

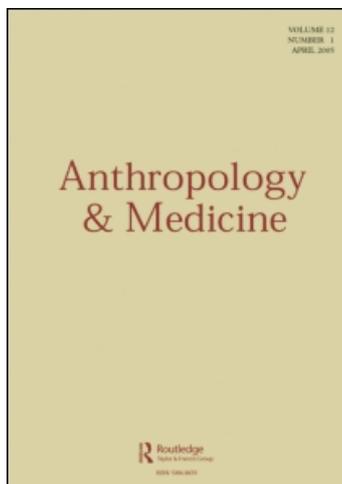
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# Stigma, Gender, and their Impact on Patients with Tuberculosis in Rural Bangladesh

Fazlul Karim, A. M. R. Chowdhury, Akramul Islam and Mitchell G. Weiss

*In addition to marginalization by poverty and ethnicity, gender is likely to contribute to vulnerability to TB-related stigma affecting women. Stigma often contributes to psychosocial problems and emotional suffering, and it may hinder help seeking and treatment adherence. TB-related stigma and its gender-specific features have not been carefully studied in Bangladesh, and such research is needed to reduce adverse effects of stigma. This study assessed and compared stigma in women and men, and identified crosscutting and gender-specific features of TB-related stigma. To assess stigma and the context of TB-related illness experience, meaning and help seeking behavior from patients' perspectives, a cultural epidemiological study administered a locally adapted semi-structured EMIC interview to 50 women and 52 men with pulmonary TB in rural Bangladesh. Indicators of TB-related stigma were assessed individually and collectively in a validated index. They were compared by sex, and illness narratives elaborated features of stigma with reference to features of TB. The study showed that six indicators of TB-related stigma were more prominent in accounts of women and two were more prominent in men's interviews. Gender differences appeared somewhat less after adjusting for other sociodemographic variables, and age was most significantly inversely related to stigma. Features of stigma more prominent in the accounts of women included feeling shamed or embarrassed, thinking less of themselves and feeling that others refused to visit or avoided them. Men were less likely to disclose their condition to a confidant, stay away from work or report that their spouse refused sex because of TB. Effective public health information and counselling sensitive to gender-specific features of stigma are needed to protect TB patients from the adverse impact of avoidable stigma. Further research is needed to clarify effects of gender-specific features of felt and enacted stigma on help seeking and treatment adherence.*

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## Background

The global strategy for pulmonary tuberculosis (TB) control relies on passive case finding, requiring patients to present at health clinics in response to a prolonged cough or other suggestive symptoms. Despite the existence of an effective cure for TB, incidence rates in high burden countries suggest barriers to effective diagnosis, treatment and cure. Evidence suggests that sociocultural factors and TB-related stigma may inhibit patients from seeking care or maintaining a full course of treatment, increasing morbidity and mortality from TB and aggravating its spread within communities. TB patients may encounter isolation and rejection, fear of, or actual job loss (Getahun & Maher 2000; Johansson *et al.* 2000), and segregation at home (Liefooghe *et al.* 1997; Edginton *et al.* 2002; Godfrey-Faussett *et al.* 2002). Furthermore, gender-specific features of sociocultural factors, including stigma, may also discourage patients from seeking timely, appropriate care or completing a full course of treatment. In some settings, male TB patients may face threats to their roles within the family due to economic difficulties (Long *et al.* 2001) and the challenge of accommodating the need to work and earn, and a commitment to treatment (Balasubramanian *et al.* 2004). In some settings, notably in Pakistan and Ethiopia, research also suggests that female patients may have diminished prospects for marriage and more vulnerability to divorce (Liefooghe *et al.* 1997).

