

# **Understanding TB-related stigma in Asia**

**Nepal  
2009**

Funded by ESRC-DFID

**By Bethan Hatherall**

**Nuffield Centre for International Health & Development  
University of Leeds, UK**

**Health Research and Development Forum (HERD), Nepal  
Association for Social Development (ASD), Pakistan  
National Tuberculosis Control Programme, Bangladesh**

This document is an output from a project funded by the UK Department for International Development (DFID) for the benefit of developing countries, and the UK Economic and Social Research Council (ESRC). The views expressed are not necessarily those of DFID or ESRC.

# Contents

Executive Summary .....	2
1. Introduction.....	5
2. Aim .....	5
3. Methods.....	5
4. Findings.....	6
4.1 Local concepts of TB .....	6
4.2 The nature of people’s experiences of TB .....	8
4.3 The nature of stigma within those experiences.....	10
4.4 Public health implications.....	12
▶ Delayed treatment .....	13
▶ Defaulting .....	14
▶ Withholding medical histories .....	17
4.5 Understanding TB-related stigma.....	17
▶ Perceived hatred / <i>hela</i> towards TB patients.....	17
▶ Concealment of a TB diagnosis .....	25
▶ Reduced social interaction of TB patients with others .....	30
▶ Reduced marriage prospects .....	31
▶ Family tension.....	34
▶ Financial disruptiveness of TB .....	37
▶ Worry about fulfilling responsibilities/ambitions and being a burden .....	39
▶ Blame and guilt for TB infection (especially relapsed TB or TB re-infection) .....	42
5. Conclusions.....	48
6. Acknowledgements.....	51
7. Ethical approval .....	51
8. References.....	51

## 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 Nepal, 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 Nepal, their explanation, and their policy implications are summarised in the following table.

Effect of stigma, and explanation	Potential policy implications
<p>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>	<p>(1) 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.</p> <p>(2) Clarity about the duration of infectivity.</p> <p>(3) Clarity that it is not necessary to use separate utensils.</p> <p>(4) 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>
<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>	<p>(1) Ensure health workers properly inform patients that they have TB.</p> <p>(2) Maintain patients' confidentiality, including during late patient tracing.</p> <p>(3) Ensure patients and the wider community understand patients cease to be infectious after two weeks of treatment.</p> <p>(4) Share examples of real life stories of patients who had had positive experiences of disclosing, to counter patients' anticipation of negative experiences.</p>

Reduced social interaction of TB patients with others.	As for <i>Perceived hatred</i> , above.
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, and particularly children.	(1) Early diagnosis and treatment, especially for women and in areas where the average age of marriage for a woman is low. (2) Clarity on the effects of TB and TB treatment on pregnancy and fertility.
Family tension, particularly for women, and particularly if there is a perception that the patient is not helping his or her own recovery by not following advice.	(1) Clarify balance between support and precautions against TB transmission. (2) Earlier diagnosis to reduce TB's severity. (3) Less disruptive treatment provision to decrease the patient's inability to work. (4) Counselling and education for both patients and their families on how to cope with family tensions.
Financial disruptiveness of TB, particularly towards people with dependents, because of disruption to work, expenses of travel etc to clinics, and costs of nutritious food/ supplementary vitamins that is thought 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, particularly childcare, concern about impact on education and ambitions, and depression caused by being ill.	(1) Consider measures to reduce the cost, length and disruptiveness of treatment provision. (2) Consider ways of providing emotional support to TB patients, perhaps through support groups.
Blame and guilt for TB infection (especially relapsed TB or re-infection), because other behaviour that is disapproved of (including not completing or correctly taking a course of treatment) may be blamed for the 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.

Three other issues that arose strongly from the study are summarised in the following table:

<b>Issue and cause</b>	<b>Potential policy implications</b>
Delayed treatment seeking occurs when symptoms are mild, ambiguous or atypical. Misdiagnosis or inconclusive test results is more likely for extrapulmonary TB.	(1) Address misdiagnosis and the limitations of diagnostic tests, especially for extrapulmonary TB. (2) Improve access to health services to encourage quicker treatment seeking.
Default is reduced when families support and encourage adherence to treatment and therefore disclosure to families is important. Patients are unclear about length of treatment, and effects of	(1) Address factors such as patients stopping treatment because they feel better; patients' need to work (or take work when it comes); problems paying for temporary accommodation and

<p>missing a single dose. Default is increased by factors making daily attendance at a DOTS clinic difficult.</p>	<p>having to move; problems of old age and co-morbidity. (2) Increase access to health services.</p>
<p>Withholding medical histories of previous TB treatment, for fear of being scolded.</p>	<p>Awareness is needed amongst health workers that scolding TB patients may discourage their disclosure of their medical histories with negative individual and public health implications.</p>

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

This report presents and discusses the findings for Nepal 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 Lalitpur district, one urban (Lalitpur sub-metropolitan city in Kathmandu valley) and one rural (Godawari and Badikhel village development committees combined) were selected for inclusion in this study. Lalitpur sub-metropolitan city has a population of 250,000 and consists predominantly of Newars and migrants. Godawari VDC has a population of 6257 and Badikhel VDC has a population of 3212. Both comprise mostly indigenous Nepali-speaking residents who are mostly Brahmin or Chhetri\*.

---

\* Source: *Population of Nepal, VDC/Municipalities, Population Census 2001 Nepal*

Following an initial preparatory stage in which contextual information about the two sites was collected, sixteen in-depth interviews were conducted in each 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 allowing us to provide sufficient contextual information to enable an assessment of the likely applicability of the findings to other contexts.

The sixteen interviews in each site comprised five interviews with female TB patients, five with male TB patients, four with family members of TB patients and two with health workers. In addition, six focus group discussions were conducted in the rural site, one with female TB patients, one with male TB patients, two with female community members and two with male community members.

## 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 Lalitpur and Godawari and Badikhel combined. 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 defaulting from 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

Locally, two terms appear to be primarily used for 'TB'. They are TB and the Nepali word *chayarog*. *Chayarog* literally means deteriorating or damaging (*chhaya*) disease (*rog*). Other terms also exist such as *sukne rog* (lit. being thin) and *sukenash* (lit. losing weight), but these appear to be more regional and language specific. It is likely that there are at least subtle differences between people's interpretations and perceptions of TB and *chayarog* and indeed a health worker in the rural site thought that the term TB arouses more fear than the term *chayarog*. However during the interviews with TB patients and health workers the two terms were often used interchangeably and health workers in the urban site felt that the two terms had the same meaning, just that one term is English and the other Nepali.

Typical manifestations of TB were described by TB patients and family members as being weight- and appetite-loss, not responding to other treatments (e.g. paracetamol), blood in sputum, persistent cough, fever at night and skin darkening or dulling. Such symptoms are deemed to suggest the condition is severe, and not just a common cold or similar, and that a clinic or hospital needs to be consulted. Coughing blood is not necessarily seen as indicative of TB as NRIDIMpt2 thought that the blood in his sputum may be due to *garmi* (warmth) or cigarette smoking, or that it was a result of the medicine he was taking causing the expulsion of bad blood. If the symptoms are typical of pulmonary TB, the patient has heard of TB and another family member has been affected by TB previously, it seems likely that they will suspect they may have TB. However, a number of respondents, especially those with extrapulmonary TB, were confused about what they thought TB to be, and the TB

they actually experienced, as symptoms were not always typical and tests did not always immediately or conclusively confirm a diagnosis. Differences in the parts of the body affected by TB and both the duration of TB and the duration of its treatment lead some TB patients to believe that there are multiple types of TB, affecting different parts of the body and being either communicable or non-communicable. A male TB patient in the rural site described “old TB” as TB that someone has had for a long time and is infectious, while “new TB” or recently acquired TB (as he described his own), when treatment is started immediately, is not. Another male patient in the rural area said that the normal type of TB requires 8 months treatment, the medium type where the disease has matured a bit more, requires 12 months treatment and the third type, which is TB diagnosed too late, is where TB has spread all over the body.

TB appears to be viewed as one disease along a continuum of diseases, being thought to develop from other diseases (such as pneumonia experienced in childhood) and develop into other diseases (TB can develop into cancer and kill). Indeed when talking about experiences of TB, some respondents indicated that their experiences are disease-related, rather than TB specific, by saying “disease is disease”. Cancer was mentioned often, in both the urban and rural site, as more severe than TB as it is viewed as incurable and fatal and therefore is greatly feared, and in the focus group discussions comparisons were made between jaundice and “chayarog”, with both being seen as similarly transmissible.

While TB was described as now being a “simple disease” usually on account of it being curable, the length of treatment suggests it is nevertheless dangerous and TB drugs alone are thought to be necessary but not sufficient to guarantee cure. Alcohol, smoking, poor diet and insufficient rest are all thought to inhibit the effectiveness of TB drugs.

*“It is complicated due to the need to take medicine for a long time, but on the other hand it will be cured after taking medicine, so it is simple also.”*  
(NRFGDMcm2-R3, male focus group participant, rural site)

Those interviewed identified a range of causal explanations for TB which increase a person’s susceptibility to the disease, relating to physical weakness resulting from drinking alcohol, smoking, overworking and not eating sufficiently or regularly. Attributing cause seemed to be important in alleviating the fear and confusion of both to patients and their family members.

*“I thought how has it happened to me, from where has it transmitted to me, and there is no one in my family who had TB [ ] And I don’t go anywhere, I don’t go to the office either, I just stay at home [ ] How has it happened to me? I didn’t know and I tried to control my emotions. [ ] I used to ask a few people ‘How did you feel when you heard for the first time?’ and a few used to answer ‘I knew that I may have TB because I did not get enough food’ [ ] and a few used to say ‘I used to work outside, used to go to carry bricks,[ ] that’s why I knew I must have this.’”*  
(NUIDIFCPt1, female former TB patient, urban site)

*“She [a vignette character diagnosed with TB] may be fearful because she is ill and the causes of illness are not known.”* (NRIDIFFM1, wife of a TB patient, rural site)

Such causal explanations exist alongside knowledge of TB’s communicability, but contribute to explaining why one person has got TB and not another. As one family member of a TB patient put it, “sometimes it is transmitted and sometimes it emerges



*from own body*" (NUIDIFFM2). Asking how TB transmits and what causes TB results in very different responses, with the former receiving responses based on the health worker's advice, such as via sputum, *jutho* or sleeping together, while the latter receives responses relating more to susceptibility to TB. Because the explanations are varied the reason why one person got TB may be viewed as different to the reason why another person got TB and some of those interviewed seemed to acknowledge the inadequacies of the causal explanations when applied to everyone. For example, NUIDIFM2 explained his TB and that of his wife and servant girl as probably being transmitted from one of the many people who came into their shop and by not eating food regularly and on time. However, his father had not been in the shop for many years and always ate regularly, but still inexplicably developed TB.

That TB is transmissible is inadequate in explaining why one person has got TB and not another. Although the doctor of a male TB patient (NRIDIMpt2) had told him his TB is communicable and could transmit to his family, so he should wear a mask, the doctor did not explain *how* or *why* it might transmit. The patient therefore did not use the mask and said he does not believe TB is transmissible because some people have it, but some people do not. Other explanations such as that alcohol causes TB he also found unconvincing.

*"On the one hand I do believe also [that alcohol causes TB], on the other hand I don't believe. [ ] We adults, let's say it happened due to drinking Jaand/alcohol [ ], but to that child it happened because of what he ate?" (NRIDIMpt2, male TB patient, rural site)*

The susceptibility issue makes some doubt whether TB is really communicable.

*"I don't think like that [ ] It might not be [communicable]. It depends on our own health, everyone's health is not same [ ] All bodies are not the same [ ] It might have affected a weak person [ ] I think it affects to those whose body is weak and who have to work more, then they can get [TB]." (NRIDIMCpt1, male former TB patient, rural site)*

## **4.2 The nature of people's experiences of TB**

When the reactions of TB patients to their TB diagnosis were explored with those interviewed, 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, some were surprised and some concerned. What patients were initially worried about focussed on what they need to do and how they can get treatment in order to get better, the risk of passing TB on to others, especially family members, how they will manage financially (especially men) and how they will manage the housework and childcare (especially women). Worry about managing related both to the inability to work due to the symptoms of TB, the length and disruptiveness of accessing TB treatment, and the cost of accessing TB treatment in terms of travel expenses, time off work and the need to supplement the drugs with expensive nutritious food. Some were surprised as they had not thought themselves to be susceptible to TB and their diagnosis did not fit with their understanding of TB causation. Others expressed concern about the course the disease would take, even if they knew TB is curable, as not everyone with TB is cured, or they were concerned about the side effects of the TB drugs. Knowledge that TB *can* be cured is insufficient to reassure patients that in their case it definitely *will* be cured, especially if they have known people die of TB or they are experiencing difficulties accessing and taking treatment.

*“I feel I will get cured, but when I think deeply about it, I think that I won’t get cured for the next two or three years. When I think this deeply, I think that I will die from this. When I think so deeply, when I suffer this many difficulties, when I have such pain, I feel that it will kill me.” (NRIDIMpt1, male TB patient, rural site)*

*“Lower caste people are more discriminated so they have more problems. Nobody makes them aware so they think that as I am having TB I will die and there is no worth in me being alive.” (NRIDIMpt1, male TB patient, rural site)*

While people do die of TB, people with TB also die as a result of other causes. When a health worker (NRIDIMHW1) was asked whether any of his TB patients had died, he responded that they had but on explaining it became apparent that they had died of medical conditions other than TB.

*“There was one old man aged 75 years old [ ] Yeah, he had blood vomiting [ ] After that it was said that he died of a heart attack. And one died of jaundice. Jaundice and kidney failure, he was taking medicine. [ ] He was 40-45 years old.” (NRIDIMHW1, male health worker, rural site)*

This suggests a possibility that when patients suffer from multiple conditions, and perhaps the TB is the most publicly known, or their conditions are seen as interrelated, their death may be attributed by family, friends and community members to the TB, raising potential and experience-based doubts about TB’s curability.

However, one TB patient interviewed (NUIDIFpt4) felt that generally people are not as tense when they receive a TB diagnosis as they were in the past as medicine to treat it is available.

Many of the respondents described how supportive their families were: practically (e.g. doing housework/providing financial support), emotionally (e.g. providing reassurance) and in terms of providing advice (e.g. on what to eat and what not to eat, to take treatment, etc.). Indeed some respondents said they feel more loved or cared for by their families and sometimes friends since becoming ill than previously. Feelings of responsibility for the patient, not only whether the patient is blood related, seem to be important. A family member of a TB patient who was interviewed was especially concerned when his maid servant got TB as she is another person’s daughter for whom he has responsibility (NUIDIFM2).

Reactions of employers to an employee’s illness seem to vary, with some being more understanding than others and this may be dependent on the length and nature of employment and their ability and willingness to give paid or unpaid leave. For example, a female TB patient’s employer knew she had TB and gave her four months unpaid leave both for her own recovery and to protect others she worked with, and she speculated he had been so concerned and understanding because she had worked for him for four years (NUIDIFPt1).

