Community perceptions of tuberculosis: A qualitative exploration from a gender perspective

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Objective: To explore community laypersons’ perspective on tuberculosis (TB)-related illness experiences, meanings, behaviours and impact with reference to gender.

Methods: Eleven focus group discussions (FGDs) were conducted (six female and five male) in five subdistricts where the non-governmental organization BRAC operates. On average, seven purposively chosen poor, illiterate, non-TB patients participated in each FGD. Discussions were audiotaped, translated verbatim into English and analysed using MAXQDA software for qualitative data analysis, used it to assign codes to text segments to identify themes from participants’ narratives.

Results: TB was recognized as a deadly disease that could affect anyone. The discussants were fairly aware of the psychological, financial and social impacts of TB. Women faced with adverse consequences more often than men, such as trouble in ongoing and prospective marital affairs. Coughing up sputum in public by women is culturally frowned upon, resulting in enormous suffering. Women tended to describe the clinical features more vaguely than men, and often specified fewer characteristic symptoms such as blood in sputum.

Conclusions: The gender differences in the health and socio-economic impact of TB included perceived causality, curability, stigma, family and community support, fear of disclosure, and use of self-help or home remedies. Interactive health education covering various consequences of TB could be indispensable to changing negative beliefs.

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Introduction

There are several barriers to the successful control of tuberculosis (TB) using the directly observed treatment, short course (DOTS) strategy, most importantly people’s personal knowledge, attitudes and illness experiences. Compared with men, women present with fewer characteristic symptoms such as blood in sputum in Bangladesh (21% vs 16%), India (38% vs 15%) and Colombia (40% vs 35%). The reverse occurs in Malawi (24% vs 30%). Patterns of reported distress notably...
discovered a group of women with TB who were experiencing a wide range of systemic symptoms such as fever, breathlessness, weakness and chest pain that were less clearly indicative of the diagnosis. Studies in Vietnam supported these findings. Thus, they suggest a contributing factor to the under diagnosis of TB among women.

TB-related pervasive stigma worsens the quality of life of its victims. Thus, TB-related stigma is a practical public health concern as part of the so-called ‘hidden burden’ of disease, and it may affect care seeking. TB patients may hide their symptoms or diagnosis, and feel guilt and shame.

Several studies have reported that TB status can affect marital life or prospects for marriage in settings where marriage is socially arranged. In Bangladesh, although insignificant, TB affects more males than females (56% vs 46%). People with strong cultural or traditional values and beliefs about TB first undertake traditional, family or spiritual healing. If this fails, they seek treatment from various other types of provider, so called ‘treatment shopping’. Delayed treatment causes increased transmission of the disease, and financial strain for patients and their families due to lost time and income, as well as circuitous ‘treatment shopping’.

Ranked sixth of the world’s 22 countries with high TB burdens, Bangladesh strives to contain the disease using the DOTS strategy. In spite of considerable efforts, large gender disparities in TB detection and diagnosis persist, with a female: male ratio of 0.38, compared with 0.51 in South-East Asia and 0.71 worldwide.

Beliefs about health and the perceived severity of TB are vital determinants of early help seeking and diagnosis. Presently in Bangladesh, these beliefs are insensitive to gender. Other vital but neglected factors are social support mechanisms and community awareness, which can provide support and encouragement to visit health providers at the onset of symptoms and adhere to treatment strategies. Although indispensable, most TB control programmes ignore or put little value on local cultural perspectives, leading to lowered confidence in and the trust of providers, and to ineffective communication between patients and providers. As effective communication is the key to proper diagnosis and treatment, health education on TB should be an integral component of any TB control programme. This should be built on the community’s existing knowledge base, local cultural and belief systems, and the socio-economic environment. The neglect of these issues is a likely reason why health education in the past failed to improve knowledge of health behaviour. Thus, it is crucial to understand locally validated perceptions about the different facets of TB. In Bangladesh, there have been no such studies. This study aimed to explore the local cultural views in rural Bangladesh on TB-related illness experiences, meanings and behaviours, with particular attention given to the role of gender. ‘Gender’ in this study refers not only to ‘biological differences between women and men but also to the wide variety of behaviours, expectations and roles attributed by social structures to women and men’. This is part of a broader multicountry study carried out in Bangladesh, India, Colombia and Malawi, and funded by the United Nations Development Programme/World Bank/United Nations Children’s Fund/World Health Organization’s Joint Special Programme for Research and Training in Tropical Diseases.