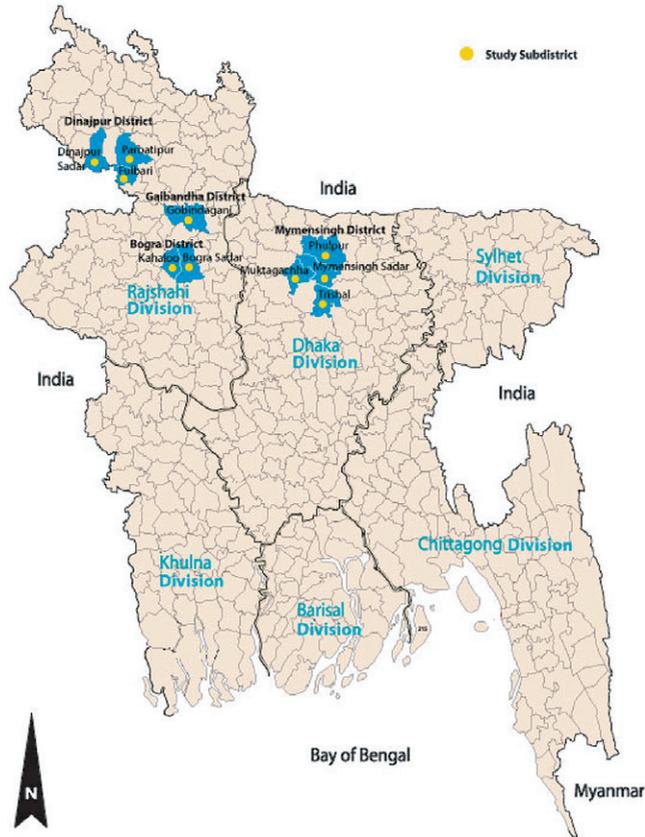
According to Goffman's (1963) original formulation, stigma is the situation of the individual who is disqualified from full social acceptance. TB-related stigma refers to felt stigma or experience with enacted social disqualification or discrimination that is directed towards an individual identified as having TB. Stigma thereby contributes to a so-called hidden burden of disease (WHO 2001). Illness-related stigma is not only a manifestation of social vulnerability; it may also contribute to vulnerability, poorer prospects for treatment and adverse effects of TB.

Experience with TB control in various settings, including Bangladesh (Fair *et al.* 1997), suggests that TB-related stigma may be worse for female patients (Long *et al.* 2001; Balasubramanian *et al.* 2004; Eastwood & Hill 2004). As one site in a four-country study of gender and tuberculosis (Weiss *et al.* 2006), research in Bangladesh examined crosscutting and gender-specific features and effects of TB-related stigma relevant to TB control. This report examines the gender-specific nature of TB-related stigma and its sociodemographic features, based on interviews with patients in rural BRAC treatment centres in Bangladesh.

## Methods and Materials

### *Study Setting*

The study was implemented in 10 upazilas (subdistricts) of the BRAC TB control program, covering about 2.5 million people in four districts (Figure 1). BRAC is a non-governmental organization that has been implementing TB control programs in partnership with the Bangladesh National TB Control Program (NTP), and it manages health centers, like those of this study, in designated areas across the country. BRAC has trained female volunteer health workers, known by the term



**Figure 1** Map of Bangladesh Showing the Study Subdistricts.

*shastho shebika*, who are supervised by medical doctors and other paraprofessionals. Their work constitutes a component of outreach in a community health system that provides services to the rural population. They maintain contact with community residents, identify people with symptoms of TB and may collect sputum samples for TB testing at laboratories. For identified cases, they initiate community-based DOTS and provide follow-up services to patients undergoing treatment. BRAC services have been implemented in 283 upazilas of the country.

#### *Data Collection*

A cultural epidemiological study with particular attention to questions of stigma administered semi-structured EMIC interviews to identified TB patients. The EMIC investigated the variety of experience, meaning and help seeking behavior related to TB. Responses were coded to facilitate analysis of the distribution of features of TB illness, and topically focused illness narratives were an integral component of the data set, both quantitative and qualitative components, based on questions examining 18 indicators of stigma. Responses to these questions about various aspects of stigma

were coded based on a response of yes, possibly, uncertain or no, and represented with a prominence ranging from 3 to 0, with higher values indicating more stigma. A clearly affirmative response about an aspect of stigma was coded 3, an equivocal response suggesting the possibility of stigma was coded 2, uncertainty about the relevance of the indicator was coded 1 and denial of its relevance was coded 0.

