

Causes of tuberculosis stigma in South Asia

**Developing explanatory theories through
multi-country qualitative research**

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The candidate confirms that the work submitted is her own and that appropriate credit has been given where reference has been made to the work of others.

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Abstract

Although tuberculosis (TB) stigma has been widely reported in South Asia and elsewhere, few interventions have been introduced to reduce it. Whilst it is recognised that stigma interventions need to address the fundamental causes of stigma and that their design needs to be theory-driven, causal theories to explain TB stigma are lacking. In this thesis I present the development of causal theories to explain manifestations of TB stigma and identify theory-driven approaches to addressing TB stigma in South Asia.

Causal theories to explain TB stigma were developed using a multi-country comparative approach, involving qualitative methods and the principles of grounded theory, alongside a realist conceptualisation of causality. Qualitative data was collected through 73 interviews with people with TB, their family members and health care providers in three rural and two urban sites in Bangladesh, Nepal and Pakistan, and through eight focus group discussions conducted in three of the sites.

Three manifestations of TB stigma, for which causal theories were developed, were identified from the data: reduced marriage prospects, the perception that people with TB are hated, and the attribution of blame for the course and reoccurrence of TB. All three manifestations are rooted in different psychological processes and it is between these manifestations and their roots that the realist causal theories lie. The mechanisms and contexts which explain how, for whom and in what circumstances TB stigma becomes manifest provide the theory that can be used to underpin approaches to addressing TB stigma. These approaches focus on influencing the legitimacy of rejection, hatred and blame, on reducing vulnerability to TB, on empowering people with TB, and on mainstreaming TB stigma and pre-empting the changing nature of its manifestations.

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Chapter 1 INTRODUCTION

1.1 The purpose and value of this study

In *The Lancet Infectious Diseases*, Mario Christodoulou (2011) describes how in Peru, in order to reduce stigma and promote test- and treatment-seeking for TB, health promotion campaigns attempted to promote the beliefs that TB is widespread and treatable. However, it was among those who held these very beliefs that delays in test-seeking for TB were subsequently found to be longest. The unintentional effect of the campaign seemed to be to promote exactly that which it had intended to prevent, namely delayed test-seeking. According to Carlton Evans, the head of a Peru-based charity called Innovation for Health and Development (IFHAD), this highlights the importance of evaluating health promotion campaigns (Christodoulou, 2011).

Whilst evaluation is certainly important, trying and testing an intervention is not the only way to get an idea of what works, for whom and in what circumstances. It is, after all, a costly endeavour to deliver and evaluate health promotion campaigns and other types of intervention, and especially so if the interventions are found to have little, no or a negative impact. The campaign in Peru was based on the assumption that TB stigma and delayed test-seeking are driven by the beliefs that TB is uncommon and untreatable. With a funding shortfall of almost US\$2 billion per year for tackling TB in low- and middle-income countries for 2014 and 2015 (WHO, 2013c), it is especially important that already scarce resources are not wasted on ineffective and potentially counterproductive interventions. To considerably reduce the risk of wasting resources, interventions need to be based not on assumptions, but on solid and explicit theories.

In Bangladesh, Nepal and Pakistan (as in many other countries), TB is thought to be associated with stigma (Baral et al., 2007; Liefoghe et al., 1995; Weiss et al., 2006a; Bond et al., 2002). Whilst the National TB Control Programmes in the three countries recognise TB stigma as a problem, little has as yet been done to understand and reduce it.

In 2004 an international workshop on health-related stigma research was held in Amsterdam with over 70 participants representing 55 organisations and academic institutions. The report of the workshop states that theoretical frameworks need to underpin interventions and that stigma needs to be tackled at its “deep-rooted sources” (Royal Tropical Institute (KIT), 2004). Link and Phelan (2001) have also argued that to effectively reduce stigma, the fundamental causes of stigma need to be addressed.

This thesis presents a cross-country comparative qualitative research study, the aim of which is to develop theories to explain the causes of TB stigma in and across three Asian countries (Bangladesh, Nepal and Pakistan), in order to provide a solid theoretical basis for interventions to address TB stigma.

1.1.1 Why address TB stigma?

The manifestations of TB stigma presented in Chapters 6-8 of this thesis impact negatively on experiences of illness, causing additional and potentially avoidable distress. The new Global TB Strategy for post-2015 explicitly states patient-centred care and prevention as the first of its three core components, with the protection and promotion of human rights, ethics and equity as one of its core principles (WHO, 2013b). Preceding this new strategy but in line with its ethos is the Patients’ Charter for Tuberculosis Care (World Care Council, 2006) which was initiated and developed by people with TB from around the world and has been promoted by the World Health Organisation. The charter states that those with TB have:

*The right to be treated with respect and dignity, including the delivery of services without stigma, prejudice, or discrimination by health providers and authorities
.... with moral support from family, friends, and the community*

To reduce additional distress experienced by those with TB and to comply with the Patients’ Charter, TB stigma needs to be addressed.

As stated at the beginning of this chapter, resources to address the global TB pandemic are limited and insufficient. It could therefore be argued that the distress caused by TB needs to be prioritised over the additional distress caused by TB stigma. However, the interventions to address each are not necessarily distinct, as can be seen from the opportunities for addressing TB stigma which I present in Chapters 6-8 (sections 6.6, 7.4 and 8.4) and summarise in Chapter 9 (section 9.3). Furthermore, TB stigma may also have public health implications, with many

researchers believing that the fear and shame of having a stigmatised disease contributes to delayed treatment seeking and poor treatment adherence (Balasubramanian et al., 2000; Nair et al., 1997).

1.1.2 A multi-country comparative approach

Keutsch et al. (2006) point out that “too little research has been done in recent years to better understand the pathogenesis and implications of stigma, how beliefs are generated, perpetuated, and translated into behaviours, and the cost of stigma to individuals, families, communities and nations” (p525). Research on stigma has tended to conflate causes, functions and effects (Deacon et al., 2005a), with explanations for TB stigma focussing on its perceived contagiousness and fear of infection, on perceived associations of TB with other disvalued characteristics (such as HIV, malnutrition, poverty, being foreign-born and low social class), and on the belief that those with TB are to blame for their infection (Courtright and Turner, 2010). Research focussing *explicitly* on the causes of TB stigma or, to use Keutsch et al.’s terms, its pathogenesis, generation and perpetuation, is particularly scarce. Three notable exceptions focus on Nicaragua, Nepal and Ghana (Macq et al., 2005; Baral et al., 2007; Dodor et al., 2008). All three studies were country-specific, but as Parker and Aggleton (2003) argue, comparative approaches are needed in order to distinguish between local aspects of stigma and those aspects shared across contexts and cultures.

Just two comparative multi-country studies of TB stigma have been published to date, both using the methodology of cultural epidemiology. This involves collecting ethnographic data to inform the development of an Explanatory Model Interview Catalog (EMIC), a semi-structured instrument used to collect quantifiable data that can be compared across groups. Somma et al. (2008) compared the relative importance of different stigma indicators for men and women across four different country contexts (Bangladesh, India, Malawi and Colombia) and found both common and distinctive features of TB stigma across the sites. Coreil et al. (2010) compared Haitians living in two very different contexts (Haiti and the USA) to investigate the influence of political, economic and institutional (rather than cultural) forces on the production of TB stigma. They conclude that their transnational approach highlighted the structural underpinnings of social stigma in a way that a single country study could not have.

My own research uses a multi-country comparative approach to explore TB stigma across different contexts and to elucidate the structural as well as cultural underpinnings of stigma. As yet, no published studies of TB stigma using a multi-country comparative approach have used the qualitative grounded theory approach. One of the core principles of the grounded theory approach is constant comparison of data with data and then of data with emerging theory. By comparing data from urban and rural sites in three different countries with emerging theory, the theory can be challenged, expanded and improved, giving it relevance beyond a single specific local context.

1.2 A collaborative venture

The research presented in this thesis was funded by the Economic and Social Research Council (ESRC) and the Department for International Development (DFID) through their joint fund for poverty alleviation research (RES-167-25-0142). The grant application was submitted by James Newell of the University of Leeds with partners in Bangladesh, Nepal and Pakistan. The grant included funding for a UK-based researcher to coordinate the research study and it was for this role that I was appointed at the Nuffield Centre for International Health and Development at the University of Leeds in 2007. I came to the post with degrees in anthropology (BA Hons) and health promotion (MSc) and with experience of conducting research and building research capacity in developing country settings. I was keen to now build my own capacity in qualitative research methods and was attracted by the challenge of conducting a multi-country study. Once in post, I registered to do a PhD based on the study, revised the study design and planned the research process.

The research was conducted in collaboration with partners in the three Asian countries with which the Nuffield Centre already had established links. The partners were the National TB Control Programme in Bangladesh, the Health Research and Social Development Forum (HERD) in Nepal, and the Association for Social Development (ASD) in Pakistan. Both HERD and ASD are non-governmental organisations which have worked closely with the Ministries of Health and National TB Control Programmes of their countries.

Although the Nuffield Centre had previously conducted collaborative research projects with all three of the partners, this was the first large-scale, solely qualitative

research project conducted in collaboration with the partners, and it was the first time the three partners had worked together on a research project.

The research partners were primarily responsible for collecting data and assisting with its analysis. Each research partner recruited or identified at least two members of staff (one female, one male) to work on this study and in all three cases one of the two members of staff took primary responsibility for the study and acted as my main point of contact.

My role was to design the research study (within the broad remit of the original grant application), to manage the research process, to ensure rigour, depth and comparability of the data collected, to analyse the data, and to write up the findings in reports for the funders and the National TB Control Programmes of each country.

1.3 Objectives

The objectives of the research presented in this thesis were threefold:

- To gain an understanding of the nature of the stigma associated with TB in the contexts of selected rural and urban areas in Bangladesh, Nepal and Pakistan
- To develop theories to explain the causes of TB stigma within and across the study areas
- To assess, in light of the theories developed, the potential for policy and programme responses to address TB stigma

Reflecting the study objectives, I present in Chapters 6-8 of this thesis three manifestations of TB stigma identified from the data and, using the approach to developing grounded theory and a realist conceptualisation of causality, present causal theories to explain each.

I also describe the challenging, complicated, and arguably messy process of developing grounded theories in a large-scale study coordinated from one country (the UK) but conducted across three others (each with its own logistical and political challenges), involving six different languages (English, Bengali, Nepali, Newari, Urdu and Punjabi) and teams of researchers with variable qualitative research capacities. The generous word limit of a PhD thesis allows me to be transparent about what this actually entailed in practice (see Chapters 3-5).

1.4 Ethical approval

Ethical approval was sought and received on 8 February 2007 from the University of Leeds Research Ethics Committee, on 14 June 2007 from the National Bioethics Committee in Pakistan (Ref. F.4-87/NBC/ASD-Project/10/5404), on 13 February 2007 from the Institute of Medicine at Tribhuvan University in Nepal and on 22 March 2007 from the National TB Control Programme in Bangladesh (memo no. 5-15/TB-2EP/TB Research/04-07/10253). Copies of the letters of ethical approval from Pakistan, Nepal and Bangladesh are presented in Appendix E.

1.5 Overview of study design and thesis

The approach to grounded theory which was first outlined by Glaser and Strauss in 1967 is an established and rigorous approach to developing theories through the process of qualitative data collection (Glaser and Strauss, 1967). The approach fits well with the aim of the research (to develop theories to explain the causes of TB stigma) and the philosophical orientation which underpins it (symbolic interactionism) fits well with the conceptualisation of stigma as a social construct, produced, resisted and negotiated through interactions between people (see Chapter 2: Conceptualising Stigma).

The study has a three-stage design, comprising planning, preparation, and then theory development through the iterative processes of collecting data, coding data, analysing data and writing. The first stage, planning, involved a broad review of the literature to understand the different ways in which stigma and its causes have been conceptualised. I reflected on how these conceptualisations may be relevant to TB and this study whilst also reflecting on references to stigma in the media and conversations with colleagues and friends. My reflections generated ideas and

questions which, through further reading of specifically sought out literature, I began to develop, challenge and answer. This involved at times reading more by the same authors, reading literature referenced by the authors and searching for additional literature across disciplines using bibliographic databases and the library catalogue. This broad and theoretically driven review of the literature informed the development of a broad and inclusive definition of manifestations of TB stigma (see Chapter 2, section 2.1) as well as the development of a conceptual framework of stigma causality (see Chapter 2, section 2.2). A three-day workshop was then organised and held in Islamabad in Pakistan in October 2007. Partners from all three countries attended, as did James Newell and I from the University of Leeds. The aims of the workshop were to cultivate a common way of thinking about the topic of research and a common understanding of the research process; to identify training, support and resource needs; and to plan and prepare for the second stage of the research process.

As shown in Figure 1, the introductory workshop was followed by selection of research sites and an extensive period of preparation during which the research teams applied rapid appraisal techniques and conducted preparatory focus group discussions. The purpose of this second stage was to collect potentially useful background data about the study contexts; to establish links with potential 'gatekeepers'; to learn from any logistical difficulties; and to develop the qualitative research skills of the research teams. Whilst the process of this stage has been described in some detail (see Chapter 3), the data collected has not been presented in this thesis, but did inform the development of the interview guides used in the third stage of the research process (see Chapter 4).

With the assistance of research teams in each of the three South Asian countries, I explored potential TB stigma manifestations and began the process of discovering theories to explain them through theoretical sampling and the processes of conducting and analysing 73 individual in-depth interviews across five sites (Chapter 4). To develop the theories further I incorporated my theorising into vignettes which were used as the basis for discussions with eight focus groups across three of the research sites (see Chapter 5).

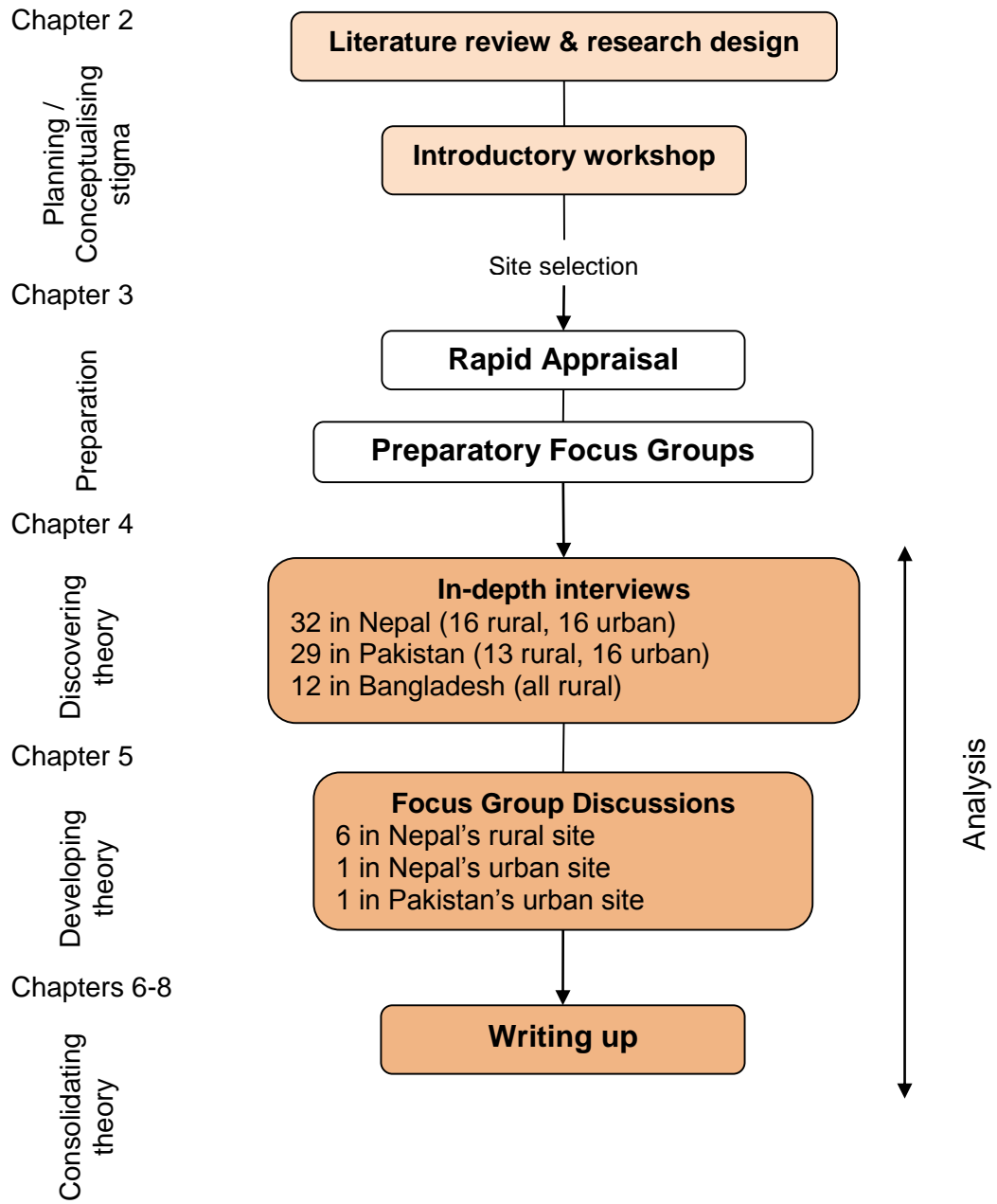
Realist causal theories to explain three specific manifestations of TB stigma identified from the data were consolidated through the process of analytical writing and are presented in Chapters 6-8. The causal theories are presented in

discussional form and explain why, for whom and in what circumstances TB stigma becomes manifest. Whilst the three specific manifestations of TB stigma which I identified through this research can serve as the outcomes for TB stigma interventions to target, the causal theories developed can provide the theoretical underpinning of such interventions. At the end of each of these chapters I reflect upon the causal theories and propose, in light of the theories, approaches to addressing TB stigma.

In the final chapter of the thesis (Chapter 9), I consider the significance and utility of the research, and summarise the key findings and the opportunities they present for addressing TB stigma in South Asia. Finally, I reflect upon the relevance of the theories beyond the five research sites and the limitations of the research, before suggesting how the causal theories could be developed even further.

Figure 1 The research process

Thesis chapters



Chapter 2

CONCEPTUALISING STIGMA

In the first part of this chapter (2.1) I will consider the various ways in which the concept of stigma has been defined and will present the TB-specific definition I developed to guide this study. I will then, in the second part (2.2), consider what causality means in relation to the concept of stigma, and in the process will build a conceptual model which will serve as a framework for the development of causal theories.

2.1 What is stigma?

‘Stigma’ is a familiar word in the English language that is often used without its meaning being made explicit and with reference to a wide range of attributes, emotions, attitudes, beliefs, behaviours and experiences. How diversely the term has been applied in the media is illustrated by the following: in 2008 the BBC News website used the term stigma with reference to dementia, breast size, mental illness, being a contestant on the TV show Big Brother, gastric banding, divorce, and the name of the road upon which a serial killer had lived (Hutchinson, 2008; Pryor, 2008; BBC News, 2008b; BBC News, 2008e; BBC News, 2008c; BBC News, 2008d; BBC News, 2008a). Even among social scientists the term, as Manzo (2004) states, has been “under-defined and over-used” (p401), and Aggleton argues that the concept has been so overstretched that it is at risk of becoming meaningless (Royal Tropical Institute (KIT), 2004).

In this section I present the need for an explicit and inclusive definition of the stigma concept prior to beginning data collection. I explain how such a definition opens up, rather than narrows, the perspective of the researcher, allowing the development of theories to explain specific manifestations of stigma which are determined by the data rather than pre-determined by the researcher. I then reflect on the broader literature on the stigma concept, considering in the process the critical question ‘*Who decides what constitutes stigma?*’ before I finally present the definition developed for this study.

2.1.1 An explicit and inclusive definition of stigma

For any research on stigma, an explicit definition of the concept is important, but for multi-country comparative research it is especially so. In the absence of an explicit

and shared definition, the data collected may lack comparability as the researchers in each country investigate their own disparate interpretations of a European word. This can be demonstrated by the following incident.

At the workshop held in Islamabad at the outset of the study, the research teams from Nepal and Pakistan and I spent some time discussing the stigma concept and the definition we were to use for this study. Whilst a representative from the National TB Control Programme in Bangladesh did attend, the two Bangladeshi researchers who collected the data for this study were not recruited until after the workshop. Once they had been recruited I flew to Bangladesh to provide guidance and training prior to their commencing data collection. As the two Bangladeshi researchers recruited were relatively new to qualitative research, I presented to them the definition of stigma intended to guide the research, but focussed mainly on developing their qualitative research skills. During a data analysis exercise it became apparent that our understandings of stigma might be very different and that, whilst I had presented and explained my conceptual thinking around stigma to them, I had not adequately considered their own. As one of the researchers understood little English, the other took on the role of interpreter. Having realised through the data analysis exercise that our understandings of the English term stigma might be very different, I was interested to know how he was translating the term stigma. The translation given to me without hesitation (*ku shongskar*) transpired to literally mean 'misconception' or 'wrong belief'. Realising that this study on TB-related stigma could so easily and accidentally have become a study on misconceptions, I interrupted the analysis exercise and revisited the research aims and definitions with the Bangladeshi researchers in greater depth. I also contacted the Nepali and Pakistani researchers who had attended the Islamabad workshop and asked them what stigma was in Nepali and Urdu. Reassuringly, they did not provide a one-word answer but instead explained that the concept cannot be so easily translated. Nichter (1994) points out that not all concepts are translatable as not all concepts are universal. However, that not all concepts are translatable may apply even if what it is we are conceptualising is universal (as disease-related stigma is thought to be, see section 2.2.3); *how* it is conceptualised is likely to vary across cultures and contexts.

The definition of the stigma concept needed to guide and ensure comparability in a multi-country qualitative research study therefore needs to be explicit and shared (among research partners), but not be overly specific. Whilst definitions, on the whole, serve to narrow the researcher's focus of inquiry, this study required a

definition which would do the opposite: one which would serve to broaden our perspectives on what might potentially constitute a manifestation of stigma, but then allow the data to determine what, in the contexts of the research sites and from the perspectives of the research participants, actually is such a manifestation.

In the following sections (2.1.2 to 2.1.4) I consider the different ways in which the term stigma has been used and defined in social science and health literature, before borrowing aspects of these definitions to construct my own TB-specific definition to guide this research (see section 2.1.5).

2.1.2 Stigma as symbolism

The word 'stigma' is believed to be derived from the Greek via Latin meaning a mark, such as a tattoo, made by a pointed instrument (OED, 2010). It has acquired specialised meanings in both medicine and botany, but it is the use of the term stigma in late 16th century Europe for the tattoo or branding given to people to indicate their slave or criminal status that is likely to have given rise to the concept of social stigma (Brewer, 1963; Paul, 1992), the discredited status which the physical stigma, the tattoo, conveys. Goffman (1963) noted fifty years ago in his sociological book on stigma that the term stigma is now overwhelmingly applied to the discredited status conveyed by a mark or attribute, rather than to the attribute itself. The mark or attribute comes to symbolise, albeit often unreliably, a wide range of imperfections. It becomes associated with negatively defined characteristics, behaviours or groups in society and it is this "negative social baggage" (p49) which can be seen to constitute social stigma (Deacon et al., 2005a).

Definitions of stigma which focus on symbolic meanings tend to view stigma as attitudes and beliefs (ideology), with the behavioural expression of these described as 'discrimination' (Deacon, 2006; Deacon et al., 2005b). Others view stigma as both attitudinal and behavioural, referring to the behavioural aspect as 'enacted stigma', rather than as discrimination, on the basis that not all forms of discrimination are always or necessarily stigma-related (Scambler, 2004; Lorentzen and Morris, 2003; Steward et al., 2008).

A number of the authors who focus on stigma as attitudinal have distinguished between stigma characterised by instrumental or evaluative attitudes and stigma

characterised by symbolic or expressive attitudes (Crandall et al., 1997; Deacon et al., 2005b; Herek and Capitanio, 1998; Herek, 1986). Instrumental attitudes are based primarily on anticipated consequences and utility of actions, such as (an inflated) fear of becoming infected with TB and consequent avoidance of a person with TB. By contrast, symbolic stigma is based on moral judgments, such as blaming someone for developing TB disease. Put simply, the former relate to pragmatic concerns whilst the latter relate to values (Crandall et al., 1997). Researchers focussing on AIDS-related stigma seem to have particularly embraced this instrumental/symbolic distinction, with the view that instrumental stigma is easier to rectify than symbolic stigma as the former is thought to be based on misconceptions about modes and risks of transmission, while the latter is thought to be based on more entrenched, long-standing values (Crandall et al., 1997). In effect, this distinction defines two types of attitudinal stigma based on their perceived basis: misconceptions and moral judgments.

The trouble with the notion of instrumental stigma is that it classifies those behaviours based on instrumental or evaluative attitudes only as stigma if they are, as Weiss et al. (2006b) put it, “medically unwarranted” (p280) and therefore, by implication, based on a lack of medical or scientific understanding. Those behaviours which are ‘medically warranted’ would therefore be merely instrumental, rather than instrumental *stigma*. This inclination to equate stigma with a lack of scientific or medical understanding (or misconceptions and ignorance) suggests that stigma interventions should focus on educating individuals or communities. However, Deacon et al. (2005b) point out that the difficulties addressing stigma through education have challenged the conceptualisation, apparent in early HIV/AIDS work, of stigma (or prejudice - an overlapping and often synonymous concept) as a problem of individual ignorance. Similarly, Scambler (2004), whose research on stigma has focussed on epilepsy, argues that, at the heart of stigma interventions focussed on better informing the public is an assumption, based on received wisdom, that when a person is labelled ‘epileptic’ by a doctor, he or she becomes exposed to the “active and destructive prejudices of an ill-informed public” and that this “enacted stigma” constitutes the greatest threat to his or her life story (p33). This assumption, that stigma is primarily enacted by an ill-informed public, is challenged by the findings of Scambler and Hopkins’ research on stigma and epilepsy (see section 2.1.4) (Scambler and Hopkins, 1986).

A further problem with equating stigma with ignorance or misinformation is that it suggests that stigma is ‘caused’ by ignorance or misinformation. As a causal

explanation this is inadequate, as even where a misconception prevails, people with TB experience stigma in different ways and to different degrees. 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; Weiss et al., 2006a; de-Graft Aikins, 2006).

Deacon et al. (2005b) reject the concept of 'medically unwarranted' instrumental stigma altogether on the basis that "definitions of what constitutes instrumental stigma based on risk of infection would have to change as scientific knowledge or the nature of the disease changes" (p46). Instead they suggest focussing on symbolic stigma alone as stigma proper. However, the problem with the concept of instrumental stigma is not so much, as Deacon et al. claim, that definitions of what constitutes instrumental stigma would need to change as scientific knowledge changes. After all, why should perceptions of what constitutes stigma not be allowed to change over time? The problem with the concept of instrumental stigma is that it places the decision as to what constitutes instrumental stigma firmly in the hands of the medical profession. If two people fear becoming infected with TB from a third person who has TB, it is for those with the most up-to-date medical knowledge to decide whose fear is warranted (and therefore justifiably instrumental) and whose fear is unwarranted (and therefore constitutes instrumental stigma). The perspectives of the two people who fear TB and the person with TB become largely irrelevant. The concept of symbolic stigma raises a similar problem. As I will explain in Chapter 7, avoidance of a person with TB can be interpreted as a sensible precaution (based on instrumental considerations regarding risk and resources) by one person, and as a sign of hatred (a moral and value-based judgement) by another.

The question as to whose perspective to take relates to the critical question which I will consider in section 2.1.4 of *who decides what constitutes stigma?*. Before focussing on this question, I will first consider an alternative to conceptualising stigma as ideology or symbolic meanings: stigma conceptualised as a process.

2.1.3 Stigma as a process

The meanings associated with an attribute - its 'social baggage' - whether instrumental, symbolic or a combination of the two, are constructed, negotiated and resisted through social interactions between people, requiring, as Goffman (1963)

put it, “a language of relationships” rather than of attributes (p13). Consequently an alternative to defining stigma as the symbolic meanings associated with an attribute is to define it as the processes and relationships that generate those meanings and related discriminatory behaviours. This focus on stigma as a process has become increasingly popular (Link and Phelan, 2001; Weiss et al., 2006b; Parker and Aggleton, 2003; Royal Tropical Institute (KIT), 2004).

An immediate problem with defining stigma in this way is that it is not congruent with the way the term is commonly used in the English language. The noun simply does not lend itself well to being a process. Crandall et al. (1997), within the same article, refer to stigma as a social process, but then use the term to refer to a mark or attribute. In an attempt to rectify the incongruity between the noun stigma and the definition of it as a process, some authors have become more inclined to substitute the term stigma with the verb-derived noun stigmatisation (the act of stigmatising) (Parker and Aggleton, 2003).

Link and Phelan (2001) view stigmatisation as a four stage process dependent on social, economic and political power. The first stage involves distinguishing and labelling differences which, whilst not inherently important, are *deemed* to be important, socially and subjectively. Whilst Link and Phelan give the example of the racial labels ‘black’ and ‘white’, the medical classification or label ‘TB’, applied to those who exhibit distinguishable differences such as symptoms and positive sputum test results, is no less socially constructed. Just as the racial categories involve oversimplification in order to create distinct groups, ‘TB’ is also an oversimplified label for a broad and varied range of symptoms affecting any part of the body. The common factor with the medical label ‘TB’ is the mycobacterium, but it could have just as well have been based on other common factors. Based on his ethnographic work in the Phillipines, Nichter (1994) describes how what the western biomedical system classifies as pulmonary TB is grouped with other chest infections under the label ‘weak lungs’, whilst forms of extrapulmonary TB are classified completely separately. In Vietnam, by contrast, the biomedical concept of TB has been traditionally categorised into four disease types: hereditary, physical, mental and lung (Long et al., 1999).

The second stage of Link and Phelan’s four-stage stigmatisation process is the association of these labels with additional information about the person’s behaviour, character and values. In other words, Link and Phelan (2001) prefer the term ‘label’

to 'attribute' but still view the symbolism attached to the label or its negative social baggage as a key stage in the stigmatisation process. However, where they fundamentally differ from those who define stigma as symbolism is that they argue that power is central to the notion of stigmatisation and so these first two stages of the process do not constitute stigmatisation on their own. After all, everybody differentiates, labels and stereotypes.

The third stage of the stigmatisation process, according to Link and Phelan, involves regarding the negatively labelled person as fundamentally different, separating 'us' and 'them', based on the negative social baggage the label carries. The fourth and final stage is the status loss and discrimination which ensues. Only those with the social, economic or political power can see the process through to the final stage and so only those with power can stigmatise.

Link and Phelan are not alone in viewing stigma as a process. Kurzban and Leary (2001) consider stigmatisation to be the process by which we systematically exclude individuals from our social interactions because they possess a certain characteristic or belong to a particular group. Leary (2001) refers to this as relational devaluation: a process whereby people are devalued because they possess characteristics consensually regarded as legitimate grounds for rejection. Parker and Aggleton (2003) similarly view stigma as a social process, involving devaluation and exclusion, that needs to be understood in relation to the broader concepts of power and domination.

Conceptualisations of stigma as a process place emphasis on the contextual and structural issues of power and legitimacy and therefore present stigma as far more complex and contextualised than conceptualisations of stigma which focus on symbolic meanings. However, whilst stigma seen as the negative symbolic meanings attached to an attribute or label lends itself relatively easily to quantitative investigation, stigmatisation seen as a complex, multi-stage process to which power is central does not. This is perhaps why Crandall, Glor and Britt (1997), despite viewing stigmatisation as a complex process, opt to focus on just one aspect, namely attitudes, in their quantitative primary research, whilst Macq et al. (2005) opt for qualitative methods in their social system analysis.

One thing that the process models of stigma share is a focus on ‘enacted stigma’ or discriminatory behaviours: a process whereby one person stigmatises another. There is a stigmatiser and a stigmatised. Deacon et al. (2005b) argue that this process of judging and devaluing others requires a completely separate understanding to the process of judging and devaluing oneself. For this reason they exclude from their definition of stigma, self- and even perceived stigma (for which I will provide definitions in the following section, 2.1.4). The idea that stigma refers not to one process, but to multiple processes, each requiring a completely separate understanding, is supported by Prior et al. (2003), who argue that stigma as a concept is currently “creaking under the burden of explaining a series of disparate, complex and unrelated processes” (p2192).

If stigma is an overly broad umbrella-term for multiple disparate processes, it may be beneficial to break the concept down into more meaningful parts and to avoid using the umbrella-term altogether. Indeed, an issue of the journal *Stigma Research and Action* (Vol. 2, No.2, 2012) was dedicated to debating the question “Is it time to retire the term stigma?”.

Whilst still using the term stigma (rather than sending it into retirement), concepts such as ‘enacted stigma’, ‘self-stigma’ and ‘perceived stigma’ offer a way of breaking down the overly broad umbrella-term. The concepts of enacted-, self- and perceived stigma break down the stigma concept on the basis of who the central actor is. For ‘self-stigma’ and ‘perceived stigma’ the central actor is the person with the stigmatised attribute, whereas for ‘enacted stigma’ the central actor is the person who acts in a way that is considered to be stigmatising. This, of course, still begs the question as to *who* it is that considers the actions of the person to be stigmatising: *Who decides what constitutes stigma?*

2.1.4 Who decides what constitutes stigma?

Keen to include actions or behaviours in my definition of TB stigma manifestations, I initially included the term ‘enacted’. However, as the study got underway, I realised that, like the concept of instrumental stigma, the concept of enacted stigma is likewise problematic. ‘Enacted stigma’ requires someone to make the judgment call that a behaviour or action is stigmatising. If it is to be the recipient of the action alone, then it could be termed ‘experienced stigma’ (Royal Tropical Institute (KIT), 2004) or ‘received stigma’ (Holzemer et al., 2007), but this then relies on the recipient’s interpretation of another person’s actions (what I would prefer to call

perceived stigma) rather than being based necessarily on the other person's intentions. If it is to be the 'enactor' him or herself, then the term 'enacted' can be substituted with 'intended', which I have done in my definition (albeit at a late stage in the study) which I present in section 2.1.5. Of course, it is possible that no enacted or intended stigma exists if no one either admits to or interprets their own actions as being stigmatising. In a small single-country study on the causes of TB stigma conducted in Nepal as a preliminary to this one, it was found to be difficult to get people to openly admit stigmatising views or to acting in a stigmatising way (Baral et al., 2007). Indeed, it has been recognised as a problem faced by stigma researchers that what people say is often different to what people do (Crocker et al., 1998; Royal Tropical Institute (KIT), 2004).

As an alternative to relying on the 'enactor' to classify his or her actions (or attitudes or emotions) as stigmatising, the researcher could make the judgement that, for example, avoiding a person with TB constitutes enacted stigma. This has happened in studies which have sought to measure stigma by using indicators or proxies such as social distance (Jaramillo, 1999). The problem with the researcher deciding what is and is not enacted stigma is that she or he is imposing an interpretation on an action, assuming intent and ignoring the multiple ways in which a single action can be interpreted by different people. The apparent methodological problem in stigma research that no one will admit to stigmatising – what people say is often different to what people do – may in fact be a conceptual problem, whereby stigma is seen as a definite and measurable phenomenon rather than one which is subjective, nuanced and contextualised.

Scambler and Hopkins (1986) found that it was not enacted stigma that featured predominantly in their interviews with epileptics, but the fear of encountering enacted stigma and feelings of shame. This fear and shame they term 'felt stigma' but these have also been referred to as 'perceived stigma' (Royal Tropical Institute (KIT), 2004). Studies on HIV-related stigma have similarly found felt or perceived stigma to be more prevalent than enacted stigma (Green, 1995; Steward et al., 2008) and, indeed, even Goffman himself focuses much of his book on the effects of anticipated stigma and the management of undisclosed discrediting information by those possessing the discreditable attribute (Goffman, 1963).

Others have since divided the concept of felt stigma into two, applying the terms 'anticipated stigma' to the fear of encountering enacted stigma and 'self-' or

'internalised-stigma' to the feelings of shame. The concept of self or internalised stigma implicitly challenges the assumption that there is a clear distinction between the stigmatised and the stigmatiser. Steward et al. (2008) define internalised stigma as when a person accepts their own discredited status as valid; the stigmatised becomes simultaneously the stigmatiser. In interviews with people living with HIV in India, Steward et al. (2008) found expressions of internalised stigma to be complex and nuanced. One interviewee considered herself an innocent victim of HIV, but others to be blameworthy, and another HIV positive interviewee felt that isolating people living with HIV is wrong, but that some restrictions on marriage are appropriate. Reflecting on her own research findings from a survey on HIV stigma in Scotland, Gill Green suggests that most people may hold both stigmatising and non-stigmatising attitudes towards people with HIV and that it is dependent on time and place which attitudes come to the fore (Green, 1995).

The lack of clarity with regards to who is stigmatised and who stigmatises is further emphasised by the notions of courtesy stigma (Goffman, 1963) or associated stigma (Holzemer et al., 2007). These terms refer to the stigmatisation of people who do not themselves possess the stigmatised attribute or label, but who are associated with those who do: for example, the family or friends of people with TB or health professionals working with people with TB. Borrowing from the concept of courtesy stigma, the last part of the definition I developed for this study (presented in the following section) acknowledges that those affected by TB-related stigma may not necessarily always be people with TB. They may include those only suspected to have TB or those thought to be particularly susceptible to or somehow associated with TB, perhaps because of their occupation, lifestyle, social status or because they have a family member or friend with TB.

