

Understanding TB-related stigma in Asia

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Executive Summary

Stigma is thought by many to be a major barrier to effective TB control in many countries. While we know that TB-related stigma exists, we know little about the forms it takes, why it exists or what can be done about it. Studies in Bangladesh, Nepal and Pakistan were carried out to deepen our understanding of TB-related stigma and to develop improved theories to explain its causes. The intention was to inform development of strategies to reduce TB-related stigma.

In Bangladesh, qualitative interviews were carried out with TB patients and health workers in a rural site. The effects of stigma associated with TB in the study area in Bangladesh, their explanation, and their policy implications are summarised in the following table.

Effect of stigma, and explanation	Potential policy implications
Concealment of a diagnosis of TB, because of anticipated negative consequences.	Consider ways to protect patients' (and particularly women patients') confidentiality.
Anticipated avoidance/separation of TB patients, because of fear of transmission, and fear of rejection/discrimination.	Consider the 'side-effects' of harnessing people's fears of TB infection to promote treatment adherence or other health-related behaviours. Increase clarity and consistency (especially for TB patients) on what constitutes necessary precautions (focussing on those which are feasible and socially appropriate) and promoting a positive view of precautions as caring.
Reduced marriage prospects, particularly for women, in part because good health is a particularly valued attribute of a bride, but also because TB's transmissibility is thought to pose a risk to others.	Increase clarity and consistency on risks of transmission and necessary precautions. Promote positive stories of women with TB marrying successfully.
Family tension and (the threat) of divorce, particularly for women, and especially if the marriage was recent, partly because of overall gender inequities within Bangladesh, and partly because a woman joins her husband's family when she marries.	Address broader gender and structural inequities.
Financial disruptiveness of TB, particularly men of working age with dependents, because TB causes physical weakness, treatment is lengthy and requires regular visits to a health facility and nutritious food is thought to be necessary for complete recovery.	Consider measures to reduce the cost, length and disruptiveness of treatment provision.
Low self-esteem and worry about fulfilling responsibilities, because of inability to work or fulfil one's responsibilities.	Consider measures to reduce the cost, length and disruptiveness of treatment provision. Consider ways of providing emotional support to TB patients, perhaps through support groups.

Two other issues arising strongly from the study are summarised in the table below:

Issue and cause	Potential policy implications
Delayed treatment occurs because patients often initially visit alternative health care providers, because TB symptoms can be ambiguous and initially mild.	Increase referrals from private and alternative practitioners to ensure rapid diagnosis.
Non-completion of treatment can occur particularly because of the need to travel long distances while weak or suffering from side-effects.	Consider ways of making services and treatment more accessible for patients over the lengthy course of treatment. Promote belief in the importance of adherence to discourage defaulting, but balance this with understanding that TB will be cured (to avoid perpetuating stigma).

These issues and the potential policy implications now need to be discussed by stakeholders.

1. Introduction

In many parts of Asia, people affected by TB suffer doubly, both from the disease and from the stigma associated with it. While we know that TB-related stigma exists, we know little about the forms it takes, why it exists or what can be done about it. The purpose of this study is to deepen our understanding of TB-related stigma in and across three Asian countries and to develop improved theories to explain its causes. If we can explain what *causes* TB-related stigma, then we are in a better position to develop strategies to sustainably reduce TB-related stigma.

Few previous studies have set out to explore the causes of TB-related stigma and those that have tended to identify correlations of TB-related stigma and inferred causality, with insufficient evidence for a causal association. This can lead to inappropriate stigma-reduction interventions being developed which at best do not work and at worst may even increase stigma. For example, both TB-related stigma and a misconception regarding TB may prevail in a community, but this does not necessarily mean that the misconception is the cause of TB-related stigma. If it were, then in this community all those with TB would experience stigma in exactly the same way, all the time. This clearly is not the case and indeed research on various stigmatised conditions has shown a wide variation in people's experiences of stigma according to gender, marital status and individual circumstances (Liefoghe et al. 1995), (Khan et al. 2005); (de-Graft Aikins 2006) (Weiss et al. 2006). Even if the study involves in-depth interviews in which community members themselves speculate that a misconception is the cause of stigma, this still does not constitute evidence of a causal link. The theory that a misconception causes TB, though plausible, requires testing and developing, so that the theory eventually explains not only why the misconception leads to stigma, but also why in some circumstances, for some people, it does not. Such a theory needs to be firmly grounded in rich, exploratory data and then presented in such a way that its implications for policy and programme development can be contemplated. Our study and this report set out to do just that.

2. Aim

The overall aim of the research study was to gather new empirical evidence and further theoretical understanding of the *causes* of stigma associated with TB in and across Bangladesh, Nepal and Pakistan.

This report presents and discusses the findings for Bangladesh only.

3. Methods

This study involved qualitative in-depth interviews and applied the grounded theory approach: an established and rigorous approach to developing theories through the process of qualitative data collection.

One rural site was selected for inclusion in this study, namely Norshingdi district, because rather than wanting a representative, nationwide sample, the aim of this study was to collect a large amount of very rich, good quality data from a small number of people in order to generate theories on the causes of TB-related stigma.

Following an initial preparatory stage in which contextual information about the site was collected, twelve in-depth interviews were conducted, using the *theoretical sampling*

method. This provided sufficient rich, in-depth data from which to develop and refine theories on causes of TB-related stigma, while also allowing us to provide sufficient contextual information to enable an assessment of the likely applicability of the findings to other contexts.

Of the twelve in-depth interviews conducted, five were with female TB patients, five were with male TB patients and two were with health workers (*shasthyo shebikas*).

4. Findings

Before considering what underlies TB-related stigma, it is important to have an overview of the general context of TB and stigma in Norshingdi district. Such an overview includes an understanding of how TB is conceptualised locally, the nature of people's experiences of TB and the nature of stigma within those experiences. While there are potentially many reasons which can be put forward for addressing stigma, consideration is given to what the findings from this study reveal about those relating to TB prevention and control: specifically, delayed treatment and not completing treatment regimens.

This report then goes on to consider each dimension of TB-related stigma individually, interweaving *explanations* of why a dimension is related to TB, for whom and in what circumstances. Policy implications have also been put forward for discussion and further development.

4.1 Local concepts of TB

The term *jokkha* was commonly used by those interviewed with reference to TB and both *shasthyo shebikas* interviewed said they tend to use this term, rather than the term "TB" as it is the more familiar. Both felt that TB and *jokkha* mean exactly the same, the only difference being that the former is the English term and the latter is Bangla. However, the literal meaning (silent killer or deadly disease) and former usage of the word *jokkha*, can make it difficult to convince people that TB is treatable. One of the *shasthyo shebikas* interviewed (BRIDI BRAC Shebika) told of a patient who was initially relieved to have a confirmed diagnosis, but then worried he might die of this "deadly disease". Indeed, a male TB patient said that TB is now more commonly used as the term *jokkha* instills fear.

"Now this TB is no longer a harmful disease at all. Our local community used to know of 'jokkha' as a deadly disease, as meaning there is no more hope." (BRIDI BRAC Shebika)

"When hearing the term 'jokkha', everyone fears. It's strange when you hear the word, it implies a serious disease. [TB and jokkha] are the same, but on hearing..." (BRIDIMpt3, male TB patient)

During her interview, one of the *shasthyo shebikas* (BRIDI BRAC Shebika) at times described TB as a harmful, treacherous disease and at other times as a simple, curable disease, simultaneously emphasising the seriousness of TB, especially to public health, and the simplicity and curability of TB nowadays, although until just a few years ago it was deadly for the community. This illustrates the paradox that TB is seen as both dangerous and curable.

