctor					0.07	0.12						
Private doctor					−0.05	0.19						
Magico-religious					−0.42	0.03						
Female sex	0.46	0.03			0.14	0.82						

Adjusted R^2 in Bangladesh (0.35), India (0.40) and Malawi (0.16).

Patterns of distress

Physical weakness was associated more with stigma in Bangladesh but less in India. In India and Malawi, social isolation, reduced income and emotional distress (depression or anxiety reported as sadness or worries) were significant explanatory variables. Job loss in Malawi was more likely to be linked to stigma for women than for men. The analysis of grouped variables (Table 5) highlighted the influence on stigma of financial stress in Malawi and Bangladesh, and of social problems in Bangladesh and India.

In Bangladesh, patients' narratives showed that the association of weakness and stigma resulted from limitations on the ability to work. Men explained this as a threat to their family's livelihood, and women explained that their husbands would scold and physically abuse them. A man from Bangladesh explained the linkage between weakness, an inability to work and stigma:

> I have stopped working because of my weak health. At present, I do not have any income. There is nobody except me to earn for the family. We had to borrow because there is a crisis in our family. People did not say anything in front of my face after I got this disease, but they have said things in my absence.

Illness narratives in Malawi suggested that acute symptoms of fever that were thought to be from malaria could be reassuring, because that condition was not socially stigmatising.

Perceived causes

No particular perceived causes were associated with stigma in Bangladesh, and the clearest associations of perceived causes were notable in Malawi. Smoking and sexual contact reported by men as causes, especially the latter, were associated with more stigma but with relatively less stigma for women identifying these causes. Some women in Malawi explained that their partner's promiscuity was to blame for having contracted TB. 'Maybe sexual contact [is the cause]. I was only with my husband, but you do not go everywhere your husband goes.' In India, the perceived cause 'contamination or contact' was associated with stigma.

Help seeking

Among help-seeking variables, prior use of an urban government hospital was more stigmatising for men and less for women in Malawi. Previous use of a private hospital was more likely to be associated with stigma for female TB patients in Bangladesh and India. However, having sought prior help at a private allopathic practitioner was related to less stigma among Indian patients. Many such patients explained that they considered the private allopathic practitioner trustworthy and the 'family doctor' to whom they turned for all health concerns. A female patient's ex-planation also suggests that patients may have sought initial help from a private practitioner because they did not suspect TB: 'I thought it was an ordinary fever. Usually for any disease, I used to consult the private practitioner.'

DISCUSSION

The level of stigma is to some extent a barometer indicating the success of programmes to help patients and communities rethink the nature of TB and use clinical services more effectively. This study identified features of TB-related stigma, assessed by locally validated indicators among patients in treatment at four TB clinic sites. Feeling stigmatised because of having TB was a shared experience among patients across sites, contributing to considerable personal and social distress beyond the somatic burden of disease. Patients at all sites consistently affirmed the stigma indicator 'others have avoided you' (item 7), highlighting a fundamental feature of stigma based on disease status, and recalling Goffman's[20] original formulation of stigma as 'disqualification from full social acceptance'. These findings highlight persisting widespread fear of the disease, lack of information about TB and its treatment and a dearth of support for TB patients. Narrative accounts of patients with high self-reported stigma reflect concerns that disclosure will cause problems. Low-stigma patient narratives, particularly those suggesting little concern about disclosure, indicate high expectations of treatment and show that stigma reduction programmes should aim to transform stigma into support.

Findings also identified site-specific and gender-specific features and determinants of stigma. In Malawi, stigma was closely linked to HIV/AIDS, and concern about marriage prospects were a characteristic concern for women in India and Bangladesh. Qualitative and quantitative accounts described stigma in terms that show how social exclusion contributes to emotional suffering and financial hardship. These constitute a hidden burden that persists after bacteriological cure.[4,21] Key findings suggest a psychosocial burden of TB-related stigma among women and a financial and work-related effect among men, although not exclusively, as indicated by the greater sensitivity of stigma to job loss for women in Malawi. Narratives highlight the importance of exaggerated fears of risk and spread despite effective treatment as characteristic features of TB-related social disqualification, which may also be self-imposed as internalised stigma.[23]

The findings in the Malawi study also indicate the need to further examine the effect of HIV/AIDS on TB-related stigma, as this may increase delay in health seeking and non-disclosure of status. Positive messages about TB cure are less likely to be believed by TB-HIV co-infected patients in areas where antiretroviral treat-

ment is not available, and this may further increase stigma. Specific gender effects of this enhanced TB-HIV-related double stigma require further study, considering the role of gender and HIV and their impact on uptake and adherence to DOTS treatment and ART as it becomes more widely available.

