

# Stigma and discrimination associated with TB in Asia

## Research Report

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## 1. Background

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* or *mechanisms*. If we can understand these mechanisms, 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 or mechanisms 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 a 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).

## 2. Objectives

The overall objective of the research study was to gather new empirical evidence and develop further theoretical understanding of the mechanisms of stigma associated with TB in Asia. This objective has been met.

## 3. Methods

This study involved qualitative research methods (in-depth interviews and focus group discussions) and applied the grounded theory approach to develop theory.

Data was collected in three countries: Pakistan, Nepal and Bangladesh. In each case, we intended to collect data from one urban site and one rural site. In each site, we conducted an initial preparatory stage in which contextual information about the two sites was collected.

Interviewees were selected using the theoretical sampling method. This provided sufficient rich, in-depth data from which to develop and refine theories on the causes of TB-related stigma, while also providing sufficient contextual information to enable an assessment of the likely applicability of the findings to other contexts.

## **4. Results**

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.

Similar results were found in all sites, independent of country or urban/rural site. The results given below refer to all sites unless otherwise stated.

### **Pakistan**

Two sites in Rawalpindi district, one urban (Sultan Pura) and one rural (RHC Bagga Sheikhan), were included in the study. In the urban site, of the sixteen in-depth interviews conducted, five were with female TB patients, five with male TB patients, four with family members of TB patients and two with health workers. A focus group discussion was conducted with a group of seven married female community members. In the rural site, of the fifteen in-depth interviews conducted, five were with female TB patients, five with male TB patients, three with family members of TB patients and two with health workers.

### **Nepal**

Two sites in Lalitpur district, one urban (Lalitpur sub-metropolitan city in Kathmandu valley) and one rural (Godawari and Badikhel village development committees combined) were included in this study. In each site, sixteen interviews were performed, comprising five interviews with female TB patients, five with male TB patients, four with family members of TB patients and two with health workers. In addition, in the rural site, six focus group discussions were conducted, one with female TB patients, one with male TB patients, two with female community members and two with male community members.

### **Bangladesh**

Although both a rural and an urban site were selected for inclusion in this study, data was obtained only from the rural site, Norshingdi district. This was because of political unrest and prolonged illness of one of our data collectors: it proved impossible to identify a suitably trained interviewer with appropriate local knowledge to replace him. Twelve in-depth interviews were conducted: five with female TB patients, five with male TB patients and two with health workers (shasthyo shebikas).

### **Implications of incomplete data from Bangladesh**

The similarities between the findings from the five sites from which data was successfully obtained, and the similarity of broad policy implications, suggests that our inability to get data from the urban site in Bangladesh is likely to have limited impact on the overall findings and policy implications.

#### **4.1. Perceived hatred towards TB patients**

Self-protective behaviours arising from a fear of infection are both seen as justified or natural and, paradoxically, are interpreted as signs of hatred towards a TB patient because

precautions against TB transmission (reduced proximity and increased separation) are in direct opposition to caring behaviours. Whether avoidance, for example, is interpreted as simply a precaution or as hatred depends on the emotional state of the patient (feeling unwell heightens sensitivity), what precautions are deemed necessary, who initiates them and how noticeable the avoidance is.

Confusion as to what precautions are necessary to prevent the transmission of TB is likely to arise from differing advice given to patients and/or those accompanying them by different health workers or by the same health worker to sputum positive and negative patients, and pulmonary and extrapulmonary TB patients. Advice on necessary precautions also needs to be balanced with the cost and feasibility of enforcing them. The less close or valued the relationship previously and the more feasible a precaution is both practically and within the bounds of social norms and customs, the more likely it is to occur.

*“It is not a matter of hatred, but people should take some precautions” (PRIDIFM1, sister-in-law of a male TB patient, rural site).*

*“Our society hates [TB patients] and [people] don’t sit near a TB patient, they don’t eat from his plate or sit and stand near him to chat. [They think] this will infect us also. [ ] It is an infectious disease.” (PUIDIFM4, mother of a male TB patient, urban site)*

*“In our Nepali society, if it is said you should not get close [to someone with an illness] then people get scared and think badly [ ] Like if it is said it can transmit then people get scared to touch also.” (NUIDIFM2, son of a male TB patient, urban site)*

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. Indeed, there is a general understanding that self-protective behaviours or precautions can be hurtful to a patient and can be counter to norms of etiquette, so sometimes obvious precaution-taking is avoided.

The message that anyone can get TB and that this is ultimately determined by Allah serves to counter negative suggestions of blame or responsibility, but runs the risk of implying that precautions are futile.

**Potential policy implications:** Increasing clarity (especially for TB patients) on what constitutes necessary precautions and promoting those which are feasible and socially appropriate, and can therefore be interpreted positively, is important for both TB-related stigma and TB control. Messages that TB is preventable need to be balanced against the potential implication that those with TB have therefore been careless or are to blame.

