

**Gender barriers to tuberculosis control: Fade-out or in?**  
*Key findings and recommendations from the preliminary analysis*

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## **1. Introduction**

Fewer females than males (1:1.7) were diagnosed with TB each year worldwide. Nonetheless, despite the prevalence of pulmonary TB in females appears to be lower, progression from infection to disease is as much as 130% higher in females aged between 10 and 44 years. But why are fewer females than males diagnosed with tuberculosis? What factors play role in making differences between males and females in help-seeking, diagnosis, treatment and its compliance?

Over the last couple of years, interest in identifying and addressing gender issues in TB control programme has increasingly been growing. Thus, in June 1999, the Joint Coordinating Board of the Special Programme for Research and Training in Tropical Diseases (TDR) endorsed the expansion of TDR's disease portfolio to include TB, which opened up the way for WHO and TDR's Task Force on Gender Sensitive Interventions (GSI) to work together to develop approaches to identify and address gender issues in TB control. However, following several meetings on this critical issue, the TDR funded four research teams from Bangladesh, India, Colombia and Malawi for the study. To reveal gender differentials and barriers towards TB control programme, the study planned to cover six broad components of TB control in each of the 4 study sites. These were: review of programme data, in-depth interviews with male and female TB patients, quantitative survey of male and female TB patients, observations of patient-provider interactions at labs, observations of patient-provider interactions during treatment initiation at community, and key informant interviews with health providers. The Bangladesh study forms a part of this multi-country study.

## **2. Objectives**

The objectives of the overall study were to:

- i) document sex differences in key aspects of TB control;
- ii) identify gender-specific barriers to case detection, appropriate treatment, adherence, and cure; and
- iii) recommend potential interventions to ensure gender sensitivity in TB programmes and services, and thus improve TB control.

## **3. Methodology**

The study was implemented in rural settings of BRAC TB control programme area, drawing populations from 10 *upazilas* (subdistrict), viz. Mymensingh sadar, Trishal, Muktagacha, and Phulpur in Mymensingh district; Bogra sadar and Kahaloo in Bogra; Gobindaganj in Gaibandha; and Dinajpur sadar, Fulbari and Parbatipur in Dinajpur district. Quantitative and qualitative

methods were used for data collection. This report highlights the core findings and recommendations from the initial analysis of five components of the study (excluding the situation analysis). The component-specific objectives and methods of data collection are as follows:

**i) Community perceptions of tuberculosis and gender-** Eleven focus group discussions (5 male and 6 female) with the illiterate and poor community people were conducted to identify community views of TB-related experience, meaning and help-seeking with particular attention to the role of gender.

**ii) Tuberculosis and gender differences in help-seeking and diagnosis-** One thousand pulmonary TB patients (500 female and 500 male) were surveyed to measure different lag times from symptom onset to help-seeking, diagnosis, and treatment at community level (using DOTS).

**iii) Role of gender in clinic use, sputum examination, and treatment outcome for tuberculosis-** Epidemiological information of 3,600 cases, 1,200 from each of outpatient, TB laboratory, and TB treatment registers was collected retrospectively to explore the role of gender in clinic use, referral for laboratory sputum examination, and outcome of TB treatment at community level. The reference period for outpatient, and TB lab registers was 12 months (March 2000-February 2001), but for TB treatment register it was 17 months (December 1998-April 2000).

**iv) Gendered interactions of TB suspects with laboratory personnel, and patients with providers-** To assess the quality of instructions and pattern of interactions between providers at laboratory and treatment initiation at community, with a particular attention to gender differences, 200 observations were conducted at both levels of observations (laboratory 100, and DOTS initiation 100) drawing equal number of female and male patients covering 10 *upazilas*.

**v) Cultural epidemiology of TB, role of culture in help-seeking, and self-perceived stigma of TB with reference to gender-** Semi-in-depth interviews were conducted with 102 pulmonary TB patients (50 female and 52 male) receiving treatment from BRAC to elicit the pattern of TB-related distress, perceived cause of TB, help-seeking for TB, and to examine self-perceived TB-related stigma with reference to gender.

The samples for all the study components were selected by using non-probabilistic sampling methods.

All the narrative data including FGDs were translated into English and entered in computer for word processing under the close supervision of a senior researcher. Later, the translated qualitative

accounts of narratives were imported into MaxQDA, a computer package for qualitative data analysis. This data base was used to retrieve particular coded text segments from selected respondents, so as to enable the researchers to assess features from specific accounts of experience, meaning and help-seeking behaviour in general, and for subsets of patients identified in the quantitative analysis of categorical data. The quantitative data were initially entered in Epi Info version 6.04, but analysed by SPSS version 10.0. The data were analysed for interpretation by using univariate and bi-variate approaches.

#### **4. Core findings**

##### **4.1 Community perceptions of tuberculosis and gender**

**Local taxonomy of TB-related illness-** All FGDs with the community lay persons (6 female and 5 male) recognized tuberculosis (TB) as a very bad disease that could affect anyone, regardless of their age and sex. In general, the perceived types and risks of TB, its curability, socioeconomic and health impact on personal, family, social and community life were almost similar for both females and males.

A variety of locally perceived names of TB-related illnesses such as whooping cough, TB (*Jokkha*), asthma, bronchitis, pneumonia, etc. came up from the discussions. All these could be occurred to anyone, regardless of their age and sex.

**Signs/symptoms-** A host of signs and symptoms emerged from FGDs, which could be commonly seen in both sexes of patients included: breathing problem, chest pain, cough, weakness, vomiting, blood with sputum, pain in ribs, and sleeping problem.

**Ways of identifying TB-** Both female and male FGDs mentioned about some severe conditions through which they could understand/recognise that someone had TB. These were blood in sputum, severe coughing, fever, and loss of appetite. "When blood comes out with sputum, too much coughing, mild fever, and no appetite is called TB"- some FGDs commented.

**Impact of TB on personal, family, social and community life-** Multi-dimensional issues emerged from both female and male FGDs such as:

**Reduced work and income-** Any female or male, if attacked by TB would loose her/his strength leading to reduced work and income. Such problem would be more acute especially for the male service holders. They explained that a TB patient would have to take leave for treatment. Because, the employer would advice for treatment and cure first, and then to resume duty. On the contrary,

some FGDs mentioned that the employees with TB would lose their job. “..... When attacked by TB, office will not keep one as other officials sitting around her/him will suffer....Thus, the employer will say that you will not be kept.”

***Mental sufferings-*** As a result of TB and its severe consequences both females and males had to suffer from a lot of mental anxieties. They might have thought that they would die.

***Marriage -*** Most female and male FGDs indicated that females were more vulnerable than males with respect to getting married unless fully cured by proper treatment.

***Social relation-*** TB would provoke social dissociation and negligence. Most discussions indicated, “People will hate the TB patients and as such will not come forward by her/his side in fear of transmission.”

