

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

Effect of stigma, and explanation	Potential policy implications
Perceived hatred towards TB patients, because of confusion between self-protective measures and hatred, confusion about risks of transmission and necessary precautions; and notions of blame and responsibility.	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.
Concealment of a diagnosis of TB, because of anticipated negative consequences, lack of knowledge that the patient has TB, or lack of knowledge about the infectivity of TB.	Ensure health workers properly inform patients that they have TB. Ensure patients and the wider community understand patients cease to be infectious after two weeks of treatment.
Fear of gossip and speculation may encourage patients to conceal their diagnosis.	Identify ways to reduce the social impact or disruptiveness of a TB diagnosis, to reduce its value as a topic for gossip.
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. This is tempered by positive factors such as close family relationships and earning power.	Early diagnosis and treatment, especially for women 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.

Family tension and (the threat) of divorce, particularly for women, and especially if the marriage was recent, partly because of overall gender inequities within Pakistan, 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.	(1) Consider measures to reduce the cost, length and disruptiveness of treatment provision. (2) Promote awareness that TB treatment is provided free of charge at Government facilities. (3) Encourage referral of suspects by private and alternative practitioners.
Worry about fulfilling responsibilities and being a burden, 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.
Blame and guilt for TB infection, because of knowledge of the infectivity of TB.	Consider the effect on blame and guilt of strategies to increase knowledge of and emphasis on TB's transmissibility and patients' ability to prevent transmission by taking precautions.

Two other issues that arose strongly from the study 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 of the need for an escort for women; and because of a lack of money and time.	Increase referrals from private and alternative practitioners to ensure rapid diagnosis. Increase access to health services, particularly for women and for those living far from health facilities.
Non-completion of treatment can occur because of the need for an escort for women; because of a lack of money and time; and because of problems when patients move from one facility to another.	(1) Increase access to health services, particularly for women and for those living far from health facilities. (2) Promote family support. (3) Consider measures for improving the integration of services to allow patients to move their treatment seamlessly from one facility to another.

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 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). 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. The study and this report set out to do just that.

2. Aim

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

This report presents and discusses the findings for Pakistan only.

3. Methods

This study involved qualitative research methods (in-depth interviews and focus group discussions) and applied the grounded theory approach; an established and rigorous approach to developing theories through the process of qualitative data collection.

Two sites in Rawalpindi district, one urban (Sultan Pura) and one rural (RHC Bagga Sheikhan), were selected for inclusion in this study. Following an initial preparatory stage in which contextual information about the two sites was collected, sixteen in-depth interviews and one focus group discussion were conducted in the urban site and fifteen interviews were conducted in a rural site, 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.

Of the sixteen in-depth interviews conducted in the urban site, five were with female TB patients, five were with male TB patients, four were with family members of TB patients and two were with health workers. The focus group discussion was conducted with a group of seven married female community members. Of the fifteen in-depth interviews conducted in the rural site, five were with female TB patients, five were with male TB patients, three were with family members of TB patients and two were with health workers.

4. Findings

Before considering what underlies TB-related stigma in the urban and rural sites in which this study was conducted, it is important to have an overview of the general context of TB and stigma in Sultan Pura and RHC Bagga Sheikhan. 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. Potential policy implications have also been put forward for discussion and further development.

4.1 Local concepts of TB

'TB' seems to be the most commonly used term for *tuberculosis* in both the rural and urban sites, which, according to a health worker in the urban site, is largely attributable to the media. According to a health worker in the rural site the term 'TB' is most commonly thought of as a lung disease. While other terms such as *sokma* and *tapediq* exist, they are not specifically or exclusively used for TB. While the TB patients interviewed spoke just of their TB, the health workers spoke of different types of TB, with one referring to pulmonary and extrapulmonary TB (PRIDIMcp1) and another distinguishing between sputum positive and negative TB, describing the former as a little dangerous and the latter as nothing for the patient to worry about (PUIDIFcp1).

From the perspectives of the TB patients interviewed, other diseases and initial symptoms are thought to be able to develop into TB, suggesting a perceived interconnectedness between diseases.

*"[] there was water in my lungs and pneumonia and now it has become TB"
(PUIDIMpt5, male TB patient, urban site)*

While cancer may be feared more than TB as it is seen as fatal, it is TB's transmissibility that contributes to the perception that it is dangerous. The sister-in-law of a TB patient said *"it is a dangerous disease as all live together and there is a fear that all will get it"* (PRIDIFM1). A male TB patient felt that a negative perception of TB still lingers from the past when TB was thought of as transmissible *and* incurable, requiring patients to be

isolated in sanatoria, while other interviewees suggested it is still considered a “big” disease, unlike a flu or cough, as cure and recovery take a long time.

While some of those interviewed said that TB is not viewed as a lifelong affliction and does not necessarily have a direct impact on people’s lives after cure, the experience of having had TB can remain in people’s memories. A female TB patient whose brothers had also had TB in the past spoke of how the disease is curable, but that the label of having had TB sticks (PRIDIFpt5). A health worker said that while people recover fully from TB, the experience always stays with them and in future, when they feel unwell, they wonder whether the TB has come back. Indeed, he said TB is known for its persistence and reoccurrence (PRIDIMcp1).

4.2 The nature of people’s experiences of TB

A persistent cough which does not respond to cough remedies was generally recognised by respondents as a tell-tale sign of TB, especially if they or a family member or friend had personally known someone with similarly symptomatic pulmonary TB previously.

“Because of my cough, my family members said you must go for a TB test. We knew that at that place there is a facility for testing for TB. My brother said that I should go for a check-up.” (PRIDIMpt1, a male pulmonary TB patient in the rural site whose aunt had previously had similar symptoms and been diagnosed with TB)

However, the TB patients interviewed reported a wide range of initial symptoms, many of which were ambiguous, mild or atypical. A female TB patient (PRIDIFpt5) described how she had headaches, pain in her ribs and a fever, but no cough, while another patient (PRIDIFpt4) said she only had a cough. The mother-in-law (PRIDIFM2) of a female TB patient described how while her husband had had a severe cough which made her suspect TB, her daughter-in-law initially had very different symptoms, namely problems with her stomach and mouth, and is likely to have had extrapulmonary TB.

Many of the patients described the long process they went through before finally being diagnosed with TB, especially if they had extrapulmonary TB, but also if they had pulmonary TB. A female pulmonary TB patient in the urban site (PUIDIFpt1), whose initial symptoms included fever, weakness and throat infections, went through a lengthy process of consulting various doctors, going for various inconclusive tests and taking various unsuccessful treatments. It took several doctors before TB was diagnosed as initially the doctors she saw said that what showed on her x-ray was not current TB infection, but the remnants of TB she had had as a child. Only after another four months did she see another doctor who this time, based on the same x-ray, diagnosed current pulmonary TB. Another TB patient (PUIDIMpt2) described how initially he consulted a few doctors about his fever and persistent cough and was given injections for the fever which only helped temporarily. It was not until he vomited blood that he himself decided to go directly to the TB clinic for testing as his father who had previously had TB had also had this same symptom.

When the reactions of the TB patients interviewed to their TB diagnoses were explored, it was apparent how varied and multifaceted reactions are. Some felt relief (particularly those who had been ill for a long time and had previously been misdiagnosed), many were worried and some were surprised.

"If the patient was not diagnosed initially, he will have been worried because he'd have been taking treatment but not getting better. So then he is satisfied that at least the illness has now been identified. Family members are also satisfied that the illness has been identified. [However], if somebody has this illness all of a sudden, then it is a shock for them." (PRIDIMcp1, male health worker, rural site)

Being worried and unhappy about a TB diagnosis is considered natural as no one is happy about being ill.

"Disease is disease after all." (PUIDIMcp1, male health worker, urban site)

"Patients [] feel that they are ill. 'I am suffering from this type of disease. I don't feel good about sitting with others. This is the mental effect.'" (PUIDIFcp1, female health worker, urban site)

However, while saddened by their illness, some patients were additionally worried about its curability and confidence that it is curable, through having been reassured by a health worker or having known someone who has been successfully cured, seems to lessen the worry. A male TB patient (PUIDIMpt9) described how he was not particularly worried when he received his TB diagnosis as he knew that TB is now curable and the doctor reassured him of this as well. The mother-in-law (PUIDIFM1) of a female TB patient said that she had seen TB patients successfully cured at the health facility where she works as a sweeper and her daughter-in-law had a nephew who had had TB and been treated successfully, so neither of them were worried.

Even when a patient knows that TB *can* be cured, they may still worry about *whether* it will be cured for them, as treatment takes a long time and while the drugs are available free-of-charge, additional expenses for travel and nutritious food or vitamins deemed important for full recovery are incurred. Patients also worry that their illness and the need to attend a health facility regularly for treatment will make it difficult for them to manage their responsibilities. A health worker in the urban site (PUIDIMcp1) said that young unmarried women with TB worry about their marriage prospects, about taking treatment for such a long time and how they will afford it, and about finding someone to accompany them on the frequent visits required to the health facility. Two female TB patients in the rural site (PRIDIFpt4 and PRIDIFpt6) were both initially worried about who would take care of their children, but received consolation and practical support from others.