Gender-specific vulnerability of women to TB-related stigma

The gender focus and vulnerabilities of women to the social impact of TB, as identified in the four studies, contribute to a recognised body of literature on the topic.[22] Findings presented here provide further evidence of the gender-specific social effects of TB, as reflected by stigma. Women in these studies, particularly in South Asia, experienced considerable TB-related social disqualification and feelings of rejection associated with gender roles, resulting in psychological, social and emotional distress. With reference to concerns about gender and women's health, and consistent with other studies,[11,16] we found that women were particularly vulnerable and fearful of abuse, abandonment, divorce and other marriage-related problems. Nevertheless, it was also notable that simply looking at female sex as a determinant of more stigma was a significant finding only in Bangladesh. Our cultural epidemiological methods helped to clarify the more complex relationship of gender and stigma for TB, which is important for both men and women.

Gender-specific features and financial impact of TB-related stigma among men

Financial and work-related issues were associated with the stigma of TB among men at all sites. Many men had to stop working for social reasons and due to disability, further complicating the expense of treatment with loss of income, contributing further to financial distress and worries about supporting themselves and their families. Physical symptoms were often closely connected to financial issues, such as weakness in agrarian Bangladesh that impaired patients' ability to earn a livelihood through farm work, thereby compromising their social status within families and communities. Male patients in Malawi similarly reported less social and financial authority in their household when they could not work as before. These findings suggest the need to mitigate the social repercussions of time spent away from routine responsibilities by emphasising needs for familial and social support throughout a course of treatment. Development of community-based care, treatment programmes at work and income-generating programmes are all likely to stimulate effective support for patients and their families.

Mitigating stigma and controlling disease

Combined cultural concepts of TB and misperceived risk from exaggerated concerns about spread of the disease synergistically contributed to the stigma of TB. Fear of transmitting TB from casual contact moti-vated some patients to isolate themselves from family, and to take extraordinary measures to prevent spread based on locally accepted ideas about the risk of spread that they endorsed.[5,6] Exaggerated perceptions of risk, realistic precautions against spread and the effects of enacted, anticipated and internalised stigma should be informed by public education and mitigated by efforts to promote social support.[23]

Effective TB control requires efforts both to prevent spread and to minimise unreasonable fear of spread despite effective treatment, which constitutes stigma. Titrating these complementary interests, however, is not a trivial matter. Assessments of stigma, including ours, may have difficulty distinguishing problems of stigma from critical social responses that promote responsible behaviour, timely help seeking and adherence to treatment. Research needs to distinguish stigma more carefully from reasonable concerns about a serious condition. Public health services must balance the interests of disease control that promote awareness of risk without contributing to stigma. Achieving this goal is especially challenging in settings where co-morbid TB and HIV/AIDS amplify stigma.[24]

Notwithstanding these ambiguities, the undesirable effects of stigma that discourage help seeking and treatment are often crystal clear. Considerable research has shown effects of stigma on delaying patients' help seeking,[14] compelling patients to hide or deny a TB diagnosis,[15] seeking care from private (and sometimes less qualified) practitioners for fear of being identified in a public TB clinic,[5] dropping out of treatment[17] and sometimes stigmatisation by health service personnel.[25,26] Further research is required to clarify other practical public health effects of stigma,[27] such as the contribution of stigma to diagnostic delay, as considered in another cross-site analysis of these studies.[28] More detailed studies of patient help-seeking delay and treatment adherence with reference to socio-cultural features of TB and gender are also needed.