***Family life-*** The spouses suffering from TB would not meet each other in fear of transmission. Thus, their conjugal life would be disturbed. Many husbands would hate their wives but the wives were to offer their normal services to the husbands. More agonising was that in many instances, wives were transferred to their parental homes if had TB. Sometimes, husbands did not arrange treatment for their wives. If wives would die they would get married again easily, but it was difficult for the wives to do so.

***Impact on pregnancy and breastfeeding-*** All FGDs especially of females said that TB had an impact on pregnancy and breastfeeding. They said that the pregnant women with TB would transmit it to their babies in the womb. This might weaken the baby in the womb and lead to obstructed delivery. They also said that a breastfeeding mother with TB might have transmitted TB to her child during breastfeeding. Besides, she would be unable to produce enough breast milk to keep on feeding the baby due to TB. Lack of money deprived them to afford nutritious food like fruits, meat and milk causing poor production of breast milk, they further added. However, more female FGDs than males mentioned these factors with a greater frequency, because such particular issue matters the females more than males.

***Ideas about the cause of TB and gender-specific causes-*** The female FGDs mentioned that TB generally caused by contact, sharing of utensils and bed with the TB patients. They further pointed out that the males were more susceptible to TB due to their harmful behaviour related to smoking/addiction to a variety of substances viz. cigarettes, bidhi and tobacco. Contrary to this, the male mentioned about lack of nutritious food, hard work, smoking, and eating betel leaves were the causes of TB. Some female FGDs strongly raised the issue of unequal intra-family food distribution, an inherent traditional norm that often deprive females from their required share of

daily food. “Most females eat less, whatever remains after serving all the family members. Thus, they fall in TB.” However, some females expressed that TB also could occur from torn sandal (slipper). “The poor people used to keep the sandal in a corner of house wherein germs could form, and thus could affect human beings.”

**Stigma-** Both female and male FGDs mentioned that the TB patients always would think that they would die. If become known, the people might hate the TB patients and would less likely to mix with them. For such adverse consequences, the TB patients would like to hide their problem.

**Nature of social exclusion-** Both female and male FGDs underscored that the common people would not like to associate with TB patients in fear of transmission, and thus would isolate themselves from each other. None would like to develop marital relations with TB patients. This was more acute and harmful particularly for females.

**Cultural and gender-specific meaning of sputum and coughing-** Sputum and coughing have had some gender-specific implications in Bangladesh society. The males could freely cough up with a sound and spit sputum anywhere. In contrast, coughing with unpleasant sound and spitting sputum in open air by the females was viewed badly. Besides, many females worried about coughing. They tended to think that as a result of it their neighbours might come to know that this female has had TB leading to loss of face in the society. Thus, the females had to suppress coughing even in course of TB.

**Health seeking-** Initially, the females used to seek help hidden. On failure of the self-help and traditional treatment, they tended to go for physicians’ help. But males usually took suggestions from the educated ones, followed by hospital treatment.

**Locally known institutes that treat TB-** Both female and male FGDs mentioned about various locally known sources in this regard viz. BRAC Health Centres, Mission Hospital, Lamb Hospital and private qualified physicians.

## **Recommendations**

1. The community knows TB lay persons (non-patient) by different names. Of them, some do not correspond to that of biomedical concepts. This may obstruct understanding of the impact of TB, and delay in appropriate help-seeking. Effective health education covering the symptoms of TB, causes, transmission, social, personal and familial impact, help-seeking, sources of professional health sources, stigma, proper treatment, curability, and gender issues needs to be designed and implemented to improve people’s knowledge, attitude and practices. The providers should also be trained on these crucial issues.

2. Poor understanding about the proper causal factors of TB e.g. bacteria rather people mostly mix up the transmission with cause. Also, there are some deep-rooted irrational beliefs about the causality of TB. Such misconceptions may be counter-productive for disease prevention. Community should be given scientific information through easily understandable process. Mass media, health workers, opinion and religious leaders can be instrumental in reaching information on a continuous basis. TB patient could also be another powerful source of correct information for other people.

#### **4.2 Tuberculosis and gender differences in help-seeking and diagnosis (delays)**

**Age-** The female patients' mean age was significantly lower than males (33.6 vs. 41.8 years,  $p=0.000^1$ ). Compared to males, more teenage females had TB. For females, the proportion of TB diagnosis increased up to 29 years with a gradual fall among the older age groups. It increased for males up to 39 years, and then fell up to 59 years, but it again mounted to 22% among the 60 or more years of age group.

**Lag time-** The mean lag time between onset of symptoms and the first help-seeking outside home was identical for both sexes (14 days). The time lapse between onset of symptoms and contact with BRAC Health Centres was significantly longer for females (52 days) than males (49 days) ( $p=0.015$ ). The average lag time from onset to visit to a clinic with sputum examination facility (BRAC Health Centre) was almost similar for both females and males (53 vs. 52 days), but the lag time between onset and sputum examination was significantly higher for females than males (61 vs. 59 days) ( $p=0.024$ ). No significant differences were observed between females and males regarding time lapses between the first help-seeking and visit to BRAC Health Centres (female 38 and male 35 days), between BRAC Health Centre visit and sputum examination (female 9 and male 10 days), and between the first help-seeking and sputum examination (female 47 and male 44 days).

#### **Recommendations**

1. TB suspects, especially the females, should be sensitised to seek care from professionals at the onset of any symptoms, and thereby providers should be motivated to quicken the process of diagnosis and treatment.
2. TB programme must take into account the special circumstances of females and people with less education to maximise the patients' access to services. Longer delays for females

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<sup>1</sup> T-test

correspond to more lost work days and lost income, financial constraints, decision making power and stigma.

3. To reduce diagnostic delays appropriate education package should be developed and implemented incorporating the impact of TB on socioeconomic and health, its signs/symptoms, curability, and sources of professional treatment for all people.
4. A network with the traditional healers, family members, in-laws and private sector should be developed and sustained so that they can refer symptomatic cases to the professional caregivers. Routine coordination meeting may be useful to uphold their motivation.

#### **4.3 Role of gender in clinic use, sputum examination, and treatment outcome for tuberculosis**

**Outpatient register-** Amongst all the 1,200 outpatients visiting BRAC Health Centres for treating respiratory symptoms, the female/male (F/M) ratio was 0.81, highest in Dinajpur sadar *upazila* (1.45) and lowest in Parbatipur (0.48).

**Lab register-** The F/M ratio of the TB suspects (1,200) undergoing microscopy sputum test in lab was 0.52, highest in Dinajpur sadar *upazila* (0.97) and lowest in Phulpur (0.36). But the F/M ratio of patients with at least one smear +ve was 0.38.

**TB treatment register-** The F/M ratio of the 1,200 patients who started treatment was 0.41, with the highest in Parbatipur *upazila* (0.54) and lowest in Phulpur (0.33).

The overall scenario reflected that the females in Bangladesh have less access to outpatient clinics compared to males, and if they seek help for respiratory problems they are less likely to undergo sputum test. Even if examined, females are less likely than males to be smear positive.

#### **Patients by age**

**Outpatient register-** The F/M ratio was highest amongst 15-24 and 25-34 years of age groups (1.09 and 1.03 respectively), and lowest amongst 65 or more years old (0.28).