"I was worried thinking 'when will the nine months [of treatment] be over?'. 'Will I get better or not?' [] I was worried about my daughters. I used to think now that I am suffering from this disease what will happen to my daughters, who will take care of them?" (PRIDIFpt4, a married female TB patient in the rural site who lives alone with her young children and whose husband works overseas)

A health worker said that the immediate effects on a TB Patient are the symptoms, the inability to work and the social isolation from other people.

"He gets fever and for some days he can't go to work, then he is socially cut off from people. These are the immediate effects on him." (PUIDIMcp1, a male health worker, urban site)

Like the reactions of patients, the reactions of their family members ranged from relief to concern, though generally they were described as caring and supportive.

Some patients who had been ill for a long time and had sought treatment from various providers said that their family members were relieved when their TB was finally diagnosed.

"[Relatives and neighbours] were happy to know that the disease had been identified. [] They were happy that at least it is known what is wrong." (PUIDIFpt10, female extrapulmonary TB patient in the urban site who had been ill for a year and had undergone surgery twice)

Another TB patient (PUIDIMpt9), with pulmonary TB, said that his wife was obviously worried about his illness, but relieved that he had been diagnosed and is now taking medicine which had improved his breathlessness.

A number of TB patients interviewed described how their family members in particular had been supportive and caring since they had become ill. An unmarried female pulmonary TB patient (PUIDIFpt6) living with her parents and siblings, described how her mother and friends had become more caring towards her since her illness and likewise a male pulmonary TB patient (PUIDIMpt2) said that his children had become more caring towards him since he had become ill. Similarly, another male TB patient said:

"[My wife] is totally fair with me []. My family members are alright with me. [] In fact it's just that they care more now than before []. Since I have been ill, they are taking more care of me." (PUIDIMpt9, male pulmonary TB patient, urban site. The family members he is referring to are his non-relative in-laws living next door)

4.3 The nature of stigma within those experiences

Some of the health workers interviewed spoke of TB-related stigma, using the English word "stigma". A health worker in the urban site (PUIDIMcp1) linked stigma with reduced marriage prospects for women and TB's association with low income and lack of cleanliness, saying that the disruptiveness and difficulty of treatment contributes to its stigma. Another health worker (PRIDIMcp1), in the rural site, also linked TB stigma with reduced marriage prospects for women, as well as gossip, and similarly theorised that the stigma attached to TB is a consequence of its lengthy treatment which he blamed on a lack of investment in medical research.

"For girls it is stigma. People gossip that a girl has TB. [] People might not like to sit with her. It also creates problems with marriages. Definitely there is a stigma attached to it, especially among girls. [] There is more stigma attached to [TB] because people have to take medicine for a long time. If TB could be cured in one week then there would be no stigma attached to it." (PRIDIMcp1, male health worker, rural site)

Reduced marriage prospects and gossip were also mentioned as negative consequences of TB disease by many of the TB patients and their family members

interviewed. Overall the negative consequences of TB that were apparent from the data were:

- Perceived hatred towards TB patients
- Concealment of a TB diagnosis
- Gossip and speculation
- Reduced marriage prospects
- Family tension and (the threat of) divorce
- Financial disruptiveness of TB
- Worry about fulfilling responsibilities and being a burden
- Blame and guilt for TB infection

However, it is important to note that most of these negative consequences, while sometimes TB-related, are not always and inevitably TB-specific. This means that they do not constitute reliable indicators on their own of the existence of TB-related stigma and need to be explored within the wider context of people's lives.

From the interviews with TB patients and family members of TB patients, as well as the focus group discussion with female community members in the urban site, it is apparent that the expression of negative attitudes, emotions or behaviours (i.e. stigma) is often subtle and open to interpretation and that it is generally deemed inappropriate or unacceptable to be openly and obviously negative towards a TB patient.

*"Nobody talks [to your] face. They must be doing it deep down in their hearts"
(PUIDIFM3, mother of a female TB patient, urban site).*

"If I came to your home you would not make it obvious of course, but it must be in your heart that he has this problem" (PUIDIMpt9, male TB patient, urban site).

Furthermore, those interviewed generally felt that once a patient is cured, they no longer experience any problems at all.

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 little suggestion that health workers experience any kind of TB-related courtesy stigma, although one female health worker did say her family are fearful of her getting TB because of the nature of her job.

"My husband tells me daily to change my job. 'God forbid after retirement you might have a cough'. Daily he discusses it with me." (PUIDIFcp1, female health worker, urban site)

However, a male health worker in the rural site (PRIDIMcp1) said that in his experience people generally do not think a doctor can get TB.

"Usually people think that doctors can not have any disease. [] They might think that doctors already take precautions or medicines." (PRIDIMcp1, male health worker, rural site)

Other health workers interviewed said their family and friends were very supportive (PUIDIMcp1) and that they got enormous satisfaction from treating TB patients (PRIDIMcp1).

While TB is viewed as a 'family disease', any negative attitudes, emotions or behaviours towards family members of a TB patient are embedded in existing relations between those family members and their wider social networks and so cannot irrefutably be attributed to TB. Indeed, it is not surprising that TB is viewed as a family disease, as even one of the health workers interviewed (PUIDIMcp1) emphasised the importance of asking a patient about their family history of TB as usually more than one person in a family has TB. Consequently, when a patient learns that he or she has TB, the patient is particularly surprised by the diagnosis if no one in his or her family has had TB previously.

"I had an idea that I might have TB as TB is very common in our family. My two elder brothers had TB, as did my grandmother. It is in our family. [] I knew that I might be ill because of that." (PRIDIFpt5, female TB patient, rural site)

However, although this respondent herself described TB as a disease of her family, she viewed it negatively when others described it as such, suggesting the context in which it is said and by who is important as to whether it is interpreted as negative or simply factual.

"This comes from Allah this disease. You shouldn't taunt somebody about this. Our relatives have taunted us a lot. [] They say 'they are the ones with TB, their whole family has TB'. [] Once my mother met this woman [] who referred to us as 'the ones with TB'. My mother cried so much, she said 'it has happened to my sons, I wish everybody would get it. She has taunted me'. (PRIDIFpt5, female TB patient, rural site)

In the focus group discussion with female community members in the urban site, the interpretation of TB as a 'family disease' was explored. After a lengthy discussion as to whether TB is hereditary or infectious, the group concluded that TB can pass from one generation to another or from one family member to another if not cured, but that once a family member is cured of TB, it can no longer be passed either vertically or horizontally. In this way TB *can* be a family disease, but is not inevitably or permanently a family disease.

A TB patient interviewed speculated that because TB is known to be infectious, some people *may* keep their distance from the family members of a TB patient suspecting that they may have TB as well, but he had not experienced or witnessed this himself.

"I have heard this that if one family member gets it, then another one can get it too. [] Yes, all the family members could become suspects and will get it too." (PUIDIMpt9, male TB patient, urban site, who believed he got TB from his sister-in-law)

Despite the knowledge that TB is transmissible, multiple explanations as to why one family member has got TB exist. The mother of a TB patient (PUIDIFM3) acknowledged that multiple family members often get TB, as indeed had been the case in her own family, and suggested this may be caused by something in their food, or because it is

transmissible or even hereditary. However, she believes her daughter got TB due to weakness.

4.4 Public health implications

In TB control, rapid identification of new cases of TB and adherence to TB treatment regimens are seen as crucial. Consideration is therefore given to what this research reveals about TB patients' reasons for delayed treatment and defaulting from treatment regimens and the influence, if any, of stigma.

► Delayed treatment

Summary: The patients interviewed did not tend to delay seeking treatment, but sought treatments and diagnoses from multiple health care providers before eventually being diagnosed with TB at a government health facility. Where a person seeks treatment from is influenced in some cases by positive experiences of, or recommendations from, other people. From the interviews, when treatment seeking from Government facilities is delayed it seems not to result from stigma particularly, but most commonly to result from a lack of money and time, especially if living at a distance from a health facility, and dependence on others escorting a, usually female, patient.

Policy implications: Easy and convenient access to health services may encourage quicker treatment seeking providing the cost, in terms of money and time off work, is minimal. Accessing health facilities is particularly problematic for women and those living at a distance from health facilities.

The data indicates that recommendations and previous positive experiences are important influences on health seeking behaviours and so word-of-mouth within communities and consistent, patient-focussed health service provision are likely to promote treatment seeking at government facilities. Furthermore referrals from private and alternative practitioners could play an important role in promoting case findings.

The patients interviewed did not tend to delay seeking treatment, but sought treatments and diagnoses from multiple health care providers before eventually being diagnosed with TB at a government health facility. Because the symptoms of TB can be ambiguous and initially mild, patients often self-treated first with known remedies such as paracetamol. Some opted, on the advice of elder women, for (additional) alternative therapies such as *dum* (verses read from the Quran to relieve symptoms) or *haddi jor* (a traditional orthopaedic doctor who, through massage, repairs damaged joints and broken bones). When these first line treatments were found not to provide sustained improvement, symptoms worsened or new symptoms considered indicative of something more severe appeared, further treatment was sought. For example, the mother of a TB patient (PRIDIFM4) spoke of initially giving her son panadol[®] for his fever which then improved, but when his symptoms worsened she took him to the hospital. A health worker (PRIDIMpt1) said that if someone coughs blood that person will go to the doctor,

even if he has already been suffering with a cough for three months, because coughing blood is considered a serious symptom.

