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Gender matters

Understanding of access barriers to community-based tuberculosis care in Bangladesh

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The cover pictures were taken from BRAC's (an NGO) community-based TB control programme to illustrate the programme's partial operational features at grassroots.

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“The pain in our shoulder comes
You say, from the damp; and this is also the reason
For the stain on the wall of our flat,
So tell us:
Where does the damp come from?”

Bertolt Brecht

From-Later Svendborg Poems and Satires, 1936-1938.

To

My revered late parents.

And my favourite teacher Moulvi Anwarul Hoque, who prematurely
died of tuberculosis.

ABSTRACT

Background: Females' lesser use of TB control services is a grave concern worldwide, entailing more gender research in quest of practical remedies.

Objective: To understand the gender differences in various clinical steps for TB care, explore gender-specific access barriers to TB control; and measure smear-positive PTB prevalence in different population groups of rural Bangladesh.

Methods: The studies were implemented in 12 subdistricts under the BRAC community-based DOTS programme, representing 10 subdistricts for Studies I-IV and 2 for Study V. Studies I, II and V embraced the cross-sectional design, and III and IV the cultural epidemiological descriptive qualitative design. Using the programme registry cases data of 3,600 systematically selected patients from outpatient clinic, laboratory and TB treatment registers (1,200 from each), the Study I examined female-male differences at various clinical steps for TB treatment. Study II surveyed 1,000 conveniently chosen newly diagnosed PTB patients (500 females and 500 males), and assessed sex differences in different delays in help seeking for TB treatment. Study V, a population-based survey measured the smear-positive PTB prevalence in different population groups, and assessed socio-economic-demographic profiles of the sputum-positive PTB incident cases, and non-cases. Employing the 30 cluster survey methods, the study visited 44,455 households spread over 60 clusters (30 each in Monohardi and Shibpur subdistricts), identified persons with prolonged cough for at least three weeks, collected two sputum specimens (morning and spot) from each reported person, and these were tested in field laboratories for AFB. Socio-economic-demographic data were collected from the smear-positive PTB incident households and also from 239 non-TB incident households. A patient with at least one sputum-positive slide was defined as a smear-positive PTB case. Descriptive and inferential statistical analyses compared the outcomes of these studies between females and males, and different socio-economic groups. Data for Studies III and IV were collected from 102 purposively selected patients (50 women and 52 men) undergoing TB treatment. Locally adapted semi-structured EMIC (Explanatory Model Interview Catalogue) interviews inquired about the TB-related patterns of distress (PD), perceived causes (PC) and help seeking behaviour (HS), and TB associated stigma. Prominence of reported categories was evaluated by frequency of respondents reporting the category, and comparing between women and men. Qualitative meaning of gender-specific features of PD, PC and HS, and stigma was clarified from patients' narratives. TB-related stigma was assessed individually, and in a validated index by sex, and related illness narratives elaborated the identified quantitative relationships. Chi-squared test for trend assessed female-male differences in PD, PC and HS.

Salient results: Female-to-male ratios (FMR) were consistently less than 1 at different clinical steps for TB treatment, but positive treatment outcome revealed no sex disparity (female 93% vs. male 89%). Female sex was associated with longer 'total delay', 'total diagnostic delay' and 'patient's delay.' Both women and men patients frequently reported diverse features of stigma, but these adversely affected more women than men. Gender differences in the patterns of distress, perceived causes, and help seeking behaviours were substantial. Women patients reported more diverse somatic distress, whilst men reported more about TB-related financial distress. As perceived cause of TB, men emphasised on smoking and women on food shortage stemming from their limited access to economic resources. Most women initially relied predominantly on informal home remedies for the cure. The estimated 'true' smear-positive PTB period prevalence was 122.2/100,000, more common in males than females. The prevalence rate was almost identical across different wealth quintiles, indicating that all social groups are at risk of TB. Rise in the age of TB patients, and smoking habit substantially increased probability for remaining undetected.

Conclusion: Sex differences existed at different clinical steps for TB control. Women compared with men, encountered longer delays at various clinical stages for TB treatment. The adverse effects of stigma both reflected and worsened gender inequalities. Gender disparities were evident in the patterns of distress, perceived causes, and help seeking behaviours, affecting more women, whilst TB-related financial distress affected more men. The estimated 'true' period prevalence of smear-positive PTB was high in the community, and almost all socio-economic groups were at risk of TB.

Key words: Community-based DOTS programme, Bangladesh, Gender, Delays, Stigma, Cultural epidemiology, Socio-economic divides, Smear-positive PTB prevalence.

LIST OF PUBLICATIONS

This thesis is based on the following original papers:

- I. F. Karim, F. Ahmed, I. Begum, E. Johansson, and V.K. Diwan. Female-male differences at various clinical steps of tuberculosis management in rural Bangladesh. *Int J Tuberc Lung Dis* 2008; 12: 1336-1339.
- II. Fazlul Karim, Akramul Islam, AMR Chowdhury, Eva Johansson, and Vinod K Diwan. Gender differences in delays in diagnosis and treatment of tuberculosis. *Health Policy and Planning* 2007; 22:329-334.
- III. Fazlul Karim, AMR Chowdhury, Akramul Islam, and Mitchell G.Weiss. Stigma, gender, and their impact on patients with tuberculosis in rural Bangladesh. *Anthropology & Medicine* 2007; 14: 139-151.
- IV. Fazlul Karim, Imran Matin, Eva Johansson, Mitchell G.Weiss, AMR Chowdhury and Vinod K Diwan. Cultural epidemiology of tuberculosis in rural Bangladesh with reference to gender. *Manuscript*.
- V. Fazlul Karim, Shafayetul Islam, Munshi Sulaiman, Md. Akramul Islam, Eva Johansson and Vinod K Diwan. Socio-economic divides in smear-positive pulmonary tuberculosis prevalence in rural Bangladesh. *Manuscript*.

The papers will be referred to by their Roman numerals I-V.

CONTENTS

1	Background	1
1.1	Tuberculosis (TB) through the historical lens	1
1.2	Overview of the burden of TB	1
1.3	TB, poverty and gender	2
1.4	TB infection, progression to disease and gender vulnerability	4
1.5	TB, HIV/AIDS and gender	5
1.6	TB control—the global approach.....	5
1.7	The challenges to the DOTS strategy: An analysis with reference to the thesis research questions	6
1.7.1	Factors stemming from health care service provision and delivery ...	6
1.7.2	Patients’ dimensions: Knowledge, attitudes and beliefs.....	9
1.8	Significance of gender research in TB control	13
2	Bangladesh	15
2.1	Promoting gender equality in Bangladesh.....	15
2.2	Charting the progress towards gender equity in health and development, and the challenges.....	16
2.2.1	Gender dimension in health	16
2.2.2	Gender dimension of education	16
2.2.3	Gender asymmetry in economic participation	17
2.2.4	Gender dimensions of governance and political participation	17
2.2.5	Gender-specific social and cultural dimensions	17
2.2.6	Gender dimensions in decision-making	18
2.3	TB epidemiology in Bangladesh.....	18
2.3.1	Risk-related conditions and behaviours.....	19
2.3.2	Health system characteristics.....	19
2.3.3	TB programme characteristics	21
2.3.4	Government (GO) and NGO partnership — a unique approach to TB control in Bangladesh	22
2.4	BRAC TB control programme.....	22
3	Methodology	25
3.1	The study problem and setting	25
3.2	Objectives of the thesis.....	25
3.3	Towards construction of a conceptual framework for the overall research ..	26
3.4	The study sites	29
3.5	Study design	29
3.6	Ethical considerations.....	37
4	The results	38
4.1	Socio-economic divides in smear-positive PTB burden in the community (<i>Study V</i>)	38
4.2	Female-male representations at different clinical steps for TB care at community level (<i>Study I</i>).....	39
4.3	Sex-specific features of delays in TB diagnosis and treatment (<i>Study II</i>)....	40
4.4	TB-related stigma: Unmasking the magnitude, effects, features and determinants (<i>Study III</i>).....	41

4.5	Cultural epidemiology with semi-structured qualitative EMIC interviews (<i>Study IV</i>).....	42
5	Discussion.....	47
5.1	Methodological issues	47
5.2	Main findings	56
6	Conclusions and recommendations	62
6.1	Conclusions	62
6.2	Recommendations	63
7	Acknowledgements	64
8	References	67
9	Annexure	74

LIST OF ABBREVIATIONS

BBS	Bangladesh Bureau of Statistics
BCG	Bacillus Calmette Guerin, an inactive strain of tubercule bacilli used as a vaccine against TB in many countries
BDHS	Bangladesh Demographic and Health Survey
BHC	BRAC Health Centre
BMRC	Bangladesh Medical Research Council
BRAC	Bangladesh Rural Advancement Committee, a Bangladeshi NGO, is working in different countries for pro-poor development
DALY	Disability Adjusted Life Years
DGHS	Directorate General of Health Services
EMIC	Explanatory Model Interview Catalogue
EPI	Expanded Programme on Immunisation, for preventing vaccine preventable childhood diseases
ESP	Essential Service Packages
FWA	Family Welfare Assistant
FWV	Family Welfare Visitor
GoB	Government of Bangladesh
HA	Health Assistant
HIC	High Income Country
HIV	Human Immunodeficiency Virus
HKI	Helen Keller International
IUATLD	International Union Against Tuberculosis and Lung Diseases
LIC	Low Income Country
MA	Mitra and Associates
MoHFW	Ministry of Health and Family Welfare
MTB	Mycobacterium TB
MWCA	Ministry of Women's and Children's Affairs
NGO	Non-governmental Organisation
NIPORT	National Institute of Population Research and Training
NSW	New South Wales (Australia)
ORC Macro	Opinion Research Corporation, Macro (USA based)
PCA	Principal Component Analysis, being used in the evaluation of poverty status in micro-finance programmes
SS	<i>Shastho Shebika</i> (Female Community Health Worker)
TDR	Special Programme for Research and Training in Tropical Diseases of UNDP/UNICEF/WB/WHO
UHC	<i>Upazila</i> (subdistrict) Health Complex
UHFWC	Union Health and Family Welfare Centre
UNDP	United Nations Development Programme
UNFPA	United Nations Population Fund
UNICEF	United Nations Children's Fund
USD	United States Dollar (American currency)
WB	The World Bank
WHO	World Health Organization

1 BACKGROUND

1.1 TUBERCULOSIS (TB) THROUGH THE HISTORICAL LENS

TB has always been a deadly infectious killer in humans from time immemorial. The catastrophic history of TB can be traced in humans back to about 6000 BC. In 1882, Robert Koch discovered and isolated the Mycobacterium as the aetiological agent of TB (Harries 2008), and correctly asserted, “Pulmonary TB cases are infectious, tubercle bacilli are killed by light, and cases need to be notified by tuberculin test.” Following this scientific breakthrough, humankind discovered the chemotherapy, streptomycin, and all the currently used first-line anti-tuberculosis drugs in 1944 and put these in practice to cure TB. Over 25 years of use of these technologies, the industrialised world achieved a steady decline in the prevalence rates between the late 1970s and the early 1980s (Harries 2008). It is argued that TB morbidity and mortality began to decline in Europe long before the introduction of BCG and chemotherapy, suggesting that medical interventions may have contributed little to controlling TB (McKeown 1976), rather it has been ascribed to the improved nutrition, housing, reduced overcrowding, better ventilation, lower family size, reduced poverty and social inequity (McKeown 1976). Nevertheless, the low income countries (LIC) evidently failed to reap such benefits from this scientific breakthrough, nor could improve socio-economic and environmental conditions during the period (Raviglione et al. 2002). Consequently, TB until now continued taking its heavy tolls there (Ogden et al. 2003). A pointless neglect of the ‘forgotten disease’ gave a sharp rise in the TB epidemic not only in the LICs, but also in the high income countries (HIC). Now TB is a serious public health hazard globally.

1.2 OVERVIEW OF THE BURDEN OF TB

In 2006, an estimated 9.2 million new cases of TB occurred worldwide (139 per 100,000 population), including 4.1 million new smear-positive cases (62 per 100,000) (WHO 2008). South-East Asia and Western Pacific regions account for 55% of global cases, and Africa for 31%; the other 3 regions account for relatively a small fractions of global burden of cases. Comparison between global regions reveals an asymmetrical case notifications — 23% in the African region, 36% in South-East Asia region, and 25% in Western Pacific region, giving a total of 83% of all notified new and relapse cases in 2006. About 2.5 million new smear-positive cases were notified from the DOTS and non-DOTS sources, representing 62% of the 4.1 million estimated cases in 2006, a trivial increase from 60% in 2005. Of the 9.2 million new TB cases in 2006, 709,000 (7.7%) were HIV-positive; a many term it, a ‘deadly duo.’ As in the previous years, the African region accounts for 85% HIV-positive cases, and the South-East Asia region accounts for 6%. There were an estimated 1.7 million deaths caused by TB in 2006, and of them 0.2 million were among HIV-positive people, showing that TB still remains a major global public health problem (WHO 2008).

The ‘deadly duo’— link between TB and HIV/AIDS

The advent of the Human Immunodeficiency Virus (HIV) epidemic has fuelled the upsurge of TB, especially in Africa and South-East Asia. HIV progressively weakens the immune system, making people vulnerable to a host of opportunistic infections such as TB. A large majority of people with HIV/AIDS live in countries where the TB prevalence is high. Thus, TB is a leading killer of people with HIV (AVERT¹ 2008; WHO 2008), and it can account for up to a third of AIDS deaths globally (WHO 2006). People with co-infections of HIV and latent TB have up to 800 times higher risk of developing active TB and becoming infectious compared with the HIV-non-infected persons (AVERT 2008).

Multidrug-resistant TB: a growing troubling state

Drug-resistant TB refers to a tuberculosis in which a competent laboratory test has confirmed resistance to one or more anti-TB drugs (Thomas et al. 2002). The WHO and Stop TB Partnership (2008) jointly reports that more than 400,000 cases of MDR-TB emerge each year as a result of under investment in basic activities to control TB, poor management of anti-TB drugs and transmission of drug-resistant strains. The WHO classified both MDR-TB and XDR-TB as a serious emerging threat to global public health, particularly in countries with a high prevalence of HIV infections (WHO 2008). The patients infected with the ‘deadly duo’ (HIV/TB co-infection) are at greater risk for developing MDR because apart from damaged immune systems, they may not absorb the medicines as well as others may do (Helen et al. 2007).

The diagnosis and management of MDR-TB are complicated and expensive. Single case of MDR-TB management costs about USD 100,000-250,000 in America, while costs are substantially lower in Asia, the differential cost between treatment of drug-susceptible and drug-resistant TB is enormous— the cost increasing from USD 10 per case for medications, to more than USD 3,000 (Thomas et al. 2002).

1.3 TB, POVERTY AND GENDER

Today the expanded definition of poverty encompasses notions of material well-being, an absence of infrastructure, a lack of power and voice, and an unraveling of social structures (cited by Nhlema et al. 2003). Although, the concepts embedded in this definition of poverty are less amenable to quantification, but gender analysis provides a useful tool for critically examining power relationships in society, and adds an important dimension to poverty analysis. Poverty is the biggest risk of TB, and TB in turn exacerbates poverty, entrapping the poor in a vicious circle. A conservative estimate shows that the poorest 20% of the global population experience 47% deaths caused by communicable and related diseases (Gwatkin et al. 1998). Deprivations associated with poverty, increase the risks of infections and development of disease. Airborne Mycobacterium can easily spread in overcrowded places with inadequate ventilation, poor lighting, and poverty. Intercurrent diseases and poor nutrition reduce the immune systems of the

¹ AVERT stands for AVERTing HIV and AIDS, an UK-based charity organisation, works with HIV/AIDS projects in higher risk countries.

people living with these conditions. Thus, 95% of all global TB patients live in the LICs (WHO 2002). TB also affects the socio-economic development of a country, as it generally afflicts the most economically active age groups of populations (15-54 years olds). Of 2 million people died from TB in 2002, 75% were between the ages 15 and 54 years (WHO 2002). Studies in both the HICs and LICs (e.g. USA, UK, Germany, Norway, Vietnam, Mexico and Philippines) reveal significantly higher rates of TB in poor populations (some examples in Table 1; cited by WHO 2005a).

Table 1. Higher risk groups of infection

Study country/area	Findings
Economically advanced*	Persons originating from low income countries are at higher risk of harbouring infection than their counterparts originating from economically advanced countries.
Urban Philippines*	MTB infection levels among those surveyed were 4 times greater among the urban poor than the non-poor.
San Francisco, London, Western Europe*	Nearly 10-fold higher infection levels among homeless compared with the average populations.
Rural South India**	The overall smear-positive TB prevalence was 175 per 100,000 population, with respectively 343, 169, and 92/100,000 in the population with low, medium and high standard of living index scores ($p < 0.001$). TB prevalence was significantly higher among the people living below the poverty line compared with those above the poverty line (242 vs. 149, $p < 0.01$).

Sources: *Cited in: WHO Report on Addressing poverty in TB control: Options for national TB control programmes. WHO/HTM/TB/2005.352. 2005a. **Muniyandi et al. 2007.

Besides, established infections are more likely to progress to a disease, as a result of the health consequences of poverty, especially malnutrition (e.g. vitamin D and zinc deficiency). In many patriarchal societies like Bangladesh, women are socialised in a way that they eat last and least after serving all the family members, resulting in malnutrition and increased vulnerability to infectious diseases. In a vicious circle, TB itself causes poverty, imposing a severe economic burden on individual patients, their households, their healthcare systems, and their communities, particularly through the costs of diagnosis and treatment, and the loss of income due to illness. Though diagnostic services and drugs are free in the public sectors of many countries, other costs such as travel and special nutrition during treatment, are often unaffordable to a mass of the poor, especially those live on less than 1 dollar a day. Generally, the costs incurred are higher before diagnosis (Kamolratanakul et al. 1999). A study in India found that TB patients lost on average 83 working days, with 48 days before treatment and 35 days during treatment. Indirect costs represented 65% of the families' cost for TB disease (Rajeswari et al. 1999). This is because the patients make several visits often to inefficient health care providers before a proper diagnosis (Long et al. 1999), and the lengthy course of treatment incurred substantial costs from lost production and income. Thus, TB thrives in conditions of poverty, and can worsen poverty.

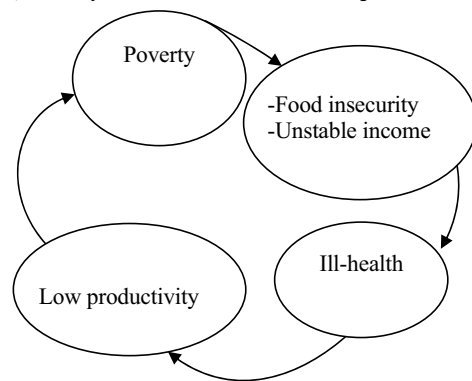
Women constitute 70% of the poor, for example, the interaction between poverty and gender may be the most important risk factor to curb the communicable diseases especially among

women (UNDP 1995). In the LICs, women are triple hit, respectively by social structure, males and poverty, resulting in their poorer access to health care, delays in diagnosis and treatment, leading to needless spread of the disease (Diwan et al. 1999; Long et al. 1999; Yamasaki-Nakagawa et al. 2001; Xu et al. 2005).

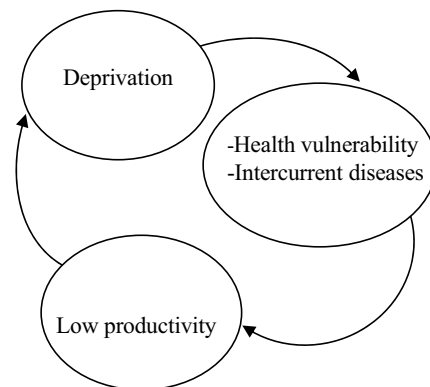
Poverty not only causes ill-health, but also exacerbates poverty, putting men and women in a vicious cycle (Figure 1A). Figure 1B depicts how women in a society are entrapped in the vicious circle of poverty. Societies with a strong patriarchal social system often keep control over every sphere of women's life, resulting in discriminations and deprivations. All forms of deprivations eventually put women in a vicious circle of health vulnerability, low productivity, and deprivation, making them the poorest of the poor. If we consider women and men are two legs of a society, the former is paralysed due to chronic discriminations, requiring emergency remedies.

Figure 1. Tuberculosis-poverty: a vicious circle

(A) Poverty-ill health circle: hit all the poor



(B) Poor women confront triple hit



- The poor loose 20-30% wages annually
- Globally, USD 12 billion economic costs each year

Source: Cited in: WHO Report on Addressing poverty in TB control: Options for national TB control programmes. WHO/HTM/TB/2005.352.2005a.

1.4 TB INFECTION, PROGRESSION TO DISEASE AND GENDER VULNERABILITY

Worldwide, about 2 billion people live with latent infections of Mycobacterium TB. Among the non-HIV but latent TB infected people, only 10% will turn into active TB patients at any stage of their life cycle. The strengths of human immune systems mediate the progression of infections to disease. Evidences from some Western European countries during the 1930 to 1950, reflect no substantial difference in TB between sexes in childhood and pre-adolescence, a higher incidence in female than in male adolescents and young adults, and a higher incidence in men than women after 40 years of age (Ottmani et al. 2008). Studies in various settings have

also shown progression from infection to disease is likely to be faster for women compared with men in reproductive years, and faster for men after 40 years (Holmes et al. 1998).

1.5 TB, HIV/AIDS AND GENDER

Among 42 million people living with HIV (PLWH) in the world, 19.2 million are women (Türmen 2003). Likewise the case-fatality rates seem to be greater in women because of decreased immune function caused by poor nutritional status, and delay in care seeking; and these are functions of gender indeed. Besides, evidences show that male to female transmission of HIV infection is 2-4 times more efficient than female to male (UNFPA 2002). These are compounded by women's limited or no access to quality health care, inferior socio-economic status, powerlessness in decision-making, unnecessary violence and discriminations against women. Besides, the costs of TB and HIV/AIDS are catastrophic for households (more than 10% of the income) (Russell 2004).