**Lab register-** The F/M ratio of the patients with at least one smear +ve was nil for less than 15 years of age group and highest for 25-34 years of age group (0.88). The overall age distribution indicated a non-linear pattern of F/M ratio.

**TB treatment register-** The F/M ratio consistently declined with the increase in age of the patients for both the pre-treatment smear +ve and -ve groups. The ratios were highest amongst the patients aged less than 15 years (smear +ve 2.5 and smear -ve 1.3), and lowest amongst 65+ years old (smear +ve 0.08 and smear -ve 0.08).



### **New pulmonary TB cases by age**

The overall F/M ratio of the new pulmonary cases with pre-treatment smear +ve and -ve was 0.42 and 0.48 respectively. In the smear +ve and -ve groups, the F/M ratio declined with the increase in age from 2 to 0.08 and from 1.25 to 0.08 respectively.

### **Treatment outcome**

A higher proportion of female patients with pre-treatment smear +ve (93%) than male (89%) got cured. More males than females died during treatment (8% vs. 5%). Treatment completion amongst females with pre-treatment smear -ve was higher (88%) than males (78%). The death rate was higher for males than females (18% vs. 12%).

### **Treatment outcome by age**

Unlike females the proportion of cure among the males with smear +ve gradually declined with the increase in age up to 55-64 years and then increased slightly for 65 or more years of age. The male patients in less than 15 years age group had highest cure (100%), and it was lowest (78.6%) amongst 55-64 years of age group. For females, highest cure was amongst 35-44 years of age group (97%) and lowest (70%) amongst 15 years old or less. The proportion of treatment completion among the patients with pre-treatment smear -ve did not show any uniform pattern by age of patients regardless of their sex.

**Treatment success rate of new pulmonary TB cases-** The female new pulmonary cases had a higher treatment success rate (93%) than male (89%). However, treatment success rate of the new female patients was lowest amongst the under 15 years old (70%) and highest (97%) amongst 15-24 and 35-44 years of age groups. Among the new male patients it followed an opposite direction, i.e. except in 65+ years of age group, the rate decreased with the increase in age. The success rate was highest (100%) among the younger age group and lowest (80%) among 55-64 years of age groups.

### **Recommendations**

1. Smearing and lab services should be increased to boost the access particularly of females.
2. Special training should be arranged for private doctors, traditional healers, clinic, hospital, etc. so that they can identify TB suspects and thereby refer to TB treatment facilities.
3. Service providers should be reoriented and sensitised on gender equality to enhance help-seeking behaviour of females, diagnosis, and effective treatment of TB patients. The training should be followed by regular refreshers courses.

4. To overcome socioeconomic barriers and more case finding and holding, BRAC may integrate TB control activities with its rural development package wherein all development workers irrespective of their main role will look for TB suspects for sputum test during interactions with people.
5. The service providers should give special attention to the females so that they can produce quality sputum for test.
6. Follow-up of the TB suspects should be strengthened.
7. BRAC may establish its lab facilities for private doctors for sputum test and thereby increase case finding and treatment.
8. A large number of the TB suspects particularly females are still uncaptured. To address this, women-friendly service should be introduced, service quality be improved, morale boosting should be organised for providers. The providers should be trained to address the emerging issues of females in gender sensitive manner.
9. Local volunteers could be developed and their potentials be used for peer education, escorting females and elderly to the clinic, and helping in sputum transportation. All volunteers should be given training to build rapport with the community and thereby do social mobilisation.
10. To improve females' access to health care their status in terms of access to income, family decision making, legal rights, and education must be improved.
11. TB control programme should routinely review and monitor routine programme reports and detect gender differentials in case finding and treatment, and thus take appropriate measures to increase women patients.
12. Record keeping should be improved in outpatient, lab and treatment registers with accurate information such as age, sex, and dates by type of patient.
13. Elderly people especially the females are neglected in poor countries. Providers should pay special attention to the special needs of the elderly women.

#### **4.4 Gendered interactions of TB suspects with laboratory personnel and patients with providers**

##### **Lab observation**

**Greetings-** The providers exchanged greetings with half of the female patients and 48% of male patients.

**Instructions given on sputum production-** The providers gave instructions on how to produce effective sputum for more females than the males. Most instructions covered a wide variety of items such as cough up from deep of chest (68% females and 60% males), go outside for coughing up (64% females and 46% males), stand upright, take deep breath and then cough up (60% females and 64% males).

**Instructions given for the next action-** The providers gave a wide spectrum of instructions for the next action by the patients. These were mostly centred on “if found smear +ve, will be informed at home,” followed by “told the time and day for return visit by the patients.” A higher<sup>2</sup> proportion of females than males received instructions on former item (62% vs. 38%,  $p=0.016$ ), while in the case of the latter item; it was opposite to the former (56% males and 32% females,  $p=0.015$ ).

**Politeness and caring-** The providers were highly polite and careful to most patients (60% females and 58 % males). The following note of an observer provides some insights about provider’s attitude and behaviour towards a female patient:

On arrival the TB programme organiser wrote down the particulars of the patient and then took her weight. Later he demonstrated how to produce sputum. The patient produced sputum in pot and put it in a particular place. The provider told the patient about two more samples. For this, he requested the patient to come on next Tuesday. You have nothing to be worried.

**Comfort-** Over two-thirds of the patients felt comfort at laboratory, with a slightly higher proportion for the males (76% vs. 72%). This means less than one-third of the patients seemingly felt discomfort during laboratory interactions. Observer’s note revealed several factors that perhaps contributed to such discomfort included: difficulties in producing effective sputum for smearing, physical weakness, pain, insufficient sitting facilities, etc.

**Mean time spent-** The mean total time spent by the patients at laboratory was almost identical for both females and males (20.5 vs. 21.4 minutes). No noticeable sex difference in the mean waiting time at laboratory was found (female 8 minutes and male 7.1). The females had a slightly higher mean consultation time than the males (13.5 vs. 12.3 minutes).

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<sup>2</sup> Chi-square test

## **Patient-provider interactions during DOTS initiation at community level**

**Providers' audience of instructions-** The female providers in case of female patients gave instructions mostly to both the patients and their guardians (61%) compared to male patients (16%) ( $p=.0005$ ). But in the case of instructions providing directly to the patients, the female providers largely aimed at the male patients (90%) compared to the female (33%), indicating male bias. In the same event, the male bias of the male providers was clearly apparent. The male providers mostly targeted to the male patients (61%) as opposed to female (48%). Perhaps, both female and male providers assumed that the female patients alone were unable to internalize the instructions and act on them accordingly. Such an attitude indirectly undermines the ability of the female patients.

**Greetings-** More male providers than the female exchanged greetings with patients at the onset of interactions. Notably the female providers exchanged greetings with more male patients (52%) than the female (50%). Contrast to that, the male providers greeted with a higher proportion of female patients (88%) than the male (71%). Traditionally a male enjoys a higher position in the society and the females usually show respect to males. But the male providers' female bias may be resulted from the gender awareness training given by BRAC.