Where a person seeks treatment from is influenced in some cases by positive experiences of, or recommendations from other people. A health worker in the rural site (PRIDIFcp3) said that if a patient has had a family member who was successfully treated at another facility then they too want to be treated there. Likewise a TB patient (PRIDIFpt4) interviewed said that she initially went to a private clinic which had previously successfully treated her daughter for another condition.

From the interviews, when treatment seeking is delayed it seems most commonly to result from a lack of money and time, and not particularly from stigma. A health worker said that even though TB medicines are provided free of charge, if someone is struggling financially and has to pay for diagnostic tests, medicine or travel expenses to health facilities, they delay seeking treatment at government health facilities (PRIDIMcp1).

Interrelated with the issue of money is the issue of time. A male TB patient interviewed (PUIDIMpt2) said he had lost weight recently and his family were worried that his TB might have relapsed. Although he planned to get tested, he said he just had not yet found the time. Health workers in both the urban (PUIDIFcp1) and rural site (PRIDIFcp3) spoke of the need for queuing, waiting and testing over the course of several visits before a TB patient is diagnosed and starts treatment and how this frustrates patients and causes some to give up and seek more immediate treatment elsewhere.

“Whatever the disease, they don’t go to the hospital because they think that today I will go to the hospital, tomorrow I will also have to go to the hospital to get my tests. [] They think of the money that they will spend on fares to visit the hospital which they can use instead to buy medicine from the private clinics. [] In private clinics they just prescribe medicine to the patient. [] I have one patient who I’ve told should go for a check up, but he says I will go tomorrow or the day after tomorrow. Now he is in Rawat on business. He is saying I am busy with work. I asked him ‘is your work more important or your health?’ He said ‘both things are important but what can I do, I have started my work’.” (PRIDIFcp3, female health worker, rural site)

As with the patient described by the health worker in the quote above, a male TB patient (PUIDIMpt5) explained that when a clinic referred him for tests at a hospital, he delayed going for two months as it was the wheat harvesting season and he needed to work.

Exacerbating the difficulty of finding time to seek treatment at a government health facility is the difficulty one extrapulmonary TB patient faced when she moved to her village from Rawalpindi where she was initially diagnosed and treated. She found that in order to continue her treatment from the clinic nearest to her village, she was required to undergo diagnostic testing all over again (PRIDIFpt2).

A female TB patient (PRIDIFpt7) explained that although she had been advised to get tested for TB, she did not go to the hospital initially for tests as her husband is a wage labourer and so could not afford to take time off work to take her. This highlights the financial barrier to treatment seeking, but also the difficulty accessing treatment that people living at a distance from health facilities face, and in particular women, who are dependent on others accompanying them.

“In villages people are dependent. They wait for other people to come and bring them to the hospital. That is why they do not come. That is what happens. Women become dependent. They do not come by themselves.” (PRIDIMcp1, male health worker, rural site)

► Defaulting

Summary: While this study did not find evidence directly linking defaulting from TB treatment regimens with stigma, some of those interviewed felt that families are important in supporting and encouraging adherence to treatment and therefore disclosure of a TB diagnosis to families, which can be inhibited by the anticipation of stigma, is important.

As with initial treatment seeking, lack of money and time and the absence of someone willing and able to accompany a female TB patient to the clinic can make adherence difficult, as well as the sheer length of the course of treatment which continues even after symptoms subside and the patient may appear already cured. Taking multiple tablets, which sometimes cause side-effects, on an empty stomach is also difficult.

Given the length of TB treatment, scope for patients to move from one facility to another, requiring integration of services, is important.

Potential policy implications: See *Concealment of a TB diagnosis*, page 17, and *Delayed treatment*, page 8.

Consider measures for improving the integration of services to allow patients to move their treatment seamlessly from one facility to another.

Once a TB patient has been diagnosed and has started treatment, some patients face difficulties adhering to the treatment regimen. While this study did not find evidence directly linking defaulting from TB treatment regimens with stigma, some of those interviewed felt that families are important in supporting and encouraging adherence to treatment and therefore disclosure of a TB diagnosis to families, which can be inhibited by the anticipation of stigma, is important.

As with initial treatment seeking, lack of money and time and the absence of someone willing and able to accompany a female TB patient to the clinic can make adherence difficult, but in addition one health worker (PUIDIFcp1) said that patients may interrupt their treatment regimens because of the fatigue of having to collect medicine regularly or because they think they have already been cured.

A health worker interviewed (PUIDIFcp1) said that patients find it difficult taking their medicine early in the morning on an empty stomach as advised and that they find taking multiple tablets daily difficult. This was confirmed by some of the TB patients interviewed. Furthermore, two patients (PUIDIMpt7 and PUIDIFpt1) interviewed said they had defaulted because of the side-effects they had either experienced or were told about. Both the ideas that patients may default because they think they are cured and because they experience side-effects were supported by a health worker in the rural site

(PRIDIFcp3), who, although none of her patients had defaulted, speculated that patients who do default are likely to do so for those reasons.

According to one health worker (PUIDIMcp1), high recorded rates of defaulting are due to problems with the system of registration and do not reflect actual rates of defaulting. He explained that when a patient registers with another health facility to continue his or her treatment, it appears on the registration system of the facility where the patient began the treatment as if the patient had defaulted. Indeed a patient can find him or herself with four or five treatment cards from different health facilities which can make treatment irregular.

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. This is preceded by a brief summary of the explanations and their implications for TB and stigma policies and programmes.

► Perceived hatred towards TB patients

Summary: 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.

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.

Fear of infection, linked to perceived personal risk, is thought to play an important role in health promotion, but is also thought to be one of the underlying mechanisms behind stigma (Kurzban & Leary 2001). A health worker interviewed emphasised his belief that it is the fact that TB is infectious that causes it to have a substantial impact on people's lives.

"If you say does that patient experience any effect on his or her household or social life, when you label a patient in society by saying he or she is a TB patient [] definitely it does have an effect for sure. This disease is like that, it's a communicable disease." (PUIDIMcp1, male health worker, urban site)

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.

"My parents and siblings didn't take any precautions. None of them sit at a distance, they don't feel hatred. [] You know everything about me, you know that I am suffering from TB, you did not hate me, you sat beside me. But our relatives do not sit beside a person suffering from TB, they hate them. They say it is a bad disease and they avoid them. They say that it is transmitted from one person to another." (PRIDIFpt2, female TB patient, rural site)

"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)

"It is obvious that everybody tries to save himself from [TB]. [] In life every person has this thing in their mind" (PUIDIMpt5, male TB patient, urban site)

"Yes people do [feel hatred towards TB patients]. They say that they cough, their utensils should be separate, things should be separate. []. When our relatives came to know they started hating. They think maybe she has eaten with the same utensils we are using." (PUIDIFM1, mother-in-law of a female TB patient, urban site)

A general understanding that taking precautions can be hurtful to the patient and can be counter to norms of etiquette, means that sometimes *obvious* precaution-taking is avoided. A health worker in the rural site (PRIDIFcp3) said she covers her face with a veil as a precaution when she sees a TB patient, but it is intentionally not obvious to the patient whether she is doing this as a precaution against their TB or out of modesty.

The fine line between precautions against infection and being uncaring leaves some people in a dilemma. A female TB patient in the rural site (PRIDIFpt2) spoke of the difficulties reconciling a lady health worker's advice to separate utensils and eat separately with the family norm of eating together. Her family members were also reluctant to enforce such separation as they felt it would make her feel bad.

"When [the LHW] asked me to take care then I started taking care. [But] it doesn't look good to separate utensils. It's a big family. [My siblings] were like she is our sister, she would feel bad, she is at her parents now and will feel bad that my parents are doing this to me." (PRIDIFpt2, female TB patient, rural site)

Likewise a health worker in the urban site (PUIDIFcp1) said that her daughter urges her to keep more of a distance from her patients as her daughter is fearful that she may contract TB, but she does not want to do so as it would hurt the feelings of her patients. Indeed, a belief in the importance of positive emotions for recovery is reflected in the urdu saying *happiness can cure half the disease of a patient*.

Whether avoidance is interpreted as simply a precaution or as hatred depends on the emotional state of the patient, what precautions are deemed necessary, who initiates them and how noticeable the precautions even are.

"When a person is ill he becomes more sensitive. I have also seen that sometimes family members also keep a distance, they keep their utensils separate, they take care and only the patient knows how it affects him." (PRIDIFcp3, female health worker, rural site).

What precautions are deemed necessary centres around perceptions of risk and susceptibility, balanced against the feasibility and cost of enforcing the precautions. While most of those interviewed believed that TB is transmissible, as a causal explanation of stigma, transmission is inadequate as it does not fully explain why one person has TB and not another. Respondents provided a wide range of additional explanations for a person's susceptibility to TB, including a poor or inappropriate diet (such as excessive consumption of chillies), tension, heat, humidity and fever.