1.6 TB CONTROL— THE GLOBAL APPROACH

Effective TB control depends on the rapid TB case identification, treatment and cure. For this, the WHO adopted the DOTS (directly observed treatment, short-course), as an effective and cheap global strategy for all the countries in 1994. Out of 210 countries, 184 have been implementing the strategy since 1994. Alongside WHO, the Stop TB Partnership, the Global Fund to Fight HIV/AIDS, TB and Malaria (GFATM) are also engaged in this global mission. DOTS is not merely a clinical approach to patients, rather a management strategy for public health systems that includes political commitment and technical elements (Stop TB Partnership/WHO 2006; WHO 1999). The DOTS principles apply to all the patients regardless of age, and forms of TB.

The Millennium Development Goals and TB control

The global targets and indicators for TB control were developed within the framework of MDGs as well as by the Stop TB Partnership and WHO's World Health Assembly (Stop TB Partnership/WHO 2006; WHO 1993). The impact targets are to halt and reverse TB incidence, and to halve prevalence and death rates by 2015 compared with a benchmark of 1990. The outcome targets include achievement of at least 70% case detection and to attain 85% cure rates in DOTS cohorts under the DOTS strategy. The ultimate vision is TB elimination by 2050. The Stop TB Strategy launched by WHO in 2006, sets out major interventions that should be implemented to achieve the MDG, Stop TB Partnership and World Health Assembly targets. These are divided into 6 broad components: (i) Pursuing high quality DOTS expansion and enhancement; (ii) Addressing TB/HIV, MDR-TB and other challenges; (iii) Contributing to health system strengthening; (iv) Engaging all care providers; (v) Empowering people with TB, and communities; and (vi) Enabling and promoting research (WHO 2008).

1.7 THE CHALLENGES TO THE DOTS STRATEGY: AN ANALYSIS WITH REFERENCE TO THE THESIS RESEARCH QUESTIONS

In spite of an impressive progress towards TB-related MDG (WHO 2008), the approach faces considerable constraints, especially in case detection and reduction of TB incidences. Besides, women's representations in services utilisation are disproportionately lower than men indicating an M/F ratio of 1.8 in new smear-positive case notification worldwide (WHO 2008). The excess case notification in men compared with women may be explained by the fact that the TB occurs more in men, or women may confront gender barriers to accessing the existing TB control services. How can the gender differences in TB control be explained?

The gender problem is complex and it may stem from several fronts, viz., (i) weak and gender insensitive health care service systems; (ii) personal (motivations, knowledge, attitude, illness experience, meaning, behaviour, stigma); and (iii) structural (poverty, poor decision-making power, gender discriminations, deprivations). All these are intricately linked and likely to have a combined effect in patients' treatment seeking behaviour. In recent years, gender issues are strongly recognised to be the major impediments towards health and development including TB control. Consequently the prominence of the issue increasingly growing in health and development research in general, and in TB control in particular, in order to help the policy makers for taking evidence-based measures to improve gender equity.

In line with the research problems of this thesis, the following sections present some crucial evidences on how society, health care service system and patient's personal characteristics facilitate or create gender-specific differences in and barriers to TB care seeking behaviour, and most of these are explicitly or implicitly relevant to Bangladesh TB control interventions, and the research questions of this thesis.

1.7.1 Factors stemming from health care service provision and delivery

DOTS approach to case finding and gender

By 2006, only 61% of the global smear-positive TB cases were detected, 9% less than the target. Besides, the M/F ratio of the smear-positive cases detected was 1.8:1 (WHO 2008). Consistently, lower case detection among females has been a persistent problem in most settings (Hudelson 1996; Weiss et al. 2006; Karim et al. 2004). Formidable barrier to rapid detection may be full reliance on passive case finding, and TB case diagnosis through sputum microscopy (Thorson 2003). These may not be fully efficient and useful for capturing TB cases in the community. Passive case finding strategy is defined as the lack of active initiative from the health care providers for TB case detection, rather relies on patients' self-presentation to a health facility, whereas in active case finding approach, health care providers play an active role for screening the population for TB case detection, which is seldom followed by the DOTS strategy, resulting in a likely poor case detection.

Self-presentation to a health facility does not adequately occur in the LICs due to peoples' inability to determine early signs/symptoms, and thereby seek help on time (Weiss et al. 2006).

Moreover, implementation of the strategy is more difficult in a society where a lack of effective knowledge on TB, inherent enacted or self-imposed stigma, fear of isolation and rejection as well as social and family negligence, absence of needful social and familial support and financial constraints are deep-seated (Liefoghe et al. 1995; Liefoghe et al. 1997; Long et al. 1999; Hudelson, 1996; Weiss et al. 2008a). These factors extremely inhibit timely help seeking, case detection, diagnosis, and treatment of TB. In most settings including Bangladesh, females are largely victims of these avoidable impediments leading to poor case detection, treatment and full adherence to treatment. Another most important but neglected factor is a lack of social support, and awareness of the community people, who can provide backup support to their peers to visit the providers, just on the onset of the symptoms, encourage for appropriate treatment and adherence to it. In essence, the success of passive case finding endorsed by the DOTS strategy is solely dependent on many keys, the important among others are: (i) patients' TB-related illness experiences, meanings and behaviours (Weiss et al. 2008a); (ii) the gender sensitive awareness and skills of the care providers of TB symptoms together with their motivation to act on them; and (iii) the extent of social support available to the patients. The degree of importance of the providers' side is high, as a patient has to pass a long pathway beginning from symptom onset, diagnosis, treatment and positive treatment outcome. Gender barriers may affect patients' TB care seeking at each clinical step for TB management (Uplekar et al. 2001).

Gender differences in active versus passive case finding

Comparative research on the effect of passive or active case finding in relation to gender is scant. Population-based screening survey in Vietnam (Thorson et al. 2004) found a higher prevalence among women than men (M/F ratio 0.7:1) (Table 2), whereas the routine programme data showed an opposite picture with an M/F ratio of 2.7:1. In 1982, a study in Eastern Nepal which used active case finding methods for detecting TB cases by visiting households, found that 46% of the detected cases were females compared with 28% in the self-referral group. The active case finding strategy yielded an M/F ratio of 1.2:1, whereas it was 2.6:1 among the

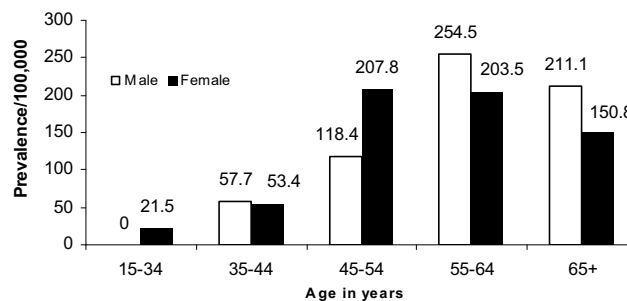
Table 2. Results from different studies on mass screening of smear or culture positive pulmonary TB and male-to-female ratio of cases (modified from the Ph.D. thesis of Anna Thorson, 2003)

Country	Investigator/s (Year)	Year published	Screening/diagnostic methods	Population screened	M/F ratio
Vietnam- Fila Bavi district	Thorson et al. (2000)	2004	Household survey, sputum exam, X-ray	35,832 (≥ 15 years)	0.7:1
India-South	Kolappan et al. (2001-2003)	2007	Household survey, sputum exam, X-ray	93,945 (≥ 15 years)	3.4:1
India-Bangalore*	Chakraborty et al. (1984-86)	1995	Tuberculin test, sputum exam	29,400 (NA)	2.6:1
Bangladesh	Salim et al. (2001)	2004	Household survey, sputum exam	223,936 (≥ 12 years)	3:1
Nepal*	Cassels et al. (1980)	1982	Household survey, sputum exam	67,068 (NA)	1.2:1
Britain: England & Wales	French et al. (2001-2003)	2007	Sputum smearing and culture, X-ray	Non-UK and UK born**	1.1:1 & 1.4:1

NA= Age not available. *Original information taken from the Ph.D. thesis of Anna Thorson (Thorson A 2003). **Total population unknown.

self-referral group (cited by Thorson 2003). However, this study was deficient in presenting the age and gender distribution of the population. Salim et al. study (2004) in Bangladesh showed a higher F/M ratio in the routine programme data than in the household screening survey (0.44 vs. 0.35). These findings somehow contradict with Cassels et al. and Thorson et al. studies. An active case finding study (Thorson et al. 2004) shows age and gender gaps in PTB prevalence, but the scale varies across different age groups (Figure 2). However, except Vietnam and Nepal studies, the M/F ratios found in all other active case finding-based studies are similar to what are reported currently worldwide.

Figure 2. Prevalence rate of smear-positive pulmonary TB among males and females found in population-based screening survey in FilaBavi, Vietnam; based on data from Anna Thorson et al. (Thorson A 2004)



Mycobacterium pulmonary TB diagnostic methods: the gender-specific features of sputum microscopy

The national TB control programmes (NTP) that use DOTS strategy, massively rely on a 125-years-old microscopic method for sputum examination for TB diagnosis, which detects a half of the cases in the best circumstances, and even fewer of those infected with HIV, is virtually worthless for diagnosing children (Small 2008). As it is relatively cheap, affordable and easy to put in practice, most countries use this to detect and treat the most infectious smear-positive TB cases (WHO 1999).

A wide body of literatures indicates that more men than women undergoing sputum smear tests have sputum-positive test results (Begum et al. 2001; Salim et al. 2004; Karim et al. 2004; Weiss et al. 2006). Women, particularly in the LICs, neglect cough or fever which can be the early signs/symptoms of TB requiring diagnosis and treatment. They often consider it as normal as flu and common cold (Thomas undated), and would be self-limited. Thus, they may not appear for sputum test (Karim et al. 2007, unpublished). A majority of patients do not seek help solely due to a cough. Fear of disclosure, divorce, social stigma (Lifooghe et al. 1995; Khan et al. 2000; Long et al. 2001; DANTB 2002; Weiss et al. 2006; Somma et al. 2008), isolation and economic barriers could also be hindrance to undergoing sputum test. Besides, females are less likely to produce quality sputum for lack of knowledge and/or physical difficulties in producing effective sputum, and cultural constraints in coughing up with sound in public (Karim et al. 2008, unpublished; Weiss et al. 2008a). Sputum microscopy indeed has been shown to be less sensitive in detecting TB in women than in men (Somma et al. 2005). Although all the patients

seeking sputum test services, were given instructions by the health workers on how to produce effective sputum for smearing, the proportion of females facing difficulties in producing effective sputum exceeds the proportion of males (70% vs. 15%, $p=0.000$) (Karim et al. 2007, unpublished). A cross-sites study in Bangladesh, India, Colombia and Malawi suggest that providing an adequate private and well-ventilated place to produce diagnostic sputum may be of particular benefit to women (Weiss et al. 2006).

Studies (Karim et al. 2008, unpublished; Weiss et al. 2006) also report that sputum and coughing have some gender-specific implications in Bangladesh society. Unlike men, cough up with unpleasant sound by the women was a matter of shame and viewed badly. They would have thought that their neighbours might come to know that this woman had TB resulting in loss of face in the society. Thus, the women might have to suppress coughing even in course of TB leading to ineffective sputum production. This has been a serious issue of privacy, but most facilities fail to ensure it to female patients. Besides, studies revealed women's serious concerns that a diagnosis of TB may result in threats of divorce or their husband taking a second wife; they described a web of social and financial problems, and emotional distress. Such accounts indicate the motivation for concealing a diagnosis of TB from others (Khan et al. 2000; Liefvooghe et al. 1995; Long et al. 2001).

Misdiagnosis of symptoms

Even patients made several visits to different providers; they encountered misdiagnosis (Weiss et al. 2006; Karim et al. 2004). In Pakistan, only 11 out of 36 new cases were correctly diagnosed with TB on their first consultation with medical doctors (Khan et al. 2000). Care providers at health centres have been shown to share the same beliefs and folk definitions of TB as patients do. Symptoms of back pain would not motivate the doctors to investigate respiratory symptoms (Jaramillo 1998).

1.7.2 Patients' dimensions: Knowledge, attitudes and beliefs

Symptomatology of TB

The persistent productive cough for three weeks or more is the prime characteristic to suspect a person with PTB (Nair 2002; Toman 1979). Cough, in fact, can occur in a wide range of respiratory conditions, indicating that the symptom may be non-specific to TB. The duration of persistence seems to be long, giving a chance to miss out some cases. A recent assessment from India reveals that by using a threshold of ≥ 2 weeks to prompt collection of sputum specimens the number of TB suspects increased by 61%, and case identification by 46% (Santha et al. 2005). Thus, choosing a threshold of coughing duration is difficult. In high incidence countries, all outpatients seeking care for respiratory illnesses should be asked for sputum microscopy. But unfortunately, not all such patients receive sufficient evaluation for TB (WHO 2001a; Lonroth et al. 1999).

Gender-specific features of TB symptoms, illness experiences, meanings and behaviours

Women more frequently than men present with fewer characteristic symptoms such as blood in sputum in Bangladesh (16% vs. 21%), India (15% vs. 38%), Colombia (35% vs. 40%), but the

picture is opposite in Malawi (30% vs. 24%) (Weiss et al. 2006). Patterns of distress reported were notable for the occurrence 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 (Weiss et al. 2008a). Studies in South Asia (Banerji et al. 1963) and other settings including Vietnam (Johansson et al. 2002) acknowledged these findings. Thus, this remains an issue that is likely to contribute to under-diagnosis of TB among women.

As TB often develops slowly, and especially the poor suffer from intercurrent diseases, symptoms of TB may be easily ignored. Prolonged cough, a possible symptom of TB, seldom recognised openly until accompanied by other serious systemic symptoms such as haemoptysis, and weight loss (Liefoghe et al. 1997; Jaramillo 1998). However, TB is frequently confused with other conditions including asthma, pneumonia, cancer, malaria and AIDS (Liefoghe et al. 1997). Women are more likely to associate TB with a constellation of systemic symptoms especially loss of appetite, weight loss, weakness, and breathlessness (Weiss et al. 2006).

Perceived causes of and susceptibility to TB

Munro and colleagues review (2007) identified two causes of TB viz. germs and worry. Sufferers from worries are unlikely to seek appropriate care, rather are more likely to address the sources of their worries. For instance, financial matters, or spouse's doubts about their own faithfulness are the sources of worries. In Colombia and Malawi, focus group discussions' (FGD) discussants specified airborne exposure, in Bangladesh personal contact with a TB patient was emphasised, and in India and Bangladesh stepping over the sputum of a patient was identified as cause of TB (Karim et al. 2004; Weiss et al. 2006). In Colombia, poor nutrition and a weak immune system were specified as cause of TB. In Bangladesh, apart from poor nutrition, its close association with household gender inequalities was also mentioned.

TB-related stigma and gender

In addition to structural factors (Munro et al. 2007), socio-cultural and behavioural aspects such as TB-related pervasive stigma contributes to worsening of the quality of life of people with TB (Somma et al. 2008; Jaramillo 1999; Hudelson 1996). According to Goffman's (1963) original formulation, stigma is the situation of the individual who is disqualified from full social acceptance. TB-related stigma refers to felt stigma or experience with enacted social disqualification or discrimination that is directed toward an individual identified as having TB (Weiss et al. 2006). More recently, the issue of TB-related stigma, its adverse consequences on individual, familial and social lives of TB patients (Munro et al. 2007), received attention of public health experts (Somma et al. 2008). TB-related stigma is a practical public health concern because it contributes to suffering as a component of the so-called 'hidden burden' of disease (WHO 2001b), and it may affect care seeking. TB patient may hide their symptoms or diagnosis (Munro et al. 2007), and feel guilt and shame because of the disease (Somma et al. 2008; Weiss et al. 2006).

Several studies reported that TB status could affect marital life or prospects for marriage (Khan et al. 2000; Johansson et al. 2002; Somma et al. 2008) in the settings where marriage is socially

arranged. Patients encounter isolations and rejection at different levels of family and social life, and fear of job loss (Johansson et al. 2000). The occurrence and features of stigma are also likely to reflect local gender roles. TB-related stigma is worse for females than for males (Johansson et al. 1999; Weiss et al. 2006; Somma et al. 2008), potentially resulting in divorce or transfer to natal homes. These and other factors of gender-based vulnerability such as limited autonomy, and financial dependency may deter women with TB from seeking care. It is not clear how widespread and powerful such gender-based features of TB-related stigma, which has implications for patients' social interactions and emotional well-being. Therefore, it is imperative to answer to such questions for TB control using DOTS, which solely relies on passive case finding and hence illness behaviour (Somma et al. 2008).

Gender-specific features of care seeking and treatment for TB

Traditional practice and systems

As mentioned above, people have cultural or traditional values and beliefs about TB that lead to traditional, family or spiritual healing first; on failure, they seek treatment from various types of providers, so called "treatment shopping" around, and seek modern care only when these measures fail. Weiss et al. cross-site study (2006) revealed that patients, especially women commonly relied initially on informal self-help to treat their symptoms. Sources of help outside homes were reported to be a many. Half of the patients in Bangladesh reported using rural doctors with limited credentials. Some accessed to private allopathic doctors and some especially men made their way to an urban government hospitals before going to TB clinics.

As the pathway of TB patients to diagnosis is long, patients visit many ineffective private care sources; some repeatedly does it, before being diagnosed with TB. For example, in Vietnam, women had to visit more providers than men on average (1.7 vs. 1.5, $p=0.04$) (Long et al. 1999). Multiple reasons might motivate the patients for seeking care from ineffective private sources, before coming to TB clinics included husband's or in-law's decision; notion of normal and self-limiting disease; prior familiarity with the provider; proximity; belief in disease causality (e.g. evil spirit); flexible time; friendly behaviour; and medicine available on credit (Karim et al. 2007, unpublished).

Accessibility

Smooth accessibility may be characterised by different tangible constituents such as geographical distance (Karim et al. 2005), convenience, provider's behaviour, and costs.

Geographical distance — Long distance to a service point presents a major barrier to accessing the TB care, and it directly affects the poor and women disproportionately. In a society where women have no autonomy to travel outside home, they are powerless in financial decision-making, and surrounded by poor transportation systems, are most likely to remain undiagnosed and untreated. Besides, long distances mean more travel time, working hour lost, out-of-pocket costs for patients, which affect both women and men patients alike.

Conveniences — In Colombia, TB patients delayed due to the narrow opening time of the service delivery facilities (Jaramillo 1998). Whereas shorter delay in diagnosis was reported in

Bangladesh where sputum samples were collected in the community and delivered to laboratory by the grassroots volunteer health workers (Chowdhury et al. 1997).

Provider’s behaviour — Provider’s friendly behaviour, rapid sputum sample collection, test and report back are key to a successful DOTS strategy. But in many settings, such ideal conditions seldom exist or practiced. Rather some providers behave rude with and/or intimidate the care seekers or their accompany (Aziz et al. 1999).

Costs — Both patients and health service systems bear a considerable costs in the treatment pathways of TB. The main costs to the patients are: cost of seeking alternative care, before being diagnosed with TB, loss of work, travel expenses, costs during any hospital stay, if needed, and social costs such as divorce, and removal of children from school to assume the household chores (Saunderson 1995). However, studies revealed that the costs incurred were generally higher before diagnosis, and most expenses were incurred for transportation for both patients and guardians (Kamolratanakul et al. 1999). The economic consequences of TB as noted above, are considerable shocks for all groups, and may even push the non-poor to poverty, and it can be ever devastating for the poor patients and their households. Muniyandi et al. study in India (2006) estimated the overall provider unit cost for treating a TB patient was Indian Rupees 1,587/- for Category (Cat) I, 1,924/- for Cat II, and 1,417/- for Cat III, indicating an economic burden on overall health systems.

Determinants of delays to pathways to TB care

Delay to treatment causes increased transmission of the disease, and likewise financial strain for the patients and families due to loss of time and income, as well as circuitous “treatment shopping” from ineffective providers (Weiss et al. 2008a; Gosoniu et al. 2008). Both women and men may confront gender-related barriers when trying to access the long TB care pathways (Uplekar et al. 2001). Gender barriers associated with different socio-economic factors may result in delayed care seeking or dropout from the pathway to TB care. For example, fear of losing a job often discourages the working men from care seeking, resulting in delayed diagnosis and treatment and/or high dropout or default rates (WHO 2005a). Women often have less access to general health care than men, and they may face limitations in their travel and financial

Table 3. Summary of total delay from first symptom onset to treatment initiation from several studies by sex (in weeks)

Study	Country	Patient delay		Health provider delay		Total delay	
		Male	Female	Male	Female	Male	Female
Ngamvithayapong et al. 2001	Thailand*	2	1	1	2	NA	NA
Yamasaki-Nakagawa et al. 2001	Nepal*	3.2	2.4	3.2	5.2	9.9	14.22
Ward et al. 2001	Australia*	3.9	4.3	3.1	3.3	NA	NA
Long et al. 1999	Vietnam**	7.6	7.9	5.5	7.7	11.4	13.3

* Median; and ** Mean. NA= Not available.

resources. In many countries, women have to overcome several surmountable barriers before they can access health care (WHO 2005a). Where they undertake multiple roles in reproduction, production and child care, they may be left with less time to reach a diagnostic and treatment service than men. Families often take the girls out of school if a family member, especially the mother is suffering from TB and there is a need for person to assume the household chores. A wide body of studies was carried out on delays for diagnosis and treatment with varied definitions and categorizations (Ngamvithayapong et al. 2001; Yamasaki-Nakagawa et al. 2001; Ward et al. 2001; Long et al. 1999). Most studies, however, show that women than men had a longer delay in care seeking, and also the care providers' longer delay to respond to women's needs (Table 3). The cross-sites study (Weiss et al. 2006) in Bangladesh, India, Colombia and Malawi indicates a consistently mean longer diagnostic delay for women (ranging from 72 days in Bangladesh to 195 days in Malawi) than for men (ranging from 64 days in Bangladesh to 93 days in India).

1.8 SIGNIFICANCE OF GENDER RESEARCH IN TB CONTROL

The extent to which, identifying fewer women with TB globally is due to sex (as a biological determinant) or gender (as a socio-cultural determinant affecting access to TB treatment) have been issues for robust studies. The differentials are likely caused by various factors as featured in the preceding sections, including access barriers to care, discriminations, particular forms of TB, diverse biological, social and cultural variables (Ottmani et al. 2008; Weiss et al. 2008b; Allotey et al. 2008). But the reasons behind the differences need to be explained from patients' local worldviews with reference to gender. Thus, gender has become an increasingly significant domain of socio-cultural studies of the disease burden, and it is an important consideration for TB (Weiss et al. 2008b). "The disease persists largely for social reasons that have not been addressed due to the overmedicalisation of the conditions. Gender analysis allows an explanation of the dynamics of vulnerability, disadvantage, inequities between women and men in access to resources and decision-making power, and thus provides multiple potential points of interventions at grassroots for reducing risks, inequalities and disease burden" (Allotey et al. 2008).