### Methods

#### Study area

The study area comprised of five rural subdistricts inhabited by 1.5 million people, spread over three districts where the non-governmental organization BRAC operates its TB control programme (Mymensingh, Gaibandha and Dinajpur). Bangladesh Rehabilitation Assistance Committee (BRAC) implements a comprehensive community-based programme focusing on social mobilization to identify and refer suspected TB sufferers, organize peripheral smearing centres, implement a community-based DOTS strategy, follow-up patients and provide referral support. BRAC-trained, community-based health volunteers provide education on TB and inform the community about the availability of free treatment.

#### Participants and data collection

Poor, illiterate, non-TB patients were purposively selected from community members within the BRAC micro-credit programme. Participants were chosen in collaboration with BRAC community-based health workers who assisted in recruitment. Before recruitment of a participant, the field researchers together with the health workers briefed the potential participants about the purpose of the focus group discussions (FGDs), and only those consenting to take part were recruited. Table 1 depicts the major background characteristics of the FGD participants.

From October to December 2001, 11 FGDs (six female and five male) were conducted using the saturation point, when data collected does not uncover new information for the development of the study. Each FGD consisted of six to nine participants and lasted for 45–90 min. Two anthropologists and two sociologists were trained to conduct the FGDs in teams. The former

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Gender</th>
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<tbody>
<tr>
<td>Average no. of participants per focus group</td>
<td>Female</td>
</tr>
<tr>
<td>Average age (years)</td>
<td>Female</td>
</tr>
<tr>
<td>Married (%)</td>
<td>Female</td>
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<tr>
<td>Occupation (%)</td>
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<tr>
<td>Day labour</td>
<td>Female</td>
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<tr>
<td>Cultivation</td>
<td>Female</td>
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<tr>
<td>Small trading</td>
<td>Female</td>
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<tr>
<td>Housewife</td>
<td>Female</td>
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<tr>
<td>Literacy (%)</td>
<td>Female</td>
</tr>
<tr>
<td>Illiterate</td>
<td>Female</td>
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<tr>
<td>Can sign only</td>
<td>Female</td>
</tr>
<tr>
<td>Poverty status (%)</td>
<td>Extremely poor</td>
</tr>
<tr>
<td>Poor</td>
<td>Female</td>
</tr>
<tr>
<td>Non-TB patient (%)</td>
<td>Female</td>
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<tr>
<td>Seen TB patients (%)</td>
<td>Female</td>
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</tbody>
</table>

**TB** = tuberculosis.
mainly moderated the FGDs and the latter were note takers. The male team conducted FGDs with men and the female team with women. The FGDs were held inside homes in villages.

FGD topic guides included: types; causes; symptoms; vulnerability; transmission; action taken for diagnosis and treatment, beliefs and stigma associated with the disease, and treatment. These were adapted from World Health Organization guidelines for the study of gender and TB, which was translated into Bangla and pretested before use. Discussions were audiotaped with prior permission of the participants.

**Data management and analysis**

Data were transcribed verbatim into Bangla within 48 h of an FGD held. The moderators also considered their field notes to check the consistency and completeness of the narrative. The data were further translated and transcribed in English. MAXQDA software for qualitative data analysis was used.

Final analysis was conducted jointly by the first, second and fourth authors with continuous support from the third author. Although the first author was responsible for coding, subcoding, and categorization of findings, the outcomes (categories, themes/subthemes) were discussed continuously with the other authors to make use of their multidisciplinary views. Gender differences were studied between female and male FGDs. Data were analysed using inductive methods, and appropriate text segments were retrieved for quotations towards further clarification of phenomena.

Informed consent was obtained from each participant. It was made clear that any refusal to provide information would not affect one’s access to services/benefits from BRAC. Strict confidentiality of data was ensured throughout the study. Ethical clearance for the project was obtained from the Research and Evaluation Division, BRAC.

**Results**

**Theme 1: local perceptions of causes and recognition of TB**

**Causes**

Contact with TB patients (e.g. sharing utensils and beds), sexual intercourse, poor hygiene, weather and colds were identified as causes of TB. According to women, men were more susceptible to TB due to smoking and addiction to a variety of substances, such as cigarettes, ‘biddi’ and tobacco. They also recognized hard work as a factor. Men emphasized the unaffordability of nutritious food, hard work, smoking and eating betel leaves as causes of TB.