Some felt that whether or not a person gets TB is ultimately out of their control as it is determined by their fate, and therefore nobody should be taunted for having TB and precautions may be futile.

"We say that whatever Allah has decided will happen. [] People say that these days there are germs [so you should] do this and do that. But we do not follow that. We eat together, sleep together. The doctor used to say you can get disease through breathing openly. I replied that whatever God has decided that will happen. [] If I have to have TB then I will catch it anyway. It doesn't make any difference to me. We eat together, live together." (PRIDIFM3, the wife of a TB patient, rural site)

This particular respondent's husband had been ill with TB for a while, so perhaps also because she had not yet developed the illness herself, she did not view herself to be particularly susceptible. Furthermore, separate eating and sleeping may sit uncomfortably with her perception of the role of a wife (See under *Reduced marriage prospects*, page 24).

According to a health worker interviewed (PUIDIMcp1), although he does not tell patients and their families that there is a risk in sharing food and eating utensils, many patients and their families tend to separate food and utensils anyway. Confirming this, a male TB patient in the rural site said that the doctor had not told him to separate his eating utensils and he has not done so, but that people usually say that *"TB is spread by eating and drinking from the same plate and glass"* (PRIDIMpt1). Indeed some of the other health workers interviewed did advise patients to separate food and utensils and some of the patients interviewed also reported that they had received this advice from health workers.

A health worker interviewed (PUIDIMcp1) suggested that the more vulnerable one feels, the more fearful one will be. He himself had always been in good health, but told of two other doctors, already suffering from diabetes, who are constantly fearful of contracting TB. While not constantly fearful himself, he does feel fearful when a sputum positive patient coughs or spits, but considers this fear to be normal and his response, to politely tell them off and ask them to sit outside his office, as justified given that the hospital has not provided any precautionary measures. He views education of the patient on the prevention of transmission as the way to reduce others' fear of catching TB, but was frustrated about the lack of time he has for each consultation to provide such education. A precautionary measure provided to health workers, namely face masks, was deemed infeasible and ineffective.

"The so called mask that is provided to us, it's just useless. Like a soldier goes on the front line and can get a bullet at any time." (PUIDIMcp1, male health worker, urban site)

"If I wear mask to see my patients this will be very difficult for me." (PRIDIMcp1, male health worker, rural site)

"I can't use mask because I have to wear glasses and by using mask there is the steam and it become difficult to read and write. Otherwise we are advised to use a mask." (PUIDIFcp1, female health worker, urban site)

Another health worker (PUIDIFcp1) also distinguishes between sputum positive and negative patients, advising precautions to those accompanying the former and advising against any separation to those accompanying the latter as it will make the patient feel bad. When a patient is sputum positive, she said she asks them to wait outside once a TB diagnosis has been confirmed and only discusses the outcome and necessary precautions with those accompanying the patient, acknowledging that this can affect and confuse the patient.

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. One extrapulmonary (and therefore non-infectious) TB patient (PRIDIFpt2) reported having been told by a Lady Health Worker not to cough or breath on others as the TB may be transmitted.

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 TB patient (PRIDIFpt4) illustrated this by saying that she avoids other people as a precaution against TB transmission, but they do not avoid, and therefore hate, her.

Respondent: I myself avoid meeting people. I never kiss my daughters. I do not take them in my lap due to TB, because it is said that if precautions are not taken then it can transmit to the children. []

Interviewer: Has it ever happened that women from your neighbourhood came to your home and sat at a distance from you?

Respondent: They don't do that, but I myself avoid. Our village is ok. They do not hate.

(PRIDIFpt4, a married female TB patient, rural site)

Some precautions were deemed justified by virtually all respondents and therefore could not be interpreted as expressions of hatred. For example, children are thought by many of those interviewed to be particularly vulnerable and so even when the mother of a TB patient (PUIDIFM4) insisted on continuing to eat together with her son, she ensured that her son's children ate separately. Supporting the view of children as particularly vulnerable and unable to take care of themselves, a TB patient in the rural site (PRIDIMpt3), said the doctor had advised him to refrain from touching or kissing his children.

Fear of infection seems to influence behaviour more when there is little cost in the behaviour change. The less close the relationship previously and the more feasible precautions are both practically and within the bounds of social norms and customs, the more likely it is to occur. A female TB patient (PRIDIFpt7) said that her doctor had advised her to sleep separately from her children, but when she has tried to, her youngest child in particular, who is still a baby, cries, so she lets him sleep with her. Another respondent, the wife of a TB patient (PRIDIFM2), felt that precautions are not feasible within a marital relationship.

"Whenever I used to have [my husband's] leftover food, he used to get angry with me and I used to reply that there can't be any precautions in a husband-wife relationship." (PRIDIFM2, mother-in-law of a female TB patient, rural site)

A female TB patient (PUIDIFpt2) living with her parents told her mother to eat separately as a precaution against TB transmission, but her mother insisted they eat together as "*mother is mother*". It seems the 'cost' of not eating with her daughter, and thereby being unmotherly and uncaring, was too great and outweighed any perceived benefits of reducing the risk of transmission by eating separately. This was supported by the female participants of a focus group discussion in the urban site who described a parent's

relationship with their child as more intimate than that of a sibling and especially a friend or non-blood relative and so felt that a parent, and specifically a mother, simply cannot enforce the separation of eating utensils if her son or daughter has TB. Indeed in the interviews with TB patients, close family members were usually described as supportive and caring, while behaviours interpreted as hateful were attributed to in-laws or more distant relatives, friends and neighbours.

Being avoided by someone with whom one has had little previous interaction anyway is unlikely to be noticed and therefore interpreted negatively. In the study sites, visiting and making enquiries about a relative or friend who is ill is deemed customary. A person with many relatives and friends nearby, who is embedded in their local community, has a greater chance of receiving support when ill, but also of noticing uncharacteristic avoidance when ill. For example, a Christian respondent (PUIDIFM1) said she has little contact with her Muslim neighbours anyway and another respondent living in the urban site, but whose family were not originally from the area, said he did not usually receive visits from neighbours even before his TB diagnosis (PUIDIMpt1) as was the case of another respondent in the rural area (PRIDIFM3).

If there are relatives, friends and neighbours who would ordinarily visit a person when he or she is ill, then avoidance may arise from a fear of infection. A male TB patient in the urban area (PUIDIMpt9) said that when someone is ill with TB, others will still visit out of courtesy as this is the custom, but they will feel a little “*allergic*” towards him or her and will make excuses when offered tea or water. Another respondent (PUIDIFM2), the son of a TB patient, said that if people do not visit someone who is ill, it is probably due to their fear of infection, but it may negatively affect relations between them. Likewise, the mother-in-law of a TB patient in the rural site (PRIDIFM2) attributed not visiting an ill person to self-protection, as did the mother of a TB patient in the urban site (PUIDIFM4) who went on to link self-protection with hatred.

“People have reduced their visits as they might think they will get the disease, they will get the germs. [] Some people do not think that way while some do think that way. Like this water and tea, they say don’t touch it with your lips []. They say that the breath that comes out can transfer germs from inside. Is this right or wrong? But we people don’t think about these things.” (PRIDIFM2, mother-in-law of a TB patient, rural site)

“[People may not visit] because people hate [TB patients]. [They think] that one should protect oneself from such people, avoid such patients, because of the germs. [] They say that germs also spread by breathing and they also spread by air.” (PUIDIFM4, mother of a TB patient, urban site)

However, even when a fear of infection amongst relatives, friends and neighbours exists, it may still be overridden by the patient’s (or the patient’s family’s) status or social standing and the need or desire to maintain good relations. A male TB patient (PUIDIMpt5) said that despite many of his family members having had TB, people continued to visit “*because they are very noble people*”. Furthermore, receiving fewer than expected visitors is also open to interpretation and a mother of a TB patient (PUIDIFM3) thought that a possible reason for a TB patient receiving fewer visitors might be due to their financial inability to host them adequately. However, her own neighbours had never stopped visiting her home or interacting with her and her family as they have very good relations.

► Concealment of a TB diagnosis

Summary: 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. While perceived origin or attributability of TB may also play a role, it seems plausible that some patients may be more likely to anticipate the same consequences from disclosing to others that they themselves have thought, felt or enacted previously towards others with TB.

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.

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. The mother-in-law of a TB patient (PUIDIFM1) emphasised the importance of patients disclosing their TB to their families as family support can make it easier to take treatment correctly and regularly. Likewise, a male TB patient (PUIDIMpt2) explained how he had to disclose as he needed help from others.

"I did not conceal anything from anyone. I was unable to walk due to weakness and I had to take help from other people." (PUIDIMpt2, male TB patient, urban site)

A male TB patient (PUIDIMpt5) did not tell his sister about his TB diagnosis because she is deaf and dumb and he did not tell his brother as there had been conflict between them recently. However, other family members had been told and were reassuring and comforting towards him. He sees concealing a TB diagnosis as futile as everyone will

find out anyway, but seemed to distinguish between intentionally concealing and simply choosing not to disclose. A health worker in the rural site (PRIDIMcp1) also suggested attempts to conceal a TB diagnosis are futile, but specified that this is particularly the case in rural areas if the health worker lives in the same village as the patient.