"Gender studies are taking shape from second-wave of feminism of the mid-1960s, as an academic discipline. The first-wave feminism addressed women's fundamental rights through movements, second-wave feminism introduced notions of equality and equity and the feminists tend to relate these to socio-economics, family dynamics, health, well-being and sexuality. Thus, the broader discipline of women study has taken a shape of gender studies despite it has roots with its feminist origins" (Allotted et al. 2008).

The taxonomies for organising medical and social thinking about communicable diseases have left out gender consideration (Hartigan 1999). Current prevalence data suggest that TB is 'more a disease of men than women' (Borgdorff et al. 2000). This clearly highlights the need for a robust gender analysis to understand the reasons for the differences and to identify effective interventions for gender-sensitivity and equity in TB control. Gender equity recognises the influence on health of women and men, the impact which is experienced in different ways (Sen et al. 2007; Weiss et al. 2008b; Allotted et al. 2008). TB epidemiological data present the

complexities, showing higher rates in men, but active case finding reverses the scenario in some settings, for instance, in Vietnam (Thorson et al. 2004). However, beyond the biological factors, there is an interactive effect with risk and exposure including lifestyle, such as smoking, alcoholism (Watkins et al. 2006), and occupation, both from indoor air pollutants associated with cooking and from industrial exposure. Differential access to health care, health seeking behaviour and stigma can be other explanations in this regard (Upbear et al. 2001). In fact, both women and men face gender-specific barriers to accessing the long pathways for TB diagnosis and treatment.

Historically, gender has not received due importance in social science studies of TB. While consideration of sex differences based on classical epidemiology and monitoring of health system performance is necessary, such approaches should be complemented by efforts to explain the features of differences to contribute to improved programmatic outcomes. “Development of some means of quantifying various social and cultural dimensions of TB-related experiences, meanings and behaviours facilitates comparison between women and men. The need for qualitative accounts of relevant contexts and analysis of socio-cultural factors influencing illness behaviour of both women and men is high” (Weiss et al. 2008b), to enable to ‘negotiating the culture’ (UNFPA 2008), for gender equity in TB control. UNFPA document emphasises that “Understanding the diversities of cultural meanings is essential for designing and implementing effective cooperation for change within a cultural context.” The researchers, policy makers and donors, however, are seldom attentive to this important dimension in TB control, or do they have substantial evidences to act on the issue.

The workshop held in Gothenburg, Sweden (Diwan et al. 1998), paved the way to consider gender issues in TB control. Following this, based on the decision of the Special Programme for Research and Training in Tropical Diseases (TDR) of UNICEF/UNDP/World Bank/WHO funded a multi-country operational study in Bangladesh, Colombia, India and Malawi to document sex differences and identify gender issues hindering the efficiency of TB control programmes (Weiss et al. 2006). In December 2000, a workshop was held in Geneva with participants from each of these sites (where the author of this thesis also attended), to develop a generic research protocol, methods and instruments. *Studies I-IV* of this thesis is based on the Bangladesh part of the multi-country broader study, and *Study V* is based on another independent multi-component study sponsored by BRAC, a Bangladeshi NGO. All the five studies in this thesis, attempted to measure the magnitude of the problem, and to explore the critical gender barriers to and their features and effects in TB control in Bangladesh from the patients’ perspective.

2 BANGLADESH

The People's Republic of Bangladesh is one of the world's largest deltaic countries, emerged as an independent and sovereign entity in 1971, following a nine-month long bloody war, against the Pakistan Armies. It is a populous country with an area of 147,570 sq. km and over 144 million population; 978 people per sq. km. Females form nearly a half (48.5%) of the population (BBS 2008). By religion, most people are Muslims (89.7%), followed by Hindus (9.2%), and the remaining belong to other religions. The country is homogeneous by language, and over 98% people speak in *Bangla*. Bangladesh is covered with maze of interconnecting rivers and canals. The country is bounded by India from north, west, and east (except a small border with Myanmar). The south is open to the Bay of Bengal (Figure 6, section 3). It enjoys a moderate tropical climate (BBS 2008).

As a medium low income country, Bangladesh ranks 140th among the UN member nations, with human development index value of 0.547 in 2005; lower than Pakistan (0.553) and the neighborhood India (0.619). Its per capita gross domestic products (GDP) measured by purchasing power parity (PPP) is USD 2,053, lower than Pakistan (2,480) and India (3,452) (UNDP 2008). As newly independent, Bangladesh had a dream in building a nation of hope, tolerance, justice, equity, and peace, but frequent natural disasters and political unsteadiness, have been a barrier towards its development thrust.

2.1 PROMOTING GENDER EQUALITY IN BANGLADESH

The Bangladesh constitution grants equal rights to women and men in all spheres of public life (Article 28 (1 to 4), and 29 (1 to 3)). Various laws have been enacted and amended to supplement to be effective for safeguarding and protecting women's rights (Asian Development Bank 2001; German Development Bank/KfW 2006). The country also established the Ministry of Women's and Children's Affairs (MWCA) in 1978 to develop and implement policies and programmes on women's and children's rights. The gender equity-related issues were strongly reflected in Poverty Reduction Strategies, and planned activities to reach the gender equality goals.

A host of non-governmental organisations (NGO) deliberately included gender equality goals in their development package programmes, and directly implement innovative pro-poor and pro-women development programmes such as health, microcredit, income and employment generation programmes to empower women for gender equity, covering over 8 million poor, mostly women (Asian Development Bank 2001). Thus, recent years have witnessed increased awareness of women's productive roles, mobility, and their contribution to development. In the face of pervasive poverty, natural disasters, political volatility, and adverse effects of global policy changes, Bangladesh has achieved substantial improvements in many sectors, and women empowerment, and they are increasingly participating in different sectoral activities. Despite appreciable gains registered, Bangladesh is to go a long way to establish sustainable gender equality in all spheres of socio-economic and political life of its people.

2.2 CHARTING THE PROGRESS TOWARDS GENDER EQUITY IN HEALTH AND DEVELOPMENT, AND THE CHALLENGES

2.2.1 Gender dimension in health

Life expectancy at birth — Over the years, the life expectancy at birth increased from 56 years in 1990 to 65 years in 2004, slightly higher for females than for males (65.7 vs. 64.4 years) (BBS 2006).

Morbidity — Diarrhoeal diseases, abdominal pain, all types of ARI, intestinal worm infestations, skin diseases, anaemia, and malnutritional diseases cause highest morbidities. Women and under-five children are particularly at high risk of these illnesses. Though the HIV infection remains low — less than 1% (DGHS 2003) in Bangladesh, the risks factor for spreading HIV/AIDS such as injectable drug users, unsafe blood transfusion, needle sharing, commercial sex and HIV/AIDS epidemics in neighbourhood countries are highly prevalent. Among the 1,006 newly diagnosed TB smear-positive cases that underwent a serological test at two outpatient facilities in Dhaka city in 1999, only one was found HIV positive (0.1 percent) (MoHFW 2001).

Nutritional status of mothers — A substantial improvement in women's nutritional status as measured by the BMI (body mass index) has occurred. Since 1996-97, the mean BMI has increased steadily, from 18.8 to 19.7 in 2004; consequently, the proportion of women below BMI cutoff-point of 18.5 has dropped from 52% in 1996-97 to 38% in 2004, a decline of 27% in less than a decade (NIPORT/MA/ORC Macro 2005). Forty-seven percent of the women in the poorest wealth quintile have chronic energy deficiency, and even in the richest quintile, 17% fell below the international standard cutoff-point for acute undernutrition (HKI 2006). Besides, 70% of the mothers suffer from anaemia.

Maternal mortality and fertility — The maternal mortality ratio (MMR) has fallen from 4.78 per 1,000 live births in 1990 to 3.65 in 2004 (BBS 2006), but still is one of the highest in the world. Bangladesh needs to make a structural break in the trend, if it is to move to anywhere near the MDG targets on the maternal mortality ratio (143 deaths per 100,000 live births).

Total fertility rate (TFR) has declined sharply from 6.3 in 1971-1975 to 2.7 in 2004-2006 (NIPORT/MA/ORC Macro 2007). Both total fertility rate and maternal mortality status in Bangladesh raise a concern for poverty reduction.

Although in 2004, the contraceptive prevalence rate among all the married females increased to 58% from 8% in 1975, but it slightly fell to 56% in 2006 (NIPORT/MA/ORC Macro 2007); the reasons could be interruptions in supply systems or social barriers to accessing the services. However, seemingly it could not affect TFR adequately.

2.2.2 Gender dimension of education

Bangladesh made provision of compulsory and free primary education for all children, stipends for girl students at primary, secondary and higher secondary levels. All the efforts contributed to achieve gender parity in primary education enrolment. The estimated net enrolment in primary school is 94% (UNDP 2008), with a higher rate for the girls. Overall adult (15+) literacy rates

show a greater gap between females and males (43% vs. 61%) (German Development Bank/KfW 2006). However, besides the government, NGOs also have played enormous role in improving access to education, for example, BRAC non-formal primary education programme offers 3-year course to thousands of poor children each year, over 70% of whom are girls. Achieving and sustaining the MDG 2 target of ensuring that boys and girls are able to complete a full course of primary schooling will require continued investments and focus on this key sector.

2.2.3 Gender asymmetry in economic participation

Though traditionally, women are mainly involved in the non-monetised sector and in subsistence activities, their participation in non-farm and farm activities is increasing. The government has also introduced a quota system for women, setting employment targets of 10% for gazetted officers and 15% for other categories. Besides, thousands of women work in garments sector. Thus, the women are contributing to household level poverty reductions and to macro economic growth (German Development Bank/KfW 2006). But a considerable gender disparity persists in the wage rates. On average, women's wage rates are substantially lower than men, that women's earnings would be about 59% of men's (BBS 2005). Besides, 61% of women salaried workers earn less than Tk. 1,000 per month, whereas only 16% men earn an equivalent amount – confirming ingrained wage-based gender discrimination. Such disparity may occur in informal or autonomous bodies where no formal wage rates or pay scales exist.

2.2.4 Gender dimensions of governance and political participation

Bangladesh's unicameral legislature consists of a parliament with 300 members elect, of these 30 reserved seats for women. Though reservation does not restrict their contest in the election, only 18 seats held by women in the 2008 general election (6%), which is far less than neighbourhood countries Bhutan (9.3%, and India (8.8%) (German Development Bank/KfW 2006). The local government structures consists of various tiers of governance, the lowest is the Union Council (union *parishad*), which is formed by 1 chairman, 9 directly elected members, and 3 selected female members. However, in 1997, the 3 selected seats for women were converted into regular seats. Today, there are about 12,828 elected women members in the 4,198 union *parishads* all over the country. But they have no clear-cut job descriptions or resources. In the 2009 local government election, the GoB created two vice chairpersons posts, one for woman and one for man at newly provisioned subdistrict councils. Thus, over 476 female vice chairpersons were elected in this election.

2.2.5 Gender-specific social and cultural dimensions

“The life of a woman is dominated by patriarchal system, and the society is based on class and gender divisions; class mobility permits movement between rich and poor, but division of social space and differences in behavioural norms between men and women are rigidly maintained. Family, the basic unit of social control, sets norm for males and females roles and responsibility. Within this system, the father, or in his absence, the next male kin is the household head. Thus, both decision-making powers and economic control are vested in the hands of men, disadvantaging the women. This system gives a high value to sons as potential providers and

perpetrators family names. Women, on the other hand, are generally viewed in their reproductive roles and given subsidiary status as economic dependents, making the women vulnerable to violence, ill-health, divorce, and entitlement of properties” (Asian Development Bank 2001).

2.2.6 Gender dimensions in decision-making

Women have a little decision-making power, even at family spheres. Despite increasing access to productive works and political processes, women’s voice in the family and the community is weak and often unheard. They have no decision-making rights, even for their health issues (World Bank 2008).

2.3 TB EPIDEMIOLOGY IN BANGLADESH

TB in the community –The National TB Control Programme’s (NTP) nationwide survey of 1987-88 showed that 0.87% of the population aged 15 years or more were sputum smear-positive, and TB was twice as common in males than females (1.08 vs. 0.60%) and more common in urban than in rural areas (DGHS 1989). Table 4 shows that except in HIV prevalence in incident TB cases, other figures are worse for Bangladesh than India, Nepal and Myanmar, and SEAR (South-East Asia Region). Male-to-female ratio of smear-positive case notification is comparable across these countries, ranging from 2.0 to 2.3, and it is at 2.1 for Bangladesh, higher than the global ratio of 1.8 (WHO 2008).

Table 4. Estimates of epidemiological burden of TB in Bangladesh: a comparative picture, 2006

Indicators	Percent or rate/100,000 population				
	Bangladesh	India	Nepal	Myanmar	SEAR*
Incidence of all forms of TB	225	168	176	171	180
Incidence of new smear-positive cases	101	75	79	76	81
Prevalence of all forms of TB	391	299	244	169	289
New smear-positive cases notified	65	48	51	83	55
M/F ratio of smear-positive cases notified	2.1	2.3	2.1	2.0	2.0
TB mortality of all cases	45	28	23	13	30
HIV prevalence in incident TB cases (%)	0.0	1.2	1.4	2.6	1.3
MDR cases among new TB cases (%)	1.6	NA	NA	NA	NA

Source: WHO 2008. * Bangladesh, Bhutan, DPR Korea, India, Indonesia, Maldives, Myanmar, Nepal, Sri Lanka, Thailand, and Timor-Leste. NA= Not available.

Among 104,284 new smear-positive cases reported in 2007, only 33% were females (Barua et al. 2008). Most reported cases were between 15 and 54 years old. The notification rates increased with the increase in age, but it was higher for males than for females (Barua et al. 2008). As of 2007, NTP has reached all over the country with DOTS strategy for TB control, and consequently the case detection rates steadily increased to 72% in 2007, which is consistent with the WHO target. This evidence indicates a strong commitment of all stakeholders, uninterrupted funding and strong collaboration and cooperation between government and non-governmental partner NGOs. Treatment success rate has improved remarkably, and the present rate is 92% in 2006 (Barua et al. 2008).

Progress towards reaching TB-related MDG targets

The Bangladesh NTP moves sharper to reach TB mortality and prevalence targets enshrined within MGD (Table 5). But if special boost is not given it may take 41 and 39 years, respectively to achieve the targets of incidences of all forms of TB, and new smear-positive TB.

Table 5. Progress towards reaching the TB-related MDG targets

Particulars		Indicators			
		All forms TB mortality	All forms TB prevalence	All forms TB incidence	Incidence new SS+ TB
(a)	(b)	(c)	(d)	(e)	(f)
A.	1990 benchmark status ¹	76	630	264	119
B.	Half of the 1990 benchmark (MDG target) ¹	38	315	132	59.5
C.	Status as of 2006 ¹	45	391	225	101
D.	Reduction achieved on targets by 2006 ¹	31	239	39	18
E.	Percent reduced on target*	81.6	75.9	29.6	30.3
F.	Percent reduced per year (1990-2006=17 years)**	4.8	4.5	1.7	1.8
G.	Percent target to be achieved***	18.4	24.1	70.4	69.7
H.	Year to be needed to achieve MDG targets****	3.8	5.4	41.4	38.7

Source: Barua et al. 2008. ¹Rate per 100,000. *E=D/Bx100 for the columns c, d, e and f. **F=E/17 years for the columns c, d, e and f. ***G=100-E for the columns c, d, e and f. ****H=G/F for the columns c, d, e and f. SS+=Smear-positive.

2.3.1 Risk-related conditions and behaviours

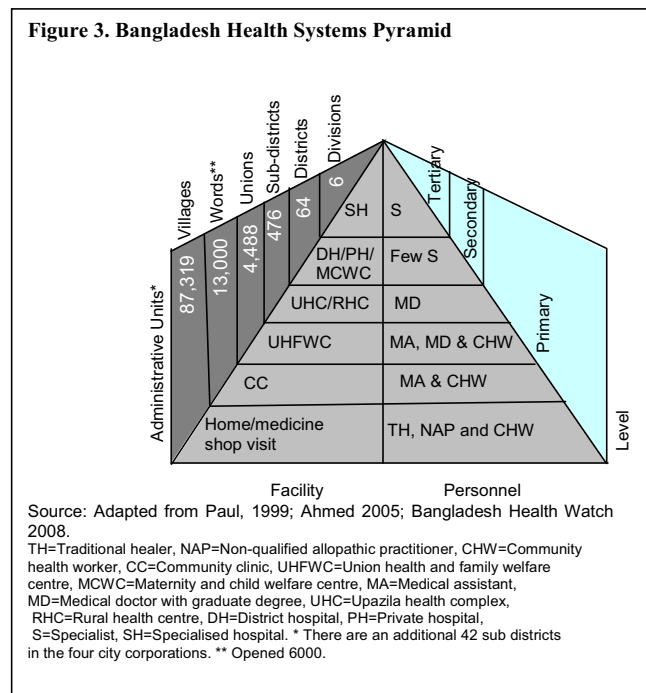
Smoking — Despite smoking is a risk factor of TB, over one-third of the population aged 10 years and above in Bangladesh were smokers (BBS 1997). A recent study (WHO 2005b) revealed that 58% of men and 4% of women were tobacco smokers in Bangladesh.

Exposure to cooking smoke/gas — Our traditional society gives all cooking responsibilities to females. They are to cook at least thrice, sometimes even more a day for the family members. Only 20% of the population, particularly urban has privilege of using natural gas as fuel. The remaining 80% of rural and urban or semi-urban people use a wide variety of traditional materials for cooking, for example, jute sticks, dry cow dung, etc. that produce injurious smokes while cooking and the females are highly exposed to and compelled to inhale at least thrice a day while cooking for the family members. Apart from burns, this may cause respiratory problems including TB.

2.3.2 Health system characteristics

Administratively, Bangladesh is divided into 6 divisions, 64 districts, 476 *upazilas* (subdistrict), and 4,488 unions. In addition, there are 6 major cities, and 254 municipalities in the country (BBS 2008). Though the GoB has the mandate to provide health services to the entire population, a plethora of NGOs, private agencies and individuals are also involved in health service delivery. The first referral health care unit in Bangladesh is the *Upazila* Health

Complexes (subdistrict health complex) at *upazila* level covering over 260,000-300,000 populations (Figure 3). Usually, 9 graduate doctors, two health assistants, and several nurses are employed to provide outpatients, inpatients and emergency services. Secondary and tertiary health services are ensured by general and specialised hospital at district and divisional level. In the national level there are specialised hospitals, as well as university and medical college hospitals. Apart from the public facilities, there are huge private clinics, specialised and general hospitals operating, especially in the cities and towns, which render services on payment. But these are not well-regulated and coordinated nor monitored to control quality of services.



Bangladesh has a central “command and control” management system, oriented towards input rather than outputs and outcomes. In 1998, integrating all the project activities on health, population, and nutrition, the Ministry of Health and Family Welfare developed a Health and Population Sector Programme (HPSP), now renamed as Health, Nutrition and Population Sector Programme (HNPS). The HNPS developed a package of Essential Health Care Services (ESP) for the people of Bangladesh and to control population growth (MoHFW 1998). The ESP elements include: (1) reproductive health care; (2) child health care; (3) communicable disease control; (4) limited curative care; and (5) behaviour change communication. The government health care is almost free compared to a private clinic or hospital. Patients can receive medicine from hospital for general health care. The government health care centres are open six days a week from 9:00 AM to 2:30 PM for outdoor patients with the emergency facilities for 24 hours.

However, lack of modern laboratory facilities at both UHCs and district hospitals sometimes hinders proper diagnosis and treatment. There is a tremendous shortage of female doctors in the rural areas, disproportionately affecting the female patients.

Expenditure on health in 2004 amounted to PPP USD12.0 per person (UNDP 2008). However, 64% of the total expenses were borne by the households themselves mostly on drugs, whereas government and NGOs shared 23.3 and 9.2% (WB 2008). The hospital system is overused, with high rates of self-referrals, bypassing the UHCs, the first referral station of the primary care.

2.3.3 TB programme characteristics

The public national TB control programme (NTP)

The GoB instituted the NTP in 1965 for providing sanatorium-based services through 44 TB clinics, 13 hospitals, including 8 segregation in Bangladesh. The NTP adopted the directly observed treatment, short course (DOTS) strategy in 1993, and further expanded it progressively to the entire country by 2007. The government has been implementing the NTP under the Communicable Diseases Control component of the reformed health, nutrition and population sector programme (HNPS), with the following specific objectives: (a) to detect 70% of the existing new smear-positive pulmonary TB cases; and (b) to cure 85% of the new smear-positive pulmonary TB cases detected.

Budget and expenditure for NTP

The global fund to fight AIDS, TB and malaria (GFATM) committed to finance the NTP for the period from 2004-2011 by 88.44 million USD to be disbursed through 2 principal recipients (PR) namely the PR-government of Bangladesh (PR-GoB), and PR-BRAC. The amount was approved for the 3rd and 5th rounds. PR-BRAC share consists of 27.02 million USD for the 3rd round and 19.54 million for the 5th round.

NTP structure

NTP of the GoB is structured with five different levels as follows: The Line Director, TB-Leprosy, is responsible for the programme at central level, under Director General of Health Services (DGHS). NTP is integrated into the general health system, with the Divisional Director (Health) (DDH) at divisional level, the Civil Surgeon (CS) at district level, the *Upazila* Health and Family Planning Officer (UHFPO) at *upazila* level, and the Health Inspector at union level, and they are all responsible for their command areas. They coordinate and supervise the NTP services provided by designated staff to strengthen the programme at various levels (Hoque, 1999). Forty-four government TB clinics are also supporting the NTP through their careful diagnosis of pulmonary TB and sputum smear-positive cases, proper referral of patients to their resident *upazilas* for treatment, and provision of technical advice on the national TB control guidelines (DGHS 2004). The NTP staff refers complicated cases to TB and other tertiary care hospitals. At the community level, field health personnel and volunteers provide basic services like referral of chest symptomatic, DOTS, tracing of treatment defaulters and health education. In Annexure, Tables 6a and 6b show the case definitions of NTP, and Tables 7 and 8 illustrate treatment regimens and dosages of fixed dose combination drugs (DGHS 2004).