A health worker interviewed (NUIDIFHW1) said that most patients feared passing TB on to their families and asked about infectiousness and the precautions they should take. The interviews with TB patients seemed to support this.

*“I felt so scared that time, [thinking] ‘what type of disease do I have?’ I have children. I know it is a communicable disease [ ] I have read that, now what if it transmits to my children? [ ] At home my husband is also there. [ ] What if it*

*transmits to my husband or children? [ ] So I really get scared.” (NUIDIFCPt1, a female former TB patient, urban site)*

Contributing to this is the perception of TB as a “family disease”. From the interviews it appears that TB is not thought to be hereditary in a direct way (although a weak constitution may be), but it is thought that if one family member gets TB, another one is likely to as well.

### **4.3 The nature of stigma within those experiences**

This research set out with a very broad definition of stigma, in order to allow context-specific definitions to emerge. In Nepal, the concept of *hela* appears to be important to understanding anticipated, perceived and enacted negative attitudes, emotions and behaviours. According to Turner’s *comparative and etymological Nepali dictionary*<sup>†</sup>, *hela* can be translated as “contempt”, “insult” or “disgrace” or as the verbs “to revile” or “to scorn”. However, it is also associated with the concept of neglect and not caring for someone. Indeed, *hela* may not be specifically associated with TB, but generally associated to diseases deemed to be dangerous and communicable.

*“[ ] to dangerous and communicable disease I feel they do a little bit hela.” (NUIDIFpt4, female TB patient, urban site)*

Being diagnosed with TB is not desirable from the patient’s point of view or a public health point of view and ultimately all diseases are viewed as undesirable and negative.

*“If you have a disease then it is obvious to have tension.” (NUIDIMpt4, male TB patient, urban site)*

*“I think all diseases are the same. It will be difficult until it is cured. [ ] All diseases cause difficulties equally.” (NUIDIFFM2, wife of a TB patient, urban site)*

*“Definitely there will be worry about the disease. It is especially while living alone. All [diseases] are dangerous.” (NRIDIFpt1, female TB patient, rural site)*

However, when the *person* with the disease is perceived negatively or perceives him- or herself negatively, then this can jeopardise their health and well-being, and, if preventable, needs to be addressed.

From the interviews it was clear that TB patients sometimes do anticipate negative or undesirable reactions from other people and so may conceal their diagnosis or avoid social interactions with others. Patients struggle emotionally with their diagnosis and its impact, and sometimes interpret the actions of others as uncaring and hateful (*hela*) or lacking in patience and understanding. Less evidently, they may delay or alter their treatment-seeking behaviour for fear that their TB status will become evident to others or their marriage prospects may become affected. Others may avoid visiting or interacting with a TB patient or may blame the patient for their TB.

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

---

<sup>†</sup> Turner, R. L. (Ralph Lilley), Sir. A comparative and etymological dictionary of the Nepali language. London: K. Paul, Trench, Trubner, 1931 (available online at <http://dsal.uchicago.edu/dictionaries/turner/>).

- Perceived hatred / *hela* towards TB patients
- Concealment of a TB diagnosis
- Reduced social interaction of TB patients with others
- Reduced marriage prospects
- Family tension
- Financial disruptiveness of TB
- Worry about fulfilling responsibilities / ambitions and about being a burden
- Blame and guilt for TB infection (especially relapsed TB or TB reinfection)

While some of these experiences which have become manifest while a person has TB may have an impact that persists beyond their cure, this study found no suggestion that the experiences themselves continue or occur after cure. However, one patient interviewed (NRIDIMpt4) felt that a cured TB patient is not the same as someone who has never had TB because a few germs persist. This links to a notion that was apparent in a number of interviews that even once TB has been cured, a person's bodily constitution has changed and greater care is needed in terms of diet and behaviour to prevent relapse. Also referring to the longevity of TB, a focus group participant (NRFGDMpt1-R1) said that while TB can be cured, the damage TB can cause is permanent.

While families were reported to be generally supportive, the reactions of others outside the immediate family, as well as the interpretations of those reactions, vary.

*"It cannot be said that patients are discriminated against by their friends if they disclose their disease [ ] Some patients get love and some get hate."  
(NUIDIFTBV1, female health worker, urban site)*

Indeed, it is clear from the data that stigma can be and often is very subtle and based on perceptions of how others feel, rather than necessarily what others say or do, with a recognition by a number of those interviewed that one can only speculate how others feel.

*"What is in a neighbour's heart we don't know." (NUIDIFM1, mother of a female TB patient, urban site)*

*"[ ] those who don't have disease [ ] though they don't say anything in words, but there is a difference in their feelings." (NRIDIMHW2, male health worker, rural site)*

Few of those interviewed reported treating (other) TB patients negatively for a number of possible reasons. Firstly, anticipated and perceived stigma may be more prevalent than enacted stigma. For example, a male TB patient (NUIDIMpt4) had not actually experienced any negative behaviours towards him, but had heard that others with TB experience problems with people being afraid to go near them and from movies he saw that patients were isolated or kept separately. Secondly, if enacted stigma is uncommon, the inclusion of mostly TB patients in the sample and the small sample size may have resulted in "overt stigmatisers" simply not having been included. Thirdly, treating TB patients negatively may itself be viewed negatively and so those interviewed may have felt reluctant to "confess" to it. If this is the case, then there is a social cost to stigmatising as well as being stigmatised. This idea is supported by an interview with the wife of a TB patient who seemed a little defensive during the interview conducted with her, stating adamantly that no one treats her husband badly or any differently since he has been ill.

*"I have not hated my husband due to having disease. [ ] You can ask him. I have done nothing." (NUIDIFFM2, wife of a TB patient, urban site)*

While the nature of the sample may have contributed, in all likelihood, the lack of self-reported enacted stigma is a result both of perceived stigma being greater than enacted stigma, and enacted stigma being frowned upon.

A male TB patient interviewed indicated that visible symptoms of disease which are thought to be aesthetically displeasing or shameful are a problem and deter him from going out in public. However, it was his swollen face resulting from his kidney disease that he referred to, rather than any of his TB symptoms. Likewise, a female TB patient (NRIDIFpt3) was advised by her doctor to wear a face mask, but she finds it shameful to wear it outside as people stare at her and wonder what is wrong. She worries not that they may assume she has TB, but that they will stare, wonder and think she has a shameful wound on her mouth. The mask suggests she has something to hide and makes illness, rather than TB *per se*, evident.

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". In this study, evidence of "courtesy stigma" towards family members of TB patients was not found and although just two health workers were interviewed in each site, there was no indication that they suffered from "courtesy stigma" either. However, the health workers were sometimes a little fearful of getting TB themselves, but generally felt pride in their jobs. Indeed, one of the health workers in the rural site stated that the community consider them as highly knowledgeable service providers, inferring there is some status in being a health worker.

*"They take us as a service provider. [ ] They believe that we know everything though we don't know much, we are general health workers only [ ] But also they think of us as resource people. Till now it is okay for us." (NRIDIMHW2, male health worker, rural site)*

While the family of one of the health workers did not disapprove of her job, they were concerned for her and her mother scolded her when she felt her daughter had taken an unnecessary risk by going to a patient's home to give him his treatment.

*"My family told me to take some precautions, [but they know I] have to work. It's a social work to provide the service to the patients. They constantly tell me to be careful. [ ] [Once] my mother scolded me [and] said that you may also suffer from TB by going to a patient's home in this way." (NUIDIFHW1, female health worker, urban site)*

#### **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:** Delayed treatment seeking seems most commonly to result from mild, ambiguous or atypical TB symptoms and the need to work or take care of other responsibilities. If symptoms were considered severe (coughing blood, weight loss) or interfered with a person's ability to work, health care was sought. However, in some cases, diagnosis rather than treatment seeking was delayed, because of misdiagnosis or inconclusive test results, and this seems to be especially likely for extrapulmonary TB.

However, there was some suggestion from the health workers interviewed that stigma (shame of TB and fear that others may find out) may influence the health seeking behaviour of some patients, though there was little evidence of this from the experiences of the patients themselves who were interviewed. There was some indication that there is status in being able to afford and in obtaining health care from private services (viewed as of higher quality) which outweighs any stigma of TB.

**Potential policy implications:** stigma may play a role in delaying treatment seeking, but the role is likely to be negligible compared to other barriers to treatment seeking. Misdiagnosis and the limitations of diagnostic tests, especially for extrapulmonary TB, need to be addressed. 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.

---

From the interviews, delayed treatment seeking seems most commonly to result from mild, ambiguous or atypical TB symptoms (which may or may not be explained away by something else – e.g. cough caused by eating too much spicy food or smoking), and the need to work or take care of other responsibilities. If symptoms were considered severe (coughing blood, weight loss) or interfered with a person's ability to work, health care was sought. Previous experiences of unpleasant side-effects from medicines prescribed by a doctor can also influence health seeking behaviour. One of the TB patients interviewed had been reluctant to consult a doctor with her symptoms because of this.

*“When I take medicine I feel dizziness and cannot wake up for 3-4 days. After dizziness I feel cold and shiver and get headaches also. I suffer with that...”*  
(NUIDIFpt3, female TB patient, urban site)

However, in some cases, diagnosis rather than treatment seeking was delayed. Patients with symptoms suggestive of TB were not immediately diagnosed, despite the patients seeking health care, often from multiple providers, because they were either misdiagnosed as having, for example, allergies or pneumonia, or because tests for TB were inconclusive. One pulmonary TB patient (NUIDIFCpt1) did not suspect TB, despite having a cough and fever, because she was not losing weight and her initial x-ray was inconclusive (although a later sputum test showed she was positive for TB). Delayed diagnosis, rather than delayed treatment seeking, seems to be especially likely for extrapulmonary TB.

However, there was some suggestion from the health workers interviewed that stigma may influence the health seeking behaviour of some patients, though there was little evidence of this from the experiences of the patients themselves who were interviewed. One health worker (NUIDIFTBV1) said that in some places, but not her

locality, people are hesitant to go to the clinic for fear that others will find out they have TB. Another health worker interviewed (NUIDIFHW1) recalled a patient 8 or 9 years ago who although he did not delay seeking treatment because he was ashamed of his condition, he chose to access treatment from a (more private) medicine shop rather than the (more public) DOTS clinic.

There was some indication that there is status in being able to afford and in obtaining health care from private services which outweighs any stigma of TB.

*“The patients who are rich they can take medicine by buying. [ ] People who can afford the cost say proudly that they are taking medicine from outside.”*  
(NUIDIFHW1, female health worker, urban site)

Indeed another health worker in the rural site (NRIDIMHW2) thinks that medicines from the Government facilities are seen as lower quality than those from private clinics and medicine shops, so people with money and education seek medicine privately. He went on to say that he felt this belief is not completely unfounded as medicines distributed through the government health centres are sometimes unavailable and on one occasion were even recalled. Faith in the quality and efficacy of medicines, whether herbal, supernatural or biomedical, is important: as a male TB patient in the rural site (NRIDIMpt3) suggested *“if I take something, but I don’t believe in it then it will not work on me”*.

## ► Defaulting

**Summary:** While this study did not find evidence directly linking defaulting from TB treatment regimens with stigma, many of those interviewed felt that families are important in supporting and encouraging adherence to treatment and therefore disclosure to families is important (see *Concealment of a TB diagnosis*, p25).

Some of those interviewed acknowledged the importance of adherence, expressing a belief that if just one tablet is missed, the course of tablets has to be started again from the beginning. However, the length of TB treatment can vary not only according to the type and severity of TB, but also according to the health care provider, with some saying six months and others saying eight months.

Factors which interrupt TB’s lengthy treatment or make daily attendance at a DOTS clinic difficult were implicated by health workers as the main causes of defaulting. These included that the patient feels better and no longer thinks the medicine is necessary, the need to work (or take work when it comes), living in temporary accommodation (either rented or with friends or relatives) and having to move, and old age and co-morbidity. Difficulties keeping strict clinic appointments for those living in rural areas and the importance of *reliable* access to services when daily or regular clinic visits are required were also highlighted.

**Potential policy implications:** While knowledge of the importance of adherence to the full course of treatment, even after symptoms have subsided, is important, tailoring health service provision more to the needs of patients and patient groups is likely to be particularly beneficial. For example, daily clinic visits and strict appointments pose difficulties for people living far away, without reliable transport, who need to earn for their families, who are old or weak, and who are not permanent residents in a particular area.

While this study did not find evidence directly linking defaulting from TB treatment regimens with stigma, many of those interviewed felt that families are important in supporting and encouraging adherence to treatment and therefore disclosure to families is important. For example, a female TB patient (NUIDIFpt3) said that one day she forgot to take her drugs and her sons and daughter-in-law helpfully counted the drugs and then alerted her. While most of the TB patients interviewed had disclosed their TB to their families, they tended to be more selective about who they disclosed to outside of their immediate family.

The health workers interviewed thought that the main reasons patients default are that the patient feels better and no longer thinks the medicine is necessary, especially if his or her employment is not fixed and so s/he has to take work when it comes, or if the patient is a temporary resident in the area, living in rented accommodation or living with friends or relatives for the course of the treatment in order to ease access to the treatment centre. This can be burdensome for the friends or relatives and so the patient may not remain living there for the full course of the treatment, resulting in the treatment being interrupted. Another factor making adherence difficult, according to a health worker interviewed (NUIDIFHW1) was old age and co-morbidity. She said that older TB patients often also have diabetes, making it difficult for them to attend DOTS daily and to eat as is advised for TB recovery.

A male TB patient in the rural site, when asked at the end of his interview whether there was anything else he would like to say, spoke of the problems faced by poor people living in rural areas in keeping strict clinic appointments.

*“The TB centre asks patients to come after a few days to give the disease diagnosis which is very difficult for a poor person coming from outside for the treatment or if there is a strike and ‘bandha’ [lit. stop, i.e. no vehicles because of a strike]. People must go there on the date specified by them. That is a problem which needs to be resolved.” (NRIDIMpt1, male TB patient, rural site)*

Reliability of access when daily or regular clinic visits are required is also important. A male TB patient (NRIDIMpt2) went to a hospital for tests, but was referred for treatment to another health facility, 25 minutes walk from his home, as the hospital is difficult to travel to daily because strikes and fuel shortages can prohibit vehicle use at any time.

The son of a male TB patient (NUIDIFM2), who himself had had TB previously, said that the long length of TB treatment, the need to take time off work to access treatment and the knowledge that adherence is essential caused tension.