If perceived vulnerability to TB and the consequences of TB increases fear of TB (and therefore fear of people with TB) then increasing risk perceptions may increase stigma. Reducing vulnerabilities, rather than simply increasing risk perceptions, is likely to reduce stigma.

## **4.2. Concealment of a TB diagnosis**

Most of the patients interviewed disclosed their TB diagnosis to their immediate family members either because they saw no need to conceal the diagnosis (particularly as TB is now curable), because disclosure was unavoidable or because they considered disclosure beneficial or necessary in order to get support from others. Beyond the immediate family, patients tended to be more selective about who they disclosed to, although concealing a diagnosis can be futile, difficult (given the need to access and take regular treatment over a

long period of time) and impossible (e.g. if the health worker has decided not to tell the patient s/he has TB to prevent them worrying). Some patients reported intentionally not disclosing, if they were able, to those with whom they have distant or poor relations on the grounds that disclosure is not necessary and may simply worsen poor relations. Another important reason for non-disclosure was the anticipation of being avoided by others because of their knowledge and fear of TB's transmissibility.

*"The fear is if TB is diagnosed, will people avoid me? Maybe my family members will not behave well with me. And it might cause problems for other people, like they might suffer from it. This is the fear."* (PUIDIFcp1, health worker, urban site)

*"I was scared if he disclosed it to my husband [ ] And after that, if they ... if neighbours will know, then..."* (NRIDIFPt2, female TB patient, rural site)

*"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)

**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. Non-disclosure of a TB diagnosis by a health worker to a patient in order to prevent the patient from worrying, while well meant, is likely to uphold the perception that TB is fearful. Increasing knowledge that TB is transmissible, without emphasising that it ceases to be transmissible after just two weeks of treatment and without clarifying which precautions against transmission are effective and necessary, is likely to discourage disclosure as patients will fear being avoided by others.

### 4.3. Gossip and speculation

This issue arose primarily in interviews in Pakistan, and was not a major issue that arose in interviews in Nepal or Bangladesh. Some TB patients in Pakistan worry about gossip (particularly by women, about women with TB) and may conceal a TB diagnosis as a result. However, concerns about gossip are likely to be disease- rather than specifically TB-related, although the potential impact of TB on marriage prospects, household finances and the ability to fulfil responsibilities may contribute to its suitability as a topic of negative conversation.

*"I didn't tell [people about my son's TB] because our people gossip, you know people gossip. [ ] In every society people gossip, as is our tradition in Pakistan."* (PUIDIFM4, the mother of a male TB patient, urban site)

*"Men mostly live outside the home so if they do something wrong their mistakes are always hidden, whereas women live in the home, so even if they are at home behind closed doors, in spite of this people would say that she must be doing something wrong inside her home."* (PRIDIFpt2, female TB patient, rural site)

**Potential policy implications:** Reducing the social impact or disruptiveness of a TB diagnosis is likely to reduce its value as a topic for gossip.

### 4.4. Reduced social interaction of TB patients with others

In Nepal, but not elsewhere, it was reported that as well as selectively disclosing their TB status to others, patients may also avoid social interactions with others because they feel too

ill, they want to protect others from TB transmission or so that others are not able to avoid interactions with them. While self-initiated separation is, or at least can be, interpreted by the patient and others as the patient caring for and protecting others, separation from the patient initiated by others is more likely to be interpreted as uncaring.

*“Some [patients] keep a distance from others themselves. They do not go close to their friends. [ ] They think ‘I have TB, why make others suffer?’” (NUIDIFTBV1, female health worker, urban site)*

**Potential policy implications:** See *Perceived hatred towards a TB patient*.

#### 4.5. Anticipated avoidance/separation of TB patients

In Bangladesh, 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 (especially when symptoms are apparent) and health workers may sometimes harness people’s fears of transmission to encourage healthy behaviours, such as treatment adherence.

*“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)*

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.

*“[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)*

*“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)*

**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.

#### 4.6. Reduced marriage prospects

Incapacitating and lengthy illness (or illness requiring lengthy treatment) is likely to impact on the marriage prospects of those hoping or planning to marry soon and this is further compounded if the illness is perceived to be transmissible. For a prospective wife or daughter-in-law in particular, in a context where many marriages are arranged, good health and the ability to work hard are highly desired and the cancellation of an already agreed marriage can rouse speculation and gossip. However, other highly desired characteristics, such as being a cousin in areas where cousin-marriage is favoured, can outweigh the undesirability of poor health and postponing the marriage until the patient is cured. However, where eligible marriage partners are few, postponing a marriage for the 6+ months of TB treatment can jeopardise marriage prospects, especially for a woman, who cannot guarantee she will receive suitable proposals in future and whose optimum marriageable age range is narrower than men's.