“If the health worker knows then everybody could know about this.” (PRIDIMcp1, male health worker, rural site)

While the patients interviewed did generally disclose their TB diagnoses to their immediate families, some patients interviewed delayed disclosure or considered not disclosing to their families so as not to cause them worry or because they feared being avoided. A female TB patient in the rural site (PRIDIFpt2) considered not disclosing to her family (parents and siblings) as they would be worried and might fear catching TB from her, but when she did, she found them to be supportive and caring. Likewise, according to the wife of a TB patient (PRIDIFM3) her husband did not disclose his diagnosis to her for one month because he did not want to cause her worry, although he himself (PRIDIMpt8) explained that he is quite secretive generally, and that he feared gossip and judgement if others outside his family found out about his TB. Likewise, another male TB patient in the rural site (PRIDIMpt9) did not disclose his TB to his wife as he did not want his in-laws, who are not relatives of his, to find out. Instead he just told his wife that he was taking vitamins for fever.

Whether widespread disclosure of a TB diagnosis beyond one’s immediate family is necessary or beneficial is debateable. One TB patient (PUIDIMpt5) suggested a patient has a responsibility to disclose their TB to others so that others can take precautions to prevent becoming infected.

“This is the disease that we can’t hide because it is transmissible to others. For example, I work, sometimes [my colleagues and I] drink from the same glass. I do not keep my utensils separate, so I can transmit to others as well. They will also suffer because of me. [] If they know about this they will definitely take care even if I don’t.” (PUIDIMpt5, male TB patient, urban site)

However, those interviewed tended to be selective about who, outside of their households, they disclosed to. When asked whether a character in a vignette would have told others about her son’s TB, an interviewee (PUIDIFM2) said that it is not the kind of disease that one tells everyone about. He and his family had only told those relatives that visit often about his father’s TB, but they had not told neighbours or more distant relatives with whom they are not on good terms. However, if any of them were to ask what his father has, he would tell them truthfully rather than intentionally conceal it.

“It is the kind of disease that a person doesn’t tell everyone about.” (PUIDIFM2, the son of a male TB patient, urban site)

A male TB patient (PUIDIMpt9) told his family as he saw it as inevitable that they would come to know anyway, but neither he nor his family have told anyone outside the family, saying that when they come to know he is ill, they will pretend he has either typhoid that has become complicated or malaria, so that they do not see a need to keep a distance from him for fear of infection. His sister-in-law had also had TB five years ago and told people outside the family that she had typhoid or jaundice for the same reason.

Likewise, another family intentionally describe a family member's TB as a chest infection.

*"We didn't tell anyone about this disease. We only said he has a chest infection and that is why the doctors did some tests. We haven't told anyone about this."
(PUIDIFM4, the mother of a male pulmonary TB patient, urban site)*

While disclosure to all is not deemed necessary, some fear that if others find out they have TB they will behave negatively or differently for fear of infection, even if the TB is extrapulmonary or no longer infectious. Indeed, the interviews suggested a clear link between non-disclosure, knowledge that TB is transmissible and the fear of therefore being avoided by others.

*"Some people hide it, some don't. It depends on them. [] Some people hide it because other people think that its germs spread, they start avoiding that person."
(PRIDIMpt1, male TB patient, rural site)*

*"I didn't tell them as I feel they will get a bit far from me because I have got TB."
(PUIDIMpt7, male TB patient, urban site)*

*"I think people hide it because they know that it can transmit to others because of them."
(PUIDIFpt6, female TB patient, urban site)*

Indeed, a female TB patient in the rural site (PRIDIFpt7) had never previously heard of TB and so knowing little about it, and therefore seeing no reason to hide it, disclosed her TB to all. A male TB patient in the urban site (PUIDIMpt5) said he thought that diabetes, pneumonia, epilepsy and even fatal cancer and hepatitis are disclosed because they are not thought to be transmissible. Likewise, a male TB patient in the rural site (PRIDIMpt10) said he would comfortably tell people if he had pneumonia or epilepsy as these conditions are not transmissible. By contrast a TB diagnosis is less likely to be disclosed because it is both transmissible and has an enduring bad name, as in the past it was thought to also be incurable and fatal, and patients were sent away to sanatoria. A male TB patient in the urban site (PUIDIMpt7) seemed torn between his feeling that his TB can and might transmit to others and his fear of being avoided if he is open about it.

From whom a TB patient conceals his or her diagnosis depends on previous relations with others. A male TB patient in the urban site (PUIDIMpt9) disclosed his TB to his immediate family, colleagues and friends, but concealed it from relatives and acquaintances of his in-laws living around his home and specifically his uncles-in-law with whom he has had strained relations.

*"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)*

A male TB patient (PUIDIMpt9) had not disclosed to his acquaintances and relatives whom he visits as he anticipates and fears a change in their hearts, even if not in their behaviour.

"It's just that they will feel allergic deep down inside their hearts. [Suppose] I come to your home. You would not make it obvious of course, but it must be in your heart that he has this problem." (PUIDIMpt9, male TB patient, urban site)

While non-disclosure was mostly related to distant or poor relations with others and a fear of being avoided by others, one TB patient (BUIDIMpt2) also linked it with the perceived origin of TB and attributability implying that as it is no one's fault, he did not deem it necessary to conceal his diagnosis and disclosed to anyone who asked.

"There was nothing to conceal. When something occurs naturally and is God given, what can one do? This is not given by any human being." (PUIDIMpt2, male TB patient, urban site)

Another TB patient (PRIDIMpt8) withheld his TB diagnosis from others because he anticipated they might think he had acquired TB as a result of unspecified wrongdoings. As the quote below indicates, he anticipated others would view him negatively as he himself had held negative views of TB patients previously, suggesting that patients may be more likely to anticipate negative consequences from disclosing to others if they themselves have previously felt negatively about TB patients.

"People gossip []. Some say this, some say that. [] They think he was involved in wrongdoings. He got TB by getting into such activities. People do not feel good about it. We also never thought good about it." (PRIDIMpt8, male TB patient, rural site)

However, to counter the idea that concealing a TB diagnosis may be necessary if it is believed it was *caused* by wrongdoings or has been *given* to others, one TB patient (PUIDIMpt2) emphasised that ultimately disease is from God, it is *"not given by any human being"*, thereby implying that concealing a TB diagnosis is not necessary. Indeed it may be that the very notion of a disease being communicable can contain a negative suggestion that it is passed or given to one person from another, implying liability and blame.

One female TB patient (PUIDIFpt1) said that at this point in her life, where she is fifty years old and her children are married, she sees no need to conceal her TB from people and this may be because potential negative reactions from others would not have such an impact as if she were younger, with responsibilities and yet to be married children. Indeed, a male TB patient (PUIDIMpt5) felt that women are more likely to try to conceal their TB diagnosis because of the impact it can have on their marriage prospects, but feels it is futile as everyone will find out anyway.

Concealing a TB diagnosis may be futile, difficult or even impossible for a number of reasons. For example, disclosure of a TB diagnosis by a patient is impossible if the patient has not been informed of his or her diagnosis and two respondents suggested health workers may intentionally not disclose a diagnosis to a patient to prevent them from getting anxious.

"If a young girl is suffering from TB then I don't tell her. I tell her mother about her disease because I feel that if I told her about TB she might suffer from other things like depression or [] anxiety and tension." (PRIDIMcp1, male health worker, rural site)

Likewise, a female TB patient in the urban site (PUIDIFpt2) said that the doctor had informed her husband and mother-in-law of her TB diagnosis, but advised them not to tell her to prevent her from worrying. However, despite the doctor's advice, the mother-in-law did inform her.

The need to access and take regular treatment over a long period of time can make concealing a diagnosis difficult. A male TB patient in the rural site (PRIDIMpt3) said that he did not initially want to tell his friends about his TB because although TB is now curable, medicines to treat TB have only in recent years become available, and so it is still seen as a fearful disease. However, he found concealing his diagnosis from them impossible as he had to explain why he was taking time off work and what his medicines were for.

Another TB patient (PUIDIMpt9) chose to tell people when they ask where he is going simply that he is going to the doctor for treatment, without specifically saying for TB, while a woman interviewed (PUIDIFM4) said that because her son takes his medicine in the morning before breakfast, no one sees and therefore asks what his medicine is for.

► Gossip and speculation

Summary: Some TB patients 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.

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

Being the subject of gossip – being spoken of negatively behind one's back – was mentioned as a concern and a reason for not disclosing a TB diagnosis by several of those interviewed and in particular the female TB patients or family members interviewed.

"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)

While a male TB patient in the urban site (PUIDIMpt7) felt that people are likely to gossip about some diseases, such as TB and hepatitis C, but not about others, such as pneumonia, according to female respondents, gossip, especially about women, occurs regardless of the disease.