Although incurable diseases such as cancer (BRIDIMpt1, BRIDIMpt4) are viewed as more serious than TB, TB is still viewed as serious, or as “the younger brother of cancer” (BRIDIMpt5), because of the pain it causes. Indeed any disease that is not treated properly is considered potentially serious, and severity was also to some extent equated with transmissibility. However, while TB is viewed as a serious disease, according to one patient it is not considered shameful in the way that STIs are (BRIDIMpt1).

4.2 The nature of people’s experiences of TB

The TB patients interviewed, as well as the *shasthyo shebikas*, suspected TB only when the symptoms were considered typical of pulmonary TB (i.e. persistent cough, fever, weight loss).

“Actually I knew before getting TB disease that there should be a continuous fever and repeated coughing, but I didn’t have a cough at all. For this reason, it took some time before I was convinced. [] Till now I am quite confused, I’ve not lost any weight. I’ve just had chest pain and mild fever, no other symptoms.” (BRIDIFpt3, female TB patient)

Three of the male TB patients interviewed were surprised at their TB diagnoses because they had initially put their atypical symptoms, such as chest, stomach or back pains, down to excessive or heavy work (BRIDIMpt4, BRIDIMpt5, BRIDIMpt6).

The TB patients interviewed spoke positively about the behaviour and attitudes of the health workers they had encountered during their TB diagnosis and treatment.

Reactions to a TB diagnosis varied, with some feeling relief because they had feared incurable cancer (BRIDIFpt3), but many reacting with fear and despair.

“Patients react badly. They can’t easily accept [the diagnosis].” (BRIDI BRAC Shebika2)

“After hearing the news I became sicker. I couldn’t get up from bed for the next few days. [] After hearing I had TB I thought I might die.” (BRIDIFpt5, female TB patient)

“The feeling was very bad indeed. So, so bad, it can’t be expressed in words.” (BRIDIMpt3, male TB patient)

“After hearing the news? [Silent for a few seconds]. The shasthyo shebika and others working at the centre gave me courage. Before that I was afraid about my diagnosis. When they told me I had TB, the whole sky came down on my head. I couldn’t understand what to do, what my future would hold.” (BRIDIMpt4, male TB patient)

“I was totally expressionless. I didn’t understand what to do next. I lost my mother in childhood. I have no mother. What will happen if my stepmother gets to hear this news? Thinking about this I almost became faint.” (BRIDIMpt6, male TB patient)

Patients diagnosed with TB tend to feel depressed about their illness and diagnosis, but this was thought to be natural. Indeed one patient whose family had been supportive,

who was given paid sick leave from her job and who viewed precautions positively, spoke of the tension she nevertheless feels.

*“I’m always feeling tense, thinking when will I get relieved from this custody.”
(BRIDIFpt3, female TB patient)*

“Mentally I was not so good because I have got a wasting disease. Suppose it spreads, it grows inside my body. So it is normal that the psychological condition might be bad.” (BRIDIMpt1, male TB patient)

Many of the TB patients described their families and sometimes friends and colleagues as sympathetic and supporting, with one emphasising that her family is more caring than previously.

*“Now they are more caring than previously, especially my sister-in-law and mother.”
(BRIDIFpt4, female TB patient)*

4.3 The nature of stigma within those experiences

Whether TB-related stigma exists or not depends on how stigma is defined. Using the intentionally broad definition of “negative attitudes, emotions or behaviours”, local concepts of components of TB-related stigma (i.e. perceived negative consequences of TB) could be identified and explored. Overall, the negative consequences of TB that were apparent from the data were:

- Concealment of a diagnosis of TB
- Anticipated avoidance/separation of TB patients
- Reduced marriage prospects
- Family tension and (the threat) of divorce
- Financial disruptiveness of TB
- Low self-esteem and worry about fulfilling responsibilities

However, it is important to note that these negative consequences, while sometimes TB-related, are not inevitably and exclusively so. Some may be negative consequences of disease in general or of particular groups or characteristics of diseases. For example, during the preparatory stage of this study, in which contextual information about the study site was collected, indications of an overlap between perceptions of TB and asthma were found, as both relate to the lungs and require lengthy treatment and one is thought to lead to a predisposition to the other.

Those affected by TB-related stigma may not necessarily always be people with TB disease. They may include those thought to be somehow associated with TB, perhaps because of their occupation or because they have a family member with TB. This is what (Goffman 1963) refers to as ‘courtesy stigma’. From the data collected for this study there was no suggestion from the *shashthyo shebikas* interviewed that they had experienced any negative attitudes, emotions or behaviours towards them as a result of their work associating them with TB. Just one of the interviews with a TB patient suggested an anticipation of ‘courtesy stigma’ or anticipated negative attitudes, emotions or behaviours towards a person associated with a TB patient, rather than just the TB patient herself. A female TB patient (BRIDIFpt4) said that she did not want her sister’s

parents-in-law, who live in another village, finding out she has TB because they would make life difficult for their daughter-in-law.

“They are not good people, they may torture my sister. [] Yes, torture, mental torture. They might tease my sister and even block her from coming to our home.”
(BRIDIFpt4, female TB patient)

4.4 Public health implications

In TB control, rapid identification of new cases and adherence to treatment regimens are seen as crucial. We therefore consider what this research reveals about TB patients’ reasons for delayed treatment and not completing treatment regimens and the influence, if any, of stigma. The study also revealed a third possible outcome of stigma with public health implications, namely relapsed or re-infected patients withholding their medical histories from health care providers.

► Delayed treatment

Summary: Most of the patients interviewed did not delay seeking treatment, but sought treatments and diagnoses from alternative health care providers before eventually being diagnosed with TB at a government or BRAC health facility. A number of the TB patients interviewed first bought medicine from the market and only when the medicine failed to bring about a sustained improvement did they seek treatment elsewhere, usually based on the recommendations or referrals of others. Just one of the ten TB patients interviewed did delay getting tested for TB, despite a private doctor suggesting it, because she was fearful of the diagnosis and its implications.

Potential policy implications: Because TB symptoms can be ambiguous and initially mild, it is not surprising that government or BRAC health facilities are not sufferers’ first point of contact with health care providers. The data indicates that recommendations and referrals are important influences on health seeking behaviours and so word-of-mouth within communities and referrals from private and alternative practitioners could play an important role in ensuring rapid diagnosis.

The patients interviewed did not tend to delay seeking treatment, but sought treatments and diagnoses from alternative health care providers before eventually being diagnosed with TB at a government or BRAC health facility. One of the *shasthyo shebika* told of a man who spent more than 6000 taka trying to get an accurate diagnosis for his symptoms before she suggested he get tested for TB. A TB patient interviewed (BRIDIMpt4) spent a similar amount on medicines following a consultation with a doctor about his fever.

A number of the TB patients interviewed first bought medicine from the market and only when the medicine failed to bring about a sustained improvement did they seek treatment elsewhere, usually based on the recommendations or referrals of others. A neighbour told one TB patient (BRIDIMpt6) to go to the BRAC centre when the medicine he had bought in the market failed to improve his condition. The medicine seller in the

market, as well as community members, told a female patient to go to the hospital where she was then diagnosed with TB (BRIDIFpt1). Likewise, another TB patient (BRIDIMpt5) consulted a doctor in Norshingdi town, recommended by his relatives, who advised him to go to a government hospital where he was tested for TB. A neighbour of another patient (BRIDIFpt3) recognised her symptoms and advised her to go to the BRAC centre: she was diagnosed with TB. Although she and her husband then sought the advice of a private doctor, the private doctor advised they get treatment free-of-charge from their nearest BRAC centre or government hospital. The brother of another TB patient (BRIDIMpt4) who had himself had TB in the past, advised him to get a sputum test. However, this was only after he had already consulted a private doctor and a *hujur* (a religious leader and healer) recommended by neighbours and relatives. The sister-in-law of BRIDIFpt4 told her to go to the government hospital and accompanied her there, when her symptoms did not improve following three months of homeopathic treatment which had been recommended by her neighbours. On her mother's advice, a female TB patient initially went to a *fokir* for treatment; a *fokir* being someone who treats illness inflicted intentionally by another person, or black magic. Despite the *fokir's* treatment, her symptoms did not go away fully, so, although she has continued the *fokir's* treatment, she went to a doctor who diagnosed, and is treating her for TB.