**Politeness and caring-** A lesser proportion of male providers than the female were highly polite and caring to the patients. The female providers did not show any discrimination between sex, while the male providers showed bias to the male patients (87% males and 59% females). An observation note narrates about a male provider's behaviour:

The provider exchanged greetings with patient. He offered a *piri* (a low wooden seat) to the patient to sit in a squatting fashion. He assured the patient saying that his disease would be cured soon, nothing to be worried. In the past there was no treatment for TB, but now it is available. Many patients became cured by free treatment from BRAC.

One observer's narratives on the attitude of a male provider to a female patient indicated:

The provider asked the patient to put a handkerchief on her mouth for two months to avert transmission to other. The provider himself put a handkerchief on his mouth too and spitted frequently indicating a kind of negligence to the patient.

**Comfort-** More male (90%) than female (88%) patients felt comfort while interacting with the male providers. In contrast, almost all females and males felt comfort during interacting with the female providers.

**Advice given on side-effects-** The providers mentioned about a host of side-effects along with corresponding advice for each. The frequently cited side-effect along with their advice to the patients by female providers were: red urine (female 72% vs. male 68%), scabies (female 61% vs. male 63%), yellow eyes (female 39% vs. male 32%), and the items least mentioned and advised were jaundice, vertigo, vomiting, etc. Whilst the male providers mentioned and gave advice on the following side-effects: red urine (female 88% vs. male 84%), and scabies (female 47% vs. male 42%).

**General advice given-** A variety of general advice was given to the patients to follow. The female providers gave advice to a greater proportion of males on most aspects of treatment than the females. These included: use separate container for spitting cough (95% vs. 83%), no smoking (42% vs. 6%), no alcohol (16% vs. none), no hard exercise/work (16% vs. none), no sexual act (42% vs. 33%), test sputum after some days (84% vs. 72%), must adhere to complete treatment (95% vs. 83%), and eat nutritious food (95% vs. 89%). Except in a few cases, the male providers provided advice on most aspects to a higher proportion of male patients.

**Time spent-** The mean total time spent was higher for males than the females (29 vs. 26 minutes). The mean waiting time was identical for both females and males (7 minutes). Furthermore, the mean consultation time was higher for the males than the females (21 vs 19 mins).

### **Recommendations**

1. Sitting facility for the patients in service centres need to be improved.
2. Reorientation/refreshers course should be arranged for the providers at different layers to further improve gender-sensitive interactions at lab and DOTS initiation.

## **4.5 Cultural epidemiology of TB, role of culture in help-seeking and self-perceived stigma of TB with reference to gender**

### **Basic characteristics**

The mean age was higher for males (40.6 years) compared to females (32.5 years) ( $p=.004$ ). Unlike males the incidence of TB was higher among the young age groups of females. Over one-third (38%) of the females' household income was dependable compared to 56% of males.

## Pattern of distress

Nineteen pre-coded individual items under 5 broad groups (physical, social, financial, psychological and miscellaneous) were investigated on the patterns of distresses/symptoms of TB. The categorical responses to each item were coded with values from 0 to 2 indicating not mentioned, mentioned after probing, and mentioned spontaneously. Significantly higher proportion of females was more spontaneous in reporting different symptoms of distress than the males at the outset of problem. In a few cases for both females and males, probing was needed in mentioning symptoms. The grouped data showed that all females and males were equally concerned about the physical distresses. More females than males spontaneously reported about social (22% vs. 10%) and psychological distress (92% vs. 86%). In contrast, more males than females were concerned about the financial distress (64% vs. 12%). However, the examination of individual items of distress revealed that the trend in increase in responses from probing to spontaneous was significantly<sup>3</sup> higher for females than males in fever (98% vs. 73%,  $p=.001$ ), chest pain (78% vs. 35%,  $p=.000$ ), breathlessness (60% vs. 10%,  $p=.000$ ), weight loss (70% vs. 4%,  $p=.000$ ), loss of appetite (88% vs. 35%,  $p=.000$ ), weakness (88% vs. 52%,  $p=.000$ ) and concern for illness (84% vs. 40%,  $p=.000$ ). For males, it was significantly higher in reduced income (58% vs. 10%,  $p=.000$ ). This indicates that the females were predominantly concerned about the physical distresses/symptoms, and males about the financial issues.

The consequences of females' physical symptoms in some instances raised annoyance of their husbands leading to physical torture and transfer to in-law's homes. An illiterate divorced/separated female of 32 years of age described as:

I got fever, cough and physical weakness needing treatment. My husband could not accept me for this, and warned me that nothing would be done further for me. He expected my death. He also beat me. Eventually he left me away. He has 7 more wives. During my illness, he first took me to his sister's home, but after 6 months he left me in my mother's home.

Most females and males reported that cough and fever mostly increased in the evening and morning. However, many females initially thought that the symptoms appeared in them were not serious, and minor treatment might cure them. A 40 years old illiterate married female said:

I had fever and cough. Initially, I thought I got cold because I was going to work early in the morning everyday. But one day, I got very high fever. I

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<sup>3</sup> Chi-square trend test

could not even move for that. I was sick for 8 days, and at one stage I lost my sense. I could not eat. I got chest pain and cough. Thus, I could not sleep.

Although fewer males than females mentioned about individual items of physical distress, their suffering was so acute that compelled them to stop daily work in many occasions. A 45 years old illiterate married male narrated, “Initially I had fever that continued for many days. I thought it would stop at one time. But after few days, I got headache associated with fever. I became very weak, and thus stopped working myself.” Most females compared to males suffered from a variety of troubling symptoms raising serious concern about the disease and its course. A 55 years old illiterate widow expressed her concern about the distresses she was facing. She says, “I had cough, fever, weak health and lack of appetite associated with vertigo. I also had breathing problem. I was even unable to sleep. However, I still have weakness, and vertigo. I do not have appetite.”

More males than the females were very concerned about financial impact of distress on their life. This is because traditionally males are considered to be the breadwinner of a family in Bangladesh and their absence from work due to illness has deadly consequences on income leading to poverty. Indeed, due to physical weakness compounded with other psychosocial distresses, males could not work for earning. In many cases, the landowners did not lease out land to the poor share croppers for cultivation, and the employers did not recruit the wage labourers in their enterprises because of the disease resulting in personal and familial income loss. Thus, males’ concern for reduced income got prominence in their narratives. An illiterate 45 years old married male narrated:

I can not work due to physical weakness leading to loss of income. I have to borrow to meet my family needs. I have some paddy crops at home. We consume them now. We are worried to think that if the paddy crops are finished then what will we eat?”

The reasons of females’ less concern about the financial issues were embedded in socio-cultural milieus. In Bangladesh traditional familial tie is very strong. With some exceptions, traditionally husbands or adult children usually look after females. They bear the expenses of their mothers depending on their ability. As such, some females seemingly tended to express less concern about the financial issues of their families despite they did have such problem. A 48 years old married illiterate female viewed the financial issue as follows:

There is no reason for losing income. My son went far from home to work and earn money for my treatment. He wants so much to keep me alive. Despite hardships, my son says me to drink milk. When he is unable to work, he

borrow money to run the family including my treatment. To repay loan he later worked hard, more than normal hours.