2.1.5 My definition of TB stigma manifestations

In the first section of this chapter, I have considered the different ways in which the term stigma has been conceptualised in the literature. The term has been applied both to symbolic meanings (and related attitudes and behaviours) and to the relational processes through which these meanings are produced (and negotiated and resisted). These two contrasting conceptualisations are not incompatible, but the application of the same term for both is unhelpful and demonstrates how the term has, as Aggleton has stated, been over-stretched (Royal Tropical Institute (KIT), 2004). For the sake of clarity, the definition I have developed to guide this study is not one of stigma, but of the *manifestations* of TB stigma – specific

observations from the data which call for theoretical understanding or causal explanation. Within the causal explanations, conceptualisations of stigma as a process can then be situated.

It is in their view of what constitutes a manifestation of stigma that there is significant dissonance between those who define stigma as symbolic and those who define stigma as a process. Manifestations of stigma tend to be viewed by the former as attitudinal and by the latter as behavioural – as acts of discrimination. In my definition of TB stigma manifestations (presented below) I have chosen to include behaviours, rather than conceptualising them separately with the term ‘discrimination’, because I want to avoid any implicit suggestion that stigma ‘causes’ discrimination or that attitudes ‘cause’ behaviours in a unilinear successionist way. Whilst the central purpose of the research is to develop causal theories, the purpose of my definition of TB stigma manifestations is solely to guide the identification of that which the theories are to explain. Furthermore, to keep my definition as broad and inclusive as possible, I have included emotions alongside attitudes and behaviours to cover the whole spectrum of how people think, feel and behave.

Manifestations of TB stigma are:

Anticipated, perceived, internalised and/or intended *negative* attitudes, emotions, or behaviours towards or by a person on the basis that he or she is known or suspected to have TB, or is perceived to be particularly susceptible to or associated with TB.

As described in section 2.1.3, conceptualisations of stigma as a process of labelling, stereotyping, devaluing and discriminating against *others*, in which social structures and power relations are central, exclude the experiences and perceptions of stigma from the perspectives of those with or associated with the discreditable attribute or label. Concepts such as anticipated stigma, perceived (or experienced or felt) stigma and internalised (or self) stigma broaden the focus out to the individual with the attribute. Given that studies have found felt or perceived stigma to be more prevalent than enacted stigma in some cases, this broadening of perspective is welcome (Green, 1995; Scambler and Hopkins, 1986; Steward et al., 2008). Indeed, I have excluded the term ‘enacted’ from my definition altogether. As stated in section 2.1.4, as the concept of ‘enacted’ stigma requires someone to make the judgement call that a behaviour or action is stigmatising, I prefer to use

the terms perceived stigma (if the judgement call is made by the recipient) or intended stigma (if the judgement call is made by the enactor). The last part of my definition acknowledges the notions of courtesy stigma (Goffman, 1963) and associated stigma (Holzemer et al., 2007) which refer to the stigma experienced not just by those with TB but potentially by those suspected to have TB, or perceived to be particularly susceptible to or somehow associated with TB.

The purpose of the definition is to increase the sensitivity of myself and the other researchers to *potential* manifestations which could be considered TB stigma-related, but not to predetermine exactly what they are in the contexts of the research sites. The definition guides the research as to what to investigate (negative attitudes, emotions and behaviours), from whose perspective (anticipated, perceived, internalised and intended) and in relation to whom (towards or by a person on the basis that he or she is known or suspected to have TB or is perceived to be particularly susceptible to or associated with TB). The specific anticipated, perceived, internalised and/or intended negative attitudes, emotions or behaviours for which explanatory theories were then developed were identified from the interview data. Crucially, the word 'negative' in my definition of TB stigma manifestations has been italicised for emphasis as this seems to be the common implicit factor running throughout all existing definitions and conceptualisations of stigma.

The two broad approaches to conceptualising stigma as either symbolism (as outlined in section 2.1.2) or as a process (as outlined in section 2.1.3) reflect differences in disciplinary background, with some focussing on individual psychology and others on social, economic and political structures. De-Graft Aikins (2006) argues that a synthesis of disciplines and approaches is needed in order to comprehensively examine stigma, bringing together micro-social approaches used by social psychologists and macro-social approaches used by sociologists. Campbell and Deacon (2006) too support an interdisciplinary and multi-level investigation of stigma on the grounds that stigma is "a phenomenon rooted in the individual psyche, yet constantly mediated by [...] material, political, institutional and symbolic contexts" (p416). Whilst my definition of TB stigma manifestations reflects a micro-social or social psychological perspective, it needs to be placed within the conceptual model of stigma causality presented in the following section (see figure 2, section 2.2.7). This model attempts to link not only the micro-social with the macro-social perspective, but also to link both of these with an evolutionary or functional perspective on the roots of stigma.

2.2 Conceptualising stigma causality

As the term stigma has been used both to refer to an outcome and to the cause of an outcome, I will first consider the very notion of stigma causality (see section 2.2.1). I will then build a conceptual model of stigma causality which provides a framework for the development of causal theories. At the top of the model are the manifestations of TB stigma for which causal theories are to be developed.

Although specific manifestations will be identified from the research data with my broad and inclusive definition as a guide, I review here what manifestations have previously been identified by studies conducted in South Asia (section 2.2.2). I will then give an overview of the psychological and sociological literature on stigma's roots and dimensions (sections 2.2.3 and 2.2.4), and consider the notions of power, legitimacy and cost (section 2.2.5). I suggest that terms such as iatrogenic, institutional and structural stigma point toward the contexts which influence the dimensions of stigma and the power and legitimacy which distinguish stigma from idiosyncrasy (section 2.2.6). Finally I bring together the preceding five sub-sections into a conceptual model of stigma causality (section 2.2.7).

2.2.1 The notion of stigma causality

The problem with identifying causes of stigma is that stigma is a concept which, as stated in the introduction to this thesis, conflates causes, functions and effects (Deacon et al., 2005a). Stigma can be seen both as an outcome and as the explanation for an outcome. As discussed in section 2.1, stigma has been defined both as discriminatory attitudes and behaviours, and as a process leading to these. Despite realising this early on, at numerous points in the research process I have slipped back by default to viewing stigma as an outcome, primarily because of the wording of the study's aim: to develop theories to explain *the causes of TB-related stigma*. Upon reflection, a slight but significant re-wording of the aim might have been helpful: to develop theories to explain *the causes of TB-related stigma manifestations*. However, even this is not without its problems as the cause of a manifestation of stigma is surely stigma itself. To avoid getting tangled in semantics, throughout the research process described in Chapters 3-5, I have avoided, where possible, using the term stigma and instead have focussed on developing explanatory theories of manifestations which were identified from the data and which were consistent with my definition of a TB stigma manifestation.

What is clear is that whatever it is this study seeks to develop theories to explain, the theories will not comprise a single linear cause. Stigma, despite having its roots

in underlying evolutionary or functional processes (see section 2.2.3), is still a *social* phenomenon, a concept rooted in the social world. In a complex social world, an effect is rarely, if ever, simply the result of a cause. To guide my thinking I sought an alternative to the successionist (cause leads to effect) view of causality; one which would have greater applicability to the complex concept of 'social' stigma.

Whilst the design of this study is based on the approach to grounded theory which has its roots in the constructionist epistemology of symbolic interactionism, for my conceptualisation of causality I have drawn from the realist perspective of Pawson and Tilley (1997). According to Pawson and Tilley, causality in the social world involves a combination of an underlying mechanism and context. In certain contexts the mechanism will operate to produce certain outcomes; it becomes generative. In other contexts, the mechanism will remain dormant or will produce very different outcomes. Whilst identifying underlying generative mechanisms is a crucial step in understanding what causes stigma (manifestations), identifying these mechanisms alone, without considering the contexts in which they become generative, is meaningless.

At the time of the review of my provisional PhD status, I presented in my transfer report a version of the conceptual model of stigma causality presented in Figure 2 (section 2.2.7) which had 'context' encircling the space between manifestations of TB stigma and its dimensions and roots. This reflected Pawson and Tilley's equation of causation (Mechanism + Context = Outcome), suggesting that the mechanisms can be found in a combination of stigma's roots and dimensions, and that once identified, these distinct mechanisms in specific contexts would generate stigma manifestations. However, Pawson and Tilley presented their view of causality as a formula to visually contrast it with successionist and configurational views, not because causality in the social world is really that formulaic. To better reflect how intrinsic context is to explanations of stigma manifestations in the model which I build over the next five sub-section (2.2.2 to 2.2.6) and present in its entirety in section 2.2.7, I have placed context at the heart, underlying stigma dimensions, power, legitimacy and sources.

Pawson and Tilley's perspective of causality has been applied to the development of evaluation methodologies in social policy. Whilst this study is not an evaluation of an intervention, the intention is that it will produce a useful theoretical basis for developing interventions to reduce TB-related stigma. As a result the central

question of this study - *Why does stigma manifest itself in a particular way, for whom and in what circumstances?* - is not so dissimilar to the central question of an evaluation - *What works for whom in what circumstances?* (Pawson and Tilley, 1997). An evaluation of a stigma intervention would shed light on the mechanisms and contexts in which stigma does and does not manifest itself. This study aims to shed light on these *before* an intervention is implemented so that the intervention can be designed and implemented with an explicit theoretical basis.

2.2.2 Manifestations of stigma

At the top of the conceptual model of stigma causality are the manifestations of stigma.



The stigma definition which I developed for this study indicates the forms stigma may take (negative attitudes, emotions and behaviours) and the different perspectives to consider (anticipated, perceived, internalised, intended), but it does not tell us exactly how TB-related stigma manifests itself in the contexts of the three Asian countries included in this study. At the start of this study, I did not know specifically what anticipated, perceived, internalised or intended negative attitudes, emotions and behaviours I would find, if any, and so I did not know what it was I would be trying to explain. My aim was to develop theories to explain the causes of outcomes I had yet to discover. Whilst the first objective of this research was to gain an in-depth knowledge of the nature of the stigma associated with TB in the contexts of selected urban and rural areas in Bangladesh, Nepal and Pakistan, I looked at the existing literature to see what forms this stigma (or more precisely these stigma manifestations) *might* take.

A review of qualitative research on TB stigma, which included studies from Asia, suggests manifestations of TB stigma might include isolation from other members of the community, concealment of a TB diagnosis, a sense of shame and guilt leading to self-isolation, job loss and reduced income, an adverse impact on marriage prospects and being shunned or rejected by family (Courtright and Turner, 2010).

A study by Somma et al. (2008) looks at socio-cultural determinants of TB stigma in four countries, including Bangladesh, and assesses the degree of TB stigma with an index comprising 18 indicators selected on the basis of previous studies and local ethnographic and clinical data. These indicators, which could be viewed as or related to manifestations of stigma, include 'desire to keep others from knowing', 'think less of yourself' and 'others have avoided you'. Similarly, Baral et al. (2007) found that in Nepal some people with TB hide their diagnosis from others in their community and isolate or separate themselves. From research conducted in neighbouring India, Atre et al. (2009) describe stigma indicators and themes as 'an exaggerated fear of spread of disease', 'hiding the disease', 'adverse impact on marriage' and 'intense emotional suffering'.

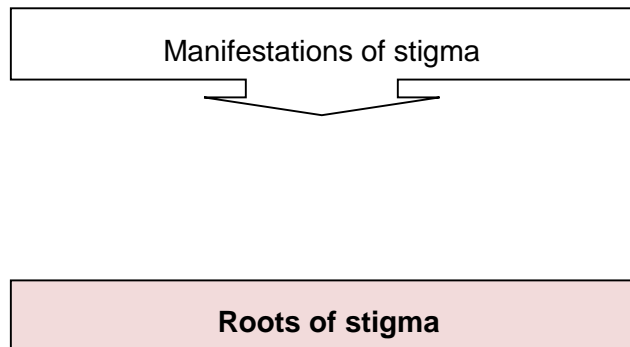
An international workshop on health-related stigma held in the Netherlands in 2004 also identified a number of potential indicators of stigma, relating to both what people fear or anticipate and what they actually experience (Royal Tropical Institute (KIT), 2004). These include such manifestations as exclusion from social gatherings, no longer being visited, being isolated in the household, being abandoned by a spouse, and being gossiped about.

Following my definition of TB stigma manifestations presented in section 2.1.5, these indicators can only constitute stigma manifestations when they are interpreted by someone (preferably other than the researcher) as being *negative*. Attempts to measure stigma using such indicators will always be imperfect and problematic unless context and interpretation are taken into account. As I shall explain in Chapter 5 (section 5.5), in this study potential manifestations such as being avoided or avoiding others and the desire to keep a TB diagnosis confidential were not always spoken of as negative and so do not in and of themselves qualify as stigma manifestations following my definition. However, both of these were found to be closely related to the intrinsically negative perception that people with TB are hated (see Chapter 7).

2.2.3 Roots of stigma

As stated in section 2.1.5, Campbell and Deacon (2006) describe stigma as "a phenomenon rooted in the individual psyche, yet constantly mediated by [...] material, political, institutional and symbolic contexts" (p410). At the base of the conceptual model of stigma causality are the underlying psychological processes or

internal mechanisms in which attitudes, emotions and behaviours are deeply-rooted.



Studies of TB stigma have described how people with TB may be isolated or avoided because of the fear of TB transmission (Atre et al., 2009). Given that TB is infectious, airborne and often fatal - in 2012 there were an estimated 1.3 million deaths from TB worldwide (WHO, 2013c) - this fear seems well-founded and surely instinctive. Disease-related stigma is believed to exist in every human society and is thought to have existed throughout history (Herek, 1999). This apparent universality of disease-related stigma suggests underlying psychological processes or internal mechanisms may be involved which we all, as humans, share. Some describe these processes as evolutionary (i.e. resulting from past social or environmental pressures), others as functional (i.e. resulting from current social pressures) (Kurzban and Leary, 2001; Phelan et al., 2008; Fiske, 1998; Crocker et al., 1998). However, whilst there is disagreement on why or how these processes developed, there is broad agreement on what these processes are and that the stigmas attached to different types of attribute are likely to be deeply-rooted in *different* underlying psychological processes.

The underlying psychological processes or internal mechanisms thought to be relevant to stigma are known as parasite avoidance, the need to belong, dyadic cooperation, exploitation and domination, and norm enforcement.

The first, **parasite avoidance**, refers to the affective and cognitive systems we, as a species, have developed to help us avoid parasites (Kurzban and Leary, 2001). Schaller (2006) refers to these as our 'behavioural immune system' and they help explain why, as Crandall, Glor and Britt (1997) claim, life-threatening illnesses are inherently stigmatising. These affective and cognitive systems are not unique to humans. The avoidance or exclusion of those who are visibly parasitized has also

been observed among other animal species, ranging from fish to chimpanzees (Kurzban and Leary, 2001; Schaller, 2006).

The affective and cognitive systems to help us avoid parasites, and to which Kurzban and Leary (2001) refer, include (a) the ability to detect correlates of parasite infestation (which are linked to our aesthetic preferences, see *Aesthetics* in section 2.2.4) and to evoke affective responses such as fear and disgust, (b) the desire to avoid physical contact with parasitized others, and (c) a bias towards false positives (i.e. erring on the side of caution in response to detected correlates, even when the risk of infection is uncertain). The avoidance of people with TB is among the indicators of stigma used by other researchers (as described in section 2.2.2), and it is the fear of infection which is, according to a systematic review of the research literature, the most commonly reported 'cause' of TB stigma (Courtright and Turner, 2010).

Whilst the underlying psychological process or internal mechanism is referred to as *parasite* avoidance, the process or mechanism is likely to play a role in our responses to diseases more broadly, including those which are not caused by parasites. For example, our affective responses evoked by a correlate of parasite infestation, such as severe weight loss, may be evoked even when the weight loss is caused by cancer or anorexia nervosa. Furthermore, these cognitive and affective responses may be evoked even in the absence of detectable physical correlates of disease. Just as psychological processes underlying parasite avoidance may have evolved in humans, parasites too evolve and can infect a host without any obvious signs. When there are no or few correlates of parasite infestation (e.g. obvious symptoms, deformities) we have to rely on less reliable symbols. Goffman (1963) argues that the less visible the condition, the more we rely on other signs which are thought to symbolise it, such as group affiliations and behaviours. These *stigma symbols* are based on our knowledge of the condition, beliefs regarding who gets it, and so on. Goffman explains that the meanings inferred from such symbols are variable, vary in reliability and may include those people an individual is with (see section 2.1.4, courtesy or associated stigma). For example, others may conclude that a person has TB because they have been seen at the TB clinic or because a member of their family is known to have TB.

Gangestad, Haselton and Buss (2006) link parasite avoidance with mate preference, stating that we should expect mate preferences amongst humans (and

indeed any pathogen host) to have evolved which discriminate among potential mates on the basis of health, and presenting evidence to indicate that in areas with high parasite prevalence, good health and heredity in a partner is favoured more than in low prevalence contexts. Schaller (2006) draws our attention to the evolutionary concept of 'inclusive fitness', which refers to the idea that our reproductive fitness (i.e. the passing on of our genes) is not just determined by our own individual outcomes, but also the outcomes of those with whom we share genes, such as our children, siblings and other relatives. Both the association of parasite avoidance with mate preference and the concept of inclusive fitness may be important for understanding TB stigma, given that previous studies in Pakistan and Bangladesh have indicated that infection with TB has a negative impact on a person's, and in particular a woman's, marriage prospects, and because marriages in these contexts are often arranged between families (Khan et al., 2006; Khan et al., 2005; Liefoghe et al., 1995; Weiss et al., 2006a; Karim et al., 2011).

As well as having evolved affective and cognitive systems to help us avoid disease, we are also subject to an underlying psychological process or internal mechanism referred to as **dyadic cooperation**. Kurzban and Leary (2001) argue that human beings want to benefit from social relationships, so we avoid those where the cost is greater than the benefit. Those who are not deemed good social exchange partners, such as those who do not reciprocate or cooperate in some way, are avoided, rejected or excluded. They implicate this process of dyadic cooperation in the stigmatisation of people who are mentally ill, homeless or who have committed crime. Later in this thesis I suggest that it is likely to also underlie two of the manifestations of TB stigma identified from the data collected in the five research sites across Bangladesh, Nepal and Pakistan (see sections 6.5 and 7.3).

Whilst parasite avoidance and dyadic cooperation contribute to explaining why those with TB may be avoided, another underlying psychological process can explain why being avoided makes us feel so bad. According to Baumeister and Leary (1995), much of human interpersonal behaviour is driven by a **need to belong** – the desire to form and maintain social bonds. The need to belong manifests itself, they suggest, in our tendency to feel pleasure from social contact and relationships and to experience emotional distress (such as anxiety), and possibly ill-health, when deprived of, or anticipating the loss of, social contact or relationships. Our need to belong may in part explain why people with TB may feel anxious and depressed when they are avoided or excluded and suggests that their emotional response or ability to cope may vary according to whether they still retain

close, caring relationships with others. It may also contribute to explaining, from a psychological perspective, why friends and family may support a person with TB despite a perceived risk of infection to themselves and why someone may feel reluctant or unable to openly counter attitudes or behaviours of which they do not approve – because of the fear that confronting a group or individual with whom one has a relationship may threaten that relationship.

Exploitation and domination, as referred to by Phelan et al. (2008), or coalitional exploitation, as referred to by Kurzban and Leary (2001) is based on the premise that we cooperate within groups, but compete between groups. Kurzban and Leary (2001) argue that as a sociable cooperative species we have specific adaptations that cause both the desire to belong to groups, and, under certain conditions, the desire to systematically exclude and exploit members of other social groups. This, they claim, is the basis for certain instances of stigmatisation characterised by out-group discrimination and exploitation, and so is most likely to underlie stigmas associated with race, caste, religion and nationality – what Goffman (1963) refers to as “tribal stigma” (p14).

According to Phelan et al. (2008), those who deviate from social norms in a way that is deemed to be voluntary may experience stigma which serves to either make them conform to or to demonstrate to others the boundaries of acceptable behaviour. This process they refer to as **norm enforcement**. They relate norm enforcement-based stigma, which parallels Goffman’s (1963) “blemishes of individual character” (p14), to homosexuality (if deemed voluntary), crime, substance abuse, smoking and obesity.

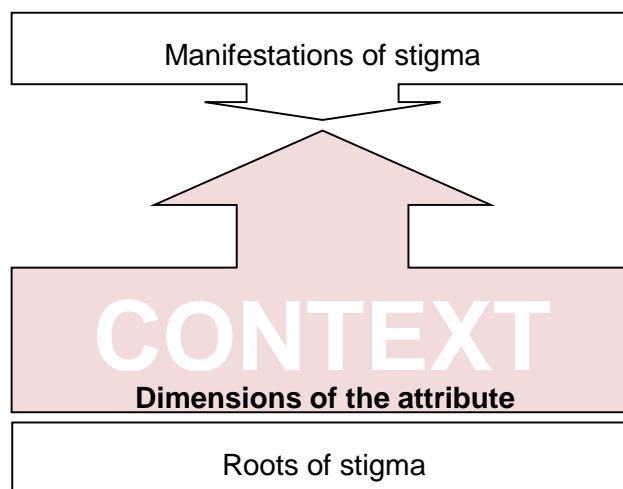
Although it may be more obvious how the processes of parasite avoidance, dyadic cooperation and the need to belong may underlie TB stigma, the processes of exploitation and domination and of norm enforcement are not to be disregarded. Attributes associated with stigma are not always distinct and so the stigmas associated with them can become entangled. For example, in a qualitative study on TB stigma in Nepal, Baral et al. (2007) reported perceived links between TB and other causes of discrimination, in particular poverty and low caste. In areas with high prevalence of HIV and TB co-infection, the stigma associated with HIV is thought to have contributed to the stigmatisation of TB (Courtright and Turner, 2010). Smoking, which Phelan et al. (2008) relate to norm enforcement-based stigma, has been shown to be a risk factor for TB infection and TB disease (Bates

et al., 2007) and, as with TB's association with poverty and low caste, has been implicated as contributing to TB stigma in Nepal (Baral et al., 2007).

2.2.4 Dimensions of stigma

The underlying psychological processes or internal mechanisms described above may make disease-related stigma universal and ever-present, but not all diseases are associated with stigma all of the time, everywhere, in the same way. Not even life-threatening diseases, which Crandall, Glor and Britt (1997) describe as inherently stigmatising, are considered to carry a stigma by all people. Although TB kills 1.3 million people worldwide (WHO, 2013c), when I have told people in the UK the topic of my PhD, a common response from those not working in the field of international or public health, has been surprise that TB stigma exists at all. Whilst the underlying psychological processes in which stigma is rooted are important, they do not fully explain why manifestations of TB-related stigma exist in one context but not in another.

To understand why TB is associated with a manifestation of stigma in one context but not another, or why the manifestation differs in degree or form in different contexts, we need to consider both the attribute (TB) and its context. By focussing on what lies between a manifestation of stigma and its deeply-rooted underlying psychological processes (its roots), we can begin the process of developing explanatory theories which bridge the two. In this and the following two sections (2.2.4-2.2.6) I consider what others have suggested lies in the shaded area between stigma's manifestations and its roots.



Goffman (1963) did not view any attribute as inherently stigmatising and described a number of important factors that influence whether a person with a particular attribute becomes stigmatised. These include the evidentness of the attribute (which he also refers to as visibility and perceptibility), its known-about-ness, its obtrusiveness and its perceived focus. Jones et al. (1984) describe these as dimensions of stigma and expand upon them to include aesthetic qualities, concealability, disruptiveness, origin, course and peril. For different attributes or in different contexts, different dimensions may be more or less important or may be important in different ways.

I will give an overview of each of the dimensions proposed by Jones et al., grouping them into three: i) origin, course and peril, ii) evidentness and disruptiveness, and iii) aesthetics. In the process, I will consider how the dimensions could relate to stigma manifestations associated with TB.

i. Origin, course and peril

Three of the dimensions relate to the characteristics of the stigmatised attribute, such as TB, itself. The first of these, *origin*, refers to how the attribute was acquired and who was responsible. Dijker and Koomen (2006) argue that if a person acquires an attribute, such as a disease, due to their own, controllable behaviour it arouses anger in others, whereas if it is deemed uncontrollable it arouses mostly fear and pity. The second dimension, *course*, refers to the way the attribute is perceived to change over time and its perceived ultimate outcome. As previously mentioned, Crandall, Glor and Britt (1997) claim that life-threatening illnesses (i.e. illnesses which become more severe over time and result in death) are inherently stigmatising. The third dimension is *peril* and refers to the perceived type and degree of danger posed to others by the attribute.

Fear, relating to the dimensions of peril and origin, has been widely implicated as a 'cause' of the stigma associated with TB. A systematic review of the literature on TB stigma found that most authors identify the perceived infectiousness of TB, and the fear it arouses, as a leading 'cause' of TB stigma (Courtright and Turner, 2010). If interventions are to be developed to address the causes of stigma, then identifying fear of infection as a cause gives very little guidance on what kind of intervention to develop. A leap is required, and any intervention will inevitably be based on assumptions about what generates fear. Dodor et al. (2008), who implicate fear of infection as a cause of TB stigma in Ghana, propose addressing stigma by

involving community members in the provision of care for people with TB, thereby reducing the myths and misconceptions surrounding TB. This assumes that fear (and by implication, stigma) is driven by myths and misconceptions (or ignorance). As discussed in section 2.1.2, we should be cautious of such an assumption.

Pawson and Tilley (1997), whose realist conceptualisation of causality in the social world I have used for this study and describe in section 2.2.1, view an outcome as a result of a combination of a mechanism and the context in which it becomes generative. If stigma is viewed as the outcome and the fear of infection as the mechanism leading, in certain contexts, to this outcome, then an intervention addressing the fear of infection would be addressing a mechanism. However, if an intervention is seeking to address the mechanism, then the mechanism by definition becomes the outcome. To then change the outcome (i.e. reduce fear of infection) an intervention based on an explicit theory of the mechanisms and contexts which generate fear of infection is needed. Whilst not presented in this way, Dodor et al.'s findings do support a theory that the separation of TB services from general services fuels fear and so they advocate complete integration of TB services into the general health care system (Dodor et al., 2008). If they had viewed the fear of infection as a manifestation of stigma (an outcome) rather than as its cause, then they might have investigated and described in more detail how the separation of services increases fear, for whom and in what circumstances. This would then provide a useful theoretical basis upon which to make decisions about whether to or how to integrate services. In the process of identifying TB stigma manifestations from the data collected for this study, fear of infection was certainly a potential candidate. However, fear and behaviours attributed to fear were not consistently spoken of as negative by research participants in this study and so did not sufficiently fit my definition of a TB stigma manifestation. Whilst dimensions such as origin and peril both relate to fear of infection and contribute to the explanatory theory I have presented in Chapter 7, fear of infection is not in and of itself a cause of TB stigma.

ii. Disruptiveness and evidentness

Unlike origin, course and peril, the dimensions of disruptiveness and evidentness focus not so much on the characteristics of the attribute (or knowledge, attitudes and perceptions of the attribute), but more on the wider impact of the attribute and how easily (if at all) it can be concealed.

Jones et al.'s dimension of disruptiveness is essentially the same as Goffman's obtrusiveness and refers to how much an attribute or condition interferes with 'normal' life and social interactions (Goffman, 1963; Jones et al., 1984). Whilst the examples Goffman gives refer to the direct impact of an attribute, such as a physical disability, on 'normal' life and social interactions, the dimension can also be used more broadly with regards to TB to include the indirect impact or disruptiveness of TB treatment. For example, a person with TB who has to travel far, take time off work (whether paid employment or household chores) or find childcare to attend a clinic daily for directly observed treatment (as was the case for many of the participants at the time of data collection) is likely to find his or her condition highly disruptive, regardless of whether the TB itself presents physical symptoms or impairment.

A study by Somma et al. (2008) which measured TB stigma and looked at its socio-cultural determinants in four countries, including Bangladesh, found that in Bangladesh stigma was associated with younger age and being female, but also with physical weakness (linked with the inability to work) and financial stress. They found no association of stigma with any particular perceived causes of TB, such as contamination, smoking or sin/fate, suggesting that *origin* may be less important than *disruptiveness* to understanding TB-related stigma in this context.

Evidentness (Goffman, 1963) and concealibility (Jones et al., 1984) refer to how detectable the attribute is and how much control the person with the attribute has over revealing and concealing it. A person's TB status may be very evident because he or she has disclosed it. However, if the stigmatised attribute is not itself evident, then other more evident signs are used as indicators of the existence of the attribute (Goffman, 1963), such as seeing the person walk into a TB clinic or cough persistently. These indicators are subject to varying interpretations and vary in their reliability. The issue of evidentness also relates to Goffman's "known-about-ness". Even if a person's past or present TB status is not evident, it may be known about through disclosure and gossip. As stated in section 2.2.2, the desire to conceal a TB diagnosis has been identified in previous stigma research and featured as a prominent theme in this study (see section 6.4).

iii. Aesthetics

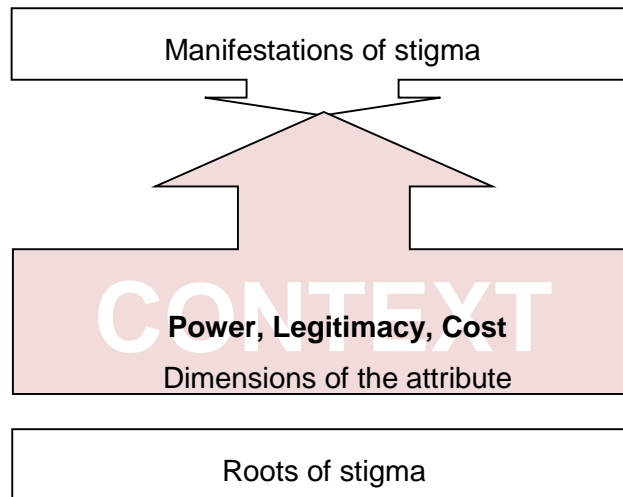
Kurzban and Leary's claim that we have evolved ways of detecting and responding to correlates of parasite infestation (Kurzban and Leary, 2001) is consistent with the

idea put forward by Jones et al. (1984) that stigma relates to the aesthetic qualities of a condition. Aesthetic preferences parallel, to some extent, correlates of parasite infestation or disease. In other words, signs of good health are generally considered to be beautiful and signs of poor health (or disability or deformity) are considered ugly and may evoke emotions such as disgust and fear. Indeed, a study conducted across four countries and an international airport found that signs of ill health, such as sweat, spittle, vomit and blood, evoke disgust, as do people perceived to be in poor health (Curtis and Biran, 2001). In relation to pulmonary TB, symptoms such as coughing, sweating and weight loss may evoke affective responses such as disgust and fear. *If* these affective responses are considered to be manifestations of TB stigma, then as symptoms change or treated TB becomes asymptomatic, the stigma manifestation may change too, highlighting the need to consider manifestations of TB stigma as fluid rather than static. As the attribute and its context change, so does stigma.

The dimensions which Goffman (1963) and Jones et al. (1984) outlined are useful additions to a conceptual model of stigma causality because they include, but crucially are not limited to, perceptions and understandings of the stigmatised attribute. They encourage consideration not only of the varied and context-dependent characteristics of the attribute, but of its impact and evidentness as well.

2.2.5 Power, legitimacy and cost

Although those who have conceptualised stigma as a process emphasise the central role of power and legitimacy, I chose not to include either as criteria for identifying manifestations of stigma in the definition I developed for this study, and which I have presented in section 2.1.5. As a result the criticism, put forward by Link and Phelan (2001), that the stigma concept is “too vaguely defined and individually focussed” (p363) is certainly true of my definition, but this is because it is a definition of TB stigma *manifestations* and has been kept *intentionally* vague, or rather broad and inclusive, to guide rather than dictate the focus of the research. The individual focus of the definition is balanced by the inclusion of power and legitimacy at the centre of my conceptual model of stigma causality.



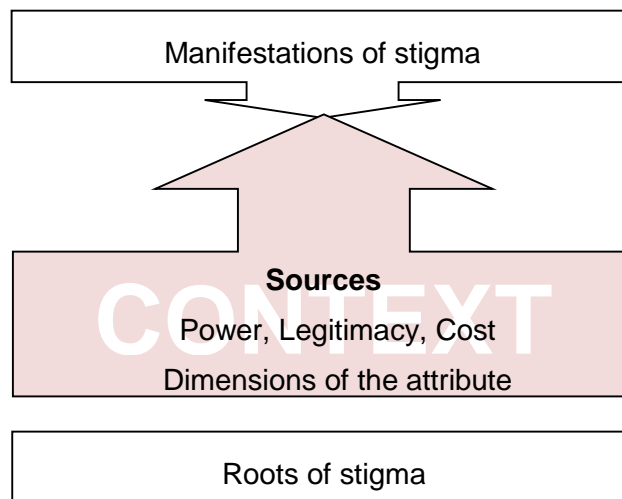
Leary (2001) argues that stigma involves a person being devalued (or devaluing themselves) on the basis of his/her possession of an attribute or attributes that are “consensually regarded as legitimate criteria for rejection” (p7). This emphasis on consensus and legitimacy serves to distinguish stigma from that which is idiosyncratic, such as one individual’s negative views or avoidance of people who are tall, work in accountancy or wear yellow coloured clothing. The addition of legitimacy to the conceptual model of stigma causality is therefore useful as it distinguishes that which National TB Control Programmes can justifiably take measures to address, and that which is too idiosyncratic to warrant attention above or beyond an individual or interpersonal level.

Related to legitimacy is the notion of power. Link and Phelan point out that stigma is dependent on social, economic, and political power and that it takes power to stigmatise (Link and Phelan, 2001). It also takes power to elude stigma. As Crocker et al. (1998) point out, being in a position of power decreases one’s vulnerability to being stigmatised, and this may be because stigmatising a person in a position of power (whatever that may be) incurs a cost. For example, avoiding a person with infectious TB (if that is what is deemed to constitute stigmatising) has the benefit of reducing the risk of transmission, but, if that person is your employer, has the potential cost of your losing your job. The notion of cost as a constraint to stigma may not always be so obviously related to power. Dissolving a planned marriage because you discover your prospective spouse has TB comes at a cost if there is emotional attachment or if your chances of finding another are small. Whilst the notion of power may provide the necessary conditions for stigma to manifest and may determine its legitimacy, to fully understand for whom and in what circumstances TB stigma manifests, it is also useful to consider the costs of, or constraints to, manifestations of TB stigma.

With reference to the psychological processes underlying parasite avoidance and which play a role in disease-related stigma, Schaller and Duncan (2007) point out that where cues in the environment indicate that the functional benefits of aversive responses towards a potentially infected person outweigh the functional costs, the manifestation of aversive responses is most likely. They speculate that a high perceived vulnerability to infectious disease is likely to increase the perceived functional benefits of aversive responses over any potential costs, but that the costs may not only be resource-related (Schaller and Duncan, 2007). Valued cultural concepts and expectations such as generosity, love and what it *means* to be a good husband, wife, parent or friend may be challenged by aversive responses and the cost of this may be considered too great. In an ethnographic study on the conceptualisation of TB in the Philippines, Nichter (1994) states that “debts of gratitude and the norms of reciprocal exchange as well as Christian charity and compassion took precedence over fears of physical risk” (p655).

2.2.6 Sources of stigma

Terms such as iatrogenic, institutional and even vicarious stigma suggest where to look for the causes of stigma, but do not in themselves fully explain what the causes are. I have therefore included them in the model as ‘sources’ of stigma.



Iatrogenic stigma is a term used for the stigma promoted or created through health education and medical interventions and services (Royal Tropical Institute (KIT), 2004). Examples of what has been referred to as iatrogenic stigma include the separation in Ghana of TB services from general health care services, identified by Dodor et al. (2008), or the poor circulation of information from the TB control programme in Nicaragua and the implicit information gleaned from the way in which

care pathways for patients with TB are organised (Macq et al., 2005). Macq et al. (2005) also identified as an iatrogenic source of TB stigma in Nicaragua the domination of health personnel over patients with TB because of their low social status, and the domination of other health personnel over the often less qualified TB health personnel, highlighting the central role of power relations and the structures which promote these in understandings of TB stigma. Indeed Coreil et al. (2010) refer to these as structural sources of stigma, where services, institutions, government policies and political-economic contexts underpin the phenomenon. Hatzenbuehler and Link (2014) add to this cultural norms in their definition of structural stigma. Similarly, structural discrimination or institutional stigma refer to the accumulated institutional practices and the social and physical organisation of an institution that works to the disadvantage of people with TB even in the absence of individual prejudice or discrimination (Link and Phelan, 2001).

With reference to HIV, Steward et al. (2008) coin the term 'vicarious stigma' to refer to the transmission of information about enacted (or experienced or perceived) stigma: in other words the stories people hear about others being mistreated because of their HIV (or TB) infection which then fuels anticipated stigma. In Chapter 6 of this thesis, I discuss how most of those interviewed anticipated that an unmarried woman would have problems getting married following a TB diagnosis, although many did not personally know of a woman who had had such problems. This may be an example of vicarious stigma, where stories about such cases are spread and so, although rare, such experiences are widely known about and therefore anticipated. However, although this may be a potential and plausible source, based on the data generated from this research I propose in Chapter 6 an alternative.