*“I felt tension because of the need to take medicine for a long time. [ ] ... need to go out for work. What if I can’t take medicine on time or I forget? That also causes me tension.” (NUIDIFM2, son of a TB patient, urban site, who had also had TB ten years ago)*

Indeed two of those interviewed (NUIDIFFM2 and NUIDIFM3) said that if just one tablet is missed, the course of tablets has to be started again from the beginning, while another (NRIDIMpt3) said that the doctor’s emphasis that discontinuing medicine will result in the TB not being cured added to his tension and fear. The length of TB treatment varies according to the type and severity of TB, but also according to the health care provider. A health worker interviewed (NUIDIFHW1) said



that patients coming from the Government Hospital report having been told treatment takes eight months, while those coming from private practices have been told six.

A former TB patient, when asked what the negative points of TB disease are, focussed her response on the inconvenience and difficulty of DOTS.

*“Negative points are firstly the need to take medicine regularly and not being allowed to take medicine home also, the need to come here.... At the beginning it used to be difficult to come such a long distance to take medicine.... [ ] That is, if the medicines could be taken home then it might be better.” (NUIDIFCPt1, female former TB patient, urban site)*

Likewise, in the rural site, a health worker spoke of how patients would find it much easier if they did not have to attend the DOTS clinic daily for treatment.

*“[ ] it would be better if they don’t have to come to this DOTS daily, it would be better if they would give medicine for 2-3 days.” (NRIDIMHW2, male health worker, rural site)*

And another patient (NRIDIFpt1) spoke of how she sometimes cried because of the difficulty of affording and taking treatment, because of the initial side-effects and the long and difficult walk to the clinic daily.

However, some DOTS providers do exercise flexibility. Some of those interviewed said that the TB clinic had agreed that a family member collects medicine on behalf of the patient whose job coincides with clinic opening times (NUIDIFHW1) or who is too ill to attend the clinic daily themselves (NUIDIFpt2 and NUIDIFpt3).

*“It’s difficult to run the programme by following all the rules.” (NUIDIFHW1, female health worker, urban site)*

The husband of a TB patient (NRIDIMFM2) who had himself had TB previously, recalled the difficulties he had balancing his work with the need to take nine different tablets spread out over three times of the day. When he explained the difficulty to his doctor, the doctor told him he could take all nine tablets together in the morning with his tea and then go to work.

A health worker (NRIDIMHW2) describes how he reassures patients who have just had a TB diagnosis by telling them that treatment is available and that if they have difficulty attending the clinic daily, they will figure out a way.

*“That is [patients are] a little bit afraid, thinking it is a big disease they have and they think they will never get cured, like those one or two things I have experienced. Therefore now I have changed my language a little bit nowadays. How I have changed it is [ ] ‘you will get treatment, we have treatment for 8 months, don’t worry you will get medicine from us, we will give always. But for two months you have to come daily. If you have major problems and you can’t come then we will consider [giving you medicine] for 1-2 days’. Just to convince them that it is not a big disease.” (NRIDIMHW2, male health worker, rural site)*

The same respondent explained that a DOTS health committee had established accommodation near the clinic for those living far away and with no relatives that they can stay with nearby, so that they can access treatment daily.

## ► Withholding medical histories

**Summary:** Some patients with relapsed TB or TB for the second time may withhold their past TB from health care providers for fear of being scolded, affecting the treatment prescribed for them.

**Potential policy implications:** Awareness is needed amongst health workers that scolding TB patients may discourage their disclosure of their medical histories with negative individual and public health implications.

---

Some patients with relapsed TB or TB for the second time may withhold their past TB from health care providers for fear of being scolded. The extent to which this happens is unknown and would require further research, but the individual and public health implications may be significant as medication prescribed for new and relapsed cases differs. The possibility of relapsed patients withholding their medical histories was brought to light by one of the health workers interviewed who said cases referred to her as new, turned out to be relapsed cases and that she thought this was either due to health workers taking incomplete medical histories or due to patients concealing their past TB. As she had heard reports of TB patients being scolded and kept at a distance by colleagues at another health facility and she knew for sure of one patient who was reluctant to disclose that he had been taking TB treatment previously, the latter explanation may well play a role.

### **4.5 Understanding TB-related stigma**

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

## ► Perceived hatred / *hela* towards TB patients

**Summary:** As the transmissibility of TB is linked to proximity, being caring towards a TB patient can become difficult and keeping a distance can appear as uncaring and hateful. There is recognition that precautions against TB transmission can be hurtful to patients.

Precautions against TB transmission, requiring distance and exclusion, are in opposition to the close proximity and inclusion required to care for a patient. Taking precautions against TB transmission can therefore appear as uncaring and hateful, and there is a recognition that they can therefore be hurtful to patients, especially as increased, rather than decreased, proximity and inclusion can provide valuable comfort and distraction to a patient, helping them cope emotionally with their illness. This leaves friends and families in a dilemma.

Whether restrictions (such as avoidance and separation) are interpreted as simply precautions or as *hela* depends on the emotional state of the patient, what precautions are deemed necessary and justifiable, who initiates them and how noticeable the precautions even are. Which precautions are deemed necessary

centres around the perceived longevity of TB's infectiousness period (over which there is some confusion) and confidence in a patient's adherence to treatment, perceptions of risk and susceptibility (with many factors contributing to susceptibility), as well as the feasibility and cost of enforcing the precautions. 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 they are to occur. Separating food/eating utensils or not sharing food seems to be deemed necessary and to be relatively feasible and acceptable to do in both rural and urban sites, where the principle of *jutho* (contamination of food) is common.

It is likely that the evidentness of illness also plays a role, with fear of infection being exacerbated when symptoms are evident. Likewise, the 'evidentness' to a TB patient of attitudes, emotions and behaviours which could be interpreted as negative is important too and it seems the more a person interacts with a community (and so would therefore expect visitors and enquiries from others when they are ill), the more evident discrepancies in others' behaviour can be and yet the more potential there also is for support from others.

**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. Greater emphasis and clarity on the limited longevity of pulmonary TB's infectiousness once treatment has begun, and therefore the short-term (i.e. two weeks, rather than two months or the full course of treatment) necessity of precautions against transmission, is needed.

It should be noted that increasing knowledge of or emphasising TB's transmissibility as part of a TB prevention and control strategy, may increase fear which may in turn increase 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).

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

A female TB patient (NUIDIFP1) distinguished between the stigma of TB and the stigma of HIV, saying that people are fearful of TB because of its transmissibility, but that people with HIV/AIDS are hated. However as transmissibility is linked to proximity, being caring towards a TB patient therefore becomes difficult and so keeping a distance can appear as uncaring and hateful. Indeed the recognition that precautions against TB transmission can negatively impact on the emotions of a patient left some respondents in a dilemma.

*"We know that an ill patient should not be kept separate as it will make them feel hurt." (NUIDIFFM3, daughter-in-law of a female TB patient, urban site)*

*"Though we feel love for the person, we can't love the disease." (NRFGDFcm1-R7, female focus group participant, rural site)*

Likewise a former TB patient (NUIDIFCpt1) said that separating an ill patient can be hurtful to the patient and so should not be done. A health worker interviewed (NUIDIFTBV1) spoke of the need to protect herself from getting TB, but without making the patient feel bad. She said she tries to keep a little distance from those patients with severe TB only and asks them to wear a mask, saying that if she were to wear a mask, rather than asking the patient to, it would make the patient feel bad.

The conflict between the need to take precautions against transmission, and the need to demonstrably care for a TB patient, was apparent in an interview with the son-in-law of a TB patient (NRIDIMFM1). He felt disease should be feared, and particularly feared the impact it would have on his ability to support his family if he were to become ill, but he also kept emphasising that while precautions are necessary, it does not mean he does not love his father-in-law.

*"I think disease can affect everyone and we have to be afraid of disease. In my heart there is love and I keep disease a little bit far. But to father.....there is love but because of love we should not share food, or share their clothes, sit near to them, share his water... So we need to keep disease a little bit far. Love is there in our heart." (NRIDIMFM1, son-in-law of a male TB patient, rural site)*

Likewise, the mother of a TB patient (NUIDIFM1) stressed that within families any behaviour/attitude change reflects hatred of the disease, not the person (which was reiterated in the focus group discussions), as families are mainly concerned about the patient's health and welfare.

*"We should be negative towards the disease only, not towards the person. [ ] [The vignette character's] son and grandson are her own, so the daughter-in-law also becomes her own, so she should not be negative towards her son, daughter-in-law or grandson." (NRFGDMcp1-R5, male focus group participant, rural site)*

The perceived support of friends and family and continued or even increased interactions with others can provide valuable comfort and distraction to a patient, helping them cope emotionally with their illness. A former TB patient described how distractions, such as working and talking with others, helped her control her feelings.

*"I tried to forget that I used to do other work, so I would watch TV, or would work in the kitchen. Or I'd go out and would talk with others. In that way I'd control my feelings." (NUIDIFCpt1, female former TB patient, urban site)*

Similarly, another female TB patient (NUIDIFpt4) said that when she hears something negative about TB she feels it for a few minutes, but then tries to forget it and put it out of her mind. She puts her ability to cope in this way down to the fact that she talks and jokes a lot with friends.

However, precautions against TB transmission, requiring distance and exclusion, are in opposition to the close proximity and inclusion required for continued or increased social interactions. A female TB patient (NRIDIFCpt1) explained how she did not feel bad about her diagnosis, but the separation from her friends (whether initiated by her or her friends) did make her feel bad and sometimes cry. When asked whether she ever felt she was being hated (*hepne*) due to the disease, she said she did. However, she coped with the separation, by trying to rationalise it and by acknowledging the necessity of it for the health of others.

Even when behaviours of others are attributed to their fear of infection, it may still be viewed negatively if not deemed to be justified. The son-in-law of a male TB patient was afraid of how others may react to his father-in-law's TB diagnosis. He clearly linked their potential negative reactions to a fear of infection, but in turn linked this with a lack of understanding and consideration for his father's feelings.

*"Those who don't understand will say, 'Hey! It will transmit to us, stay away.' That's why I feel a little bit afraid." (NRIDIMFM1, son-in-law of a male TB patient, rural site)*

Those interviewed often linked lack of knowledge or education with *hela* in a linear way (just as health professionals tend to). However, knowledge can also increase fear and stigma, with knowledge that TB is curable reducing fear, but knowledge that it is communicable increasing fear. Indeed, of two patients with little previous knowledge of TB, one (NUIDIMpt5) received his diagnosis with no expectations or baggage, while another (NUIDIFCpt1) reacted with fear as she knew nothing about TB and so did not know what to expect.

Some precautions were deemed justified by virtually all respondents and therefore could not be interpreted as expressions of hatred. For example, while adults (such as the elderly and those who drink alcohol) are deemed most at risk of TB, children and babies are deemed most vulnerable and in need of protection. As the mother of a TB patient explained, children are "*small and weak-hearted*" (NUIDIFM1) and the female TB patients participating in a focus group discussion (NRFGDFpt1) felt that the safety of a baby should override the feelings of TB patients. A male TB patient (NRIDIMpt3) said that TB patients have a responsibility to protect babies by keeping a distance from them, not holding or hugging them and not sneezing or coughing near them.

*"A TB patient should not hold a baby. If they hold a baby then also they should not hug them, should play with them from a distance only. Should not sneeze near to them, should not cough. [ ] We should do all this ourselves as the baby doesn't know about it." (NRIDIMpt3, male TB patient, rural site)*

A male TB patient (NUIDIMpt1) described the difficulty of not being able to embrace his son as he believed TB can transmit to children very easily, and a female former TB patient avoided visiting her mother for the full 8 months of her TB treatment as her brother, who lives in the same household as her mother, had a baby daughter.

*"I have my younger brother and he has a young daughter [ ] And it is said that this disease can transmit to small babies more. [ ] So I thought how can I tell them? After thinking a lot I said to them that for eight months I will not come there." (NUIDIFCpt1, female former TB patient, urban site)*

One of the TB patients interviewed felt that people become more understanding if they have had personal experience of TB.

*"If it has happened to their family, then it may change their views [ ] They may then get a chance to know about it better, but if there is no one who has been infected amongst their family members or close ones than it will be difficult for them to change." (NUIDIFCpt1, female former TB patient, urban site)*

Whether restrictions (such as avoidance and separation) are interpreted as simply precautions or as *hela*, as well as depending on what precautions are deemed necessary, depends on the emotional state of the patient, who initiates the precautions and how noticeable the precautions even are.

A female patient (NRIDIFpt1) seemed in a very good mood during the interview, laughing a lot, and reported only positive behaviour from others towards her and her TB. However, she did reveal that when she quarrels with her brother she feels hated because of her illness.

*“Sometimes I quarrel with my brother and I’m hurt. Then I weep. [ ] Thinking that I am hated by all due to my illness and I get angry. [ ] They do not hate me, [but I feel they do] when we are quarrelling.” (NRIDIFpt1, female TB patient, rural site)*

In the focus group discussions, participants acknowledge that when ill, a person’s moods are changeable.

*“When one is ill, then one will feel tension about where to go, how to earn money and sometimes one is happy and sometimes sad. That could happen.” (NRFGDFcm1-R3, female focus group participant, rural site)*

What precautions are deemed necessary centres around perceptions of risk and susceptibility, as well as the feasibility and cost of enforcing the precautions. The mother of a female TB patient (NUIDIFM1) saw no need to keep separate, as the doctor had told them her daughter’s TB is not communicable. She knew, however, that some types of TB are communicable and in such cases she sees precautions as necessary and would feed her daughter separately, not sit face to face and not sleep together. There was no sense that this was negative, just necessary.

A daughter-in-law of a TB patient (NUIDIFFM3) believed it was important for her mother-in-law’s recovery from TB that she eat the right foods (pulses, water) and avoid sour and oily food. She reported that her mother-in-law, who likes sour and oily food, was not so convinced and so interpreted her daughter-in-law’s imposition of food restrictions negatively, especially when she got frustrated with her mother-in-law’s non-compliance.

*“She says we are doing hela though we have not done so. [ ] She should not take much oily food. She may have jaundice. She was not convinced [ ] She likes to take sour, oily food like before. Without reasons she said she had hela done to her regarding food.” (NUIDIFFM3, daughter-in-law of a female TB patient, urban site)*

There appears to be some confusion over the longevity of TB’s infectiousness period once treatment has begun. According to (WHO 2003) infectious pulmonary TB patients cease to be infectious within approximately two weeks of regular treatment. With the intensive phase of DOTS being two months, the impression patients and communities seem to be getting is that TB remains infectious throughout the two month intensive phase, if not beyond.

*“[TB] is cured now by taking medicine regularly. It doesn’t get transmitted after taking medicine for two months. [ ] If they know that it doesn’t get transmitted [any longer than 2 months], good behaviour should be shown to those people who have got TB.” (NUIDIFPt1, female TB patient, urban site)*

*“For two months like that, they had told me not to live together for two months. And after that if we stay together then it will not transmit.” (NRIDIFCpt1, female former TB patient, urban site)*

The wife of a TB patient (NRIDIFFM2) said she thinks that people only avoid TB patients when they do not know that TB is curable and no longer transmissible once treatment has begun.