One patient interviewed (BRIDIMpt3) decided himself to go directly to the BRAC centre to be tested for TB, as he had TB once before in the past and recognised the symptoms.

While one TB patient did indicate, when his neighbours suggested he should get tested for TB, that he was fearful of getting a TB diagnosis, he did not appear to have delayed being tested as a result. However, one of the ten TB patients interviewed (BRIDIFpt5) did delay getting tested for TB, despite a private doctor suggesting it, because she was fearful of the diagnosis and its implications. She decided not to tell her husband about the doctor's suggestion as her mother advised her not to because husbands do not take care of ill wives. Instead she sought ayurvedic treatment from a *kabiraji* in Norshingdi town, accompanied by her husband. While such treatment is available nearer to her home, she preferred to go to town, even though it proved difficult when ill and required her husband to accompany her, to avoid suspicions amongst her neighbours. Having received the treatment weekly for over six months, her condition deteriorated and she was again advised, this time by the *kabiraji*, to get tested for TB. On this occasion her husband was with her and so took her to a government hospital where she was diagnosed and is now being treated for TB. Despite her anticipation, fuelled by her mother, of a negative response from her husband and neighbours, she describes her husband as reassuring and encouraging following the diagnosis and despite now having disclosed her TB to all, she has not received any negative reactions from anyone.

► Non-completion of treatment

Summary: According to the interviews, adhering to the lengthy course of treatment requiring daily visits to the health facility proves challenging for some patients, especially if they have to travel long distances while weak or suffering from side-effects. Despite this, many persevere and indeed some patients emphasised the importance of adherence to the curability of TB and were worried that if they missed treatment for just one day, the entire course of treatment would need to be started again or they would not be cured.

Potential policy implications: DOTS (involving daily visits to a health facility) is difficult for patients, especially if they are weak, elderly, have to travel long or difficult distances or are struggling to balance responsibilities. The perseverance of the patients interviewed to continue treatment despite these difficulties highlights their determination to recover from illness. A belief in the importance of adherence may discourage defaulting, but is also likely to cause worry and fuel a perception that TB's curability is conditional and that it is therefore to be feared, with fear of TB leading to stigma.

Some patients emphasised the importance of adherence to the curability of TB. For example, a female TB patient (BRIDIFpt1) said she had been told that if medicine is missed even for just one day, the entire course of treatment must be started again from the beginning. Another patient (BRIDIFpt4) said she had heard that if regular treatment is not taken, TB may not be cured and this was what was causing her most tension. She worried what her fate would be if she missed her treatment for a day and didn't feel confident that she could take regular treatment for 6 consecutive months, describing the course of treatment as "very difficult".

"Proper DOTS treatment can bring them back again to their regular lives, but this treatment process is quite long, so the patient should consider the length of the treatment to get well." (BRIDI BRAC Shebika)

Indeed, some of the TB patients elaborated on the difficulties they face accessing medicine from a health facility on a daily basis. A male TB patient (BRIDIMpt3) said that he found the daily 12 mile journey on foot to the health facility for his treatment, administered by injection, difficult especially when he feels weak or is struggling with the treatment's side effects. Another male TB patient (BRIDIMpt4), living 7km from the health facility, said it would be much easier for him if he could collect his medicine on a weekly, rather than on a daily, basis. Likewise, another patient (BRIDIMpt5) who takes a bicycle or rickshaw to the BRAC centre, 10 miles away from his home, spoke of the difficulties and disruptiveness of making the journey daily.

However, according to one of the *shasthyo shebikas* interviewed (BRIDI BRAC Shebika2), very few patients need to be followed up and given their medicine at their homes, and those that do tend to be older and feeling unwell, sometimes (according to BRIDI BRAC Shebika) due to the side-effects of the medicine, although she considers most defaulters to simply be irresponsible.

"Some patients complain to me that this DOTS medicine is more harmful than the TB." (BRIDI BRAC Shebika)

Younger (male) patients, according to BRIDI BRAC Shebika2, adhere to the treatment because they are particularly eager to recover so that they can return to work to support their families. However, to encourage adherence of her patients she tells them and their family members that if a patient defaults he or she risks transmitting TB to others, thereby instilling fear and guilt to prevent defaulting.

"[I say to patients that] it is very unfortunate that you are infected with TB, but if you do not continue your DOTS treatment, then your entire family may be infected with

the same disease, so for the sake of your family members you should continue your DOTS, get well soon and save your family members too. [] I have met patients who are reluctant to continue their treatment from the DOTS centre and avoid us. In this situation I try to convince the other family members that the patient needs to continue the treatment by saying that this patient is harmful to you too. The family members then make sure they continue the treatment.” (BRIDI BRAC Shebika2)

4.5 Understanding TB-related stigma

In this section, we explore each of the negative consequences which emerged from the data as having an association with TB for some people in some circumstances, and explanations for the associations and their contexts are presented, following a brief summary of the explanations and their implications for TB and stigma policies and programmes.

► Concealment of a TB diagnosis

Summary: The TB patients interviewed spoke of intentionally being selective as to who they disclosed their TB diagnoses, or even actively trying to conceal their diagnoses from others, mostly because they anticipated negative consequences. Female TB patients and the female relatives of male TB patients appear to be particularly concerned about the negative consequences of disclosure. Such anticipated or feared consequences include reduced marriage prospects or marital tensions (especially if the marriage was recent) and particularly for women, being made unemployed and being avoided by others who fear TB transmission.

However, concealment of a TB diagnosis can only occur when there is both a will to conceal and an ability to conceal, with the ability to conceal being compromised by gossip (which in turn may be linked to proximity), the evidentness of the illness (such as symptoms, but also daily attendance at a DOTS clinic) and patient tracing and home visits.

Potential policy implications: Whether patients should or need to be encouraged to disclose their TB more widely is debateable, as is the need for measures to enable more TB patients to determine themselves who is informed and who is not informed. However, given how much of a concern the issue of disclosure is, especially to women (even if the consequences they anticipate do not necessarily manifest themselves), consideration of ways to protect and not jeopardise their confidentiality may improve health seeking and satisfaction with services and relieve worries and fears.

The TB patients interviewed spoke of intentionally being selective as to who they disclosed their TB diagnoses, or of even trying to conceal their diagnoses from others, mostly because they anticipated negative consequences.

Concealment or selective disclosure appears to be more common in relation to a woman’s TB diagnosis, and even amongst the male TB patients interviewed, it was often

their female relatives (wives, mothers, sisters) who requested that they should not disclose to others. For example, a male TB patient (BRIDIMpt4) said his mother advised him not to disclose his TB to anyone in his native village and so he decided to postpone moving back there, even though that had been his intention. Similarly, a male TB patient (BRIDIMpt5) who had been happy to disclose his TB to most people, had not disclosed to his parents-in-law at his wife's request. Although they were aware that he is sick, they were not made aware that he has TB.