### **Single most troubling symptom**

Coughing particularly by females (60% as opposed to 33% of males) was identified as the single most troubling symptom. A 25 years old married female with 9 years of education cited:

Urine and stool came out while coughing. Cough tended to increase in the evening and morning. I got blood with cough. It seemed that my breathing function would be stopped. I felt pain in both sides of my chest.

Males also experienced similar distress with severe coughing. A 50 years old illiterate and married male said, "I got breathing problem while coughing. It tended to increase at night. I could not sleep properly."

In fact, beyond medical implication, coughing has other socio-cultural implications particularly for females. Unlike females, males are free to coughing and spitting sputum hither and thither. But in most Bangladeshi societies, coughing and sneezing by females with unpleasant sound are viewed as bad act. Thus, females have to suppress coughing even in course of TB. This is a painful distress for females.

### **Perceived causes**

Thirty-one pre-coded individual items under 8 broad groups (ingestion, health-ill-injury, heredity, psychological-emotional, environmental, traditional-cultural, sexual and miscellaneous) were assessed to know the perceived causes of TB. The categorical responses to each item were coded with values from 0 to 2 indicating not mentioned, mentioned after probing, and mentioned spontaneously.

Patients attributed to a wide range of causes responsible for their problems. The grouped items showed that more females than males mentioned about health-ill-injury (54% vs. 35%,  $p=0.046^4$ ), environmental (42% vs. 15%,  $p=0.003$ ), hereditary (24% vs. none,  $p=0.000$ ), and traditional-cultural (14% vs. 8%). On the contrary, more males than females specified ingestion (69% vs. 38%,  $p=0.000$ ), and miscellaneous (27% vs. 14%). A few mentioned about psychological-emotional and sexual clusters of causes.



However, when examined by individual items of perceived causes, the trend of increase in responses from probing to spontaneous was significantly higher for females compared to males in blood problem (6% vs. none,  $p=.043$ ), prior illness (30% vs. 4%,  $p=.000$ ), constitutional weakness (6% vs. none,  $p=.014$ ), heredity (24% vs. none,  $p=.000$ ), germs/infections (26% vs. 6%,  $p=.003$ ), contamination-contact (36% vs. 14%,  $p=.011$ ), and fate, God, *karma* (6% vs. none,  $p=.025$ ). For males it increased in smoking (42% vs. none,  $p=.000$ ) and abusing drug (12% vs. none,  $p=.005$ ).

Most females, who mentioned food as a cause of their problem, emphasised on food crisis and poverty. For example, a 25 years old illiterate and divorced female said, "I am a poor woman. I could not eat enough food due to food crisis. This resulted in broken health leading to cough." Males emphasised both on irregular food intake and poverty. "I have been taking meals irregularly. I am to eat my lunch at night; because of poverty I cannot manage food on time. This caused my TB," said by a 40 years old married and illiterate male. Taboos attached with food and drinking water also came up. A 35 years old married and illiterate female narrated, "I drank a glass of water while visiting one of my relative's home. I think that I might get this disease from that place." Some also blamed drinking unboiled water. Drinking milk mixing with pineapple was also believed to be the cause of TB. A 17 years old unmarried boy with 10 years of education said, "I might get this disease, because one day I drank milk with pineapple." Unlike males, most females mentioned that their disease was hereditary. A 15 years old unmarried girl with 8 years of education narrates, "My father had TB. I nursed him. I went close to him and fed him rice. Thus, I think I have got this disease from him." Males reported about various addictive substances including smoking as perceived causes of TB. The addictive substances include alcohol, chewing tobacco, taking tobacco with betel nuts, etc. "I used to smoke a lot. I have got this disease because of smoking. Everyday, I used to have 100-150 *kolki* (the bowl of a hookah which holds tobacco and cinder) of marijuana," said a 50 years old married male with 4 years of education. No females blamed smoking as the prevalence of smoking among females is very low. But a 40 years old widow said, "While I was working as a cook, I got exposed to a lot of smokes. Perhaps, thus I got TB."

More males than females mentioned about hard physical work. A 40 years old married and illiterate male expressed, "I have worked very hard in my life. I pulled rickshaw (3 wheelers) for 22 years. I got dust inside me while pulling rickshaw. For these reasons I got TB." A 16 years old illiterate and unmarried girl told, "I had to work very hard in a garment factory for a longer period each day, but received a little salary. I could not eat enough food due to lack of money. This caused my TB."

More females than males reported prior illness as a cause of TB. The illness reported were bad fever; boil in throat, injury, water in stomach, common cold, etc. A 16 years old married girl with 5 years of education narrates, "I find no reason for my disease. I think it is caused by fever and cough." Although 26% of the females reported germs or infection as a cause of their TB, but in narratives they did not mention it. Females also frequently reported contamination and contact as causes of infections. Many patients either contacted or nursed TB patients earlier that might help transmission to them. A 35 years old illiterate married female noted, "A year ago my younger son fell sick, and we hospitalised him for a night. I stayed with him, and drank water there. I think I have got TB because I have drunk water in hospital." Although 13.5% of males said about contamination or contact as a cause of TB, only one of them gave narratives. He said, "I work in a transport company. My two co-workers had TB. I think that thus I got TB from them." Hot-cold humor also came up in the narratives. A 45 years old illiterate widow cited, "One day at noon the sky was cloudy, and I went to bring my goat from the grazing field. I got cold wind in my body at that time. On that day I got fever because of cold. I think I got this from the cold touched me on that day."

Although males did not mention about hot-cold humor in their narratives but they mentioned about some superstitions. For example, an 18 years old married boy with 3 years of education said, "I think that I have got TB because I have stepped over sputum of some TB patients on the street or I have eaten food which was touched by TB patients." A 25 years old married female with 5 years of education associated the perceived cause of TB with marriage and childbirth. She said, "I think that I got TB because I got married and have given birth of a baby in early age."

### **Most important perceived causes**

When grouped perceived causes considered, it was found that more females than the males identified health-ill-injury and environmental issues as most important causes of their problems (34% vs. 19% and 24% vs. 10%). On the contrary, a higher proportion of males specified ingestion (54% vs. 20%,  $p=0.000^5$ ) and miscellaneous causes as the most important causes of their problems. More females than the males mentioned the most important individual items of perceived causes. These were: food (14% vs. 10%), prior illness (18% vs. none), contamination-contact (20% vs. 10%). Reversely, a higher percentage of males than females identified smoking and physical exertion as the most important perceived causes (35% vs. none, and 19% vs. 8% respectively).