Purposive samples of 102 pulmonary TB patients (50 women and 52 men) were studied. Approximately half were engaged in the intensive phase of treatment (2–4 weeks), the other half were in the continuation phase (4–5 months). After pilot testing, research interviews took place from October 2001 and January 2002 at the patients' homes, in a private place. The principal investigator and the senior researchers supervised field activities.

BRAC and the WHO local office gave ethical approval for the study. Each patient's consent was obtained, and responses were kept confidential throughout the project period to avoid any effects on treatment.

### *Data Management and Analysis*

Categorical and numeric data from the EMIC interviews were double entered in Epi Info and analyzed using SPSS. Narrative data were transcribed verbatim in Bengali, translated into English and entered into MAXqda, a qualitative data management and analysis software program.

The prominence of stigma indicators was compared between women and men and assessed with a non-parametric statistic (Wilcoxon test). Responses were analyzed individually and validated collectively as an index of stigma, which was validated for internal consistency with the Cronbach's alpha statistic. Our analysis identified stigma-related themes, and their gender-specific features, identifying crosscutting and distinctive aspects of stigma reported by male and female TB patients. In addition to a crude analysis of sexwise comparisons, to control for confounding, multivariate analyzes of each of the stigma indicators and the stigma index examined the effects of sociodemographic variables. The analysis for each of the stigma indicators used logistic regression, dichotomizing 'yes' and 'possibly' responses as positive and 'uncertain' and 'no' responses as negative. Multivariate linear regression was used for analysis of the stigma index.

Sex-specific differences identified quantitatively were clarified and explained by selecting narrative data referenced to topics by thematic coding, and selecting respondents with illustrative accounts, identified and retrieved using selection variables from interview data. Qualitative comparisons were based on phenomenological analysis of narrative accounts of features of stigma, with reference to coded items of the interview.

## **Results**

### *Sample Characteristics*

The mean age of patients in the sample was higher for men (40.6 years) compared to women (32.5 years) ( $p=0.004$ ). Most of these patients were married

(72% of women, 94.2% of men), the rest were either never married (12% of women, 3.8% of men), or they were separated, divorced or widowed (16% of women, 2% of men). The vast majority was Muslim (86% of women and 88.5% of men), and the rest were Hindu. Women reported more schooling (mean of 6.6 years) compared with 4.3 mean years of schooling for men ( $p=0.00$ ), but the quality of their education favored men; most women were illiterate (60%), compared with 48% of men. Most women identified themselves as housewives (68%), and men were either farmers or fishermen (32.7%). Twenty-eight per cent of the women and 11.5% of men reported that their household income was neither regular nor dependable.

### *TB-Related Stigma*

Comparison of the prominence of responses to stigma queries (Table 1) showed several differences between reported stigma indicators among female and male patients. Female patients emphasized psychosocial and marriage or family-related indicators more than men. Women said that they thought less of themselves (item 3) due to TB, and felt ashamed or embarrassed (item 4). Female patients also more frequently reported those indicators that suggested social isolation, including, 'others have avoided you' (item 7) and 'others refused to visit' (item 8). Female patients also emphasized that their illness might result in marital problems even after a cure (item 14). Male patients more frequently emphasized the stigma items that dealt with sexual relations (item 13), their ability to marry (item 11) and work (item 17).

The value of the standardized Cronbach's alpha for the 17-item index was 0.77, denoting good internal consistency. The overall stigma index for female TB patients was significantly higher than it was for males ( $p < 0.05$ ) (Table 2).