"My wife doesn't want to let them know. She asked me not to let slip to any member of her family, as I am the new husband of their home. [] They know I'm sick, but they don't know what the disease is." (BRIDIMpt5, male TB patient)

Many of those interviewed linked intentional non-disclosure with concerns over marriage prospects and marriage (especially if the marriage was recent). One female TB patient (BRIDIFpt4) said that generally TB patients avoid disclosing their TB to others as they may face problems with marriage, although she had not actually known of any woman who had faced such problems because of her TB. The mother of an unmarried female TB patient (BRIDIFpt2) told her not to disclose her TB to anyone for fear that she may face problems getting married in future. While she thinks both men and women can face problems in this regard, she thinks the unwillingness to disclose is most prevalent amongst the family members of unmarried girls with TB who fear that other families will not want their sons to marry their daughters. Supporting this, a male TB patient (BRIDIMpt5) felt that men do not generally feel a need to conceal their TB diagnosis, whereas women do.

An unmarried female TB patient (BRIDIFpt2) said she knew of a girl who had got TB after marriage and her mother-in-law instructed her husband to leave her, even arranging the divorce, because TB is infectious and so the husband may get the disease. However, rather than deterring her from disclosing her TB to her fiancé, she felt that in order to avoid any problems after marriage, it was important for her to disclose her TB to him and his family. By contrast, another female TB patient (BRIDIFpt5), although already married with two children, concealed, on the advice of her mother, a doctor's suggestion that she get tested for TB as her mother told her that husbands do not take care of their wives when they are found to have a serious illness. As a result she did not get tested for another six months. When she did and was found to have TB, it transpired her fears (or her mother's fears) were unfounded. Her husband was supportive and reassuring.

"At that time, when the doctor advised [me to get tested for TB] I was afraid of the diagnosis. [] I thought my disease was normal, I couldn't think that it might be TB. My mother also told me not to tell the doctor's suspicion to my husband willingly. My mother told me that it's better not to let men know everything. They don't like a wife to be ill, so for this reason I didn't let him know. [] It is better not to tell a man everything, even a husband. They can neglect their wives, although I think my husband is different." (BRIDIFpt5, female TB patient)

Another reason for concealing a TB diagnosis is the fear of losing one's job or receiving a perceived negative reaction from colleagues. A male TB patient (BRIDIMpt4) said his wife feared he would lose his job if his colleagues found out about his TB and so advised him to conceal it. Although he did initially, he decided to leave his job anyway as he needed to rest and he did not feel comfortable concealing his TB.

"Initially my colleagues didn't know, but now everyone knows. I didn't want to hide it. I've left my job. [] I'm poor, it's true, but I'm not selfish. [] They might be afraid of my disease and be wary of inhaling air when I am with them." (BRIDIMpt4, male TB patient)

Another male TB patient, who sells vegetables at a market stall, purposely did not tell his fellow stall holders about his TB for fear of their reactions.

"They might not be interested to give me a chance to sit there, they might avoid me, they might fear my disease, so I didn't tell them." (BRIDIMpt3, male TB patient)

In addition to a fear of losing one's job or being avoided by colleagues who themselves fear becoming infected by TB, some of those interviewed spoke of concealing a TB diagnosis so that others would not avoid them. For example, two of the female TB patients interviewed concealed their TB diagnosis, in both cases on the advice of female relatives and friends, for fear that others may avoid them. The first (BRIDIFpt4) said her sister-in-law advised her not to disclose her TB diagnosis to anyone else as people are afraid of TB and avoid TB patients.

"I didn't tell anyone. [] We know that most of the people are afraid of TB disease. I have heard previously that villagers avoid TB patients. For this reason my sister-in-law advised me not to tell anyone else and I didn't tell anyone else." (BRIDIFpt4, female TB patient)

Likewise, the second (BRIDIFpt2) initially told her mother and maternal aunt, but did not tell anyone else for fear that others would avoid interacting with her. Once her friends did find out, her fears were not realised as her friends continued to interact with her and were encouraging and supportive. However, her friends in turn also advised her not to disclose her diagnosis to anyone else.

While for many the fear of TB infection may well be the primary reason for keeping a distance from a TB patient, it can also be the justification needed in order to legitimately distance oneself from someone with whom one previously has had a strained relationship. This can be illustrated by the case of a male TB patient living with his father, stepmother and half-siblings. He seems to have always had a difficult relationship with his stepmother and so she was the one person he did not want to find out about his TB as he feared her reaction. When his stepmother did eventually find out, although her reaction was not confrontational towards him, she said she feared that her own children might catch TB and requested that the respondent's father ask the respondent to move out of the family home.

"[My stepmother] didn't say anything in front of me. Later I understood that she was afraid of my disease [] because I've another brother and sister. She was afraid, thinking of their safety. [] After that, my stepmother discussed it with my father and then one day my father told me to stay with my friends for some days, he will bear all expenses. He will hire a single room for me in a bachelors' mess. For his sake I agreed with his proposal and since then I'm living separately in a mess." (BRIDIMpt6, male TB patient)

Concealment of a TB diagnosis occurs when there is both a will to conceal and an ability to conceal, the latter being compromised by gossip (which in turn may be linked to proximity), the evidentness of the illness (such as symptoms, but also daily attendance at a DOTS clinic) and patient tracing and home visits.

A male patient (BRIDIMpt5) whose wife asked him not to disclose his diagnosis to her parents was no doubt able to do so without too much difficulty as his parents-in-law live in another district 90 miles away. However, without such geographical distance, according to one male TB patient (BRIDIMpt6), attempts to conceal a diagnosis of TB are futile. Another TB patient (BRIDIMpt4) was of a similar view:

"I think most of [my neighbours] know. Most know from the [BRAC] centre, before I informed them. [] TB spreads by air and this news also spreads by air, faster than TB even. Our people have very much the ability to spread bad news quickly in the interest of humiliating others." (BRIDIMpt4, male TB patient)

Attending a DOTS clinic daily for treatment can make concealing a diagnosis problematic. A female TB patient (BRIDIFpt4) described how her sister-in-law and mother would not let her collect her treatment for fear that her TB diagnosis would become evident, later going on to explain that accessing DOTS treatment raises fewer suspicions for men than for women, and thereby suggesting that DOTS may actually favour men.

"My mother and sister-in-law don't allow me to go to the centre [because] our neighbours may come to know about my disease. Most of the people are afraid of TB. They then try to avoid a person affected by TB. They even avoid talking with a TB patient. For this reason, they don't allow me to go to the centre." (BRIDIFpt4, female TB patient)

"In the case of men, they can easily go for medicine to the centre. No one asks them. But when any girl goes to the centre, everyone asks why, why has she gone there, what is her problem? It is very embarrassing." (BRIDIFpt4, female TB patient)

As well as a TB diagnosis being made known if a patient is seen accessing TB services, the need for patient tracing if a patient defaults from the treatment regimen can also jeopardise confidentiality. When asked how she reconciles the need for patient tracing with the patient's need for confidentiality, one of the community health workers (*shasthyo shasthyo*) interviewed was quite clear that the patient's right to confidentiality is not as great a priority for her as protecting the public's health.

"Actually patients should handle their family problems. I'm responsible for ensuring DOTS is adhered to for the sake of other community members." (BRIDI BRAC Shebika)

Physical symptoms can also make it difficult to conceal an illness. At first a male TB patient (BRIDIMpt6) found it difficult concealing the physical symptoms of his illness from his step-mother and was relieved when the TB treatment began to take effect, reducing his symptoms. While physical symptoms may not necessarily alert others to the presence of TB, they may prompt others to speculate or enquire as to what the diagnosis is.

▶ Anticipated avoidance/separation of TB patients

Summary: Some of the TB patients interviewed intentionally did not disclose their TB to people or avoided people that they thought might be fearful and avoid interacting with them. Whether others fear TB is influenced by perceptions of its curability, transmissibility and its evidentness (esp. when symptoms are apparent) and health workers may sometimes harness people's fears of transmission to encourage healthy behaviours, such as treatment adherence.