Women raised the issue of unequal intrafamily food distribution, a traditional norm that often deprives women of their required daily share of food. A female participant commented, ‘Most females eat less, whatever remains after serving the family members. Thus, they contract TB’.

Women reasoned differently on the causes of TB, identifying the preservation or use of tattered sandals as a factor. One female participant explained, ‘Poor people used to keep sandals in a corner of the house where germs could form, and thus affect human beings’. Two female focus groups and one male group stated that weather, cold and time of bathing could cause TB. A female participant said, ‘When the body is washed with water in the morning or evening, the person will get a headache together with a cold and mild feaver. That will ultimately turn into TB’. Some women and men stated that stepping over the sputum of a TB patient could cause the disease.

**Recognition**

Women and men reported that TB was usually identified based on the following symptoms: blood in sputum, severe coughing, fever, loss of appetite and chest pain. Some male participants noted that ‘Sputum with blood is a particular kind of TB, and sputum alone is another kind’, but did not have names for these types of TB. The sputum of TB patients was believed to be foamy mucus; either red, white, green or yellow in colour, with a rotten egg-like odour. Unlike women, men expressed that they could loudly cough up and spit sputum anywhere. Coughing and spitting in public by women was viewed badly. For women, a TB infection could be furthermore a cause of shame. Many women revealed that they consequently suppressed their coughs and swallowed sputum instead of spitting it out.

**Similarity between TB and other respiratory conditions**

The participants recognized TB as a deadly disease that could affect anyone. Participants said that the risks, treatment and impact of TB were similar for women and men. A variety of vernacular names for chronic respiratory illness emerged; for instance, ‘cough’ encompassed whooping cough, TB, cough, asthma and bronchitis. Women conflated TB with pneumonia, heart disease and gastroenteritis, while men did so with malaria. Men tended to identify TB as a chronic respiratory illness more often than women, suggesting that women had less knowledge about TB. Both women and men identified the following signs and symptoms of chronic respiratory illness: difficulty with breathing, chest pain, cough, weakness, vomiting, blood in sputum, rib pain and difficulty with sleeping. Coughing was seen as a symptom of whooping cough, TB, cough, asthma, bronchitis, pneumonia, heart disease, gastroenteritis and malaria. During coughing, wheezing rather than the appearance of sputum would occur in cases of bronchitis, pneumonia, heart disease, gastroenteritis and malaria. None of the participants identified certain crucial symptoms of TB. For instance, the women did not identify weight loss and fever, and the men did not mention weight loss. Both genders specified whooping cough and cold cough as closely related to TB, with similar signs/symptoms, causes and treatment. Women were thought to be more susceptible to whooping cough and colds than men, whilst men were believed to be more susceptible to TB.

The discussants ranked the severity of chronic respiratory illnesses as ‘samanno kharap’ (slightly severe), ‘motamuti kharap’ (moderately severe) or ‘choromi’ (extremely severe), identifying and categorizing TB-like symptoms (Fig. 1):

- slightly severe (‘samanno kharap’): mild cold in the evening and at night. In the morning, a patient does not feel very bad and is able to perform daily work. If untreated, a patient gradually loses weight and appetite, resulting in weakness;
- moderately severe (‘motamuti kharap’): chest pain, fever, headache, loss of appetite and coughing appear together; and
extremely severe (chorom kharap): increased and recurrent fever, weight loss, severe coughing, blood in sputum and sleeplessness. If untreated, a patient may die.

Theme 2: Dealing with TB

Data from all FGDs for both genders pointed out that people largely rely on self-help and home remedies at the onset of respiratory problems. These measures include eating bat and frog meat, drinking the juice of basil leaves and hot water, wearing amulets, applying rubs of hot oil and garlic, etc. When these measures failed to resolve the problem, people would seek outside help, often from drug sellers, village doctors or herbalists. Medical care is sought as a last option. Women said that they would often seek help in secret. The participants said that doctors gave equal attention to women and men in cases of respiratory illness.

All participants correctly identified various locally known places where TB treatment is available, including BRAC Health Centre, Mission Hospital, Lamb Hospital and private qualified physicians.