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<sup>5</sup> Fisher's Exact test

More males than females mentioned ingestion in terms of food unavailability and irregular intake as the most important perceived causes of TB. A 40 years old married and illiterate male said, "I have taken meals irregularly that might have caused my disease. Since we are poor we are to eat food at others' homes resulting in irregular intake. This is other cause of my disease." Females' narratives in this regard also indicated similar themes. A 80 years old illiterate widow said, "I could not take myself or let my children to take sufficient food since my husband's death. I took only betel leafs. Perhaps lack of food has caused my disease."

Substance abuse and heavy smoking appeared to be the most important perceived cause of TB according to males. A 50 years old married and illiterate male said, "I was a chain smoker. Such an over smoking might have caused my TB." A 16 years old unmarried girl with 8 years of education narrates how contamination-contact transmits TB, "I sat close to my parental uncle and some time I ate food from his hands when he had TB. At that time I did not know if someone would associate with a TB patient might get TB. Now it seemed to me that I got TB because of such contact." A 35 years old married and illiterate male said, "My wife had TB 2 years back. I might get TB from her."

### **Help-seeking**

#### **Self-help**

Soon after appearance of the problems/symptoms many patients relied on self-help or family help or help from friends to tackle the problem while some did nothing. Their efforts to find relief included the following measures: i) taking or restricting special foods to recover from the symptoms, ii) practicing herbal and traditional treatment, and iii) exercise. Most males did nothing as a part of self-help compared to females. A few females did exercise along with other measures, while many males stopped smoking or chewing tobacco but did not report about any exercise. Feeling supportive to relief their symptoms the patients took multi-faceted measures. A 25 years old married female with 4 years of education explained, "I have done morning walk. I have eaten parched rice and bread. I have fomented my body, and rubbed warm mustard oil with onions in my chest. I have stopped drinking milk as it might increase cough."

Rubbing warm mustard oil in combination with garlic was not uncommon among males too. "I massaged warm mustard oil on my chest. I ate grinded black cumin, so that the sputum could come out from the deep-chest," said a 45 years old married male with 7 years of education. Interestingly, some females and males massaged kerosene oil to relief the symptoms. "I have massaged kerosene oil at home. I did not do anything else," said a 55 years old married illiterate female. Some males

stopped smoking and rubbed kerosene oil as a remedy. A 25 years old married illiterate male cites, "I have stopped smoking after getting TB. I have massaged warm kerosene oil from chest through throat."

Twenty-three individual sources of help-seeking under 7 broad categories (informal, health clinic, traditional healer, private doctor, TB/BRAC Health Centre, and others) were investigated. The categorical responses to each item were coded with values from 0 to 2 indicating not mentioned, mentioned after probing, and mentioned spontaneously.

When the grouped sources of prior help-seeking were considered, the data revealed that more females than the males spontaneously reported about informal sector (80% vs. 28.8%), private doctor (54% vs. 40.4%), traditional healer (18% vs. 9.6%), while all of females and males reported about this clinic (TB clinic/BRAC Health Centre). On the other hand, more males compared to females spontaneously reported about other sources (51.9% vs. 50%) and health clinic (32.7% vs. 24%). Overall, when both sex taken together, The BRAC Health Centre appeared to be the major choice of all the patients for past help-seeking, followed by informal sector (53.9%), others (51%), private doctor (47%) and health clinic (28.4%).

Analysis by individual sources of prior help-seeking showed that a higher proportion of females than the males spontaneously reported about home remedies (72% vs. 19.2%,  $p=0.000$ ), druggist/pharmacy (30% vs. 13.5%,  $p=0.056$ ), local herbal healer (18% vs. 9.6%), private practitioner-allopathic (40% vs. 28.8%), whereas a greater proportion of males compared to females reported about urban government hospitals (25% vs. 10%). The trend in increase in responses from probing to spontaneous was significantly<sup>6</sup> higher for females in home remedies and for males in urban government hospital.

Home remedies encompassed a wide range of actions taken viz. change in diet, food restrictions, use of herbals, rubbing oils, etc. The females predominantly practiced these remedies. A 16 years old married girl having 7 years of education mentioned, "I stopped eating hilsha fish, beef and pigeon's meat because of this disease." Some females drank juice of date leaves, *telkuchi* (a kind of creeping plant), *thankuni pata* (a kind of edible bitter herb). Some females and males gave heat by warm leaves of *akun* tree (sun plant), and rubbed warm mustard oil mixed with garlic over their

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<sup>6</sup> Chi-square trend test

chest, throat, hands and feet. "I rubbed mustard oil with garlic in my hands, and in the sole of foot. I did gargling with hot water to prevent cough," said a 50 years old illiterate and married female. A 45 years old married male having 7 years of education also gave similar accounts of herbal use. He said, "I massaged warm mustard oil on my chest, and ate black cumin so that the sputum come out of my chest." Some females also massaged kerosene oil over their body that seemed to be very injurious.

BRAC Health Centre appeared to be the prominent source of prior help-seeking as professional source of help outside home for both females and males. The narratives revealed that both females and males sought professional help from multiple sources, and BRAC Health Centre was the last resort. This happened as most patients did not get cured in earlier sources. An 18 years old married girl with 5 years of education cited:

At first I visited a local herbal healer who gave me a *tabiz* (amulet) and some *panipora* (sanctified water) but I did not get cured. Then I visited another herbal healer, and got a little bit cured. But after a few days, I got typhoid and went to a trained private specialist doctor. I recovered significantly after his treatment. But unfortunately a tumor appeared on my back, and revisited the specialist doctor. He cleaned my boil, and gave me tablets and syrup. But I did not get cured. Lastly I came to BRAC Health Centre.

Males' narratives also contained similar themes. A 40 years old married and illiterate male cited:

After two months of my problem, I visited a village doctor but I was not recovered by his treatment. One and a half months later, I visited another village doctor, and got treatment for 15 days without any cure. Then I went to another village doctor, but got no positive result, rather I got ulcer in my mouth and pains in the ribs. Then I went to a trained private specialist and got treatment for one week. Later, having no effect, I visited BRAC Health Centre.

The females went for a minimum of 7 health actions compared to 6 of males (average female 3.8 vs. male 3). Most patients resorted to home remedies, and family or friend's care as a first action (female 76% and male 37%), followed by unqualified doctors (female 10% and male 33%), and druggist/pharmacy (female 6% and male 4%). From the second resort or action, BRAC Health Centre got prominence as a prior help-seeking source.

The overall number of visits to health care providers as a source of prior help-seeking was higher for males (4.2) than females (2.8). Almost all patients coming to BRAC Health Centre sought first help from multiple sources outside home (excluding family or friends). Unqualified doctor appeared to be most preferred source of help for both females and males, although the proportion was higher for males than females (46% vs. 40%). Druggist/pharmacy was the second most choice of sources, where the proportion of females was higher than males (26% vs. 12%).