Professional standards — For effective NTP services delivery, the health professionals train both the community level and the central level workers (paid/unpaid). The volunteers are more seen in the NGO activities than the government activities. To enhance the professional quality in NTP, more than 31,000 health personnel, including health workers, medical students and faculties at medical colleges were trained. Every year, many volunteer workers receive training from both the GoB and NGOs.

Diagnosis — TB is diagnosed by examination of the symptomatic patients attending the health facility (passive case detection). Diagnosis of TB is based on internationally recommended procedures (Hoque 1999). The most peripheral diagnostic unit under the NTP is the UHC. At this level, the workload is considered sufficient to maintain quality sputum smear microscopy. The NGOs have their own laboratories. Each laboratory has binocular microscopy, basic equipment, reagents and other materials to maintain quality sputum test. Laboratory personnel receive training for one week. Quality control of microscopy is ensured by quarterly cross reading of a sample of smears by a second level laboratory or external quality assurance laboratories, or even by a third level laboratory (Hoque 1999).

2.3.4 Government (GO) and NGO partnership — a unique approach to TB control in Bangladesh

To combat the TB havocs, the GoB in partnership with different NGOs including BRAC has been implementing the NTP using DOTS strategy. The approach was intensified in 2004 with the GFATM's financial support. Being in lead, BRAC alone covers 283 subdistricts (62.8% of total 460²) of the country including the 12 subdistricts, where the studies of this thesis were carried out. Among the remaining 177 *upazilas*, Damien Foundation covers 101, Health Education Economic Development or HEED 25, Lamb Hospital 3, Danish-Bangladesh Leprosy Mission 10, Rangpur Dinajpur Rural Services 14, and LEPR 24. Besides, 6 city corporations are allocated to 16 NGOs, including BRAC. These partner NGOs follow the NTP guidelines in programme implementation.

2.4 BRAC TB CONTROL PROGRAMME

BRAC has infrastructures all over the country for running its development programmes including health. Each BRAC health centre/office has a medical doctor and para-professionals who work for TB control programme. BRAC-trained female volunteer health workers known as *shastho shebikas*, are the nucleus of this programme. They work under the direct supervision of *shastho kormis* (paid health worker), *para*-professionals and physicians. The *upazila* level staffs are supervised by the Regional Sector Specialists (Health), and they are in turn accountable to TB control Programme Coordinator based at the Head Office (Figure 4).

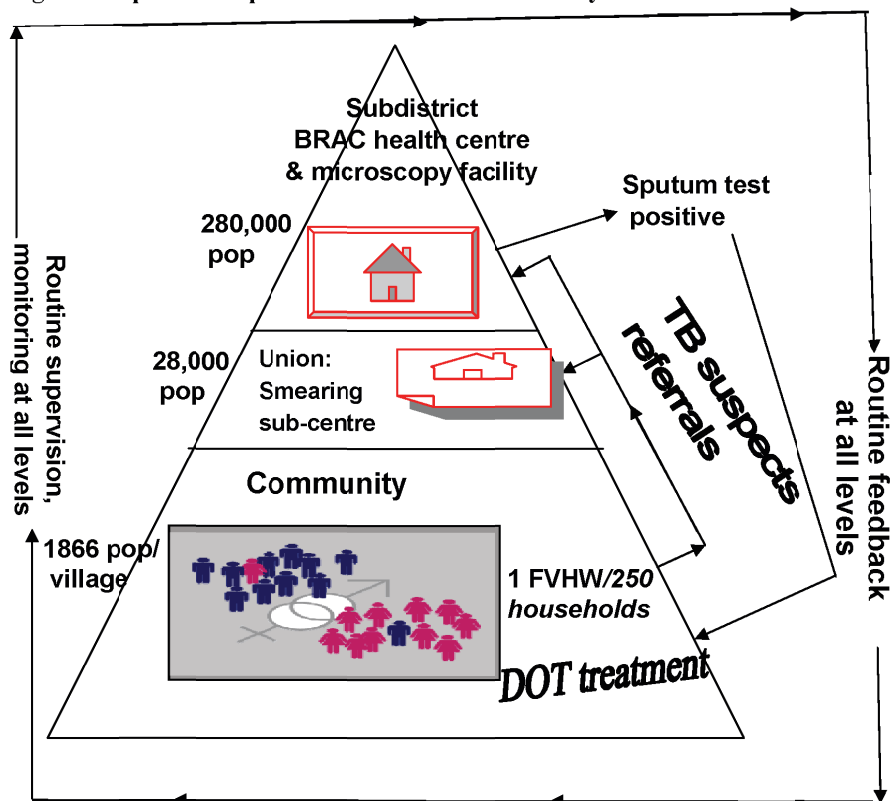
The uniqueness of BRAC approach is that it manages TB cases at community level, instead of at clinics. To make the programme gender-sensitive, BRAC methodically trained and engaged

² Recently, some were split for overall administrative conveniences, giving a total 476.

70,000 community-based *shastho shebikas*. They are poor and nominated by the community to work in the community. BRAC assigns 250 neighbourhood households on average to each *SS*. BRAC has a sputum collection sub-centre at union level, which operates once a month, and a sputum microscopy facility operates for 6 days/week at each subdistrict. Any TB suspect can easily access these facilities for help.

As frontiers, the *SSs* maintain a semi-active case finding strategy, and they mobilise the community people during their routine home visits, search for TB suspects (persons with prolonged cough for at least three weeks), and refer them to either BRAC union level sputum collection sub-centre or subdistrict microscopy facilities, depending on the patients' conveniences, for sputum test. The smear-positive test cases are sent back to *SSs*. They typically initiate DOT to the newly diagnosed cases, and directly observe them taking treatment during the initial 2-3 months. Subsequently, patients collect medicines once a week from the *SSs'* homes, and the *SSs* ensure follow-up over the full course of treatment.

Figure 4. Operational procedures of BRAC community-based DOTS



Notes: Pop= Population. Estimated populations. Pictures from the internet.

Deposit money— Prior to the treatment commencement, a smear-positive patient has to deposit Taka 200 (USD 3) and sign a bond, guaranteeing adherence to full treatment. Following a

successful treatment, BRAC returns the amount to the patient. However, the extreme poor are exempted from depositing money, and all diagnosed cases are put on treatment.

Supervision, monitoring and feedback — The programme operations at all levels are routinely supervised, and monitored by para-professionals and medical doctors. BRAC monitoring department conducts periodic monitoring, whilst its research and evaluation division conducts periodic studies. Thus, the staffs at all hierarchies get continuous feedback for quality control.

The government role — Extends technical and logistic support, and monitors the overall programme quality.

Staff training — A basic training is given to BRAC staff at all levels, including field level managers, medical doctors and supervisors according to the NTP training curriculum. Training materials and logistics are mostly supplied by the NTP. The WHO training modules for district level managers are used to train managers and medical doctors. Laboratory technicians are trained in the centre of NTP. BRAC doctors and para-professionals train the SSs, covering TB control, nutrition, reproductive health, safe water supply and sanitation, family planning, acute respiratory infection, and expanded programme on immunization (EPI). Particularly the grassroots staffs attend a one-day refresher training course every month to share information, discuss their performance and problems encountered during the preceding month, towards better solutions.

Challenges to NTP in Bangladesh

The NTP in Bangladesh registered phenomenal achievements in recent years in case detection and positive treatment outcomes. The successes are undeniably attributable to a host of NGOs' participation in programme implementation. However, despite successful in many respects, the programme is likely to encounter some tangible problems to reach the MDG targets. Women's low participation in the programme is still a critical problem, requiring research to find out the reasons for proper remedial actions.

3 METHODOLOGY

3.1 THE STUDY³ PROBLEM AND SETTING

Involvement of volunteer *SSs* at the grassroots chosen from the community, by the community, for the community is believed to be a practical step towards ensuring gender-sensitive and women friendly environment in health interventions. Despite this, the TB case detection is significantly lower in females than in males (30% vs. 70%) (Fair et al. 1997; Begum et al. 2001). Besides, substantial attrition of females in different steps of clinical pathways for TB care is evident (Begum et al. 2001; Karim et al. 2004; Weiss et al. 2006). Probably, females in Bangladesh, confront more structural and gender-related barriers than males in accessing the existing health care services (Munro et al. 2007; Ahmed 2005). And these barriers may be ingrained in socio-economic, gender and cultural milieus including health care system, and from the patients themselves or combination of all. The key issues remain to explore how gender shapes experiences of illness, meanings, and behaviours, and how likely the gender influences help seeking decisions. Besides, local conceptualisations of illness, especially of TB and its treatment are not well understood from peoples' cultural contexts. Understanding of lay conceptualisations will help comprehend why people do not take appropriate treatment or delay in taking it. This will involve acknowledging that patients have agency and are active in shaping their own treatment decisions.

For a successful DOTS programme, the policy makers, planners and managers should critically understand about these tangible issues to help patients for proper treatment of TB. But, Bangladesh lacks in systematic research in these critical issues. Thus, taking TB control as a tracer case, studies in this thesis endeavoured to explore the critical barriers to and their features and effects in TB control with reference to gender.

3.2 OBJECTIVES OF THE THESIS

General

The general objective was to understand the scale of gender differences in various steps of clinical pathway for TB treatment; to explore the features and effects of gender-specific barriers to TB control, and to measure prevalence of smear-positive PTB in different population groups of rural Bangladesh.

Specific objectives

The specific objectives were to:

- Examine the scale of female-male differences in various steps of clinical pathway for TB management, and compare selective indicators with some published results for measuring changes over time (*Study I*).

³ The terms study and paper are used interchangeably in the thesis.

- Assess the gender variations in different delays from symptom onset to help seeking, diagnosis, and treatment of TB using DOTS at community level (*Study II*).
- Assess and compare stigma in women and men, and identify crosscutting and gender-specific features of TB-related stigma (*Study III*).
- Explore the patients' TB-related illness experiences, nature of the meaning of TB for women and men, and whether there were differences in aspects of behaviour relevant to TB control (*Study IV*).
- Measure the prevalence of smear-positive pulmonary TB in the community and compare the background characteristics of the incident cases with non-cases (*Study V*).

3.3 TOWARDS CONSTRUCTION OF A CONCEPTUAL FRAMEWORK FOR THE OVERALL RESEARCH

The preceding sections presented a wide body of evidences of gender-specific adverse impact of TB on socio-economic, physical, mental domains of humans and health service delivery systems, and these have relevance to the research questions in this thesis. Thus, our study framework was largely shaped in line with these evidences and Uplekar and colleagues' (2001) stepwise gender barrier framework.

The framework we developed contains two domains (Figure 5): the upper domain represents the clinical, and health system/service provisions; and the lower domain the possible barriers, which can be categorised as economic; socio-cultural; power; and geographical. Overlaps and interdependence between the barriers in each category are not unlikely. The clinical domain shown in the upper part of the framework seems a linear pathway to TB care, but in reality it is rarely so. All the core barriers depicted in the lower part of the framework have likely influence in all the seven steps with varied degrees. During illness, people search around for a wide range of remedies (steps two and three) from diverse sources., resulting in a so called "treatment shopping" around, often in the ineffective sources that not only increases expenses, loss of income and productive time, but also delay in effective treatment and contribute to severe psychological and emotional sufferings. Consequently, some may not progress toward the subsequent steps (steps four and beyond).

Power is a crosscutting issue that more or less influences all the steps in the clinical pathway. The poor and the marginalised groups, especially the women often confront extreme difficulties in each step of the pathway to TB care. In a patriarchal society, a woman has no decision-making power for her health issues; her solitary mobility is restricted, resulting in delay or dropout or non- treatment.

Lack of appropriate knowledge and recognition of TB, coupled with traditional illness experience, misconceptions about the causality and curability may influence the steps one to three leading to improper care seeking and delay. Wrong perceptions compounded with TB-related stigma lead to fear of social exclusion, diminished socially arranged marital prospects, job and income loss, affecting particularly the step four. Women more often than men, encounter severe reactions to TB and stigma. Such fear promotes denial, reduced self-esteem, and thereby prevent from timely care seeking, sputum testing, or accepting a diagnosis, treatment, adherence

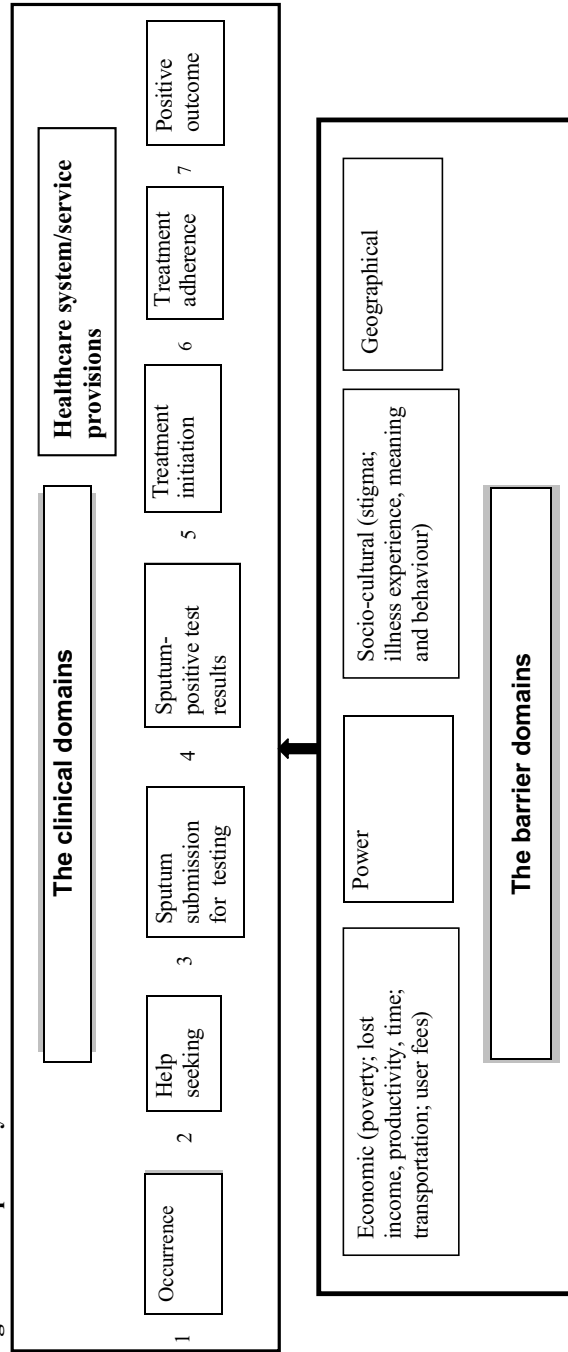
and positive outcomes (steps two to seven). Geographical distance often poses a barrier to accessing the services, and it disproportionately affects women at steps two and three, leading to dropout from the subsequent steps.

However, the first step is the occurrence of pulmonary TB in the community. Like other global settings, TB occurrence in Bangladesh may vary between different population groups, between female-male, and many may remain undetected by the routine programme. The *Study V* thus assessed the extent of smear-positive PTB prevalence in different groups of populations in the community, and case detection by the routine TB control programme. Once TB symptoms develop, the patients should access to the subsequent steps for diagnosis and cure. But in these steps, women's and men's representations may vary, and gender may mediate such variations. But what is the level of female-male representations at these crucial steps, and does the level change over time? *Study I* sought the answer to this question. Patients,' doctors' and health system's delay frequently pose barriers to TB control. Who defers more, women or men? *Study II* assessed different delays from a gender perspective. Gender is likely to contribute to vulnerability to TB-related stigma affecting more women. Stigma often contributes to psychosocial problems and emotional suffering, denial to a diagnosis and it may hinder timely help seeking and treatment adherence. Unequal gender roles, decision-making power, discriminations and social positions may pose gender-specific stigma to the patients with TB in seeking TB care and in their social life. *Study III* assessed and compared stigma in women and men, and identified crosscutting and gender-specific features of TB-related stigma. Process of socialisation, socio-economic power relations may influence patients' gender-specific TB-related illness experiences, meanings and behaviours that must be understood from local cultural context, for serving them with effective TB management. *Study IV* explored the patients' TB-related illness experiences, meanings of TB for women and men, and whether there were differences that they relate to aspects of behaviour relevant for TB control.

Operational definition of gender with reference to studies of the thesis

Gender in this thesis refers not only to biological characteristics of females and males but also to a socio-cultural construction of the female and male identity that goes beyond the biological differences between woman and man (known as sex). Gender leads to different social, political and economic opportunities and expectations for men and women. These opportunities and expectations are not always equal (NSW Health Department 2000; WHO 1998). The WHO's and NSW's concept of gender equity regards "equity as a state of fairness and justice. The concept recognises that men and women have different life experiences, different needs, different levels of power and access to decision-making levels in our society, differing expectations by others and different ways of expressing illness. Gender strategies recognise that gender leads to different social, economic and political opportunities for men and women.

Figure 5. The pathways to TB care services



* Adapted from Uplekar et al. 2001, and WHO 2005a.

Therefore, these differences should be identified and addressed in a fashion that rectifies imbalance between the sexes. Gender equity strategies seek to achieve fairness and justice in the distribution of benefits and responsibilities between men and women, and recognise that different approaches may be required to produce equitable outcomes.” We also considered the sex differentials in TB control to provide an insight of the magnitude of gender differentials in different aspects of TB control and the need for gender equity. Gender is regarded as one of the vital social determinant of health (Sen et al. 2007).

3.4 THE STUDY SITES

The *Studies I-IV* were carried out in 10 subdistricts of 4 districts (Mymensingh Sadar, Trishal, Muktagacha and Phulpur in Mymensingh district; Gobindaganj in Gaibandha; Dinajpur Sadar, Fulbari and Parbatipur in Dinajpur; Bogra Sadar and Kahaloo in Bogra district); and *Study V* in Shibpur and Monohardi subdistricts of Narsingdi district (Figure 6). All these subdistricts (*upazila*) are under BRAC TB control and socio-economic development programmes.

Basic socio-economic-demographic profiles of the study sites

Majority of the population are Muslim by religion (82-97%, highest in Trishal of Mymensingh district and lowest in Dinajpur Sadar of Dinajpur district (Table 9). The population density per sq.km is very high, ranging from 662 in Fulbari of Dinajpur to 1,736 in Mymensingh Sadar of Mymensingh district. Like the national scenario, sex ratio favours the males; 103 males for 100 females in Muktagacha of Mymensingh district, and highest at 111 in Bogra Sadar of Bogra district, the only exception is Monohardi subdistrict of Narsingdi district, where it is slightly in favour of females (99 males for 100 females). Female (7+ years old) literacy is consistently lower than the males across all the subdistricts. Though over a half of the households in most subdistricts, own agricultural land, majority live on subsistence level with poor housing, latrine and electricity facilities.

Disease profile of the study sites

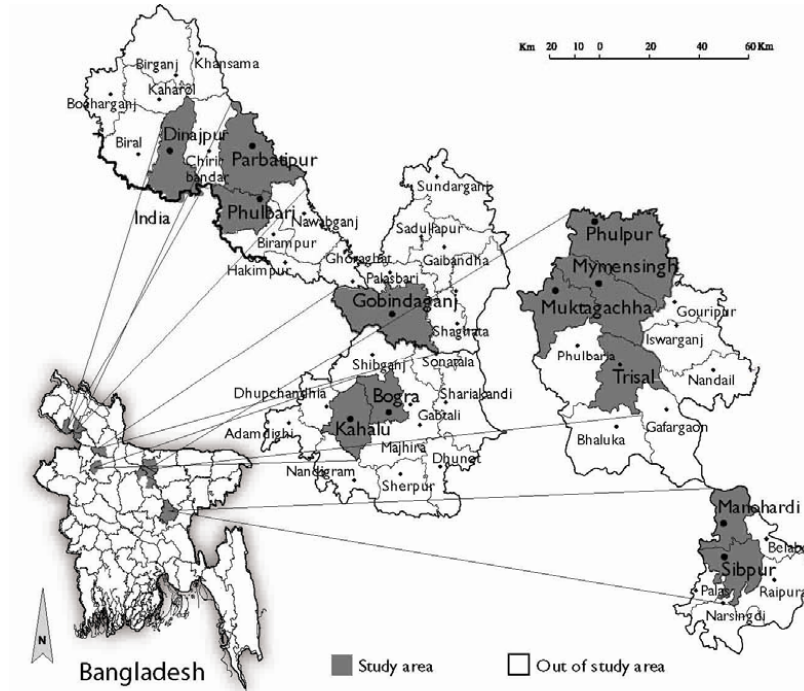
Across all the 12 subdistricts, peptic ulcer, helminthiasis, PUO (fever/pyrexia of unknown origin), skin diseases, anaemia, malnutrition, common cold, diarrhoea and dysentery are common among both women and men. Anaemia affects highest proportion of women (32%) in Mymensingh Sadar subdistrict, whilst in Shibpur it affects more men than women (20 vs. 10%). Unlike all other subdistricts, asthma appears to be pronounced among the patients, more in women than in men (53 vs. 15%). Helminthiasis is also higher among both women and men in Mymensingh Sadar compared with other subdistricts (women 13 and men. 21%), followed by Shibpur (women 16 and men 11%). Dysentery is more common among women than men in Shibpur (18 vs. 16%).

3.5 STUDY DESIGN

The studies in this thesis embraced a multi-method design to achieve the overall objective/s (Table 10). The five studies including their specific designs were:

Study I: Embracing the cross-sectional design, the case registry data of BRAC TB control programme were reviewed to identify the scale of female-male representations at outpatient

Figure 6. Bangladesh map showing the study areas



Source: UNDP, Dhaka, 2004.

clinics for respiratory symptoms management, TB suspects submitting sputum for testing, sputum-positive test results, sputum-positive treatment, and its outcome.

Study II: Structured outpatient survey based on cross-sectional design assessed sex differences in different delays in diagnosis and treatment.

Studies III and IV: Cultural epidemiology of TB assessed TB-related illness experience, meaning, behaviour, and felt and/or enacted stigma. The cultural epidemiological study is built on the descriptive, qualitative design.