### *Multivariate Analysis*

To control for confounding, multivariate analyzes that considered the role of sociodemographic factors with the index of stigma and with individual stigma indicators were also performed (Table 3). Increasing age was the most consistently significant variable in these models, negatively associated with nine of the stigma indicators and with the overall index. A positive association of female sex with stigma was of borderline significance. Female sex was significantly associated with greater prominence of the stigma indicators 'shamed or embarrassed' (item 4) and 'others refuse to visit' (item 8). Female sex was also associated with willingness to disclose their illness to a community or family member to enlist support (item 2). Patients in treatment over a longer duration (4–5 months, compared with others in treatment 1–2 months) were more likely to report receiving adequate support from their spouses (item 12).

### *Features of Stigma in TB Illness Narratives*

Among female patients, psychosocial dissociation, mental and emotional suffering emerged as a prominent theme in their illness narratives. Women who reported feeling ashamed or embarrassed (item 4) explained how these concerns contributed

**Table 1** Reported Indicators of Stigma and their Mean Prominence (%)

Indicator	Female (n = 50)				Male (n = 52)			
	Frequency reported				Frequency reported			
	Yes	Pos	Unc	Mean Prom	Yes	Pos	Unc	Mean Prom
1. Keep others from knowing	54.0	2.0	0.0	1.66	34.6	5.8	1.9	1.17
2. Did not disclosure to confidant	94.0	0.0	0.0	0.18	82.7	0.0	0.0	0.52
3. Think less of yourself	56.0	6.0	0.0	1.80	25.0	17.3	7.7	1.17**
4. Shamed or embarrassed	52.0	8.0	0.0	1.72	21.2	5.8	1.9	0.77***
5. Others would think less of you	40.0	6.0	0.0	1.32	26.9	9.6	15.4	1.15
6. Adverse effect on others	8.0	2.0	6.0	0.34	1.9	5.8	11.5	0.29
7. Others have avoided you	28.0	6.0	0.0	0.96	5.8	13.5	3.8	0.48**
8. Others refuse to visit	22.0	8.0	0.0	0.82	3.8	5.8	5.8	0.29**
9. Others think less of your family	34.0	8.0	0.0	1.18	28.8	9.6	11.5	1.17
10. Problems for your children	28.0	4.0	2.0	0.94	13.5	5.8	13.5	0.65
11. Problems getting married despite cure	46.0	6.0	4.0	1.54	55.8	3.8	9.6	1.85
12. Did not expect support from spouse	78.0	0.0	6.0	0.54	90.4	1.9	1.9	0.23
13. Partner refuses sex due to TB	36.0	2.0	0.0	1.12	53.8	0.0	0.0	1.62*
14. Other problems in marriage (after cure)	32.0	8.0	4.0	1.16	0.0	0.0	3.8	0.04***
15. Problem for relative to marry	24.0	2.0	6.0	0.82	15.4	15.4	11.5	0.88
16. Asked to stay away from work or groups	14.0	2.0	0.0	0.46	0.0	5.8	0.0	0.12**
17. Decided to stay away from work or groups	46.0	8.0	0.0	1.54	63.5	17.3	0.0	2.25***
18. Presumed other health problems	32.0	2.0	12.0	1.12	17.3	5.8	25.0	0.88

\*Items 2 and 12 were reverse coded, so that responses presented in the table indicate more stigma. Interview questions, however, asked about willingness to disclose and expected support.

<sup>b</sup>Mean prominence (prom) based on values assigned to response: yes = 3, possibly (pos) = 2, uncertain (unc) = 1, and no = 0.

\* $p < 0.10$ , \*\* $p < 0.05$ , \*\*\* $p < 0.01$ , Wilcoxon test for crude comparison of the prominence of stigma indicators.