*"[If] somebody knows that [TB] is not transmitted after taking medicine, such a person thinks nothing about it. A person who does not know about it says we should not touch them." (NRIDIFFM2, wife of a TB patient, rural site)*

However, even if the longevity of TB's infectiousness period once treatment has begun is known, confidence that a patient is taking the treatment correctly and regularly is required. A male TB patient said that his friends do not treat him any differently to before – they do not “discriminate” – so long as they are assured that he has been taking his medicine.

*"When the medicine is not taken they don't know what has happened and don't come nearer." (NUIDIMPt2, male TB patient, urban site)*

Even if TB is known to be both curable and transmissible, perceptions of personal risk and susceptibility vary, in part because many factors are deemed to contribute to a person's susceptibility. While most of those interviewed said that anyone can get TB, those who drink, smoke, do not eat adequately and regularly and those who work outside are seen as more susceptible. As a result the wife of a TB patient who was interviewed did not think she would get TB from her husband because while he drinks alcohol and smokes, she does not, and when he had TB previously she did not get it herself (NUIDIFFM2). Similarly, a TB patient (NRIDIFpt3) did not believe her TB would transmit to others in her family, even though the doctor had said it is transmissible, because she believes it can only be transmitted to those who are physically weak and not healthy or well-built. As a result she did not sleep separately or use separate eating utensils. A TB patient in the rural site (NRIDIMCpt1) did not anticipate that others in his village would treat him differently or avoid him because he thought most believe it can only be transmitted via blood and so there was little risk of transmission from proximity alone, although he did acknowledge that views on this vary.

It is likely that the evidentness of illness also plays a role, with it being difficult to fear infection when a patient shows no obvious signs of being infectious, or being worried about someone's illness when they do not appear to be ill. A female TB patient (NUIDIFpt4), having taken medicine for 12 months for extrapulmonary TB, said she does not really feel she has TB and others do not behave towards her as if she is ill. Similarly, the mother of an unmarried female extrapulmonary TB patient was not particularly worried about her daughter as she is living a fairly normal life and does not appear sick.

*"I don't view her as sick. [ ] She is walking and eating food also. Because there is no need to restrict anything, we feel like there is no need to be worried much." (NUIDIFM1, mother of a female TB patient, urban site)*

The health workers interviewed admitted to feeling a little fearful at times about getting TB, but also felt they could not really say anything or act in any way that would make their fear obvious in front of the patient. They would therefore try to subtly keep a little extra distance.

*"If that disease will transmit due to being nearer to us, there is fear of its transmission, [so] don't talk directly face to face. From respiration, sit a little bit far*

*and if possible tell them to cover their mouth with a hanky.” (NRIDIMHW1, male health worker, rural site)*

If they began feeling unwell or developed a cough, they would quickly entertain the possibility of TB and so would seek a sputum test as a precaution.

A health worker (NRIDIMHW2) spoke of the influence what and how he tells a patient about TB can have on how the patient copes with the diagnosis and the disease. He particularly emphasised the importance of immediate and sufficient counselling following a diagnosis, for both the patient and the family together, to clarify what are and what are not necessary precautions, as the patient is likely to feel bad if separated. However, due to a lack of time, he felt he was not able to do this sufficiently.

*“We need to give counselling to him also and need to give medicine also and daily we don’t have time to talk with him more. For this there should be a separate team.” (NRIDIMHW2, male health worker, rural site)*

Fear of infection seems to influence behaviour more when there is little cost in the behaviour change. The less close the previous relationship and the more feasible precautions are, both practically and within the bounds of social norms and customs, the more likely precautions will be taken. A mother of a TB patient (NUIDIFM1) spoke of a parent’s responsibility, which overrides any fear of infection, to bring up his or her children and to feed them no matter what. A wife of a TB patient spoke of the incompatibility of her role and responsibilities of a wife and the need for separation as a precaution against TB transmission.

*“I never think like that he is ill and I should not enter his room. He needs to be looked after by me. It’s the responsibility of a wife to look after her husband when he is ill” (NUIDIFFM2, wife of a TB patient, urban site)*

The husband of a TB patient who had been married for almost fifty years spoke of how he cared for his wife, but felt that younger people would not care as much as they are now more self-focussed.

*“I don’t think people nowadays will do that much [ ] Now people think about themselves, what they eat, what they wear. That’s enough for them. Children nowadays are not like us [ ]. We think if we get hungry then others might also be hungry.” (NRIDIFM2, husband of a TB patient, rural site)*

This suggests there is a cost to avoiding a patient and the cost is being viewed by others as uncaring or self-focussed.

The wife of a TB patient (NRIDIFFM1) had heard that the TB patient should be given a separate plate that only he uses and had tried to implement this precaution for a week or two, but found it too difficult to sustain as their young children would mix up the plates. She suggested the difficulties of separating plates with young children in the home outweigh the potential benefits of doing so, especially as TB treatment is available anyway. The fact that no one else close to her had had TB before might also have influenced her perception of risk.

Along similar lines, the sister of a TB patient (NRIDIFFM2) said that in the past patients would be isolated and their eating utensils separated because there was no treatment for TB. However, now that medicine is available, such separation no longer



usually occurs and even her grandmother, who remembers when TB patients used to be isolated, no longer sees a need for it.

Separating food/eating utensils or not sharing food (*jutho*) seems to be relatively easy and acceptable to do in both rural and urban sites, even if a person (e.g. NUIDIFFM2) does not really believe TB can be transmitted that way (i.e. there is little cost). Generally, such separation is seen as a necessary and feasible precaution against TB transmission to other family members. A male TB patient (NRIDIMpt3) had been advised by the health worker not to share food or sleep with his wife. He saw some logic in not sharing food or not eating from the same plate, but little logic in not sleeping together.

*“Here the nurse said not to sleep together, should not share food [ ], but I didn’t believe these things [ ]. Either they were not able to make it clear to me or I myself didn’t believe them [ ]. We should not eat from the same plate, but what will happen if we sleep in the same bed?” (NRIDIMpt2, male TB patient, rural site)*

A male TB patient (NUIDIMpt4) had been advised about precautions against transmission by his nurse and informed his family, but his family decided just to enforce the precaution of using separate eating utensils. Indeed in some households, as one former TB patient indicated, such separation is easy as they had always eaten from their own, separate plates and had never shared leftovers anyway. However, NUIDIFFM3 felt that separating utensils and food would hurt the feelings of her mother-in-law.

*“If we kept separate utensils and give food separately she will feel hurt.” (NUIDIFFM3, daughter-in-law of a female TB patient, urban site)*

Patients reported being advised by health professionals to avoid sleeping together, which some (NRIDIMFM1) interpreted as abstaining from sexual intercourse. When a male former TB patient (NRIDIMCpt1) was probed as to whether he thought TB could be transmitted via sexual intercourse, he did not think this was an issue as *“it does not happen while being sick”* anyway. However the need for separate sleeping seemed to most often be related to the need to reduce the proximity between a patient and another family member, so patients reported sleeping separately from their children or parents.

A 50 year old male TB patient interviewed (NRIDIMpt3) was convinced that his TB is not infectious as he is taking medicine twice a day and so when others indicated that they did not want to eat with him or that they felt at risk, he would directly confront them by telling them that he is not infectious. This requires self-confidence, confidence in one’s own knowledge of TB’s infectiousness, and a degree of status to acceptably confront others, which not all patients have.

Being avoided by someone with whom one has had little previous interaction anyway is unlikely to be noticed and therefore interpreted negatively. Indeed, the ‘evidentness’ to a TB patient of attitudes, emotions and behaviours which could be interpreted as negative is important. The adult son of a TB patient in the urban site (NUIDIFM2) was asked whether people avoid his father since his father got TB or whether he had noticed any change in other people’s social interactions with his father. The respondent pointed out that his father had had a leg problem that preceded his TB diagnosis and so rested at home a lot, and by implication didn’t interact much with outsiders anyway. Similarly, a female TB patient in the urban site (NUIDIFpt3) said she used to grind black beans and so did not have time to go out

and talk with others, so had not heard either negatively or informatively of others with TB.

It is customary, when a friend, neighbour or relative is ill, to visit them and ask about their health, especially in the context of a rural village. A health worker interviewed (NRIDIMHW2) said that if someone has TB they are often not visited as is the usual custom, although their health, diagnosis and treatment may be enquired about via others, such as the health worker at the health post. However, receiving fewer than expected visitors is, in the absence of a specified and definitive reason, open to interpretation and a husband of a TB patient (NRIDIMFM2) speculated that if people were avoiding visiting them since his wife got TB, it might be because they were worried they would have to provide food or financial support.

It seems that the more a person interacts with a community, the more evident changes in others' behaviour can be and yet the more potential there also is for support from others. A 66 year old male patient (NUIDIMpt5) had not experienced TB particularly negatively and his diagnosis did not seem to be a great worry to him. He has no dependents and is still working, so his TB has not been particularly disruptive to his life. In the interview, he came across as somewhat of a loner and so was not aware of other TB patients and their experiences and had not picked up much gossip or information about TB from others in his neighbourhood.

### ► Concealment of a TB diagnosis

**Summary:** Patients tend to be selective about who they disclose their TB to, but normally disclose to their families. Concealing or selectively disclosing a TB diagnosis may, for some patients, be futile (everyone will find out anyway – in fact health workers themselves may divulge a TB patient's diagnosis, either intentionally or unintentionally through patient tracing and home visits), difficult (as daily visits to the DOTS centre are required) or even impossible (if a health worker has not disclosed the diagnosis to the patient). When patients are able to withhold their diagnosis from others, they may choose to do so to avoid worrying others or because they do not deem disclosure to be necessary or beneficial. However, sometimes patients or their family members avoid telling (specific) people in the community (friends and neighbours) who they anticipate may think or act negatively towards them. Patients may be more likely to anticipate negative consequences from disclosing to others if they themselves have previously felt negatively about TB patients or if they have heard others speak negatively about or act negatively towards TB patients previously. Even when the perceived risk of a negative reaction from friends is small, the potential cost of disclosing (i.e. the risk of feeling hurt) outweighs the perceived benefit of or need to disclose to friends. The anticipation of negative reactions relates to gossip and a fear of infection and while some felt efforts to conceal TB were more common in the past when treatment was not available, memories of TB's past dangerousness as well as its current communicability and lengthy, and not always guaranteed, treatment still instil fear.

**Potential policy implications:** As patients normally disclose to their families, whether there is a need to encourage wider disclosure or whether patients should have the right and ability to determine to whom their diagnosis is disclosed needs to be considered. Maintaining a patient's confidentiality, the need for daily DOTS centre visits and especially the tracing of patients who have failed to attend the clinic for treatment sometimes conflict, and the relative importance of patient confidentiality and the current form of service provision need to be considered.

If wider disclosure is to be encouraged, as a health worker in the urban site suggested, examples of real life stories of patients who had had positive experiences of disclosing should be shared, to counter the anticipation of negative experiences.

See also *Perceived hatred / hela towards a TB patient*, page 17.

---

Patients tend to be selective about who they disclose their TB to, but normally disclose to their families and take a family member to the clinic with them (at least for the diagnosis). Selective disclosure was more common outside a patient's immediate family, although actively trying to conceal a diagnosis was deemed by some in both the rural and urban sites to be pointless as news spreads anyway.

*"Disease cannot be hidden even if you try to hide it. People who know about your disease will make those who do not know about it aware." (NUIDIFFM2, wife of a TB patient, urban site)*

*"Though I didn't tell them, but they also know [ ] Why should they not know, others will tell them, one person to another person." (NUIDIFM1, mother of a female TB patient, urban site)*

*"Why do I need to tell anyone? Everyone knows anyway [laughing]."*  
*(NRIDIFFM1, wife of a TB patient, rural site)*

*"[Neighbours/friends] asked what happened and then I told them I have this disease. Everyone knows if one person knows. One communicates to another and another to others. In this way everyone gets to know." (NRIDIFpt3, female TB patient, rural site)*

Concealing a TB diagnosis may be futile, difficult or even impossible for some patients 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. One respondent, an extrapulmonary TB patient, said that the doctor had initially withheld the diagnosis from him, telling his sisters that he knew what was wrong with the patient but did not intend to tell him his diagnosis as the fear might worsen his condition. The respondent felt strongly that this was both wrong and counter-productive.

*"[ ] doctors must share openly about the disease whatever the diagnosis is so the patient's parents can do whatever treatment is available. They can do nothing if it is a disease with no treatment. Doctors should not give a wrong assurance to the patient that they will cure the disease by hiding the disease. If they can't cure the disease then why should they say they will cure the disease?" (NRIDIMpt1, male TB patient, rural site)*

Even if a patient is aware of their diagnosis and wants to conceal their diagnosis from others, it can be difficult to if treatment requires daily visits to a clinic. A female patient interviewed pointed out that, while there is variation from family to family, this is generally more difficult for women than for men, as a man is usually freer to move around without being questioned. A woman, by contrast, will be asked where she is going, with whom, when she will be back and so on. Another reason why concealing a TB diagnosis may be impossible is if the patient has to be accompanied to the

health facility. According to a male TB patient in the rural site (NRIDIMCpt1), female patients cannot go to the health facilities on their own as they cannot usually read.

*“How can we send a female alone, she can’t read so wherever she goes she needs a male along with her.” (NRIDIMCpt1, male former TB patient, rural site)*

A daughter-in-law of a female TB patient felt that economic status plays an important role in influencing the evidentness of a TB diagnosis. Those who are rich are better able to conceal their TB diagnosis as they can afford to access treatment privately, rather than from the (public) DOTS centre. She also felt that poor people’s lesser knowledge about TB leads them to disclose their TB when they should not, resulting in discrimination.

Health workers themselves may divulge a TB patient’s diagnosis to others, either intentionally or unintentionally. A TB volunteer interviewed whose role included tracing patients who had not come for treatment (NUIDIFTBV1), did not deem confidentiality of the patient’s TB status to be important and strongly felt that TB patients should disclose, both for their sake and the sake of others. In response to a vignette in which a man with TB had not disclosed to his wife who then met and asked his doctor what was wrong with her husband, those participating in the focus groups generally felt that the doctor ought to divulge the diagnosis, for the sake of both her and her husband, and that concealing TB from a spouse is wrong, not least because the husband will need his wife’s support in changing his diet, as deemed necessary for recovery.

*“It is not possible for the doctor not to tell her. It is his responsibility also, his social responsibility which he has to fulfil. He should not hide it at all. If the patient has hostility in his neighbourhood then that is another matter. Otherwise, the doctor should tell the truth.” (NRFGDMcm2-R4, male focus group participant, rural site)*

*“Hot, sour, everything. They will think he has no problem and will give him whatever is prepared in the home. Oily, hot, sour, everything he will eat. If he discloses his disease then food will be prepared according to the disease.” (NRFGDFcm2-R8, female focus group participant, rural site)*

A male TB patient (NUIDIMPt1) spoke positively about how during holidays, when the clinic is shut, the health worker comes to his home to give him his treatment, which he receives in the form of injections. However, to the health worker’s frustration, not all patients are as appreciative, behaving as though they do not recognise him, presumably because the visits have not been agreed in advance and the health worker’s presence in the patient’s home raises the suspicions of others to whom the patient has not disclosed their TB. Supporting this, a female patient in the rural site (NRIDIFpt2) described how when the doctor came to her home she was terrified that he might disclose her TB to her husband and neighbours.