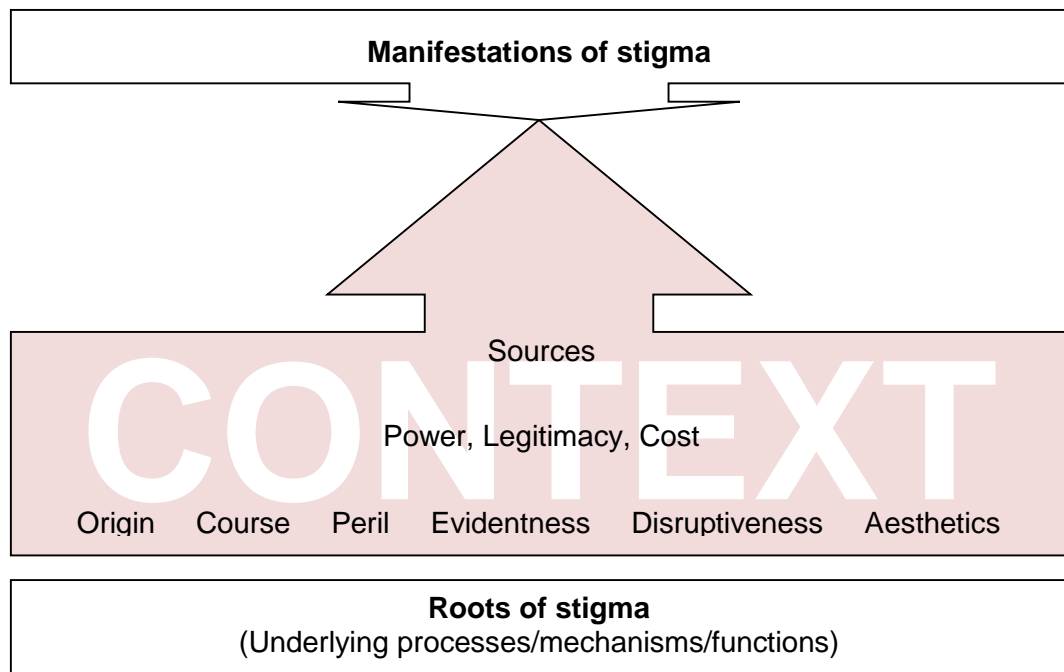
Sources of stigma, be they iatrogenic, institutional, vicarious or otherwise, point to the contextual factors which influence both the dimensions of a stigma-related attribute (see 2.2.4) and the power and legitimacy which distinguish stigma from idiosyncrasy (see 2.2.5). For example, in their paper on structural forces and the production of TB-related stigma amongst Haitian populations, Coreil et al. (2010) point towards the location of TB clinics in the same building as HIV and sexually transmitted disease services in south Florida, and, the clinic staff in a hospital in Haiti announcing in the general waiting area that all people with TB should come forward. Whilst the former may impact on the dimensions (described in section 2.2.4) of origin, course and peril, the latter impacts on the dimension of evidentness.

The advantage of investigating sources of stigma is that it provides guidance on where to focus interventions and so can better inform interventions. Exploring the dimensions of stigma alone requires a greater leap to be made between research findings and proposed interventions, with the temptation to simply address dimensions such as *course* (e.g. the belief that TB is fatal) through health education targeted at the individual and community levels (e.g. with messages such as 'TB is curable'). By focussing on sources, rather than just on dimensions of stigma, institutions, social structures and political-economic contexts are given greater consideration.

2.2.7 My conceptual model of stigma causality

Over the course of the previous five sections (2.2.2 to 2.2.6) I have built a conceptual model of stigma causality and present it in full in Figure 2 below.

Figure 2 Conceptual model of stigma causality



The manifestations of stigma are the anticipated, perceived, internalised and/or intended *negative* attitudes, emotions or behaviours relating to those infected with or suspected to be infected with TB and potentially others with whom they are

associated. The manifestations are presented in an arrow pointing downward to indicate that the manifestations themselves may form part of the explanatory theories, with manifestations of stigma potentially perpetuating the anticipation of stigma.

At the base of the model are the roots of stigma, the underlying psychological processes described in section 2.2.3. These deeply rooted psychological processes do not, on their own, fully explain manifestations of TB stigma, and acknowledging them does not mean accepting that TB stigma manifestations are inevitable and fixed. After all, the affective and cognitive systems which constitute an underlying psychological process do not operate in a vacuum and sometimes conflict with other deeply rooted psychological processes or are overridden or suppressed by social norms, values and structures. Acknowledging these processes does, however, contribute to a fuller understanding of why TB stigma exists, as it prompts us to ask not just 'How, for whom and in what circumstances does stigma manifest?', but also, if stigma is rooted in our psyches, 'How, for whom and in what circumstances does stigma then *not* manifest?'. In Chapter 7, asking the latter question was particularly useful for identifying opportunities for addressing the perception that people with TB are hated.

Positioned in the shaded central area of the model are the explanatory theories which I have presented in Chapters 6-8 and which were developed through a process, described in Chapters 3-5, of data collection and analysis based on the grounded theory approach. I have included the word 'context' in large capital letters behind the dimensions of the stigmatised attribute (origin, course, peril, evidentness, disruptiveness and aesthetics), power, legitimacy and cost, and sources, as contextualising these is essential to understanding stigma causality. Whilst there are no fixed formulas as to the forms that the dimensions of the stigmatised attribute need to take, and their relative importance for disease-related stigmas, they are nevertheless useful. They provide a framework for thinking about the mechanisms and contexts of stigma; and because there are multiple dimensions, they encourage us to look beyond simplistic explanations for stigma relating to just one. Kurzban and Leary (2001) argue that the dimensional accounts of stigmatisation "may be best thought of as micro-theories that apply to specific stigmatizing conditions under particular circumstances" (p190). By considering dimensions alongside the underlying psychological processes (or roots) and the notions of power and legitimacy, and by doing so in relation to data collected in both

rural and urban sites across three different countries, more comprehensive and useful middle-range theories can be developed.

2.3 Summary

A research study investigating the causes of TB-related stigma requires at the outset a consideration of how stigma and causality are conceptualised. In this chapter I have considered the multiple ways in which stigma has been defined before developing a broad definition of stigma manifestations which incorporates elements of these existing definitions and is tailored to tuberculosis. Throughout the data collection and analysis process, the definition served as a guide to the Bangladeshi, Nepali and Pakistani research teams and myself, as to what might potentially be a TB stigma manifestation, allowing the research participants themselves to ultimately determine what is.

Whilst the definition served to guide the identification of that for which explanatory theories were to be developed, the development of the explanatory theories was aided by the conceptual model of stigma causality presented in section 2.2. The conceptual model is based on a realist conceptualisation of causality and links a micro-social perspective on what constitutes stigma as a manifestation with a macro-social perspective on stigma as a contextualised, relational process. Furthermore, it links both these perspectives with an evolutionary or functional perspective on the roots of stigma.

Chapter 3 PREPARATION

Having developed a definition of TB stigma manifestations which would guide the research, I met with the research teams and grant co-applicants in Islamabad, Pakistan, for a three day workshop. This chapter describes the workshop (3.1) and the subsequent period of preparation which preceded the start of formal data collection. The preparation included the selection of urban and rural sites for inclusion in the study (3.2), visits to these sites and the application of rapid appraisal techniques (3.3) and the facilitation of preparatory focus group discussions (3.4). During this time I visited each of the research teams in their respective countries to provide tailored training and support.

3.1 Workshop

The definition of TB stigma developed to guide this study and the conceptual model of stigma causality presented in Chapter 2 were presented and discussed at a three-day workshop in Islamabad held in October 2007. The research partners from all three countries attended, as did James Newell, my PhD supervisor.



TB stigma study workshop, 27th-29th October 2007
Islamabad, Pakistan

The aims of the workshop were to cultivate a common way of thinking about the topic of research and a common understanding of the research process; to identify training, support and resource needs; and to plan and prepare for the next stage of the research process. It was an opportunity for me to meet the researchers from

Pakistan and Nepal who would be most involved in data collection, but also to ensure their direct managers, who were also present, appreciated the research process and likely workload involved, and for us all to agree upon roles, responsibilities and lines of communication. As researchers for this study had yet to be recruited by the National TB Control Programme of Bangladesh, only the study administrator from Bangladesh attended the workshop.

3.2 Site selection

Following the workshop in Islamabad, research partners were asked to identify up to two geographical starting points from which to conduct the research. Whilst in Bangladesh a rural and an urban site were selected, the research was only conducted in the rural site due to delays in the recruitment of local researchers and the ill health of one of the local researchers recruited.

Heterogeneity of sites and populations within sites was sought to enable the potential sampling of participants with different backgrounds and lifestyles for the purpose of comparative analysis. As well as heterogeneity, factors considered in the selection of sites were the prevalence of TB (and therefore the likelihood of being able to recruit people with TB for the interviews), accessibility of the area (in terms of distance, transport infrastructure and facilities, and safety and security) and the language spoken in the area (which was to be the same as the language of the researchers). The exact geographical boundaries of the sites were not specified from the outset, as the availability and ease of recruiting research participants would determine these.

In Bangladesh the rural site selected as a geographical starting point for collecting data was West Shilmandi village in Norshingdi district in central Bangladesh. Being situated 50 kilometres north-east of Dhaka, the village could be relatively easily reached by car. It was also chosen because of the high TB prevalence across the district and because it falls within an area within which BRAC, a national non-governmental organisation and partner of the National TB Control Programme, is active.

In Nepal the urban site selected for the study was Lalitpur. Lalitpur was selected because of its socio-economic diversity and mixed indigenous and migrant

populations, as well as its accessibility. The research team also spoke the predominant language of Lalitpur, namely Nepali, and had good established relationships with the health service providers in the area.

Initially, Kapilvastu district in Nepal's Terai region was selected as the rural site for this study. However, following the first visit to the area, civil unrest prevented further visits. The areas covered by the Godawari and Badikhel Village Development Committees (VDCs) within Lalitpur district were selected as substitutes following discussions with the District TB and Leprosy Office's TB focal person for Lalitpur district. As both these rural areas and the urban area selected fall within the same district, good relationships had already been established with district level health service providers. Though rural, the VDCs are relatively close to the city, making them accessible to the researchers even in the event of any civil unrest.

In Pakistan, two sites in Rawalpindi district, one urban (Sultan Pura) and one rural (Bagga Sheikhan) were selected because of their accessibility and because the area within which both lie was deemed relatively safe and secure.

The map in Figure 3 shows the locations of the districts in which the urban and rural research sites were situated in the three South Asian countries.

Figure 3 Map of South Asia showing the approximate locations of the districts within which the five research sites were located



Source: Wikimedia Commons/By Cacahuate [CC-BY-SA-3.0-2.5-2.0-1.0
(<http://creativecommons.org/licenses/by-sa/3.0/>)]

3.3 Rapid appraisal

After selecting geographical sites from which to begin data collection, the research partners visited each site up to three times in order to familiarise themselves with the locations, using a number of rapid appraisal techniques, including observation, informal discussion and pile-sorting, in an opportunistic and flexible way.

Rapid appraisal techniques were first developed in the late 1970s and early 1980s and were termed Rapid Rural Appraisal (RRA) as they were particularly well-suited to research in rural and non-literate community settings in developing countries. Chambers (1983) makes a useful distinction between appraisal (less formal, briefer)

and research (more formal, takes longer), viewing an appraisal as a useful preliminary to more rigorous and focussed research. Indeed, as a preliminary to research, rapid appraisal techniques can provide a valuable overview and understanding of the context in which the research is to take place and the feasibility of conducting the research.

Whilst all qualitative research methods require a similar set of skills, rapid appraisal techniques in particular demand the researcher to be creative, responsive, opportunistic, flexible and sensitive, as well as to be skilled in observing, listening, learning and determining quickly what information is of relevance to the research study. One way to develop those skills is to put the techniques into practice and to learn from the process. Incorporating rapid appraisal techniques into the preparation stage of the study was intended to contribute to the research teams' capacity development as well as generating information of relevance to the research topic.

I delivered training in rapid appraisal techniques to the researchers from Nepal and Pakistan at the workshop in Islamabad. The researchers in Bangladesh, who were recruited later, received training subsequently during my visit to Bangladesh in March 2008. All research partners were provided with detailed guidelines on the purpose of the rapid appraisal, the techniques available to them, and a possible rapid appraisal scenario. Following each visit to the research sites, the research partners documented the process and what they had learned in a report which they sent to me and to which I gave feedback via phone and email.

Table 1 shows the rapid appraisal techniques employed by the researchers and is followed by descriptive accounts of this preparatory stage of the study for Nepal (section 3.3.1), Pakistan (section 3.3.2) and Bangladesh (section 3.3.3). These accounts do not include the findings of the rapid appraisals as their primary purpose was to 'warm-up' and prepare the research teams prior to data collection proper. However, in Chapter 4 (section 4.1) I explain how some of the learning from the rapid appraisals was reflected in the development of the interview guides.

Table 1 Rapid appraisal techniques used, by country and site

| Bangladesh | Nepal | Pakistan |
|--|--|--|
| <p><i>Rural site</i></p> <ul style="list-style-type: none"> • Observation • Informal conversations with local people and health care providers • Informal group discussions • Free-listing • Ranking (worst illness) • Pair-wise sorting | <p><i>Rural site</i></p> <ul style="list-style-type: none"> • Observation • Discussions with local people and health care providers <p><i>Urban site</i></p> <ul style="list-style-type: none"> • Observation • Informal conversations with local people and health care providers • Free-listing • Pile-sorting | <p><i>Rural site</i></p> <ul style="list-style-type: none"> • Observation • Mapping • Group discussions with local people • Free-listing • Pair-wise sorting • Pile-sorting • Informal conversations with health care providers (key informants) <p><i>Urban site</i></p> <ul style="list-style-type: none"> • Observation • Informal conversations with health care providers • Group discussions with local people • Free-listing • Pair-wise sorting • Pile-sorting • Mapping |

3.3.1 Nepal

The research team's first visit to Godawari and Badikhel focussed on observing the locality. The researchers also delivered a letter to the District Public Health Office (DPHO) requesting support for the research study and received a letter in return, which they could carry with them, stating that the DPHO had given their full support.

During the second visit the researchers visited Badegaun Primary Health Care Centre to inform the centre's staff about the research. Badegaun Primary Health Care Centre is a referral centre for the health posts or practices located in the research site. This was followed by visits to both Godawari and Badikhel sub-health posts to meet the staff, inform them of the research, and to discuss health-seeking and services as well as issues relating to research feasibility and logistics. Whilst the researchers waited for their bus back, three people waiting for the same bus enquired about the purpose of their visit. An informal, opportunistic discussion ensued from which the researchers learned more about the local community. They also learned that a single visit by public transport takes much longer than they had expected and that they would either need to factor extra time into their planning or extra money into their budget for taxis.

During their third visit to the area they discussed local perceptions of TB and stigma with health workers from Godawari and Badikhel sub-health posts. In Badikhel they explained that they would also like to meet some of the people from the community, so were taken to a house where several men and two women were chatting whilst making bamboo handicrafts. The researchers initiated a discussion about health and health-seeking in general and then directed the discussion towards TB. The men spontaneously began discussing the changing concept of TB and so the research team were able to increase their understanding of relevant local terms and concepts. The two women remained silent, just nodding occasionally, probably, according to the researchers, because their father-in-law was present.

As with the rural site, the team's first visit to the urban site focussed on introducing the research project to the District Public Health Office and the District TB and Leprosy Office to gain their support. The lead researcher also spent some time walking around the locality to familiarise herself with its geography and facilities.

During the second visit they met with the District TB and Leprosy Officer again for further discussions and also met those in charge of Kumbheshwor TB Centre, which provides treatment for those with TB, and the TB clinic at Patan Hospital. These discussions focussed on the research aims and procedures, but also health services and seeking and on local perceptions of TB and stigma. After leaving

Kumbheshwor TB centre the researchers saw a group of thirteen people, comprising men and women of a range of ages, sitting in the sun discussing politics. The researchers introduced themselves and asked to join the discussion. Initially the discussion focussed on politics and the weather, but gradually the researchers directed it to the topic of health, asking the group to name all the most common health problems (free listing) and to categorise them as either bad or not bad illnesses (pile sorting). This led to a long discussion about TB.

During the third visit, the researchers visited Kumbheshwor TB centre again, discussing any outstanding issues with the staff. They then sought a group of people with which to initiate discussion and found a group of men sitting together in a tea shop. They requested to join the group and, at an appropriate moment, asked the group about the local community and about illness and health.

The rapid appraisal visits were essential for gaining permission and support for the research and particularly recruitment for the research, and for assessing its feasibility and planning the logistics. However, the research team also learned about the local communities and began exploring issues of relevance to TB and stigma. From the visit reports sent to me it was apparent that the researchers had clearly understood the purpose of and principles behind rapid appraisal, and had been opportunistic, flexible, and reflective, as well as meticulous in their reporting. Whilst they would benefit from further training and support, they clearly already had the approach and skills needed for conducting qualitative research.

3.3.2 Pakistan

The research team in Pakistan visited their urban site twice. They discussed the research with local health service staff, and, with the assistance of a vaccinator, sketched a map of the area and noted down information relating to local facilities and infrastructure. As well as discussing the research and research topic at some length with the vaccinator, the vaccinator also helped organise a group of men and a group of women for two separate discussions. The group discussions included free listing of health problems in the community, matching together similar diseases (pair wise sorting), and categorising them as either bad or not so bad illnesses (pile sorting).

When the research team visited the rural site, as with the urban site, they made contact with the local vaccinator and mapped the area. They also discussed the research, its feasibility and logistics with a dental technician at the rural health centre in Bagga Sheikhan and requested that he assist with gathering community members together for a group discussion. As with the groups in the urban site, the group in the rural site was asked to list the local health problems, compare them and group them into bad and not so bad illnesses.

It was clear from the rapid appraisal reports sent to me by the researchers in Pakistan that the researchers needed support in developing their skills in judging what information is relevant to the topic under investigation and what information is not. This skill is essential to being able to probe or redirect a discussion or conversation appropriately.

One of the reports also stated that the community members with which the team had spoken were mainly interested to know how the study would help them. I therefore thought it useful to remind the researchers of the importance of managing participants' expectations regarding the likely personal benefits of participating in the research, emphasising the need to be upfront and honest.

3.3.3 Bangladesh

The research team in Bangladesh had been recruited after the introductory workshop in Islamabad and had little previous research experience, so I visited Bangladesh to provide some training before the rapid appraisal was to begin. Following three days of research training, we visited the rural site together. We informed the regional health coordinator from BRAC, a national non-governmental organisation, whose remit covered Narshingdi and Manikgonj districts, about our research and he told us about the local area generally as well as more specifically about local health and TB services. The feasibility and logistics of the research were also discussed. He then accompanied us to a nearby village where community members had been summoned. We introduced ourselves to the community members and initiated an informal discussion about the illnesses that they most feared.

The second and third visits were conducted after my departure. During the second visit, the researchers met with local health workers and a *shebika* (a volunteer

health worker) and a discussion was again held with the BRAC regional health coordinator, but this time focussing on local perceptions of TB and stigma. They also visited a woman who had been identified during the first visit as a potential key informant or contact as she appeared to be well known in the community. The feasibility and logistics of the research were discussed and the researchers requested her assistance in gathering together a group of community members for an informal discussion. She was both willing and able to gather together a mixed group of people at the premises of the local primary school. Following a general discussion about farming, the group were asked to name the most common health problems in their community (free listing). They were then asked to rank the problems from most feared to least feared, followed by a more detailed discussion about TB in particular.

After considering what further information they needed, the researchers returned to the village a third time and spoke with the same people (the BRAC regional health coordinator and the female key informant/contact) to collect any missing information and to request another informal group discussion. The group discussion had a similar format to that held during the second visit, but included, as an addition, pair-wise ranking. This involved the research team selecting three health problems mentioned by the group and asking the group to identify the two which are most similar, giving the reasons why. This generated additional information regarding perceptions of TB.

3.4 Training visits and preparatory focus groups

Following the rapid appraisal, focus group discussions were conducted in each country to explore local terms and concepts relating to TB and stigma. These focus groups were not transcribed and their analysis is not presented in this thesis. Their purpose was to inform the development of the in-depth interview guides and to provide an opportunity for the research teams to develop their moderating, note-taking and critical reflection skills, and to test the digital recorders prior to beginning data collection.

The focus group discussion guides were developed collaboratively with the research teams and I planned visits to each country to coincide with these preparatory focus groups. During these visits I provided tailored training to the research partners which included ethical research conduct, and observed and gave

feedback on at least one preparatory focus group discussion per country. The visits allowed me to get to know the research teams better and to experience firsthand the contexts in which they would be working.

I visited Bangladesh first (3-7 Feb, 2008), spending three full days briefing the newly recruited researcher for the stigma study and introducing myself and the research project to key people at the National TB Control Programme. I found I was often asked questions about the methodology and sample size, especially by those less familiar with qualitative research. Realising that the research teams may be asked similar questions in my absence, I put together a “Frequently asked questions” document regarding the methodology for reference for the research teams, so that, if asked questions, they would be equipped to answer convincingly and consistently.

I then flew to Nepal and spent four days working with the researchers to prepare for and conduct preparatory focus group discussions. This was followed by a more formal three-day workshop on qualitative research methods, attended by the research team, their colleagues at the Health Research and Social Development Forum (HERD) as well as staff of the National TB Centre and World Health Organisation (WHO) office. From the preparatory focus group I observed in Nepal we realised that recruitment of research participants would need to be done via a variety of means, as it transpired that a focus group of ‘ordinary community members’ arranged by a health worker was almost entirely comprised of TB volunteers. It also became clear that when planning the research, the severe fuel shortages and power cuts, as well as the upcoming elections, would need to be taken into account.



Preparatory focus group discussion, Nepal

I then returned to Bangladesh on 16 February, by which time a second researcher had been recruited. I spent six days working with the two researchers to introduce them to the study, to provide them with training and to support them with the rapid appraisal and preparatory focus groups.

My trip to Pakistan was delayed until April 2008 because of security concerns in the run up to the elections. During my visit I provided training and support over four days and observed two preparatory focus group discussions. This proved useful as we could address and discuss issues as they arose. For example, I observed the researchers turn the digital recorder on prior to asking for consent as, in the absence of written consent, they felt verbal consent needed to be recorded. I reassured them that this was not necessary, and that our priority was to conduct research ethically rather than to prove we have, especially if the means of obtaining such proof is unethical. I also suggested that, if they felt it important, they could ask for permission to record first, turn the digital recorder on and then request verbal confirmation that permission had been granted.

3.5 Summary

In preparation for data collection and following a workshop held in Islamabad, the research partners selected and visited five research sites across the three countries. During the visits contextual information for the planning of the study was collected through the use of rapid appraisal techniques followed by preparatory focus group discussions. During this time I visited each of the research teams to

provide tailored training and support. These visits enabled me to build rapport with the research teams and to experience first-hand the contexts in which they would be working. As well as providing time to plan and clarify roles, responsibilities and lines of communication, this preparation stage enabled the research teams to gain experience and develop skills in conducting qualitative research in advance of the core stages of data collection outlined in the next two chapters.

Chapter 4

DISCOVERING THEORY

Following the preparation stage, the core stages of data collection and analysis began. In this chapter I outline how the development of the interview guides was informed by the literature review described in Chapter 2 and the preparation stage of the research described in Chapter 3. I then outline how the interviews were conducted and analysed, before providing a detailed description of the sampling process, which both informed and was informed by the development of emergent explanatory theories.

4.1 Qualitative interviews

The individual semi-structured interview is a commonly used method for obtaining in-depth qualitative data and is particularly well suited to exploring an individual's personal experiences and perceptions (Patton, 1980). Particularly for a potentially sensitive topic, such as stigma, research participants are likely to feel more comfortable speaking personally and openly in the privacy of a confidential one-to-one interview than they would in a group setting (Lewis, 2003).

The research teams and I set out to conduct up to 16 interviews per site with people with TB, family members of people with TB and health care providers. I chose these three broad categories of participant as all would be able to speak of their experiences of TB, whether those experiences were of having TB, knowing someone with TB, or providing care to someone with TB. If TB stigma exists, then personal experiences of TB can be expected to reveal its manifestations.

4.2 Development of interview guides

Three separate interview guides were developed, one for each of the three broad categories of participant. In chapter 2 I considered how stigma has been conceptualised and found that definitions are variable and often vague. The interview guides therefore intentionally did not contain the word stigma, but instead focussed on encouraging participants to talk about their experiences of TB. The broad and inclusive definition I developed and presented in section 2.1.5 primarily

guided analysis and the later identification from the data of manifestations of TB stigma which are locally relevant.

4.2.1 Interview guide for people with TB

In the interviews with people with TB we primarily sought to encourage them to describe their personal experiences of TB from first symptoms or suspicions onwards. The same interview guide was used across all five sites and contained a series of general questions, such as *How has your life changed since you got TB?* (see Appendix A). Each general question was followed by suggestions for probing.

At the bottom of the interview guide I included a box containing a list of things for the researchers to have in mind during the interviewing process, to help them interpret, analyse and probe. The content of the box was informed by the literature review, discussions with the research teams, the rapid appraisal and the preparatory focus group discussions. Whilst most of the content of the box was the same for all three countries, some of it was country-specific and had been included as a result of ideas or questions which had arisen from the rapid appraisal and preparatory focus group discussions. In many ways these differences represent the beginnings of theory development. For example, the box at the end of the Bangladeshi interview guide reminded the researchers in Bangladesh to always have in the back of their minds the possibility that TB may be associated with inner weakness. The preparatory focus group discussions had explored perceived causes of TB, and two of those mentioned were addictive substances (such as tobacco) and “inner weakness”. I wondered whether “inner weakness” referred to physical vulnerability and whether this is thought to be exacerbated by addictive substances, or whether “inner weakness” and addiction had any moral connotations relating to personal weakness or weakness of character. Whilst the subsequently collected interview data did not adequately answer this question, the data from Nepal, which was greater in both quantity and quality and explored susceptibility to TB, did enable me to develop a theoretical understanding of the attribution of blame as a TB stigma manifestation (see Chapter 8).

For all three countries the boxes contained reminders to consider socio-demographic factors, such as social status, educational level, age and gender, and, related to these, social expectations and roles, and position and status within the family or household. As I was interested in understanding how TB and stigma are conceptualised, I was keen for the researchers to be alert to use of language and

semantics and the perceived stages or even types of TB, as well as to take note of and probe for comparisons with other illnesses. Also, to understand the longevity of any TB-related stigma, I wanted the researchers to be sensitive to experiences of TB changing over time.

4.2.2 Interview guide for health care providers

Health care providers were interviewed for their vast experience of meeting and talking with patients with TB and to explore whether health care providers and health services generate or promote stigma in some way (known as iatrogenic stigma) or whether health care providers themselves experience stigma because of their association with TB. As stated in Chapter 2 (section 2.1.4) this is known as courtesy stigma (Goffman, 1963) or associated stigma (Holzemer et al., 2007).

As with the interview guides for participants with TB, the guide for health care providers comprised a series of main questions followed by suggested probes (see Appendix B). The questions sought to explore the nature of the health care providers' roles; the terms they use for TB; their thoughts on how people experience TB and the impact it has; their views on the reasons for delayed treatment seeking and non-adherence to treatment; their own fear of TB and that of their family and friends; and their ideas for improving the experiences of people with TB.

Health care providers were asked when they use the term "TB" and when they use an equivalent local term, such as *chhayarog* in Nepali, *jokhka* in Bengali, *tapedik* in Urdu and *sokhma* in Punjabi). However, all other questions in the guide were identical across the three countries.

As it was anticipated that health care providers may be reluctant to share their own personal fears, the interview guide included a question beginning with an interviewer confession, to reassure the participants that it is ok to admit to feeling things one thinks one should not, as a professional, feel: *Sometimes we instinctively feel things, even if our jobs or heads tell us not to. After all we're only human. As a researcher I know I mustn't show fear of catching TB, but deep down sometimes I fear anyway. It must be the same for you.* Phrasing the 'question' in this way proved effective both for eliciting discussions on fear during the interviews and for encouraging the researchers to reflect on their own fears prior to the

interviews. Indeed, prior to the interviews, during my visits to the three research teams, I encouraged discussions about personal experiences and perspectives on TB and stigma, both to nurture empathy and reflexivity and to provide springboards for theorising. Glaser and Strauss (Glaser and Strauss, 1967) point out that “the researcher can get – and cultivate – crucial insights not only during his research (and from his research), but from his own personal experiences prior to or outside it”, and go on to suggest we look at personal experiences as “springboards to systematic theorizing” (p252).

Initially health professionals working in clinics were invited to be interviewed and so the guide was developed with such people in mind. It was later adapted slightly for interviews with community-based TB volunteers in Nepal and with volunteer health workers (*shebikas*) in Bangladesh.

4.2.3 Interview guide for family members of people with TB

For the interviews with family members of people with TB, the vignette technique was used (see Appendix C). Although family members were recruited via those with TB, there was still a chance that they might not be aware or fully aware of the medical condition of their relative. The vignette allowed the participants to respond to questions about a realistic but fictional scenario, drawing from their own experiences, but without the obligation to speak directly about their personal experiences if they did not want to do so. This way it was left to the participant, and not the researcher, to disclose that their relative has TB. The nature and strengths of the vignette technique are discussed in more detail in the next chapter on focus group discussions (see section 5.2).

In this study, the vignette technique was first used in Nepal for an interview with a mother of a person with TB and then applied to the other two countries. This staggered approach to data collection across the three countries, whilst not intentional, had the advantage that the research teams in Pakistan and Bangladesh could gain foresight from the lessons learned in Nepal. In this way, I knew the interview guide ‘worked’, but also could share with the other research teams that, from the experience of the Nepali researchers, it needed to be used particularly flexibly as the family members usually preferred to speak about their own personal situation and experiences rather than respond to the vignette, and that this should be welcomed rather than seen as a problem. By the third interview conducted with a family member of a person with TB in Pakistan, it became apparent that the

interview guide assumed the participants had just one family member with TB, whereas in reality they may have several, and indeed may have had TB themselves in the past. Whilst the guide did not need to be changed, it was useful to alert the researchers across all three countries of this probability and to advise them on how consequently to probe.

4.3 Sample size and strategy

In total, 73 interviews were conducted across the five study sites. Each interview's audio-recording and transcript was given a unique name comprising the first letter of the country in which it was conducted, followed by either an 'r' or 'u', according to whether it was conducted in a rural or urban site, and a number.

Whilst three broad categories of participant were decided upon in advance (people with TB, family members of people with TB, and health care providers), this was with the proviso that we would exercise flexibility if someone outside these categories was identified as having the potential to contribute significantly to the study. For example, part-way through the interview stage I requested that the research team in Nepal interview one or two people with past TB to gain greater insights into the longevity of TB's impact and perceptions of susceptibility to TB.

Table 2 below shows how many interviews were conducted, in each site, with participants from each of three broad categories.

Table 2 Number of interviews conducted, by country, site and category

| | Nepal | | Pakistan | | Bangladesh | Total |
|--------------------------------------|-----------|-----------|-----------|-----------|------------|--------------|
| | Urban | Rural | Urban | Rural | Rural | |
| People with TB (Current and past) | 10 | 10 | 10 | 8* | 10 | 48 |
| Family members | 4 | 4 | 4 | 3 | - | 15 |
| Health care providers | 2 | 2 | 2 | 2 | 2 | 10 |
| Total | 16 | 16 | 16 | 13 | 12 | 73 |

* Two additional interviews were conducted with people with TB in Pakistan's rural site, but were not transcribed/translated and so have not been included in this thesis. The research team in Pakistan did, however, make notes on the themes which emerged from the two interviews, and these were included in the report to the funder, ESRC-DFID.

Research participants were initially identified and recruited with the assistance of gatekeepers (usually health workers) identified during the initial rapid appraisal process, and, as the research progressed, research participants themselves became active in identifying other potential participants. As, following the principle of theoretical sampling, the analysis of interview data informed the subsequent sampling criteria, having multiple people assist with identifying and recruiting potential research participants increased the chances of achieving the inclusion of participants with the desired characteristics. Furthermore, the importance of recruiting participants in a range of ways or through a range of people was identified as being important during preparatory focus group discussions, where a TB clinic nurse recruited 'general members of the community' entirely from a committee of TB volunteers (as mentioned in section 3.4).

Each interview took approximately 45-60 minutes and was conducted at a venue convenient to the participant. In all but two cases (pr4 and pu12), the sex of the interviewer and interviewee were matched. The two exceptions were interviews in Pakistan with men with TB conducted by a female interviewer, as the male interviewer was unavailable and the research team did not want to delay progress. Matching the sex of the interviewer and interviewee was deemed important, given the potentially sensitive nature of the research and the potential gender dimension of the topic. Indeed, it was clear from the preparatory focus group discussion conducted with men in Pakistan, conducted by a male researcher but observed by myself and two female Pakistani researchers, that the presence of women influenced what was said. One participant even stated that he wanted to say something but could not in the presence of women, and I observed another male participant looking at the two Pakistani women every now and then for their reactions.

With the consent of those interviewed, all interviews were audio-recorded using an Edirol R-09 digital recorder. Initially I requested that all interviews be transcribed and translated. However, transcription proved to be too time-consuming, especially as it had to be done by hand as not all the researchers could type in their mother tongue script. As a result I requested that the researchers translate directly from the audio-recordings and this proved to be much more time-efficient.

4.4 Analysis during interview data collection

All interviews were audio-recorded and, as soon as possible after an interview had been conducted, were translated and the translation was sent to me by email, together with any additional comments made by the interviewer or translator which were thought to be of potential relevance to the interpretation of the transcript.

As soon as I received a translated transcript I uploaded it using the qualitative data analysis software NVivo, I read through the transcript and I coded its content, highlighting key text and making notes of key issues to explore further. As the transcripts were lengthy, ranging from 5-37 pages, I wanted a more manageable summary of the key text, codes and notes, presented in context, with which to work. For each interview I produced a word document of 1-10 pages, summarising the background of the participant, the key issues with narrative descriptions and relevant verbatim quotes and my notes on theoretical ideas evoked by the data. These summary documents were useful, not only because they brought together data, context and analysis notes in a manageable form, but also because I could send them to the research partners to share my initial analysis with them and to check that it reflects their understanding of the interviews. This was especially useful as a way of identifying where translation may have affected meaning and interpretation.

For the first few interviews in particular, in order to give the interviewers feedback to improve their interviewing techniques, I also noted on the full transcript where a question could have been asked differently or where a response could have been pursued or probed more. I then shared my analysis and comments with the research partners by email, and, as often as possible, by phone.

In all three countries, a sample of the audio-recorded interviews was analysed by the research partners and the translations of those interviews were analysed separately by myself and then compared. The size of the sample varied enormously by country, with the research partner in Nepal analysing 26 of their 32 interviews and the research partners in Bangladesh and Pakistan, which both faced greater time and capacity constraints, analysing two and one interview respectively. The research partners' analyses allowed me to compare my interpretation of the data with theirs and to gauge the likely impact of the translation on my analysis. Whilst the analyses of the research partners tended to be more descriptive than analytical,

I was nevertheless reassured to find that the discrepancies between my analysis and theirs related more to depth than kind, and whilst a certain amount must inevitably be lost through the process of translation, the main issues appeared to have been retained.

4.5 Sampling and theory development

A core component of the approach to discovering grounded theory is theoretical sampling. With theoretical sampling, sampling decisions are driven by the emergent theory and so the researcher jointly collects, codes and analyses data, deciding what data to collect next and from where on the basis of its theoretical purpose (Glaser and Strauss, 1967). Below I describe the sampling process of this study in six stages. My sampling strategy was mainly driven by the need for comparison groups to facilitate comparative analysis for the purpose of theory development. The characteristics of the comparison groups began broad and preconceived (e.g. men and women with TB) and I refer to this below as selective or open sampling (see stages 1 and 4). As Gibson and Hartman (2014) point out in their book *Rediscovering Grounded Theory*, the selection of the characteristics of the initial participants must inevitably be preconceived in some way.

As I began to analyse the initial data, the characteristics of the comparison groups became more specific and theory-driven (e.g. those with TB who are indigenous and migrant) and I refer to this as relational or variational sampling (see stages 2, 3 and 5). Setting overly specific criteria for the recruitment of participants was impractical as it can be difficult to ascertain prior to an interview whether someone meets those criteria. Also, people meeting the criteria may be few and far between and so difficult to find and recruit. Of course, theoretical sampling is not just about emergent theory driving *who* is interviewed, but also *what* is asked and *how*. The analysis of data during the data collection process, which was continuously discussed between myself and the research partners, served in particular to influence directions of questioning and depth of probing during subsequent interviews, and lead to my coding of the data becoming increasingly discriminate (see stage 6).

Stage 1: Selective / open sampling

My pre-selected criteria for sampling for the first few interviews were broad: TB status and sex. The research team in Nepal were the first to begin data collection, and did so by conducting interviews with a man and woman with TB in their urban site.

nu1. Woman with TB (22/04/08)

nu2. Man with TB (22/04/08)

The two interviews were translated and analysed and the process and content of the interviews were discussed by telephone between the lead researcher in Nepal and myself. Although the interview guide developed for Nepal was not identical to that developed for Pakistan, it was similar in content, format and style and so I was able to inform the researchers in Pakistan, before they conducted their first interview, that it had been tried and tested and had worked well in Nepal.