"People's mouths cannot be stopped in the case of any disease. Just like people from a village say [if someone has fever] that she is making excuses, she does not

have fever. People gossip whatever the disease is.” (PUIDIFpt2, female TB patient, urban site)

“If you take a slightly different course than usual, there is a slight problem. In the case of relatives, they take care of you [] but outsiders they gossip.” (FGD-R1, a female focus group participant, urban site)

The female community members participating in a focus group discussion in the urban site felt that gossip is less prevalent amongst and about men. Likewise, a female TB patient interviewed (PRIDIFpt5) also thought that gossip tends to be about women and speculated that this may be because the woman joins her husband’s household, making her more vulnerable to being spoken of negatively, particularly by other women such as her mother- and sisters-in-law.

Two female respondents, both in the rural site, spoke of being gossiped about because of suspicions regarding their symptoms or behaviours rather than because their TB diagnosis was known about. A divorced female TB patient (PRIDIFpt2) whose neighbours are the relatives of her ex-husband spoke of how they suspected her pains were due to pregnancy, implying she had committed adultery, and did not accept her claim that she had TB until she showed them the TB test result. She felt that generally women, even when confined to the home, are judged harsher than men.

“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)

Likewise, another female TB patient in the rural site with a similar experience spoke throughout her interview about her and her family being the subject of gossip and taunts and of how she has struggled emotionally to cope with this, even though much of the gossip has not been directly to her face.

“People have talked a lot. They have said such weird things, such bad things. They started saying that her fiancé used to go to her house [] they took her in a car, got medicines, got her tests done, don’t know what the problem is with her. [] People used to say that they give her soup [implying she may be pregnant], so what is the problem with her? [] We didn’t tell anybody but people made their own guesses [].” (PRIDIFpt5, an unmarried female TB patient, rural site)

Shedding light on why TB or poor health may be deemed conversation- and gossip-worthy, a female former TB patient in the urban site (PUIDIFpt2) said she finds it hurtful that her in-laws still mention to people that she had TB at the birth of her first child as in her view it is not important as she is now cured. However, she said she does not think they talk about it with negative intentions, but just to express what a difficult time it was, how worried they were and how they felt hopeless. While she did not think they would have been less likely to continue talking about it if she had had another disease, rather than TB, she felt disease in general is a topic of conversation because village people, like her in-laws, are generally healthy and so disease is an unusual and therefore a conversation-worthy occurrence.

► Reduced marriage prospects

Summary: 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.

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*, page 8) 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.

Respondents in both the urban and rural sites (PUIDIMpt7 and PRIDIMcp1) defined TB stigma (using the English term stigma) as reduced marriage prospects following a TB diagnosis, and this is recognised as a problem especially for women of marriageable age, although a man may also be worried that his proposal may be rejected following his TB diagnosis. Ensuring a suitable marriage can be a worry, irrespective of TB, so anything which jeopardises marriage prospects, including an evident, transmissible, debilitating or lengthy illness (or illness requiring lengthy treatment), is seen as negative and attempts may be made, if at all possible, to conceal it.

“If you go somewhere to get a proposal, nobody discloses that he or she has a particular disease. People hide their diseases. [] They hide disease to get a good proposal for their daughter. That is why they hide. [] They hide all types of diseases.” (FGD-R2, a female focus group participant, urban site)

It does not seem to be TB *per se* that threatens marriage prospects, but the effects of a lengthy, debilitating and in addition potentially transmissible illness on a person's desirability as a marriage prospect. TB can cause a person to become weak and unable to work and the desirability of a prospective husband is judged in part on his financial situation (which links with his ability to work but also the financial support from, and status of, his family), and for a prospective wife on her health and ability to look after the home.

“With TB people become weak. They have difficulties in doing their work. People say it is better to have no relations with them.” (PRIDIMpt8, male TB patient, rural site)

“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)

A bride's good health and ability to work seem to be particularly valued, as a wife's, and particularly a housewife's role is seen as being to *"take care of my home, my husband, [] give him breakfast, do the washing, take care of my kids, fulfil their needs"* (PUIDIFpt2). Since a woman generally joins her husband's family, living with his parents and possibly also siblings, her poor health would result in a greater workload for her mother-in-law or sisters-in-law and so it is in the interest of not just the husband, but also his family, that he has a healthy, hard-working wife. As many marriages are arranged between families, practical (rather than emotional) criteria for assessing a potential wife, such as good health and being hard-working, are prioritised.

Of course with many cases of TB, a person recovers fully, following a minimum six month course of treatment, but a six month or more delay in marriage is significant especially for a woman of marriageable age who cannot guarantee she will receive a suitable marriage proposal six months or more later, and whose optimum marriageable age range is narrower than that for a man. Many of those interviewed were told they needed to take TB treatment for longer than six months and indeed the more advanced the TB is at diagnosis, the longer the necessary course of treatment. Some of the TB patients interviewed told of the often lengthy process to get their TB diagnosis, involving initially self-treatment with, for example, paracetamol, followed by multiple visits to health care providers, multiple diagnoses and treatments prescribed, and multiple time-consuming and costly tests.

If a proposal has already been made and accepted, withdrawing the proposal and thereby cancelling the engagement, while not necessarily affecting a person's future chances of marriage, can result in tensions and taunting.

"Initially she will face tension. Lots of taunts from people. [They] will ask what is the reason for calling off the engagement, they will gossip about it. She will get another one obviously as whatever God does is for the best, so she will get one, but will have to bear some gossip as well." (FGD-R1, female focus group participant, urban site)

However, having TB alone is not reason enough for an engagement to be cancelled, as some choose to simply postpone the marriage until the TB patient is cured, both to allow the patient to recover fully before taking on the role and responsibilities of a spouse and to prevent transmission. Indeed, marriage of a TB patient prior to complete recovery (or of anyone while ill) is not seen as desirable, especially for a woman, as taking on the role of a wife involves joining the husband's family (who are likely to be less loving than the woman's own parents) and taking on the responsibilities of a wife and daughter-in-law of looking after the home. A female respondent (PRIDIFM2) spoke of her worry about the need to ensure the eventual marriage of her unmarried daughter who is of marriageable age, but who suffers from kidney problems. Although she has received marriage proposals, the mother has had to reject them to ensure her daughter is taken proper care of so she can recover fully. However, as her daughter is of marriageable age and her younger son is already married, the postponement of her daughter's marriage and the uncertainty that suitable proposals would continue to be received caused her concern.

As TB treatment is lengthy (6+ months), if there are other eligible and equally or more desirable alternative marriage candidates, the family may choose to reject or withdraw a marriage proposal. If, aside from her illness, he or she is considered a desirable

marriage partner (e.g. a cousin, in some cases educated, from a family with whom good relations are valued, or emotionally close to her prospective spouse *and* in-laws) and her prospective spouse and in-laws feel confident that her illness and inability to work are just temporary, the marriage will probably still go ahead.

“My in-laws have this concept that first of all they want the girl to be from their own family. Obviously they also check that the girl is in good health. Nobody wants to have a daughter-in-law who is not healthy. [] Obviously if a girl has any illness nobody brings that girl to his family.” (FGD-R5, a female focus group participant, urban site)

A male TB patient from the rural site described how in the area where he lives marriage is usually between relatives and when there are many eligible relatives to marry, TB illness does not have such an impact on marriage prospects.

“Here it’s a family system where one individual has at least three or four proposals. It’s not an issue. [If I was not married] then there would have been problems obviously [] that we are not giving you our daughter as you are ill. But in our family it doesn’t happen as we have four or five relations, like she is my cousin from my father’s side [], double, triple relations, so no such problem occurs normally []” (PRIDIMpt3, male TB patient, rural site)

In the urban site, a female TB patient studying to become a nurse had received a proposal prior to her diagnosis and said the marriage is still likely to go ahead. She theorised that this was because her education and future earning potential are highly valued, outweighing the negative implications of ill-health/TB:

“If a girl is doing a job then there is no problem. If that girl is just a housewife then there can be many problems. Nowadays everyone wants a daughter-in-law who earns money” (PUIDIFpt6, female TB patient, urban site).

However, the nature of the work and the urban setting may make a difference here as by contrast, in the rural site, an uneducated and divorced female TB patient spoke of how she considered doing paid work in other people’s homes to ease the financial hardship of her family, but that it would be seen as degrading and shameful for her father and brothers.

“I thought of working at people’s homes, but that is also very degrading for my father and brothers. People gossip a lot. It is difficult to get out of home I swear, [so] then I started doing embroidery at home.” (PRIDIFpt2, female TB patient, rural site)

Other factors which may come into play are the views that a prospective wife may bring TB into the marital home and that TB is a ‘family disease’ (meaning to some that it can transmit from one family member to another, and to others that it is hereditary) as well as concerns over potential risks to a pregnancy of having TB or TB treatment.

“[A female TB patient] asked one question from me. She asked is there any danger if there is pregnancy. [] She was afraid of that” (PUIDIFcp1, a female health worker, urban site).