While to some extent fear of transmission and the need for precautions against transmission is understood, such fear and precautions are also sometimes viewed negatively and this is in part determined by whether they are viewed as legitimate, for example if precautions have been advised by a health worker (and it seems there may be inconsistency and confusion as to what precautions are necessary and for how long), and in part on whose behaviour it is and towards whom and in what circumstances, and of course whether avoidance, for example, is even noticeable. Self-initiated precautions are easier for TB patients to cope with emotionally than precautions (such as avoidance) initiated by others. Indeed precautions initiated by the TB patient can be interpreted positively by the TB patient as caring towards others and as simply necessary, whereas precautions initiated by others are more likely to be interpreted by the TB patient as negative and uncaring.

Policy implications: The 'side-effects' of harnessing people's fears of TB infection to promote treatment adherence or other health-related behaviours need to be considered, particularly how this approach might simultaneously and unintentionally fuel TB stigma.

Increasing clarity and consistency (especially for TB patients) on what constitutes necessary precautions (focussing on those which are feasible and socially appropriate) and promoting a positive view of precautions as caring is important for both TB-related stigma and TB control.

Some of the TB patients interviewed intentionally did not disclose their TB to people or avoided people that they thought might be fearful and avoid interacting with them. While avoidance of TB patients was mostly anticipated or explained as a consequence of the fear of infection, one TB patient feared being avoided by others not because she thought they would fear catching TB from her, but because she had TB for the second time and might be viewed as a burden.

"I am anxious about people avoiding me, not for spreading disease, but for being repeatedly ill. Everyone may feel disturbed and may avoid me." (BRIDIFpt1, female TB patient)

However, most linked avoidance with fear of infection, and while the anticipation of being avoided for fear of infection did not always materialise, it is worthwhile looking at why people may fear TB and why this fear may be responded to with avoidance.

Perceptions and fear of TB are influenced by knowledge regarding its curability. When a TB patient (BRIDIFpt2) was asked how she would have felt had she had another

disease, such as asthma, cancer, gonorrhoea or paralysis, she said she'd be more fearful and anxious of those for which treatment is not available.

"I would be afraid of these diseases more because I don't know whether treatment for them is available or not.[] Till now cancer has no treatment." (BRIDIFpt2, female TB patient)

However, perceptions regarding TB's transmissibility also play a large role and while knowing that TB is curable (and that the treatment is accessible and effective) can decrease fear, the knowledge that it is transmissible and that proximity increases risk of transmission can exacerbate fear. Indeed, one of the *shasthyo shebika* interviewed (BRIDI BRAC Shebika2) used the fear of transmitting to others to persuade patients to adhere to their treatment, and the fear of being transmitted to, to persuade the family members of TB patients to play a role in ensuring treatment adherence of the patient.

Those interviewed believed that a number of factors, such as smoking (and passive smoking), alcohol, drugs, dust, heavy work and previous illness, can increase a person's susceptibility to TB, mostly by weakening the body. Such factors can help address the inadequacies of transmission as a causal explanation for TB-related stigma, as not everyone who interacts with a TB patient gets TB. One TB patient (BRIDIFpt1) said during the interview both that Allah imposed the disease on her and only He knows why and only He can cure it, and also that she thinks doing heavy work before being completely cured of TB may have been the reason for her getting TB again, but that she had no choice as she is poor. This suggests an acceptance of multiple contributory causal explanations, some under a person's control and some not. Reference to Allah as ultimately determining who gets disease and who gets cured does not suggest punishment or wrong-doing, just a recognition that who gets TB and why is not always explicable.

TB appears to be feared more when symptomatic. Indeed, (Kurzban & Leary 2001) claim that we have an innate tendency to fear and consequently avoid others in which we have detected correlates of infection. When such correlates are not detected, the fear of infection is reduced, or else proxy correlates are employed. A male TB patient (BRIDIMpt1) said that his friends, who have not treated him any differently since his diagnosis, find it difficult to believe he has TB as his symptoms are not typical of pulmonary TB.

"My circle of friends don't want to believe that I am a TB patient because they know that when you have TB there are certain symptoms, such as coughing, coughing up blood, fever and so on. I don't have any of these symptoms, so they don't want to believe I have TB." (BRIDIMpt1, male TB patient)

While a TB patient is more likely to be avoided or to perceive precautions against transmission as necessary when they are symptomatic, information from health workers and others regarding the length of time pulmonary TB continues to be infectious once treatment has begun is also important. One of the *shasthyo shebika* interviewed (BRIDI BRAC Shebika2) said she advises patients' family members to keep a distance from the patient during the "*coughing period*", while the other (BRIDI BRAC Shebika) said she specifies the need for distance for the first three weeks of treatment. However, for one of the female TB patients (BRIDIFpt1), the period of time when precautions were

necessary was a few months, as it was not until a few months after treatment began that the doctor said she could interact normally with her family again.

"[The health workers] advised me to maintain a safe distance from others and to avoid mixing freely with other members of the family. I also told my children that the doctors had advised me to avoid mixing freely with them. My youngest child was too young to understand. We have another two rooms in our home. I kept myself within one of those rooms, but the youngest one used to cry all the time as he wanted to stay with me, although I didn't let him. [] They did an X-ray after a few months, when the symptoms had subsided, and they told me that now it wouldn't be a problem for me to stay with my family members." (BRIDIFpt1, female TB patient)

Another TB patient (BRIDIFpt2) said she had been advised by a *shasthyo shebika* to use separate eating utensils from the rest of her family and even after four months of treatment was still continuing to do so, equating the period of treatment with the period of time in which precautions are necessary. It is unclear whether or not the *shasthyo shebika* had actually specified a length of time when precautions were necessary or whether the patient had just assumed they were until treatment was complete.

While to some extent the need for precautions against transmission is understood, fear of transmission is also sometimes viewed negatively. For example, a female TB patient (BRIDIFpt5) linked fear of disease with illiteracy and ignorance, claiming that no one avoids her. Whether a behaviour is interpreted as negative or as simply a precaution is in part determined by whether it is viewed as legitimate, for example if it has been advised by a health worker (although it appears there may be confusion and a lack of consistency with regards to the precautions advised and the length of time they are necessary), and in part on whose behaviour it is and towards whom and in what circumstances.

"[My husband's] behaviour was the same [towards me]. Of course, as the doctor from the health centre advised, he had to maintain a safe distance." (BRIDIFpt1, female TB patient)

Some of those interviewed referred to children as being particularly susceptible and so fear of transmission to children is particularly strong. For example, a male TB patient (BRIDIMpt1) did not particularly think his parents or siblings would worry about getting TB from him, but he did think perhaps his siblings might be worried for their children.

One TB patient (BRIDIFpt3) interviewed who said she had been advised by a health worker to separate herself and her eating utensils from others, emphasised when asked whether she was following these restrictions that they were not restrictions, which have negative connotations, but simply necessary precautions, which have positive connotations.

"No, no, these are not restrictions! We all know these and we try our best to maintain these. It's for our own protection. For the protection of our family we have to follow these." (BRIDIFpt3, female TB patient)

However, even when separation is viewed as a positive precaution, it still makes a difference who initiates the separation and the existing nature of the relationship between the TB patient and that person. The TB patient quoted above, although viewing

separation as a necessary and positive precaution, spoke negatively of her sister-in-law's efforts to encourage separation.