I requested that the first four interviews in Pakistan's urban site be conducted with married and unmarried men and women with TB, as I knew from the existing literature on TB and stigma and from the preparation stage of this study (the rapid appraisal and preparatory focus group discussions) that experiences of TB, in all three countries, are likely to vary by gender and marital status. Whilst the researchers were able to find married people with TB quite easily, they were only able to find one unmarried woman with TB at this stage, and she had been widowed. These interviews were translated and the translated transcripts sent to me for analysis.

pu1. Woman with TB, unmarried/widow (30/04/08)

pu2. Man with TB, married (06/05/08)

pu3. Man with TB, married (06/05/08)

pu4. Woman with TB, married (06/05/08)

Bangladesh was the last of the three countries to begin data collection. Two people with TB were interviewed, one male and one female, and the translated transcripts were sent to me for analysis.

b1. Woman with TB (08/05/08)

b2. Man with TB (08/05/08)

As the first two people with TB interviewed in Nepal's urban site were both married, I specified that an unmarried man with TB and unmarried woman with TB should be interviewed next. The researchers were able to find an unmarried woman with TB at this stage, but not an unmarried man with TB.

nu3. Woman with TB, unmarried (09/05/08)

Stage 2: Relational / variational sampling (Comparison sub-groups)

Strauss and Corbin (1990) refer to relational or variational sampling as collecting and analysing data in order to discover and understand the relationships among categories. I had coded the first few interviews conducted in each of the three countries, and had begun to ask questions about some of the issues arising in the data. These issues can, using the language of Grounded Theory, be referred to as provisional categories. To learn more about the properties and scope of some of these categories, I instructed the researchers to interview people with TB with particular characteristics and to be alert to information potentially relating to the categories arising in the interviews and to probe to explore them further. In the first interview conducted with a woman with TB in Nepal's urban site (nu1), the participant was of the opinion that the experience of having TB is worse for a married man than for a woman because a man is relied upon to provide for his wife and children and these responsibilities are difficult to meet when ill with TB. However, from the first interview with a man with TB (nu2), it did not appear that his experience of TB had been worse than that of the female participant, perhaps because he was living with his extended family, who he indicated had been very supportive. I wondered whether the experience of having TB is worse for those for whom illness is particularly disruptive, because they have responsibilities or dependents and because they have little or no support network. I also wondered how this disruptiveness affects their experience of TB, their feelings about themselves, and their perceptions and interpretations of the feelings and actions of others' in relation to their TB.

To help answer these questions, I requested that the researchers in Nepal try to find a married man to interview who has to provide for his wife and children without the support of an extended family. They interviewed two men with TB, one living in a nuclear family and the other with his extended family.

- nu4. Man with TB, married, living with extended family (09/05/08)
- nu5. Man with (extrapulmonary) TB, married, living in a nuclear family (09/05/08)

It is common in all three countries for a married woman to live in the same household as, or within close proximity to, her husband's family. The first woman with TB to be interviewed in Nepal (nu1), however, did not live with or near her in-laws, so I instructed the research team in Nepal to interview a married woman with TB who did live with her in-laws in order to compare their experiences. Whilst at this stage the researchers could not find a woman with TB living with her parents-in-law, they did find a woman with TB living with her daughter-in-law.

- nu6. Woman with TB, married, living in an extended family (husband, sons, daughter-in-law, grandson) (11/05/08)

At this point, interviews nu3 and nu4 had been translated and sent to me for analysis. I discussed these two interviews, and the subsequent two which were still in the process of being translated, with the research team in Nepal.

I had instructed all three research partners to avoid translating words with no clear English equivalent, but instead to italicise the original language word in the translated transcripts. One such word which the researchers in Nepal italicised was *hela*. This term had been used in two of the interviews. In the first (nu3), the participant said her family had treated her well since her TB diagnosis, elaborating that they do not do *hela*, that they do not give her food separately. Later in the interview, the participant equated *hela* with talking negatively about someone and to keeping someone separate or washing their clothes separately. In the second (nu4) the participant said he had not been to visit his in-laws for fear they may do *hela* and that he thought *hela* is more likely to be done by in-laws than one's own (biological) family. From the contexts in which it was used, the term clearly had

relevance to the concept of stigma. I asked the research lead in Nepal to explain its meaning and she described *hela* as the opposite of love, specifying all types of love, rather than just marital love. An online Nepali dictionary defines the term as *contempt, insult, disgrace, or to revile*, but also *to neglect or not care for* (Turner, 1931).

As a relationship between TB and alcohol had been alluded to in more than one of the interviews, in order to explore this perceived relationship further we agreed to interview someone who drinks alcohol regularly. In particular, those interviewed so far had mentioned alcohol and tobacco as increasing susceptibility to TB and as they did not drink or smoke excessively they had been surprised by their diagnosis. I wondered how a heavy drinker would react to his or her diagnosis.

nu7. Alcoholic/Heavy drinking man with TB (26/05/08)

As a drinker and smoker, the first *unusual* symptom for the participant had been coughing blood which, as a relative had had cancer previously, made him fearful that he may have the same. The fact that he was diagnosed with TB, which he attributed to his smoking, and treated as an outpatient reassured him that his condition was not as severe as that of his relative.

During my initial analysis of the transcript I noted that whilst the participant reported being told to take various precautions against transmission, he and his family only followed the advice to separate eating utensils. I wrote a memo saying *Perhaps disease causation via shared utensils/jutho [a Nepali term for leftover food] fits better with existing understandings of disease than physical separation. Or perhaps it's simply more do-able.*

The first few interviews from Nepal also suggested a perceived relationship between vulnerability to TB and old age, and, with the impact of TB seeming to differ according to a person's circumstances and responsibilities, we decided to interview an older person with TB without dependents.

nu8. Older man with TB, aged 66 years (28/05/08)

From this interview I began theorising that there is a close relationship between experiences of TB and TB's disruptiveness to a person's life and ability to fulfil responsibilities, but also that 'stigma' (perceived negative talk or actions) may be more evident to some than others. In my analysis of interview nu8, I wrote *I wonder whether his lack of negative TB experience and lack of tension about his diagnosis is linked with his age. Perhaps at 66 years [in Nepal] you expect to be ill? As he has no one else to support and is still working, his TB hasn't been very disruptive. Although he's now living with his cousin, he seems a bit of a loner and so wasn't aware of other people with TB and their experiences and hadn't picked up much gossip/information from the neighbourhood about TB.*

Some of the participants had compared the impact of TB on married and unmarried people, saying that it is preferable to have TB when unmarried as one has fewer responsibilities. However, two of those interviewed so far (nu4 and nu7) had talked about TB's impact on marriage prospects, especially those of women. In addition, one (nu4) had suggested there is a difference if a marriage is arranged or based on love. To explore the issue of TB and marriage prospects further we sought to interview a woman with TB who was engaged to be married when she was diagnosed or an unmarried woman with TB of marrying age who is likely to have an arranged marriage. The research team in Nepal was successful in finding an unmarried woman with TB aged 19 years to interview.

nu9. Unmarried woman with TB, aged 19 years (01/06/08)

In Pakistan, as no unmarried people with TB had been interviewed yet, I requested that the next four interviews be with people with TB who are unmarried or recently married. In the first two interviews with women with TB (pu1, pu4), there was some suggestion that there may be a perceived link between good health and fertility and so I requested that this be explored further in the next set of interviews, in case it underlies the impact of TB on a woman's marriage prospects.

The researchers found it difficult to find unmarried and recently married people with TB, although they were able to find and recruit one woman with TB who was unmarried. This is likely to be because the majority of the adult population is married (Pakistan Census Organisation, 1998) with the mean age at marriage being 21 years for both men and women (United Nations, 2000). I therefore suggested

they try to find young married people with TB in the hope that they will have married relatively recently.

- pu5. Woman with TB, unmarried (10/06/08)
- pu6. Man with TB, recently married (10/06/08)
- pu7. Married woman with TB, aged 26 years (11/06/08)
- pu9. Man with TB, unmarried (18/06/08)

The first two interviews conducted in Bangladesh had been translated, sent to me and coded. As with the other two countries, I wanted to explore TB's perceived effect on the marriage prospects of women with TB. During my visit to Bangladesh in February 2008, the research team and I had visited the TB clinic in Norshingdi and discussed the research project with the regional health coordinator for the district from BRAC, a national non-governmental organisation. During our discussions we talked about patient confidentiality and the coordinator said that, in his experience, only unmarried women request that their TB diagnosis be kept confidential by the clinic as they fear it will affect their marriage prospects. In the first interview conducted with a man with TB in Bangladesh (b2), the participant, who had cancelled his engagement following his TB diagnosis, did not think his future marriage prospects would be negatively affected but seemed certain that they would be for a woman. His certainty was not based on knowing women whose marriage prospects had suffered as a result of TB but from knowing that good health is an attribute sought in a prospective wife. This made me wonder whether it is TB, disease in general, or diseases with particular characteristics (such as those which are thought to be communicable, hereditary, lifelong or disabling) which are thought to affect a woman's marriage prospects. To explore these lines of inquiry further, I requested that one or two unmarried women with TB be interviewed next.

In the first interview with a man with TB (b2), there was also mention of the susceptibility of children to TB, so I requested that a married man with TB, preferably with young children, be interviewed as well.

- b3. Woman with TB, unmarried (25/05/08)
- b4. Man with TB, married, with two wives and three children (12/06/08)

Participant b3 spoke of a girl she knew whose husband divorced her when she was diagnosed with TB. I asked the researchers whether they could find out who the girl, her ex-husband and her mother-in-law were, urging them to be sensitive in the process, as such an apparently extreme case would contribute greatly to theory development. The researchers were able to locate the girl and said she was willing to be interviewed, but the interview was, as far as I know, never conducted.

It was clear from the first three interviews conducted in Bangladesh that the fear of TB is influenced by the knowledge and belief that TB can be treated and that treatment is available and accessible. In the case of participant b3, she felt confident that TB could be cured and she was easily able to access the treatment; the clinic was only 15 minutes away and her mother and the *shebika* (a volunteer health worker) would bring her the medicine. I shared with the researchers that I thought it would be interesting to interview someone who has much more difficulty accessing treatment, perhaps because they live much further away. As many of the participants across the three countries had spoken of the disruptiveness of TB and the challenges they faced during its lengthy treatment, I was interested to explore the relationships between 'stigma' and the disruptiveness and challenges.

The researchers in Bangladesh conducted five more interviews with married and unmarried men and women with TB, exploring issues of access to and the disruptiveness of TB treatment. The exact dates these interviews were conducted is not known and transcripts of the interviews were not sent to me until all five interviews had been completed.

b5. Woman with TB, married

b6. Man with TB, married, lives 7km from health centre

b7. Woman with TB, unmarried, 30 mins from health centre

b8. Man with TB, married, lives 10 miles from health centre

b9. Woman with TB, married

b10. Man with TB, unmarried

Stage 3: Relational / variational sampling (Comparison groups)

Glaser and Strauss (1967) emphasise the importance of comparison groups in the approach to discovering grounded theories. Comparison groups help stimulate theorising. Their purpose is “to help generate, to the fullest extent, as many properties of the categories as possible, and [to] help relate categories to each other and to their properties” (p49). As well as sampling sub-groups within the group ‘People with TB’, I also wanted to get perspectives on TB stigma from those without TB. Family members of people with TB were selected as a comparison group because of their potential to stigmatise and be stigmatised (courtesy stigma) and to provide different perspectives on interpretations of attitudes, emotions and actions.

The first family member to be interviewed was the mother of someone with TB, living in the urban site in Nepal. As the interview guide included a vignette, I asked the research partner to initially conduct just one family member interview, so that we could then discuss whether alterations to the interview guide or vignette were necessary.

nu10. Mother of a person with TB (01/06/08)

I discussed the interviews conducted so far by telephone with the research partner and received the partner’s analysis notes by email for the preceding four interviews (nu5-9). The translated transcripts were sent to me later. We agreed that the next interview in the urban site should be with another family member of a person with TB.

nu11. Adult son of a person with TB (22/06/08)

From my analysis of nu10, I noted that the participant spoke of holding a neighbour responsible, not for developing TB disease but for continuing to chew tobacco whilst being treated for TB and so for ultimately dying from TB. I therefore began theorising that issues of blame and responsibility do not only relate to the dimension of stigma referred to as ‘origin’ by Jones et al. (1984), but also to the dimension referred to as ‘course’, which I described in section 2.2.4.

In Pakistan, where the researchers were having difficulties finding unmarried people with TB to interview, so as not to delay progress, I requested that they begin interviewing family members of people with TB.

pu8. Mother of a person with TB (11/06/08)

Stage 4: Selective / open sampling

At this stage I felt I needed more time to further analyse the interviews that had already been conducted in the three countries, so that the sampling for the remaining interviews would be more discriminate and based on their potential relevance to developing theories. Glaser and Strauss (1967) advocate respites during the data collection and analysis process for theory development and even suggest taking months off data collection to think through emergent theories before returning to the field. Such a respite was not possible due to the restricted timeframe required by the funder. To keep the data collection momentum going, but still give myself time to analyse the interviews in greater depth, I asked the researchers in Nepal and Pakistan to suspend interviewing in their urban sites and to begin the first four interviews in their rural sites, with the same broad sampling criteria (male/female, married/unmarried) used at the start of data collection in the urban sites. In Pakistan's rural site, opportunities presented themselves and were also taken to interview a divorced woman with TB and a sister-in-law of a person with TB.

nr1. Man with TB, married (22/06/08)

nr2. Man with TB, unmarried (25/06/08)

nr3. Woman with TB, unmarried (25/06/08)

nr4. Woman with TB, married (30/06/08)

pr1. Man with TB, unmarried (01/07/08)

pr2. Woman with TB, divorced (01/07/08)

pr3. Woman with TB, married (01/07/08)

pr4. Man with TB, married (01/08/09)

pr5. Sister-in-law of a man with TB (01/08/08)

pr6. Woman with TB, unmarried, 23 years old (18/08/08)

I analysed the transcript for one of the interviews conducted in Nepal's rural site (nr3) and discussed the content of the other three with the research team in Nepal. I requested that they interview four more people with TB, including, if possible, a recently married man and woman with TB. This was to compare the experiences of people with TB living in different circumstances and with differing responsibilities.

nr5. Woman with TB, unmarried (13/07/08)

nr6. Man with TB, married (14/07/08)

nr7. Man with TB, unmarried (16/07/08)

Stage 5: Relational / variational sampling (Comparison groups)

At this stage I requested that family members of people with TB be interviewed in both the rural and urban sites in Nepal. I was particularly keen for a husband or fiancé and a mother-in-law or other in-law of a person with TB to be interviewed, as it might reveal more about the impact of a TB diagnosis on marriage and marital accord in a context where, after marriage, a woman commonly joins her husband's family. A husband of a person with TB was interviewed, as well as a range of other types of family member, but the researchers were unable to identify and interview a mother-in-law.

nr8. Wife of a person with TB (16/07/08)

nr9. Sister of a person with TB, unmarried (16/07/08)

nr10. Son-in-law of a man with TB (30/07/08)

nr11. Husband of a person with TB (30/07/08)

nu12. Wife of a person with TB (07/08/08)

nu13. Daughter-in-law of a person with TB (08/08/08)

In the translated transcript of nr10, the participant said: *"If we control our food intake, if we care about it, then If medicine is taken with the intent to get cured, then it will cure. But if after getting cured, after just two or three days, he starts*

drinking alcohol and smoking cigarettes then he will not get cured. It won't be because of the medicine that he didn't get cured, it will be because of his own behaviour." In response to this excerpt and building on my earlier realisation from my analysis of nu10 at stage 3 of the sampling process that blame and responsibility relate not only to the dimension of 'origin' but also, if not more so, to the dimension of 'course', I noted that whilst people believe that anyone can get TB, they may also believe that only well-behaved, responsible people get cured.

In Bangladesh, communication with the research team by phone and email was infrequent and unreliable. I had received just three of the translated transcripts for the ten interviews already conducted. The lead researcher's worsening health problems meant that progress was being delayed and his colleague, who could not speak English, was continuing to transcribe the interviews in Bengali but was unable to take over the translation. It transpired that hiring a temporary translator was not an option as the lead researcher had travelled to Singapore for medical treatment, taking the remaining transcripts with him. So as not to delay progress I requested that in his absence his research colleague in Bangladesh proceed by interviewing two health care providers who work directly with TB patients.

b11. Volunteer health worker (04/08/08)

b12. Volunteer health worker (04/08/08)

The remaining seven translated transcripts were eventually completed and sent to me, together with transcripts for the two interviews with health workers. Although the researchers reported that they had conducted four interviews with family members of people with TB, the translated transcripts were never completed or sent and so have not been included in this study.

As in Bangladesh, I requested that the researchers in Nepal and Pakistan interview at least two health care providers per site who work directly with people with TB. It was clear from the preparatory focus group discussions and the interviews conducted so far, that health care providers can play a role in fuelling or exacerbating 'stigma' through their own attitudes, emotions and behaviours, whether during or outside of working hours, and by disclosing (intentionally or unintentionally) a patient's TB status to others. As the theme of disclosure was so apparent from the data collected so far, I was interested to know how, if at all, health workers or TB volunteers balance patient confidentiality with late patient

tracing, and whether they are sympathetic or disapproving of patients who have defaulted their treatment regimens.

nu14. Health worker, female (07/08/08)

nu15. TB volunteer (08/08/08)

nr12. Clinician in charge of the TB clinic (12/08/08)

nr13. TB health worker (14/08/08)

pu10. Health worker known as a 'DOTS facilitator' (25/08/08)

pr7. Senior medical officer (28/08/08)

pr8. Community health worker, known as a 'Lady Health Worker' (10/10/08)

pu11. TB focal person/health officer (14/11/08)

In my research diary I began not only theorising on what underlies TB-related 'stigma', but also noting down thoughts on possible interventions or policy considerations. For example, on 14/08/08 I noted: *There is such a wide range of ideas on what TB is, how it transmits, what it means and so on, that I wonder whether there are simply too few reliable and comprehensible sources of information on TB. Doctors give information, but sometimes only partial, and the patient has to fill the gaps in often logical and plausible, but incorrect, ways. We don't expect everyone to be TB experts, but they do need to know how to get correct information when they need it.* Likewise, on 28/08/08 I noted that the importance of TB's severity to perceptions of stigma was becoming increasingly apparent to me, adding: *A person who thinks they're seriously ill and might die is likely to feel pretty down. If you're feeling down, you also feel vulnerable and sensitive, and so are more likely to perceive people's actions towards you in a negative way. Tackling stigma may, in part, involve making people with TB feel better about themselves and their future.*

Stage 6: Discriminate sampling / selective coding

By the time I had coded 15 transcripts from Nepal, 11 transcripts from Pakistan and three transcripts from Bangladesh, my coding became noticeably more selective and my memoing more prolific. Whilst the criteria for selecting the remaining

interview participants did not become significantly more discriminate, my coding of the interview transcripts did.

At this stage I had only received 16 transcripts for the 28 interviews conducted so far in Nepal, although I had received the research partner's analysis notes for a further nine of the interviews. I requested that the researchers conduct one more interview in the urban area with a woman with TB and, in order to explore her attitudes and behaviours towards people with current TB, suggested it be someone who had had TB in the past. It was clear from the interviews so far that fear and perceived vulnerability contribute to TB-related 'stigma' and I wondered whether people with past TB would, because of their own past experience, be more sympathetic and supportive of those with TB, or whether they might be more distant because of a fear of relapse or reinfection.

nu16. Woman with past TB (03/09/08)

For the rural site, I requested three more interviews, two with women with TB and one with a man with TB, again suggesting they try to find someone with past TB to interview.

nr14. Woman with TB, sputum positive (08/09/08)

nr15. Woman with past TB (10/09/08)

nr16. Man with past TB (28/09/08)

Of the 19 interviews so far conducted in Pakistan I had received 16 translated transcripts. Based on my analysis of these I requested that in both sites further interviews be conducted with family members of a range of types and with people with TB. I specified that people with TB with young children be sought to explore how having TB impacts on their role as parent. Experiences of TB seemed to be influenced by the degree to which TB impacts on a person's roles and responsibilities and, as both caring and providing for dependent children can be difficult when ill and as children seem to be deemed particularly vulnerable to TB, I thought that including parents of young children in the study would contribute to theoretical development. I also requested that, should the opportunity arise, the interviews with either the family members or people with TB explore the issue of in-

laws either being or not being blood relatives. Two participants (pr3 and pr6) attributed their difficulties with their in-laws in part to the fact they are not relatives. However, even prior to the analysis of these two interviews, a pattern emerging from the interviews across the three countries that one's (biological) family is generally thought to be more supportive than one's in-laws, made me wonder what the situation would be if one's in-laws were one's biological family, as is commonly the case in Pakistan where over 60% of marriages are thought to be consanguineous (Hussain & Bittles, 1998).

pr9. Mother of a woman with TB (25/10/08)

pr10. Married woman with TB with relative in-laws (25/10/08)

pr11. Married woman with TB with non-relative in-laws (15/11/08)

pu12. Married man with TB with non-relative in-laws (19/11/08)

pu13. Son of a person with TB (19/11/08)

pu14. Married woman with TB (01/12/08)

pu15. Mother of a woman with TB (05/12/08)

pu16. Mother of a man with TB (10/12/08)

pr12. Wife of a person with TB (02/02/09)

pr13. Married man with TB with relative in-laws (02/02/09)

4.6 Data analysis after completion of interviews

Once all the interviews for a site had been completed I uploaded all the summary documents into a new NVivo software project. I then coded the text in Nvivo using both the codes I had used in the summary documents and any relevant additional codes and categories I had developed since. For each site I then produced a list of all the codes and categorised them under headings which broadly corresponded with the model of stigma causality presented in Chapter 2. As an example, table 3 overleaf shows the categories and codes developed for the data from the urban site in Nepal.

I then ran coding queries in Nvivo to categorise all the coded data under these broad headings and printed the categorised data out. The categories used for the five sites were, for the most part, similar. In Nepal's urban site, whilst the code "relapse" was initially categorised under "course", I later created a separate category for "relapse" as I felt my notes warranted this.

I also compiled and printed out a document containing the brief descriptions of each participant for easy reference, so that the categorised data would retain some of its context.

Box 1 Categories and codes, Nepal urban site

| MANIFESTATIONS | IATROGENIC STIGMA | COURSE |
|------------------------------|--|--|
| | Iatrogenic stigma | Course |
| 1. Anticipated stigma | Tracing | Alcohol & smoking |
| Courtesy stigma | Accessing services & care | Food |
| Perceived stigma | Health seeking | Pregnancy |
| Self stigma | | Longevity of TB |
| Self-discrimination | TB CONCEPT | Relapse |
| | Length of treatment | |
| 2. Avoidance | TB concept | ORIGIN |
| Disclosure | TB vs. other diseases | Origin |
| Disclosure of stigma | TB not suspected | Familial transmission or family disease |
| Gossip | TB suspected | Susceptibility |
| Joking | | Alcohol & smoking |
| Adherence | CONTEXT | Food |
| Delayed treatment seeking | Children & babies | Pregnancy |
| Visiting the ill | Double disease burden | Sexual transmission |
| Marriage | Gender | |
| Marriage prospects | Evidentness of stigma | AESTHETICS |
| Longevity of stigma | Family dynamics | Aesthetics |
| Supportive family | Age | |
| Supportive employer | No previous knowledge of TB | DISRUPTIVENESS |
| Supportive others | Responsibilities | Disruptiveness |
| Separation | | Finances |
| <i>Hela</i> | COST | Length of treatment |
| Behaviour change, others' | Cost | Alcohol & smoking |
| Experiences vary | | Food |
| | EVIDENTNESS | Pregnancy |
| 3. Emotions | Evidentness of TB | |
| Reaction to diagnosis | First symptoms | OTHER |
| Worry | TB suspected | Addressing stigma |
| Shame | | Knowledge counters fear |
| Coping | PERIL | Side-effects |
| Self perception & sick role | Peril | Sources of information |
| | Familial transmission or family disease | |

I then read through each of the print-outs and made brief notes of key issues and my developing theoretical understanding, within and across sites. As these brief notes for each category were on average a page in length, I could easily lay out all notes for one site or all notes relating to one category from across the five sites, to get an overview and to see how the ideas within the notes interrelate. As an example, box 1 below contains the notes relating to the category “origin” from Nepal’s urban site. The vignettes I developed for the final focus group discussions, which I describe in the next chapter, were based on these notes.

Box 2 Example of analysis notes for the category “origin”, Nepal urban site

Having an explanation for TB (i.e. answering the ‘Why me?’ question) seems to be important to those with TB and others.

‘How does TB transmit?’ and ‘What causes TB?’ result in very different responses. The former receives responses based on health workers’ advice (avoid *jutho*, sleeping together, sputum). The latter relates more to susceptibility (alcohol, lack of food, weakness, etc)

People with TB don’t seem to be blamed for their TB unless the perceived cause was previously disapproved of. They do, however, seem to be held responsible for their cure.

Although there was no suggestion that TB might have been a curse from God, prior to nu9’s diagnosis others speculated that her bent back might be, and her mother told her to go for ritual/traditional treatment.

4.6 Summary

My review of the literature on TB and stigma (presented in Chapter 2) and the rapid appraisal and preparatory focus group discussions (described in Chapter 3) informed the development of interview guides for three broad categories of participant: people with TB, their family members, and health care providers. The

same interview guides were used across all five research sites. A total of seventy-three interviews were conducted between April 2008 and February 2009, equating to 12-16 interviews per site. In this chapter I described the process of sampling, demonstrating how it was driven both by the need for comparison groups to aid the development of theory and by emerging theoretical ideas. In the process I have also sought to convey the reality and challenges of theoretical sampling across three different countries and directed from a fourth.

Chapter 5

DEVELOPING AND CONSOLIDATING THEORY

The next step was to further develop the theoretical ideas which had emerged from my analysis of the interview data by incorporating them into vignettes and using the vignettes as a basis for group discussions with people living in the research sites. In this chapter I present the vignettes used and explain how my theorising was woven into them. I also outline the sampling process and describe how the focus group discussions were conducted and analysed. Finally and to precede Chapters 6-8 in which I present my causal theories, I reflect upon the process of analytical writing, a process through which I articulated specific TB stigma manifestations and consolidated grounded causal theories to explain them.

5.1 Focus group discussions and vignettes

Individual in-depth interviews are well suited to obtaining accounts of sensitive personal experiences, such as those relating to stigma. However, stigma is a social phenomenon. Whether defined as symbolism or as a process (see Chapter 2), it is dependent on interactions between people. Focus group discussions allow interaction between participants and so can give valuable insight into how meanings and ideas are socially produced and expressed in a social setting (Green and Thorogood, 2004; Kitzinger, 1994; Krueger, 1994).

The focus group discussion guides included vignettes to enable me to (member-) check my analysis of the interview data by seeing whether my developing theories 'rang true' with the views and experiences of the participants. The vignette technique uses short stories depicting characters and scenarios which are hypothetical, but to which the research participants can relate. The participants are invited to respond to the vignette, eliciting and clarifying beliefs, perceptions, opinions and attitudes relating to the context provided in the vignette (Barter and Renold, 1999). Vignettes have been used in individual interviews to explore a range of health-related issues, including drug injecting and HIV risk (Hughes, 1998), malaria (Ahorlu et al., 2005) and TB (Atre et al., 2004). Whilst less has been written about using vignettes in focus group discussions, they present a less personal and less threatening way of exploring a potentially sensitive topic such as stigma, so they are likely to be well suited to research with groups, where participants can

draw from their personal experiences but may be unwilling to talk directly about them (Barter and Renold, 1999). Two studies using vignette-based focus groups with Mexican and Central American immigrants in the USA and with elderly people in Canada, found participants responded well to the approach and that the approach encouraged open and in-depth discussion (Brondani et al., 2008; Easter et al., 2007).

In this study we used the vignette technique for both the individual interviews with the family members of people with TB and for the focus group discussions and found that the technique worked particularly well for the latter. Indeed, that vignettes can work well in focus group discussions had been established at the preparation stage of this study, as the technique was used with reassuring success in the preparatory focus group discussions in Pakistan. With the individual interviews the participants often preferred to talk about themselves rather than a hypothetical scenario, whereas in the group setting focus group participants actively discussed the scenarios, drawing on their personal experiences to theorise as to why a vignette character may think, feel or act in a certain way.

5.2 Theorising within the discussion guides

The focus group discussion guides were developed by myself, based on the analysis of the individual interviews. Three separate guides were developed: one for Nepal's rural site, one for Nepal's urban site, and one for Pakistan's urban site. I have included one of these in full as an example in Appendix D. The guides, together with explanations of what issues were to be explored through the vignettes, were sent to the research partners in Nepal and Pakistan for their comments. The researchers confirmed that the vignettes were applicable to their country's context and that the issues they raised and ideas they contained corresponded with their own interpretations of the interview data.

The research teams in each of the two countries chose names for the vignette characters with the instruction that they should be as neutral as possible. The discussion guides were translated into Nepali and Urdu by a member of each research team and the accuracy of the translations was checked by and discussed with other employees of the partner organisations, HERD and ASD.

In the following sections (5.2.1-5.2.3) I shall present the vignettes used in the focus group discussions, highlighting how my theorising is woven through them. Whilst different vignettes were developed for each of the research sites, some of the themes they sought to spark discussion on were shared. Through the vignettes I explored how the manifestations of TB stigma related to a person's circumstances or context (their family set-up, relationships with others, income and support), the way in which TB disrupts their roles and responsibilities, and the evidentness both of TB and of behaviours or attitudes which could be interpreted as being manifestations of stigma.

5.2.1 Nepal's rural site

The focus group discussion guide for Nepal's rural site contained two vignettes with multiple characters to which both men and women, with or without TB, could potentially relate. The vignette was read out in four separate parts with questions in between. Incorporated into the vignettes were the following themes: family dynamics and set-up; previous state of relationships; impact of delaying marriage until completion of TB treatment; pregnancy/anticipated pregnancy/breast-feeding; family situation (including presence of young children); separation and *hela* (hatred/neglect); and susceptibility to TB (smoking, drinking, weakness, food, overwork).

Nepal Rural Site

Vignette 1

a. Radha lives in a village in Lalitpur. Her son has just got married. His new wife is almost 25 years old – older than Radha had hoped (in fact Radha wonders why she isn't already married) – and she doesn't come from the best family but at least her son is now married and so Radha hopes they will give her lots of grandchildren.

After a few months, Radha notices that her daughter-in-law, Kamala, has been working less in the home and has seen her son, Syam, take her to the clinic. She is concerned because Kamala looked thin and her skin looked dull. Even Syam's skin is looking a bit dull. Radha wonders whether they have been eating properly.

b. Kamala seems to get better quickly and it's not long before she falls pregnant; and when the child is born everyone is very happy, especially Radha. But it's not long before Kamala seems thin again and this time she is coughing a lot. They take her to the clinic, where they do some tests, and the health worker tells them that Kamala has TB.

c. Radha tells Kamala that she will look after the baby and that Kamala should not go too close to the baby while she is ill. She says even breastfeeding is dangerous. Kamala is very upset about this and thinks that her mother-in-law hates her.

d. Syam tries to reassure his mother that TB is a simple disease that will get cured with medicine, but Radha wonders why, if TB really is such a simple disease, it requires taking medicine for such a long time.

In the first part (a) of the vignette the scene is set and the mother-in-law / daughter-in-law relationship is presented. Whilst the relationship is ok, there is a suggestion that the mother-in-law, Radha, may feel some underlying dissatisfaction about her son's choice of wife. It was apparent from the interviews that family dynamics and relationships prior to a TB diagnosis seem to make a difference to relationships following diagnosis (e.g. if a woman didn't like her daughter-in-law before diagnosis, she's unlikely to like her after, and in fact might like her even less).

From the interviews I theorised that when someone has TB it may not affect their marriage prospects forever, but they are expected to and will probably want to delay getting married until they are cured. Waiting six or more months before getting married may be less of an issue for men who have a longer time in which to get married than for women who are already considered a little old if they are not yet married by 25 years of age. To explore this, the daughter-in-law in the vignette, Kamala, had married at 25 years of age with no specific reason given, but the suggestion is made that most women in the area get married at a younger age.

The interviews also highlighted that some people think it is risky if a woman with TB gets pregnant or takes TB treatment whilst pregnant. As pregnancy may be

expected to follow marriage quite closely, the vignette sought to explore the perceived impact of a TB diagnosis on a newly married woman whose mother-in-law is hoping will produce grandchildren soon.

The second part of the vignette (b) provided further information to which the participants' responses were expected to illuminate the perceived link between weakness (following childbirth or previous illness) and susceptibility to TB. Furthermore, as the interviews suggested babies and children are perceived to be particularly vulnerable and that someone with TB should avoid close contact with them, the vignette sought to encourage discussion relating to the disruptiveness and difficulties of a TB diagnosis for a mother with a young child

In part c of the vignette Kamala is upset and so thinks others hate her. The intention of this was to explore a person's state of mind and how they interpret the intentions of other people. The analysis of the interviews highlighted that there seems to be a paradox that people struggle with between the need to care for someone who is ill and the need to take precautions against transmission by separating that person.

The intention behind the final part of the vignette (d) was specifically to explore understandings and definitions of a "simple disease", a phrase which had appeared often in the interview transcripts.

Nepal Rural Site

Vignette 2

a. Ram lives in a rented house in Lalitpur district with his wife and three young children. A year ago he had TB/*chayarog* and took medicine for 8 months. When he discovered he had TB his wife told him to stop drinking alcohol and since then he only occasionally drinks. A month ago Ram started coughing and although he took some cough syrup it didn't help. He was worried so he went to the clinic to get tested. The doctor told him that he has TB ... again.

b. Ram has not been able to work for weeks and Ram and his wife have been arguing. Some days, especially when Ram isn't feeling well, he feels like everyone hates him because of his TB. Other days he feels like he will get cured soon and will return to work, so he is happier. His wife is finding his changing moods difficult to cope with.

The interviews suggested that TB experiences differ according to whether someone lives in rented accommodation or in their ancestral village. For those living in rented accommodation the need to pay rent puts pressure on a family in which the income-earner is unable to work because of illness. Furthermore, people in rented accommodation neither have a right to land on which to farm nor do they have extended family nearby for support. On the other hand, people living in their ancestral villages have wider social networks and so changes in others' behaviour (e.g. not visiting, avoiding sitting close, etc.) may be more evident and gossip may be more of an issue.

In the first part of this vignette (a) I sought to explore whether people who get TB for the second time are held more responsible or to blame than those who have TB for the first time. The interviews suggested that the first time someone gets TB they are deemed unlucky, but the second time they are deemed careless. TB, it seems, is believed to change bodily constitution permanently and so even after cure it is believed TB may reoccur if a person continues or resumes drinking, smoking or eating certain foods (or the wrong balance of foods). The impact of TB therefore lasts longer than the eight months of treatment.

In the second part of the vignette (b) I wanted to explore the impact on the psychological and emotional state of a person with TB of not being able to fulfil roles and responsibilities, in this case that of a husband and father, and of struggling financially. I also wanted to explore the idea that the illness of one family member affects all family members, potentially contributing towards family tensions which may be interpreted as somehow TB stigma-related on some occasions and not on others, perhaps depending on the emotional frame of mind of the person with TB.

5.2.2 Nepal's urban site

Nepal Urban Site

Vignette 1

a. Gita lives in Kathmandu. Her neighbour, Rama, has been unwell and so she has gone to visit her. On her way she meets a friend who tells her that she has heard that Rama has TB. Gita has heard of TB and is worried. She has heard that TB can pass from one person to another. She's not sure whether she should continue now or head back.

b. Gita goes over to Rama's home to visit, but she doesn't stay for long. She tells Rama that she has to get back home to wash clothes. Rama suspects Gita doesn't care because she usually stays longer. She thinks Gita hates her now she has TB.

c. When Gita keeps a distance it makes Rama feel bad, but Gita doesn't intend for Rama to feel bad. Gita fears and hates the disease, not Rama, but of course Rama feels she is feared and hated.

d. Gita tells her husband that Rama has TB and she doesn't know what to do as she has heard that it's important to keep a distance from people with TB because it can transmit to her. Gita's husband says he thinks it only affects those who are weak, and as she doesn't smoke or drink and she eats well she'll be ok.

In the first part of the vignette (a) I set the scene, introduced the characters, and presented the dilemma between visiting an ill friend as is customary and protecting oneself from TB, with the view to exploring what is deemed appropriate or justifiable behaviour and why. Once the participants had discussed what Gita should do, they were informed in part b of what Gita actually did. In parts b and c I wanted to explore the dilemma between wanting to protect oneself from TB, but not wanting to make a person with TB feel bad, and to explore the intentions behind and interpretations of Gita's actions, in order to establish what are deemed justifiable precautions and what is deemed hateful.

I suggested to the Nepali research team that they ask the group whether they think people with TB are feared or hated and that they explore what constitutes fear and what constitutes hate in greater depth by comparing TB with other diseases, in particular HIV/AIDS and cancer. In one of the interviews, a woman with TB said people with TB are feared, but that people with HIV/AIDS are hated, and in a few of the interviews cancer was mentioned as being more feared than TB.

In part d, I wanted to explore issues of risk and susceptibility and therefore what are deemed necessary precautions for whom. The interviews indicated that 'weakness' increases a person's susceptibility to TB (or indeed any disease), with smoking, drinking, not eating properly or regularly, being overworked, doing strenuous work or being stressed contributing to weakness. I wondered whether weakness is only used as a post-hoc explanation as to why someone has developed TB disease, or whether it also influences for whom and in what circumstances particular precautions are deemed necessary or justifiable. Certainly the interviews suggested that children are deemed to be particularly susceptible and so separating those with TB from children was rarely, if ever, spoken of as hateful.

I also asked the Nepali researchers to explore whether "weakness" is purely physical (as the interviews had suggested) or whether it relates to a person's morals or character as well.

Nepal Urban Site

Vignette 2

a. Hari lives in a rented house in Kathmandu. The doctor has told him that he has TB. The doctor speaks with his wife, Mina, and advises her to make sure he takes his medicine regularly and that he eats well. He also advises her to keep some distance from him, to not sit too closely when he's talking, and to sleep separately. Mina doesn't know what to do. As she is his wife she needs to care for him, but if she stays a little far from him it will make him feel bad.

b. Hari is unable to work because he is ill and because he needs to go to the clinic every day for medicine. His wife has found some work but is struggling to earn enough for the family and to look after the children and home. As they are living in rent*, they have no relatives nearby to help. Hari's wife is feeling the strain of all the work she has to do and Hari feels guilty that he is not providing for his wife and children. Sometimes, when he is feeling low, he thinks that his wife must blame him for causing such problems.

c. Hari had had TB before, two years ago, and Hari's wife wonders why he has it again. She wonders whether he got TB again or whether the TB he had before wasn't cured properly. She thinks he might have been careless.