*"If the boy is not financially strong then no one will consider him [for marriage], but if the boy is financially strong then [they] will." (Lady Health Worker, rural site)*

*"No one will get married to a diseased person. Everyone looks first and only then gets married. [ ] Like if she has a disease and if there are any diseases amongst her family members, like that they marry someone who is able to work." (NRFGDMcm1-R3, male focus group participant, rural site)*

*"[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)*

*"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)*

**Potential policy implications:** The later the diagnosis or the more severe the TB, the more debilitating the illness and potentially the lengthier its treatment. Therefore, earlier diagnosis and treatment is needed, especially for women (see Delayed treatment) and in areas with high rates of arranged, but not cousin-marriage, where female education/employment is low and the average age of marriage for a woman is low.

#### 4.7. Family tension and (the threat of) divorce

While divorce as a result of a TB diagnosis does not appear to be common and is unlikely to occur as a result of the TB diagnosis alone, it may occur, be threatened or advised if the marriage was recent and not wholeheartedly approved of by the family, and in particular the husband's family. More common than divorce is tension within a family and particularly between a female TB patient and her in-laws (especially if they are living together), which may exist prior to the TB illness, but can be exacerbated by the illness. In Nepal, divorce was not mentioned as a risk, but concerns about family tension remained.

*"His mother said 'you have brought an ill girl from Lahore. Who told you to marry out of this family?' That is why she was divorced. [ ] In spite of [knowing TB is curable] they forced their son to divorce his wife because it was a love marriage." (Lady Health Worker, PRIDIFpt4)*

*“Everybody told my mother-in-law and husband to leave me as I have got TB. So go for a second marriage. She will never get cured. When you have kids they will also have TB” (PUIDIFpt2, a married female former TB patient, urban site).*

*“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)*

**Potential policy implications:** Address broader gender and structural inequities

#### **4.8. Financial disruptiveness of TB**

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. Although TB drugs are provided free of charge from Government and NGO health facilities (benefiting patients so long as they are aware of this and the required drugs are in stock), becoming ill with TB can have a substantial financial impact on households because TB causes physical weakness (making it difficult to continue working or find work), treatment is lengthy and requires regular visits to a health facility (requiring time off work and therefore lost income, and incurring travel expenses) and nutritious food or supplementary vitamins are thought to be needed to counter the side effects of TB drugs and to ensure full recovery. The prior financial situation of a household, the opportunities for financial support, whether the TB patient has dependents and responsibilities, and the nature and flexibility of a person’s work determine the extent of the disruptiveness of their TB illness and its treatment on the household.

*“It is a lengthy process, for eight months. How to get the medicine, how to take the medicine, there are thousands of worries. There is also a problem of fares. They do not have fares to go to hospitals to take medicines. Some of the patients who are poor, I help them. I go to their homes and give them medicines.” (PRIDIFcp3, female health worker, rural site)*

*“How much can we earn? I myself am so weak, where can I go to earn? [ ] Some times I borrow from friends. [ ] I have my father at home. [ ] Everything I have to do, I need to take care of him.” (NRIDIMpt3, male TB patient, rural site)*

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

**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 (such as incorporating flexibility and outreach into DOTS). Awareness that TB treatment is provided free of charge at Government facilities could be promoted as well as ensuring adequate drug supplies. Furthermore, private and alternative practitioners need to be able and willing to refer patients suspected of having TB.

Increasing clarity (especially for TB patients) on what constitutes necessary precautions and promoting those which are feasible is important for both TB-related stigma and TB control.

#### 4.9. Worry about fulfilling responsibilities and being a burden

Although the TB patients interviewed generally described their families as supportive, some felt worried about being a burden to their families and about not fulfilling their responsibilities, impacting on their self-esteem. As with the financial impact of TB, the extent to which a TB patient worries about not being able to fulfil responsibilities depends, in part, on what responsibilities he or she has. For example, the perceived heightened susceptibility of babies and young children can make fulfilling parental responsibilities difficult and this in turn can be emotionally difficult to cope with for both parent and child.

*“I got really sad, was thinking what a long treatment.” (PRIDIFpt7, female TB patient, rural site)*

*“When my mother [-in-law] cries I had to do many things, like I have to send the children to school. At the same time food has not been prepared and I have fetch water. But mother is crying in front of me. Then sometimes I scold her. [ ] I forget she is ill when I scold her. [ ] Then later I regret it.” (NUIDIFFM3, daughter-in-law of a female TB patient, urban site)*

*“[ ] 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)*

**Potential policy implications:** The later the diagnosis or the more severe the TB, the more debilitating the illness and potentially the lengthier the treatment. Therefore, earlier diagnosis and treatment is needed (see *Delayed treatment*). Furthermore, measures to reduce the cost, length and disruptiveness of treatment provision need to be considered and support for patients and their families to help them cope emotionally with a TB diagnosis and its impact may be helpful. See also *Financial disruptiveness of TB*.