Theme 3: Mental suffering due to TB

Isolation and exclusion

According to the participants, TB patients would always think that they were going to die. Men tended to view TB as more contagious than women.

Fear of death and social neglect were widely reported causes of mental suffering. Women suffered more than men for fear that they would be neglected or abandoned by their husbands.

According to men and women in this study, women would experience more difficulties in getting married than men unless they were fully cured of TB. Such worries pressure women not to disclose TB, resulting in silent transmission to others. One female participant said, ‘It is difficult to marry off a girl with TB. So people tend to hide it’. Such a problem is not as serious for men, but a woman would not marry a man if it was known that he had TB. Ongoing marriages could also be broken. In many instances, wives were forced to move to their parental homes during the course of the disease. One woman said:

“In the case of a wife suffering from TB, the husband will remarry. In contrast, when a husband suffers from TB, the wife will think that the husband will not be able to love her. The husband does not give proper attention to a wife’s treatment, as he can marry another girl if she dies and receive more dowries. He may think that treatment is a waste of his money.”

TB negatively affects conjugal life. Male and female participants noted that spouses with TB should sleep separately, avoid intercourse and use separate utensils. However, husbands with TB compel their wives for sexual intercourse, but husbands would deny sexual intercourse to wives with TB.

Exclusion and its features

Two forms of exclusion were identified in the interviews: (i) community exclusion and (ii) self or mental and psychological isolation. The latter was a consequence of the former. Participants in this study agreed that TB patients would face ostracism, denial and apathy. Such feelings often stem from over exaggerated fears of transmission. A female participant commented, ‘People will hate the TB patients and as such will not stand by their side for fear of transmission’.

For fear of transmission, the family members of a TB patient would not interact with him or her, and would separate the patient’s utensils and bed. Neighbours would often not like to talk with a patient; if they did, the patient would be asked to hold a handkerchief over his or her mouth. No one would stand near the patient. TB patients were said to suffer from different forms of mental torture, including social isolation and neglect. In all FGDs, it was noted that TB patients think of death due to the disease and social exclusion. Their psychosocial anxiety increased immensely when they found that everybody hated them and no one came close. As a result, TB patients keep themselves isolated from other people.

Inability to work

Men expressed concern that the loss of physical ability due to TB would result in reduced work and income. Men working in service industries were more affected, as those suffering from TB would inevitably have to take leave for treatment. Others reported that contracting TB might lead to job loss. A male participant said, ‘When attacked by TB, one will spread it to his/her colleagues sitting around him/her in the office…. Thus, the employer will say that you will not be kept on the job’.

Women and men agreed that employers might re-employ the employees once they had received proper treatment. However, women expressed concern about the financial consequences of TB for children and the family.
Discussion

Diverse perceptions about TB and its socio-economic and health impacts on personal, familial and social life emerged from the FGDs. These findings have considerable implications for TB control programme managers, policy makers and researchers in Bangladesh to help people access TB treatment services using the DOTS strategy.

A clear understanding about the curability of and treatment sources for TB is a determinant of patients’ motivation for timely care seeking. However, confusion about the curability of the disease was expressed in this study. Studies in Sialkot, Netrokona and Uasin Gishu support this finding. Consequently, a lack of clear understanding about the curability of TB may lead people to delay seeking care. Minimizing the gap in knowledge is crucial for a successful TB control programme. An interactive community education and communication package can critically improve people’s knowledge base, leading to earlier case detection, diagnosis and treatment. At present, this is rare in many settings, including Bangladesh.

Understanding the vernacular names for TB is essential, as these indicate the symptoms that people tend to associate with the disease. If not effectively educated, people will confuse TB with other diseases such as whooping cough or asthma, obscuring communication between patients and care providers, and obstructing diagnosis and treatment. Thus, care providers must be aware of the local names for TB and its symptoms for effective differentiation between the biomedical name of TB (‘Jokkha’) and the associated symptoms.

Women tend to present more ambiguous symptoms, and they seldom mention symptoms such as blood in sputum. Consequently, it is more difficult to diagnose TB in women. Perceived patterns of distress emerging from explanatory modeling of interview data were noteworthy for women with TB, who experienced mixed symptoms that were less likely indicative of diagnosis. People generally ignore the early signs/symptoms such as cough or fever, and respond to the symptoms that appear at the severe stage of TB, resulting in a delay in care seeking. This conclusion is re-inforced by other studies. Likewise, studies in other settings found that the majority of patients did not seek help solely due to a cough.