*“I was scared if he disclosed it to my husband [ ] And after that, if they ... if neighbours will know then...” (NRIDIFpt2, female TB patient, rural site)*

Maintaining a patient’s confidentiality and the tracing of patients who have failed to attend the clinic for treatment sometimes conflict and the relative importance of the two need to be considered. A health worker interviewed (NRIDIMHW2) involved a patient’s brothers, nephews and the Maoist party in tracing a patient who after two months failed to return to the clinic.

When patients are able to conceal or selectively disclose their diagnosis, they may choose not to disclose or to conceal their diagnosis for a variety of reasons, many of which are not stigma-related, such as not wanting to worry others, deeming disclosure to be neither necessary nor beneficial and not feeling confident that the diagnosis is correct. For example, a woman interviewed who had been ill for many years and had visited many health facilities, had many inconclusive tests and had been operated on twice, had not disclosed to others that she was now being treated for suspected extrapulmonary TB because she anticipated some would worry and some would avoid her, but also because her diagnosis was suspected and not confirmed.

*“If it is not TB then people will say I have become mad and that I change the story frequently.” (NRIDIFpt2, female TB patient, rural site)*

Another patient delayed telling his family about his TB diagnosis for a week because his father was sick and scheduled to have an operation, so he didn't want to add to the worry. A female TB patient interviewed said there was no need to tell “hi-hello” friends (NUIDIFpt2) and a health worker interviewed saw it as pointless to inform relatives living separately who cannot provide expenses or support anyway (NUIDIFHW1). However, some patients or their family members avoid telling (specific) people in the community (friends and neighbours) who they anticipate may think or act negatively towards them, while others, drawing from past experience, may disclose, confidently anticipating receiving support.

*“If we go out together, you and I, then they say to you, ‘hey the person you were with just now has TB’: like that they immediately and secretly do back biting [ ] And he says to another person and another person says to the next... [ ] It spreads all over from one ear to two ears to every ear.” (NRIDIMpt3, male TB patient, rural site)*

*“[Others] are not doing hela much to me. Whatever happens, even if I get HIV, I think my friend [his best friend with whom he shares everything] will never behave like that.” (NRIDIMpt4, male TB patient whose close friends were very supportive when his father died)*

Patients may be more likely to anticipate negative consequences from disclosing to others if they themselves have previously felt negatively about TB patients. One female patient had not known anyone else with TB, but knew how she would have reacted if someone told her they had TB.

*“They have disease and why do they have such a disease. [ ] This disease is not good, I don't like it. [ ] This disease is like chayarog, isn't it?” (NRIDIFpt2, female TB patient, rural site)*

It is not only TB patients who may anticipate stigma, but also their family members. The son-in-law of a man with TB (NRIDIMFM1) was worried that others may keep their distance from his father-in-law. For this reason a patient with the intention of being open about their disease may be advised by others not to disclose.

*“[My sister-in-law] was saying ‘why did you tell me, you should not tell anyone about your disease’”. (NUIDIMpt4, male TB patient, urban site)*

The anticipation of negative reactions relates to gossip and fear of infection. A male TB patient (NUIDIMpt1) said that he may disclose his TB to more people once he has

been on medication for two months and his TB is no longer infectious, but not before for fear that people will stay away from him (even though he is now staying away from them so as not to infect them) and for fear that they may say bad things about him, implying that avoidance and speaking badly of a TB patient is related to TB's infectiousness. It should be noted however, that TB as a topic of conversation can be both negative (gossip) and positive (information dissemination). A former female TB patient (NUIDIFCPt1) had been apprehensive about telling her mother she has TB, but when she did, her mother said she already knew, from people coming into her shop, that TB is curable and will not transmit to others.

A patient may have heard friends speak negatively of people with TB previously, and so perceive a risk, even if small, that they may react negatively towards him or her. For example, a TB patient's friends (and possibly himself) had said of others in the past *"that person is thin and probably has TB and will die"*, and although he suspected they would not actually say that to him if they knew he had TB, he did not want to risk it. *"When they say then it hurts in my heart. They don't say it seriously, but it hurts"* (NUIDIMpt1). Even though the perceived risk of a negative reaction from friends is small, the potential cost of disclosing (i.e. the risk of feeling hurt) outweighs the perceived benefit of or need to disclose to friends.

A female suspected extrapulmonary TB patient knew that in the past TB patients were separated from others and so anticipated a risk that the same might happen to her if she disclosed her TB to others. She described how she did not know for sure how others would react, and sometimes felt they would most likely react positively, but she could not know for sure. Once TB is disclosed, it cannot be 'un-disclosed'.

*"It's a disease of the past. In villages such patients were kept separate and had separate beds and were left to sit separately. I knew that. [ ] If they will do [this to me] or not can only be discovered once they know. [ ] Sometimes I feel they will not do this and sometimes they will do, I don't know."* (NRIDIFpt2, female TB patient, rural site)

Those participating in the focus group discussions generally felt that disclosure was important for the sake of the patient and of others. If a married male TB patient did not tell his wife and family about his TB it could cause problems, as they would not understand why he could not work and his wife would not provide him with the nutritious diet he needed for recovery. To receive support from others, others have to know that support is needed.

*"Nobody will provide support if he does not tell his problems. Disease will become serious if he does not say."* (NRFGDMpt1-R5, male TB patient participating in focus group discussion, rural site)

A health worker (NUIDIFTBV1) who deemed disclosure of TB to be important both for the patient and for others, felt that as patients sometimes did not disclose their TB status because they anticipated negative reactions from others, examples or real life stories of patients who had had positive experiences of disclosing should be shared.

Some felt efforts to conceal TB were more common in the past when TB was not a simple disease. "Simple" seems to mean not dangerous, with dangerousness linked with curability, ease of curability (inc. length of treatment), severity of symptoms and likely outcome.

*“It was dangerous in the past and no medicines were available. Now medicines are available. They become frightened and ask whether TB will be cured or not.” (NUIDIFTBV1, female TB volunteer, urban site)*

However, even now TB is not incontrovertibly seen as a ‘simple disease’, and understandably so. One respondent, contrasting dangerous communicable diseases with ‘simple diseases’ said that “[ ] to dangerous and communicable disease I feel they do a little bit hela” (NUIDIFpt4). While another respondent acknowledged that cancer is thought to be more dangerous than TB, the word “TB” nevertheless still instils fear and some respondents said that if careless or negligent, TB could turn into cancer.

*“Everyone will take it in a bad way at the beginning [ ] While saying TB, there’s a little bit in the word .... I can’t explain.” (NUIDIFpt4, female TB patient, urban site)*

*“I think a small wound develops in the lungs due to coughing and that leads to a big wound. We know if there is one rotten potato, all potatoes will rot [and] the same thing applies here. Likewise the small wound damages the whole lungs. Due to negligence the wound increases in size and develops definitely into cancer.” (NRIDIMpt1, male TB patient, rural site)*

A male patient theorised that people gossip about and hate those with TB because TB cannot be quickly treated with a short course of medicine, making it a dangerous disease despite being treatable.

*“[TB] disease is a little bit dangerous. [ ] That’s why people try to do ‘hepne’ [hela]. When we have diarrhoea, dysentery, fever, common cold... [ ] nothing will happen, it’s normal, take one [para]cetamol and it will cure it. [TB] has a long life that’s why...it needs 8 months, 10 months... [ ] Need to take medicine so it costs thousands.” (NRIDIMpt4, male TB patient, rural site)*

Similarly, a female former TB patient (NRIDIFCpt1) felt that TB is more dangerous than typhoid because you “need to take more medicine” for it, whereas another female TB patient (NRIDIFpt3) felt that while cancer is the most feared as it is incurable, TB, like typhoid, is only dangerous if detected late.

► **Reduced social interaction of TB patients with others**

**Summary:** As well as selectively disclosing their TB status to others, patients may also avoid social interactions with others because they feel too ill, they want to protect others from TB transmission or so that others are not able to avoid interactions with them. While self-initiated separation is, or at least can be, interpreted by the patient and others as the patient caring for and protecting others, separation from the patient initiated by others is more likely to be interpreted as uncaring.

**Potential policy implications:** See *Perceived hatred / hela towards a TB patient*, page 17.

---

As well as selectively disclosing their TB status to others, patients may also avoid social interactions with others. As with selective disclosure, there are varied reasons

for avoiding social interactions, including feeling too ill and wanting to protect others from TB transmission.

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

However, sometimes TB patients avoid interactions with others so that others are not able to avoid interactions with them. The observable outcome is the same – reduced social interaction – but the underlying motivations and interpretations are different. A male TB patient interviewed (NUIDIMpt1) explained how he avoided others so as not to infect them, but concealed his diagnosis from them so that they would not avoid him for fear of infection. It seems that self-initiated separation is, or at least can be, interpreted by the patient and others as the patient caring for and protecting others, whereas separation from the patient initiated by others is more likely to be interpreted as uncaring. Likewise, a female TB patient (NRIDIFpt1) explained how she separated herself from others, such as neighbours and friends, rather than others separating themselves from her. She saw this as a precaution she had decided to take and seemed quite content with the separation as a result.

*“I myself sit separately. If they sit on the bed, I sit on the sofa, but they said it’s OK if I come near to them. They say nothing [bad].” (NRIDIFpt1, female TB patient, rural site)*

Such social isolation by a TB patient may arise not just from the anticipation of being avoided by others, but from experience of it as well. The daughter-in-law of a female TB patient (NUIDIFFM3) felt pity for her mother-in-law when her mother-in-law’s friends came to visit, but then left one by one. The respondent put this down to her mother-in-law having told them she had TB and them knowing it was infectious. Leaving a sick person because she is believed to be infectious was interpreted as hate/hela *“I felt they hate my mother [ ] they did hela”* and so the respondent advised her mother-in-law to stay home and not go outside.

## ▶ Reduced marriage prospects

**Summary:** Postponing marriage when ill is preferred, but for some a postponed or cancelled marriage can have an impact on their longer term marriage prospects. The impact of a TB diagnosis on a person’s marriage prospects depends on whether or not marriage is on the immediate agenda, the age (and optimum marriagability period) and gender of the patient, the pool of eligible marriage partners and the attitudes of the prospective in-laws. In particular, women who join their husband’s family after marriage face difficulties if they are seen to be weak or unable to work hard and while this can result from many diseases, TB is more severe, longer-lasting and therefore more disruptive than, for example, a common cold. Furthermore, the belief that if a pregnant woman gets TB or a woman with TB becomes pregnant, her unborn child may be affected, either immediately or later on in life, by the TB or the TB treatment, may contribute to making a TB diagnosis particularly disruptive to a pregnant woman or someone wanting or expected to get pregnant, such as a soon-to-be or newly married woman.

**Potential policy implications:** The later the diagnosis or the more severe the TB, the more debilitating the illness and the lengthier the treatment. Therefore, earlier diagnosis and treatment is needed, especially for unmarried women (see *Delayed*



*treatment*, page 13), as is clarity on the effects of TB and TB treatment on pregnancy and fertility.

---

Postponing marriage when ill is preferred, but for some a postponed or cancelled marriage can have an impact on their longer term marriage prospects. The impact of a TB diagnosis on a person's marriage prospects depends on whether or not marriage is on the immediate agenda, the age and gender of the patient, the pool of eligible marriage partners and the emotional attachment between a couple.

One of the female focus group participants (NRFGDFpt1) said that if the groom-to-be likes and especially loves the bride-to-be he will think the illness is curable and will marry her anyway. An unmarried female TB patient's (NRIDIFpt1) mother told her that if she disclosed her TB diagnosis to everyone it would affect her chances of getting married. However, she herself did not think TB was such a bad disease as it is curable and her own future plans were focussed on learning a trade and starting a business, rather than marriage.

Generally, marriage prospects were thought more likely to be affected for unmarried women, rather than unmarried men, with TB. Although the unmarried female TB patients reported that their families had been supportive, a male TB patient (NRIDIMpt4) felt strongly that parents felt and acted differently according to whether it was their son or their daughter that had TB, and that this was because sons were expected to take care of their parents in old age, whereas daughters married into another family and once they had TB, their marriage prospects were jeopardised. The same respondent put the effect of a TB diagnosis on a woman's marriage prospects and marriage in essence down to economic factors and her perceived inability to work, as did the focus group participants.

*"Nowadays, the problem of marriage I think is an economic problem. Whenever there is a problem with the economic status of a female, there is a problem with marriage, in that if she gets a disease, if she gets sick, then people start to say this female is weak economically because she has this disease. She has this so she can't do anything and in our home, she can't handle the home either."*  
(NRIDIMpt4, male TB patient, rural site)

*"Some [families] may need a daughter-in-law who can do household activities. An ill person cannot do such work. It depends on what type of family they are, like are they a happy family who do not need to do lots of work. It depends on the type of family and their social status."* (NRFGDFpt1-R2, female focus group participant, rural site)

Supporting the link between a woman's reduced marriage prospects and disease's effect on her ability to work, an unmarried female former TB patient (NRIDIFCpt1) felt that even after marriage if a daughter-in-law had any small weakness, her in-laws would do *hela* towards her. Likewise, an unmarried male TB patient (NRIDIMpt4) said that society was harder on girls, not just if they had TB, but if they had any disease or they did not or could not work hard.

*"If we talk about girls, in our society, if a girl has any [ ] disease or she does not work well [ ] or she has problems, then it will be hard for the girl."* (NRIDIMpt4, male TB patient, rural site)

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

*“There is a culture of keeping females at a lower level than males. [ ] That effect might have come to the mother-in-law [in a vignette]. Without trying to get to know her own son’s weakness, she blames the daughter-in-law only.”*  
(NRFGDMcm2-R3, male focus group participant, rural site)

However, attitudes of in-laws and prospective in-laws vary and a 16 year old unmarried male TB patient (NRIDIMpt4) who was still at school did not think his chances of getting married would be affected if his prospective in-laws were “understanding”, even if he were to get married while ill. He explained that by “understanding” he means that they knew about TB and they knew someone with TB could be healthy and still work later on.

Another factor which may come into play in relation to women’s reduced marriage prospects is the belief, held by some of those interviewed, that if a pregnant or lactating woman gets TB or a woman with TB becomes pregnant, her unborn child may be affected, either immediately or later on in life, by the TB or the TB treatment, making a TB diagnosis particularly disruptive to a pregnant or lactating woman or someone wanting or expected to get pregnant, such as a soon-to-be or newly married woman.