Study V: Spearheaded by the cross-sectional design, a household survey screened out persons with at least three weeks of cough; their smear tested, and measured the prevalence of smear-positive pulmonary TB in different population groups.

Table 9. Basic socio-economic and demographic information of study areas by *mpuzilas* (subdistrict), 2001

Indicators	Districts and subdistricts											
	Mymensingh		Gaibandha		Bogra		Dinajpur		Narsingdi			
	M. Singh Sadar	Trishal Sadar	Muktasgacha	Phulpur	Gobindaganj	Bogra Sadar	Khaloo Sadar	Dinajpur Sadar	Fulbari	Parbatipur	Shibpur	Monohardi
Area (sq km)	388.5	339.0	314.7	580.2	481.7	398.6	239.0	354.3	229.6	395.1	206.9	195.6
Population	674,452	372,498	366,397	524,720	461,428	694,077	195,565	424,776	151,939	325,070	265,177	244,540
Male	348,372	190,428	185,909	269,980	235,622	365,223	99,515	221,697	78,803	168,070	134,255	121,484
Female	324,080	182,070	180,488	254,740	225,806	328,854	96,050	203,079	73,136	157,000	130,922	123,056
Household size	4.7	4.7	4.5	4.7	4.2	4.5	4.3	4.6	4.6	4.6	4.8	4.5
Religion (%): Muslim	93.6	97.1	95.0	96.1	92.7	94.5	93.6	82.4	83.0	85.5	95.8	95.3
Hindu	6.2	2.8	4.7	3.6	6.4	5.4	6.3	16.2	13.7	13.0	4.2	4.7
Others	0.2	0.1	0.3	0.4	0.9	0.1	0.1	1.4	3.3	1.5	0.0	0.0
Population density (sq km)	1,736	1,099	1,164	904	958	1,741	819	1,199	662	823	1,282	1,250
Sex ratio (M/F)	108	105	103	106	104	111	104	109	108	107	103	99
Literacy (7+ years) (%)	49.9	40.2	35.3	33.1	37.8	55.5	47.9	58.7	48.2	46.5	49.3	42.7
Male	53.4	42.1	38.4	35.4	42.9	60.0	53.2	62.8	52.1	50.9	51.1	44.7
Female	46.1	38.2	32.2	30.7	32.5	50.5	42.4	54.1	44.0	41.7	47.6	40.9
HH with access to safe drinking water (%)	94.7	94.1	90.7	93.6	92.4	96.3	93.8	95.5	95.2	93.1	94.3	91.1
HH with sanitary latrine (%)	36.4	23.0	27.2	13.3	10.4	49.8	30.1	32.9	15.8	13.3	40.7	29.2
Main source of income: agriculture (% of HH)	34.6	62.7	59.3	74.5	66.9	35.1	67.3	33.3	68.8	64.1	54.6	48.9
Agri. land owned (% of HH)	45.3	58.5	55.5	61.2	59.4	49.8	63.1	42.2	50.3	47.4	67.4	71.4
HH with access to electricity (%)	38.4	11.5	21.5	4.2	12.0	47.7	34.5	41.5	22.9	19.8	42.1	23.4

HH= Household. Sources: BBS, 2004, 2005, 2007. Note: The population in the 10 subdistricts of Mymensingh, Gaibandha, Bogra and Dinajpur districts, increased from about 2.5 million in the national 1991 Census to over 3.3 million in the 2001 national census, and even more in the subsequent years. For this, the study area related population statistics mentioned in the background of *Studies I-IV* varies.

Table 10. Summary of studies by specific research question/s, study design, participants and data collection methods

Parameters	Studies				
	I	II	III	IV	V
Status	Published	Published	Published	Final manuscript	Final manuscript
Research question	How large is the gender disparity in various steps of clinical pathway for TB care along the path to cure of TB? What trend does it follow over time?	What is the state of delays at different steps of clinical process for TB control? Who delay more, women or men?	What are the gender-specific nature of TB-related stigma, its features and effects? What are the determinants of stigma?	How patients understand and construct the TB-related illness experience, meaning and behaviour from their local cultural context; with reference to gender? What are the gender-specific barriers they encounter to accessing TB care?	How big is the smear-positive TB burden in different population groups in the community? What are the determinants of smear-positive PTB occurrence and remain to be undetected?
Study design	Cross-sectional	Cross-sectional	Descriptive, qualitative	Same as study III	Population-based cross-sectional >= 12 years old people
Study participants	Registry patients viz., outpatient, TB laboratory, treatment registers	Newly diagnosed smear-positive patients	TB patients undergoing DOT treatment	Same as study III	144,023 people
Sample size	3,600 (1,200 from each registry)	1,000 (half females and half males)	102 (50 females and 52 males)	Same as study III	30-cluster
Sampling methods	Systematic	Convenient	Purposive	Same as study III	30 cluster survey method
Data collection methods	Registry record reconnaissance	TB patient survey	Explanatory Model Interview Catalogue or EMIC- semi-structured qualitative interview technique in cultural epidemiology	Same as study III	Two different semi-structured pretested schedules
Data collection instruments	Three different pretested data extraction formats	A short 10-items pretested schedules	Semi-structured pretested qualitative schedules	Same as study III	Two different semi-structured pretested schedules

Plan for the multi-method studies

A multi-method approach guided plans for five studies of this thesis. The data for *Studies I-IV* came from the Bangladesh part of a multi-country study on gender and TB commissioned by TDR of UNDP/WB/UNICEF/WHO in Bangladesh, Colombia, India, and Malawi. The methods, tools, sampling strategies and sample sizes for these studies were designed by the scientists of the collaborating countries including the author of this thesis, in a project development workshop in Geneva in December 2000 (Weiss et al. 2006). These were translated and adapted at the local project sites.

Review of BRAC programme cases registry data (Study I) — Registry data were collected retrospectively from outpatient, laboratory and treatment registers, over a reference period of 12 consecutive months, representing 10 subdistricts with 3.3 million people spread over 4 districts. Using three different pretested structured formats, data were extracted from the record on a total of 3,600 systematically selected subjects, (1,200 from each of the 3 registers). These were double entered and cleaned in Epi Info version 6.04 and analysed by SPSS version 10.0. To compare female-male representations, ratios and confidence intervals of patients were computed at each step, included: (i) patients presented at outpatient clinics for respiratory illness care, (ii) TB suspects submitting sputum for testing, (iii) patients with smear-positive test results, (iv) smear-positive patients put on treatment, and (v) positive treatment outcome.

Outpatient survey (Study II) — An outpatient survey of new TB patients (first month of diagnosis) used a short 10-item semi-structured interview comprising questions, for instance, on lag time from onset of symptoms to the first outside help seeking for symptoms of TB (patient delay), and lag time from first outside help seeking to making a diagnosis of TB (provider delay). For this, 1,000 smear-positive PTB patients (500 women and 500 men) were conveniently drawn from the 10 study subdistricts. The data were double entered and cleaned in Epi Info version 6.04 and analysed by SPSS version 10.0. Delays were classified into six categories; each of them was given an operational definition (Method section, *Paper II*). Computation of descriptive statistics compared female-male differences in delays. Multiple linear regressions on the log transformed data identified the predictors of different delays in care seeking for TB.

Cultural epidemiology with semi-structured qualitative EMIC interviews (Studies III and IV) — Cultural epidemiology is an interdisciplinary approach of research on locally valid representations of illness and their distributions in patients' cultural context. Cultural epidemiological studies identify the features of TB-related illness experiences, meanings and behaviours. The EMIC interview known as Explanatory Model Interview Catalogue, which combines both quantitative and qualitative assessments in semi-structured qualitative interviews, has been an effective tool for such study (Weiss 2001; Weiss et al. 2006).

Ethnographic knowledge from previous studies guided the EMIC instruments development for this study. The EMIC refers to a family of explanatory model interviews and a framework for cultural epidemiological study. The EMIC interviews examine (i) the pattern of TB-related distress (PD), that encompasses an entire length of symptoms and the socio-economic, cultural, and emotional context of sufferings associated with TB, (ii) perceived cause (PC), i.e. patients'

understanding and locally held beliefs in the causes of TB, and (iii) various help seeking (HS) actions including self-help, help from family and friends, and professionals and non-professionals.

The structure of instruments in each section includes open-ended questions first to identify what spontaneously comes to mind without prompting for specific categories. Initial questions include “what is the problem?” “what is the cause?” and “what kind of help did you get?” The next phase of inquiry in each section probes on various locally relevant but unmentioned categories. Each section concludes with questions about especially important categories in their previous responses, such as most troubling symptoms of their problems, most important perceived cause, and first help seeking. Thus, the semi-structured qualitative interviews generate complementary qualitative and quantitative data to facilitate cross-referencing and clarification of each component of PD, PC and HS (Weiss 2001).

Based on an EMIC interview, a combination of qualitative and quantitative research methods, provides descriptive accounts, facilitates comparisons, and clarifies the cultural basis of risk, course, and outcomes of practical significance, and the outcome-related behaviour (Weiss et al. 2006).

The EMIC interviews collected data from 102 purposively selected TB patients representing intensive (2-4 weeks) and continuous (4-5 months) phases. Four university graduates in anthropology or sociology with extensive experience in field research (2 women and 2 men) were given a 2-day preliminary orientation on the draft instruments for pilot testing for the suitability, completeness, clarity, understandability of the questions, categories of responses, and completeness of narrative accounts were meticulously examined and finalised. This was followed by a 6-day classroom and practical training on the modalities of interview, note-taking, structure of questions, ease of understanding of the questions by the respondents, categories of responses, and narrative accounts.

They collected data in two teams, each comprised of one anthropologist and one sociologist. The men interviewers interviewed the men patients, and the women interviewed the women patients. In each team, the anthropologist acted as a moderator and conducted the session of interview, and the other took notes on responses. Immediately after completion of each session, both the moderator and the note taker checked the notes together to assess the completeness of the notes taken, before leaving the interview place. Besides, in each evening they sat together at field office to review the notes and check the completeness and consistency of responses. The Principal Investigator and the senior researchers continuously supervised the field activities. The author of this thesis also conducted some EMIC interviews along side the field researchers, mainly during the pilot testing and initial stage of actual data collection. The interviews were carried out between August 2001 and April 2002.

All interviews were convened at patients’ homes. Most sessions were held inside room ensuring privacy and easiness of the patients. To comply with patient’s request, a few sessions, especially with the men were held at open place. However, at any situation, the interviewers prevented the influence of bystanders during interview, by using local guardians, by giving attention only to the respondent’s responses and ignoring the comments of the others. Each

interview usually took two and a half hours to three hours to complete. Multiple sessions were needed to complete an interview, particularly with the patients from intensive phase of treatment. Overall, some respondents, especially at the latter half of the sessions felt uncomfortable, because of longer interview. In such cases, multiple sessions were organised.

The dataset comprised both categorical data for quantitative analysis, and patients' narrative accounts elaborating the nature and context of PD, PC and HS. Responses to EMIC queries on PD, PC and HS distinguished spontaneously reported categories from those elicited by probing specific categories. Categorical and numeric data derived from EMIC interviews were double entered for verifications and cleaned using Epi Info software (version 6.04) and analysed by SPSS (version 10).

Two anthropologists rigorously checked and edited the entire answer sheets/questionnaire/note. Immediately, after completion of data collection, four field researchers of these studies including a Bangladeshi Ph.D. student pursuing his Ph.D. in sociology in Finland transcribed and translated *Bangla* versions of narratives into English and entered in computer under the close supervision of the PI. The respective field researchers checked the English translation of narratives for completeness and consistency and thereby finalised for analysis. Later, the translated qualitative narratives of each interview imported into MaxQDA, software for qualitative data analysis. These data were coded, based on the cultural epidemiological framework and in the structure of the EMIC interview. 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 illness-experience, its meaning and help seeking behaviour in general, and for subsets of patients identified in the quantitative analysis of categorical data.

For the *Study III*, eighteen stigma indicators were evaluated. Responses to each stigma question were coded based on a four-point scale of yes, possibly, uncertain, or no, and represented with a prominence ranging from 3 to 0, with higher values indicating more stigma. A clearly affirmative response about an aspect of stigma was coded 3, an equivocal response suggesting the possibility of stigma was coded 2, uncertainty about the relevance of the indicator was coded 1, and denial of its relevance was coded 0. The means of these responses were computed to summarise the dimension of stigma emerged from that variable. Responses were analysed individually and validated collectively as an index of stigma, which was validated for internal consistency with the Cronbach's alpha statistic. Our analysis identified stigma-related themes, and their gender-specific features, identifying crosscutting and distinctive aspects of stigma reported by male and female TB patients. Multivariate analyses of each of the stigma indicators and the stigma index examined the effects of socio-demographic variables. The analysis for each of the stigma indicators used logistic regression, dichotomizing "yes" and "possibly" responses as positive and "uncertain" and "no" responses as negative. Multivariate linear regression was used for analysis of the stigma index.

For *Study IV*, responses on each indicator on patterns of distress (PD), perceived causes (PC), and help seeking (HS) were coded with values from 0 to 2, indicating not specified, specified after probing, and specified spontaneously. Response variables were analysed as coded in the interview and also reconfigured in groups that specified broader categories (e.g. fever, cough,

etc. grouped under broader heading of physical symptoms among grouped categories of distress). The prominence computation for each category was how it was reported (spontaneously, probed or not at all), and whether it was identified as most troubling PD, most important PC or first help seeking. Patients were also asked to specify self-rated most troubling PD, the most important PC, and first HS. Comparison of women-men responses specified by the ranked prominence for PD, PC and HS, based on reporting spontaneously, and after probes was performed by the Cochran-Armitage test for trend. Fisher's exact test compared the most troubling distress, most important perceived causes and first help seeking. T-test compared the mean of continuous variables (age, money, time, etc.). However, the PD, PC, and HS data were summarised with frequencies of quantitative variables from the perspective of gender, with cross-referencing of qualitative accounts (Weiss et al. 2006).

Population screening survey for smear-positive PTB prevalence (Study V) — The cross-sectional survey was implemented in rural areas of Monohardi and Shibpur subdistricts of Narsingdi district with comparable socio-economic and demographic characteristics. Using the cluster survey methods a total of 44,455 households with 209,738 populations (105,900 female and 103,838 males), spread over these subdistricts were surveyed. The adult persons (≥ 12 years) with chronic cough for at least three weeks were screened. From each TB suspect 2 sputum samples (morning and spot) were collected and tested for Acid Fast Bacilli (AFB) at two field laboratories. Socio-economic information was collected for all the households where smear-positive TB patients were diagnosed. The same information was also collected from 239 randomly selected households from the village census (where no TB case was detected). These households represent general population of those communities and had been used to assess socio-economic divide in PTB prevalence.

For ensuring quality and completeness of data collection, management and analysis, different measures were taken, for example, preparation of a field guideline incorporating overall description of the study, its instruments, and methods for sputum and data collection, extensive field trial of all the techniques and tools, training to all the staffs at different levels, supportive supervision, and involvement of separate monitoring teams to monitor and verify 10% of randomly selected interviewed households for accuracy and completeness of data. One laboratory expert from the Capital City Dhaka paid weekly visit to check the quality of field lab technicians' performance. Besides, 10% sub-samples of sputum from amongst the samples tested by the field lab technicians were re-checked by independent experts at reference laboratory in Dhaka.

Data were entered, cleaned and analysed by SPSS and STATA software packages. To explore the socio-economic divide in accessing the services, both expenditure and asset based measure were used. To derive a composite indicator of asset holding, principal component analysis was performed using 19 different types of assets (Anex 1, *Paper V*). One principal component was extracted and by the signs of the factor loadings it was inferred that the component was the wealth status of the households. Factor loadings show the strength of association between the indicators and the wealth status and usually a value of at least 0.30 is considered adequate (Henry et al. 2003). Overall KMO sample adequacy was 0.92, a highly acceptable level. Finally, the value of index for each household was estimated using regression coefficients specified in the last column of Annex 1, *Paper V*. This exercise was carried out on the sampled

households where no TB case was detected during the screening survey. Using these same coefficients, wealth scores were estimated for the households with patient(s). To demonstrate the relative poverty concentration of the households with TB patients, the non-TB patient households were ranked into quintiles by their wealth scores. The same cut-off marks from their wealth quintiles were used to have the distribution of the TB patients' households.

For health vibrancy we used distance from 9 sources of health care (government primary health centre, government *upazila* health complex, government district hospital, private clinic, private hospital, NGO clinic, NGO hospital, trained government doctor, and trained private doctor). We categorised distance from each into 5 categories (0=does not have access to it by distance, 1=have beyond 6 km, 2=have within 3-6 km, 3=have within 1-3 km, 4=have within 1 km). Then the scores were added for all 9 sources. Therefore, higher score means greater vibrancy. Later, we divided it into 3 groups: low (<4), medium (4-5) and high (6 or above). These cut-offs were arbitrarily decided to keep adequate number of frequencies in each group.

3.6 ETHICAL CONSIDERATIONS

All studies were completed following the ethical norms. BRAC Research and Evaluation Division (RED) gave ethical clearance for the *Studies I-IV*, and Bangladesh Medical Research Council (BMRC) for the *Study V*. Data were collected through face-to-face interviews. A written consent was taken from each participant. It was made clear that s/he had no obligation to participate and that even if s/he refused, it won't affect her/his receiving BRAC inputs in any way. Code numbers identified the individuals and all data were used for solely research purpose. Confidentiality of the data was maintained throughout the project life cycle.

4 THE RESULTS

4.1 SOCIO-ECONOMIC DIVIDES IN SMEAR-POSITIVE PTB BURDEN IN THE COMMUNITY (STUDY V)

The research population survey-based smear-positive PTB point prevalence in the community was estimated to be 52.8 per 100,000 people (female 23.3 vs. male 83.0; F/M ratio 0.29), whereas the routine programme detection-based period prevalence was 69.4 (female 50.7 vs. male 88.7; F/M ratio 0.59). Estimate of ‘true’ smear-positive PTB period prevalence rate (by adding up all the cases) found by both the research and programme was 122.2/100,000 (female 74 vs. male 171.7; $p=0.000$; F/M ratio 0.44). However, the routine programme missed out 76 cases (female 17 and male 59) out of total 176 (43.2%) (Table 11). Geographical variation in PTB prevalence was evident; Monohardi subdistrict shared a higher rate than Shibpur (128.4 vs. 116.4/100,000). (Table 1, *Paper V*) Fewer females than males were detected with smear-positive PTB in both the subdistricts (Monohardi 91.0 vs. 166.9; and Shibpur 58.2 vs. 176.1 per 100,000) (Table 1, *Paper V*). For females, smear-positive PTB was more likely to occur in younger age groups (12-29 years), and for males the occurrence increased with the increase in age (Figure 1, *Paper V*).

Table 11. Estimated smear-positive PTB prevalence rates by sex and type of tracer (research and routine programme)

Indicators	Female	Male	F/M ratio	All
A. Total population ≥ 12 years old	72,965	71,058	1.03	144,023
B. Research team identified cases	17	59	0.29	76
C. Routine programme identified cases	37	63	0.59	100
D. Point prevalence based on B	23.3	83.0	-	52.8
E. Period prevalence based on C	50.7	88.7	-	69.4
F. ‘True’ period prevalence based on B+C*	74.0	171.7	-	122.2

Notes: Figures in rows A-C are solid numbers. Figures in rows D-F are rates per 100,000 people. F/M=Female/Male. *F/M ratio 0.44

Socio-economic determinants of smear-positive PTB prevalence — Smear-positive PTB prevalence was almost identical across different wealth quintiles, except for the 4th quintile (Figure 2, *Paper V*), showing no clear association between wealth status and smear-positive PTB prevalence. Increased per capita space of dwelling house by square feet, use of tubewell water for all purposes, and medium level proximity to health facilities, reduced smear-positive PTB prevalence by -0.000004, -0.002515 and -0.000483, respectively (Table 2, *Paper V*). Increased per capita food expenditures were associated with increased smear-positive PTB prevalence.

Determinants for remaining undetected — Probit analysis explored the determinants for being remained undetected (76 cases) by the routine programme. The outcome variable was whether or not the regular programme detected the patient. Holding the other variables (Table 3, *Paper V*) constant at their means, increase in the age of PTB patients by one year increased the probability for remaining undetected by 0.006. Chances of smokers to remain undetected

increased by 0.316. Medium and high health vibrancy reduced the chances for remaining undetected by -0.228 and -0.232, respectively.

4.2 FEMALE-MALE REPRESENTATIONS AT DIFFERENT CLINICAL STEPS FOR TB CARE AT COMMUNITY LEVEL (STUDY I)

Diagnosis and treatment — Female-to-male ratio (FMR) was lower than 1 among the patients seeking care at outpatient clinics for respiratory complaints (0.81), TB suspects submitting sputum for testing (0.52), and patients with smear-positive test results (0.38) (last row, Table 12). Sex adjusted distribution of the rural population generating the cases affected the FMRs, and the effect varied between the age strata (Table 12). For instance, FMR was slightly lower in general population (0.96), highest among 25-34 years of age group (1.18), and lowest among 65 and plus years of age (0.63). The lower crude FMR among the elderly is partly explained by the low FMR in the general population above 65 years of age. FMR of the patients underwent TB treatment was 0.41 (Table 13).

Table 12. Sex adjusted female-to-male ratio (FMR) in the rural general population of four study districts and the patients at various steps of clinical pathways for TB care by age

Age (Yrs.)	Rural population			Outpatients with respiratory symptoms			TB suspects submitted sputum for testing			Patients with smear-positive		
	F	M	FMR	F	M	FMR	F	M	FMR	F	M	FMR
<15	2009900	2253620	0.89	71	83	0.86	21	21	1.00	2	0	0
15-24	949780	836440	1.14	83	77	1.08	67	83	0.81	7	14	0.50
25-34	925840	781760	1.18	113	109	1.04	113	124	0.91	22	25	0.88
35-44	605300	689940	0.88	98	104	0.94	88	180	0.49	11	35	0.31
45-54	422420	425920	0.99	76	98	0.78	61	123	0.50	9	17	0.53
55-64	219420	258440	0.85	69	97	0.71	43	138	0.31	4	32	0.13
65+	142680	228120	0.63	27	95	0.28	19	119	0.16	3	29	0.10
Total	5274980	5474240	0.96	537	663	0.81	412	788	0.52	58	152	0.38

F= Female, M= Male. FMR= Female-to-male ratio.