Most males came for first help on their own (own decision) (67%) compared to 12% of females ( $p=.000^7$ ). This implies that most females have no chance to decide on their own to seek help in need requiring permission of some body. Most female patients were asked by males (66%) for first help-seeking while it was the males for the males (90%) ( $p=.000$ ). This also in a way reveals males' dominance in care seeking decision making. Only 16% of females compared to 65% of males could go for help on their own, indicating that the females were unable to move alone without permission of husbands or in-laws ( $p=.000$ ). The females had to go for a longer time to the first help-seeking sources than males. The mean was 31.5 days for females and 26.7 for males. The common reason for a longer duration of visit to first help-seeking was that the treatment failed to alleviate symptoms of distress, indicating that the females often seek help from traditional and inefficient sources requiring longer time for treatment. The mean travel cost in this regard was higher for females (TK. 28) than males (Tk. 8). The mean travel time was higher for females than males (40 vs. 21 minutes). The mean treatment cost for the first help-seeking was higher for males than females (Tk. 477 vs. Tk. 371). More females than males said that the cost posed a strain on their families.

The travel cost to BRAC Health Centre was much higher for females than males (Tk. 36 vs. Tk. 13). The females also had a higher travel time than males (70 vs. 32 minutes). While the mean treatment cost in BRAC Health Centre was higher for males than females (Tk. 353 vs. 216). Most females compared to males expressed that the expenses increased their mental anxiety, indebtedness and hardship.

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<sup>7</sup> Chi-square test

However, most patients viewed the providers' behaviour and cooperation as very positive with no gender bias. Most patients (94%) regardless of their sex received counseling on the dosage of drugs.

**Lag time-** The mean lag time from onset to TB diagnosis was higher for females than males (72 vs. 64 days). While the mean lag time from onset to the first help-seeking was higher for males than females and (16 and 13 days).

### **Stigma**

Eighteen stigma indicators were investigated. These were: non-disclosure of the problem, disclosed to confidant, think less of yourself, shamed/embarrassed, others think less of you, effects on others, others have avoided you, others refuse to visit you, others think less of the family, problems for children, problem to marry, expected support from spouse, spouse refuses sex, other marital problem, problem for relative to marry, stay away from work, decided to stay away, and presumed other health problems. Each indicator was coded with values from 0 to 3 indicating no indication, uncertainty, the possibility, or definite concern and the values were combined in a scale. The overall stigma scenario indicated that a significantly higher number of females than their counterpart males had stigma in most indicators except in "decided to stay away" (male 64% vs. female 46%), "problem to marry," (male 55% vs. female 46%), and "spouses refuse sex" (male 53% vs. female 36%). However, the trend of increase in responses from 'no' or 'uncertain, or 'possibly' to 'yes' was significantly<sup>8</sup> higher for females in "think less of yourself" (56% vs. 25%,  $p=.023$ ), "shamed or embarrassed" (52% vs. 21%,  $p=.001$ ), "others have avoided you" (28% vs. 6%,  $p=.041$ ), "others refuse to visit" (22% vs. 4%,  $p=.012$ ), "other marital problem" (32% vs. none,  $p=.001$ ), and "stay away from work" (14% vs. none,  $p=.037$ ). For men it was "decided to stay away" (64% vs. 46%,  $p=.008$ ).

Most females (56%) compared to males (25%) ( $p=.023$ ) expressed that they would think less for themselves because of the problem. But the narratives regarding the issue did not fully correspond with frequencies; rather most females were concerned about themselves. Such concerns were expressed in different forms, for instance, the disease reduced their esteem and pride, increased social isolation, in-law's and husband's negligence. A 30 years old illiterate married female cited, "My husband is scared of me. He thinks that I am suffering from a communicable disease. He does not appreciate me as before. In fact, my pride, dignity and honour have decreased to a large extent

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<sup>8</sup> Chi-square trend test

because of this disease. Nobody associates with me as before.” Most males explained that they bothered a little about the loss of their respect and image as an effect of the disease. “I think I will get cured and will be able to work as before. My prestige is not decreased,” said 35 years old married male with 2 years of education.

More females than males felt embarrassed because of the problem (52% vs. 21%,  $p=001$ ). Fear of stigma or reduced social status, disapproval on taking part in social happenings, neighbours’ unwanted bad comments, ill-health, restriction in mixing with people, etc. were the major factors for being ashamed. An 18 years old illiterate and divorced girl noted, “I did not go anywhere, rather stayed at my room. I kept myself isolated from others because of the disease. I was worried of people’s insult.”

Although fewer males than females quantitatively mentioned about shame attached to the disease, their narratives indicated that many of them in fact faced embarrassment because of the problem. They lost dignity, faced restrictions in mixing with people and experienced avoidance by the peers. A 40 years old married male with 4 years of education mentioned, “One of my friends once wanted to know as to what happened to me. In reply I told him about my TB. Instantly he started to move far from me. From that day he never met me again. I got hurt by his unusual conduct.”

A higher number of females than males felt that other people avoided them because of the problem (29% vs. 6%,  $p=.041$ ). Both females and males easily understood the issue of avoidance from people’s certain behaviour, for example, people refrained from taking foods together, avoided to visit, and kept them away in fear of disease transmission. A 20 years old married female with 9 years of educations said:

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 big disease, and he often says me to commit suicide with poison. At this, I get shocked and asked him to buy poison for me. Thus, I am really in a state of mental torture.

A 45 years old illiterate married male cited, “People do not like to talk face-to-face rather take their faces to the other directions while talking to me. Moreover, they dislike visiting me in fear of transmission of TB.”

More females than males confirmed that other people refused to visit them predominantly for fear of transmission of TB. “My neighbours refused and forbade others to visit our home in fear of



transmission of TB,” said a 25 years old married female with 5 years of education. A 22 years old married illiterate male said, “..... My neighbours told that they would not come to my home as long as I got cured.”

About one-third of married and would be females as opposed to none of the males had concern on other marital problems even after cured from the disease. The major themes came up from narratives of the married females were husband would remarry, marriage would be broken, husband would rebuke, children would get TB, whilst would be married females said that none would like to build marital relations with TB patients in fear of transmission. A 35 years old illiterate married female said, “.....My husband misbehaves with me because of this disease and he would like to get married again with another girl.”

In contrast to none of the males, 14% females said that they were asked to stay away from work especially by the doctors and employers. They did so for preventing spread of TB. A 25 years old separated illiterate female said, “I was a cook in a family. When my health condition became very bad, the household head asked me to quit the job because of TB. They were afraid of transmission of the disease.” Besides, there were some restrictions from the families, and the community. Their utensils and bed were separated, and they were not invited to social gatherings. A 15 years old unmarried Hindu girl having 8 years of education said, “I was not allowed to do any work at home during the *Durga Puja*<sup>9</sup>, the biggest religious festival of the Hindu community, rather was asked to stay away from others. However, I somehow managed to go out of home to view the idol of the *Durga*. Nobody told me anything for that. In fact, nobody from outside of our home knows about my disease.”

More males than the females decided on their own to keep aloof from work or social groups (64% vs. 46%,  $p=.008$ ) in fear of transmission of disease to others, shame, social isolation, etc. The males’ narratives gave more occupational reasons. A 37 years old married and illiterate shopkeeper added, “I myself have decided not to go for any work. If I sit in the shop, people may criticise me. They tell that they are not eager to buy anything from a TB patient.” “I will not attend any social activity because of my disease. If I associate with others, they can get it from me,” said a 15 years old unmarried girl with 8 year of education. However, physical weakness was another important leading factor for staying away from work or social groups.