* "Living in rent" means living outside of one's ancestral village in rented accommodation. This phrase originated from the Nepali research team in their translations of interviews and correspondence with me.

As with the previous vignette, through this vignette I wanted to explore the dilemma between needing to take care of someone who has TB and needing to keep a distance to avoid transmission. In the context of the study sites a wife's role is primarily to care for (rather than provide for) her family, including her husband. The focus group participants discussed how she would deal with the contradiction between her role and the need to take precautions, exploring both the interpretations and social costs of precautionary measures. In addition, I wanted to explore the idea that keeping a distance is distressing to a person with TB and the perceived importance for recovery of feeling positive and supported.

As the interviews indicated some confusion about the length of time TB remains infectious once a course of TB treatment has begun, and therefore the length of time that precautions are necessary, I requested that the researchers probe this.

In part b I wanted to explore the relationships between context and the disruptiveness and strain of TB disease, and how these influence family tensions, self-esteem and perceived stigma.

In the final part of the vignette (c) I wanted to explore attitudes towards relapsed TB. From the interviews, and with reference to the model of stigma causality presented in Chapter 2, it appeared that 'peril' (fear of transmission) and 'course' (TB's severity, treatability and likely outcome) underlie behaviours and attitudes

more than 'origin'. However, whilst people with TB may not be blamed for getting TB in the first place, they do seem to be held responsible for their recovery. In this part of the vignette I wanted therefore to explore whether people with TB are blamed if they do not recover from TB or if they develop TB disease again.

5.2.3 Pakistan's urban site

The discussion guide for Pakistan's urban site was tailored to a focus group discussion with women and contained one vignette divided into five parts, again containing multiple characters to which participants could potentially relate.

Pakistan Urban Site

Vignette

a. Hameeda lives in Rawalpindi. Her sister, who has been unwell, has just been told by a doctor that she has TB. Hameeda has heard that TB is communicable. They say it's a "family disease". So she's worried both about her sister and about getting TB herself.

b. Hameeda feels she has a dilemma. She's to be married soon and is worried that, if she gets TB, her in-laws will call off the engagement. This would be terrible. So to protect herself from getting TB she thinks it's important to keep a distance from her sister and to separate her utensils and laundry. But this may upset and sadden her sister. In fact her sister may feel hated and lose confidence, which could hinder her recovery.

c. Hameeda's sister Shamim doesn't want anyone outside her family knowing she has TB because she says people will gossip.

d. Some friends have discovered that Shamim has TB. They've visited her, as is customary, but they seemed to sit a bit far and didn't take tea when offered. They said they couldn't stay long as they have work to do at home, but Shamim feels like they wanted to avoid her. She feels they hate her.

e. Shamim doesn't want her brother's children coming too close to her as she doesn't want them to get sick. She insists they stay away until she is better.

In many of the interviews from the Pakistan sample, TB was referred to as a “family disease”. In the first part of the vignette (a) I wanted to clarify whether TB is seen as a family disease because it is considered hereditary (either the disease or susceptibility to it), because of proximity, because of shared behavioural risk factors, or because of something else. I also introduced the beginnings of a possible dilemma - Hameeda is worried both about her sister and about herself – to see whether participants would identify the dilemma themselves before elaborating upon it further in the second part of the vignette. In part b I wanted to explore the short- and long-term implications of a cancelled engagement (esp. in relation to gender), the precautions deemed necessary to take when a family member has TB, the belief that a person's emotional state influences their recovery from illness, and the dilemma that precautions which may protect one person may worsen the emotional state of another.

Whilst the vignette featured just two main characters, Hameeda and Shamim, I asked the Pakistani research team to probe as to how the participants' views of the dilemma would be different if the characters were different in terms of gender, age, status within the family, and closeness of relationship (for example, friend or family, love or arranged marriage, cousin or non-cousin marriage).

The interview data suggested some people intentionally conceal their TB to people outside of their immediate family because they do not want others to gossip. In the third part of the vignette (c) I wanted to explore who gossips about whom, what is deemed gossip-worthy and whether being gossiped about is necessarily negative (i.e. is it that people talk badly or just that they talk?). In the report for the funder on the findings from Pakistan I devoted a separate section to the issue of gossip, which appears to have a strong gender dimension. In this thesis, however, I have not sought to explain it as a manifestation of TB stigma. Whilst the term ‘gossip’ certainly has negative connotations, it did not emerge as particularly TB-specific. Indeed one participant with TB, whose noticeable ill health had sparked gossip, said she intentionally disclosed her TB diagnosis to others in her community in order to counter rumours that her change in health was due to pre-marital pregnancy.

In part d I sought to continue to explore the relationship between fear of infection and the perception that people with TB are hated, but this time from the perspectives of friends rather than family. The interview data and discussions with the Pakistani research team revealed that when a person is sick it is customary and caring to visit him or her. I wondered how people deal with the contradictions between these social norms and precautions against TB transmission, and in which circumstances social norms and expectations override concerns regarding personal risk.

Finally, in part e I wanted to 'test' the theory that how avoidance or separation are interpreted is dependent on who has initiated the avoidance or separation; whether initiated by the person with TB (seen as taking necessary precautions, following doctor's advice, wanting to protect others) or by others (seen as being hateful and uncaring). In the interviews from Pakistan, as in those from Nepal, children are perceived to be particularly vulnerable and so will be separated from someone ill with TB, even when adults are not. In the interviews there was no suggestion that this has or could be interpreted as hateful. I was interested to check whether the focus group participants' responses would be consistent with the interviews and to explore when separation or avoidance is deemed justifiable, outweighing any distress it may cause the person with TB.

5.3 Sample size and strategy

Initially focus group discussions were to be conducted with groups of men and women in each of the five sites. However, due to time constraints they were conducted in just three sites. In total, eight audio-recorded focus group discussions, each lasting approximately one hour, were conducted; six in Nepal's rural site, one in Nepal's urban site and one in the urban site in Pakistan. Soon after each focus group discussion was conducted I telephoned the research partners to discuss the content and process. The audio-recordings were then translated into English and sent to me by email for analysis, together with any notes made by the researchers about the composition, dynamics and setting of the focus group discussions. Each of the transcripts was assigned a unique name comprising the letters 'n' or 'p' (for Nepal or Pakistan), followed by an 'r' or 'u' (for rural or urban site), followed by 'FGD' (for focus group discussion) and a number.

The first focus group discussion to be conducted was in the rural site in Nepal. In a telephone conversation, followed up with an email, the researchers in Nepal and I agreed that the first focus group would comprise up to eight female community members. We had learned from the preparatory focus group discussions conducted at the start of this study that focus groups comprising a maximum of eight participants are preferable for the facilitation and adequate sound recording of discussions. The eight female community members for the first focus group were to be both indigenous and migrant, aged 40+ years and all with a similar educational level. From the preparatory focus groups the researchers discovered that having people of different statuses within one group (e.g. a mother- and daughter-in-law) can inhibit some from participating, so by restricting participation to only those of a certain age it was hoped that this would be prevented. The participants were recruited with the assistance of a health worker and community health volunteer.

nrFGD1. Women aged 40+ years with mixed residency (07/12/2008)

In reality, the seven participants were aged 27-45 years, a wider age range than intended, but all were married and either literate or semi-literate. Two were indigenous to the area and the remaining five had migrated to Lalitpur district.

As the first focus group comprised mostly women younger than 40 years, for the second focus group with female community members, women older than 40 years were sought.

nrFGD2. Women aged 40+ years with mixed residency, all of a similar educational level (21/12/2008)

This focus group comprised ten women aged 38-65 years, all with no or limited literacy, and all indigenous to the area. Not all could speak Nepali, as their mother tongue was Newari, and although some of the discussion was dual-language, those with very little knowledge of Nepali remained silent.

Two focus group discussions were to be conducted, each with up to eight men of working age (approximately 20-40 years). As with the previous focus groups, homogeneity in terms of educational background was sought. One of these focus

groups was to comprise men indigenous to the area and the other migrants to the area. From the interviews it seemed that those indigenous to an area may have the advantage of having family nearby for support and eligibility to land (so having no need to pay rent and perhaps having some income from farming), but that they may also find it harder to conceal their TB diagnosis and may notice changes in the attitudes or behaviours of others more.

nrFGD3. Men of working age, indigenous to the area (30/12/2008)

nrFGD4. Men of working age, migrant to the area (24/01/2009)

The first of the two focus groups with men comprised nine participants aged 20-45 years, all literate and all indigenous to the area (Godawari). The second comprised six men aged 24-45 years, all either literate or semi-literate and all migrant to the area.

Two focus group discussions were also conducted with men and women with TB in the rural site. As recruiting participants for these focus groups was anticipated to be more difficult than for those with general community members, no additional criteria was specified and a minimum number of four per group was set.

nrFGD5. Women with TB (08/01/2009)

nrFGD6. Men with TB (17/02/2009)

The focus group with women with TB contained five participants aged 15-30 years, four of whom were aged 20 or younger and were unmarried secondary school students. The eldest participant was a married housewife and literate. The focus group with men with TB contained five participants aged 33-50 years, all either literate or semi-literate and all married.

Having by February analysed all the interview transcripts from the urban site in Nepal, I developed a focus group discussion guide for the urban site which I sent to the research partner in Nepal together with a document explaining the content and aims of the vignettes. Following email correspondence with the researchers, some

aspects of the guide were amended and clarified and the first focus group discussion was conducted in the urban site with women with TB.

nuFGD1. Women with TB (02/03/2009)

The focus group comprised six participants aged 14-25 years. All were literate with either primary or secondary school education. Half were married and half unmarried, varying in ethnicity and caste as well as in area of origin. Four had sputum positive pulmonary TB and two had extrapulmonary TB.

Although I had specified that participants should be no younger than 16 years and had stated in the ethics application that no children would be involved in the research, two focus groups (nrFGD5 and nuFGD1) each contained a participant under 16 years. However, as with all other participants, they gave informed consent to participate and were free to participate as much or as little as they wanted.

Following analysis of all the interviews conducted in Pakistan's urban site, I developed a focus group discussion guide featuring vignettes tailored to female community members or women with TB. I sent the guide together with an explanation of the content and aims of the vignettes to the research team in Pakistan for comments. I requested that a focus group discussion be conducted with female community members aged 18-25 years, as we thought it likely that women of this age would be either unmarried or recently married, and TB's impact on marriage prospects and marital accord was one of the issues to be explored through the vignettes. Whilst the criteria for participation (18-25 year old women) was specified, the seven women recruited by an intermediary/gate keeper were in reality from a wider age range (24-45 years) and consequently all married.

puFGD1. Female community members (19/02/09)

As the grant funding this research was due to end at the beginning of May and time for transcription and further analysis was still needed before the findings could be written up in reports and discussed at workshops with National TB Control Programme staff in the three countries, we decided to stop data collection at this point.

5.4 Analysis of focus group data

As with the interviews, as often as possible I telephoned the research partners to discuss the process and content of a focus group discussion soon after it had been conducted. The focus group discussions were translated directly from the audio-recordings and the transcripts sent to me by email. The transcript for the first focus group discussion conducted in Nepal (nuFGD1) was sent to me before any further focus group discussions were conducted. This enabled me to check the quality and depth of the data and to give the researchers feedback on their facilitation.

The transcription of the first focus group discussion was hampered by the Nepal Electricity Authority's increase in load shedding which meant the research partner's office only had 2-3 hours of electricity per day – insufficient time for the backup generator to fully charge. Nevertheless, computer access aside, transcription was relatively easy as the translator/transcriber had also been the note-taker during the focus group discussion and so could easily identify participants' voices. By contrast, the second focus group discussion (nrFGD2) was more difficult to translate, requiring two people and more time, as the participants had discussed in both Nepali and Newari. So as not to delay progress, while the second focus group discussion was still being translated a further two focus group discussions were conducted (nrFGD3 and nrFGD5). Once I had received the transcripts for the second, third and fourth focus group discussions, I read them through and gave feedback on the facilitation. The researchers then conducted and transcribed the fourth focus group discussion (nrFGD4) which I analysed and discussed with them before the final focus group discussion in the rural site (nrFGD6) and the first and final focus group discussion in the urban site (nuFGD1) were conducted.

In Pakistan, the first and final focus group discussion in the urban site (puFGD1), the vignettes for which were based on the analysis of the urban interview data, was conducted while the final interviews in the rural site were still being conducted and transcribed. Once data collection was complete, I re-read the focus group transcripts and added memos and references to my notes from the interview data analysis. For the most part, the focus group data confirmed, elaborated upon and added clarity to my emerging theoretical understanding of TB 'stigma'.

5.5 Analytical writing

By incorporating my theorising from the interview data into vignettes for the focus group discussions, I sought to obtain data which would confirm, challenge and enhance my developing theories. Whilst the focus group discussion data certainly did this, the theories were only really consolidated once I had all the data available to me and the time and clarity of thought to clearly articulate both the explanatory theories and what they sought to explain.

At the time of the focus groups, which were closely followed by writing the end of project reports for the funder (ESRC-DFID) and the National TB Control Programmes, I had not yet determined which of the multiple and disparate behaviours, attitudes and emotions constituted manifestations of TB-related stigma. Whilst the stigma definition which guided the study was intentionally broad, it contained two fundamental prerequisites: that a behaviour, attitude or emotion be both negative *and* TB-related. Some of the potential manifestations identified through the interviews were only sometimes deemed negative by some people. For example, concealing a TB disease was sometimes spoken of as negative, relating to fear of consequences of disclosure, and sometimes as positive (for example, not wanting to cause others to worry) or as neither positive nor negative (for example, not seeing any point in telling others). Likewise, the avoidance of other people by those with TB was sometimes linked with the anticipation that others would be fearful or hateful, and sometimes spoken of as a necessary or simply precautionary behaviour when ill or contagious. Other potential manifestations identified through the interviews did not appear to be always directly TB-related. For example, when those with TB spoke of tensions with other family members following their TB diagnosis, probing often revealed that these tensions pre-existed the diagnosis or that they related to the disruptiveness and financial burden of an illness such as TB, rather than to TB specifically. Developing theories to explain family tensions, avoidance of others or concealing a diagnosis in terms of stigma would ignore the many other terms in which these experiences could be explained.

At this point I made the conscious decision to present within the reports to the funder and the National TB Control Programmes both the negative and the conditionally negative themes which either directly related to TB or were less directly associated with TB. I justified this on two counts. Firstly, getting entangled in a debate over what constitutes stigma would impede progress and the end-of-grant reports had to be submitted by a set and fast approaching deadline.

Secondly, whether stigma or not, themes such as ‘the financial disruptiveness of TB’ and ‘family tensions’ emerged strongly from the data as important to those interviewed.

After the reports had been submitted to the funder and sent to the National TB Control Programmes in each of the three countries, I took some time away from the data and then returned to it with fresher eyes and without the pressure of an impending deadline. I realised that the behaviours that I had identified as conditionally stigma-related, such as avoiding others, being avoided by others or not disclosing a TB diagnosis to others, all became stigma-related (according to the definition presented in Chapter 2) under one condition. Whilst those interviewed gave the behaviours multiple (positive, negative and neutral) explanations, the condition under which they all became negative was when they were associated with the *perception* that people with TB are hated. In other words, avoiding others or withholding a TB diagnosis for fear that others will be hateful towards you, or interpreting the avoidance of others as being hateful, are all indisputably negative. It is therefore the perception that people with TB are hated, rather than the behaviours perceived to be hateful, that requires explanation.

A second manifestation of TB-related stigma identified was the attribution of blame for TB disease and a third was the anticipation or experience of reduced marriage prospects following a TB diagnosis. As with the perception that people with TB are hated, none of the research participants spoke of the attribution of blame or the anticipation or experience of reduced marriage prospects as positive or as neither positive nor negative. Therefore, the three manifestations, identified from my analysis of the data as being both TB-related *and* unconditionally or inherently negative, are:

- 1) Reduced marriage prospects following a TB diagnosis
- 2) The perception that people with TB are hated
- 3) Blame for TB disease (especially if severe or recurrent)

Having identified specific TB stigma manifestations, my next task was to consolidate my theorising into realist causal theories. This I did through the process of writing and re-writing (as well as presenting at conferences and seminars), a process during which I kept going back to the original data. In the next three

chapters (Chapters 6-8) I present my consolidated causal theories to explain each of the above three manifestations of TB stigma.

5.6 Summary

Having begun to theorise about potential TB stigma manifestations through the individual in-depth interviews (described in the previous chapter), I then incorporated my theorising into vignettes which formed the basis for discussions with eight focus groups across three sites in two countries (Nepal and Pakistan). These vignettes enabled me to check, explore and expand on theoretical propositions discovered through the interview data. It was only once I began analytical writing that I was able to articulate three specific manifestations of TB stigma and consolidate the sets of propositions to explain them. Using the realist ontology of causality described in Chapter 2, I sought to answer why, for whom and in what circumstances each of the three TB stigma manifestations is experienced.

Chapter 6

REDUCED MARRIAGE PROSPECTS

Consistent with previous research on TB in South Asia (Somma et al., 2008; Liefoghe et al., 1995; Ganapathy et al., 2008; Nair et al., 1997; Atre et al., 2009), the negative impact of TB on marriage and marriage prospects, particularly for women, was raised by participants of the focus group discussions conducted at the preparatory stage of the study. Because of this, the first stage of sampling, as described in Chapter 4, involved recruiting both married (including recently married) and unmarried men and women with TB for the interviews. The analysis of these interviews both informed subsequent sampling and generated ideas to be explored in subsequent interviews.

In this chapter I present, with reference to interview and focus group data, a realist causal theory to explain how, for whom and in what circumstances TB reduces marriage prospects. I begin, in section 6.1, by considering whether it is reduced marriage prospects or the anticipation of reduced marriage prospects that is the manifestation of TB stigma identified from the research data. I then explain the strong gender dimension of this TB stigma manifestation which relates to the impact of TB (and its treatment) on the evaluation of a woman as a prospective wife and mother (section 6.2), before considering why, when TB reduces a person's desirability as a spouse, some people are still considered to be or have good marriage prospects (section 6.3).

Before considering, in section 6.5, the explanatory theory in relation to the conceptual model presented in Chapter 2, I will present findings relating to the ability of those with TB to determine whether and to whom their diagnosis is disclosed (section 6.4) – what Goffman (1963) refers to as “the management of undisclosed discrediting information about self” (p58). Whilst not part of the causal theory, this is of relevance to the final section (6.6) in which I consider the opportunities, based on the causal theory developed and the findings presented, for National TB Control Programmes to address this specific manifestation of TB stigma.

6.1 Anticipation or experience?

Across the research sites in all three countries research participants spoke of concerns regarding marriage prospects. In the two sites in Pakistan, two of those interviewed (pu6 and pr8) even defined the English term 'stigma' as reduced marriage prospects following a TB diagnosis. However, whilst most of those interviewed anticipated that those who are unmarried would have problems getting married following a TB diagnosis, many did not personally know of anyone who had. This may be because the majority of people with TB are already married. Most cases of TB occur in the age group 15-54 years (WHO/SEARO, 2009). Near the lowest end of this range are the average ages of marriage for women, which are 18 years in Bangladesh and Nepal and 21 years in Pakistan, and for men, which are 24 years in Bangladesh, 22 years in Nepal and 21 years in Pakistan (United Nations, 2000). Furthermore, research participants anticipated that TB would have a greater impact on the marriage prospects of women than on those of men. Fewer women than men have TB disease, with a 2:1 male/female ratio among newly detected cases (WHO/SEARO, 2009), although this is reversing in areas with high rates of HIV (Marais et al., 2010). It is therefore possible that the research participants may not have personally known of anyone who had had problems getting married because of TB, because they had not personally known of any unmarried women with TB. However, it may also be because unmarried women and their families conceal the TB from others in their communities in anticipation of difficulties. Certainly the health workers interviewed reported that unmarried women in particular are anxious that their diagnoses be kept confidential.

If the research participants did not personally know of any unmarried women who had had difficulties getting married because of TB, then why did they anticipate that unmarried women would have difficulties? Steward et al. (2008) in their paper on HIV-related stigma in India have coined the term *vicarious stigma*, which I refer to in Chapter 2, section 2.2.6. Vicarious stigma refers to anticipated stigma fuelled not by personal experiences or experiences observed first-hand, but by stories shared, through word-of-mouth or the media, about other people being rejected or devalued. However, the data from this study indicates that the anticipation of reduced marriage prospects is not fuelled by the sharing of stories, or at least not fuelled by the sharing of stories alone. This is illustrated by the quote below.

I haven't known any woman [who couldn't get married because she had TB]. It's from my own perception that I'm telling you she would have problems. I

haven't heard of it happening to a woman either. It's from my own thinking that this type of problem could occur. (b2, man with TB, Bangladesh)

Across all three countries, for parents especially, ensuring their children marry was found to be a matter of great concern regardless of whether they or their children had TB. Whilst TB exacerbates this worry, the data suggests that worry is exacerbated not by TB *per se*, but by illness in general.

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

"If someone hears that an unmarried girl has TB, there would be a problem with her marriage. Who will marry a diseased girl?" (b2, man with TB, Bangladesh)

Supporting the idea that "*all types of diseases*" (puFGD-R2) affect marriage prospects, research studies conducted in South Asia on the stigma associated with other diseases, such as leprosy and thalassemia, have found reduced marriage prospects to be similarly of concern (Try, 2006; Chattopadhyay, 2006). However, in the context of South Asia, TB may be of particular concern because of its much higher prevalence. For example, there were an estimated 148,198 new cases of TB in Bangladesh in 2011, but only 3970 new cases of leprosy (WHO, 2012; WHO, 2013a). Furthermore, as will be discussed in Chapter 7, TB's severity and its lengthy and disruptive treatment, as well as its transmissibility, contribute towards it being viewed as a dangerous and feared disease. However, just as not all diseases are likely to be of equal concern, TB is not of concern to all equally. As the quote above, from a man with TB in Bangladesh states: "Who will marry a diseased *girl?*".

6.2 Marriage and gender

From the interviews conducted across all three countries there was generally a view that the negative social consequences of TB, and in particular the detrimental impact on marriage prospects, are more pronounced for women than for men. This was thought to be partly because of overall gender inequalities.

“There is a culture of keeping females at a lower level than males.” (nrFGD4-R3, male focus group participant, rural site, Nepal)

“In our society no one blames a man. All faults go to women []. Our people can't ignore even the very small faults of women, but they constantly ignore the big faults of men.” (b3, woman with TB, Bangladesh)

However, simply attributing the gender dimension of this particular manifestation of TB stigma to overall gender inequalities is inadequate for understanding how National TB Control Programmes may be able to effectively and realistically address this manifestation of TB stigma. Through the interwoven processes of data collection and analysis, I sought to build a theoretical understanding of the relationships between TB, marriage prospects and gender in the contexts of the research sites. At the centre of the theoretical understanding built are contextualised gendered roles and responsibilities.

6.2.1 A hard-working wife

Consistent with the general view expressed by participants that there is overall gender inequality, an unmarried man with TB in Nepal (nr7) said that society is harder on women if they have any disease, but also if they do not (or are not able to) work hard. The impact of TB on a person's ability to work, and in particular on a woman's ability to work, may be as much of an issue as the TB itself. This idea was supported across the interviews.

“With TB people become weak. They have difficulties in doing their work. People say it is better to have no relations with them.” (pr14, man with TB, rural site, Pakistan)

“No one will get married to a diseased person. Everyone looks first and only then gets married. [...] they marry someone who is able to work.” (nrFGD3-R3, male focus group participant, rural site, Nepal)

In the research sites marriages are often arranged between families, and participants said that being healthy and hard-working are characteristics sought in both a bride and a groom. However, the groom's financial status emerged as equally if not more important.

“If a boy is not financially strong then no one will consider him [for marriage], but if a boy is financially strong then [they] will.” (pr9, ‘Lady Health Worker’, rural site, Pakistan)

TB disease can be detrimental to a person's health, their ability to work hard, and their ‘financial strength’, and indeed the financial strain and consequences of TB emerged as a prominent theme throughout the interviews and focus groups. However, in all five study sites it is customary after marriage for a woman to join her husband's household, living with his parents and sometimes siblings too. Because of this, ‘financial strength’ may be a family characteristic rather than an individual characteristic. Therefore, even if a prospective groom is unwell and unable to work, this may be compensated for by the status of his family and the ability of other family members to provide an income.

To understand why being hard-working is deemed particularly important in a prospective wife, it is necessary to consider the role and responsibilities of a wife in the contexts of the research sites. In one of the preparatory focus groups, a participant had implied that a wife's role is to care for her husband, rather than be cared for by him, suggesting that her becoming ill would conflict with this spousal role. Because of this, the research teams and I began exploring the relationship between TB and spousal roles from the very first interviews conducted.

Consistent with the preparatory focus group, a married woman interviewed in Pakistan described her role as a wife as being to *“take care of my home, my husband, [...] give him breakfast, do the washing, take care of my kids, fulfil their needs”* (pu4). Another married woman in the same site in Pakistan (pu14) described how this role had been jeopardised by her TB diagnosis and said that her husband had been advised to leave her as a result. When asked what she thought would have happened if their situations had been reversed, she said she thought she would have been advised to stay and take care of him.

“[A wife] has a lot to do at home by herself. People otherwise taunt her that she is sick. [A man is not taunted in this way] as the household belongs to him.”
(pu14, a married woman with TB, urban site, Pakistan)

If a wife is unable to work because of illness, this not only makes her unable to fulfil her role as a wife, but, living in her husband’s family’s household, it may also result in a greater workload for her mother-in-law and, until they get married, any unmarried sisters-in-law. It is therefore in the interest of not just the husband, but also his mother in particular, that he has a healthy, hard-working wife.

“Some [families] may need a daughter-in-law who can do household activities. An ill person cannot do such work.” (nrFGD5-R2, female focus group participant, rural site, Nepal)

In Bangladesh, a perception that abstinence from food preparation is necessary when a person has TB may further compound the problem for women, although it is unclear from this study whether food preparation by a woman with TB is thought to pose a risk to others, or to jeopardise her own health.

“[If a woman has TB] there will be more problems. They can’t cook, they are not allowed to cook. Even they are not allowed to go to the kitchen sometimes.” (b4, married man with TB, Bangladesh)

Whilst in the interviews conducted in Nepal and Pakistan no reference was made specifically to the need to abstain from food preparation, emphasis was given to not sharing food and eating utensils for the prevention of TB transmission. As Try (2006) writes in her paper on leprosy stigma within the Maithili ethnic group in Nepal, restrictions over the daily activity of food preparation affect women more than men, as the socially expected role of women is located within the domestic sphere.

6.2.2 A healthy mother

Across all three countries, some of those interviewed expressed concerns over the potential risks of TB to a pregnancy or to an infant. As a result a TB diagnosis can

be seen as particularly problematic for a woman who is pregnant or who is wanting or expected to become pregnant, such as a soon-to-be or newly married woman.

“Born from that person with TB [a baby] can get TB [...] because the baby is in the womb of an infected mother who already has TB [...] If at that time that baby does not get [TB] then it may be affected in later life.” (nu16, women with past TB, urban site, Nepal)

“If a mother has TB her baby can get it from her. [...] I think if a father has TB his baby will not get this from him because a man doesn’t bear the child in his body.” (b10, man with TB, Bangladesh)

Indeed, untreated TB in pregnancy has been associated with poor obstetric and perinatal outcomes, including premature birth, low birth weight and perinatal death (Marais et al., 2010; Getahun et al., 2012). Very rarely, the foetus can be infected in utero via the umbilical cord, but the greater risk of infection is after birth if the mother has untreated infectious pulmonary TB or if she has been taking treatment for less than two weeks (Ormerod, 2001). However, the data from this research suggests there are still concerns about the transmission of TB from mother to child, even if the mother’s TB is not thought to pose a risk to adults. This is because of the heightened vulnerability of infants to TB infection perceived by the research participants and indeed confirmed by the WHO (WHO, n.d.).

That children are thought to be particularly vulnerable to TB infection first emerged early on in the interviews (see Chapter 4, section 4.5) and recurred in later interviews across all sites. A research participant in Nepal (nu13) said that her mother-in-law, who had been diagnosed with extrapulmonary TB, had been told by a health worker that she was not infectious, but that she should limit contact with her grandchildren anyway as a precaution. Although this was the experience of a grandmother, it seems plausible that concerns about the particular vulnerability of infants and children may contribute to concerns about marriage to (and having children with) a woman with current or indeed treated TB.

The developing overarching idea that the social consequences of TB relate to TB’s disruptiveness to gendered roles and responsibilities (such as those of wife and mother) informed the sampling decision to specifically include people with TB who

have young children (see section 4.5). One of these (pu4) had been diagnosed with TB during pregnancy and her experiences highlight just how disruptive TB can be, not just to the role of wife, but also to becoming and being a mother. She said that she had been diagnosed just after giving birth and that her immediate admission to a sanatorium for treatment meant that she had not been able to see her baby for the first month of its life. Even once discharged she was forbidden physical contact with her baby until completion of her nine month course of treatment, during which time it was cared for by her mother-in-law.

Even if TB is diagnosed before or early in pregnancy, concerns were expressed by some participants about the safety of TB drugs during pregnancy, although this issue was not fully explored in the interviews and focus groups. According to the WHO (1998), first line anti-TB drugs, namely isoniazid, rifampicin, pyrazinamide and ethambutol, are safe for use in pregnancy. However, previous qualitative research with people with TB in Pakistan suggests that, even if known to be safe, TB drugs are believed to be less well tolerated and less effective in pregnancy (Liefoghe et al., 1995).

6.2.3 The long-term impact of TB on marriage prospects

If, because of the heightened vulnerability of infants and children, it is deemed wise for a person with non-infectious or treated TB to err on the side of caution and limit contact with children, then it is within the realms of possibility that it may be deemed wise to err on the side of caution and not marry (and have children with) a woman who has had TB in the past. Indeed, focus group research conducted in Pakistan by Liefoghe et al. (1995) suggests that the marriage prospects of people with TB remain diminished even after cure.

A definitive statement about the longevity of TB's impact on marriage prospects cannot be made on the basis of the data from the present study. Participants' views were mixed and, just as the relationship between marriage prospects and current TB is context-dependent (as will be highlighted in the following section, 6.3), so is the relationship between marriage prospects and past TB. However, theoretical propositions can be drawn out from my analysis, which could serve as useful spring-boards for future research seeking to develop a theoretical understanding of marriage prospects over time. One such proposition, as stated in the previous section (6.2.2 A healthy mother), relates to the perception that a woman's past or treated TB can potentially pose a risk to her and her child both during and after

pregnancy. Another relates to the idea of 'a hard-working wife' and the reality of TB's longer term impact on health and a person's ability to work hard. If not treated early, pulmonary TB can cause permanent damage to the lungs and extrapulmonary TB, which can be particularly difficult to diagnose and therefore treat early, can also cause permanent damage to whichever part of the body is infected (Elder, 1992).

Even for those whose TB is treated promptly and effectively, causing no permanent damage, there are potential long-term implications for women of marriageable age of delaying marriage until treatment completion. Treatment of TB requires a six month or more course of drug therapy and participants generally considered it preferable to delay marriage until the course has been completed. In all five sites, it was evident that women are generally expected to get married at a younger age than men and that the optimum age range for marriage for women is lower and narrower than that for men. Consistent with this, and as stated earlier (in section 6.1), the average ages at first marriage for women in Bangladesh, Nepal and Pakistan are 18, 21 and 21 years respectively, whereas for men they are 24, 22 and 26 years respectively (United Nations, 2000). A woman in her late teens or early twenties who delays marriage for six months or more because she is taking treatment for TB could find herself at an age considered too old for marriage.

This idea, that the *length* of TB treatment could affect marriage prospects, particularly of women, developed from an interview with a woman with TB in Nepal (nr4). She implied that she had married late at the age of 25 years because of an 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 suspected extrapulmonary TB. Subsequent focus group discussions explored and confirmed the idea that for a woman in Nepal marrying at 25 years of age is considered late and would arouse suspicion.

"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." (nrFGD3-R3, a male focus group participant, rural site, Nepal)

However, the focus group participants also raised the idea that marriage at 25 years of age would arouse less speculation and suspicion if a woman has been engaged in education or employment.

6.3 For whom and in what circumstances?

Having developed explanations as to why the impact of TB on marriage prospects is anticipated to be greater for women than for men, I will develop the explanatory theory further by considering variation in the anticipation of a negative impact of TB on the marriage prospects of women. For which women, in which circumstances does a TB diagnosis reduce marriage prospects? From the data, a number of factors which appear to safeguard marriage prospects were identified. These include having other desired characteristics, which compensate for the TB, and, associated with this, family approval of a marriage, as well as having multiple potential marriage partners.

In the urban site in Pakistan, a woman with TB studying to become a nurse had received a proposal prior to her diagnosis and said the marriage was still likely to go ahead, theorising that her education and future earning potential were highly valued, outweighing the negative implications of her ill-health.

“If a girl is doing a job then there is no problem. If that girl is just a housewife then there can be many problems. Nowadays everyone wants a daughter-in-law who earns money” (pu5, woman with TB, urban site, Pakistan).

In Nepal, one of the female focus group participants (nrFGD5) said that if a groom-to-be likes and especially loves the bride-to-be he will think the illness is curable and will marry her anyway. However, in contexts where marriages are often arranged between families, emotional ties between a couple do not invariably make marriage more likely in the face of a TB diagnosis. Indeed, if the marriage has already taken place, some of those interviewed in Pakistan and Bangladesh anticipated tension between the new wife and her in-laws, and the potential for divorce, regardless of whether the wife is loved by her husband. Consistent with this, a volunteer health worker interviewed in Bangladesh (b11) told of the husband of a woman with TB who requested that she not disclose his wife's TB to his family members, that she not come to their home and that he collect his wife's treatment

weekly rather than his wife having to do so daily, so as not to arouse suspicion. He was particularly worried that his mother might ask his wife to leave if she found out about the TB.

The importance of family approval of a marriage is highlighted in a story told by a female community health worker, known as a Lady Health Worker, in Pakistan. She described a case she knew of where a man married a woman in Lahore and returned with her to his family. After just one month of marriage she was diagnosed with TB and he divorced her. On the face of it, it appears the divorce was due to her TB or at least her ill health, but the man had married for love without his parents' approval, and following her illness and confirmed diagnosis his parents insisted that they divorce. Her confirmed poor health provided them with a 'legitimate' reason to insist on the dissolution of a marriage of which they already disapproved.

"His mother said 'You have brought an ill girl from Lahore. Who told you to marry out of this family?' That is why she was divorced. [...] In spite of [knowing TB is curable] they forced their son to divorce his wife because it was a love marriage." (pr9, Lady Health Worker, rural site, Pakistan)

The disapproval for marrying "out of this family", expressed in the above quote, refers to the custom of consanguineous or cousin marriage. Consanguineous marriage is practised in all three countries included in this study, although not among the ethnic groups, including Newar and Hindu castes, to which the research participants in the urban and rural sites in Nepal belonged (Subedi, 2001). Whilst participants from the sites in Bangladesh and Pakistan emphasised good health and being hard-working as desirable characteristics in a bride or groom, being from within the extended family was seen as equally, if not more, important. A cousin with TB may be a more desirable prospective bride (or a niece with TB may be a more desirable daughter-in-law) than a woman without TB who is unrelated.

"My in-laws have this concept that first of all they want the girl to be from their own family. Obviously they also check that the girl is in good health. Nobody wants to have a daughter-in-law who is not healthy." (puFGD-R5, a female focus group participant, urban site, Pakistan)

Finally, marriage prospects may be greater, and the impact of TB therefore less, if a woman has many potential eligible marriage partners. For example, if, due to TB and its lengthy treatment, a woman's marriage to her cousin does not go ahead, then it is not her last opportunity to marry if she has many other as yet unmarried cousins to marry once she is in good health again.

"Here it's a family system where one individual has at least three or four proposals. It's not an issue. [If I had not been married] then there would have been problems obviously [...] 'We are not giving you our daughter as you are ill'. But in our family it doesn't happen as we have four or five relations. For example, my wife is my cousin from my father's side [...] so no such problem occurs." (pr4, married man with TB, rural site, Pakistan)

Whilst the anticipated impact of TB on marriage prospects may be less for women with other desired characteristics (such as an education and earning potential, or, where consanguineous marriage is practised, being from within the same extended family), in the absence of such characteristics, or of absolute confidence that these characteristics will compensate for TB disease, being able to keep a TB diagnosis confidential takes on particular importance. Unmarried women with TB in particular expressed concern or were reported to be anxious about the confidentiality of health services and their own ability to conceal their diagnosis from others.

6.4 Confidentiality and disclosure

Although it is within the capacities of National TB Control Programmes to lessen the impact of TB on people's health and their ability to work hard (see 6.6.1), it is not within their capacities to either increase compensating factors, such as social standing and educational levels, or to change the contexts in which good health and hard work are highly valued. Although it has been argued that to reduce stigma its deep-rooted or fundamental causes need to be addressed (Link and Phelan, 2001), there is also a case to be made for simultaneously enabling people to manage stigma. Reducing the evidentness of TB would enable people with TB to determine to whom their TB is disclosed and to consequently protect their marriage prospects. In this section I present the findings relating to the influence of TB service provision on TB's evidentness and, in section 6.6.2, will draw out the opportunities for National TB Control Programmes to address TB's impact on marriage prospects by reducing TB's evidentness.

Amongst the participants of this research study, disclosure of a TB diagnosis was generally considered to be very important in order to receive support.