**Table 2** Stigma Index by Sex

	Female	Male	Total
Mean	19.0	15.0	17.0
Median	20.5	15.0	16.0
Standard deviation	10.6	8.8	9.9
Minimum	2.0	2.0	2.0
Maximum	40.0	34.0	40.0

Note: Based on a 17-item index of stigma with a theoretical maximum of 54.  $p = 0.04$ , Student's *T*-test

to their low self-esteem and lack of pride. Women's narratives also reflected feelings of increased social isolation and rejection by in-laws and husbands, as indicated in the following account:

Whenever my nephews come close to me, my mother-in-law takes them away. She always keeps on saying that she will arrange another marriage for my husband. My husband also labels TB as a serious disease, and he often asks me to commit suicide with poison. At this, I get shocked and ask him to buy poison for me. I am really enduring a state of mental torture.

Although fewer men than women reported feeling ashamed because of the disease, their narratives indicated that for some, feeling socially ostracized was a serious issue. Several men said that their peers had stopped meeting them socially because of fears they would get TB. Characteristic of these accounts, one man explained:

One of my friends one day wanted to know what happened to me. I told him about my TB. Instantly, he started to move far away from me. After that, he did not meet with me again. His odd behaviour hurt me.

Many women felt that others in their community had avoided them (item 7) or refused to visit (item 8) because of TB. These experiences and perceptions generated fears about socializing, leading many of these women to isolate themselves as protection against anticipated public insult or embarrassment. A young, divorced woman noted, 'I did not go to anywhere. I stayed in my room. I kept myself isolated from others because of the disease. I was worried that people would insult me.'

TB-related stigma reflected fears and exaggerated concerns about TB's communicability and its easy transmission to others. Such fear of contagion coupled with other aspects of stigma motivated these patients to take extraordinary and unwarranted preventive measures, even after several weeks of treatment. One woman said:

I stay very carefully, and take medicines by myself. I pass others with care and keep a safe distance. I always dry my beddings in the sun. I have a separate plate, glass, and other objects. Only since I have taken these precautions do I feel that if anyone associates with me, they will not get the disease from me.

Both married and unmarried women were concerned about the impact of their TB on marital problems (item 14). Some also expected these problems to persist even after they were cured. They feared being reprimanded by their husbands, the possibility of divorce so their husbands could remarry, and the potential for their

**Table 3** Adjusted Analyses of Sociodemographic Variables Related to Stigma Indicators and an Index of Stigma

Sociodemographic explanatory variables														
Indicators of stigma	Female sex		In treatment over a longer duration (4–5 months)		Age		Education		Income		Never married		Separated, divorced, widowed	
	Estimate	P-value	Estimate	P-value	Estimate	P-value	Estimate	P-value	Estimate	P-value	Estimate	P-value	Estimate	P-value
1. Desire to keep others from knowing							–0.16	0.05						
2. Did not disclose to confidant <sup>a</sup>	–1.77	0.05									2.33	0.11		
3. Think less of yourself	0.70	0.14			–0.03	0.06	–0.23	0.01						
4. Shamed or embarrassed	1.36	0.00			–0.03	0.07								
5. Others would think less of you														
6. Adverse effect on others														
7. Others have avoided you					–0.05	0.04								
8. Others refuse to visit	1.16	0.06			–0.06	0.04								
9. Others think less of the patient's family					–0.04	0.04							–1.66	0.15
10. Problems for your children					–0.08	0.00							–1.68	0.06
11. Problem getting married despite cure														
12. Did not expect support from spouse <sup>a</sup>			3.07	0.01	–0.10	0.02			1.01	0.05				
13. Partner refuses sex due to TB	–1.34	0.01			–0.05	0.01							1.41	0.09
14. Other problem in marriage (after cure)					–0.06	0.02								
15. Problem for relative to marry														
16. Asked to stay away from work or groups														
17. Decided to stay away from work, groups	–1.13	0.03											–1.59	0.08
18. Presumed other health problems														
Stigma index	0.30	0.13			–0.02	0.00							–0.65	0.06

<sup>a</sup>Items 2 and 12 presented as reverse coded, so that a 'yes' response in the table indicates the most stigma, consistent with other items.