**Stigma score-** Originally we considered 18 stigma indicators and later deleted 1 item (number 2) as this had very low coefficient correlation. By 17 remaining indicators we calculated stigma scale,

followed by its descriptive statistics. The mean and median scores of stigma for females were higher than males (female 19 vs. male 15; and female 20.5 vs. male 15 respectively). The score for females ranged from 2-40 while it was 2-34 for males.

### **Recommendations**

1. Patients and the community people do not know that TB is no more infectious after 4-8 weeks of treatment. Such a lack of knowledge creates social problems, and increase stigma of the patients. All providers should provide education on this particular issue with special emphasis on gender.
2. TB programme should actively explore the ways and means to improve social support for TB patients. This can be done by educating/sensitising the community. Support groups for TB patients should be developed and linked up with TB patients and the community leaders.
3. Special arrangement should be in place to sensitise females so that can seek care at the onset of any sign/symptom of any illness including TB. To be most effective, efforts should be made to educate and involve husbands, in-laws and caregivers in a family.
4. The community-based interventions should address the issues of women's concerns about decision making, provision of attendant (to escort) while visiting clinic, transport, financial issues and household responsibility to seek care.
5. Association that people make between TB and other diseases may have deadly consequences for health care seeking for TB diagnosis, treatment and compliance. Massive education on TB using multi-channel could be instrumental in effectively educating and motivating the people on signs/symptoms of TB along with its curability. Providers should reinforce this during their routine interactions with TB patients and family members/caregivers.
6. Treatment is free, but the "not free" issue of patients should also be considered. For example, loss of income, travel cost, etc. may impose a high financial burden especially on the poorer groups. This is more acute for women. So, these and other poverty related issues should be addressed.
7. Stigma may delay treatment seeking. So, appropriate education to patients along with the community should be given on a continuous basis.

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<sup>9</sup> Worship of a Goddess

8. The community and the providers should take into account the social stigma of TB particularly among the women. The providers should be more responsive to the need for anonymity, confidentiality and trust. Thus, innovative strategies ought to be developed and implemented for overcoming social stigma.

**5. How the above recommendations relate to the following**

**i) Interpreting symptoms as possibly TB**

People usually neglect the symptoms of chronic respiratory diseases, and often tend to mix up these symptoms with other diseases, e.g. common cold, etc. They also have poor understanding about the consequences of chronic respiratory illnesses and their symptoms and the TB as a whole. The recommendations formulated on the need of development and implementation of health education with a special focus on TB and gender will help improve people's critical understanding of the symptoms of TB enabling them to identify the symptoms close to TB, thereby increase self-reporting of symptoms leading to a higher case detection, early diagnosis and proper treatment.

**ii) Help-seeking (selecting services and delays in seeking help)**

People, especially the females, do not report their respiratory symptoms due to a lack of effective knowledge and lack of awareness on and access to the professional service sources available for TB management. The practice of 'wait and see' largely delays appropriate care seeking. Social stigmas along with financial constraints also contribute to delay the help-seeking. Massive health education could act as a driving force and motivating factor for seeking professional health care for chronic respiratory problems as well as to overcome the barriers of social stigma.

**iii) Health service issues (quality and responsiveness of services)**

Quality of services in terms of accessibility, availability, waiting facility in the centre, provider behaviour, costs, gender sensitivity, etc. appeared to be the live barriers especially to the women in seeking professional care in most cases. Effective training and routine refreshers course for the providers are expected to improve their performance in delivering patient-friendly services.

**iv) Diagnosis (effectiveness and timeliness)**

Both patient's and provider's delays largely interfere timely diagnosis. Sometimes, application of inadequate diagnostic tools delays diagnosis. Also, a lack of proper instructions on effective sputum production leads to improper diagnosis. Training of providers and provision of adequate diagnostic tools (e.g. combination of radiography and smearing) could enhance effective and timely diagnosis of TB.

## **v) Treatment**

### **1. Timely initiation of treatment**

Timely initiation of treatment is fully dependent on the providers. Appropriate training on the necessity of timely initiation of treatment and monitoring mechanisms as proposed in our recommendations may bring positive change in the mind set of the providers to ensure timely initiation of treatment.

### **2. Adherence**

Adherence is dependent on both the patient and providers' initiatives. The providers should motivate and follow-up the patients to take drug regularly and comply with the full course. This will lead to positive outcome of treatment. The proposed health education and training of the providers will boost up the required awareness and carefulness of both sides.

## **6. Gender issues of concern**

- 1) About 52% of the patients' household income was not dependable. Besides, most patients were in their economic productive age. The females were even more vulnerable.
- 2) Females were less likely to report their symptoms, get sputum examined, if so happened; they were less likely to be smear positive.
- 3) Females were unable to make self-decision, their mobility was restricted (females needed males' permission and someone to escort on movement), their travel to health service sources needed more time and cost, they needed permission to move outside home.
- 4) The health issue particularly of the elderly females was neglected.
- 5) The females did not receive social support to the extent they expected neither from the in-law's side nor from the parental during TB.
- 6) Female patients were victims of physical and mental torture from husbands and in-laws. Intra-family discrimination was also widespread.
- 7) Often husbands were reluctant to arrange proper treatment for their wives. They rather transferred the wives to their parental homes for treatment.
- 8) Females' physical distress was more severe than males. Among the physical distresses coughing brought unbearable sufferings to women. While coughing tears and urine came out putting them in a vulnerable condition. In spite of physical weakness, women were to continue daily household chores without rest. Unlike males they often were unable to bypass it.

9)

Those sought help outside home usually did it in non-professional sources e.g. drug-sellers, etc.

- 10) Females were more victims of social stigma, exclusion, and unequal intra-family food distribution. Stigma also resulted in self-isolation, delayed treatment, and fear of marriage or marital life.
- 11) Females were more worried about men's TB as their inability of work due to illness might reduce income leading to financial crisis. Thus, they gave priority to males' treatment. But often males did not do so in case of women's illness.
- 12) During interactions at laboratory and DOTS initiation, the providers sometime discriminated between females and males patients in their interactions showing a bias to males. Even the female providers did the same with females in their interactions during DOTS initiation.

### **7. Further research questions**

Enormous research questions related to TB are still unanswered in Bangladesh. Comprehensive research on the following issues would be very useful to improve the effectiveness of the current TB control programmes in Bangladesh.

1. Role of private sector in TB control programme in Bangladesh,
2. Gender barriers in TB control programme in urban Bangladesh,
3. Reasons of low case notification among the elderly females,
4. Impact of TB among the garment workers in Bangladesh,
5. Gender differences in the incidence of respiratory complaints and barriers to females to attend outpatient clinic,
6. Why some members of the infected families are not infected by TB, and
7. Is there any genetic impact on sex differential in TB incidence?