#### 4.10. Blame and guilt for TB infection

The view that TB is transmissible from one person to another implies for some that one person *gives* TB to another and is therefore responsible for doing so. Likewise, some of the TB patients interviewed blamed themselves or felt guilty at the prospect of transmitting the disease to others: this issue arose primarily in Pakistan and Nepal.

Some other explanations put forward for why someone has TB (such as carelessness) suggest a person has a degree of control as to whether or not they become infected or infect others. However, to counter such explanations, including the negative implications of TB being passed from one person to another, a number of respondents spoke of TB, as with any disease, coming ultimately from God and that it is therefore nobody’s fault.

*“My young niece got sick and she went to her maternal grandmother’s house, so her grandmother said that she had shared some food with her aunt so maybe she’s got the same disease. So then she went for a check-up, but she didn’t have it. I felt so bad. I thought to myself they have doubted me.” (PRIDIFpt5, female TB patient, rural site)*

*“You know how our people [ ]. ‘He has infected us. We sit and stand with him, that’s why we also got infected. We have to protect ourselves from him.’” (PUIDIFM4, mother of a male TB patient, urban site)*



**Potential policy implications:** Increasing knowledge of and emphasis on TB's transmissibility and patients' ability to prevent transmission by taking precautions may increase blame and guilt. This needs to be considered when TB control policies and programmes are designed and implemented.

## 5. Activities

Bethan Hatherall presented the interim results of this project to the Fourth International Stigma Conference, 21<sup>st</sup>-23<sup>rd</sup> January 2009, London, UK.

We intend to present the results at the next annual SAARC meeting of TB Programme Managers, and at the next World Lung Conference.

## 6. Impacts

Prior to development of the research proposal, the National TB Programme Managers in each of the three countries subsequently involved in the research (Bangladesh, Nepal and Pakistan) identified as a national priority the need for better understanding of the causes of stigma and discrimination associated with TB. This ownership of the research by the Programmes continued throughout the study, and regular feedback of progress to the Programme Managers, is now facilitating transfer of the research findings to policy and practice.

We have held dissemination and strategy development workshops in each of the three countries. In each case the National TB Programme Manager was an active participant in the workshop: in Pakistan, the four Provincial TB Programme Managers were also involved. The research findings and broad strategy arising from the workshops has been endorsed by the Programme Manager (and in the case of Pakistan, also by the Provincial Managers).

We are in the process of helping the Programmes in each of the three countries to refine the broad strategy into specific actions and messages, and incorporate this into guidelines and training materials and methods. This process dovetails with other work we are doing to update guidelines and training materials and methods to incorporate other changes in national policies informed by other research we have been involved in.

We are in the process of preparing articles based on this work for publication in academic journals. We will place results and reports on the COMDIS website.

## 7. Outputs

Hatherall B (2009). Understanding TB-related stigma in Asia: Pakistan. University of Leeds research report.

Hatherall B (2009). Understanding TB-related stigma in Asia: Nepal. University of Leeds research report.

Hatherall B (2009). Understanding TB-related stigma in Asia: Bangladesh. University of Leeds research report.

(Reports are available on Society Today (click [here](#)) or search Awards & Outputs for stigma TB at [www.esrcsocietytoday.ac.uk](http://www.esrcsocietytoday.ac.uk) or on [www.comdis.org](http://www.comdis.org))

## 8. Capacity Building

The project has developed not only capacity in qualitative research methods in the three countries, but more importantly, a much greater understanding of the role, process and

importance of qualitative research within three research institutions (the Association for Social Development, Pakistan; SEED, Bangladesh; and the Health Research and Development Forum, Nepal), and the three National Tuberculosis Programmes in the research site countries.

## 9. Project Linked Doctoral Studentships

Although the project does not have a formal linked doctoral studentship, Bethan Hatherall has enrolled for a PhD at the University of Leeds based on this work. Beth is currently on maternity leave.

## 10. Future Research Priorities

Stigma is a major cause of distress and delay in diagnosis and treatment of many diseases, both in low-income countries and elsewhere. Better understanding of mechanisms of stigma associated with different diseases might

- assist in stigma reduction for those diseases, thereby reducing distress and delay in diagnosis and treatment
- give better understanding of how stigma operates in people multiply affected by stigma (eg those with both TB and HIV/AIDS)
- give better understanding of how stigma changes over time (eg the stigma associated with cancers in Europe is considerably less than it used to be: is this merely because survival is now much better than it used to be, or do other mechanisms play a part?).

## 11. References

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