Adjustment based on logistic regression analysis of positive (yes or possibly) and negative response (uncertain or no) for indicators and multivariate regression of stigma index. Table shows parameter estimates for variables with  $p \leq 0.15$ .

children to contract TB. Unmarried women were concerned that no one would marry them because they would always be regarded as a someone who would transmit the disease to others. A married woman elaborated:

If an unmarried person had this disease, it would be very difficult for him or her to get married, or it would take a long time to find a marriage prospect (bride or groom) for him or her. Everybody would think that TB may be passed from that person to the children and to the spouse.

Male patients were also concerned about the effects of TB on their marriage prospects. The social system of arranged marriages did not fully protect them from that possibility, as this man explained:

If the other party would come to know that I had TB, then they would not be interested to give me the girl that had been agreed upon for me to marry. They would think that the girl might get this disease from me.

Married men commonly reported that their partner refused sex because of TB. The impact of TB on sexual relations, however, was not exclusively a result of stigma. Some men reported that they refrained from such intimacy with their wives because they felt too weak or too ill for that. Most commonly, however, men described a combination of factors; their wives refused sex, and their doctors also recommended them to refrain from sexual relations. 'We have stopped making love in the last one and half months,' a man explained. 'The doctor has forbidden it for us. And my wife also does not want to have sex.'

A combination of enacted and anticipated (felt) stigma and debilitating effects of the disease affected many aspects of patients' lives, with considerable financial and socioeconomic impact. Stigma, combined with physical weakness, contributed to patients' decisions to stay away from work or not to participate in group activities (item 17). Such avoidance affected both economic and emotional well-being, it was a more prominent issue for men. 'I myself have decided to stop working,' a man explained. 'I was weak, and that is why I do not go to the fields to farm as I did before.' Some men emphasized the financial repercussions of their inability to work for their family households: 'Of course my income has decreased. I can not repair shoes nowadays, so I can not earn.' Another reason reported by a 25-year old married man for avoiding groups was fear that socializing would spread TB:

I do not go to social activities intentionally. I do not feel like going because of my weak health. Moreover, the others can get TB from me. If I go out socially, the disease can go into inside the others from my cough.

Women reported that they stayed away from work or groups because of fears of transmission, negative comments, weakness, and because they felt ashamed. A 25-year-old married woman said, 'I myself decided to keep away from any social activity. If I go for social activity, people around can get it from me.'

## **Discussion**

This study examined features of stigma affecting patients with TB in rural Bangladesh, indicating the importance and the limitations of a gender perspective

as a focus of social analysis for disease control. Although some aspects of stigma were influenced by gender and other sociodemographic variables, others were cross-cutting (viz., items 6, 15, 16 and 18 in Table 3). Reducing stigma and enhancing gender equity are both priorities for health services and national TB control programs. Previous studies of TB in other settings have emphasized the positive relationship of female gender and the inverse relationship of age on stigma (Balasubramanian *et al.* 2004; Eastwood & Hill 2004), and our findings support that, but with some qualifications and questions. Although our crude analysis showed more prominent features of stigma and the overall index for women, adjustment for other sociodemographic descriptors showed that in this sample, which represented clinical epidemiological patterns of younger women and older men with TB, age was a more substantial factor than gender in explaining stigma.

Findings suggest that the differences in stigma reported by men and women reflect the influence of various factors and experiences, in which gender plays an important, though not exclusive, role. As a feature of increasing age but with its own independent effect, we found that fewer concerns about getting married or staying married were also associated with less stigma, as suggested by an inverse relationship with being separated, divorced or widowed. Illness narratives elaborating the nature of stigma showed that women's experiences reflected both enacted and felt stigma and identified some particular psychosocial vulnerabilities. Shame, embarrassment and reports of isolation were common concerns among women. Women's reports of social and emotional distress are also consistent with findings from other studies elsewhere, in Vietnam (Long *et al.* 1999; Johansson *et al.* 2000) and Pakistan (Liefoghe *et al.* 1995).