"She always tries to motivate my husband and my son to maintain separation from me. She is not so educated. I think it is because of her lack of education, her lack of knowledge. It is her ignorance." (BRIDIFpt3, female TB patient)

Precautions initiated by the TB patient are likely to be interpreted positively by the TB patient as caring towards others and as simply necessary, whereas precautions initiated by others are more likely to be interpreted by the TB patient as negative and uncaring. While the resulting outcome may be the same, for example an increased physical distance between two people, the interpretation of the motivation behind the outcome differs according to who has initiated it. A male TB patient (BRIDIMpt4) said by his own choice he sleeps and eats separately from the rest of his family, and uses separate eating utensils which he then washes himself. (He also washes his laundry himself.) He deems this self-imposed separation to be important to protect his family members from becoming infected. He even went on to say that his relationships with other people had not been affected by his TB diagnosis, despite the fact that he had given up his job and separated himself from others, and this may be explained by the fact that leaving his job and separating himself had been *his* choice and initiated by *him*. Likewise, another TB patient spoke of separating herself, and particularly her eating utensils, from other family members for their safety and by her own free will.

"I try to maintain some separation when I stay at home, although I don't always remember to. I do it by my own free will. [] I am maintaining a safe distance from my family members [] for their safety." (BRIDIFpt4, female TB patient)

Self-initiated avoidance is easier for the TB patient to cope with emotionally and so a TB patient may avoid others in order not to be avoided. A male TB patient (BRIDIMpt3), with a vegetable stall at the market, said that if people avoided buying vegetables from him he would be depressed and shocked and so he did not continue to work on his stall when he was diagnosed with TB. He went on to say that if he feels someone is fearful of his disease, he will avoid that person so that that person does not have to avoid him. By not giving people the opportunity to avoid him, he was protecting himself emotionally.

Being avoided by someone with whom one has had little previous interaction anyway is unlikely to be noticed and therefore interpreted negatively. When asked whether any of his relatives had visited him and enquired about his health since he had become ill with TB, a male TB patient (BRIDIMpt4) said they had not, but that they do not normally visit him anyway. Likewise, a female TB patient (BRIDIFpt4) indicated that her TB had not particularly affected her social interactions with others outside her home as *"normally I rarely go outside of our home"*.

► Reduced marriage prospects

Summary: While some of those interviewed felt that the fewer responsibilities one has, the easier it is to cope with a TB diagnosis, and an unmarried person tends to have fewer responsibilities than a married person, an unmarried woman of marrying age was

thought to face particular difficulties in relation to her marriage prospects following a TB diagnosis. It appears that reduced marriage prospects are far more a concern for unmarried women and their families than for unmarried men, in part because good health is a particularly valued attribute of a bride, but also because TB's transmissibility is thought to pose a risk to others and abstinence from cooking is deemed necessary and because of an idea that the TB may persist and/or pose a risk to a woman's (future) children.

The degree to which unmarried women *actually* face problems getting married following a TB diagnosis is uncertain. While most of those interviewed anticipated that unmarried women would have problems in this regard and so felt that they would conceal their TB diagnoses, many did not personally know of a woman who had had such problems. This is perhaps because unmarried women and their families are reluctant to disclose a TB diagnosis or may themselves decide to postpone an arranged marriage due to illness, rather than risk the groom's family cancelling it due to TB, or because the anticipation is greater than the manifestation of problems.

Potential policy implications: Increasing clarity and consistency on risks of transmission (e.g. via cooking, in-utero, etc.) and necessary precautions is needed.

If the anticipation of reduced marriage prospects is greater than the reality of reduced marriage prospects, then perhaps positive stories of women with TB marrying successfully need to be shared.

When an unmarried woman is diagnosed with TB, she and her family are especially concerned about her marriage prospects. While some of those interviewed felt that the fewer responsibilities one has, the easier it is to cope with a TB diagnosis, and an unmarried person tends to have fewer responsibilities than a married person, an unmarried woman of marrying age was thought to face particular difficulties in relation to her marriage prospects following a TB diagnosis.

"Still in Bangladesh most of the people think TB is a deadly disease as well as a communicable one. As a bride, [a woman with TB] is not treated as a primary choice. Especially older people treat TB as a curse, thinking it can't be cured properly and will stay with the TB patient their entire life, as well as it being harmful to others." (BRIDI BRAC Shebika)

"[An unmarried woman] will face great problems getting married. A man and even his family might not agree to marry her. Even after she is cured of the disease she may face problems during marriage." (BRIDIFpt3, female TB patient)

"Till now if anyone hears that a young woman is suffering from TB it is too tough to get her married in our society." (BRIDI BRAC Shebika2)

A married male TB patient (BRIDIMpt5) also indicated that coping with his TB diagnosis would have been easier had he not been married with children, but did not suggest that it would have had an impact on his marriage prospects. It is the transmissibility of TB, the risk it poses to others, that he highlighted, rather than its disruptiveness to his ability to manage his responsibilities.

“Of course, if this disease had occurred before my marriage, I wouldn’t have married at this moment and wouldn’t have had a baby at this time. Now my baby is at risk. [] It’s very unfortunate for my family.” (BRIDIMpt5, male TB patient)

It appears that reduced marriage prospects are far more of a concern for unmarried women than for unmarried men. An unmarried male TB patient (BRIDIMpt1) said that if his fiancée had been diagnosed with TB rather than him, his parents would have disapproved of the marriage.

“If someone heard that this is an unmarried girl and she has TB, there would be a problem with her marriage. Who will marry a diseased girl?” (BRIDIMpt1, male TB patient)

While the respondent highlights the value placed on the health of a bride (*“Who will marry a diseased girl?”*), it seems not all illnesses have such an anticipated impact on a woman’s marriage prospects. TB may be particularly problematic for an unmarried woman because of its perceived transmissibility posing a risk to others and a perception that abstinence from cooking is necessary (although it is unclear whether cooking is thought to pose a risk to others, or to jeopardise the patient’s own health), and because of an idea that the TB may persist and pose a risk to a woman’s children. Concerns over potential risks to pregnancy and future children of a woman having TB or TB treatment were expressed by some respondents.

“If a mother has TB, her baby can get it from her. [] I think if a father has TB, his baby will not get this from him because a man doesn’t bear the child in his body.” (BRIDIMpt6)

A perception that abstinence from cooking is necessary can make a TB diagnosis particularly difficult for a woman whose role is seen to be, or is expected to become, primarily to look after her husband and household. When a male TB patient (BRIDIMpt5) was asked how the situation would have been different if his wife had had TB, rather than him, he said it would be even more difficult for the whole family.

“Definitely in that case, [my wife] would face more problems. [] She has to abstain from cooking food because of her illness which would create more problems in our family.” (BRIDIMpt5, married male TB patient)

“[If a woman has TB] there will be more problems. They can’t cook, they are not allowed to cook. Even they are not allowed to go to the kitchen sometimes.” (BRIDIMpt3, married male TB patient)

The degree to which unmarried women *actually* face problems getting married following a TB diagnosis is uncertain, and while most of those interviewed anticipated that unmarried women would have problems in this regard and so felt that they would conceal their TB diagnoses, many did not personally know of a woman who had.

*I: Do you know such a girl who couldn’t get married because of having TB?
R: I haven’t known any woman to whom this has happened. It’s from my own perception that I’m telling you she would have problems. I haven’t heard of it*

happening to a woman either. It's from my own thinking that this type of problem could occur. (BRIDIMpt1, male TB patient)

However, not personally knowing of woman who has faced difficulties with marriage as a result of a TB diagnosis may in part be because unmarried women and their families are reluctant to disclose a TB diagnosis and may themselves decide to postpone an arranged marriage due to illness, rather than risk the groom's family cancelling it due to TB.

"Before getting ill, I received some marriage proposals. Agreement on one proposal had almost been reached, but because of this disease it was postponed. [] They knew about my illness, but they didn't know it's TB. [] Now I've decided I will not marry until I've recovered completely." (BRIDIFpt4, female TB patient)

Despite the perceived link between TB and reduced marriage prospects or difficulties within a marriage, BRIDIFpt4 did not actually know of any women who had faced such problems because of TB. Her own family had themselves decided to postpone a marriage that was in the process of being arranged, so that she could recover fully first.