The participants in this study considered whooping cough and cold cough to be very close to TB, and thought that women were more likely to contract them than men. In contrast, men were considered to be more vulnerable to TB. Such perceptions can lead women to neglect vital signs/symptoms and delay in seeking help.

TB often impairs working ability, leading to reduced income, increased economic vulnerability and mental stress. Men were reported to suffer more than women due to their perceived role as ‘breadwinner’ in the family. However, economic hardships arising from TB also affect women. As a first-contact caregiver for family members, an adult woman must cook for and feed all family members, including children.

As noted before, mental sufferings stemming from TB were more acute and diverse among women than men. Women’s inferior position in society and the family put them in a precarious mental state. For example, husbands can remarry if their wives die of TB. Often, a wife with TB loses the love of her husband with TB, and may not receive proper treatment if he refuses to provide financial support.

Female TB patients suffer from the fear of divorce or desertion. Such worries often compel a wife to hide the disease, leading to avoidable deaths. If a wife has TB, her husband refrains from sexual intercourse with her. In contrast, if a husband has TB, he most likely compels his wife to have sexual intercourse.

Women are more vulnerable to the consequences of social stigma than men. FGD data emphasized the problems raised by disclosure, particularly its impact on women’s marriages. Considerable research has also shown the delaying effects of social stigma on patients’ help seeking, compelling patients to hide or deny a TB diagnosis, and/or seeking care from private but often less qualified practitioners for fear of being identified going to a TB clinic. More women than men believe that anybody in contact with a TB patient will get the disease. Women are more vulnerable to such a perceived cause, as women care for any sick person in a family, even if the patient has an infectious disease.

Another perceived cause of TB in men that differed between women and men was that women believed that smoking/addiction to various substances, such as cigarettes and tobacco, caused TB among men. Men countered this argument by specifying the lack of nutritious food and the hard work of providing for the family. Women also highlighted unequal intrafamily food distribution as a cause of TB, explaining that they always ate last and least after serving all other family members. Men rebutted that they undertook hard work and ate less than their daily requirement. Therefore, to redress gender inequalities, any disease control interventions should reconsider the issues of women and poverty.

Although both women and men were aware of the availability of professional TB treatment facilities in their locality, women relied more on self-medication or home remedies during the initial course of the disease. Only when these approaches failed did they go for professional help, leading to delayed diagnosis and treatment. Contributing factors to this phenomenon are social stigma and financial and mobility constraints. A study in Bangladesh reported that the main barriers that women face in accessing TB services are lack of finances and control over financial decision making. Thus, the role of family in getting women to seek professional help and providing social and financial support is crucial for women. It is of less importance for men, who have the autonomy to seek professional help when they see fit.

This study only revealed the perceptions of rural, poor, non-patient women and men, including some indigenous people. Trustworthiness of the qualitative data (similar to reliability/validity in a quantitative inquiry) was ensured through establishing credibility, transferability, dependability and confirmability. These are hence limitations on the generalizability of the findings. The participants did not represent a cross-section of the population, and were chosen on the basis of who wanted to participate. Although the participants themselves were not TB patients, most of their perceptions were comparable with the findings of other studies.
This study has triangulated the work of researchers from different backgrounds (i.e. anthropologists, epidemiologists, sociologists and medical doctors) through analysis, sharing of views, etc. Moreover, semi-in-depth interviews with TB patients under treatment revealed relatively similar perceptions and beliefs about TB.

Conclusion

In conclusion, this study highlighted the significance of reinforcing the role of sociocultural views of people on TB while underscoring the need to provide appropriate information and increasing access to TB in rural settings, creating a therapy-friendly atmosphere. Information delivery is crucial to promote social acceptability of antiretroviral therapy among youths. Efforts to improve access to antiretroviral drugs should re-emphasize prevention counselling to minimize sexual transmission of human immunodeficiency virus.

The overall findings revealed gender differences pertaining to the perceived causality, curability, stigma, family and community support, fear of disclosure, and use of self-help or home remedies. Interactive health education on the various aspects of TB could be indispensable to change negative perceptions.

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Ethical approval

Research and Evaluation Division of BRAC.

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Competing interest

None declared.

References