As in other South and Southeast Asian settings (Liefoghe *et al.* 1995; Long *et al.* 2001), women in this study reported concerns that a diagnosis of TB may result in threats of divorce or their husband taking a second wife; they described a web of social and financial problems, and emotional distress. Such accounts indicate the motivation for concealing a diagnosis of TB from others, as others have found elsewhere (Khan *et al.* 2000; Liefoghe *et al.* 1995; Long *et al.* 2001). Despite vulnerability to their husbands' rejection, it was nevertheless notable that female patients in this study tended to disclose their illness to others, and they had substantial capacities for providing support. Many of these women's narratives reflected a tension between the danger of social repercussions of disclosure and the value of mobilizing social support needed for permission and financial support to facilitate help seeking. Disclosure cannot be regarded as completely toxic or inevitably beneficial, even though it also has value as a process affecting self-image reducing stigma. Efforts to mitigate the adverse experience of stigma should recognize that if patients' patterns of disclosure change without comparable changing social patterns balancing stigma and support, disclosure may introduce problems by inviting insult, shame and isolation from family or community.

An important motivation for disclosure was based on concerns that others need to know so that family and community can protect themselves from acquiring tuberculosis. Such accounts typically indicated exaggerated concerns about the spread of TB, and the tendency to underestimate the value of treatment in reducing

contagiousness further enhanced stigma. It led to a kind of self-stigmatization through self-imposed isolation. As suggested from findings in a study in Pakistan, where patients were instructed by health workers to practise 'voluntary isolation', health staff may share and amplify exaggerated fears of contagion (Khan *et al.* 2000). Balancing public health interests in reducing spread and reducing stigma requires a thoughtful balance, and remains a serious challenge for stigmatized infectious diseases. Reducing stigma should be regarded as an integrated aspect, rather than an isolated interest, of TB control.

The nature of stigma itself is also more complex than simplistic accounts may suggest. Over inclusive formulations may have the undesirable effect of discrediting serious consideration of an important problem. Ambiguities about what constitute stigma and what results from a lack of adequate information about TB, its causes, spread and care require careful consideration and clarification. Men's frequently reported concerns about maintaining a sexual life with their wife appear to have largely fuelled by their doctor's recommendations to refrain from sex. Although some men reported that their wives did refuse sex, it is unclear to what extent this has to do with stigma and avoidance, and to what extent it deals instead with exaggerated precautions against spread and the authority of the health professional. The healthcare provider should explain the duration of infectivity after a patient has begun treatment. Similarly, issues regarding males' inability to return to work because of stigma should be distinguished from the decision to refrain from work because of debilitating symptoms, or in response to medical advice. Healthcare providers should of course be sensitive to the financial impact of limiting work and the importance of male gender roles as financial providers. Further research among health care providers in Bangladesh needs to clarify the accuracy of information patients receive about TB spread and the rational basis of prescribed precautions.

## Conclusion

The adverse effects of stigma both reflect and exacerbate gender inequalities, posing a challenge for a gender-sensitive DOTS strategy for controlling TB. Although this study indicates crosscutting and gender specific features of TB in rural Bangladesh, further research also needs to clarify the impact of stigma on help seeking and treatment adherence. Such research should examine the role of stigma generally, and the impact of particular features of stigma. Does stigma operate as an undifferentiated force, or do particular features of stigma have specific effects on help seeking, disease control and health system operations? Study and interests in reducing stigma of tuberculosis need acknowledge its impact, but not so much as an isolated phenomenon as an integral feature of social life and disease control. Developing a more contextualised appreciation of stigma with reference to gender and its effects constitutes a challenge not only for TB, but also for other infectious diseases and other stigmatized conditions.

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