► Family tension and (the threat of) divorce

Summary: As well as the anticipation of TB affecting a woman's marriage prospects, those interviewed also spoke of problems occurring within a marriage, especially if the marriage was recent. Generally, respondents viewed the negative social consequences of TB as greater for women than for men, partly because of overall gender inequities within Bangladesh, and partly because a woman joins her husband's family when she marries. There were also some suggestions that marriage and relations with in-laws may also be affected if a man gets TB.

Potential policy implications: In addition to the potential policy implications under *Reduced marriage prospects*, page 19, family tensions and potential divorce, linked to TB, can most likely be reduced by addressing broader gender and structural inequities.

As well as the anticipation of TB affecting a woman's marriage prospects, those interviewed also spoke of the anticipation of or even known cases of problems occurring during marriage, especially if the marriage was recent.

A *shasthyo shebika* interviewed (BRIDI BRAC Shebika) told of a married woman with TB who told her that her mother-in-law was depressed and embarrassed about her having TB. The patient's husband requested that the *shasthyo shebika* should not disclose his wife's TB to his family members and that she should not come to their home as this would arouse suspicion. He also asked whether he could collect the treatment weekly for his wife, rather than her having to collect it daily as it would make her TB evident to all. The husband was worried that his mother would tell his wife to leave.

Another interviewee, an unmarried female TB patient (BRIDIFpt2), said she knew of a girl who had got TB after marriage and her mother-in-law instructed her husband to leave her, even arranging the divorce, because TB is infectious and he might get the disease. Likewise, a female TB patient (BRIDIFpt5) was advised by her mother not to disclose the doctor's suspicions that she might have TB to her husband, anticipating that he would react negatively. (In fact, when he eventually found out, he was supportive and encouraging).

Generally, respondents viewed the negative social consequences of TB as greater for women than for men, partly because of overall gender inequities within Bangladesh and partly because a woman joins her husband's family when she marries.

"In our society no one blames a man. All faults go to women []. Our people can't ignore even the very small faults of women, but they constantly ignore the big faults of men." (BRIDIFpt2)

"According to our social context, the problem for females is greater []. In fact, I've got a lot of help from my husband and family, but in most families in our country, women don't get this type of help from their families. In most families, their parents-in-law, especially the mother-in-law, behave in such a manner that the woman is responsible for getting TB. She [the mother-in-law] behaves badly towards her, as if by getting illness she committed a big crime." (BRIDIFpt3)

While the *shasthyo shebika* themselves did not appear to suffer from any "courtesy stigma" resulting from their work with TB patients, the family members of one *shasthyo shebika* interviewed were concerned about the potential harm she might do to her own family by meddling in other people's affairs.

"Once a bride came to me and told me that her father- and mother-in-law were not interested in bringing her back to their home from her parents' home due to her TB disease. So I said, don't worry, I'm here. If your father-in-law or any other person comes to your home please inform me and I will make them understand that TB is no longer a harmful disease these days. It's absolutely curable." (BRIDI BRAC Shebika)

Amongst the interviews there were two suggestions that marriage and relations with in-laws may also be affected if a man gets TB. A male TB patient (BRIDIMpt5) said his wife did not want her parents knowing about his TB, especially as they had only recently got married. However, whether she anticipated this would worsen their view of her husband or of her, as a wife, is unclear. Another respondent, a *shasthyo shebika* (BRIDI BRAC Shebika2) said she knew of a recently married man whose wife left him when he got TB.

"I knew of a case of a newly married man who suffered from TB and his wife just left him for this reason." (BRIDI BRAC Shebika2)

► Financial disruptiveness of TB

Summary: TB disease may be curable, but if at the same time it is financially crippling, it will still be greatly feared. How people cope with TB and how people perceive TB (and therefore the stigma of TB) is influenced by the impact the disease and its treatment has

on the life of a person, a family and a community. This study found that it is the financial impact of TB that is the foremost concern for some TB patients, particularly men of working age with dependents. While TB treatment is available free of charge, TB still causes considerable expense because of the view that nutritious food is necessary for complete recovery, either to counter the effects of TB or to counter the effects of the TB medicine. Furthermore, some patients lose their incomes temporarily because they are unable to work, either due to the disease or its lengthy and time-consuming treatment, and are not entitled to paid sick leave. Others may lose their job as a result of an employer or colleagues fearing TB transmission.

Potential policy implications: TB-related stigma is not just fuelled by knowledge and attitudes, but also by the disruptiveness of TB to people's lives. While TB treatment is free of charge, recovery is still costly, lengthy and disruptive. Measures to reduce the cost, length and disruptiveness of treatment provision need to be considered.

How people cope with TB and how people perceive TB (and therefore the stigma of TB) is influenced by the impact the disease and its treatment has on the life of a person, a family and a community. For example, TB disease may be curable, but if at the same time it is financially crippling, it will still be greatly feared. (Jones et al. 1984) refer to this dimension of stigma as "disruptiveness" and (Goffman 1963) refers to this as "obtrusiveness", with both terms referring to how much TB interferes with 'normal' life and social interactions. This study found that it is the financial impact of TB that is the foremost concern for some TB patients, particularly men of working age with dependents.

"Before getting TB I was working in the cinema hall, but now I am resting. My income has stopped as a result. We can't eat two full meals daily. [] I am always worried about my quick recovery as well as my earnings. I am trying to recover from this disease as quickly as possible. If not, what will be the situation of my family?"
(BRIDIMpt4, male TB patient)

A *shasthyo shebika* interviewed (BRIDI BRAC Shebika2) said that a family (and the patient) worries more if the patient is young and of working age, because of the impact TB and its treatment has on their earning ability. For older patients, who may not be the main income earners for the household and in fact may not be working at all, the disruptiveness of, and therefore the distress caused by, a TB diagnosis is less. As another *shasthyo shebika* put it "*young life is a financial heart of a family*" (BRIDI BRAC Shebika). Thus, young patients without dependents are also likely to struggle less to meet financial responsibilities.

"It is easy to maintain family expenses for a single man" (BRIDIMpt3, male TB patient)

"At present I am thinking about my children. If I were not married, there would be no tension." (BRIDIMpt4, male TB patient)

Just as age is linked to financial circumstances and dependents, so is gender and financial status. A *shasthyo shebika* interviewed (BRIDI BRAC Shebika2) said that men

suffer more depression than women when they get TB (although women may be more worried about their marriage prospects or in-laws) because of their responsibility to provide for their family and the disruptiveness of TB and its treatment on their ability to work.

Supporting this, one of the male TB patients interviewed was very emotional during his interview and wept when he spoke of his inability to provide for his family, saying that if he were not so poor his experience of TB would be different.

"We are poor. If we were landlords our condition might be different. They don't suffer. They have enough money to maintain their family expenses." (BRIDIMpt3, male TB patient)

"I've got TB, it's very unfortunate for me. I can't mix with anyone when I want to, can't move anywhere independently, can't earn money. I'm now dependent on others for my family expenses. Isn't it unfortunate? My wife is struggling to maintain the family. I can't help her at all. Did you see anything more unfortunate than this?" (BRIDIMpt3, male TB patient)

While TB treatment is available free of charge, TB still causes considerable expense. A male TB patient (BRIDIMpt4) described the difficulties of needing to consume nutritious food to speed his recovery, but not being able to afford it.

"At present I am taking more food, but I can't take more nutritious foods because I can't afford the cost. [] Along with nutritious foods I have to take vitamins for quick recovery []. Besides medicine, more nutritious foods should be taken." (BRIDIMpt4, male TB patient)

The view that nutritious food is necessary for complete recovery was shared by many of those interviewed, either to counter the effects of TB or to counter the effects of the TB medicine.