“Nobody will provide support if he does not tell his problems. Disease will become serious if he does not say.” (NRFGDMpt1-R5, man with TB participating in focus group discussion, rural site, Nepal)

However, disclosure beyond immediate family or friends (or beyond those able to provide support) was not just deemed unnecessary but sometimes also undesirable because of the anticipation of negative consequences.

Attempting to actively conceal an illness can be difficult, not least because the physical symptoms may be apparent to others but also because of the need to access and take regular treatment over a long period of time. In Pakistan, a man with TB in the rural site (pr4) said that he did not initially want to tell his friends about his TB but that he found concealing his diagnosis from them impossible as he had to explain why he was taking time off work and what his medicines were treating. Difficulties in accessing treatment confidentially are thought to be particularly pronounced for women, as illustrated by the following quote from a woman with TB in Bangladesh:

“In the case of men, they can easily go for medicine to the centre. No one asks them. But when any girl goes to the centre, everyone asks why, why has she gone there, what is her problem? It is very embarrassing.” (b7, woman with TB, Bangladesh)

In Nepal, a woman with TB interviewed (nu3) pointed out that, while there is variation from family to family, a woman is usually asked where she is going, with whom, when she will be back and so on, whilst a man is freer to move around without being questioned. Indeed, in Pakistan participants said that it is expected that a woman be escorted to a health facility by her husband or a male relative. However, even in the absence of such an expectation, discrepant literacy rates between men and women may make being escorted a necessity. According to a

man interviewed in the rural site in Nepal (nr16), women cannot go to the health facilities on their own as they are often illiterate.

“How can we send a female alone? She can’t read so wherever she goes she needs a male along with her.” (nr16, man with past TB, rural site, Nepal)

As well as TB being difficult to conceal because of the need to access health services frequently and over a lengthy period of time for treatment, health workers themselves may divulge the diagnoses of their patients. This is particularly likely, according to a health worker in the rural site in Pakistan (pr8) if the health worker lives in the same village as the patient.

“If the health worker knows then everybody will come to know about this.” (pr8, male health worker, rural site, Pakistan)

“I think most of [my neighbours] know. Most know from the health centre, before I informed them.” (b6, man with TB, Bangladesh)

Whilst a man with TB (nu2) spoke positively about how during holidays, when the clinic is shut, the health worker comes to his home to give him his treatment, a woman with TB (nr4) living in the rural site in Nepal described how she was terrified when the doctor came to her home that he might disclose her TB to her husband and neighbours.

As the theme of disclosure emerged strongly from the analysis of the interviews with people with TB and their family members, we asked in the interviews with health workers and TB volunteers how the responsibility for tracing patients who have not attended clinic appointments and the patients’ desire for confidentiality are managed (see section 4.5). A volunteer health worker interviewed in Bangladesh was quite clear that the patient’s right to confidentiality is not as great a priority for her as protecting the public’s health by ensuring adherence to treatment (referred to as Directly Observed Treatment, Short-course or DOTS – a core component of the national and global TB strategies at the time of data collection).

“Actually patients should handle their family problems. I’m responsible for ensuring DOTS is adhered to for the sake of other community members.” (b11, volunteer health worker, Bangladesh)

Likewise, in Nepal a TB volunteer interviewed (nu15), whose role included tracing patients who had not come for treatment, did not deem confidentiality of the patient’s TB status to be important and strongly felt that people with TB should disclose, both for their sake and for the sake of others. The need to ensure TB treatment adherence was clearly prioritised over and above patients’ needs or desires for confidentiality.

6.5 Reflections on the explanatory theory

In Chapter 2, I presented a broad definition of TB stigma manifestations within which specific locally-defined manifestations can be placed. One such specific manifestation is the negative effect, whether anticipated or experienced, of TB on marriage prospects, and in particular, on the marriage prospects of women. This manifestation emerged from the data across all five research sites, was defined as negative and TB-related by the research participants themselves, and has been reported in previously published research (Somma et al., 2008; Liefoghe et al., 1995; Atre et al., 2009; Nair et al., 1997; Ganapathy et al., 2008).

At the centre of the explanatory theory is the valuation of a prospective wife or daughter-in-law on the basis of her health and ability and willingness to work hard. Whilst Gangestad, Haselton and Buss (2006) link such ‘mate preference’ with *parasite avoidance* (as stated in section 2.2.3) – and indeed this may play a role – the valuation process is perhaps particularly likely to be deeply rooted in *dyadic cooperation*. As outlined in Chapter 2 (section 2.2.3), dyadic cooperation is a functional or evolutionary process which refers to the avoidance or rejection of social relationships where the cost is greater than the benefit. It is easy to see how this process might underlie the assessment of a prospective bride or groom, particularly in contexts where marriages are arranged between families, and thus where the costs and benefits of a prospective marital relationship are consciously considered. Whilst the concept of dyadic cooperation does not, on its own, constitute the explanatory theory needed to underpin measures to address the negative impact of TB on marriage prospects, it does nevertheless constitute an important part of it. To be effective, measures to reduce manifestations of TB

stigma need to work with, rather than against, deeply-rooted processes which are fundamentally human. For example, measures which attempt to persuade individuals, families and communities to accept marriages where the costs are deemed greater than the benefits, are unlikely to work. By contrast, measures which focus on reducing or compensating for the costs of marriage to someone with TB are far more likely to work. These measures need to be underpinned by a grounded theoretical understanding of how, for whom and in what circumstances TB constitutes a cost in relation to marriage.

In Chapter 2, section 2.2.4, I wrote that Goffman (1963) did not view any attribute as inherently stigmatising, but that instead a number of factors influence whether a person with a potentially stigmatised attribute experiences stigma. These factors were expanded upon by Jones et al. (1984) and referred to as dimensions of stigma. Of the dimensions, it is 'disruptiveness' which comes to the fore in my explanatory theory of TB's impact on marriage prospects in the South Asian contexts, and both 'disruptiveness' and 'evidentness' which require attention in considering how this, as a manifestation of TB stigma, could be addressed by National TB Control Programmes.

Disruptiveness refers to how much an attribute or condition – in this case TB – interferes with 'normal' life and social interactions. Goffman (1963) also writes about the "perceived focus" of the disruptiveness which refers to whether the stigmatised attribute is perceived to interfere with the ability to perform specific individual tasks or with social interactions generally, with this influencing the extent to which others can overlook what he refers to as the perceived "failing" (p66). In the following chapter, I explain how TB can interfere with social interactions generally, particularly when deemed infectious, and so, at least for a limited time period, cannot be easily overlooked. However, in addition to this, TB specifically interferes with individual tasks relating to socially expected gendered roles, in particular those of wife and mother. In the contexts of the research sites where a woman moves into her husband's household after marriage and is expected to take care of her husband, his family and the home (relieving her mother-in-law of responsibilities), the ability to work hard (and to take care of others rather than to be taken care of by others) is central to fulfilling the socially expected role of wife. Physical illness and the additional practical difficulties for women of accessing treatment (relating to, for example, restrictions on movement and illiteracy) interfere with the ability to work hard generally, whilst restrictions on food preparation and contact with shared eating utensils (discussed also in Chapter 7) interfere with the ability to work hard in

the domestic sphere specifically. Furthermore, concerns over the potential risks of TB and TB treatment during pregnancy and the perceived heightened vulnerability to TB infection of infants and children make TB particularly problematic for women wanting to become or expected to become pregnant, such as soon-to-be or newly married women.

The threat of divorce following a TB diagnosis, whilst not as prominent as TB's impact on marriage prospects, nevertheless emerged as a concern for some, particularly in the sites in Bangladesh and Pakistan, with some of those interviewed reporting that relatives or neighbours had advised that a married woman with TB either be divorced or that she conceal her TB for fear of divorce. The interference or disruptiveness of TB to the roles of wife (or daughter-in-law) and mother, can both explain why, if unmarried, a woman with TB may be considered less favourably as a prospective wife or daughter-in-law, and why, if married, a wife may anticipate being or be threatened with divorce. Similar disruptiveness to gendered roles can also arise with diseases other than TB, as highlighted both by the research participants (see 6.1., "*they hide all types of disease*") and by previous studies which have associated leprosy and thalassemia with reduced marriage prospects, particularly for women, in South Asia (Try, 2006; Chattopadhyay, 2006). For this reason, and because the negative impact of TB on marriage as well as on marriage prospects emerged from the data, further development of the explanatory theory would benefit from a review of the literature and further qualitative research which has as its central focus gender, marriage and marriagability, rather than TB. There is likely to be a thread running through the relationships between disease and the (de)valuation of a prospective spouse, marital tensions and divorce, that cannot be fully appreciated when these relationships are explained in isolation of each other and in relation to just one disease category.

As discussed in sections 2.1.3 and 2.2.5, Leary (2001) places legitimacy at the centre of his definition of relational devaluation and I have placed it at the centre of the model of stigma causality presented in Chapter 2 (section 2.2.7). TB's disruptiveness comes to the fore in my explanatory theory of TB's impact on marriage prospects, but it is specifically TB's disruptiveness to the socially expected gendered roles of wife and mother which makes it a characteristic consensually regarded as legitimate grounds for rejection. Consider the story told by the Lady Health Worker in Pakistan, described in section 6.3, of the man who had married a woman from outside his family and without his parent's approval. The woman's initial 'failing' (to use Goffman's term) that she was not a cousin, could be

'overlooked' because it did not conflict with her ability to fulfil her role as a wife, and so did not in itself constitute a sufficiently legitimate reason for his parents to insist on the dissolution of the marriage. Her subsequent diagnosis with TB, however, did. It was a 'failing' which could not be overlooked because it conflicted with her ability to fulfil her role as a wife. Goffman (1963) states that the attributes which are discreditable, in other words most likely to be associated with stigma, are those which are incongruous with society's view of what a particular type of individual should be. In the contexts of the three South Asian countries, for some women in certain circumstances TB is incongruous with what is socially expected of them as wives (or daughters-in-law) and mothers. Lessening this incongruity needs to be central to approaches to reducing the negative impact of TB on marriage prospects.

In the contexts of the research sites, factors which can lessen or counter the negative impact of TB on marriage prospects include having family approval of a marriage and, related to this, possessing desired characteristics other than good health and the ability to work hard, such as being a cousin in areas where consanguineous marriage is preferred. The high value placed on marrying within a family can sometimes compensate for the cost of marrying someone with TB. Whilst this TB stigma manifestation is associated with women more than with men, it is not exclusively associated with women. For men a factor which can lessen or counter the negative impact of TB on their marriage prospects is their 'financial strength', which in areas where a woman joins her husband's family is likely to be a family rather than an individual characteristic. For women, such factors may include education and earning potential, where their roles and contributions to the marital household are extended beyond the domestic sphere.

Link and Phelan (2001) and Parker and Aggleton (2003) argue that stigma needs to be seen in relation to broader concepts of power and domination, and so I positioned power, alongside legitimacy, in the centre of the model of stigma causality presented in Chapter 2 (section 2.2.7). The research participants also recognised that overall gender inequalities play a role in understanding the greater detriment of TB to women's marriage prospects as highlighted at the beginning of section 6.2. Socio-structural factors such as women joining their husband's household after marriage and the role of wife being predominantly located in the domestic sphere, provide the socio-structural context in which stigma mechanisms become generative. Therefore, measures to alter the socio-structural context, such as promoting education and employment amongst women, to extend women's roles beyond the domestic sphere, could be one part of a strategy to address the impact

of TB on marriage prospects. However, this may seem beyond the usual remit of a National TB Control Programme.

Firmly within the remit of a National TB Control Programme are approaches which reduce the disruptiveness of TB to gendered roles, thereby reducing the significance of TB to the valuation of a prospective spouse. Opportunities for reducing the significance of TB to the valuation of a prospective spouse are identified in the following section (6.6).

As well as taking measures to reduce the negative impact of TB on marriage prospects, there is also a case to be made for National TB Control Programmes to simultaneously take measures to enable people to manage this manifestation of TB stigma. The anticipation that TB will impact negatively on marriage prospects can cause distress and this distress can be alleviated to some extent by enabling people with TB, and unmarried women in particular, to determine to whom their TB diagnosis is disclosed. Opportunities for doing so are considered in the following section.

6.6 Opportunities for addressing TB stigma

Whilst the first two objectives of this research are to understand the nature of TB stigma and to develop theories to explain TB stigma, the third objective is to identify ways of addressing TB stigma based on these theories. The explanatory theory for the negative impact of TB on marriage prospects suggests two approaches for National TB Control Programmes to address this manifestation of TB stigma. The first focuses on reducing the significance of TB to the valuation of a prospective spouse by reducing the 'disruptiveness' of TB and its treatment to the gendered roles of wife and mother. The second focuses on enabling people with TB to manage this manifestation of TB stigma by enabling them to manage knowledge of their TB. This involves addressing TB's 'evidentness'.

6.6.1 Reduce the significance of TB to the valuation of a prospective spouse

Health and the ability or willingness to work hard are valued characteristics of a prospective wife or daughter-in-law. TB jeopardises these characteristics, but less so when it is detected early and then treated promptly and effectively. Improving

case detection and treatment, particularly among unmarried and newly married women, is therefore expected to contribute towards reducing this manifestation of TB stigma.

Whilst National TB Control Programmes are already working towards increasing early case detection and delivering prompt and effective treatment, it seems crucial that, given the strong gender dimension of this manifestation of TB stigma, the implications for women and men, both married and unmarried, are carefully and continually considered. This is known as mainstreaming gender, which the UN (1997) define as “the process of assessing the implications for women and men of any planned action, including legislation, policies or programmes, in all areas and at all levels”(p2). Clearly advice given by some health workers and TB volunteers to abstain from food preparation, to not share eating utensils (see also section 7.4.3) and to limit contact with children, as reported by research participants, has a disproportionate impact on women and contributes to creating a dissonance between TB and the gendered roles of wife and mother, a dissonance which lies at the heart of this manifestation of TB stigma.

In the 1990s all three countries involved in this study adopted the TB control strategy known as DOTS (directly observed treatment, shortcourse) which was promoted by the WHO (Kumaresan et al., 1998; WHO, 2000; NTP Pakistan, 2013). The DOTS strategy involves those diagnosed with TB taking a standardised treatment regimen under the daily direct observation of a health worker for at least the first two months, and this was the experience of participants of this study who had received treatment for TB. Attending a clinic regularly, and especially daily, for TB treatment can pose difficulties for those with TB, but these difficulties vary in degree and form according to individual circumstances and gender. As Ogden et al. (1999) point out, “in many societies, younger women have relatively junior status in their households and communities, less mobility, less autonomy and greater constraints in accessing resources for treatment than older or higher status women” (p857) or than their male counterparts. This is consistent with my research as participants reported that women have less mobility, as their movements are questioned and arouse suspicion, and less autonomy, as they sometimes require or are required to have an escort to the clinic.

Following a gradual shift in rhetoric, and even practice, away from service-centred care (Lienhardt and Ogden, 2004; Zachariah et al., 2012), the new Post-2015

Global TB Strategy has as the first of its three core components patient-centred care (WHO, 2013b). However, it is important that patient-centred care is not centred around a single type of (male, married) patient. This requires both gender mainstreaming and meaningful patient and public involvement in service design to ensure that 'improved' models of treatment provision do not simply substitute difficulties of access relating to availability and affordability of care with difficulties of access relating to the acceptability of care for unmarried and newly married women. As mentioned in section 6.4, whilst in Nepal a home visit by a health worker was acceptable to and appreciated by a male participant with TB in the urban site, such a visit was not acceptable to a female participant with TB in the rural site as she was terrified that the doctor would disclose her TB to her husband and neighbours.

6.6.2 Enable those with TB to manage knowledge of their TB

With few documented and evaluated TB stigma interventions, Courtright and Turner (2010) suggest that, as with HIV and mental illness, the most promising approach to reducing TB stigma may be to empower those with TB to resist "stigmatizing external judgments" (p38). However, another approach is to empower those with TB not just to resist but to avoid "stigmatizing external judgements", or, in this case, a detrimental impact on prospects of marriage. This approach is based not on evaluations of TB stigma interventions, but on what participants of this study reported already doing. In the following chapter (Chapter 7), in which I present a theoretical understanding of another manifestation of TB stigma, namely the perception that people with TB are hated, I give examples of how people with TB reported avoiding feeling hated or rejected by others by concealing their TB or limiting their interactions with other people (see 7.2.1). Related to TB's anticipated detrimental impact on the marriages and marriage prospects of women, participants reported a greater desire amongst women to conceal a TB diagnosis and greater anxiety over the confidentiality of their condition.

An understanding of how current TB policies and services influence the *evidentness* of a person's TB status will highlight opportunities for improving the design and delivery of services in such a way that people with TB (both male and female, married and unmarried) are given greater control over managing knowledge of their condition and therefore of any manifestations of stigma associated with it. Because of the need to access TB services frequently over a lengthy period of time, it can be difficult for both men and women to keep their TB confidential. However, the

difficulty is compounded for women because, as mentioned above, they often have less mobility and autonomy.

As part of the shift from service-centred to patient-centred care, discussion and consensus is needed on the position of confidentiality in TB care, as currently it is a priority for those with TB but not for those responsible for providing TB care and, in particular, for late patient tracing.

6.7 Summary

In this chapter, I have presented a realist explanatory theory in discussion form of the detrimental impact, whether anticipated or experienced, of TB on marriage prospects. Whilst this manifestation of TB stigma does not relate exclusively to women, it does relate predominantly to women, and so my explanatory theory focuses on the relationship between TB and the marriage prospects of women. I have reflected on this explanatory theory in light of published research and the conceptual model of stigma causality which I developed prior to data collection and which I presented in Chapter 2.

Whilst deeply rooted in the psychological process or internal mechanism of *dyadic cooperation*, it is TB's *disruptiveness* (one of six dimensions described by Jones et al. (1984)) to the gendered roles of wife (or daughter-in-law) and mother which makes it consensually regarded as 'legitimate' grounds for rejecting a woman for marriage. This constitutes the mechanism at the centre of the explanatory theory. Contextual factors determine whether this mechanism becomes generative of the stigma manifestation, and relate to broad structural factors as well as specific individual circumstances.

To effectively address this manifestation of TB stigma, its origins in *dyadic cooperation* need to be appreciated and opportunities to influence the contextual factors which generate stigma via the mechanism need to be identified. I have proposed that the National TB Control Programmes in Bangladesh, Nepal and Pakistan focus on reducing the significance of TB to the valuation of a prospective spouse by improving case detection and treatment, particularly among unmarried and newly married women, through gender mainstreaming and meaningful patient and public involvement in service design. Whilst there is a growing recognition that

TB care needs to be patient-centred rather than service-centred, it is important to ensure, given the strong gender dimension of this TB stigma manifestation, that such care is not centred around a single type of (male, married) patient. Finally, I argue that the detrimental impact of TB on marriage prospects can be tackled not just by addressing its fundamental cause, as Link and Phelan (2001) argue, but also by enabling those with TB to determine to whom and when their condition is disclosed. In other words, by addressing what Goffman (1963) terms as the *evidentness* of TB.

In the following chapter I focus upon the second of the three TB stigma manifestations identified from the data, namely the perception that people with TB are hated.

Chapter 7

PERCEPTION THAT PEOPLE WITH TB ARE HATED

From the first few interviews conducted across the three countries, research participants referred to people with TB as being 'hated' – a term with clear negative connotations. Hatred was closely aligned with fear of infection, with those interviewed saying that people with TB are hated because others are fearful of contracting TB.

“Our society hates [people with TB] and [people] don't sit near someone with TB, they don't eat from his plate or sit and stand near him to chat. [They think] this will infect us also. [...] It is an infectious disease.” (pu16, mother of a man with TB, urban site, Pakistan)

Whilst TB's infectiousness appears to play an important role in attitudes towards TB and people with TB, not all infectious diseases are equally feared and the severity of TB and its lengthy and disruptive treatment contribute to the fear.

“[TB] is a little bit of a dangerous disease. [...] When we have diarrhoea, dysentery, fever, common cold... [...] nothing will happen, it's normal to take one [para]cetamol and it will get cured. [TB] has a long life, that's why... it takes 8 months, 10 months of medicine, so it costs thousands [of rupees].” (nr7, man with TB, rural site, Nepal)

Fear of TB infection and behaviours attributed to this fear were sometimes spoken of as being hateful, but not consistently so. Sometimes research participants described such fear as natural and justified and the behaviours attributed to this fear as simply precautionary. Subsequent interviews aimed to disentangle this inconsistency by exploring the relationship between fear of infection, precautionary behaviours and perceptions of hatred.

In this chapter I consider why people with TB are perceived or perceive themselves to be hated (section 7.1), and for whom and in what circumstances this perception manifests (section 7.2). I then, in section 7.3, discuss the explanatory theory for this manifestation of TB stigma in light of other research and the conceptual model of

stigma causality presented in section 2.2 before proposing three approaches to addressing this TB stigma manifestation (7.4) which are based on the explanatory theory presented.

7.1 The incongruity of precautionary and caring behaviours

As the iterative processes of data collection and analysis progressed it became clear that behaviours referred to as necessary for the prevention of TB transmission or motivated by a fear of TB transmission were in certain circumstances and contexts referred to as hateful and, more specifically, were contrasted with caring and loving behaviours. This is because precautions against TB transmission, such as decreased proximity and increased separation, are in direct opposition to caring behaviours. Indeed, the Nepali word *hela*, which was often used in the interviews conducted in Nepal, can be translated both as *to revile* or *show contempt for* and as *to neglect* or *not care for* (Turner, 1931).

“Family members need to be made clear about TB disease and about taking care of a person with TB, like not doing ‘hela’ to people with TB, like putting them separately, feeding separately and washing their clothes separately. They should not behave like that; they should behave the same as before having TB.”
(nu3, woman with TB, urban site, Nepal)

Whilst many of those interviewed spoke of people with TB being hated, none of those interviewed said they themselves hate people with TB. This may in part be because the sample comprised primarily people with TB and their family members and in part because those interviewed may have anticipated disapproval from the researchers (although every effort was made to compensate for this possibility). However, given that hatred is so closely aligned with both neglect and precautions against TB, whether someone is being hateful, neglectful or precautionary is very much a matter of and therefore open to interpretation. There was some indication in the data that this ambiguity may present an opportunity for some to distance themselves from a person with whom they have already had a strained relationship, with the ‘legitimate’ justification that their behaviour is precautionary. Two of the people with TB interviewed (pu12 and b10) spoke of concealing their diagnosis specifically from individuals with whom they had had strained relations because they anticipated this opportunity would be taken. However, the incongruity of precautionary and caring behaviours can also present a dilemma. Family members

and health workers described their predicament: if they demonstrably care for a person with TB they may be risking infection, but if they protect themselves from infection it will be hurtful to the person with TB and they may appear to be uncaring and hateful.

“When [the Lady Health Worker] asked me to take care then I started taking care. [But] it doesn’t look good to separate eating utensils. It’s a big family. [My siblings] were like ‘she is our sister, she would feel bad, she is at her parents’ now and will feel bad that her parents are doing this to her’.” (pr2, woman with TB, rural site, Pakistan)

The conflict between the need to take precautions against transmission, and the need to demonstrably care for a person with TB was apparent in an interview with the son-in-law of a man with TB in Nepal (nr10). 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 his clothes, sit near to him, share his water... So we need to keep disease a little bit far. Love is there in our heart.” (nr10, son-in-law of a man with TB, rural site, Nepal)

The need to consider the emotional state of the patient was highlighted by a health worker in Pakistan (pu10) who said she is reluctant to keep a distance from her patients, despite her daughter urging her to for fear of infection, as she does not want to hurt the feelings of her patients. Indeed, a belief in the importance of positive emotions for recovery is reflected in the Urdu saying *happiness is half the cure*, and three research participants across the sites in Pakistan and Nepal even reported that a TB diagnosis had been withheld from a patient by a health professional as it was thought that the depression and anxiety which might follow might worsen the patient’s condition and impede recovery.

The acknowledgement that taking precautions against TB transmission can be hurtful to patients and detrimental to their recovery means that sometimes *obvious*

precaution-taking is avoided. A health worker in Pakistan (pr9) said she covers her face with a veil when she sees a person with TB, but that it is intentionally ambiguous to the patient whether she is doing this as a precaution against TB or out of modesty. Similarly, a health worker interviewed in Nepal (nu15) 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 herself, rather than asking the patient to, it would, in her opinion, make the patient feel bad.

In such cases where *obvious* precaution-taking is avoided, and precautionary behaviours are intentionally ambiguous or absent despite a fear of infection, people with TB (or others) may still detect *subtle* changes in behaviour, attitudes and emotions which they may interpret negatively and feel to be hurtful.

“It’s just that [people] will feel allergic deep down inside their hearts. [Suppose] I come to your home. You would not make it obvious of course, but it must be in your heart that he has this problem.” (pu12, man with TB, urban site, Pakistan).

In this way, TB-related ‘stigma’ can be subtle and based on perceptions of how others feel, rather than necessarily on what others actually say or do.

7.2 For whom and in what circumstances?

As the study progressed, interviewing and analysis focussed on understanding for whom, in what circumstances and why behaviours are perceived to be either precautionary or hateful. Five factors emerged as important: who initiates the behaviour towards whom; the evidentness of attitudes and behaviours; the emotional sensitivity of the person with TB; the social acceptability of behaviours; and the perceived legitimacy of precautionary behaviours.

7.2.1 Who initiates the behaviour towards whom

In this study I found that precautions initiated by the person with TB are likely to be interpreted positively by the person with TB as caring towards others or as simply necessary, whereas precautions initiated by others are more likely to be interpreted by the person with TB as hateful and uncaring. While the resulting outcome may be

the same, for example an increased physical distance between two people, the interpretation of the motivation behind the outcome differs according to who has initiated it. A person with TB (pr3) illustrated this by saying that she avoids other people as a precaution against TB transmission, but that they do not avoid, and therefore hate, her.

Likewise, a person with TB interviewed in Bangladesh (b5) said she had been advised by a health worker to separate herself and her eating utensils from others, and, when asked whether she was following these restrictions, emphasised that they are not restrictions, which have negative connotations, but simply necessary precautions. However, she then went on to speak negatively of her sister-in-law's efforts to encourage separation, suggesting that even when separation is viewed as a positive precaution, it still makes a difference who initiates the separation.

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

"[My sister-in-law] always tries to motivate my husband and my son to maintain separation from me. She is not so educated. I think it is because of her lack of education, her lack of knowledge. It is her ignorance."

(b5, woman with TB, Bangladesh)

In Nepal, a man with TB (nu2) explained how he avoided others so as not to infect them, but concealed his diagnosis from others so that they would not avoid him for fear of infection. Such social isolation by a person with TB may arise not just from the anticipation of being avoided by others but from (perceived) experience of it as well. The daughter-in-law of a woman with TB (nu13) 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 their knowing it was infectious. Leaving a sick person because she is believed to be infectious was interpreted as hate or *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.

A man with TB in Bangladesh (b6) said by his own choice he sleeps and eats separately from the rest of his family and uses separate eating utensils which he then washes himself, deeming this self-imposed separation to be important to protect his family from becoming infected. Despite the fact that he had given up his job and separated himself from others, he went on to say that his relationships with other people had not been affected by his TB diagnosis, and this may be explained by the fact that leaving his job and separating himself had been his choice and initiated by him. Likewise, another person with TB spoke of separating herself, and particularly her eating utensils, from other family members for their safety and by her own free will.

“I try to maintain some separation when I stay at home, although I don’t always remember to. I do it by my own free will. [...] I am maintaining a safe distance from my family members [...] for their safety.” (b6, woman with TB, Bangladesh)

Self-initiated avoidance is easier for the person with TB to cope with emotionally and so a person with TB may avoid others in order not to be avoided. A man with TB in Bangladesh (b4) with a market stall selling vegetables said that if people were to avoid buying vegetables from him he would feel hurt and depressed and so he did not continue to work on his stall following his TB diagnosis. He went on to say that if he feels someone is fearful of his disease he will avoid that person so that that person does not have to avoid him. By not giving people the opportunity to avoid him he was protecting himself emotionally.

7.2.2 Evidentness of attitudes and behaviours

Goffman (1963) refers to the evidentness of the stigmatised attribute and how much control a person with the attribute has over revealing and concealing it. As the data collection and analysis process proceeded, it became increasingly apparent that evidentness applies not just to the attribute (i.e. how noticeable TB is) but also to the ‘stigma’ itself. A person’s behaviour may be interpreted as neither precautionary nor as uncaring if the behaviour is not even noticeable. Also, if it is noticeable but is coming from a person from whom there is no expectation of caring behaviour anyway, it is likely to be seen as simply and unremarkably precautionary. It seems that a person with many relatives and friends nearby who interacts with, and is integrated within their local community may have both a greater chance of receiving support when ill but also of noticing uncharacteristic changes in others’ behaviour and of picking up on negative gossip. In this way, attitudes, emotions and

behaviours that can be interpreted negatively as stigma-related may be more 'evident' to some than to others. Examples of this are provided in the following paragraph.

When asked whether her neighbours interact with her differently or less since her TB diagnosis, a Christian respondent in Pakistan (pu8) said that even before her diagnosis she interacted little with her Muslim neighbours. Likewise, in Nepal, the adult son of a man with TB (nu11) said that his father had had a problem with his leg that preceded his TB diagnosis and so rested at home a lot, interacting little with people outside the home both before and after the TB diagnosis. Similarly, a woman with TB (nu6) said that because of her work (grinding beans) she did not have time to go out and talk with others so had not heard people talk either negatively or informatively of those with TB. In Bangladesh, when asked whether any of his relatives had visited him and enquired about his health since he had become ill with TB, a man with TB (b6) said they had not but that they do not normally visit him anyway; and a woman with TB (b7) indicated that her TB had not particularly affected her social interactions with others in her neighbourhood as *"normally I rarely go outside of our home"*.

7.2.3 Emotional sensitivity

The emotional state of a person with TB can influence his or her interpretation of a behaviour as either precautionary or uncaring (and therefore hateful). A health worker interviewed in Pakistan said, *"when a person is ill he becomes more sensitive"* (pr9). Sensitivity may be heightened due to feeling physically unwell and vulnerable, but also due to anxiousness over how to manage with the illness. These physical symptoms and anxieties may wax and wane, and consequently a patient's moods and outlook are changeable from hour to hour and day to day. Even factors affecting mood which are not necessarily related to the person's illness can influence the person's interpretation of how he or she is regarded by others.

"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." (nr3, woman with TB, rural site, Nepal)

The quote above is from a woman with TB in Nepal who began the interview in a positive mood, laughing a lot and reporting only positive behaviour from others towards her and her TB. However, as the interview progressed she revealed that when she quarrels with her brother she feels hated because of her illness.

7.2.4 Social acceptability of precautions

Even if a person is fearful of catching TB, precautionary (and 'stigma'-related) behaviours may sometimes be unfeasible or may incur too great a social cost. One cost is to risk being seen as uncaring or hateful, but this is a greater cost for some than for others. The wife of a man with TB in Pakistan (pr10) felt that precautions are not feasible within a marital relationship; likewise, the wife of a man with TB in Nepal spoke of the incompatibility of her role and responsibilities as a wife with the need for separation as a precaution against TB transmission.

"Whenever I used to have [my husband's] leftover food he used to get angry with me and I used to reply that there can't be any precautions in a husband-wife relationship." (pr10, mother-in-law of a woman with TB, rural site, Pakistan)

"I never think that he is ill and so 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." (nu12, wife of a man with TB, urban site, Nepal)

Just as precautions can be deemed impractical and incompatible with the role of a wife, the same applies to that of a parent. A woman with TB (pu4) living with her parents in Pakistan told her mother to eat separately as a precaution against TB transmission, but her mother insisted they eat together as "*mother is mother*". It seems the 'cost' of not eating with her daughter, and thereby being unmotherly and uncaring, was too great and outweighed any perceived benefits of reducing the risk of transmission. This was supported by the female participants of a focus group discussion conducted in the urban site in Pakistan who described a parent's relationship with their child as more intimate than that of a sibling and especially a friend or non-blood relative. They therefore felt that a parent, and specifically a mother, simply cannot enforce separation if her son or daughter has TB. Similarly, in Nepal, the mother of a person with TB (nu10) spoke of the responsibility of parents, which overrides any fear of infection, to feed and raise their children no matter what.

The less close the previous relationship and the more feasible the precautions are, both practically and within the bounds of social norms and customs, the more likely it seems that precautionary behaviours will result. Indeed, in the interviews with people with TB, parents and other close family members were usually described as supportive and caring, while behaviours interpreted as hateful were attributed to in-laws or more distant relatives, friends and neighbours.

In Pakistan, a man with TB in the urban area (pu12) said that when someone is ill with TB others will still visit out of courtesy as this is the custom, but that they will feel a little “*allergic*” towards the person with TB and will make excuses when offered tea or water. In Nepal, a health worker interviewed (nr13) said that people often avoid visiting a person with TB altogether, although their health, diagnosis and treatment may be enquired about via others, such as the health worker. Even when the reason for not visiting a person with TB is thought to be the fear of infection, it can still be seen as hateful, once again highlighting the fine line between fear for oneself and hatred of another.

“[People may not visit] because people hate [those with TB]. [They think] that one should protect oneself from such people, avoid such patients, because of the germs. [...] They say that germs also spread by breathing and they also spread by air.” (pu16, mother of a person with TB, urban site, Pakistan)

However, receiving fewer visitors than expected is, in the absence of a specified and definitive reason, open to interpretation, and a husband of a person with TB in Nepal (nr11) speculated that if people were avoiding visiting his home since his wife got TB it might be because they were worried they would have to provide food or financial support. Likewise, a mother of a person with TB in Pakistan (pu15) thought that a possible reason for a person with TB receiving fewer visitors might be their financial inability to adequately host, while a person with TB in Bangladesh (b1) feared being avoided by others because she had TB for the second time and might be viewed as a burden.

As visiting an ill person is, according to those involved in the research, usually customary, not visiting can incur a social cost. The son of a person with TB in Pakistan (pu13) pointed out that if someone decides not to visit a person with TB

because they fear infection, relations between that person and the one with TB, or between their families, can be negatively affected. As a result, even when a fear of infection amongst relatives, friends and neighbours exists, it may still be overridden by the status or social standing of the person with TB (or their family) and the need or desire to maintain good relations. A man with TB (pu9) said that despite many of his family members having had TB, *“because they are very noble people”*, others continued to visit. In this way, social status can ‘protect’ against ‘stigma’.

7.2.5 Perceived legitimacy of precautions

When a person with TB does not deem the behaviours of others or restrictions imposed upon them by others as necessary either to prevent transmission or to aid their recovery, he or she is more likely to interpret the behaviours as expressions of hatred. For example, the daughter-in-law of a woman with TB (nu13) believed it was important for her mother-in-law’s recovery from TB that she eat the right foods, such as pulses, 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 the imposition of food restrictions negatively, especially when her daughter-in-law would get frustrated with her non-compliance.

“She says we are doing ‘hela’ though we have not done so. [...] She should not take much oily food. [...] She was not convinced [...] She likes to take sour, oily food like before. Without reason she said she had ‘hela’ done to her regarding food.” (nu13, daughter-in-law of a woman with TB, urban site, Nepal)

Differences in people’s (including health workers’) views of whether, when and for how long precautions are necessary can leave precautionary behaviours open to (mis)interpretation. Confusion is likely to arise from differing advice being given by different health workers to patients with TB and/or to those accompanying them, or by the same health worker to those with sputum positive and negative TB and to those with pulmonary and extrapulmonary TB.

One of the health workers interviewed in Pakistan (pu10) said she distinguishes between sputum positive and negative patients, advising precautions to those accompanying the former and advising against any separation to those accompanying the latter as it would make the patient feel bad. When a patient is sputum positive she said she asks them to wait outside once a TB diagnosis has

been confirmed and only discusses the outcome and necessary precautions with those accompanying the patient, acknowledging that this can affect and confuse the patient. An extrapulmonary (and therefore non-infectious) person with TB in Pakistan (pr2) reported having been (incorrectly) told by a Lady Health Worker not to cough or breathe on others as the TB may transmit. As TB disease can take many forms and is neither always pulmonary nor always infectious (and so could perhaps more usefully be seen as multiple diseases caused by the same TB pathogen), confusion regarding precautions seems unsurprising.

In all three countries there also appears to be some confusion over the longevity of TB's infectiousness period once treatment has begun. According to the WHO (2003), people with infectious pulmonary TB cease to be infectious within approximately two weeks of regular treatment. Precautionary behaviours and restrictions which may be slightly inconvenient but feasible for two weeks can become difficult, both practically and emotionally, or even impossible if they are to be sustained for longer. With the intensive phase of TB treatment being two months, the impression some patients and communities seem to be getting is that TB remains infectious throughout this two month intensive treatment phase, if not beyond.

"[TB] is cured now by taking medicine regularly. It can no longer transmit once medicine has been taken for two months. [...] If they know that it no longer gets transmitted, good behaviour should be shown to those people who have got TB." (nu1, woman with TB, urban site, Nepal)

In Bangladesh, mixed advice from volunteer health workers regarding the length of time precautions are necessary adds to the confusion. One of the volunteer health workers interviewed (b12) said she advises patients' family members to keep a distance from the patient during the "*coughing period*", while the other (b11) said she specifies the need for distance for the first three weeks of treatment. However, for one of the women with TB (b1), precautions were necessary for a few months as it was not until a few months after treatment began that the doctor said she could interact normally with her family again.

Another person with TB (b3) said she had been advised by a health worker to use separate eating utensils from the rest of her family and even after four months of

treatment was still continuing to do so, equating the period of treatment with the period of time in which precautions are necessary. In this case it is unclear whether or not the health worker had actually specified a length of time when precautions are necessary or whether the patient had just inferred they are necessary until treatment is complete.