"It can be genetic like diabetes. TB can also be genetic. It can be transmitted sometimes to son, daughter, and daughter-in-law. Diseases like diabetes and TB are family diseases." (PUIDIFM1, a woman, urban site, whose daughter and daughter-in-law both have TB).

► Family tension and (the threat of) divorce

Summary: 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.

Potential policy implications: Address broader gender and structural inequities.

Divorce following a TB diagnosis does not appear to be common and when it does occur is unlikely to be due to the TB diagnosis alone. A lady health worker told of a case where a man married a woman in Lahore and returned with her to his family. After just one month of marriage, she was diagnosed with TB and he divorced her. On the face of it, it appears the divorce was due to her TB or at least her ill health, but the man had married for love, without his parents' approval, and following her illness and confirmed diagnosis the parents insisted that they divorce. It seems the parents were looking for a reason to insist on divorce and any sign of poor health or weakness would probably have sufficed.

"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)

In a context where marriage is very much a family affair, and divorce can result not from an individual's or couple's decision, but from family pressure, what is key is whether or not the marriage was wholeheartedly approved of by the family and how recently the marriage took place. Two of the recently married women interviewed, who had been diagnosed with TB shortly after marriage, expressed concern that they had been or might be viewed as having brought the illness with them into the marital home. Indeed, illness during the first few months of marriage is considered particularly unfortunate by the mother-in-law of a TB patient in the urban site.

"They tell me [] you are a patient, you were sick from your parent's house. I tell them I got this disease at this house, it wasn't there when I was at my parents' house [i.e. before marriage]." (PUIDIFpt10, a married female TB patient speaking of her previous experience of TB 8 years ago shortly after her marriage)

"Sometimes I think that if [I had got TB] after my marriage [my in-laws] would say that her parents have given us an ill daughter." (PUIDIFpt6, an unmarried female TB

patient who had received a marriage proposal and anticipated her engagement being finalised in the next month)

As the woman joins her husband's family, rather than vice versa, and because of different gender roles and expectations, a divorce is more likely to be initiated by the husband and his family rather than by the wife. The respondent quoted above (PUIDIFpt10) said her husband had been advised to leave her when she was diagnosed with TB, but had he been the one with TB she thinks she would have been advised to take care of him rather than leave him.

"Men earn and can go for second marriage, whereas a woman knows she has to spend her whole life with the one person to whom she is married so prays for grace and respect in that relationship (PRIDIFpt4, a married female TB patient).

"[A wife] has a lot to do at home by herself. People otherwise taunt her that she is sick. [A man is not taunted in this way] as the household belongs to him."
(PUIDIFpt10, a married female TB patient, urban site)

A female interviewee who developed TB shortly after she was married said that at the time neighbours (but not relatives) had advised her husband and mother-in-law to seek a divorce from her. However both chose to support her through her nine month course of treatment instead.

"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).

More common than divorce are tensions within a family and particularly between a female TB patient and her in-laws (especially if they are living together), which often exist prior to the TB illness, but can be exacerbated by the illness. A female TB patient (PRIDIFpt7) felt that her sisters treated her badly due to her illness, but when probed it transpired she had had a strained relationship with them even before she became ill. Likewise, another female TB patient (PRIDIFpt5) who had been betrothed to be married, spoke of the difficulties she had with her prospective in-laws, and in particular her mother- and sisters-in-law, prior to getting TB, but indicated that her TB further strained the situation. She attributed the difficulties she had with her prospective in-laws at least in part to the fact that they were not relatives, rather than to the TB. In the urban site, the mother-in-law of a female TB patient spoke of the difficulties daughters-in-law face, even when they do not have TB, and the importance she herself places on treating a daughter-in-law as she would her own daughter.

"I always tell others that they should treat their daughter-in-laws as their own daughter because one day their daughters also have to go to another home. [] I have seen many daughters-in-law in my relatives' homes and, although they do not have TB, their attitude towards them is not so good." (PUIDIFM1, the mother-in-law of a female TB patient, urban site)

Of course tensions within a family can also result from the financial impact of a family member having TB (see page 28), a patient's emotional struggle with illness and the apparent contradiction between precautions against TB transmission and caring for a TB patient (see page 11).

► 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. 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.

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.

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.

A male TB patient in the urban area (PUIDIMpt9) said that his life had been disrupted since he became ill with TB, but put this solely down to his poor health, rather than to any associated stigma. Indeed, although TB drugs are provided free of charge from Government and NGO health facilities, becoming ill with TB can have a substantial financial impact on households because treatment is lengthy and requires regular visits to a health facility (requiring time off work and therefore lost income, and travel

expenses) and it is believed that nutritious food or supplementary vitamins are needed to counter side effects of TB drugs and to ensure full recovery.

"I had to pay about 600 rupees for transport to the hospital []. I had to take one or two people with me and that was an additional expense." (PUIDIMpt1, male TB patient, urban site)

"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)

"I am taking my meals but there isn't much to eat here. I did tell [the health worker at the hospital about my low blood pressure]. There they also talked about good food and said eat this, eat that, but here there is nothing much to eat. [] He was like you have to have good food, that's why your [blood pressure drops] as the tablets are a bit harsh." (PRIDIFpt7, female TB patient, rural site)

"It is so difficult getting treatment for my [daughter-in-law]. And along with treatment they have to be given good food, to take care of their health, but thank God I borrow money to be able to continue the treatment." (PUIDIFM1, a mother-in-law of a female TB patient, urban site)

"The person who used to give me medicine used to say that I should have a proper diet. You mustn't only take medicines, you must take food as well. Healthy food should be taken. Take soup. I said beef is so expensive, how can I have it? How can I have soup? I pray that whatever I take God blesses my food with strength." (PUIDIFpt1, female TB patient, urban site)

One of the health workers interviewed (PRIDIMcp1) said he thought patients should only be advised to do what is feasible, but acknowledged that even ensuring a nutritious diet is difficult in the current economic climate.

"[] These days inflation is so much, how can one take care of one's health? We used to tell [patients] to take more milk and soup, but now it is difficult to have." (PRIDIMcp1, male health worker, rural site)

While TB drugs are provided free of charge at Government and NGO health facilities, patients only benefit if they are aware of this and the drugs they need are in stock. A female TB patient (PUIDIFpt1) said she initially paid 700-800 rupees for ten days worth of TB medicine until she was made aware that she could receive treatment free of charge at a Green Star clinic. The mother of a TB patient (PUIDIFM4) said she has to buy the fixed-dose combination drug *Myrin* for her son in the market, as it is not available at the hospital.

"In this society inflation has made everyone stressed. First, the person gets side-effects from the medicine, so we are purchasing medicine from the market because Myrin is not available here [in the hospital] and we have to buy it. [] It becomes stressful to think when will this treatment be completed." (PUIDIFM4, mother of a TB patient, urban site)

Many of the respondents spoke of the difficulties finding employment, even before becoming ill with TB, but how TB has exacerbated the difficulty because of the physical weakness it causes and the need for lengthy treatment. The sister-in-law of a male TB patient (PRIDIFM1), when asked why the character in a vignette might be worried by a family member's TB diagnosis, immediately attributed it to his inability to work and provide for his family and the insecurity of his income. She related this to the situation of her brother-in-law who works as a manual wage labourer and whose income is dependent on his good health and strength. However, with other brothers living in the same household and providing incomes, they were managing. By contrast, the mother-in-law of a female TB patient (PRIDIFM2), living with just her son and daughter-in-law, spoke of the financial struggle of being reliant on just one person's irregular income, especially when a member of the household has TB.

"Life is really very hard. [] [My son] does daily labour – that is when work is available. If not then he roams in search of work all day. He is out even now. [] If he gets some job he will do it, if not then there's just nothing. [] There is no elder person at home, no regular income. [] From where will I bring money? How will I manage the treatment? What will happen?" (PRIDIFM2, the mother-in-law of a female TB patient, rural site, living with just her son and daughter-in-law)

"I only think from where will the finances come and how will expenses be managed. We don't have enough money, even the home environment is awful. From where will the expenses come, what will happen? Everyone is dependent on one person's income and it's not enough. There is work on one day and not the other []. We are living hand to mouth. This situation is what stresses me most. [] I also think I am spending too much, sometimes I take a loan for the medicines, but when I have the money I go [to the health facility]. [] Medicines are free, but there are travel expenses. [] Half the medicines [multivitamins and medicines prescribed for stomach problems] I buy from outside, from the store and half I get from the hospital. Forty to fifty rupees I spend on these medicines." (PRIDIFpt6, a female TB patient in the rural site, living with her husband, children and mother-in-law)

Clearly the financial situation of a household, the opportunities for financial support and whether the TB patient has dependents and responsibilities determine the extent of the disruptiveness of their TB illness and its treatment on the household. A health worker in the rural site (PRIDIFcp3) said that the impact of TB is different for children, who are cared for by their parents, and adults, who have children to care for. An unmarried female TB patient (PRIDIFpt5) did not report any difficulties (financial or otherwise) with accessing or adhering to TB treatment, perhaps as she neither had a job nor the responsibility of taking care of a household that comes with marriage. The mother of a 13 year old TB patient (PUIDIFM3) said her daughter had never shown any reluctance or difficulty taking TB treatment, despite the length of the course and this might likewise be because the disease and its treatment had not been as disruptive to her life as it had been for others as she had few responsibilities and no dependents.