*“Born from that TB patient [a baby] can get TB [ ] because the baby is in the womb of an infected mother who already had TB [ ] If that time that baby did not get [TB] then also it may be affected in later life.”* (NUIDIFCPt1, female former TB patient, urban site)

*“I have heard that if a baby is born from infected parents then that baby also can get [TB]. It is in the blood of those parents [ ] Being of the blood of those parents it can pass to the baby as well.”* (NRIDIMFM1, son-in-law of a TB patient, rural site)

In one of the focus group discussions, a male participant’s understanding of the mother-to-child transmission risk of TB during pregnancy and breastfeeding was extrapolated from media messages on HIV, highlighting potential unintended consequences of single-disease health promotion messages.

*“Like we have heard from the media, when an HIV infected mother delivers a baby then that baby may not get HIV and will get cured after taking treatment. [ ] Then if a TB infected mother delivers a baby then we should not think that that baby might also have TB. [ ] While breastfeeding, some blood of the mother might come in the milk and it can transmit from that.”* (NRFGDMcm2-R5, male focus group participant, rural site)

A male TB patient (NUIDIMPt2) suggested there is an incompatibility between pregnancy and TB drugs and that a pregnant woman would need to terminate the pregnancy as a result. However, respondents generally thought it implausible that there is any risk if a person becomes pregnant after being completely cured of TB (NUIDIFFM2/FFM3/FM1).

The impact of a TB patient delaying marriage until after they have been cured depends on their age and when is deemed the right age to get married. Women are

generally expected to get married at a younger age than men, and a delay in marriage could find them at an age considered 'too old' for marriage. A female TB patient (NRIDIFpt2) implied she got marriage at a late age at 25 years old because of her illness and the medical investigations and treatment required. Throughout the interview she held her late marriage, and the subsequent late and closely spaced births of her five children, responsible for her becoming weak and developing TB. Subsequent focus group discussions explored and confirmed the idea that for a woman marrying at 25 years of age was late, especially if she was not otherwise engaged in education or a job.

*“How I feel is that in the context of Nepal, women especially get married at a young age. [ ] Now everyone speculates about the reason for not getting married until 25 years old, that there might be some problem.” (NRFGDMcm1-R3, a male focus group participant, rural site)*

Marriage breakdown following a TB diagnosis appears to be extremely rare, with few of the respondents knowing an actual case of this happening. However, some of them saw it as a possibility. When an unmarried TB patient (NRIDIMpt1) was asked what he thought would have happened had he been older and married with a wife and children, he said that they would have left him for fear of getting the disease from him. None of the married patients who had been interviewed had experienced this, and indeed this particular unmarried respondent had received support from both his family and friends.

## ► Family tension

**Summary:** Feeling that one's family and friends are supportive (by accompanying the patient to the health facility, encouraging them to take medicine and providing nutritious food, and not avoiding or separating the patient) appears to be extremely important to TB patients and to make a marked difference in how they cope with their diagnosis. However, sometimes, following a TB diagnosis, a family may experience tension, particularly if relations with family members were previously strained, distant or hierarchical, but also if the illness of one member increases the workload of others. While this can occur as a result of any illness, it is accentuated with TB as TB and its treatment are relatively long, debilitating and disruptive. The degree to which TB patients can continue work depends both on their health and their ability to combine taking treatment with doing their work. For some, both the illness and the need to access and take treatment daily can interfere with their jobs and affect their incomes, in turn leading to tension at home. If TB symptoms are not obvious or constant, it can be particularly difficult to be sympathetic towards a family member's inability to work.

Tension and frustration may also arise amongst family members if a patient is thought to be jeopardising his or her own recovery by not following advice and this can be interpreted negatively by the patient, as being hateful.

**Potential policy implications:** Encouragement of family and friends to be supportive sits uncomfortably with recommended or perceived necessary precautions against TB transmission. The impact of TB on a person's ability to work is influenced by the severity of the TB and the need for daily, lengthy treatment. Earlier diagnosis to reduce TB's severity, and less disruptive treatment provision (whether that means changing the requirement to attend the DOTS clinic daily, changing the opening hours of the DOTS clinic, or changing the time at which TB patients are required to

be observed taking their medicine) are likely to decrease the patient's inability to work.

Counselling and education for both patients and their families may also aid in promoting consistency in and understanding of received advice and be used to share ideas for both patients and families on how to cope with family tensions if they occur.

---

Feeling that one's family and friends are supportive appears to be extremely important to TB patients and to make a marked difference in how they cope with their diagnosis. Supportiveness can include accompanying the patient to the health facility, encouraging them to take medicine and providing nutritious food, and not avoiding or separating the patient. However, sometimes, following a TB diagnosis, family members can experience tension, which the TB patient may perceive to be associated with his or her illness.

This is particularly the case if relations with family members were previously strained, distant or hierarchical. The son-in-law of a TB patient in the rural site (NRIDIMFM1) took care of his father-in-law who had TB for two months before his brother-in-law came to take his father home. While he did not know why the brother-in-law had chosen to take on the care of his father-in-law after two months and he felt his father-in-law should stay, he could not refuse his brother-in-law as he was both elder and the son of his father-in-law. This suggests what can and can not be said, done or insisted upon depends on one's position within a family and is likely to apply to precaution-taking as much as caring.

The emotional closeness of a married couple, which is influenced by the type and length of their marriage, may contribute towards influencing the degree of tension following the onset of one spouse's TB illness. A male TB patient (NUIDIMpt2) who was interviewed distinguished between arranged marriages and marriages based on love, saying that in a love marriage there is better communication and openness between the partners and more understanding of the "heart's feelings". Changes in family structure may also play a role. A male former TB patient from the rural site (NRIDIMCpt1) lamented the loss of love and family cohesion resulting from the increasing numbers of married sons living separately from their parents.

*"People do not think about how they would feel themselves. [ ] How they would feel themselves, they should think that that is how others would feel too. There should be love to all in the same way. But nowadays people do not have love. Now, boys leave their families and take their wives to foreign countries. Now it is a time of living out." (NRIDIMCpt1, male former TB patient, rural site)*

The illness of one family member can put a strain on other family members because a decrease in one member's ability to work can increase the workload of other members. While this applies to illness in general, it is accentuated with TB as TB and its treatment last longer and are more debilitating and disruptive than, for example, the common cold.

*"If you are sick then all will suffer." (NRIDIMpt3, male TB patient, rural site)*

*"In family if I get sick they everyone gets tension [ ] If I get sick then they have to work more." (NRIDIMCpt1, male former TB patient, rural site)*

*“During sickness, [a husband] can’t bring food and can’t feed [his family], so [husband and wife] fight, ‘you did this, you did that, could not earn, got sick, where can we get food, how will we eat and drink?’ Like this happens in a family.” (NRFGDMcm1-R5,, male focus group participant, rural site)*

The degree to which TB patients can continue work depends both on their health and their ability to combine taking treatment with their work. A male TB patient (NRIDIMpt4), living with his sisters was asked whether his sisters ever complained that he was not contributing sufficiently to the household workload. While he knew that this would cause tension in some families, it was not a cause of tension in his as he was able to continue working despite his diagnosis. As a male unmarried student, the housework he was expected to do may anyway be relatively limited.

A health worker (NRIDIMHW1) said that most patients respond quickly to treatment and are able to resume work. However, for some both the illness and the need to access and take treatment daily can interfere with their jobs and affect their incomes, in turn leading to tension at home.

*“They need to take medicine so they are unable to go to their job. Because of that they have had to leave their job. They simply stay at home. [ ] It has an effect in society and within the family also. Conflict arises within the family [ ] due to not having an income [ ].” (NRIDIMHW1, male health worker, rural site)*

If TB symptoms are not obvious or constant, it can be particularly difficult to be sympathetic towards a family member’s inability to work. An extrapulmonary TB patient (NUIDIFpt4) described how due to back pain her doctor advised her not to do any strenuous work during her 18 month course of treatment, but that she had no choice but to contribute to the household chores, although sometimes she struggled due to her back pain. On such occasions she said that sometimes her sister would scold her for not pulling her weight which would make her feel bad.

Another reason for family tension is that family members might get frustrated if a patient was thought to be jeopardising his or her own recovery. The son-in-law of a male TB patient described how although he did not treat his father-in-law badly and indeed cared very much for him, his frustration towards his father-in-law when he did not eat as was deemed necessary for his recovery, could be interpreted negatively as being hateful.

*“I also shout at him if he takes anything when I am not at home [ ] I think if I am doing all these things for him to get well soon then he also has to think about it. [ ] That’s why I tell him not to take these things. ‘If you want you can have other things, but don’t eat those things’. [ ] I haven’t behaved differently towards him between being sick or healthy, but when I feel that my father[-in-law] is not controlling what he puts in his mouth, when he coughs more, then... He did this so he is not getting cured properly. So he is not getting well soon. That’s why I hate.” (NRIDIMFM1, son-in-law of a male TB patient, rural site)*

As TB patients need support and encouragement from their families, some of those interviewed emphasised the importance of counselling and educating not just the patient, but their families too, to lessen the potential for family tension.

## ► Financial disruptiveness of TB

**Summary:** Even though TB drugs are provided free of charge from Government health facilities (as long as the patient is 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 believed to be needed to counter the side effects of TB drugs and to ensure full recovery.

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

---

How people cope with TB and how people perceive TB (and therefore the stigma of TB) is influenced by the impact the disease and its treatment have 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 and difficult for patients to cope with. (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.

*"When [a TB patient] comes home and there are arguments because he hasn't brought money home, he will get sad. [ ] Whatever happens, if there is comfort at home, they he would not be sad and his disease will not press on him and it will be all right." (NRFGDFcm2-R1, female focus group participant, rural site)*

Getting a TB diagnosis can be costly. The daughter-in-law of a female extrapulmonary TB patient explained how it had taken a long time and a lot of wasted money before finally getting the TB diagnosis.

*"We had visited many places for check up and spent a lot of money. We went to other places but it turned out mother has TB. All expenses resulted in nothing. The disease was not any better. These things made me sad. We spent a lot of money." (NUIDIFFM3, daughter-in-law of a female TB patient, urban site)*

Even when the diagnosis is relatively rapid and clear-cut, the patient still has to pay for the sputum smear test (and often an x-ray) and for the time and expense of reaching the health facility. One TB patient (NRIDIMpt3) was told that he would need to be admitted to hospital for one month, but because it costs 100-150 rupees per bed per night and food is not provided regularly and the cost of transport for his wife to visit him would have been prohibitive, the respondent told the doctor he could not be admitted and the doctor agreed for him to take the treatment home with him.

Once diagnosed, TB treatment is provided free of charge from government health facilities. However, not everyone knows this and shortages of the required drugs sometimes mean a patient has to purchase the required treatment elsewhere. A female TB patient interviewed (NUIDIFpt4) explained how she paid for TB treatment from a medicine shop for two months before discovering that she could have got the

medicine free of charge from the government DOTS clinic. A male TB patient (NUIDIMPt1) had an allergic reaction to Isoniazid and so had to be treated with Rifampicin only. However, the DOTS clinic only had Isoniazid-containing fixed dose combination drugs, and so he had to purchase Rifampicin from a medicine shop.

Even when a patient does receive treatment free of charge, the perceived need for supplementary nutritious food for recovery requires financial resources. A female TB patient interviewed (NUIDIFPt1) spoke positively about TB treatment being available free of charge, but felt that TB patients also need financial support to buy food. A health worker interviewed suggested an alternative solution, that advice regarding food be tailored to the patient according to their medical situation (especially if they also have diabetes) and their financial situation, emphasising that patients should not be told they must eat food that they cannot afford in order to recover.

*“It should not be told to patients that it’s compulsory to eat meat with a meal after taking this TB medicine [ ] The main concern for them then becomes how to afford a meal with meat daily. We need to convince them in such situations that there is no need to take meat daily. ‘You should not have an empty stomach. You can eat [ ] whatever is available in the home.’” (NUIDIFHW1, female health worker, urban site)*

Contributing to the financial impact of TB is the difficulty some patients face to access lengthy and time-consuming TB treatment, and to balance the need for treatment against the need to earn an income. One of the health workers interviewed felt the patients needed to be reassured and told not to worry, but acknowledged the limitations of her role in alleviating the underlying reasons for their worry.

*“We cannot provide them with jobs, can we?” (NUIDIFTBV1, female health worker, urban site)*

Respondents generally felt that having TB was easier for those who are unmarried, as they had fewer responsibilities. For example, a married male TB patient (NUIDIMPt1) thought that if a man was unmarried then somehow the family could pull together and support him. However, if the person was married, he was responsible for financially supporting others, making a TB diagnosis even more of a problem. In fact he felt the disease was not the problem, as eventually it would be treated. The problem and his main concern was managing financially. Likewise, a male TB patient in the rural site (NRIDIMPt3), with young children and an elderly father to look after, seemed overwhelmed by the burden of his responsibilities in light of his TB diagnosis and began to cry.

*“How much can we earn? I myself am so weak, where can I go to earn? [ ] Some times I borrow from friends. [ ] I have my father at home. [ ] Everything I have to do, I need to take care of him.” (NRIDIMPt3, male TB patient, rural site)*

Worries about how to manage seemed to be especially pronounced if the TB patient had dependents (e.g. children or a dependent spouse), was already struggling financially and had little help from others (e.g. no alternative sources of income or extended family nearby). Both health workers interviewed in the urban site, and those participating in the focus group discussions, said that those living in rented accommodation, who had to pay rent in order to keep their home and whose extended family usually lived elsewhere, had the least support and greatest financial anxiety.

*“They may also be anxious about how to earn and look after the family. [ ] Local patients have no such problems, but patients who are staying on rent have such problems. [ ] The patients who have their own home are [just] anxious about their disease whether it will be cured or not.” (NUIDIFTBV1, female health worker, urban site)*

*“[The vignette character] has less economic burden if he has no need to pay rent. While staying in rented accommodation, nobody cares for each other or knows about the disease. If he is in a traditional home, there are more blood relatives.[ ] Anyway he will have fewer burdens.” (NRFGDFpt1-R2, female TB patient participating in a focus group discussion, rural site)*

Likewise, in the rural site, a TB patient’s son-in-law, who was not originally from the village and was renting accommodation, spoke of his fear of illness as he could not afford not to work.

*“Because we are farmers. We have to work, eat. We don’t have our home here. We don’t have our home so how do we eat? We have to earn the whole day and bring food for the evening. We have to earn and so if our health is weak then who will give us anything? Who will do treatment for this?” (NRIDIMFM1, son-in-law of a male TB patient, rural site)*

A female TB patient participating in one of the focus group discussions (NRFGDFpt1-R2) summed up the paradox that people living away from their ancestral villages have more understanding about health issues, but lack support from others, whereas villagers provide support, but lack understanding. Likewise, participants in a male focus group (NRFGDMcm2) said that in villages the difficulty is being far from health facilities, but the advantage is having support and sympathy from other villagers, which is often lacking in urban areas where neighbours may have little contact with each other.