A health worker interviewed in Pakistan (pu11) suggested that the more vulnerable one feels, the more fearful one will be. He himself had always been in good health but told of two other doctors already suffering from diabetes who are constantly fearful of contracting TB. Whilst fear alone does not *a/ways* result in precaution-taking (social cost and feasibility also play their role) it does make precaution-taking more likely. Indeed, according to established health behaviour theories such as the Health Belief Model and the Stages of Change model, protective health behaviours are motivated, in part, by perceptions of personal risk and vulnerability (Glanz et al., 1997).

While most of those interviewed said that anyone can potentially get TB, a wide range of factors were thought to make a person more susceptible to TB, highlighting the inadequacy of airborne transmission as the sole explanation for why one person becomes ill with TB and not another and further complicating the universal legitimacy of precautions. In Nepal, a woman with TB (nr5) 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 see a need to take precautions against transmission, and had others done so she may have interpreted their actions at best as unnecessary and at worst as uncaring and hateful.

The interviews with health workers suggest that their fears of contracting TB (and any expressions of these fears which may make a patient feel stigmatised) are likely to decrease if they feel genuinely protected from the risks of infection. The health worker mentioned above (pu11) said that while he is not constantly fearful of catching TB himself, he does feel fearful when a sputum positive patient coughs or spits. He considers fear in the face of genuine risk to be normal and his response to a sputum positive patient coughing or spitting, namely to politely tell them off and ask them to sit outside his office, as justified given that the hospital has not provided any effective precautionary measures. Health care providers interviewed

deemed the use of face masks as a precautionary measure as unfeasible and ineffective.

“I can’t use a mask because I have to wear glasses and when I use a mask my glasses steam up and it becomes difficult to read and write.” (pu10, female health worker, urban site, Pakistan)

“The so-called mask that is provided to us, it’s just useless. Like a soldier goes on the front line and can get a bullet at any time.” (pu11, male health worker, urban site, Pakistan)

In Nepal the health workers interviewed also admitted to feeling a little fearful at times about getting TB but felt hesitant about saying anything or acting 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, and if they began feeling unwell or developed a cough they would quickly entertain the possibility of TB and would seek a sputum test as a precaution.

“If the disease transmits due to being near to us, there is fear of its transmission, [so] don’t talk directly face to face, [...] sit a little bit far and if possible tell them to cover their mouth with a hanky.” (nr12, male health worker, rural site, Nepal)

Whilst many of those interviewed attributed fear and hatred to a lack of knowledge or education in a linear way, knowledge of the risks without feeling adequately protected from them is insufficient in allaying fears. Furthermore, the relationship between knowledge and fear is not clear cut. The knowledge that TB is curable (and that treatment is accessible and effective) can decrease fear, but the knowledge that TB is transmissible and treatment is lengthy and disruptive can increase fear. Indeed, the absence of knowledge can affect different people in different ways too. In Nepal, two people with TB who both had little prior knowledge of TB reacted very differently to their diagnoses; one (nu8) received his diagnosis without fear as he had no expectations, while the other (nu16) reacted with fear as she did not know what to expect.

Increasing knowledge alone without reducing vulnerability, both actual and perceived, is unlikely to reduce 'stigma'. However, increasing fear, even if with the intent to promote protective health behaviours such as treatment-seeking, may unintentionally increase 'stigma'. One of the volunteer health workers interviewed in Bangladesh (b12) said she harnesses the fear of transmitting to others to persuade patients to adhere to their treatment, and uses the fear of being transmitted to in order to persuade the family members of people with TB to play a role in ensuring the patient's treatment adherence. As fear of infection and the perception that those with TB are hated are so closely aligned, the unintended consequences of this must be considered.

7.3 Reflections on the explanatory theory

Whilst research on the causes of TB stigma is scarce, two qualitative studies which have explicitly sought to identify the causes have both implicated fear of infection (Dodor et al., 2008; Baral et al., 2007). Dijker and Koomen (2006) argue that if infection with a disease, or its *origin*, is attributed to a person's voluntary behaviour then it arouses anger in others, whereas if it is deemed beyond an individual's control it arouses mostly fear and pity. Certainly, qualitative research on TB consistently reports that TB is a much-feared disease (Noyes and Popay, 2006), and fear was more evident from the research presented in this thesis than anger. This is consistent with studies on TB stigma conducted in Colombia (Jaramillo, 1999) and Hong Kong (Mak et al., 2006), both of which found stronger associations of TB with fear and pity rather than loathing or blame. Following Dijker & Koomen's argument, this would suggest that infection with TB is deemed beyond an individual's control and this is indeed consistent with data generated from this research and presented in the next chapter (Chapter 8).

In Chapter 2, I considered the notion of causality and rejected the successionist representation as inapplicable to the complex concept of stigma. Using the approach to grounded theory and a realist conceptualisation of causality this research does not implicate fear of infection as either a 'cause' or manifestation of TB stigma but has found fear of infection to be related to a manifestation of TB stigma identified from the data across all five urban and rural sites in Bangladesh, Nepal and Pakistan. Of course, whether or not fear of infection is implicated as a cause of TB stigma depends not only on how causality is conceptualised but also on how TB stigma is defined. The term stigma has, as Manzo (2004) states and as

earlier quoted in Chapter 2 (section 2.1), been “under-defined and over-used” (p401), making comparison with other studies investigating TB stigma difficult.

Supporting the conclusions of the two qualitative studies mentioned above (Dodor et al., 2008; Baral et al., 2007) the findings of a comparative quantitative study of the stigmas associated with three infectious diseases in Hong Kong conducted by Mak et al. (2006) suggest that the stigma associated with TB, as well as SARS, are driven by the fear of these diseases, whereas the stigma associated with HIV is driven by attributions of responsibility and blame. As the authors used a uniform 14-item scale to measure stigma but based their analysis on composite stigma scores for each disease, it is unclear how stigma was defined (as not all items in the scale have been presented) or how the composition of the stigma scores may have varied between the three diseases. The authors do, however, describe the scale as containing affective, behavioural and cognitive items which they based on existing measures of psychiatric stigma as well as on their own focus group data. One of the most commonly used measures of psychiatric stigma (i.e. the stigma of mental illness) is social distance (Link et al., 2004). Social distance refers to a person’s willingness to interact with someone with a mental illness in different situations. An example Mak et al. give of a related behavioural item used in their stigma scale is “I will try my best to keep a distance from HIV/AIDS/SARS/TB” (2006). Somma et al. (2008) and Coreil et al. (2010) use a similar item relating to avoidance of someone with TB as part of their TB stigma scales. Somma et al. (2008) found significant differences across the four countries included in their comparative study with respect to all but one of the items on their stigma scale. Consistent across the samples from all four of the countries was the view among both men and women with TB that others in their community had avoided them because of their TB. The published papers by Baral et al. (2007) and Dodor et al. (2008), implicating fear of infection as a cause of TB stigma, present findings linking fear of infection (the cause) with avoidance and separation (the outcome).

Whilst keeping a distance from someone with a mental illness, or indeed HIV, may reflect how one person thinks or feels about another, keeping a distance from someone with an airborne infectious disease may reflect how one person thinks and feels about the disease, rather than about the person with the disease. As a family member interviewed said, “*we have to be afraid of disease [...] but to father there is love*” (nr10, section 7.1). The family members of people with TB and health workers participating in this study described the dilemma that the ambiguity of social distance posed for them. On the one hand keeping a distance and other self-protective measures could be interpreted as necessary and justified, and on the

other hand they could be interpreted as uncaring and hateful (i.e. as a manifestation of stigma) towards those with TB. In relation to TB and other airborne communicable diseases, social distance or avoidance are likely to be too ambiguous, or open to interpretation, to be considered valid or reliable indicators of stigma.

In section 2.1.2, I considered the distinction that some authors make between symbolic and instrumental stigma (Crandall et al., 1997; Deacon et al., 2005b; Herek and Capitano, 1998; Herek, 1986) and I questioned the usefulness and clarity of the distinction. Applied to social distance or avoidance, rather than to the broad and under-defined concept of 'stigma', the distinction is, in my opinion, a little more meaningful. Keeping a distance from someone with a mental illness, reflecting how one person thinks or feels about another, could be described as symbolic. Keeping a distance from someone with TB, reflecting how one person thinks or feels about TB, rather than the person with TB, could be described as instrumental. However, distinguishing the latter as either instrumental 'stigma' or as merely instrumental remains problematic when the distinction is based on a subjective and changeable judgement as to how scientifically or medically justified the person's thoughts and feelings towards TB are. Moreover, not only is the line between what is instrumental and what is instrumental stigma open to interpretation, but the line between what is instrumental (stigma) and what is symbolic stigma is similarly blurred. As my analysis of the data revealed, avoidance of a person with TB can be interpreted as a sensible precaution (based on instrumental considerations regarding risk and resources) by one person and as a sign of hatred (a moral and value-based judgement) by another. A solution is not to see avoidance as the manifestation of stigma (as this is at best a proxy indicator), but to see the intent behind it or interpretation of it as the manifestation of stigma. Whilst there is a relationship between the perception that people with TB are hated, fear of infection and precautionary behaviours, including avoidance, it is not the fear or behaviours which, following my definition (presented in section 2.1.5), are the stigma manifestations: it is the *perception* that people with TB are hated.

In a systematic review of the literature on TB stigma, Courtright and Turner (2010) state that community and institutional norms mediate stigma and, in particular, implicate the perceived risk of transmission of TB as a cause of stigma. However, they go on to conclude, based on the few evaluations of TB stigma interventions which have been published, that "the most promising approach to reducing TB

stigma may be to empower individuals with TB to resist stigmatizing external judgements” (p38). In other words, focussing interventions on how the person with TB perceives and feels about the actions of others, rather than on the actions themselves. This approach to reducing TB stigma makes particular sense if it is the *perception* that people with TB are hated that is considered to be the manifestation of TB stigma.

Through this research I found that self-protective behaviours arising from a fear of TB transmission (such as physically distancing oneself and separating eating utensils) are *sometimes* interpreted as signs of hatred towards a person with TB. This is because precautions against TB transmission (reduced proximity and increased separation) are in direct opposition to caring behaviours. Whilst the deep-rooted psychological process known as *parasite avoidance* underlies fear of infection, *the need to belong* underlies the social rejection that people with TB feel when they are avoided or segregated. As referred to in section 2.2.3, Baumeister and Leary (1995) suggest that underlying our innate desire to form and maintain social bonds are internal mechanisms, such as a tendency to feel pleasure from social contact and a tendency to experience emotional distress when deprived of, or anticipating the loss of, social contact or relationships. *Dyadic cooperation* is also likely to play a role in that a relationship with somebody who has developed TB disease is re-evaluated and subsequently devalued. For example, it may be considered very important to visit a relative, friend or neighbour who is ill, but not as important as avoiding the risk of TB transmission or indeed the risk that the relative, friend or neighbour may request or expect to be offered financial or other support. Even if actions are driven by *parasite avoidance* rather than *dyadic cooperation*, the person with TB may interpret the actions as devaluations of the relationship and may *feel* devalued.

The dilemma over the ambiguity of intent behind precautionary behaviours faced by the family members of people with TB and health workers who participated in this research is also a dilemma for National TB Control Programmes wishing to both promote precautionary behaviours and reduce stigma. Behavioural precautions against TB transmission (such as decreased proximity and increased separation) are so akin to rejection that TB itself is a criterion for rejection which is, as Leary (2001) puts it, “consensually regarded as legitimate” (p7). It seems the question to ask is not why do people with TB feel rejected or hated when they are avoided or segregated, but why do some people with TB or people with TB in some

circumstances *not* feel this way? In what circumstances are people with TB able to interpret such behaviours as simply precautionary and nothing but precautionary?

Drawing from Pawson and Tilley's conceptualisation of causality (see section 2.2.1), the mechanism (that precautions against TB transmission are in direct opposition to caring behaviours) only becomes generative of the stigma manifestation in some contexts, and so the mechanism alone is insufficient as an explanation. From this research I have theorised that when people with TB initiate the precautionary behaviours themselves, when they feel physically well and emotionally positive, when the precautionary behaviours are feasible, compatible with social roles and expectations and deemed legitimate, then they are less likely to feel hated or 'stigmatised'. This suggests a number of opportunities for influencing the perception that people with TB are hated and therefore reducing this particular manifestation of TB stigma.

7.4 Opportunities for addressing TB stigma

The theoretical understanding of the perception that people with TB are hated which I have presented in this chapter suggests numerous opportunities for addressing this manifestation of TB stigma. For example, focussing medical advice on patient-initiated precautions, which can be presented as positive and caring, is likely to be beneficial to people with TB.

Approaches to addressing the perception that people with TB are hated can focus on influencing the perception and/or on reducing the behaviours that are sometimes perceived as being hateful. As these behaviours are also sometimes precautionary, eliminating them would be both unrealistic and undesirable. In this section I propose three overarching approaches to addressing the perception that people with TB are hated. The first (outlined in section 7.4.1) focuses on influencing the perception that people with TB are hated, the second (outlined in section 7.4.2) focuses on reducing the behaviours which could be perceived as being hateful, and the third (section 7.4.3) addresses both.

7.4.1 Support people with TB to feel physically and emotionally well

The research suggests that the emotional state of a person with TB influences his or her interpretation of a behaviour as either precautionary, uncaring or hateful. Thus, measures to improve the emotional state of people with TB are likely to be helpful in addressing this TB stigma manifestation. Few evaluations of interventions to reduce TB stigma have been published but, of those that have, interventions focussing on people with TB, rather than on communities, have shown promising results (Courtright and Turner, 2010).

Macq et al. (2008) found a patient-centred intervention involving self-help groups and home visits in rural Nicaragua resulted in a reduction in perceived or internalised stigma (measured using a stigma scale). The focus was on supporting and empowering people with TB through self-help groups and on enabling health workers, through home visits, to be better aware of the realities of their patients. Research in Ethiopia on an intervention involving “TB clubs” has similarly found a reduction in stigma gauged from focus group data (Demissie et al., 2003; Getahun, 1998). The TB clubs are organised by a TB health worker and comprise 3-10 people with TB who meet weekly throughout the course of their treatment. These clubs offer social support as well as transportation to clinics and the monitoring of treatment side effects. Demissie et al. (2003) and Getahun (1998) attribute the impact of TB clubs on stigma to improvements in knowledge about TB disease. However, *if* the theoretical understanding of the perception that people with TB are hated presented in this chapter is also applicable to the Ethiopian context, then underlying the impact on stigma may be an alternative mechanism: improvements in the emotional well-being of people with TB due to the social, practical and emotional support provided by the clubs.

My analysis of the data also suggests that emotional sensitivity may be heightened due to feeling physically unwell and to anxiousness over how to manage with the illness. Supporting people with TB to feel physically well, through the provision of prompt and effective treatment with minimal side-effects, is therefore also likely to have an impact on the perception that people with TB are hated. In Ethiopia, the monitoring of treatment side effects which the TB clubs offered may also have helped reduce stigma by improving physical wellbeing, and in Nicaragua, the provision of patient-centred care involving home visits may have contributed to

reducing stigma by reducing anxieties over how to manage both TB and the impact of TB and its treatment.

7.4.2 Reduce vulnerability to TB

One way of addressing the perception that people with TB are hated is by reducing the precautionary behaviours which could be interpreted as hateful. This can be done by reducing unnecessary or ineffective precautionary behaviours (see section 7.4.3 below) or by lessening fear of TB by reducing vulnerability to TB.

According to Courtright and Turner (2010), who conducted a systematic review of the literature on TB stigma, most authors identify the perceived infectiousness of TB and the fear this arouses as the basis of stigma. The perceived infectiousness of TB relates to the dimension of *peril* outlined by Jones et al. (1984) and included in my conceptual model of stigma causality (see 2.2.4 and 2.2.7). As discussed at the beginning of section 7.3, another dimension, *origin*, has also been linked with fear when infection with a disease is deemed beyond an individual's control. This study confirms that TB is much-feared and that these two dimensions can help explain why.

As presented in section 7.2.5 on the perceived legitimacy of precautions, the interviews with health workers suggest that their fears of contracting TB (and any expressions of these fears which may make a patient feel 'stigmatised') are likely to decrease if they feel genuinely protected from the risks of infection. The WHO (2009) policy on TB infection control in healthcare facilities includes use of ventilation systems and ultraviolet germicidal irradiation fixtures, as well as use of particulate respirators or masks which filter TB nuclei. The standard surgical masks provided to health workers in the study sites are effective at preventing the exhalation of particles (and are therefore to be worn by the person with TB) but are not particularly effective at preventing the inhalation of particles (Harries et al., 1997) and, as described by one research participant, are not always practical to wear anyway.

Behaviours driven by the perceived infectiousness of TB, such as avoidance or separation, are also driven by the fear of the consequences of infection. Vulnerability can refer both to the risk of becoming infected with TB (or developing TB disease), and to the consequences or impact of becoming infected or

developing disease. After all, common cold viruses, which are transmitted in the same way as TB, are far more infectious than TB but are far less feared. It is therefore useful to fully consider why TB is much-feared, and the reasons can be understood in terms of the other interrelated dimensions identified by Jones et al. (1984) and outlined in section 2.2.4: in particular *course*, which like *origin* and *peril*, refers to the characteristics of TB, and *disruptiveness*, which refers to how much TB (and its treatment) interferes with 'normal' life and social interactions.

Course refers to the way TB disease is perceived to change over time and its perceived ultimate outcome. Whilst most cases of TB are curable, and health promotion messages in Bangladesh, Nepal and Pakistan have emphasised this, it can nevertheless be difficult to cure in practice. TB treatment is lengthy, can be costly, and is sometimes difficult to access and sustain. In all three countries included in this study, TB drugs are provided free of charge from Government and some non-governmental health facilities, benefitting people with TB so long as they are aware of this, are able to access the facilities, and the required drugs are in stock. However, becoming ill with TB can still have a substantial financial impact on households. TB causes physical weakness making it difficult to continue working or find work. Its treatment is lengthy, may cause side-effects, and currently requires regular visits to a health facility (requiring time off work and therefore lost income, and incurring travel expenses). Also, as will be presented in section 8.2, the regular intake of nutritious food is thought to be needed to ensure full recovery. In short, a TB diagnosis may not usually mean certain death, but its *disruptiveness*, particularly for poor households, can be substantial.

Reducing vulnerability to the consequences of TB through treatment provision which is truly patient-centred, or through the provision of (financial and other) support alongside treatment, in order to compensate for the impact of TB on households, is likely to substantially lessen the fear aroused by TB.

7.4.3 Determine legitimacy

Behavioural precautions such as avoidance and separation are not always effective or necessary, and so National TB Control Programmes can play an important role in determining and generating consensus on the legitimacy of TB as a criterion for rejection. This will both reduce the occurrence of behaviours which may be interpreted as being hateful and will assist those with TB to perceive some of the behaviours as legitimately precautionary rather than as uncaring or hateful.

My research has found inconsistency and confusion over what constitutes a legitimate precaution. This is exacerbated, if not caused, by differing advice being given by different health workers to patients with TB and/or those accompanying them, or by the same health worker to those with sputum positive and negative TB and to those with pulmonary and extrapulmonary TB. This lack of clarity and consistency is unsurprising given that TB disease takes so many different forms and that not all forms are infectious.

One way of increasing clarity and consistency would be to change the terminology of TB. TB refers to a bacillus which can cause both latent and active infection, in any part of the body, and is sometimes infectious and sometimes not. From a microbiologist's perspective it may be a useful construct, but from a patient's or community perspective it is overly broad. The term 'TB' is often used as shorthand for active pulmonary sputum-positive TB and so messages about TB's symptoms and transmission appear to, but do not, refer to all forms of TB. Changing the name of a disease is not unprecedented. In the research sites, the term 'TB' is increasingly replacing local terms referring to the same disease, such as *chayarog* in Nepali (literally 'deteriorating disease') and *jokkha* in Bangla (literally 'silent killer') and in English, the term TB has replaced consumption and phthisis (Bynum, 2012). Whilst replacing the term TB with a new term in an attempt to lessen the fear aroused or to remove any negative connotations is likely to have at best a short-term impact, revising the TB construct to increase clarity and consistency (much as the AIDS construct was revised to distinguish between the virus, HIV, and the disease, AIDS) is likely to be more purposeful and effective.

Whilst the term TB may lack clarity, this lack of clarity is not the only reason for inconsistency in advice on precautions against transmission. The data from this study suggest that even in relation to sputum-positive pulmonary TB there is a lack of consistency and consensus on necessary and effective precautions. Measures included in the WHO policy for TB infection control in households focus on cough etiquette and ventilation. The policy states that those with smear positive TB should spend as much time as possible outdoors and sleep separately in a well ventilated room (2009). However, staying outdoors and sleeping separately may not be feasible for many people with TB, and relying on a person's cough etiquette may not be satisfactory to others in the household. Research participants spoke of separating eating utensils sometimes on, and sometimes against, the advice of

health workers. Whilst the training module for doctors published by the National TB Control Programme of Pakistan includes explicitly, as a key message for patients with TB, that TB does not spread via utensils (NTP Pakistan, 2008), it is not just doctors who provide TB care but also health workers and TB volunteers.

Furthermore, in the absence of feasible or satisfactory alternative precautionary measures, separating eating utensils or restrictions on food preparation may persist despite advice to the contrary. This may be because, to manage their fear, people want to actively do something to prevent transmission and because the transmission of TB via shared food and eating utensils fits comfortably with broader understandings of illness causation and interpretations of germ theory.

It seems especially important that a person with TB and those closest to him or her have a shared understanding of what precautions are recommended. The finding that the families of those with TB are sometimes informed of necessary precautions in the absence of the (sputum positive) person with TB is therefore of concern. Of course, even when there is a shared understanding and consensus on necessary precautions against TB transmission, for the person with TB these may be feasible for the first two weeks after commencement of treatment but increasingly difficult, both practically and emotionally, if they are to be sustained for longer. Whilst people with infectious pulmonary TB cease to be infectious within approximately two weeks of regular treatment (WHO, 2003), findings from this study suggest that the impression some people with TB and their communities seem to be getting is that TB remains infectious throughout the two month intensive treatment phase, if not beyond.

7.5 Summary

In this chapter I have presented a realist explanatory theory of the perception that people with TB are hated – a manifestation of TB stigma found across all five research sites. Whilst there is a relationship between the perception that people with TB are hated, fear of infection (which has been implicated as a cause of TB stigma in previous research) and precautionary behaviours involving separation or avoidance (which have been used as indicators of TB stigma in previous research), it is not the fear or behaviours which, following my definition (presented in section 2.1.5), are the stigma manifestations; it is the perception that people with TB are hated. This is key to understanding what it is that National TB Control Programmes should aim to decrease, as decreasing fear and precautionary behaviours may be at odds with their other aims.

Whilst fear of infection and social distance are rooted in the psychological processes or internal mechanisms of *parasite avoidance* and *dyadic cooperation*, it is *the need to belong* which underlies the social rejection that people with TB feel when they are avoided or segregated. Behavioural precautions against TB transmission (such as decreased proximity and increased separation) are incongruous with caring behaviours, and are so akin to rejection that TB itself is a criterion for rejection which is, as Leary (2001) puts it “consensually regarded as legitimate” (p7). In order to identify opportunities to reduce this TB stigma manifestation, it is therefore helpful to consider for whom and in what circumstances the perception of being hated does *not* manifest.

My analysis of the data suggests that people with TB are less likely to feel hated if they have initiated precautionary behaviours themselves, if they feel physically well and emotionally positive, and if the precautionary behaviours are feasible, compatible with social roles and expectations, and deemed legitimate. Based on these findings I have proposed the following three overarching approaches to addressing the perception that people with TB are hated: 1) support people with TB to feel physically and emotionally well; 2) reduce vulnerability to TB; and 3) determine legitimacy.

There is a relationship between the fear of infection and the perception that people with TB are hated, with the former often driving precautionary behaviours and the latter being the interpretation of those behaviours as uncaring. My suggestions for reducing vulnerability and determining legitimacy are likely to, in part, address stigma by reducing what Weiss et al. (2006b) refer to as “medically unwarranted” fear (p13). However, the primary intention to reduce vulnerability and determine legitimacy rather than to reduce fear is important for two reasons. Firstly, even though fear is aligned with stigma, fear itself is not always negative and so eliminating fear entirely would not be desirable and, as already stated, may be at odds with the other aims of the National TB Control Programmes. After all, fear of infection and the desire to avoid physical contact with someone with a disease are deeply rooted in *parasite avoidance* (see 2.2.3) and have been described as important components of our ‘behavioural immune system’ (Schaller, 2006). Secondly, attempting to reduce the perception that people with TB are hated by reducing fear of TB may have another unintended consequence if the approach taken focuses on controllability. Dijker and Koomen (2006) propose that fear is

aroused if becoming ill with TB is deemed beyond a person's control, but anger is aroused if TB is attributed to a person's 'voluntary' behaviour. If attempts to reduce fear therefore focus on the issue of 'controllability', then one form of stigma (the perception that those with TB are hated) may simply be replaced by another (the attribution of blame). The attribution of blame as a manifestation of TB stigma will be the focus of the next and penultimate chapter of this thesis.

Chapter 8

BLAME

The perception that those with TB are hated and the anticipation of reduced marriage prospects following a TB diagnosis emerged as manifestations of TB stigma (following my definition) across all three countries. However, a third manifestation, that of blame, emerged predominantly from the data collected in Nepal. There were some indications of it in the data collected in Pakistan, but it was absent from the data collected in Bangladesh. This does not necessarily mean it manifests less in Pakistan and not at all in Bangladesh. The data collected in Nepal was much richer in quantity and quality due to the greater capacity of the research team and so may have revealed a stigma manifestation which is not as prominent as the perception that people with TB are hated.

In one of the first interviews conducted with a person with TB in Nepal, the attribution of personal responsibility for the severity of disease arose.

“Disease is not big in itself. Mainly it becomes serious due to one’s carelessness.” (nu2, man with TB, urban site, Nepal)

Throughout subsequent interviews the research teams and I sought to understand the attribution of personal responsibility for TB in light of notions around susceptibility and severity, exploring the contexts in which a person with TB feels to blame or blamed. Although there was little indication that those with TB blame others for transmitting it to them or are blamed for transmitting it to others (only one research participant suggested this may happen), the attribution of personal responsibility, and sometimes blame for susceptibility to TB disease (section 8.1) and, in particular, its severity, outcome and reoccurrence (section 8.2) did emerge.

8.1 Blame for becoming ill with TB

The people with TB interviewed attributed their TB infection to a range of factors thought to increase susceptibility to infection by weakening the body. These factors included drinking alcohol, smoking, overworking or doing heavy work, and not eating sufficiently or regularly. As a result, whilst a person with TB may not blame

someone else for their TB infection or be blamed for transmitting it to someone else, they may blame themselves or experience blame from others for increasing their own susceptibility to TB, especially if the TB is attributed to a behaviour which already drew disapproval – most commonly in our sample drinking alcohol and smoking, but also, idiosyncratically, playing football (nr10) and having joined a monastery (nr15).

“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 alone. TB can affect someone for other reasons too. 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 [and smoke], so then everyone would have TB.”
(nr7, man with TB, rural site, Nepal)

While smoking and drinking, especially amongst castes in Nepal where it is customary or, as Subedi (2001) puts it, “culturally prescribed” (p88), is not viewed negatively, smoking and drinking irresponsibly is. It is irresponsible drinking and smoking, rather than drinking and smoking *per se*, which is thought to make a person more susceptible to TB. Irresponsible drinking and smoking includes drinking and smoking to excess, to the point where food intake is affected, and when already ill or weakened.

“People want to drink jaand [a local alcoholic drink] but if much is drunk whilst having fever or when feeling weak then from that TB disease develops.” (nr10, son-in-law of a man with TB, rural site, Nepal)

“[TB] happens more to those who take jaand and alcohol from morning to night, who do not take enough food and who take jaand and alcohol from anywhere.” (nr13, daughter-in-law of a woman with TB, urban site, Nepal)

The connection between alcohol and susceptibility to disease due to weakness might be viewed as direct, with alcohol causing weakness, but was viewed by some of those interviewed as indirect, with weakness resulting from the tendency for people who drink alcohol not to eat properly. The perceived association between

not eating properly and TB is illustrated by this quote from a woman who had had TB in the past and who expressed sadness that her own behaviour had caused her TB:

“When I had [TB] one thing made me feel sad. Before I didn’t take food properly. I didn’t care about food. I think I had [TB] due to not eating enough. I feel from now onwards I will not do the same.” (nr15, woman with past TB, rural site, Nepal)

In Pakistan, TB infection was similarly attributed to controllable behaviours (such as *“carelessness, or excessive consumption of chillies”* PUFM2) but was simultaneously spoken of as coming ultimately from God and therefore being beyond a person’s control. It is important to emphasise that references to TB being God-given, within the context of the interviews, were clearly intended to convey that TB is ultimately beyond any individual’s absolute control rather than that TB is somehow a divine punishment. Blame for *developing* TB disease was not felt or attributed consistently, uniformly or predictably because of the recognition among the research participants that, on the one hand, anybody can get TB and that, on the other hand, there are multiple factors which can increase susceptibility to TB – helping to explain, albeit imperfectly, why one person has developed TB disease and not another.

8.2 Blame for the course and reoccurrence of TB

During my analysis of the tenth interview conducted in Nepal (nu10), I noted that the participant did not speak of holding her neighbour responsible for developing TB disease, but that she did speak of holding him responsible for the severity and ultimate fatal outcome of his TB as he continued to chew tobacco whilst receiving treatment. This association between the attribution of responsibility and the ‘course’ of a disease rather than its ‘origin’ became increasingly apparent through subsequent interviews, as the same behaviours associated with increased susceptibility to TB were also associated with impeded response to TB treatment and increased likelihood of relapse or re-infection with TB. For example, it was thought that people with TB need to pay particular attention to their diet both during treatment and after, ensuring they eat adequately and regularly but also avoiding hot, sour, spicy and fatty foods.

“Medicine alone will not work if we do not take food.” (nr16, man with past TB, rural site, Nepal)

“After taking treatment for eight months [TB] will be cured. After that if one becomes careless and starts drinking and eating spicy, hot and sour food.... I used to eat hot food, but even today I no longer take sour food. [...] 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] won't come [back].” (nr11, husband of a woman with TB, who himself had had TB previously, rural site, Nepal)

Continued alcohol consumption and smoking whilst on TB treatment were thought to be particularly risky and indeed negligent as they are thought to impede recovery and lead to relapse or re-infection.

“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 taking medicines.” (nr2, man with extrapulmonary TB, rural site, Nepal)

“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.” (nu13, daughter-in-law of a woman with TB, urban site, Nepal)

The view that continued alcohol consumption, smoking and poor diet, following a TB diagnosis, are negligent or careless suggests people with severe or relapsed TB or with TB for a second time may be especially held responsible or blamed for their condition, or may blame themselves. Referring to a character in a vignette who had developed TB disease for a second time, a focus group participant in Nepal said the following:

“[He 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 then I too would think that it's due to my own carelessness. There is no place to blame others.” (nrFGD6-R4, man with TB participating in a focus group discussion, rural site, Nepal)

One of the health workers interviewed (nu14) spoke with concern that she had heard reports of patients with TB being scolded and kept at a distance by colleagues at another health facility. It seems that this may be especially the case for those with recurrent TB disease 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 for fear of being blamed or scolded or due to health workers taking incomplete medical histories, one example she gave, of a patient who had been reluctant to disclose that he had been taking TB treatment previously, suggests that the former explanation may at least play a role. Supporting this, a man with TB (nr16) described how the doctors had treated him differently the second time he had TB, scolding him for having TB for a second time and telling him he needed to take more care and avoid alcohol and cigarettes. Likewise, a male focus group participant spoke of being scolded by a doctor for smoking and also suggested that a character in a vignette, who had contracted TB for a second time, might be deterred from consulting a doctor for fear of being blamed and scolded.

“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 if I go to the doctor he'll scold me a lot, so how can I go to the doctor?’” (nrFGD3-R5, male focus group participant, rural site, Nepal)

Of course, changing behaviours, particularly addictive behaviours, such as smoking, and, amongst some castes, customary behaviours, such as drinking alcohol, can be very difficult. Being scolded for smoking and drinking or even just being advised to abstain from these are unlikely to be sufficient without the provision of additional support. Indeed, three of those interviewed spoke of how difficult they found it to stop smoking altogether (nr6, nu12, nr16) and two described how they had resorted to smoking clandestinely, away from their disapproving families.

The emerging causal theory for this manifestation of TB stigma reveals some understanding of the contextual conditions that form part of the causal process (in particular some of its iatrogenic sources). However, a fuller understanding of for whom and in what circumstances blame for severe or reoccurring TB is attributed is needed through theoretical sampling of those with severe and reoccurring TB from across the sites in order to identify the full range of opportunities for addressing this TB stigma manifestation. Despite the theoretical understanding of this manifestation of TB stigma being at present less well developed than those of the previous two (presented in Chapters 6 and 7), I have included it in this thesis nonetheless for two reasons. Firstly, as Glaser and Strauss (1967) emphasise, theory is “an ever-developing entity, not [...] a perfected product” (p32), and so the explanatory theories presented in this thesis for all three manifestations, and particularly for this final one, are there to be developed further through future research and by other researchers. Secondly, because the issue of blame came particularly to the fore in relation to severe, recurrent and relapsed TB, the attribution of blame is a manifestation of TB stigma that is likely to become more prominent in the South Asian context in future as the prevalence of drug-resistant strains of TB, co-infection with HIV and co-morbidity with diabetes increase. The need to pre-empt and prepare for the increasing importance of the attribution of blame as a manifestation of TB stigma will be discussed in section 8.4.2.

8.3 Reflections on the explanatory theory

Mirroring public health rhetoric, in Nepal and Pakistan TB was spoken of both as a disease which anyone can get and as a disease to which some people are more susceptible, due to factors such as (irresponsible) alcohol consumption, (excessive) smoking and poor diet. Research has shown that the associations between TB and smoking, alcohol and poor nutrition are not just perceived, but also real. A systematic review and meta-analysis of epidemiological studies that provided a relative risk estimate for the association between TB (infection, pulmonary disease, or mortality) and active tobacco smoking found that smoking is a risk factor for TB infection and TB disease (Bates et al., 2007). Likewise, a systematic review of analytical epidemiological studies with individual-level data on alcohol exposure and TB disease status found that the risk of active tuberculosis is significantly elevated in people who drink more than 40g alcohol per day and/or have an alcohol use disorder (Lönnroth et al., 2008). However, Lönnroth et al.’s review was not able to establish the extent to which this association is confounded by factors related to

alcohol use, such as social mixing patterns, and to what extent it is due either to alcohol's direct toxic effect on the immune system or to its indirect effect (also suggested by some of the participants of this study, see section 8.1) through micro- and macronutrient deficiencies. Certainly, Cegielski and McMurray's review of the scientific evidence on the relationship between malnutrition and TB found that poor nutrition is an important risk factor for TB (2004).

Following Jones et al.'s (1984) classification of the dimensions of stigma (see section 2.2.4), the factors which make a person susceptible to TB and the attribution of responsibility for these factors fall under the dimension 'origin'. Dijker and Koomen (2006) argue that if infection with a disease, or its *origin*, is attributed to a person's voluntary behaviour then it arouses anger in others, whereas if it is deemed beyond an individual's control it arouses mostly fear and pity. As I have stated in section 7.3, fear was certainly more evident from the data of this research than anger, loathing or blame, and this is consistent with studies on TB stigma conducted in Colombia (Jaramillo, 1999) and Hong Kong (Mak et al., 2006). Following Dijker and Koomen's assertion, this would suggest that infection with TB is deemed beyond an individual's control and indeed this too is consistent with the data generated from my research. As presented in Chapter 7, the data indicates that TB is generally known to be infectious and airborne, and so becoming infected, especially for the first time, is deemed beyond an individual's control.

Only one other study has tried to explain TB-related stigma in Nepal to date (Baral et al., 2007), and among the reasons identified as to why people with TB are stigmatised or discriminated against, two relate to TB's perceived 'origin'. The first is the perception that TB is divine punishment for unacceptable behaviour, proposed as an explanation by a health professional interviewed. With the exception of one focus group participant, none of the Nepali participants in my study spoke of supernatural causes of TB. The data from my study overwhelmingly suggests that causal explanations for TB in the research sites in Nepal are located predominantly within what Subedi (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. Whilst amongst some of those interviewed ritual treatment was deemed necessary for illnesses with supernatural causes, both the treatment and the attribution of the illness to such causes was more a means of explaining and treating the unexplained or un-medically diagnosed rather than a means of blaming a person with TB or specific others for misdeeds. Likewise, in Pakistan, although

TB was often referred to as determined by God, within the contexts of the interviews this was clearly intended to convey that TB is ultimately beyond any individual's control, rather than that it is divine punishment.

The second reason, identified by Baral et al. (2007), why people with TB are stigmatised and which relates to TB's perceived 'origin', is the association of TB with immoral behaviour, such as visiting prostitutes, drinking and smoking. Whilst my research did find that (irresponsible) drinking and (excessive) smoking are among the factors thought to increase susceptibility to TB, and that some of the people with TB interviewed spoke of being blamed or blaming themselves for developing TB disease, blame was not attributed consistently or predictably and seemed very much dependent on whether a behaviour was disapproved of prior to the TB diagnosis. As mentioned in section 8.1, such behaviours were most commonly drinking alcohol and smoking (in excess or irresponsibly), but also included playing football and having joined a monastery. Incidents in the data of being blamed or feeling to blame for developing TB disease because of behavioural risk factors seemed to lack the consensus emphasised by Leary (2001) as necessary for distinguishing them as stigmatising rather than idiosyncratic (see 2.2.5). The findings of my study indicate that perceived causes (or factors that increase susceptibility) tend to be used to explain TB rather than to blame people for TB, and this may explain why a study by Somma et al. (2008) found no particular perceived causes of TB to be associated with indicators of self-perceived stigma in Bangladesh. Whilst Somma et al. did not specifically include blame as an indicator of stigma, some of the indicators which were included may relate to blame, such as "others would think less of you", "think less of yourself" and "shamed or embarrassed".