CONCLUSION

Stigma affects the quality of patients' lives and the effectiveness of TB control. Studies at four sites have identified common features of TB-related stigma, but also distinctive findings across sites and between men and women. This cross-site analysis shows how interdisciplinary methods enable a comparative study of gender and the cultural epidemiology of TB focusing on the manifestations and determinants of stigma and their practical implications for TB control. Recognising the importance of stigma as both an influence on, and indicator of, effective TB control, health system operational studies should assess it more routinely with a level of precision that is both useful and manageable.

Tropical Diseases (TDR) at 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. Editorial comments of E Stamhuis are acknowledged. 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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— **R É S U M É**

CONTEXTE : Programmes de lutte contre la tuberculose (TB) au Bangladesh, en Inde, au Malawi et en Colombie.
OBJECTIF : Evaluer les indicateurs de stigmatisation de TB, les caractéristiques socioculturelle de la maladie et celles liées au sexe en rapport avec cette stigmatisation.
SCHÉMA : On a interviewé 100 patients ou davantage dans les différents sites en utilisant une interview semi-structurée approfondie (EMIC), recherchant les types de détresse, leurs causes perçues et la quête d'aide. Les indicateurs de stigmatisation perçue ont été évalués de manière individuelle et dans un index validé qui a été comparé de site en site ainsi qu'à chaque site entre hommes et femmes. Les variables épidémiologiques culturelles explicatives de la stigmatisation et leurs interactions avec le sexe féminin ont été analysées à chaque site. Les données narratives qualitatives sur la maladie ont permis d'expliquer le rôle et le contexte des variables explicatives.
RÉSULTATS : L'index de stigmatisation globale est le plus élevé en Inde, le plus faible au Malawi et plus marqué chez les femmes au Bangladesh. En Inde et au Malawi, les femmes sont plus susceptibles de s'inquiéter de l'impact sur leurs perspectives matrimoniales. Au Malawi, les associations avec le VIH/SIDA contribuent à la stigmatisation de la TB où la perception des contacts

sexuels comme cause perçue s'accompagne d'une stigmatisation plus marquée chez les hommes et moins chez les femmes.

CONCLUSION : La stigmatisation influence et indique l'efficience de la lutte contre la TB. Les méthodes épidémiologiques culturelles clarifient les caractéristiques transversales et locales de la stigmatisation et du sexe en matière de lutte contre la TB.

RESUMEN

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

OBJETIVO : Evaluar los indicadores de los estigmas asociados con la TB y las características de la enfermedad, socioculturales y relativas al género, que condicionan dichos estigmas.

MÉTODOS : Se aplicaron entrevistas semiestructuradas (EMIC) como mínimo a 100 pacientes en cada centro, sobre los tipos de preocupaciones, la percepción de las causas de la TB y los comportamientos de búsqueda de atención de salud. Se evaluaron los indicadores de los estigmas autopercibidos por los pacientes individualmente y según un índice validado ; este índice se comparó entre los diferentes centros y entre los hombres y mujeres de cada uno. En cada establecimiento, se analizaron las variables explicativas culturales y epidemiológicas de los estigmas y sus interacciones con el sexo femenino. Se utilizaron los datos cualitativos de la narración con el fin de explicar la función de las variables explicativas y elucidar el contexto de la narrativa.

RESULTADOS : El índice global más alto para los estigmas se observó en India y el más bajo en Malawi ; fue mayor para las mujeres en Bangladesh. En India y Malawi, fue más frecuente que las mujeres se preocuparan por las consecuencias de la TB en sus proyectos de matrimonio. Las asociaciones con la infección por VIH/SIDA contribuyeron a los estigmas en Malawi, donde las relaciones sexuales como causa percibida de la enfermedad se asociaron con más estigmas en los hombres y que en las mujeres.

CONCLUSIÓN : Los estigmas relacionados con la enfermedad influyen y además constituyen indicadores de la eficacia del control de la TB. Los métodos de análisis cultural y epidemiológico permiten detectar las diferencias y las características locales de los estigmas en relación con el género, las cuales pueden influir sobre la lucha contra la TB.