Even if the TB patient is not the primary earner in the household, the primary earner may have to take time off work to care for the patient and collect the TB drugs from the clinic when the patient is too ill to do so. A female former TB patient (NUIDIFCPt1) described the impact her TB had had on her own family, saying her husband had had to take time off work and her son’s education had been affected at a critical time when he had had exams as he had had to take on more of the housework. By contrast, the wife of a male TB patient (NUIDIFFM2) was anxious about her husband’s illness, but was not worried about managing the household and income as she normally did most of the housework anyway and she received help from her adult son and daughter to run the family shop, so their income had not been affected.

► **Worry about fulfilling responsibilities/ambitions and being a burden**

**Summary:** As well as disrupting the (sometimes precarious) financial position of a family, TB can also disrupt a person’s role and responsibilities within the family, affecting their self-esteem. Merely being unable to work, because of illness or the need to attend the DOTS clinic daily, can be frustrating to a patient. A patient is less likely to feel a burden if the TB impacts little on their ability to fulfil their responsibilities, either because it is not severe or because their responsibilities were few anyway, and the latter relates in part to age and family circumstances. Indeed, as



babies and children are thought to be particularly susceptible to acquiring transmissible diseases, if a person's role or responsibilities include childcare, a TB diagnosis can be particularly disruptive.

However, while generally TB seems to be slightly easier to cope with for younger unmarried people, as they have fewer responsibilities and their parents are there to look after them, TB can nevertheless disrupt their education and ambitions, which in turn can make them feel depressed. Another reason why patients may feel depressed and interpret the behaviour of others negatively is that physical pain and illness does affect emotions, and coping with an ill person's varying emotions can be difficult for family members too.

**Potential policy implications:** The later the diagnosis or the more severe the TB, the more debilitating the illness and the lengthier the treatment. Therefore, earlier diagnosis and treatment is needed (see *Delayed treatment*, page 13). 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.

---

TB can disrupt the (sometimes precarious) financial position of a family, but also a person's role and responsibilities within the family, affecting their self-esteem. An unmarried male TB patient (NRIDIMpt1), living with his parents, seemed to feel blamed for burdening his family and causing them financial difficulties.

*"It happens in the home that some are loving and caring to the patients and some try not to be close for fear of the disease transmitting.[ ] They say, 'he always becomes ill, how much treatment should be given to him, we are beginning to struggle financially because of him'." (NRIDIMpt1, male TB patient, rural site)*

Another male TB patient (NRIDIMpt3), who worked as a farmer and had a family to support, was asked whether not being able to do work due to TB could cause tension within the family, either because the patient really could not work, or because his family thought he could work but he was not doing so. He responded that although his own family had not said anything, they probably thought the latter in their hearts.

Even if a patient did not have the responsibility of providing an income, he or she might still find it difficult if other responsibilities, such as taking care of the household, could not be fulfilled. A health worker interviewed (NUIDIFTBV1) said that a female patient might worry about managing her household responsibilities and might worry about what her mother- and sisters-in-law might say if she was not able to fulfil those responsibilities because of her illness. Two TB patients participating in a focus group discussion (NRFGDFpt1 and NRFGDMpt1) felt that TB patients should avoid heavy work, washing clothes and possibly cooking (because of the potential risk of transmission) on a fire (because of the smoke).

Patients were less likely to feel a burden if the TB impacted little on their ability to fulfil their responsibilities, either because their TB was not severe or because their responsibilities were few anyway: the latter related in part to age and family circumstances. A female patient interviewed (NUIDIFpt3) described how her daily activities had not changed much since her TB diagnosis because her diabetes and limb pain had previously inhibited her ability to do much anyway and her daughter-in-

law, who lived with her, was responsible for most of the housework. Perhaps as a result, she didn't appear particularly anxious or depressed about her TB diagnosis.

*"I couldn't work before either and now I don't have to do work such as cooking food. I just have to do a little bit of other work like watching the kids. The pain in my limbs is not a complication of the TB, it was there before." (NUIDIFPt3, female TB patient, urban site, living with her husband, sons, daughter-in-law and grandson)*

As babies and children were thought to be particularly susceptible to acquiring transmissible diseases, if a person's role or responsibilities included childcare, a TB diagnosis could be particularly disruptive. When a daughter-in-law of a female patient (NUIDIFFM3) was interviewed, she described how her mother-in-law did not earn or do much housework before her TB diagnosis, but she did look after her grandchildren. Even though she had been diagnosed with extrapulmonary TB and was told it was not infectious, she was still advised by the health worker to take precautions against possible transmission to children, which she found emotionally difficult to do.

*"I said to the health workers, 'TB is said to be transmitted. Mother has been told she has TB of the backbone. Can it be transmitted or not?' They said it is not such an infectious disease. Then I asked can it be transmitted to children? Then they advised me not to share food and not to let them sit together [ ] Then I said to mother, 'we have many children. You have TB. So do not take the children in your lap, do not sit near them and do not share your food. Stay a little bit far'. Immediately after saying that, she started to cry." (NUIDIFFM3, daughter-in-law of a female TB patient, urban site)*

Likewise, a TB patient interviewed who worked as a kindergarten teacher said she felt she posed too much of a TB risk to the children in her class for her to continue working. However, her husband provided an income for the household and her sister came to stay with her to help her with the housework.

Merely being unable to work, because of illness or the need to attend the DOTS clinic daily, can be frustrating to a patient. A female TB patient (NRIDIFpt1) had been working as a cook in the city, but had to return to her village when she became ill and was not allowed (by her employer) to return to her job for the full 8 month course of her treatment. However, after two months she was feeling well and seemed frustrated at not working and keen to earn money.

*"I'm used to working but I have to stay at home without working now [ ] It is very difficult going and returning [daily for DOTS]. It has hampered my work. My mum does not let me work in the village either. [ ] So I feel sad staying with her without work." (NRIDIFpt1, female TB patient, rural site)*

While generally TB seems to be slightly easier to cope with for younger unmarried people, as they have fewer responsibilities and their parents are there to look after them, TB can nevertheless disrupt their education and ambitions, which in turn can make them feel depressed. TB can be disruptive to a young person's schooling, especially if it occurs at a critical time (such as near examinations).

*"Because of this disease, in this first [examination] I may not come first [as expected] so I'm a little bit depressed." (NRIDIMpt4, a male school student with TB, rural site)*

A 19 year old female extrapulmonary TB patient interviewed, with ambitions to excel in football, wondered how much she would have progressed had she not had to stop playing for the course of her 18 month treatment. She was also worried that her back pain might still persist, inhibiting her from playing football, even once the initial cause of it – the TB itself – was cured.

*“If I didn’t have this disease then how much would I have progressed? [Laughs] [ ] I would have progressed a lot. Friends who used to play with me have progressed a lot. [ ] I used to think when will I get cured, when will I feel relief and be able to join in again [ ], but I’m scared about having back pain again in future [ ] Even when the course of medicine is complete then there might still be pain, mightn’t there? [ ] I am scared about the back pain not being cured.” (NUIDIFpt4, female TB patient, urban site)*

Part of the reason why patients may feel depressed and interpret the behaviour of others negatively is that physical pain and illness does affect emotions, and coping with an ill person’s varying emotions can be difficult for family members too. A daughter-in-law interviewed (NUIDIFFM3), who said her mother-in-law used to quarrel with her even before becoming ill, said that as a daughter-in-law she expects to sometimes get aggravation from her mother-in-law when her mother-in-law is ill and that this should not be taken to heart.

*“It should not be taken seriously if a diseased person says something. [ ] We should convince ourselves that she scolded us due to having pain.” (NUIDIFFM3, daughter-in-law of a female TB patient, urban site)*

However, sometimes coping with an ill and emotionally vulnerable person in the family can be difficult and lead to frustration.

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

In the rural site, the wife of a TB patient (NRIDIFFM1) spoke of her husband being more prone to getting irritated and crying since his illness with TB. Feeling anxious and depressed when diagnosed with a disease is generally seen as natural.

*“It is obvious to have tension. [ ] It is obvious to have weak thoughts. If we ourselves become weak then it is obvious we feel [sad and want to cry].” (NRIDIMCpt1, male former TB patient, rural site)*

► **Blame and guilt for TB infection (especially relapsed TB or TB re-infection)**

**Summary:** Given the wide range of contributory causal explanations for TB mentioned throughout the interviews (such as drinking alcohol, smoking, excessive or heavy workload, inadequate or irregular diet, stress, exposure to dust or smoke and being elderly or very young), none of those interviewed actually identified or blamed a specific person for transmitting TB to them, although one was held responsible for transmitting TB to someone else. It seems that people’s responses to TB patients have more to do with the severity of TB and the risk it poses to others,

rather than the origin of it. Nevertheless, a behaviour that was previously disapproved of by a TB patient's family members or friends is sometimes blamed for their TB and even health workers may scold patients deemed to have been irresponsible or careless. Not completing or correctly taking a course of treatment, or failing to follow the advice of a health worker (or indeed others) may be viewed as carelessness or negligence resulting in severe or relapsed TB. In particular, patients with severe or relapsed TB, or TB for the second time may therefore be scolded, blamed or blame themselves.

**Potential policy implications:** This form of TB-related stigma may especially affect patients with severe or relapsed TB or TB re-infection. While the message that TB can be prevented and people do have some control in preventing it may promote healthy behaviours, blame and guilt may discourage disclosure and appropriate treatment seeking, especially amongst those most in need of treatment and support.

---

A male patient thought that if a person knows from whom their TB was transmitted, they would be angry towards that person and say *“don't come here, I got infected because of you, then what is to be done, go from here, go away”* (NUIDIMPt1). Indeed, one interviewee (NRIDIMFM1) whose father-in-law had TB told of a woman who blamed his father-in-law for giving others TB. Because of this, and possibly because she was the wife of a friend, he accompanied her to the clinic for a check up. However, the interviewee emphasised during the interview that he did not think TB is actively or intentionally transmitted from one person to another.

*“When I came to take medicine, she said, ‘Brother! What is this, because of your father-in-law many people are saying they also get this disease.’ [But] whether it transmits depends on one's own health, it can be cured after taking treatment, they should not blame an old man, this is how I think. [ ] It is their own body. If they come to be affected, it doesn't mean someone transmitted it to them.”* (NRIDIMFM1, son-in-law of a male TB patient, rural site)

However, given the wide range of contributory causal explanations for TB mentioned (such as drinking alcohol, smoking, overworking and not eating sufficiently or regularly), none of those interviewed actually identified or blamed a specific person for transmitting TB to them. It seems that people's responses to TB patients have more to do with the severity of TB and the risk it poses to others, rather than the cause of it. Nevertheless, a behaviour that was previously disapproved of by a TB patient's family members or friends is sometimes blamed for their TB, whether it be drinking alcohol and smoking (NRIDIMPt4), playing football (NUIDIFM1), or having joined a monastery (NRIDIFCpt1).

*“What [my sisters] said is ‘you smoked too many cigarettes and too much marijuana. If you didn't get TB then who will?’ They scold like that. I said to them, I explained to them that it will not come about from smoking only. TB can affect someone for other reasons also. Anyone can have TB. Stale food, bad food can also affect you. [ ] It is one of the causes of TB, but it doesn't mean it's the only cause of TB. If it were, then in the world there are so many people who drink, so then everyone would have TB.”* (NRIDIMPt4, male TB patient, rural site)

While some of those interviewed spoke of how reassuring the health workers had been, a health worker interviewed said she had heard reports of TB patients being scolded and kept at a distance by colleagues at another health facility.

*“I would like to complain about [name of Government health facility]. Patients are very much scolded [there]. They have told us here that the doctors scolded them and that they sit by turning to the side.” (NUIDIFHW1, female health worker, urban site)*

It seems that this may be especially the case for patients with relapsed TB as the same health worker went on to say that cases referred to her as new, turned out to be relapsed cases. While she was not sure whether this was due to patients concealing their past TB or due to health workers taking incomplete medical histories, she identified it as a significant problem as it impacted on the medication they were given. One example she gave, of a patient who was reluctant to disclose that he had been taking TB treatment previously, suggests that the former explanation is likely to at least play a role. Supporting this, a male TB patient (NRIDIMCPT1) described how the doctors had treated him differently the second time he had TB, scolding him that this was the second time he had got TB and so he needed to take more care and avoid alcohol and cigarettes; and a male focus group participant spoke of being scolded by a doctor for smoking and suggested a vignette character with TB for the second time might be deterred from consulting a doctor for fear of being blamed and scolded.

*“The second time I had TB [the doctors] said this time again you have this disease now don’t take alcohol/jaand or cigarettes. You have to avoid these things. [ ] They scolded me to take more care of myself.” (NRIDIMCPT1, male former TB patient, rural site)*

*“In my opinion, [the vignette character] would have thought ‘my wife had told me not to take alcohol, but I took it anyway. Because of that I have TB again. And now when I go to the doctor he scolds me a lot, so how can I go to the doctor?’ [ ] Then the doctor would have told him that he ate unnecessarily, that he smoked and took alcohol.” (NRFGDMcm1-R5, male focus group participant, rural site)*

It may be that relapsed patients in particular are scolded, blamed or blame themselves. While smoking and drinking alcohol is thought to weaken the body and make a person more susceptible to TB, continued smoking and drinking during treatment is believed to inhibit the effectiveness of TB medicines and smoking and drinking after treatment is completed risks the reoccurrence of TB. This can be due to a person’s behaviour when they are intoxicated, as the quote below demonstrates, but is more often viewed as due to the weakening effect of these substances.

*“The husband of my friend also had TB and he smoked and drank during the treatment period. Medicines were taken to his home by the children, but were thrown out of the window. I have seen such things.” (NUIDIFFM2, wife of a TB patient, urban site)*

*“If the person thinks ‘I had TB once, so now I have to restrict the things which may harm my health’ then he or she may not have the disease again. If he or she neglects and starts to take alcohol and smoke then he or she may have TB again.” (NUIDIFFM3, daughter-in-law of a female TB patient, urban site)*

*“If jaand/alcohol or tobacco are taken then it decreases the capacity of the medicine.” (NUIDIFM2, son of a male TB patient, urban site)*

*“I feel like my TB is non-communicable as compared to those having lung or skin TB. I think I am having medicine so it cannot transmit to others. [ ] I have seen*

*many patients not get cured of the disease due to their negligence. [ ] They used to drink alcohol and continue smoking even while having medicines and then they say that they are not getting cured of the disease even though they are taking medicine.” (NRIDIMpt1, male extrapulmonary TB patient, rural site)*

*“Some used to drink while taking medicine, so for such people it will not be enough to take medicine for eight months.” (NRFGDFcm2-R1, female focus group participant, rural site)*

The reasons why some TB patients were blamed or felt guilty about their TB infection related to severe or relapsed TB being attributed to carelessness or some other factor thought to be under a person’s control and for some possibly its association with HIV.