Females' attrition at various clinical steps for TB diagnosis and treatment — FMR decreased at the first three steps of clinical process: respiratory patients seeking outpatient care, TB suspects submitted sputum for testing, and smear-positive test results, and ceased at treatment initiation (Table 13). Females were less likely than males to seek care at outpatient clinics for respiratory complaints management (FMR 0.81), and female TB suspects likewise were less frequently submitted sputum for testing (OR 0.65), and if examined, they were less likely to be smear-positive (OR 0.73). Among the sputum-positive cases, both females and males had somewhat equal likelihood for starting treatment (OR 1.06).

Table 13. Female-to-male ratios (FMR) at various steps of clinical pathways for TB care

Steps	N size	Number		FMR	OR (95% CI from previous step)
		Female	Male		
Respiratory patients seeking outpatient care	1200	537	663	0.81	-
TB suspects submitted sputum for testing	1200	412	788	0.52	0.65 (0.55-0.76)
Smear-positive test results	210	58	152	0.38	0.73 (0.52-1.02)
Smear-positive treatment initiation	1071	309	762	0.41	1.06 (0.75-1.50)

A comparative scenario of females' attrition between 1997 and 2000 — Compared with 1997, FMRs in 2000 slightly declined in the steps of seeking care at outpatient clinics (0.91 vs. 0.81), and sputum submitted for smearing (0.57 vs. 0.52), respectively, but increased in smear-positivity (0.27 vs. 0.38), and treatment initiation (0.35 vs. 0.41) ((Table 1, *Paper I*).

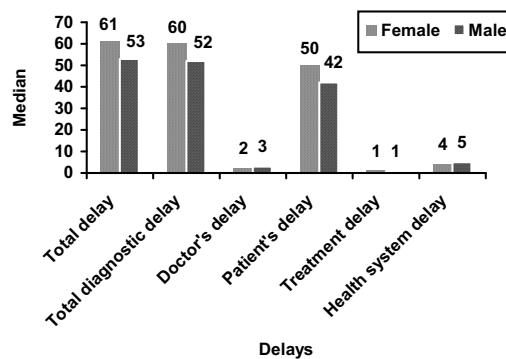
Sex and age-specific treatment outcomes of patients — Among the patients who underwent treatment; females had a slightly higher cure rate than males (93% vs. 89%). More males than females achieved cure, amongst the less than 25 years old patients (Table 2, *Paper I*). The scenario was different for patients aged 45 or more years, where a slightly more females than males attained cure. However, though the scale varied across different age strata, the cure rate among males considerably decreased with the increase in age, but this was fairly stable across different age groups of female patients. Of 15 female deaths, 4 occurred among less than 25 years of age groups, 5 among the 25-44 and 6 among the 45 and more years of age groups. Out of 59 male deaths, none was in less than 25 years age groups, rather more clustered among 45 and more years old (47 deaths).

4.3 SEX-SPECIFIC FEATURES OF DELAYS IN TB DIAGNOSIS AND TREATMENT (*STUDY II*)

Figure 7 shows that women than men had significantly longer median delays in most types of delay observed viz. total delay (61 vs. 53 days), total diagnostic delay (60 vs. 52 days), and patient's delay (50 vs. 42 days). Comparison of mean delays also indicated the similar pattern of sex differences in different delays (Table 1, *Paper II*).

Determinants of delays — The multiple linear regression analysis indicated a significant association between the patients' sex and total delay, total diagnostic delay, and patient's delay, i.e. for being females, they encountered longer delays in these delay categories ((Table 2, *Paper II*).

Figure 7. Median delays in help seeking among smear-positive patients (500 women and 500 men) for TB diagnosis and treatment by sex (in days)



4.4 TB-RELATED STIGMA: UNMASKING THE MAGNITUDE, EFFECTS, FEATURES AND DETERMINANTS (STUDY III)

The overall stigma index for female TB patients was significantly higher than for males ($p=0.04$), implying more self-reported stigma for females (Table 2, *Paper III*). Female patients emphasised more on psychosocial and marriage or family-related indicators than men. They thought less of themselves (item 3) due to TB, felt ashamed or embarrassed (item 4). They also more frequently reported those indicators that suggested social isolation, including, ‘others have avoided you’ (item 7), ‘others refused to visit’ (item 8). Female patients also mentioned that their illness might result in marital problems even after a cure (item 14). Male patients more commonly specified the stigma items that affected the sexual relations (item 13), and their ability to work (item 17) (Table 1, *Paper III*).

Determinants of TB-related stigma — Increasing age was the most consistently significant variable in these models, negatively associated with 9 of the stigma indicators and with the overall index. A positive association of female sex with stigma was of borderline significance. Female sex was significantly associated with greater prominence of the stigma indicators ‘shamed or embarrassed’ (item 4) and ‘others refuse to visit’ (item 8). Female sex was also associated with willingness to disclose their illness to a community or family member to enlist support (item 2). Patients in treatment over a longer duration (4-5 months, compared with others in treatment 1-2 months) were more likely to report receiving adequate support from their spouses (item 12) (Table 3, *Paper III*).

Gender-specific features of stigma in TB illness narratives — Psychosocial dissociation, mental, and emotional suffering emerged as a prominent theme in women’s illness narratives. Women who reported feeling ashamed or embarrassed (item 4) explained how these concerns contributed to their low self-esteem and lack of pride. Women’s narratives also reflected feelings of increased social isolation and rejection by in-laws and husbands, as indicated in the following account:

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

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

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

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

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

Both married and unmarried women were concerned about the impact of their TB on marital problems (item 14). Some also expected these problems to persist even after they were cured. They feared being reprimanded by their husbands, the possibility of divorce so their husbands could remarry, and the potential for their children to contract TB. Unmarried women were concerned that no one would marry them because they would always be regarded as someone who would transmit the disease to others. Male patients were also concerned about the effects of TB on their marriage prospects. The social system of arranged marriages did not fully protect them from that possibility.

A combination of enacted and anticipated (felt) stigma and debilitating effects of the disease affected many aspects of patients' lives, with considerable financial and socio-economic impact. Stigma, combined with physical weakness, contributed to patients' decisions to stay away from work or not to participate in group activities (item 17). Such avoidance affected both economic and emotional well-being; it was a more prominent issue for men. *"I myself have decided to stop working,"* a man explained. *"I was weak, and that is why I do not go to the fields to farm as I did before,"* he further added. Some men emphasised the financial repercussions of their inability to work for their households: *"Of course my income has decreased. I can not repair shoes nowadays, so I can not earn."*

4.5 CULTURAL EPIDEMIOLOGY WITH SEMI-STRUCTURED QUALITATIVE EMIC INTERVIEWS (STUDY IV)

Recognition, importance, and curability of TB

Fewer patients could identify their condition as TB prior to diagnosis at BRAC Health Centres (BHC). Females more often recognise the seriousness and deadly character of their TB (68%). Most patients thought their problem was curable with proper treatment.

Gender-specific features of patterns of distress (PD)

Somatic symptoms of TB were frequently reported categories of distress. Females spontaneously reported multifarious imprecise physical symptoms viz. fever, weakness, chest pain, weight loss, loss of appetite, and breathlessness — with significantly greater frequency than males. Males were more concerned about financial distress (Table 1, *Paper IV*). Experience and fears ranged from reduced income to loss of job. TB related symptoms often prevented males from going to work for prolonged period of time, resulting in familial financial setback. Such crises also affected females' psychological and emotional domains in different ways, putting them at risk for divorce. Male income earners (particularly husbands) were frequently angered at the treatment expenses and subjected the females to mental and physical torture

Psychological-mental distress — Grouped data indicated that both female and male patients commonly reported psychological distress, with a slightly higher frequency for males (96% vs. 94%) (Table 1, *Paper IV*). Fears and worries were the recurring themes in patients' narrative

accounts; they often feared of death and rejection, especially females were afraid of leaving their children as orphan. A female patient said, *“If I would die, none would nurse my child. I was afraid of my death indeed. I felt extremely bad about the fate of my child after my death.”*

As a result of somatic distress, many females failed to perform daily household chores, entailing violence, physical torture and temporary abandonment by their husbands, whilst many wives were forced to return to their parental homes during the course of illness, resulting in increased vulnerability. An illiterate deserted woman of 32 years of age said:

I got fever, cough and physical weakness requiring 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.

Stigma, social discriminations and rejections adversely affected the TB patients. Family members and neighbours were rarely positive and cooperative to TB patients. All these seriously stigmatised the patients, leading to personal isolation from family, separation of utensils and hiding disease from community. A 40 years old married male with 8 years of education cited, *“The family members separated me including my utensils. The people of our community did not know about my disease. I did not tell them in fear of reduced esteem.”* Female patients also experienced similar consequences.

Although males specified fewer individual indicators within the grouped category of physical distress, their suffering was intense enough to affect their ability to labour. In many cases, landowners were reluctant to lease out land to TB afflicted sharecroppers, and likewise employers did not employ TB patients as wage labourers, resulting in a drastic decline in household income, and increased vulnerability.

Most troubling symptoms— Cough incredibly distressed the female patients, and thus they rated it as the single most troubling category of distress (60%). They noted that coughing resulted in vomiting, urinal incontinence and tears. Cough compounded with chest pain, weakness, and blood in sputum, troubled males too (Table 14).

Gender-specific features of perceived causes (PC)

Patients commonly reported food, physical exertion or hard work, contamination and contact, smoking and prior illness as perceived causes of their TB (Table 2, *Paper IV*). Among the grouped categories, ingestion-related causes were prominent in both female and male patients (40% vs. 76.9%, $p=0.000$). The feature of these accounts, indeed, differed considerably by sex. Men commonly reported about smoking and drug abuse. *“I used to smoke a lot. I have got this disease because of smoking. Everyday, I used to smoke 100-150 kolki (the bowl of a hookah which holds tobacco) of marijuana,”* said a 50 years old married man with 4 years of education. Women typically referred to food shortage, inadequate food intake, and unhygienic eating or drinking outside home, or drinking excessive cold water. Economic hardships often compelled many women to eat less. Men emphasised on physical exertion or hard work (33%) and women on prior illness (32%). Women more frequently than men reported that suffering from other diseases for instance, diarrhoea, prior to TB, caused TB in them.

Table 14. Patterns of distress: Frequency of most troubling symptoms by sex (%)

Items and clusters	Women (n=50)	Men (n=52)	Total (n=102)	p-value*
PHYSICAL SYMPTOMS	98.0	96.2	97.1	1.000
Cough	60.0	32.7	46.1	0.009
Fever	10.0	5.8	7.8	0.483
Chest pain	18.0	21.2	19.6	0.804
Blood in sputum	0.0	9.6	4.9	0.056
Breathlessness	4.0	5.8	4.9	1.000
Loss of appetite	2.0	3.8	2.9	1.000
Weakness	4.0	13.5	8.8	0.160
Side effects of drugs	0.0	3.8	2.0	0.495
PSYCHOLOGICAL – EMOTIONAL	2.0	3.8	2.9	1.000
Concern about course of illness	2.0	3.8	2.9	1.000

*Fisher's exact test for female-male comparisons. Grouped categories computed from responses and indicated in bold type. Categories reported by less than 5% respondents were omitted from table but retained in grouped values. Higher prominence of reported values is in bold and italic.

Most important perceived causes — Among the grouped categories of most important perceived causes of TB, ingestion, ill-health and injuries, and environmental issues were

Table 15. Perceived causes: Frequency of most important perceived causes by sex (%)

Items and clusters	Women (n=50)	Men (n=52)	Total (n=102)	p-value*
INGESTION	20.0	53.8	37.3	0.000
Food	14.0	9.6	11.8	0.550
Water	6.0	1.9	3.9	0.357
Smoking	0.0	34.6	17.6	0.010
Abused drug	0.0	7.7	3.9	0.117
HEALTH-ILL-INJURY	34.0	19.2	26.5	0.117
Injury, accident	6.0	0.0	2.9	0.114
Physical exertion-work	8.0	19.2	13.7	0.149
Prior illness	18.0	0.0	8.8	0.001
Pregnancy-childbirth	2.0	0.0	1.0	0.490
HEREDITARY	6.0	0.0	2.9	0.114
Heredity	6.0	0.0	2.9	0.114
PSYCHOLOGICAL-EMOTIONAL	0.0	1.9	1.0	1.000
Mental-emotional stress	0.0	1.9	1.0	1.000
ENVIRONMENTAL	24.0	9.6	16.7	0.065
Germes or infection	2.0	0.0	1.0	0.490
Contamination-contact	20.0	9.6	14.7	0.169
Airborne exposure	2.0	0.0	1.0	0.490
TRADITIONAL-CULTURAL	6.0	3.8	4.9	0.675
Heat-cold humoral	4.0	1.9	2.9	0.614
Climate	0.0	1.9	1.0	1.000
Fate-God-Karma	2.0	0.0	1.0	0.490
SEXUAL	2.0	0.0	1.0	0.490
Sexual contact	2.0	0.0	1.0	0.490
MISCELLANEOUS	8.0	11.5	9.8	0.741
Others	8.0	9.6	8.8	1.000
Cannot say	0.0	1.9	1.0	1.000

*Fisher's exact test for female-male comparisons. Grouped categories computed from responses and indicated in bold type. Categories reported by less than 5% respondents were omitted from table but retained in grouped values. Higher prominence of reported values is in bold and italic.

frequently reported (Table 15). While the individual indicators considered, it was found that women more commonly than men mentioned about contamination and contact (20% vs. 10%), prior illness (18% vs. none), and food (14% vs. 10%).

In contrast, men more frequently than women identified smoking (35% vs. none) physical exertion or hard work (19% vs. 8%). Women's frequent mentions on contamination and contact, as the most important perceived cause of TB, was often associated with overstated notions of infectiousness.

Help seeking (HS)

Vast majority of females than males (76% vs. 36.5%, $p=0.000$) commonly relied on informal/self-medications in terms of home remedies or self-care or care from family or friends (Table 3, *Paper IV*). The nature of actions included: change in diet, food restrictions, and use of herbals, rubbing garlic mixed warm oils, and so on. Restricted foods include hilsa fish, shrimp, a tiny fish, beef, duck, and pigeon's meat, creeper and lentils. A 16 years old married girl having 7 years of education said, "*I stopped eating hilsa fish, beef and pigeon's meat because of this disease.*" Some females and males used warm leaves of *akun* tree (sun plant), and rubbed warm mustard oil mixed with garlic over their chest, throat, hands and feet. On the other hand, more males compared with females frequently reported about public doctors/facilities, especially urban government hospitals (25% vs. 10%, $p=0.047$). Both female and male patients also used private doctors or facilities, mostly unqualified private doctors (50% vs. 50%).

Narratives revealed that both females and males sought professional help from multiple sources, and they however finally resorted to BHCs after the earlier sources failed to cure them. The following narrative of an 18 years old married girl with 5 years of education is an example of the multiple sources used by TB patients and this applies for both females and males:

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.

First help seeking (FHS)

Private doctors/facilities were the most preferred sources for seeking help by both females and males, with a higher proportion for males (71.2% vs. 52.0%) (Table 4, *Paper IV*). However, within this grouped category, the patients mostly used unqualified doctors (40% females vs. 46% males), which failed to cure the problems. Beliefs and attitudes of patients and decision-makers played a role in choosing the type of healer. A 25 years old married woman having 4 years of education explained, "*People from my family thought that I was caught by an evil spirit. That's why they took me to a spiritual healer.*" Some females disliked allopathic treatment and hesitated for going to a modern healer.

Features of gender-specific mobility, social support and costs for care seeking — Most males came for first help without anybody's suggestion (67%), compared with 12% females ($p=0.000$). (Table 5, *Paper IV*). Only 16% of females, compared with 65% of males, could visit help seeking sources alone ($p=0.000$). However, in some cases, none from husband's side accompanied, as they were scared about the disease, while some were busy with their daily work. A 30 years old illiterate married female said, "*My mother-in-law did everything for me, because my husband was scared about my disease.*"

While the median travel cost (female Tk. 10 vs. male Tk. 0.50) and time (female 30 vs. male 10 minutes) for the first help seeking sources were higher for females than males. The median travel costs to BHCs was much higher for females than males (Tk.31.0 vs. Tk. 10.0), and the median travel time likewise was also much higher for females than males (60 vs. 30 minutes). The median total costs incurred for first help seeking and treatment at BHCs were higher for males than females (males Tk.290 and Tk. 303 vs. females Tk. 200 and Tk. 185, respectively). Consequently, more female patients than males reported that it posed strain on their' families (68% vs. 45% at outside; and 76% vs. 50% at BHC, respectively). A 40 years old illiterate married female said, "*I had to spend money from my savings that created a problem in our family. My husband gave me no money. Presently I cannot work. Thus, we have to sacrifice the other necessities of my life.*" Males' narratives reflected even more distress on costs. A 37 years old illiterate married male explained:

I could not buy necessary goods, for a lack of money. I have food crisis. Now, instead of buying food, I had to spend money for treatment. In fact, my income is supposed to buy food. Therefore, I face problem in running my family.

5 DISCUSSION

5.1 METHODOLOGICAL ISSUES

Data quality

Quality of epidemiological study data can be assessed by validity, reliability and generalisability (Trostle 2005). These conditions, however, depend on the control of a variety of issues. Therefore, the measures taken towards improved data quality were as below.

Rigor of study design — The more ideal rigorous design is longitudinal prospective studies, because other designs (such as cross-sectional) are less efficient to establish causality (Vogt 2005). But the latter studies are cheap, simple and ethically safe (CEBM 2008). Thus, considering the resource constraints, the *Studies I, II and V* of this thesis relied on cross-sectional design, whilst *Studies III and IV* embraced the descriptive qualitative design. Data for the *Studies III and IV* were collected using the EMIC (Explanatory Model Interview Catalogue) interviews, a semi-structured qualitative data collection instrument in the family of cultural epidemiological studies. The design of cultural epidemiological study included a preliminary ethnographic phase that employed the methods of anthropology in order to identify locally relevant variables for the study (Weiss et al. 2006) (details in methodology of *Studies III and IV*). Considering the relative strengths, recently the EMIC has been increasingly applied in studying mental health, epilepsy, TB, and in other chronic diseases (Weiss, 2001; Weiss et al. 2008a; Jadahv et al. 2001; Lee et al. 2001; Somma et al. 2008). The uniqueness of the approach is that it collects both categorical quantitative and narrative data for each item of inquiry from the same respondent, ensuring a self clarity, and complementarities of responses, that ultimately increase the internal validity or credibility; and/or reliability or dependability of data being generated.

Besides, the *Study V* embraced the population-based cross-sectional design. Such design reduces the selection biases compared with facility-based design, because it captures both care seekers and non-seekers for TB in the community. Whereas a health facility-based (here it is BHC) design captures a segment of the patients only who present for health care.

Sampling strategies and sample sizes — Though the sampling strategy often incurs random errors in epidemiological studies, it is usually more cost-effective, accurate and efficient way to understand about a large population than a census of the whole. Scientifically, probability sampling (such as simple random) methods are more efficient to understand efficiently about a large population, but resource constraints led us to employ quasi-probability sampling strategy for *Studies I and V*, and non-probability sampling methods for the *Studies II, III and IV*.

Statistical precision-based sample size was determined for *Studies III, IV and V*. Sample size determination for *Studies I and II* did not follow this. However, adequately large sample sizes for *Studies I, II and V*, as well as moderately adequate for *Studies III and IV* (Weiss et al. 2008) — were the strengths of studies in the thesis. Furthermore, we rigorously pilot tested our outcome measuring variables and data collection methods and tools before actual data

collection. These measures considerably improved reliability and generalisability of the study results.

Selection bias — The strength was that the study subject selection was less liable to the selection bias for the following reasons: (i) all subjects were patients, (ii) patients were drawn using the same inclusion criteria, (iii) TB patients (except the outpatient respiratory patients) were diagnosed with the same diagnostic, i.e., sputum microscopy, and (iv) comparisons were performed between women and men patients, not between the patients and general source population.

Study V used the EPI recommended cluster sampling and interview methods, being widely used for immunisation coverage survey (EPI 2005). The 30-cluster sampling frame was developed in a fashion that each cluster/village should represent approximately over 667 households. For this, smaller villages were merged and larger ones were split to form a cluster. Thus, a list of clusters was framed, and then selected 30 villages from the list using the 30-cluster sampling method. To avert bias in deciding the direction of the individual cluster, and selecting the first household for interviewing in each cluster, we used the bank note's serial numbers as random numbers. For determining the direction within the cluster such as east, west, north and south, we assigned one digit numbers (e.g. 1,2,3 and 4, respectively). Then, the respective interviewer drew a bank note from the pocket, and selected the direction based on the first digit of the bank note serial number. Later, the interviewer drew another note and based on the first digit (say, 5), s/he moved to the direction selected before, and reached 5th household by counting the existing households consecutively for starting the first household interview in the cluster. This was followed by the nearest household interview, the process continued until 667 households were reached. We used this method to identify the persons with at least 3 weeks of persistent cough from the households in the clusters. We maintained randomness in selecting the direction of interview from the central point of the cluster as well as in selecting the first household for starting the first interview. However, a recent comparative study between the compact segment sampling and EPI cluster sampling scheme concludes that in situations where quality of fieldwork can be guaranteed, the EPI random walk method can give accurate and precise results (Paul et al. 2004).

Response rates or nonparticipation bias — *Study I* was programme registry data review-based study, therefore less liable to nonparticipation bias. In other studies almost all participants fully participated in the interviews, except in *Study II*, where we had to replenish 15 patients (1.5%) due to their refusal to participate in the study (5 women and 10 men). Severe physical weakness might deter them from participation in interview. However, participants' interest, less sensitive study variables, our organisational credibility and interviewers' skills had significantly contributed to register high response rates.

Recall bias (Studies II-V) — The validity of recall assessments depend partly on how much time has elapsed since the event (Trostle 2005). The US National Health Interview Survey researchers found that the chronic symptoms last over 90 days in the memory of the respondents (cited by Trostle 2005). In our studies, the major variables of interest encompassed illness experiences, meanings, and behaviours, which were less prone to memory lapses. But variables with a long duration, e.g. date/s of symptom onset, first care seeking

outside home, and so on, may be liable to recall bias affecting the degree of accuracy. But the following measures significantly helped to overcome the recall bias.