A male TB patient in the urban site (PUIDIMpt2) said he had no problems collecting his medicine from the health centre as he has a van and he has stopped working following the advice of his doctor. He was able to manage financially as his sisters and family supported him and he had savings in the bank. By contrast, another male TB patient in the urban site (PUIDIMpt5) whose parents had died and who was responsible for

supporting his unmarried sisters, said that the only change in his life since getting TB was his inability to work and the loss of his income in light of the burden of his responsibilities. Similarly struggling was a mother-in-law of a female TB patient (PRIDIFM2) who said that while no one had spoken badly about her family or her daughter-in-law, her main worries focused on their financial struggle. While her late husband's brother had given them some money, nobody else had offered financial support and during the interview she suggested at some times this was understandable as they too were poor, while at others that it was evidence that they did not care, equating receiving sympathy with receiving financial support.

If a TB patient has the flexibility in his job to work less or to take on lighter work, then the financial impact of TB is likely to be less substantial. For example, a male TB patient in the rural site (PRIDIMpt3) continued to work as a steel fixer throughout his course of treatment, but was able to take on lighter work. Likewise, another male TB patient in the rural site (PRIDIMpt9) informed his line manager about his TB and as a result his line manager allocated him to tasks requiring less physical exertion.

► Worry about fulfilling responsibilities and being a burden

Summary: 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.

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*, page 8). 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*, page 28.

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. A female TB patient in the rural site (PRIDIFpt6) said she felt bad about staying in bed and not being able to contribute to the housework. Similarly, a female TB patient (PUIDIFpt1) explained how she finds it very difficult and frustrating not to have the energy to cook and assist her daughter-in-law with the housework.

"I don't like myself when I'm in bed." (PUIDIFpt1, a female TB patient in the urban site, living with her son, daughter-in-law and grandchildren)

The wife of a TB patient (PRIDIFM3) said that while she and her family were primarily worried about her husband's pain, her husband was primarily worried about being a burden to his family as he was unable to work and saw it as his responsibility as the eldest of his brothers to provide for the family. Instead he was now reliant on his father's income to support the whole family. Indeed the mother of a female TB patient (PUIDIFM3) considered it natural that a person with TB should get distressed every now and then and struggle a little emotionally with the need to rest versus the need/desire to continue life as normal, and the difficulty of continuing life as normal can be compounded by TB's lengthy treatment.

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

A divorced female extrapulmonary TB patient clearly felt down about her life and circumstances and linked the ability to work with receiving respect from others, and, it seems, self-respect.

"I wish that I had a good husband, then I would not be dependent on my parents. My brothers and sisters take care of me because my parents are alive, but if my parents were to die and my brothers get married, who will take care of me then? As long as I have some energy in my body I will get up and do work and they will respect me. If I just lie on my bed then nobody would check on me. If I had children then they would check on me. As long as you are healthy you have all the relatives around you, but if you are ill than nobody takes care of you." (PRIDIFpt2, a divorced female TB patient in the rural site, living in her parents' home)

As with the financial impact of TB, the extent to which a TB patient worries about not being able to fulfil his or her responsibilities depends, in part, on what responsibilities he or she has. A married female TB patient living in the urban site explained that her illness was not affecting her ability to take care of her husband as her husband lives elsewhere because of his job.

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. A female TB patient in the urban site (PUIDIFpt2) described how she was diagnosed with TB eight years ago, just after giving birth to her first child. She was forbidden contact with the baby, although the baby was just one day old, and spent the first month of her illness in a sanatorium where children were strictly forbidden. Her mother-in-law took the child and only after completion of her nine month course of treatment could she hold the child.

► Blame and guilt for TB infection

Summary: 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.

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.

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.

While multiple causal explanations for TB or susceptibility to TB emerged from the interviews, the view that TB is transmissible from one person to another has an implication for some that one person *gives* TB to another and is therefore responsible for doing so.

"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)

A number of respondents spoke of TB, as with any disease, coming ultimately from God and that it is therefore nobody's fault. When the mother of a TB patient (PUIDIFM3) was asked whether how a TB patient got TB (i.e. perceived origin) makes a difference to people's behaviours and attitudes towards the patient, she said that it does, but that she does not think it should as disease is ultimately from God.

A health worker interviewed (PUIDIMcp1) said that if a TB patient has had a neighbour with TB and then discovers it is transmissible and they may therefore have got it from their neighbour, they are likely to react negatively and hold the neighbour responsible, although he did not specify whether such blame would be openly expressed or just internally thought.

If the reason for a person having TB is thought to be transmission, rather than weakness, tension or some other factor, then others are more likely to feel at risk and want to protect themselves.

"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)

The son of a male TB patient (PUIDIFM2) when asked why a vignette character might have TB, named multiple possible causes of TB, all of which suggested a person has a degree of control as to whether or not they become infected or infect others.

“Due to carelessness or excessive consumption of chillies, that’s why he has TB. Other than these reasons, if someone already had TB in the home, he could have been infected by them. [] The person who has TB, when they cough, if they don’t put their hand over their mouth, then the germs will go to others.” (PUIIDIFM2, son of a male TB patient, urban site)

Alongside the anticipation of being blamed by others for transmitting TB (possibly causing some TB patients to conceal their diagnosis), some of the TB patients interviewed blamed themselves or felt guilty at the prospect of transmitting the disease to others.

“I think that people hide [their TB diagnosis] because they know that it can transmit to others because of them. [] I was careful because I didn’t want it to spread because of me.” (PUIIDIFpt6, female TB patient, urban site)

The same patient (PUIIDIFpt6) was disturbed by the idea that she might transmit TB to her family members and what a family member would think of her if he or she needed to go to a doctor and was asked by the doctor whether anyone else in the home was suffering from TB.

5. Conclusions

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

- Perceived hatred towards TB patients, because of confusion between self-protective measures and hatred, confusion about risks of transmission and necessary precautions; and notions of blame and responsibility.
- Concealment of a diagnosis of TB to people outside the immediate family, because of anticipated negative consequences. Some patients are not informed they have TB, in a misguided attempt to protect the patient. Some patients conceal their TB because they believe others will avoid them because they believe they put them at risk of TB for many months.
- Fear of gossip and speculation may encourage patients to conceal their diagnosis.
- 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. This is tempered by positive factors such as close family relationships (particularly in areas where cousin-marriage is common) and earning power.
- Family tension and (the threat) of divorce, particularly for women, and especially if the marriage was recent, partly because of overall gender inequities within Pakistan, 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.
- Worry about fulfilling responsibilities and being a burden, because of inability to work or fulfil one’s responsibilities.

- Blame and guilt for TB infection, because of knowledge of the infectivity of TB which leads to fear by the patient that s/he might infect/have infected others.

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

Effect of stigma, and explanation	Potential policy implications
Perceived hatred towards TB patients, because of confusion between self-protective measures and hatred, confusion about risks of transmission and necessary precautions; and notions of blame and responsibility.	<p>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.</p> <p>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.</p>
Concealment of a diagnosis of TB, because of anticipated negative consequences, lack of knowledge that the patient has TB, or lack of knowledge about the infectivity of TB.	<p>Ensure health workers properly inform patients that they have TB.</p> <p>Ensure patients and the wider community understand patients cease to be infectious after two weeks of treatment.</p>
Fear of gossip and speculation may encourage patients to conceal their diagnosis.	Identify ways to reduce the social impact or disruptiveness of a TB diagnosis, to reduce its value as a topic for gossip.
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. This is tempered by positive factors such as close family relationships and earning power.	Early diagnosis and treatment, especially for women 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.
Family tension and (the threat) of divorce, particularly for women, and especially if the marriage was recent, partly because of overall gender inequities within Pakistan, 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.	(1) Consider measures to reduce the cost, length and disruptiveness of treatment provision. (2) Promote awareness that TB treatment is provided free of charge at Government facilities. (3) Encourage referral of suspects by private and alternative practitioners.
Worry about fulfilling responsibilities and being a burden, 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.
Blame and guilt for TB infection, because of knowledge of the infectivity of TB.	Consider the effect on blame and guilt of strategies to increase knowledge of and emphasis on TB's transmissibility and patients' ability to prevent transmission by taking precautions.

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 of the need for an escort for women; and because of a lack of money and time.	Increase referrals from private and alternative practitioners to ensure rapid diagnosis. Increase access to health services, particularly for women and for those living far from health facilities.
Non-completion of treatment can occur because of the need for an escort for women; because of a lack of money and time; and because of problems when patients move from one facility to another.	(1) Increase access to health services, particularly for women and for those living far from health facilities. (2) Promote family support. (3) Consider measures for improving the integration of services to allow patients to move their treatment seamlessly from one facility to another

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7. Ethical approval

This study received ethical approval from

- the National Bioethics Committee (NBC) Pakistan, ref F.4-87/NBC/ASD-Project/10/5404
- the Ethics Committee of the Faculty of Medicine and Health, University of Leeds.

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