"TB medicines are antibiotics. After taking strong antibiotics vitamin-rich foods should be taken. [] Since having TB, my mother and sister-in-law force me to eat two eggs minimum per day." (BRIDIFpt4, female TB patient)

"When you have TB you experience loss of appetite and weight loss, so for recovery nutritious food should be taken." (PRIDIFpt5, female TB patient)

"Besides medicine, nutritious foods should be taken because TB makes an ulcer in the lungs. Somehow we have to repair that ulcer. If we take nutritious foods then it will help with healing. Otherwise the ulcer will not heal." (BRIDIMpt1, male TB patient)

The belief that nutritious food and vitamins are necessary for recovery is supported by the advice given to patients by the *shasthyo shebika*. One male TB patient (BRIDIMpt1) said the *shasthyo shebika* advised him to take vitamins which she provides him with. Likewise, another TB patient (BRIDIMpt6) has been given vitamin supplements by the BRAC centre to help him with his recovery.

Some patients lose their incomes temporarily because they are unable to work and are not entitled to paid sick leave. Other patients may lose their job as a result of an employer or colleagues fearing TB transmission.

“Even in the case of maid servants, if they get any contagious disease, like this disease, almost every family will avoid them. They don’t employ them in their home as maid servants.” (BRIDIFpt3, female TB patient)

As well as TB disease itself impacting on a person’s ability to work, TB’s lengthy and generally disruptive treatment can also make it difficult for patients to continue earning and managing their responsibilities. A male TB patient (BRIDIMpt1) described taking medicine as hazardous and said TB treatment is particularly difficult as you have to take the drugs at the right time and eat and rest at the right times as well. In addition, it involves going to the clinic daily. For the first few days he felt nausea, but has otherwise not had any side-effects. He was worried for the future as he’d been told that he has to take treatment for 6 months and if he’s not clear then for 9 months, and if still not clear he has to take treatment for the rest of his life. He seemed worried that he’d suspended his life, in particular his marriage and the expansion of his business, for an uncertain length of time.

► **Low self-esteem and worry about fulfilling responsibilities**

Summary: The inability to work or fulfil one’s responsibilities can affect a person’s self-esteem.

Potential policy implications: As with the policy implications of the *Financial disruptiveness of TB*, page 9, TB treatment is costly, lengthy and disruptive making it difficult to balance the need for treatment with the need to work and fulfil responsibilities. Measures to reduce the cost, length and disruptiveness of treatment provision need to be considered. Furthermore, ways of providing emotional support to TB patients, perhaps through support groups, could be considered.

Even in situations where a TB patient’s inability to work does not affect the overall household income, it can still affect the patient’s self-esteem. While a male TB patient said he was still able to continue his work while ill and so his income had not been affected, he did admit that when others have said he should not be working and *cannot* work properly, it has got him down.

“Someone said he is a sick man, he shouldn’t be working, he will not be able to do this work properly on time. Then my mental state became very bad and I thought about shooting myself in the head. In such a situation, I prefer death over life.” (BRIDIMpt5, male TB patient)

Likewise, another TB patient (BRIDIMpt3) spoke of his low self-esteem and low self-worth, exacerbated by the teasing he receives at home and from children in the

neighbourhood; teasing which he implies is justified as he hasn't been able to work for two years.

"[] Sometimes I face teasing from my own home. They have the right to tease me, because I have been continuously sick for two years. I've been unemployed for two years. For two years I am in bed, I can't earn anything for my family. Even children in the neighbourhood tease me. It's very unfortunate, isn't it? Sometimes I think death is far far better than this intolerable life." (BRIDIMpt3, male TB patient)

5. Conclusions

Six effects of stigma associated with TB and their explanations were found:

- Concealment of a diagnosis of TB, because of anticipated negative consequences. Female TB patients and the female relatives of male TB patients appeared to be particularly concerned about possible negative consequences of disclosure.
- Anticipated avoidance/separation of TB patients, because of fear of transmission, and fear of rejection/discrimination.
- Reduced marriage prospects, particularly for woman, in part because good health is a particularly valued attribute of a bride, but also because TB's transmissibility is thought to pose a risk to others. The degree to which unmarried women *actually* face problems getting married following a TB diagnosis is uncertain.
- Family tension and (the threat) of divorce, particularly for women, and especially if the marriage was recent, partly because of overall gender inequities within Bangladesh, and partly because a woman joins her husband's family when she marries.
- Financial disruptiveness of TB, particularly men of working age with dependents. While TB treatment is available free of charge, TB still causes considerable expense because of the view that nutritious food is necessary for complete recovery, either to counter the effects of TB or to counter the effects of the TB medicine. Furthermore, some patients lose their incomes temporarily because they are unable to work, either due to the disease or its lengthy and time-consuming treatment, and are not entitled to paid sick leave. Others may lose their job as a result of an employer or colleagues fearing TB transmission.
- Low self-esteem and worry about fulfilling responsibilities, because of inability to work or fulfil one's responsibilities.

The policy implications of these effects of stigma are summarised in the following table.

Effect of stigma, and explanation	Potential policy implications
Concealment of a diagnosis of TB, because of anticipated negative consequences.	Consider ways to protect patients' (and particularly women patients') confidentiality.
Anticipated avoidance/separation of TB patients, because of fear of transmission, and fear of rejection/discrimination.	Consider the 'side-effects' of harnessing people's fears of TB infection to promote treatment adherence or other health-related behaviours. Increase clarity and consistency (especially for TB patients) on what constitutes necessary precautions (focussing on those which are feasible and socially appropriate) and promoting a positive view of precautions as caring.
Reduced marriage prospects, particularly for woman, in part because good health is a particularly valued attribute of a bride, but also because TB's transmissibility is thought to pose a risk to others.	Increase clarity and consistency on risks of transmission and necessary precautions. Promote positive stories of women with TB marrying successfully.
Family tension and (the threat) of divorce, particularly for women, and especially if the marriage was recent, partly because of overall gender inequities within Bangladesh, and partly because a woman joins her husband's family when she marries.	Address broader gender and structural inequities.
Financial disruptiveness of TB, particularly men of working age with dependents, because TB causes physical weakness, treatment is lengthy and requires regular visits to a health facility and nutritious food is thought to be necessary for complete recovery.	Consider measures to reduce the cost, length and disruptiveness of treatment provision.
Low self-esteem and worry about fulfilling responsibilities, because of inability to work or fulfil one's responsibilities.	Consider measures to reduce the cost, length and disruptiveness of treatment provision. Consider ways of providing emotional support to TB patients, perhaps through support groups.

Two other issues arose strongly from the study:

- Delayed treatment occurs not because patients delay seeking diagnosis and treatment, but because they often initially visit alternative health care providers, because TB symptoms can be ambiguous and initially mild.
- Non-completion of treatment can occur particularly because of the need to travel long distances while weak or suffering from side-effects.

The policy implications of these issues are summarised in the following table.

Issue and cause	Potential policy implications
Delayed treatment occurs because patients often initially visit alternative health care providers, because TB symptoms can be ambiguous and initially mild.	Increase referrals from private and alternative practitioners to ensure rapid diagnosis.
Non-completion of treatment can occur particularly because of the need to travel long distances while weak or suffering from side-effects.	Consider ways of making services and treatment more accessible for patients over the lengthy course of treatment. Promote belief in the importance of adherence to discourage defaulting, but balance this with understanding that TB will be cured (to avoid perpetuating stigma).

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7. Ethical approval

This study received ethical approval from

- the Directorate General of the Health Services, Government of the People's Republic of Bangladesh, ref 5-15/TB-LEP/TB RESEARCH/04-07/10253
- the Ethics Committee of the Faculty of Medicine and Health, University of Leeds.

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