The interviewers were university graduates, experienced and we gave them extensive practical training. To obtain more accurate data on dates/days related variables such as delays, the interviewers proceeded by carefully asking a group of questions to each respondent included: (a) what were their problems for which they went for sputum smearing, (b) when this problem first started (local days/months, etc. was used), (c) what happened then to them? (d) Before visiting BHCs, where did they first go for help outside home, when, and why? During probing especially on the first onset of the problem, first help seeking outside home before coming to BHCs, the interviewers used local/regional, family and individual level memorable vital events occurred locally in the recent past such as religious/cultural festivals, marriage, death, flood, and cyclone. This process enabled the study participants (patients) to recall the approximate duration between the events and occurrence of their problems. Thus, the field researchers collected data on all the date-related variables in days. The days/dates on onset and first help seeking outside home were crosschecked with spouses and in-laws for deriving maximum accuracy, whilst the others were with the programme records. In this process, the dates of problem onset and prior help seeking (before visiting BHCs) were estimated, and the relative accuracy was ensured.

Population screening for TB suspect identification (*Study V*) — The WHO and IUATLD recommended strategy for DOTS that defines a person with a persistent cough for at least 3 weeks is a TB suspect (Toman 1979). Therefore, his/her sputum should be tested for AFB using the Ziehl-Neelsen technique with direct microscopy. Thus, prolonged cough of a person has been a prime symptom for TB suspicion, and his/her sputum microscopy has been a key diagnostic means for the smear-positive pulmonary TB. Studies in various settings report that cough is not openly recognised as possible TB until accompanied by more serious symptoms such as weakness, breathlessness, weight loss, chest pain and loss of appetite (Jaramillo 1998; Liefoghe et al. 1997). TB symptoms are often viewed as consequences of flu-like conditions (Liefoghe et al. 1997), which is believed to be self-limited after a few days of onset. Such beliefs give a reluctant feeling for care seeking for diagnosis, resulting in likely low case finding in women. Gender-specific beliefs and behaviours associated with perceived causes of TB, including smoking for men, and perceived causes related to food and water for women (Weiss et al. 2008a) also stimulate to ignore the symptoms, resulting in low case finding especially in women.

Although all the patients seeking sputum test services, were given instructions by the health workers on how to produce effective sputum for smearing, the proportion of females facing difficulties in producing effective sputum exceeds the proportion of the males (70% vs. 15%, $p=.000$) (Karim et al. 2007, unpublished). Pervasive stigma in association with the above factors may motivate the potential TB suspects to hide the symptoms, resulting in delay or missed cases. This also might have occurred in our study. To minimize such probability, we extensively trained up the interviewers, constantly supervised, and even monitored their daily activities by independent monitors. The detected suspects were given instructions on how to produce effective sputum, especially for overnight sample, and took an on-the-spot sample supervised apart from the overnight one. The difference between females and males in the

prevalence of chronic cough (1.7 vs. 4.8%) indicates a likely underreporting of female TB suspects. But at least one sputum sample was given for testing by equal number of females and males (97 vs. 96%).

Use of male interviewers might have caused females' underreporting of cough, but as noted earlier, the findings showed rare dropouts of females from giving sputum samples. Though both female and male interviewers were equally acceptable for discoursing the issues, during the pilot test, the former were found to be less enthusiastic to carry out interviews with the potential TB suspects, leading to involve the male interviewers and the community extended significant cooperation to the interviewers. Moreover, our smear-positive TB prevalence rate is comparable with other similar studies (Salim et al. 2004; Begum et al. 2001; Balasubramanian et al. 2004), indicating that use of male interviewers barely influenced female case detection, and the findings were most likely reliable.

Wealth index construction — In *Study V*, we also collected household wealth-related data for the principal component analysis for constructing an wealth index (Henry et al. 2003). The variables addressed were measurable and physically verifiable, for instance, number of houses, size of homestead, number of cow/buffalos, etc. (Annex 1, *Paper V*). The interviewers cross-checked the reported data with competent in-laws, and physically verified the responses in possible cases to derive complete data.

Wealth index being constructed from several economic variables using the principal component analysis (PCA) method is currently most used technique to determine the economic status quo of households in LICs (Henry et al. 2003). However, the choice of asset items may affect the categorisation of households and their poverty status (who is poor or who is rich) varies with the asset items included in the index. We constructed a wealth index using 19 different indicators for the households with smear-positive PTB cases, and non-TB cases (Annex 1, *Study V*). For obvious reasons, three issues were considered in the selection of indicators for wealth index viz. (a) the indicators were reflective of wealth status, (b) the information on DOTS patients were available in our survey, and (c) the indicators were less sensitive to the instrument design. Different combinations of such indicators were used in trails of principal component analysis. Finally, we used 8 indicators to form the index with the selected households.

One principal component was extracted and by the signs of the factor loadings, it was inferred that the component would the wealth status of the households. Factor loadings show the strength of association between the indicators and the wealth status and usually a value of at least 0.30 is considered adequate (Henry et al 2003). Overall KMO (Kaiser-Meyer-Olkin) sample adequacy was highly acceptable at 0.92. Finally, the value of index for each household was estimated using regression coefficients reported in the last column of, Annex 1 in *Paper V*. Using these same coefficients, wealth scores were estimated for the households in our survey of patients.

These scores gave a relative picture of poverty/wealth status. To demonstrate the relative poverty concentration of the households with TB patients, the non-TB patient households were ranked into quintiles by their wealth scores. The same cut-off marks from their wealth quintiles

were used to have the distribution of the TB patients' households. Clearly these households were concentrated in the lower quintiles and only 9% of them belonged to the richest quintile. However, our data demonstrated insignificant difference in PTB prevalence between the wealth quintiles except the 4th quintile. Thus, concern remains about the sensitivity or adequacy of the indicators used in wealth index construction. Poverty classification may be liable to impreciseness affecting the results. Or, this is the true picture given the Bangladesh context.

Comparison between previously published study results and this study results (*Study I*)

— A comparison was carried out between some selective comparable indicators of this study and two previously published independent study results. For this, Begum et al. study data (2001), which also analysed the BRAC programme data of 1997 adopting the same method we used, were used as the benchmark year vis-à-vis our study as the impact year, to reveal changes in FMR at various steps of clinical process for TB diagnosis and treatment. Similarly, Chowdhury et al. study results (1997) (the phase-three data of BRAC programme in 1995) were used as the base year results to compare the relative changes occurred in treatment outcomes only. But these results lacked in sex-segregated analysis. The indicators of the published results that were compared with our study results were thus comparable. Since the Chowdhury et al. study results were deficient in sexwise treatment outcomes, we also restricted us to a general comparison instead of sexwise comparison. Therefore, comparison of our study results with these published results have had strengths, since data came from the same registries of BRAC programme at different points in time, and were analysed using the same approaches.

Improved validity and the inferential statistical issues

Improved validity depends on the degree to which researchers have had control on selection bias, information bias, and confounding. By carefully selecting and applying different inferential statistical analyses, substantial improvements in the data validity can be achieved. To this end, we performed multivariate analyses such as multiple linear regression (*Study II*), multiple logistic and linear regressions (*Study III*) and probit analysis (*Study V*). Regression model fitting requires a careful thought, and precise statistical knowledge and idea about the dataset, and hypothesis. Otherwise, expected outcome may be ambiguous. We confronted such problem in using multiple regressions that resulted in some ambiguities about the utility of the 'model fit.'

Multiple linear regression in *Study II* — In the *Study II* (paper published), the bivariate analyses revealed statistically significant differences among females and males in certain delay categories despite a very small cell frequencies (Table 1, *Paper II*). Though this could be attributed to a large sample size in the study, for a greater certainty, and to identify the delay predictors we applied multiple linear regression analysis. The independent variables were age, sex, and residence of patients; and dependent variables included six categories of delays (operational definitions are in the method section of *Study II*), each with continuous values. Likewise the bivariate analysis, the multiple linear regression on the log transformed data produced significant association between several dependent and independent variables, but the R-sq value (explanatory power) were very small (Table 2, *Paper II*). However, after receiving

feedback from the evaluators, we did some exercises to improve the extent of R-sq. Initially, we added a new dummy variable namely ‘subdistrict’ available in the dataset, and ran the multiple linear regressions to determine the improvement in the R-sq. value, but a slight improvement was seen. For logistic regressions, later we dichotomised the different delays following the strategies adopted by other researchers for delay analysis (Wandwalo et al. 2000; Ngamvithayapong et al. 2001; Gosoni et al. 2008). The multiple logistic regression models without the new dummy variable, did not improve the situation. While added the dummy variable in the multiple logistic model, a slight improvement was observed but it varied across the delay categories (Table 16). However, we learned the following lessons from this multivariate analysis:

There were potential design error, specifically inclusion of few background variables, and too many categorisation of delay variable. We could classify the delays into two broad categories viz., patient’s delay and total treatment delay, as done by many researchers to fit with the multiple logistic regression models (Wandwalo et al. 2000; Ngamvithayapong et al. 2001; Gosoni et al. 2008); and since the samples were conveniently selected and were of non-random, the delay variables did not follow the normal distribution, and correlation coefficients (r) between different delay categories and independent variables were extremely low, hence the multiple linear regressions did not fit fully.

Table 16. Comparison of R-sq. values obtained by using multiple linear and logistic regressions for delay analysis in TB treatment

Regression type	Independent variables	Dependent variables (6 categories of delays) and R-sq.* values					
		TD	TDD	DD	PTD	Td	HSD
Multiple linear (original in <i>Paper II</i>)	Age, sex, residence, female sex interaction	0.002	0.002	0.00	0.001	0.001	0.00
Multiple linear with a new variable added	Subdistrict	0.059	0.065	0.020	0.072	0.041	0.021
Logistic without new dummy variable	Age, sex, residence, female sex interaction	0.017	0.006	0.004	0.002	0.00	0.001
Logistic with new dummy variable	Subdistrict	0.071	0.039	0.033	0.016	0.018	0.016

TD=Total delay, TDD=Total diagnostic delay, DD=Doctor’s delay, PTD=Patient’s delay, Td=Treatment delay, and HSD=Health system delay.
* For Logistic regression Cox & Snell R sq.

Multiple logistic regression analysis in Study III — A question aroused as to why the female sex was not associated with as many variables as in the bivariate analysis, i.e., the bivariate analysis indicated stigma among women in more variables compared to men, but in the multiple logistic regression, female sex was significantly associated with a fewer background variables. This might happen due to small and nonprobabilistic sample size.

Generalisability of quantitative findings of all the five studies

The main focus especially of *Studies I and II* was to examine the magnitude of gender disparities in various steps of the clinical pathway for TB management, delay, and socio-economic divides in the prevalence of smear-positive PTB at community level (*Study V*). Though the samples were quasi-probability for the *Studies I and V*, and non-probability for the *Studies II, III and IV*, the sample sizes were adequate for gender comparisons within and between the study areas. The sample selection was aimed at to represent the patient populations of BRAC TB control programme, which is considered to be one of the well-

functioning community-based DOTS programmes. The local clinics serve not only a segment of society, but also the subset of people with TB reaching these clinics for treatment. Most quantitative findings are generalisable not only for the patient populations, but for the source populations and some may have even broader relevance. Many of the findings are consistent with national and international studies (Begum et al. 2001; Salim et al. 2004; Borgdorff et al. 2000; Balasubramanian et al. 2004; Long et al. 1999; Wandwalo et al. 2000; Gosoni et al. 2008), indicating a strength for a greater generalisation. In spite of considerable strengths of the studies and their findings, one should be careful in drawing generalised conclusions.

Trustworthiness of qualitative findings (*Studies III and IV*)

These qualitative studies were carried out using the cultural epidemiological approaches. Design of data collection methods and instruments in cultural epidemiological studies are consistent to the pragmatist view of research, in which researchers mix different data collection methods within one study to address one research question (Dahlgren et al. 2004), for a greater trustworthiness. The semi-structured EMIC interview tools were developed based on prior ethnographic study (Weiss et al. 2008a), which underwent an extensive pilot test for assessing respondents' understandability, acceptability, suitability, and analysability of responses came in categories, and narrative accounts, before finalisation for data collection. Besides, a unique strength of cultural epidemiological study is that a research subject is allowed to first express his/her opinion quantitatively, which are coded in categories, and each quantitative question is followed by a question seeking qualitative narrative accounts to clarify or elaborate the answer given to quantitative exploration of specific item. Thus, the same respondent qualifies his/her responses that are likely to provide a greater credibility or reliability of the findings. However, several criteria are available in the literatures to judge the trustworthiness or reliability of both qualitative and quantitative domains of research (Dahlgren et al. 2004; Graneheim et al 2004; The National Science Foundation 2002; Rothman et al. 1998). Though these criteria are known in different names within the two traditions, they capture similar issues. We attempted to assess the trustworthiness of our qualitative findings using reflexivity (Grethe 2007), and three most common criteria for both traditions included credibility (or validity in quantitative study), dependability (or reliability in quantitative study), and transferability (or generalisability in quantitative study) (Graneheim et al. 2004).

Reflexivity

It is defined as to how knowledge is generated by the researcher and how this is accounted for in the research process. In qualitative research, the researcher gets involved, collects data using his/her skills, creativity and empathy. Thus, the researcher immerses as "the instrument," which tends to be liable to biases, and these may cause problems if the researcher is insensible to them. Given this, the researcher should clarify his/her position and critically reflect on it, rather than striving for objectivity and neutrality (Grethe 2007).

Being outsiders to the research participants and their communities, we wrote memos and field note together with personal reflections, feelings and interpretations of what we experienced during the whole fieldwork. Initially, we introduced ourselves as learners, and tried to remain so throughout the study, though periodic review of our personal diaries and field notes

indicated a change in our knowledge and perceptions over time. Our all initial positive and/or negative viewpoints and thoughts progressively transformed into analytical reflections and contextual considerations. More specifically, we started to “sympathise” with all the stakeholders, in particular with the study subjects and their communities. These steps usefully enhanced the discovery of the realities and truths that the study was intended to explore, and these were well reflected in *Papers III and IV*. Besides, our interdisciplinary background and gender did not pose any inconveniences during working with the subjects and other stakeholders throughout the study cycle, rather helped strengthened our rapport with the subjects.

Credibility — Credibility refers to researchers’ ability to really capture the multiple realities of those they study (Dahlgren et al. 2004), and processes of analysis address the intended focus. Different factors as noted below, can enhance credibility (Graneheim et al. 2004)

Participant selection — Choosing participants with diverse experiences increases the probability of inquiring the reality of interest from different dimensions (Dahlgren et al. 2004). Selection of women and men patients of varied ages, and involvement of local women and men interviewers with various experiences and perspectives, contributed to richer variations of the phenomena under the studies. To judge the similarities within and differences between categories of responses given by the respondents, we showed representative quotations from the narratives of the respondents.

Prolonged engagement — As researchers we spent a longer time in the study field, which provided a greater likelihood of grasping the reality of the study populations. We built a functional rapport with the community and study subjects through frequent interactions. Thus, we acquired effective familiarity, competence in local culture and trust. To avoid “going native” we maintained personal notes, and carried out peer debriefing (Dahlgren et al. 2004).

Triangulation — Is another strategy for enhancing credibility, which can be performed in different ways, viz., triangulation between two or more data sources, data collection methods, research methods, and investigators. We followed the investigators’ triangulation method in our study, which refers to the use of more than one investigators (Grethe 2007). Since our study was a part of a broader multi-country study commissioned by TDR of UNDP/UNICEF/World Bank/WHO, it had both local and international investigators. At the local level, we had several interdisciplinary investigators. We convened regular meetings in field locations to discuss about data consistency and completeness, and problems and their possible solutions towards greater credibility.

Peer debriefing — Peer debriefing were held at various levels. We presented our preliminary findings to the local scientists and programme managers and received their feedback. The pilot testing data on 8 full EMIC interviews were quickly analysed and shared with some respondents and their caregivers for clarifications, and confirmations. This contributed significantly to revise, improve and finalise the instruments and data collection techniques to suit with the local context.

In analysis phase, we also shared the preliminary findings derived from initial analysis, in an international workshop held at the Swiss Tropical Institute, Basel, wherein scientists from the

study countries and WHO Head Quarters attended. These sharing helped us to seek agreement among the co-researchers and experts, which helped to increase the credibility.

Finally, we organised several finding sharing sessions at grassroots, ensuring participation of both women and men TB patients, community health workers and clinic personnel for confirmation of the results. During finalising the reports, we incorporated most feedback received from those sharing meetings.

Dependability — The epistemological stand is that researchers and participants are inseparable, affecting each other. Therefore, when data are extensive and the collection extends over time, there is a risk of inconsistency. Such potential risks were minimised by providing extensive training to the interviewers and holding daily ‘action-reflection’ sessions after the day’s fieldwork, and by asking the same questions to all the participants. Besides, senior researchers routinely checked the process of the research, and the mechanisms for record maintenance at different layers.

Transferability — Transferability refers to how applicable are findings from a qualitative inquiry to other contexts or the source populations. As qualitative researches work with few samples to understand the realities in-depth, and hence statistically non-representative, and is difficult to transfer the conclusions to the source populations or to other settings or contexts. Our studies were aimed at to examine socio-cultural and gender-related features of TB at designated clinics in 10 subdistricts with about 3.3 million populations in rural Bangladesh. Although the samples were selected using non-probability sampling methods, the size was adequate for gender comparisons. These were selected to represent the patient populations, but they were not expected to represent TB patients for the entire country or even the source community populations. The local subdistrict TB clinics serve a segment of community, and also the subset of people with TB who reach these clinics for treatment. Thus, the qualitative findings are clearly relevant for the patient populations of these clinics, and they may also have broader relevance (Weiss et al. 2008a). To facilitate the transferability, we attempted a vigorous presentation of findings with description of context, study design including selection and major characteristics of participants together with suitable quotations. This will allow the readers to look for alternative interpretations, thus readers will decide about the transferability of the findings. However, the study clarifies programme related social and cultural dimensions of gender, and it also indicates an approach that may be conveniently adapted for other programmes.

5.2 MAIN FINDINGS

The following sections briefly discuss the salient findings with reference to gender.

Gender-specific features of smear-positive PTB prevalence in the community (*Paper V*)

Our active case finding approach reveals a lower ‘true’ period prevalence of smear-positive PTB in women than in men (Table 1, *Paper V*), which is consistent with other studies (DGHS 1989; Salim et al. 2004; Balasubramanian et al. 2004), but contradicts with those active case finding study results in Vietnam and Nepal (Thorson et al. 2004; Thorson 2003). The WHO standardised TB surveillance data based on passive case finding or self-reporting systems also show a consistently higher case notification in men than in women (Ottmani et al. 2008). Studies in different settings have shown that progression of TB infection to disease is likely to be faster for women, compared with men in their reproductive years and faster for men after 40 years of age (Holmes et al. 1998). Despite this, the prevalence was lower among females. Some attribute this to barriers the women may confront in accessing TB care (Hudelson 1996); others ascribe it to the natural epidemiology of the disease (Balasubramanian et al. 2004; Borgdorff et al. 2000). Besides, in our study, females’ underreporting might have occurred due to use of male interviewers.

TB is more common among younger women and older men (Paper V) — Sex difference in the prevalence density by age groups raises issues for TB control programme. Younger women had more occurrences, while for men; it was more in older age groups (Figure 1, *Paper V*). *Study I* also support this finding. However, studies show that women TB patients are more vulnerable due to social rejections and stigma causing severe psychosocial and mental sufferings. Such vulnerability is likely to be more intense especially for the unmarried younger females, as this period is critical for their marriages, which are socially arranged in most settings. TB may jeopardize their marital prospects, as a boy may refuse to marry a girl with TB even after a cure (Weiss et al. 2006; Somma et al 2008). On the contrary, higher occurrence in men of older age may make the process of cure difficult. In fact, ageing is major risk factor for any disease, and its effects have been attributed to depletion in numerous macrophage functions, which figure prominently in host defense in PTB (Kolappan et al. 2007). Sex and age differentiated programme strategies will thus be needed to address these two groups demonstrating divergent sources of vulnerability.

TB is common among all strata of the society (Paper V)

Smear-positive PTB prevalence was not clearly associated with wealth quintiles, implying that all socio-economic groups are likely at risk of contracting the disease. This disturbing finding contradicts with other studies that conclude TB as a disease of poverty (WHO 2002; Muniyandi et al. 2007), necessitating a thorough study for further confirmation. However, most Bangladeshis regardless of their wealth status quo are constantly exposed to environmental hazards, and adverse consequences of extremely high population density. Because, different social groups are not in isolation; rather co-exist in the same hazardous environment, increasing the likely risks of infection and progression to active TB in either group. Thus, smear-positive PTB is termed as a community disease (WHO 2002), warranting a concerted efforts to fight against.

Increased per capita food expenditures were associated with increased smear-positive PTB prevalence contrary to the expectations of poverty among patients' households. It is likely that the households with TB cases have increased their food consumptions both in volume and quality as an improved dietary support to the patients. This was clearly reflected in our dataset (*Study V*). The households with TB cases spent more significantly on milk, milk products, fruits and lentils, and though insignificant, they also spent more on fish/meat. Such practice is consistent with the dietary advices that vitamin-rich diets improve patients' treatment efficacy and effectiveness (University of Maryland Medical Center, undated). These evidences support the increased expenditures of the TB incident households for quality foods, especially for the patients. A study of people with TB in Indonesia found the zinc together with vitamin A might actually enhance the effects of certain TB drugs (Karyadi et al. 2002).

TB may remain undetected among many in the community (Paper V)

Determinants for being remained undetected (76 cases) by the routine programme were explored by performing regression analysis. Holding the other variables (Table 3, *Paper V*) constant at their means, increase of the age of TB patients by one year increases the probability of remaining undetected by 0.006. Thus, symptomatic search in older people should be enhanced to improve case detection rates. Smoking is one of the major risk factors for TB. It is also likely to influence the case detection among smokers. In our study their chances to remain undetected increased by 0.316. This implies that the smokers ignore their prolonged coughing as an outcome of their smoking but not necessarily of their getting affected by Mycobacterium. Easily accessible health services by distance can promote patients' participation in the control interventions (Karim et al. 2005), and thereby increase TB case detection, diagnosis and treatment among the poor including women, in particular. Higher health vibrancy reduced the chances for remaining undetected of TB cases. But it is unclear as to why a substantial number of cases remained undetected despite presence of health volunteers, one for 200-300 households. This confirms the synergies between the alternative service providers and importance of proper functioning of the entire health systems.