A health worker interviewed (NUIDIFHW1) linked unresponsiveness to treatment to being HIV positive. Three patients attending her DOTS clinic had been found to be HIV positive and, while she had not been told which, she suspected she knew, saying they always had positive sputum tests even after treatment. However, in general she thought TB had a greater association with diabetes than with HIV.

*“I think in the past TB was said to be related with HIV, but now it is related with diabetes. These diabetes patients are suffering more from TB. What are the main reasons? One reason may be the diet.” (NUIDIFHW1, female health worker, urban site)*

A male focus group participant (NRFGDMcm1-R7) described TB and chayarog as small diseases compared with AIDS which is out of control, suggesting that if TB becomes increasingly associated with HIV and AIDS, then the nature and degree of TB-related stigma is likely to change.

While the risk of TB reoccurring or relapsing in future did not seem to be a concern for TB patients if they had seen others recover fully and not relapse, one family member (NUIDIFM1) said that there was a risk of TB re-occurring if a patient did not complete their course of treatment so had not been fully cured. Not completing or correctly taking a course of treatment, or failing to follow the advice of the health worker (or indeed others) was viewed as carelessness or negligence resulting in severe or relapsed TB.

*“Disease is not big in itself. Mainly it becomes serious due to one’s carelessness.” (NUIDIMpt1, male TB patient, urban site)*

*“[The vignette character would think] ‘At that time when I had this disease they told me not to eat or drink those things and I got cured, but after that I thought it will not affect me again so again I started drinking so again it attacked me, so it’s my own carelessness’. If it happened to me than I too would think that it’s due to my own carelessness. There is no place to blame others.” (NRFGDMpt1-R4, male TB patient participating in a focus group discussion, rural site)*

Continuing to drink alcohol or smoke tobacco or marijuana following a TB diagnosis, either during or after treatment was considered by some to be negligent as it was thought to be particularly risky when ill or already weakened, as it inhibited recovery and could increase the severity of an illness, causing a fever or minor illness to develop into TB.

*“And people want to drink jaand [a local alcoholic drink] but if much is drunk while having fever or when weak then from that TB disease comes out.” (NRIDIMFM1, son-in-law of a male TB patient, rural site)*

The wife (NUIDIFFM2) of a TB patient blamed his TB on his drinking and cigarette smoking, although she said disease can happen to anyone. His drinking and smoking led to quarrels between them as she was convinced his TB would reoccur if he continued and so he had resorted to smoking and drinking in secret. While smoking and drinking, especially amongst castes where it is customary or as (Subedi Madhusudan Sharma 2001) puts it “culturally prescribed” (making abstinence particularly socially disruptive and therefore difficult) is not viewed negatively, smoking and drinking irresponsibly (for example, when ill or weak, or drinking “alcohol from anywhere”) may be.

*“Though we are Newar caste, we should not drink jaand, should not drink alcohol.” (NRIDIMpt3, male Newar TB patient, rural site)*

*“It happens more to those who take jaand and alcohol from morning to night, who do not take enough food and take jaand and alcohol from anywhere.” (NUIDIFFM3, daughter-in-law of a female TB patient, urban site)*

The respondent quoted above (NUIDIFFM3) went on to tell of how her father-in-law had scolded her mother-in-law for having taken alcohol “from anywhere”, suggesting both the alcohol and the source of the alcohol played a role in increasing a person’s susceptibility to TB. He seems to have scolded his wife because the diagnosis had been unexpected as nobody else in the family had had TB. By contrast, in response to a vignette about a husband with TB for the second time, a female TB patient participating in a focus group discussion (NRFGDFpt1) felt that his wife might shout at him initially upon hearing the news, but would then keep quiet because he was the husband, suggesting that blame is influenced by gender roles.

The connection between alcohol and susceptibility to disease due to weakness might be viewed as direct, with alcohol causing weakness or contaminated alcohol causing illness, but was viewed by some as indirect, with weakness resulting from the tendency for people who drink alcohol not to eat properly. The interaction between alcohol/smoking and insufficient food intake explained why not everyone who drank and smoked developed TB.

Both insufficient and inappropriate foods were thought to increase a person’s susceptibility to TB and their ability to recover from TB. A female former TB patient said she had felt saddened by the thought that her own behaviour, her carelessness with food, had caused her TB.

*“When I had that disease one matter made me feel sad. Before I didn’t take food properly. I didn’t care about food. I think I had that disease due to not eating enough. I feel from now onwards I will not do like that.” (NRIDIFCpt1, female former TB patient, rural site)*

Hot, sour, spicy and fatty foods were mentioned by many of those interviewed as needing to be avoided both during treatment and after. For example, the daughter-in-law of an extrapulmonary TB patient (NUIDIFFM3) said she gave her mother-in-law milk as she had been advised to restrict hot, fatty and spicy food. A former TB patient (NRIDIMFM2), who had had TB ten years ago but was successfully treated and cured, has felt the need to avoid spicy, hot and sour food ever since.

*“After taking treatment for eight months it will be cured. After that if one becomes careless and starts drinking and eating spicy, hot and sour food.... I use to eat hot food, but even today I no longer take sour food. [ ] Sour foods include lemon and lapsi. [ ] If I eat pickle or sour food then the next day while spitting I see blood in my sputum, so I never eat those things [ ] If I don't eat them then [TB] doesn't come [back].” (NRIDIMFM2, husband of a female TB patient, rural site)*

*“[We must] take food on time, [ ] take food regularly [ ]. Medicine alone will not work if we do not take food.” (NRIDIMCpt1, male former TB patient, rural site)*

While a range of ‘causes’ of TB, or more accurately factors contributing to a person’s susceptibility, were mentioned throughout the interviews (including alcohol, smoking, inadequate or irregular diet, stress, excessive or heavy workload, exposure to dust or smoke and being elderly or very young) they were generally put forward to relieve confusion as to why one person and not another got TB and the inability of each ‘cause’ to explain *all* cases of TB was acknowledged.

*“In my opinion TB is not due to eating habit [only], it can come without reason also.” (NRIDIMFM2, husband of a female TB patient, rural site)*

The mother of a female TB patient blamed her daughter’s football playing for her daughter’s TB, but indicated that she disapproved of her daughter’s football even before the TB diagnosis (NUIDIFM1). As with alcohol and smoking, it is likely that something that family members previously disapproved of is likely to be seen as responsible for later misfortune, such as illness.

With the exception of one focus group participant, supernatural causes of TB were not generally mentioned, although it is possible that respondents were reluctant to disclose such beliefs in front of researchers thought to be associated with the National TB Control Programme. From this study it appears that causal explanations of TB seem to be located predominantly within what (Subedi Madhusudan Sharma 2001) describes as the individual world (e.g. bodily malfunctions relating to diet and behaviour) and the natural world (e.g. environmental factors, such as exposure to dust or smoke), rather than within the supernatural world. However, even when ritual treatment was deemed necessary, it provided a means of explaining and treating an undiagnosed condition, rather than being a means of blaming the patient or specific others for misdeeds.

*“Some used to say that my back is bent. They used to say it might have happened due to my bent back, that I might have a curse from god. In my mother's time they used to think in that way.” (NUIDIFPt4, female TB patient, urban site)*

A health worker in the rural site suggested that TB is seen as a curse on not only the individual but also their family, as it was fatal in the past and so a curse to a person with whom one is not on good terms would be “Let you die by suffering from TB”. Even though treatment for TB is now available, this view of TB as a curse to be feared still lingers.

*“There is an old proverb that if a dog is beaten with firewood once, it will get scared of lightening also. Like that in the past people used to think that once someone has TB then they will not get cured.” (NRIDIMHW2, male health worker, urban site)*



A family member of a TB patient said she knew someone who continued to chew tobacco during his TB treatment, and though she used to “counsel and scold him”, he refused or was unable to give up and eventually died (NUIDIFM1). NRIDIMpt3 had difficulty quitting smoking, even though he had been advised to, so he had resorted to smoking secretly every now and then, hiding it from his disapproving family. A former TB patient who had had TB twice before had reduced the number of cigarettes he smoked daily, but had not given up smoking altogether.

*“I don’t smoke much only 1 or 2 sometimes [ ] Maybe 3 times a day if more than 4 times [ ] I smoke while drinking tea and taking snacks only [ ] I don’t smoke at any other time.” (NRIDIMCpt1, male former TB patient, rural site)*

## 5. Conclusions

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

- Perceived hatred / *hela* 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. Many patients eat separately or using separate utensils for 2 months or longer.
- 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.
- Reduced social interaction of TB patients with others, because they feel too ill, they want to protect others from TB transmission or so that others are not able to avoid interactions with them.
- 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, and particularly children.
- Family tension, particularly for women, because of the additional burden placed on other members of the family. This can be made worse if there is a perception that the patient is not helping his or her own recovery by not following advice.
- Financial disruptiveness of TB, particularly towards people with dependents. While TB treatment is available free of charge, TB still causes considerable expense because of the costs of repeated travel to clinics, and the view that nutritious food/supplementary vitamins 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, particularly childcare. TB also disrupts education and ambitions. The illness also affects emotions, leading to depression and negative interpretation of other people’s behaviour.
- Blame and guilt for TB infection (especially relapsed TB or re-infection), because other behaviour that is disapproved of (including not completing or correctly taking a course of treatment) may be blamed for the TB.

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

<b>Effect of stigma, and explanation</b>	<b>Potential policy implications</b>
<p>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>	<p>(1) 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.</p> <p>(2) Clarity about the duration of infectivity.</p> <p>(3) Clarity that it is not necessary to use separate utensils.</p> <p>(4) 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>
<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>	<p>(1) Ensure health workers properly inform patients that they have TB.</p> <p>(2) Maintain patients' confidentiality, including during late patient tracing.</p> <p>(3) Ensure patients and the wider community understand patients cease to be infectious after two weeks of treatment.</p> <p>(4) Share examples of real life stories of patients who had had positive experiences of disclosing, to counter patients' anticipation of negative experiences.</p>
<p>Reduced social interaction of TB patients with others.</p>	<p>As for <i>Perceived hatred</i>, above.</p>
<p>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, and particularly children.</p>	<p>(1) Early diagnosis and treatment, especially for women and in areas where the average age of marriage for a woman is low.</p> <p>(2) Clarity on the effects of TB and TB treatment on pregnancy and fertility</p>

Family tension, particularly for women, and particularly if there is a perception that the patient is not helping his or her own recovery by not following advice.	(1) Clarify balance between support and precautions against TB transmission. (2) Earlier diagnosis to reduce TB's severity. (3) Less disruptive treatment provision to decrease the patient's inability to work. (4) Counselling and education for both patients and their families on how to cope with family tensions.
Financial disruptiveness of TB, particularly towards people with dependents, because of disruption to work, expenses of travel etc to clinics, and costs of nutritious food/ supplementary vitamins that is thought 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, particularly childcare, concern about impact on education and ambitions, and depression caused by being ill.	(1) Consider measures to reduce the cost, length and disruptiveness of treatment provision. (2) Consider ways of providing emotional support to TB patients, perhaps through support groups.
Blame and guilt for TB infection (especially relapsed TB or re-infection), because other behaviour that is disapproved of (including not completing or correctly taking a course of treatment) may be blamed for the 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.

Three other issues arose strongly from the study:

- Delayed treatment seeking occurs when symptoms are mild, ambiguous or atypical. Misdiagnosis or inconclusive test results is more likely for extrapulmonary TB.
- Default is reduced when families support and encourage adherence to treatment and therefore disclosure to families is important. Patients are unclear about length of treatment, and effects of missing a single dose. Default is increased by factors making daily attendance at a DOTS clinic difficult.
- Patients withhold medical histories of previous TB treatment, for fear of being scolded.

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

<b>Issue and cause</b>	<b>Potential policy implications</b>
Delayed treatment seeking occurs when symptoms are mild, ambiguous or atypical. Misdiagnosis or inconclusive test results is more likely for extrapulmonary TB.	(1) Address misdiagnosis and the limitations of diagnostic tests, especially for extrapulmonary TB. (2) Improve access to health services to encourage quicker treatment seeking.
Default is reduced when families support and encourage adherence to treatment and therefore disclosure to families is	(1) Address factors such as patients stopping treatment because they feel better; patients' need to work (or take

important. Patients are unclear about length of treatment, and effects of missing a single dose. Default is increased by factors making daily attendance at a DOTS clinic difficult.	work when it comes); problems paying for temporary accommodation and having to move; problems of old age and co-morbidity. (2) Increase access to health services.
Withholding medical histories of previous TB treatment, for fear of being scolded.	Awareness is needed amongst health workers that scolding TB patients may discourage their disclosure of their medical histories with negative individual and public health implications

## 6. Acknowledgements

We would like to thank Ananta Kumar Nepal, Yeshoda Aryal, Jiv Raj Adhikari and Nisha Rana for managing the project, collecting data and being involved in the data analysis in Nepal. We would also like to thank the Nepal National Tuberculosis Programme (NTP) for organisational and other support, and the study participants for their involvement.

## 7. Ethical approval

This study received ethical approval from

- the Institutional Review Board (IRB) of the Institute of Medicine, Tribhuvan University, Nepal,
- the Ethics Committee of the Faculty of Medicine and Health, University of Leeds.

## 8. References

- de-Graft Aikins, A. 2006, "Reframing applied disease stigma research: a multilevel analysis of diabetes stigma in Ghana", *Journal of Community & Applied Social Psychology*, vol. 16, no. 6, pp. 426-441.
- Goffman, E. 1963, *Stigma, Notes on the Management of Spoiled Identity* Penguin Books.
- Jones, E. E., Farina, A., Hastorf, A., Markus, H., Miller, D., & Scott, R. 1984, *Social stigma: the psychology of marked relationships* Freeman, New York.
- Khan, M., Walley, J., Witter, S., Shah, S., & Javeed, S. 2005, "Tuberculosis patient adherence to direct observation: results of a social study in Pakistan", *Health Policy and Planning*.
- Kurzban, R. & Leary, M. R. 2001, "Evolutionary origins of stigmatization: the functions of social exclusion", *Psychological Bulletin*, vol. 127, no. 2, pp. 187-208.
- Liefooghe, R., Michiels, N., Habib, S., Moran, M. B., & De Muynck, A. 1995, "Perception and social consequences of tuberculosis: a focus group study of tuberculosis patients in Sialkot, Pakistan", *Social Science & Medicine*, vol. 41, no. 12, pp. 1685-1692.
- Subedi Madhusudan Sharma 2001, *Medical Anthropology of Nepal* Udaya Books, Kathmandu.

Weiss, M. G., Auer, C., Somma, D. B., & Abouihia, A. 2006, *Gender and tuberculosis: cross-site analysis and implications of a multi-country study in Bangladesh, India, Malawi and Colombia*, WHO, 3.

WHO 2003, *Treatment of tuberculosis, Guidelines for national programmes* World Health Organisation, Geneva.