Health care service factors and case detection — No denial that in order to encourage the patients (especially women) for diagnosis and treatment, the health care system must be efficient, accessible and acceptable to the patients. As women patients are less likely to present with precise clinical symptoms such as blood in sputum, the care providers may be less able to identify TB among patients presenting with atypical symptomology (Weiss et al. 2008a). Our prevalence survey (*Paper V*) found that the routine community-based programme missed out 76 cases (female 17 and male 59) out of total 176 (43.2%), is a matter of concern for the DOTS strategy. BRAC TB control programme has unique operational features, for example, (i) community-based services, (ii) all volunteer health workers at the community are females. They are chosen from the community, by the community, and BRAC trains and supervises them, (iii) BRAC maintains a semi-active case finding approach, (iv) unlike the traditional systems, BRAC programmes have sufficient people-oriented flexibility and upholds peoples' choice for the sputum sample submission for testing either to BRAC outreach centres or health centres (BHC), and get back results, and treatment of the smear-positive cases at community level. Given this, the evidences warrant more innovative case finding by involving the community opinion leaders, peers, private and traditional health providers, and youths. In

many settings, the care providers have been shown to share the same wrong beliefs and definitions of TB as the patients. The symptom of back pain would not motivate the doctors to investigate respiratory problems (Jaramillo 1998). Grassroots workers only invite the patients with haemoptysis, cough, weight loss and fever to give sputum samples for testing. Most patients attended some practitioners once they got cough and fever, and received prescriptions for flu or common cold, but not for sputum testing (Jaramillo 1998; Karim et al. 2004; Weiss et al. 2006). Thus, many potential cases may be missed out by the routine programmes.

Local and gender-specific features of awareness of symptoms and occurrence of TB (Paper IV) — As DOTS strategy is solely reliant on self-referral system for TB case finding, effective awareness on signs/symptoms of TB is vital for recognising early symptoms for seeking timely diagnostic care from the appropriate sources. Though both women and men commonly specified various symptomatic characteristics (breathing problem, chest pain, cough, weakness, vomiting, blood with sputum, pain in ribs, and sleeping problem) in our EMIC interviews (*Paper IV*), more women than men identified coughing as the single most troubling symptom (60% vs. 33%). Studies in other settings report that cough is not openly recognised as possible TB until accompanied by more serious symptoms like the above (Jaramillo 1998; Liefoghe et al. 1997). In Kenya for example, the patients' main defining factor for TB was that symptoms were prolonged, therefore making early diagnosis of the disease is impossible (Liefoghe et al. 1997). Women, however, are more likely to associate TB with a wide range of symptoms such as coughing, loss of appetite, weakness, and so on, implying that women are less concerned about the early TB indicative signs/symptoms, rather are confused with other conditions such as asthma, cancer, pneumonia, or common cold. TB symptoms are often viewed as consequences of flu-like conditions (Liefoghe et al. 1997), which is believed to be self-limited after a few days. Such beliefs give a reluctant feeling for care seeking for diagnosis, affecting case finding in women.

Less specific clinical presentations of TB were common in our study women, and they often had fewer characteristic symptoms such as blood in sputum (*Study IV*). Presentations with mixed symptoms such as weakness, loss of appetite, and fever was relatively less likely indicative of TB diagnosis. These evidences indicate that TB symptoms are poorly understood to be useful to self-referral to clinics for proper diagnosis and treatment, and this seems to be a more problem for women. Wang et al. study (2008) reveals that less than one-fifth of the Chinese adults (men 17 and women 15%) understand that the prolonged cough for more than 3 weeks is a symptom for TB suspicion in a person. Such a poor knowledge base is insufficient to increase case detection to 70%. Weiss and colleagues (2008a) note patients' beliefs about causes of TB influence help seeking behaviours. Gender-specific behaviours associated with perceived causes of TB, including smoking for men, and perceived causes related to food and water for women. Such beliefs stimulate to ignore the symptoms, resulting in low case finding in women. Therefore, the locally recognised patterns of TB-related distress should be carefully considered during clinical management of TB and the personnel ought to be trained on it.

Gender-specific features of psychological and emotional distress due to TB (Paper IV)

Widespread psychological-mental distress in terms of sadness and concern for the course of illness overshadowed the physical distress of both women and men patients (94 vs. 96%).

Diverse themes from the patients' narratives emerged such as social discriminations, isolations, fear of death and spoiled for life or socially arranged marital prospects (usual norms in Bangladesh), caused enormous psychological and emotional distress among TB patients, and the features of such suffering are commonly gender-specific (Liefoghe et al. 1995; Long et al. 1999). Patients' narratives on stigma related distress also support these findings (*Paper III*). The WHO estimate shows up to 46% of TB patients suffer from major depression (WHO 2001b; WHO 2003). Several patients' expressed intention for death and suicide represents the intensity of their distress, and the debilitated state of mental health (*Paper IV*). Similar psychological and mental state of TB patients is also reported by Weiss et al. (2008a) cross-sites study. TB-related stigma fuels the mental and emotional sufferings of the patients that dissuade them to take full course of treatment. In fact, mental health has been an integral part of general health embedded in the WHO definition of health, which is especially relevant for TB (WHO 2003). Considering the potential influence of the emotional component of TB-related illness on suffering, help seeking along the path of cure of TB, the control programmes ought to provide training to clinic staff, and improve networks to ensure needful counseling and social support towards effective TB management using DOTS strategy.

Gender-specific economic burden of TB and help seeking

Most TB occurs among the poor in their productive age, so the economic sufferings of TB patients stemming from wage loss, transport and treatment expenses pose strains on individual and family (Weiss et al. 2008a; Muniyandi et al. 2005; Kamolratanakul et al. 1999). Although at BRAC treatment centre, a patient is to deposit initially Tk. 200.0 (current value about 3 US dollars) as bond towards full adherence to treatment (refundable), some patients had to borrow money at interest to pay it. The women patients frequently reported it as problem posing financial strains on their families (*Paper IV*). Interestingly, even though BRAC exempted the extreme poor, some were reluctant to avail the exemption. However, men were more worried about economic impact of TB on their lives (64% vs. 14%) (*Paper IV*). This is because in a typical Bangladesh society, they are considered the breadwinners of a family. Thus, their absence from work erodes income, leading to economic shocks. This particularly affects the women with no access to resources to pay for health care. Social costs such as divorce and removal of children from school to assume the household chores are also high (Saunderson 1995). Croft and Croft studies (1998) in Bangladesh corroborate these findings. The economic consequences of TB thus are considerable shocks for all groups, and may even push the non-poor to poverty, and it can be ever devastating for the poor patients and their households (WHO 2005a).

Women's autonomy-related barriers to care seeking (Paper IV)

Though WHO recognises women's right to health and body as strategic gender needs (WHO 1998), women are less likely to seek professional help for TB, because of 'cultural silence,' relegated social position, paternalistic attitudes of men, lack of information, and decision-making power, time, and financial constraints. Our study investigated a few proxy indicators relative to patients' autonomy, which indicated women's less autonomy in outside help seeking. Thus, most women patients tried home remedies, and self care initially without proper impact elapsing substantial time, resulting in delay in appropriate care seeking (*Paper IV*).

This reflects their powerlessness to choose effective treatment sources from the onset of the problem. In our patriarchal society women have a little freedom for decision-making on their health issues, and their mobility is restricted even for care seeking. Our findings reinforce this situation that a few women patients (12%), compared with men (67%) could go for first help on their own decision, implying that women are less likely to make decision on their own health issues. Patriarchal and hierarchical power relations determine whether a woman will seek outside help. About 88% women needed prior family permission for going outside for care seeking. Besides, 84% women went for outside help with escort. Because, the family does not only prohibit a woman's solitary mobility, passers by or neighbors often may tease her, while moving around without escort. Women's solitary movement is prohibitive given the socially constructed gender norms and seclusion, and extra cost for escort is unaffordable for many, and the family often does not like to bear such costs, posing avoidable barriers to women's appropriate health care seeking.

Gender-specific TB-related stigma and its effects (*Paper III*)

The *Study III* found that adverse effects of stigma both reflect and exacerbate gender inequities. EMIC interview data revealed a widespread TB-related stigma among the patients, and women were more vulnerable to the adverse consequences of widespread stigma. Their narrative accounts indicated that fear of spoiled marital life or prospects for marriage made it difficult to go for diagnosis or accepting a diagnosis; thus compelled to hide or deny a TB diagnosis. Other studies corroborate these findings (Weiss et al. 2006; Liefoghe et al. 1995). Exaggerated fears of risk and spread despite effective treatment as characteristic feature of TB-related social disqualification, which may also prevent from taking a diagnosis (Weiss et al. 2006), compelling for seeking care from ineffective private practitioners in fear of being identified in public clinic (Johansson et al. 2000). Women often feared that because of TB, the ongoing marriage of a woman might break, or husband taking a second wife, or being sent the wife to her natal home (Weiss et al. 2006; Munro et al. 2007; Somma et al. 2008).

Massive fear of infectiousness of TB even after weeks of treatment persisted. This and other misconceptions also stigmatise the patients (*Papers III and IV*). Such misconceptions are also reported from other settings. For instance, in South Africa, red urine, a side-effect of TB medication was interpreted as harmful to the partner, causing abstinence from sex and thus familial disharmony and consequently potential non-adherence to treatment may occur (Munro et al. 2007). Somma et al. study (2008) shows social exclusion contributes to emotional sufferings and financial hardships. These constitute a hidden burden that persists after bacteriological cure (WHO 2001b). Overall, these barriers may deter women from reporting symptoms or take diagnostic tests, resulting in lower case detection. This study data on stigma (*Study III*) may be unable to differentiate problem of stigma from critical social responses that promote responsible behaviour, warranting a further study to critically measure the interrelationships of stigma with health policy option, ethics and outcomes.

Gender-specific features of delays (*Paper II*)

Both women and men delay in care seeking, and the elderly women delay more. In our study, female sex was significantly associated with total delay, total diagnostic delay, and patient's

delay, i.e. for being females; these patients had longer delays in these variables. It is likely that gender issues coupled with different socio-economic factors contribute to delays in care seeking. For instance, apprehension of losing a job often discourages the working men from care seeking, resulting in delayed diagnosis and treatment and/or high dropout or default rates (WHO 2005a). Women often have less access to general health care than men, and they may face limitations in their travel and financial resources (*Paper IV*), causing delay in care seeking. Where they undertake multiple roles in reproduction, production and child care, they may be left with less time to reach a diagnostic and treatment service than men. Often a woman needs to adjust household chores for going outside care, which requires time, resulting in delay.

A wide body of studies was carried out on delays for diagnosis and treatment with varied definition and categorisation. Most of these have shown that women than men had a longer delay in care seeking, and also the care providers' longer delay to respond to women's needs (Ngamvitathayapong et al. 2001; Ward et al. 2001; Long et al. 1999). Multivariate analysis (Gosoni et al. 2008) for cross-sites have found association of delay with female sex in Bangladesh, India, and Malawi. Traditional medical concepts (Bangladesh) and use of indigenous traditional healers (India) were associated with a delay for ≥ 90 days. This suggests that patterns of help seeking and the nature of referral from healers representing traditional orientations that are alternatives to allopathic medicine are problematic for timely diagnosis. The relevance of particular patterns of distress with respect to non-specific compared to TB-specific symptoms was also considerable. More women reported chest pain as a distress, and it was positively associated with a greater delay (≥ 90 days). But it did not immediately suggest TB in motivating care seeking or clinical evaluation (Gosoni et al. 2008).

Fewer females represented at different clinical steps for TB management (*Paper I*)

F/M ratio was consistently less than 1 in different clinical steps for TB management, raising a concern for DOTS strategy (Table 1, *Paper I*). The findings indicate that an epidemiology of TB complicated by gender roles determines sex differentials in case detection and health behaviour and access to proper care. Our *Study V* which was based active case finding also indicates less incidence of TB among females. Use of male interviewers may contribute to underreporting of females' cough in that study. Weiss et al. (2006) study reports a higher F/M ratio of TB suspects in Colombia (2.26) compared with other countries, indicating TB epidemiology may differ from context to context. TB-related stigma, fear of being identified as TB patients, loss of esteem, restricted mobility and a lack of access to resources may refrain females to seek care for TB symptoms and sputum test (Somma et al. 2008; Weiss et al. 2006). Our *Studies III and IV* also support these evidences. The providers also may be less doubtful about TB incidence among females respiratory patients because of gender bias or differential symptomatology (Weiss et al. 2008a). The issue warrants further research for identifying the determinants of females' lower representations in TB control programme.

6 CONCLUSIONS AND RECOMMENDATIONS

6.1 CONCLUSIONS

The estimated ‘true’ period prevalence of smear-positive PTB in the study populations was 122/100,000 adults. Unlike males, increased age revealed decreased occurrence in females, indicating age as a risk factor for TB. This dataset, though, showed an imprecise association between smear-positive PTB prevalence and wealth quintiles, but increased per capita space of dwelling house by square feet, use of tubewell water for all purposes, and proximity to health facilities reduced the prevalence. Older age and smoking habit increased the probability for remaining undetected.

Females disproportionately represented at different clinical steps for TB management, and thus the F/M ratio was consistently less than 1 at four clinical steps of study. Further study is imperative to find out the reasons responsible for such differences.

Female sex was associated with longer total delay, total diagnostic delay and patient’s delay. Older women and young men were less likely to be diagnosed with TB through the existing TB control interventions. TB control programmes must consider particularly, the special circumstances of elderly women and young men to maximise their access to services.

The EMIC interview data identified enormous gender-based vulnerability of patients’ to TB-related stigma. The adverse effects of stigma both reflect and exacerbate gender inequalities, posing a challenge for a gender-sensitive DOTS strategy for TB control. Although this study indicates crosscutting and gender specific features of TB in rural Bangladesh, further research also needs to clarify the impact of stigma on help seeking and treatment adherence.

Though both women and men were burdened by the somatic symptoms of TB, women were most troubled by cough. Fears and worries were recurring themes of patients’ narratives; they often feared isolations and death leaving their children orphans. Patients’ psychological and mental distress often overshadowed physical symptoms; as a result of this, a few patients expressed to commit suicide. Men’s concern for financial distress was considerable, as being breadwinners; their inability to work for income due to TB reduces income. Women’s heavy reliance on self-help, home and traditional remedies is a hindrance to effective DOTS strategy, necessitating proper measures to prevent such practices.

Along with the different socio-cultural realities of patients in TB-related illness experiences, meanings and behaviours including stigma, the studies identified gender-based vulnerabilities, cross-cutting culture-specific features of TB that influence the burden of the disease and are likely to affect timely help seeking and adherence to treatment. Cultural epidemiological techniques together with complementary methods are useful in measuring the scale of gender differences, and in eliciting insiders’ views about the role of gender vis-à-vis gender barriers to TB control programmes.

6.2 RECOMMENDATIONS

1. Developed/strengthened and implemented health education package

- 1.1 Interactive and effective social communication-based health education covering all aspects of TB particularly women's health and their TB-related vulnerability vis-à-vis their special needs and circumstances ought to be designed and implemented using different media such as interactive popular theatre and folk songs, and mass media, to improve people's critical knowledge, attitude and practices in TB as a community disease, and to mitigate delays and stigma. The health providers should also be trained on these critical issues including gender sensitivity and stigma (*Papers II, III and IV*).
- 1.2 The community-based interventions should address the issues of women's concerns about decision-making, provision of attendant (escort) while visiting clinic, transport, financial issues and delegation of household responsibility to seek care (*Paper IV*).

2. Health system strengthened

- 2.1 The existing outreach smear centres should be strengthened, the density of such centre can be increased, or mobile centre can be introduced for each village to enhance women's accessibility toward accelerated case finding among them (*Papers I and V*).
- 2.2 A female attending for seeking care for children and/or for her reproductive problem should be checked for symptomatic TB, if needed, her sputum sample should be tested (*Papers I and V*).

3. Involvement of private health sector

- 3.1 A sustainable network with the traditional healers, cured TB patients, their family members, in-laws and private sector should be developed and sensitised on gender issues so that they can refer symptomatic cases to the professional caregivers. Routine coordination meeting may be useful to uphold their motivation (*Papers I and V*).
- 3.2 BRAC may open up its lab facilities for private doctors for sputum test and thereby increase case finding and treatment (*Papers I and V*).
- 3.3 Gender-sensitive training should be arranged for private doctors, traditional healers, clinics, and hospitals so that they can identify TB suspects and refer to DOTS facilities (*Papers I and V*).

4. Financial issues

Treatment is free, but the "not free" issue of patients should also be considered. For example, loss of income, travel cost, and loss of productive time may impose a high financial burden especially on the poorer groups. Besides, financial concern of the poor females raised a question on depositing Tk. 200.0 (refundable) as a bond towards adherence to full treatment. This may be important for treatment adherence. But alternatives may be explored; for example, TB patients undergoing treatment may be given micro-finance support in feasible schemes that s/he considers convenient to carry out in course of treatment. Payback by instalment should also be gender-friendly (*Paper IV*).

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9 ANNEXURE

Table 6a. Case definition by site and bacteriological status in adults

Case classification	Definition
Pulmonary TB, smear-positive (PTB+)	A patient with at least 2 sputum specimens positive (+ve) for Acid Fast Bacilli (AFB); or a patient with only one sputum specimen +ve for AFB, and chest radiological abnormalities consistent with active TB; or a patient with only one sputum specimen +ve for AFB and a culture +ve for Mycobacterium TB.
Pulmonary TB, smear-negative (PTB-)	A patient with TB suggestive symptoms including 3 sputum specimens negative (-ve) for AFB, and persisting symptoms after a course of antibiotics, and chest x-ray abnormalities consistent with active TB and a decision by a medical officer.
Extra-pulmonary TB (EPTB)	A patient with TB of organs other than the lungs as confirmed by a qualified physician.

Table 6b. Case definition by previous treatment

Case classification	Definition
New case	A patient who has never received anti-TB drugs or received anti-TB drugs for less than one month.
Relapse	A patient who previously received treatment and was cured or treatment completed.
Extra-pulmonary TB (EPTB)	A patient with TB of organs other than the lungs as confirmed by a qualified physician.
Treatment failure	A patient who, while on treatment, remained smear +ve or became smear +ve again at 5 months or more after the start of treatment; or a patient who was initially smear -ve and was found to be smear +ve at the end of the 2 nd month of treatment.
Return after default	A patient who completed at least one month of treatment and returned after at least 2 months interruption of treatment.
Transfer-in	A patient registered for treatment in an administrative area, who is transferred to another administrative area, where s/he continues treatment.
Chronic	A patient who remained smear +ve after completing a directly observed re-treatment regimen.

Table 7. Treatment regimens for each diagnostic category

TB diagnostic category	TB patients	TB treatment regimens	
		Initial/intensive phase (Daily)	Continuation phase (3 times weekly)
I	New smear-positive patients; New smear-negative PTB with extensive parenchymal involvement, concomitant HIV/AIDS or severe forms of EPTB, e.g. meningeal, miliary, pericardial, peritoneal, massive unilateral/bilateral pleural effusion, spinal, intestinal, genitourinary and multi-organ TB	2(HRZE)	4(HR) ₃
II	Previously treated >1 month sputum smear-positive PTB: -relapse; -treatment after interruption/default; -treatment failure.	2HRZE)S/1 (HRZE)	5(HR) ₃ E ₃
III	N New smear-negative PTB (other than in Cat I); Less severe forms of EPTB, e.g. lymph node, pleural effusion (unilateral), bone (excluding spine), peripheral joint, skin TB	2(HRZ)	4(HR) ₃

Notes:(1) E=Ethambutol, H=Isoniazid, R=Rifampicin, S=Streptomycin, Z=Pyrazinamide

(2) An EPTB patient who, after a full course of Cat. I/Cat. III treatment shows clinicopathological findings consistent with recurrent active disease should be treated with Cat. II regimen and be recorded and reported under “others.”

Dosages of fixed dose combination (FDC) drugs

Below are the dosages of the FDC tablets:

- 4FDC: rifampicin 150 mg + isoniazid 75 mg + pyrazinamide 400 mg +ethambutolm 275 mg
- 3FDC: rifampicin 150 mg + isoniazid 75 mg + pyrazinamide 400 mg
- 2FDC: rifampicin 150 mg + isoniazid 75 mg

Table 8. The dosages of FDC tablets for adults

Cat. I

Pre-treatment weight (kgs)	Intensive phase (Daily during 1 st 2 months)	Continuation phase (Thrice weekly for the next 4 months)
	No. of 4FDC tablets	No. of 2FDC tablets
30-37	2	2
38-54	3	3
55-70	4	4
>70	5	5

Cat. II

	Daily during 1 st 3 months	Daily during 1 st 2 months	Thrice weekly (next 5 months)	
	No. of 4FDC tablets	Inj. Streptomycin	No. of 2FDC tablets	Ethambutol 400 mg
30-37	2	500 mg		
38-54	3	750 mg		
55-70	4	1 gm*		
>70	5	1 gm*		

* Not exceeding 750 mg daily after the age of 50 years.

Cat. III

Pre-treatment weight (kgs)	Intensive phase (Daily during 1 st 2 months)	Continuation phase (Thrice weekly for the next 4 months)
	No. of 3FDC tablets	No. of 2FDC tablets
30-37	2	2
38-54	3	3
55-70	4	4
>70	5	5

Definition of treatment outcome

Cured: A smear +ve patient completing the full course of treatment (6 or 8 months' duration), and the sputum smears are negative on at least 2 occasions, one of which is at the end of treatment.

Treatment complete: In the case difficulties in obtaining sputum of a patient, at the end of completing the entire treatment are declared as 'treatment completed.'

Died: A patient died of any cause during the course of treatment.

Failure: The smears are still +ve or have become +ve again at 5th or more months after starting the treatment, or are +ve at the 2nd month in a previously smear -ve patient.

Defaulter: A patient did not attend for treatment during 2 consecutive months or more.

Transfer-out: A patient was transferred to another administrative area from the area of treatment initiation.