However, my research shows that the same factors which are thought to increase susceptibility to developing TB disease were also found to be associated with impeded response to TB treatment and increased likelihood of relapse or re-infection with TB. It is here that attribution of blame is most evident from the data. Whilst my research does suggest that some people with TB are blamed or blame themselves for their susceptibility to TB disease, it is in relation to recurring or unsuccessfully treated TB disease that issues of controllability and responsibility particularly come to the fore. The attribution of responsibility for recovery and for the prevention of recurrent TB is likely to be rooted in the psychological process or internal mechanism referred to by Phelan et al. (2008) as *norm enforcement*. Norm enforcement is the attribution of blame (or even punishment) for deviations deemed

voluntary, with the intention of achieving conformity and demonstrating boundaries of acceptable behaviour.

Dijker and Koomen (2006) argue that anger will be aroused if a disease is thought to be acquired due to one's own controllable behaviour, linking controllability with the dimension of 'origin'. However, controllability can also relate to the dimension of 'course'. 'Course' refers to the way TB is perceived to change over time and its ultimate outcome (Jones et al., 1984). My research suggests that whilst anyone can get TB for a first time, once someone has had TB once, it is deemed their responsibility to increase their chances of recovery and to reduce their susceptibility to further infection by making lifestyle changes. Those who are unable to make, are deemed unwilling to make, or are thought not to have made those changes, are likely to find themselves blamed. This study found that to get TB once is, on the whole, deemed unfortunate, but to get it twice or severely is deemed careless or negligent.

8.4 Opportunities for addressing TB stigma

All theories can be seen as ever-developing and never perfected products (Glaser and Strauss, 1967). Of the three causal theories of manifestations of TB stigma presented in this thesis, it is the theory to explain the attribution of blame which calls for a fuller understanding not just of *why* blame is attributed for the course and reoccurrence of TB disease, but of *whether* blame is attributed, in other words for whom and in what circumstances this form of TB stigma manifests. Nevertheless, even this partial theory points to opportunities for addressing this manifestation of TB stigma. Indeed, addressing this manifestation of TB stigma may be particularly important because of the suggestion from the data that people with relapsed TB may be reluctant to disclose their TB history to health workers for fear of being blamed or scolded. For similar reasons, patients may withhold behaviours (such as smoking or drinking alcohol) which are perceived to have contributed to their TB infection and for which they are held responsible. Full disclosure of past TB infections is necessary for the prescription of appropriate treatment regimens, as a previously treated case which has relapsed is likely to require a different combination of antibiotics than a new infection (WHO, 2010). Where support with, for example, smoking cessation is available, then disclosure of such a behavioural risk factor will be necessary in order to receive it. The theoretical understanding of the attribution of blame presented with reference to the data (8.1 and 8.2) and reflected upon in light of published research and my conceptual model of stigma

causality (8.3) suggest opportunities for addressing iatrogenic sources of this manifestation of TB stigma and for pre-empting and preventing its growth.

8.4.1 Address iatrogenic sources

Important sources of this stigma manifestation are likely to be iatrogenic (i.e. arising from or promoted by health-related interventions and services). Sensitive approaches to eliciting information from and imparting advice to patients are needed, particularly for those with severe, recurrent or relapsed TB who may feel reluctant to disclose their TB history for fear of being blamed and scolded. A less direct iatrogenic source of this manifestation of TB stigma is likely to be the advice to patients with TB to abstain from smoking and drinking and to eat nutritious food, but without providing them with or referring them to support to do so. Three of those interviewed spoke of how difficult they found it to stop smoking and two described how they had resorted to smoking clandestinely. Likewise, changes in diet may be difficult due to financial constraints, personal preferences and inconsistent views on which foods need to be restricted, which need to be consumed and for how long (see also section 7.2.5).

The distinction between identifying epidemiologically-defined behavioural risk factors and attributing blame is not very pronounced. The medical affirmation that 'controllable' behavioural factors increase susceptibility and inhibit recovery gives legitimacy to the attribution of responsibility and blame. As Leary (2001) states, consensual legitimacy (which was not included in my stigma definition, but was included in my conceptual model of stigma causality, see 2.2.5), is necessary for the attribution of blame to be considered as a manifestation of stigma rather than just as idiosyncratic. As with the manifestation of TB stigma presented in Chapter 7 (the perception that people with TB are hated), National TB Control Programmes can play a role in legitimising or de-legitimising the attribution of blame, and may do so in unintended, subtle or implicit ways. For example, a paper published in 2012 in the *International Journal of Tuberculosis and Lung Disease* argues that terms such as 'defaulter', 'TB suspect' and 'control' unfairly place the blame on those with TB, rather than on the failings of the health services, and calls for a change in the language used by TB services (Zachariah et al., 2012).

8.4.2 Pre-empt the future

As indicated by this research, the issue of blame is particularly pertinent with regards to severe, recurrent and relapsed TB. Participants recognised factors which increase a person's susceptibility to developing TB disease, but developing TB disease for the first time was nevertheless deemed beyond an individual's control and therefore unfortunate. Subsequently recovering from TB disease and preventing future reoccurrence were, however, deemed an individual's responsibility and very much within an individual's control. With the emergence and increasing prevalence of drug resistant strains of TB, those with TB may be increasingly blamed for failing to manage their conditions.

Care needs to be taken, when attempting to reduce TB stigma, not to simply replace one form of stigma with another. As previously stated (in sections 7.3, 7.5 and 8.3), Dijker and Koomen (2006) argue that fear is aroused if becoming ill is deemed beyond a person's control, but anger is aroused if it is attributed to a person's 'voluntary' behaviour. Therefore, if measures to reduce the perception that those with TB are hated (which is closely aligned with fear of infection) focus on increasing a sense of 'controllability' in order to reduce fear, then one form of stigma (the perception that those with TB are hated) may simply be replaced by another (the attribution of blame). Indeed, as TB is simultaneously viewed as uncontrollable (and is therefore to be feared) and controllable (arousing anger and blame) – bringing together the underlying processes of *parasite avoidance* and *norm enforcement* – the increase in drug resistant TB (and indeed of TB co-morbidity with HIV and diabetes) is likely to elicit a particularly potent dual affective response, compounded by the added disruptiveness of even lengthier treatment. Indeed, a research paper on TB stigma in Zambia, a high HIV prevalence setting, emphasises a convergence of fear and blame in what the authors term TB-HIV stigma (Bond and Nyblade, 2006).

8.5 Summary

In this penultimate chapter, I have focussed upon the attribution of blame as a manifestation of TB stigma. Through the data collection and analysis process the attribution of blame for becoming ill with TB emerged, albeit inconsistently, in cases where the TB is attributed to a behaviour which already drew disapproval (most commonly drinking alcohol and smoking). However, it is the attribution of blame for the course and outcome of TB disease which emerged more unambiguously as a manifestation of TB stigma following my definition presented in Chapter 2. It is here

that issues of controllability and responsibility come to the fore, with the psychological process or internal mechanism of *norm enforcement* at their root.

The same behaviours associated with increased susceptibility to TB (such as alcohol consumption, smoking and poor diet) were also associated with impeded response to TB treatment and increased likelihood of relapse or re-infection with TB. However, whereas to get TB for the first time is deemed unfortunate, to get it twice or severely is deemed irresponsible.

Further theoretical sampling across the five sites, specifically of people with relapsed, recurrent or severe TB, would have been beneficial to developing an understanding of to whom and in what circumstances blame is attributed. After all, it is unlikely that all those with relapsed, recurrent or severe TB experience this TB stigma manifestation in exactly the same way and to exactly the same degree. Only by looking at variations and similarities in experience can we begin to fully understand the socio-structural and individual circumstances which promote and constrain the attribution of blame. Nevertheless, my analysis of the data and reflections do suggest that health services play a role in attributing blame and legitimising the attribution of blame, and that crucially this manifestation of TB stigma is likely to become more pronounced in future.

Chapter 9 CONCLUSION

To conclude this thesis, I will outline the significance of the research presented (9.1) and summarise its key findings (9.2). I will then synthesise and summarise the opportunities for addressing TB stigma based on the realist causal theories developed (9.3), before reflecting on the relevance of the theories beyond the research sites (9.4). Finally I will consider the limitations of the research (9.5) and make recommendations for developing the theories further (9.6).

9.1 Significance of this research

This research was conducted in partnership with the National TB Control Programme in Bangladesh and two non-governmental organisations working closely with the National TB Control Programmes in Nepal and Pakistan. The National TB Control Programmes in all three of the countries recognise that tuberculosis is associated with stigma, and this is also supported by previous research conducted in these South Asian countries (Liefoghe et al., 1995; Baral et al., 2007; Weiss et al., 2006a).

According to a systematic review of the literature on TB stigma, few interventions have been introduced to reduce TB stigma and even fewer have been evaluated (Courtright and Turner, 2010). Drawing ideas on how TB stigma could be addressed from the few interventions which have been introduced is complicated by the fact that the term stigma has, as Manzo (2004) puts it, been “under-defined and over-used” (p401). Interventions seemingly targeting the same phenomenon may therefore in fact be targeting very different interpretations or manifestations of stigma. In this thesis I explicitly define three specific manifestations of TB stigma identified from the data which can serve as the target of interventions to reduce TB stigma.

As well as explicit and specific target outcomes, TB stigma interventions also need to be underpinned by a theoretical understanding of the mechanisms and contexts involved in generating those outcomes. There is increasing recognition that intervention design and evaluation need to be theory-driven, with the Medical Research Council’s guidance on developing and evaluating complex interventions

(2008) stating that “*a vitally important early task is to develop a theoretical understanding of the likely process of change*” (p9). A theoretical understanding of the processes which generate stigma manifestations (i.e. their causes) can reveal opportunities for intervening in those processes. However, few published research studies have focussed on understanding the causes of TB stigma, and this is the first to attempt to develop grounded explanatory theories using a qualitative comparative multi-country approach and a realist conceptualisation of causality.

Whilst the three specific manifestations of TB stigma can serve as the outcomes for interventions to target, the causal theories provide their theoretical underpinning. As well as developing and presenting causal theories, I have also identified approaches, underpinned by the theories, to addressing TB stigma across the three South Asian countries.

9.2 Key findings

9.2.1 Manifestations of TB stigma

The first objective of this study was to gain an understanding of the nature of the stigma associated with TB in the contexts of the selected rural and urban areas in Bangladesh, Nepal and Pakistan. Stigma is a term used widely and vaguely, and has been conceptualised by some as a process leading to particular outcomes (usually attitudes or behaviours) and by others as the outcomes themselves. In Chapter 2 (section 2.1) I considered the different ways in which the term stigma has been conceptualised, and, borrowed elements of these to develop my own definition focussed on outcomes, or stigma manifestations, and specific to TB.

I define manifestations of TB stigma as:

Anticipated, perceived, internalised and/or intended *negative* attitudes, emotions, or behaviours towards or by a person on the basis that he or she is known or suspected to have TB, or is perceived to be particularly susceptible to or associated with TB

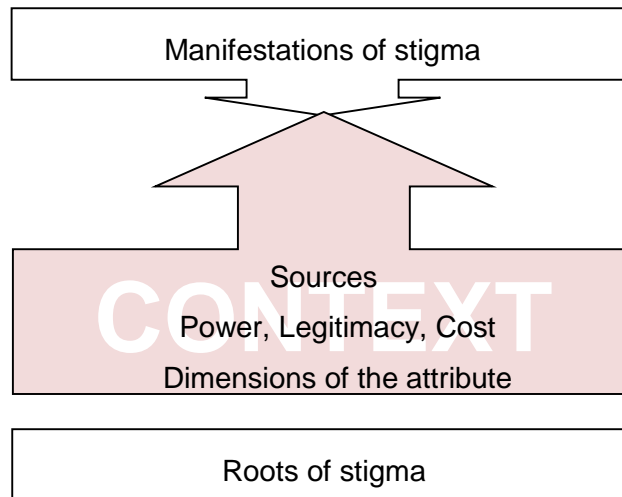
I did not want to presume how TB stigma manifests in the three countries and so did not want to predetermine what specific manifestations of TB stigma would be the focus of this study. As a result my second objective was to develop theories to

explain the causes of outcomes (or stigma manifestations) I had yet to discover. For their discovery, my definition of TB stigma manifestations served as a guide, with emphasis on the word 'negative' as the common feature implicit in all definitions of the stigma concept. My definition served to broaden the perspectives of myself and the Bangladeshi, Nepali and Pakistani research teams on what to investigate (negative attitudes, emotions and behaviours), from whose perspective (anticipated, perceived, internalised and intended) and in relation to whom (towards or by a person on the basis that he or she is known or suspected to have TB, or is perceived to be particularly susceptible to or associated with TB).

Some potential manifestations identified from the data, which have been referred to as stigma or stigma indicators by previous researchers, such as being avoided by others and the desire not to disclose a TB diagnosis, were not always presented as negative by the research participants of this study. Others, such as tensions within families, were sometimes exacerbated by but not always directly related to TB. Three manifestations which feature consistently as both negative and TB-related (though not necessarily TB-specific) in the data, and for which causal theories have therefore been developed, are: (1) reduced marriage prospects; (2) the perception that people with TB are hated; and (3) the attribution of blame for the course and reoccurrence of TB disease.

9.2.2 Roots of TB stigma

Whilst it has been argued that stigma needs to be tackled at its deep-rooted sources (Royal Tropical Institute (KIT), 2004), its deepest roots can be seen as the underlying psychological processes described in Chapter 2 (section 2.2.3) and positioned at the base of my conceptual model of stigma causality (reproduced below).



In Chapter 2 (section 2.2.3) I stated that whilst there is disagreement on why or how the psychological processes which underlie stigma developed, with some describing them as evolutionary and others as functional, there is broad agreement on what they are and that the stigmas attached to different types of attribute are likely to be deeply-rooted in different underlying psychological processes.

The underlying psychological process known as *parasite avoidance* is most often thought to be associated with disease-related stigmas (Kurzban and Leary, 2001, Schaller, 2006). Parasite avoidance refers to that which underlies our affective and cognitive responses to disease, including fear, disgust, avoidance and exclusion. My study found that self-protective behaviours arising from a fear of TB transmission (such as physically distancing oneself and separating eating utensils) are sometimes interpreted as signs of hatred towards those with TB. Whilst it is the underlying psychological process known as *parasite avoidance* which underlies the fear of infection, it is another process, *the need to belong*, which underlies the social rejection that people with TB feel when they are avoided or segregated (Baumeister and Leary, 1995). *Dyadic cooperation*, which refers to our tendency to want to benefit from social relationships and to avoid, reject or exclude those who do not reciprocate or cooperate in some way, is likely to also play a role in that a relationship with somebody who has developed TB disease is (perceived to be) re-evaluated and subsequently devalued. It is this process which is also likely to underpin in particular the impact of TB on marriage prospects. By contrast, the attribution of blame for the course and reoccurrence of TB disease is likely to be underpinned by a process known as *norm enforcement*. Norm enforcement, which evokes Goffman's (1963) "blemishes of individual character" (p14), refers to a process whereby attitudes, behaviours and emotions are elicited which serve to

make those who deviate from social norms conform, or to demonstrate to others the boundaries of acceptable behaviour.

Prior et al. (2003) argue that the term stigma is “creaking under the burden of explaining disparate, complex and unrelated processes” (p2192) and for this reason Weiss et al. (2006b) argue that separate definitions of stigma need to be developed which are condition- or attribute-specific. However, given that the three TB stigma manifestations upon which I have focussed in this thesis are rooted in *different* underlying psychological processes, even the attribute-specific term “TB stigma” creaks under the same burden described by Prior et al. (2003). It is therefore critical that interventions to address ‘TB stigma’ are explicit and specific about which manifestation of TB stigma they are designed to address, and that they are then underpinned by a corresponding causal theory.

Rather than attempting to target the psychological processes which underlie TB stigma manifestations directly, measures to reduce manifestations of TB stigma are likely to be most effective if they acknowledge and work with these psychological processes. For example (as stated in section 6.5), measures to reduce TB’s impact on marriage prospects which focus on reducing or compensating for the costs of marriage to someone with TB work *with* the underlying process of dyadic cooperation. By contrast, measures which attempt to persuade individuals, families and communities to accept marriages where the costs are deemed greater than the benefits either ignore or work against the underlying process of dyadic cooperation and are therefore unlikely to be effective.

In Chapter 2, I quoted Campbell and Deacon (2006) as saying that stigma is “a phenomenon rooted in the individual psyche, yet constantly mediated by [...] material, political, institutional and symbolic contexts” (p416). Although it has been argued that to really change stigma its deeply rooted or fundamental causes need to be addressed (Royal Tropical Institute (KIT), 2004, Link and Phelan, 2001), these causes are best seen as stigma’s mediating contexts, rather than as its roots in the human psyche. The causal theories of stigma which are needed to underpin strategies for reducing stigma straddle the shaded space in the conceptual model (reproduced above from Figure 2, Chapter 2) between stigma’s roots and its manifestations, and so ‘deeply rooted’ and ‘fundamental’ is best interpreted as meaning grounded and contextualised.

9.2.3 Causes of TB stigma

This study, which was conducted in collaboration with the National TB Control Programme of Bangladesh and non-governmental organisations in Nepal (HERD) and Pakistan (ASD), involved 73 individual interviews with people with TB, their family members and health care providers in three rural and two urban sites across the three South Asian countries, followed by eight focus group discussions across three of the sites. Using the grounded theory approach and a conceptualisation of causality based on a realist ontology, I developed causal theories (presented in Chapters 6-8) to explain the three manifestations of TB stigma identified from the data.

It is TB's *disruptiveness* (one of six dimensions described by Jones et al. (1984)) to the gendered roles of wife (or daughter-in-law) and mother which makes it, to borrow the words of Leary (2001), "consensually regarded as legitimate grounds" (p7) for rejecting a woman for marriage. This constitutes the mechanism at the centre of the realist causal theory explaining TB's negative impact (whether experienced or anticipated) on the marriage prospects of women in particular. Indeed, Goffman (1963), in his sociological book on stigma, states that the attributes which are discreditable, in other words most likely to be associated with stigma, are those which are incongruous with society's view of what a particular type of individual should be. Contextual factors then determine whether the mechanism becomes generative of the stigma manifestation, and include socio-structural factors such as the custom for a woman to join her husband's household and the narrow age range in which women are expected to get married, as well as specific individual circumstances, such as a woman's education and future earning potential, her age and her pool of potential spouses.

At the heart of the causal theory to explain the perception that people with TB are hated is the incongruity between behavioural precautions against TB transmission (such as decreased proximity and increased separation) and caring behaviours. Indeed, behavioural precautions are so akin to rejection that TB itself is a criterion for rejection which is, to use the words of Leary (2001) once again, "consensually regarded as legitimate" (p7). Nevertheless, this mechanism does not always become generative of the perception that people with TB are hated. Despite the incongruity between precautionary behaviours and caring behaviours, some people in some circumstances interpret behaviours with potentially ambiguous intent as precautionary and nothing but precautionary. From this research I have theorised

that when people with TB initiate the precautionary behaviours themselves, when they feel physically well and emotionally positive, when the precautionary behaviours are feasible, compatible with social roles and expectations and deemed legitimate, then they are less likely to feel hated or 'stigmatised'.

The attribution of blame for becoming ill with TB emerged, albeit inconsistently, in cases where the TB is attributed to a behaviour which already drew disapproval (most commonly drinking alcohol and smoking). However, it is the attribution of blame for the course and reoccurrence of TB disease which emerged more unambiguously as a manifestation of TB stigma following my definition. The same behaviours which research participants associated with increased susceptibility to TB (such as alcohol consumption, smoking and poor diet) were also associated by the research participants with impeded response to TB treatment and increased likelihood of relapse or re-infection with TB, and indeed these associations are supported by epidemiological studies (Bates et al., 2007; Lönnroth et al., 2008; Cegielski and McMurray, 2004). However, whereas to get TB for the first time is generally deemed unfortunate by those participating in this study, to get it twice or severely is deemed irresponsible.

In all three causal theories, the notion of legitimacy is central. It is TB's 'disruptiveness' to gendered roles and responsibilities which makes it *legitimate* grounds for rejecting a woman for marriage. Behavioural precautions against TB infection, whether warranted or not, are so incongruous with caring behaviours and akin to rejection that TB itself is a *legitimate* criterion for rejection. The medical and epidemiological affirmation that 'controllable' behavioural factors increase susceptibility to (relapsed or reoccurring) TB, and inhibit recovery, gives the attribution of responsibility and blame *legitimacy*.

Link and Phelan (2001) argue that stigma is dependent on social, economic and political power. However, it is not just that only individuals with power are able to stigmatise (Link and Phelan, 2001) or elude stigma (Crocker et al., 1998). It is in determining the *legitimacy* of attitudes, emotions and behaviours which for some people in some circumstances feel like rejection, hatred and blame, that stigma is dependent on social, economic and political power. The social, economic and political power lies with the structural, iatrogenic and other 'sources' of this legitimacy, and these sources point to opportunities for influencing TB stigma. One of the overarching approaches to addressing TB stigma, which I outline in the

following section (9.3.1), focuses on what National TB Control Programmes can do to influence the legitimacy of rejection, hatred and blame.

Whilst the notion of legitimacy is central to understanding the causes of TB stigma, the notion of illegitimacy is central to definitions of manifestations of TB stigma. In my definition of TB stigma manifestations (presented in section 2.1.5 and again in section 9.2.1) I italicised the word 'negative' on the basis that it is the common implicit factor running throughout all definitions of stigma. What makes stigma inherently negative is the implication that it is unwarranted, unjust and, in essence, lacking in legitimacy. This apparent contradiction, that stigma manifestations are deemed illegitimate (and therefore warrant research and intervention), but are also dependent on legitimacy, lies at the very heart of the stigma concept and explains why interpretations of what constitutes stigma are always going to be fluid, contextualised and subjective.

The theories comprise mechanisms to understand *why* TB stigma becomes manifest, combined with the contexts which determine *whether* TB stigma becomes manifest (i.e. for whom and in what circumstances). Both the mechanisms and the contexts are, as Maxwell (2012) writes, "inextricably part of the causal process" (p36). Viewed in this way, measures to address TB stigma which focus on altering the contexts in which mechanisms become generative of TB stigma, as well as those which focus on the mechanisms themselves, address the "fundamental causes of stigma" (p381) which Link and Phelan (2001) argue need to be addressed in order to really change stigma.

9.3 Opportunities for addressing TB stigma

Whilst the first two objectives of this research were to understand the nature of TB stigma in Bangladesh, Nepal and Pakistan and to develop theories to explain TB stigma, the third objective was to consider, in light of the theories developed, the potential for policy and programme responses.

In the introduction to this thesis (Chapter 1) I suggested that because there is a funding shortfall for a full response to the TB epidemic in low- and middle-income countries of up to \$2 billion per year for 2014 and 2015 (WHO, 2013c) it could be argued that priority needs to be given to tackling TB itself, rather than the stigma

associated with it. However, the realist grounded theoretical understanding of the causes of TB stigma manifestations which I have developed through the process of this research study and have presented in Chapters 6, 7 and 8 and summarised in section 9.2.3, suggests measures to address TB stigma which are not necessarily distinct from measures to address TB. This does not mean that nothing needs to be done beyond what it already being done, but means that many of the measures I propose to reduce stigma will also improve TB control. In Ethiopia, Demissie et al. (2003) found that “TB clubs” resulted in both less stigma and better treatment outcomes. If the theoretical understanding of TB stigma developed in this thesis were to also apply to the Ethiopian context, then the reduction of stigma and improvements in treatment outcomes would not be assumed to indicate that less stigma leads to better treatment outcomes, but would be interpreted as indicating that what it is that the TB clubs provide, such as social, practical and emotional support, impacts on both.

In Chapter 2, section 2.2.6, I referred to terms such as iatrogenic and institutional stigma as indicating ‘sources’ of stigma rather than constituting causal theories of stigma. In combination with causal theories, sources suggest where measures to address stigma can be taken. For example, the realist explanatory theory for TB’s negative effect on marriage prospects places the disruptiveness of TB to gendered roles and responsibilities at its heart. Sources, be they iatrogenic, institutional, socio-structural, cultural or otherwise indicate the presence or absence of policies and practices which contribute to this disruptiveness, and highlight opportunities for addressing this manifestation of TB stigma.

With the National TB Control Programmes in Bangladesh, Nepal and Pakistan in mind, I outlined approaches (in sections 6.6, 7.4 and 8.4) to addressing each of the three TB stigma manifestations based on the realist causal theories developed. These have been synthesised and summarised below.

9.3.1 Influence the legitimacy of rejection, hatred and blame

Central to each of the causal theories developed to explain the three TB stigma manifestations upon which this thesis has focussed is the notion of legitimacy. To address all three TB stigma manifestations National TB Control Programmes can take measures to influence their legitimacy.

It is TB's 'disruptiveness' to gendered roles and responsibilities which makes it *legitimate* grounds for rejecting a woman for marriage. By reducing the 'disruptiveness' of TB and its treatment to the gendered roles of wife and mother, National TB Control Programmes can reduce the significance of TB to the valuation of a prospective spouse, and in particular wife. This involves improved TB case detection and treatment, particularly among unmarried and newly married women, and meaningful and continual gender mainstreaming to ensure that even if service provision is patient-centred, it is not just centred on a single type of (male, married) patient.

Behavioural precautions against TB infection (such as decreased proximity and increased separation) are so incongruous with caring behaviours and akin to rejection that TB itself is a *legitimate* criterion for rejection. However, behavioural precautions such as avoidance and separation are not always effective and so National TB Control Programmes can play an important role in determining and generating consensus on the legitimacy of TB as a criterion for rejection. This will both reduce the occurrence of behaviours which may be interpreted as being hateful and will assist those with TB to perceive some of the behaviours as legitimately precautionary, rather than as uncaring or hateful. Current inconsistency and confusion over what constitutes a legitimate precaution and for how long such precautions are necessary open up precautionary behaviours to (mis)interpretation. Clarity and consistency of messages can be achieved through training, focussed on discussion rather than just instruction, of those involved in TB care at various levels, including new and existing community TB volunteers and doctors.

The medical and epidemiological affirmation that controllable behavioural factors increase susceptibility and inhibit recovery gives legitimacy to the attribution of responsibility and blame. It is therefore unsurprising that sources of blame which emerged from the data were found to be iatrogenic and addressing these will contribute to addressing this TB stigma manifestation. Those with severe, recurrent or relapsed TB in particular may feel reluctant to disclose their TB history to health care providers for fear of being blamed and scolded. Sensitive approaches to eliciting information from and imparting advice to patients are therefore needed as well as practical support, alongside advice, to abstain from smoking and drinking and to eat nutritious food. Terms such as 'defaulter', which place the blame for non-adherence to treatment, and by implication for persistent, severe and relapsed TB, on those with TB rather than on the failings of the health services, may contribute to the perceived legitimacy among health care providers of attributing blame to the

patient. Indeed, a change in the language used by TB services has already been called for by Zachariah et al. (2012) and Baral and Newell (2012).

9.3.2 Reduce vulnerability to TB

Another approach to reducing, in particular, the perception that people with TB are hated, focuses on reducing vulnerability to TB, including vulnerability to the consequences of TB. This could include prompt and effective treatment provision which is truly patient-centred and the provision of support alongside treatment to compensate for the impact of TB on households. Such support could include counselling, support groups and practical assistance with transport and expenses. Such measures would serve to reduce fear of TB and the expressions of that fear, whether obvious or subtle, which can be interpreted as expressions of hate towards those with TB.

The focus on reducing vulnerability to TB as a way of reducing fear, rather than on reducing fear alone, is important. Fear, in the presence of vulnerability, is beneficial to health and contributes to what Schaller (2006) terms as our behavioural immune system. Furthermore, measures to reduce fear without reducing vulnerability are likely to focus on increasing the perceived controllability of TB. As highlighted in section 7.5, Dijker and Koomen (2006) argue that fear is aroused if becoming ill with TB is deemed beyond a person's control, but anger is aroused if TB is attributed to a person's 'voluntary' behaviour. If attempts to reduce fear of infection focus on increasing the perceived controllability of TB, then a consequence is likely to be an increase in anger and the attribution of blame, replacing one TB stigma manifestation with another. The design of an intervention to address one of the TB stigma manifestations therefore needs to be considerate of the theories explaining all three.

9.3.3 Empower people with TB

Two approaches which I propose focus on empowering those with TB. The first is to enable those with TB to manage knowledge of their TB and thereby manage manifestations of stigma associated with TB. Whilst relevant to all three TB stigma manifestations, concerns over the confidentiality of TB care were apparent in particular among women and in relation to TB's anticipated detrimental impact on marriage and marriageability. Discussion and consensus on the position of confidentiality in TB care is needed at international, national and local levels and an

understanding of how current TB policies and services influence the 'evidentness' of a person's TB status will reveal opportunities for improving service design and delivery in such a way that those with TB are given greater control over managing knowledge of their condition. Such an understanding could be obtained through a review of current TB policies and services which is focussed on evidentness and confidentiality.

In section 7.2.3 I presented data to support the idea that the emotional state of a person with TB influences whether another person's actions or reactions are perceived to be precautionary, uncaring or hateful. The provision of support to people with TB to feel emotionally as well as physically well is therefore likely to be helpful in addressing the perception that people with TB are hated.

9.3.4 Mainstream stigma and pre-empt the future

A crucial step towards reducing TB stigma would be to consider the likely influence on stigma manifestations of any current, planned and future TB policies, programmes or initiatives. This approach is known as mainstreaming, a term usually used with reference to gender. Indeed, because of the strong gender dimension of stigma, gender mainstreaming is also important (as I have stated in section 9.3.1), and not entirely distinct from stigma mainstreaming. Mainstreaming involves including gender and stigma in meeting agendas, role descriptions and training sessions and having high level commitment to the importance of considering gender and stigma in the development and improvement of TB policies and services.

If the theoretical understanding of TB stigma presented is considered at all stages of TB care and prevention programme design, planning and implementation, then approaches with the most positive (or least negative) likely effect on stigma can be prioritised or additional measures to counter any likely negative effects on stigma can be considered. Mainstreaming stigma is particularly important as, just as the TB bacilli evolve and require changes in policy and programme responses, the stigma manifestations associated with TB are likely to change over time as well. How they change needs to be pre-empted and prepared for. With the emergence and increasing prevalence of drug resistant strains of TB, those with TB may be increasingly blamed for failing to manage their conditions. As TB is simultaneously viewed as uncontrollable (and is therefore to be feared) and controllable (arousing anger and blame) – bringing together the underlying processes of *parasite*

avoidance and *norm enforcement* – the increase in drug resistant TB and of TB co-morbidity with HIV and diabetes, is likely to elicit a particularly potent dual affective response, compounded by the added disruptiveness of lengthier and more complex treatment.

9.4 Relevance of the theories to other settings

The realist causal theories for the first two manifestations of TB stigma presented in Chapters 6 and 7 were developed from data collected in five different sites across three different countries. Comparative analysis was aided by collecting qualitative data from multiple geographically disparate sites and this enabled the discovery of causal theories which are grounded and local, but which also have scope beyond a single setting. Across the sites and countries the same two manifestations of TB stigma were found and the same two mechanisms form part of their causal explanations.

The two manifestations of TB stigma are TB's detrimental impact on marriage prospects and the perception that people with TB are hated. Their causal mechanisms, which form part of the explanatory theories, focus on TB's disruptiveness to gendered roles and responsibilities and the incongruity between behavioural precautions against TB transmission and caring behaviours. These mechanisms, in particular circumstances, give legitimacy to expressions and perceptions of rejection and devaluation which would otherwise be consensually deemed illegitimate.

Whilst the same causal mechanisms may generate TB stigma in other contexts, the causal mechanisms should not, as Maxwell (2012) puts it, "be seen as general laws [...] but as situationally contingent" (p36). The mechanisms do not invariably become generative of TB stigma. Their contexts are inextricably part of the causal process and so it is context we need to focus upon in considering the generality of the theories (Emmel, 2013).

In contextual conditions similar to those identified in the causal theories presented, the same TB stigma manifestations can be predicted. For the detrimental impact of TB on marriage prospects such contextual conditions relate to, for example, the nature of gendered roles, societal customs and structures, specific individual circumstances and the way in which health services and TB care are designed and delivered. Similarly, for the perception that those with TB are hated, contextual conditions relate to inconsistency and confusion over precautions against TB transmission, people's vulnerability both to TB and to the impact of having TB, and individual physical and emotional well-being, which is influenced by whether and how care and support is provided.

Certainly, TB's detrimental impact on marriage and marriage prospects has been reported in many other countries beside the three included in this study, including India, Malawi, Colombia, Vietnam, Ethiopia and Mongolia (Atre et al., 2009; Somma et al., 2008; Ganapathy et al., 2008; Long et al., 2001; Zhang et al., 2007; Gelaw et al., 2001). The perception that people with TB are hated has not been articulated in the same way in other studies as a TB stigma manifestation, but is suggested by geographically widespread descriptions of TB stigma as social isolation and avoidance and the association of TB stigma with fear of infection (Courtright and Turner, 2010). In countries and settings beyond the research sites which report the same TB stigma manifestations for which I have presented causal theories in this thesis, National TB Control Programmes can consider whether contextual conditions are comparable to those identified as part of the causal processes in my explanatory theories and therefore whether the proposed approaches to addressing TB stigma are likely to be applicable.

9.5 Limitations of the research

Whilst the discovery of theory benefitted from comparative analysis of data collected in three different countries, working across countries and languages was not without its challenges. In particular, the quality and quantity of the data collected varied between the three countries. Initial recruitment of the research team in Bangladesh was slow and the two researchers eventually recruited had no prior experience in qualitative research methods. Whilst I provided the team with additional training and support, the delayed start of data collection, their need for additional support, followed by the ill health of one of the two members of the research team, meant that interview data was collected in Bangladesh from one rural site only.

Interviews were conducted over a ten month period. This was longer than the time initially allocated in the grant application to ESRC-DFID's joint fund for poverty alleviation research. Whilst security concerns, power cuts and fuel shortages all contributed, the main reason why the interviews were conducted over such a long time period was that for sampling to be theory driven, the interviews had to be translated and sent to me for analysis first before more interviews could be conducted. Whilst this in itself is not a limitation of the research, it resulted in less time in which to conduct the final focus group discussions. The vignettes used in

the focus groups provided those living in the research sites with the opportunity to confirm, challenge, expand and refine my theories. As the ESRC-DFID grant was coming to an end and the research teams had other commitments and priorities, it was not possible to give such an opportunity to those living in the rural sites in Pakistan and Bangladesh. As a result the focus group data is overwhelmingly from just one country, Nepal.

Not only is translation of qualitative data time-consuming, but it can also result in mistranslation and loss of meaning. To account for this, and as described in Chapter 4 (section 4.5), the research teams analysed a sample of the audio-recorded interviews in the original language, allowing me to compare our analyses and detect any differences in interpretation which might be due to translation errors. I also shared my own analysis notes with the research teams to check that they reflect their own interpretations of the interviews and discussed any ambiguous or unclear translations by telephone and email. Nevertheless, as accounts of stigma can be nuanced, a closer look at language and meaning through a discourse analysis would have been potentially illuminating but beyond the scope of this study.

9.6 Developing the theories further

As stated in Chapter 8 (section 8.2), Glaser and Strauss (1967), who first put forward the approach to discovering grounded theory using qualitative data, emphasise that theory is “an ever-developing entity, not [...] a perfected product” (p32) and so the causal theories presented in this thesis to explain the three manifestations of TB stigma identified are there to be developed further. Dissemination of the causal theories in order to ignite dialogue amongst those with an interest in TB stigma (whether academic, practical or personal) can contribute to challenging and improving the theories. The theories can also be expanded or refined through the evaluation of any interventions which they underpin.

In addition to dissemination, dialogue and evaluation of theory-based interventions, the theories could also be developed through further exploratory research. For example, and as stated in section 6.5, further development of the causal theory to explain TB’s detrimental impact on marriage prospects would benefit from further research which has gender, marriageability and marriage as its primary focus. There is likely to be a thread running through the (de)valuation of a prospective

spouse, marital tensions and divorce, which cannot be fully appreciated when each is explained as a distinct manifestation and considered in relation to just one disease category. Furthermore, according to a study by Zhang et al. (2007) it is unmarried young men in rural inner Mongolia who are particularly concerned about the impact of TB on their marriage prospects. Across all the research sites in the three countries included in my study, the detrimental impact of TB on marriage prospects was anticipated to be particularly pronounced for women and so further comparative analysis with contexts in which the same stigma manifestation exists but the gender dimension varies, is likely to challenge and improve the causal theory.

My theoretical understanding of the attribution of blame emerged almost exclusively from the data from Nepal. As stated at the beginning of Chapter 8, the reason for this is likely to be that the data collected in Nepal was much richer in quantity and quality, revealing a manifestation of TB stigma which is not (yet) as prominent as the perception that people with TB are hated or TB's detrimental impact on marriage prospects. Further research in Bangladesh and Pakistan focussed specifically on the attribution of blame would enable the same cross-country comparative analysis from which the theoretical understanding of the other two TB stigma manifestations benefitted. Furthermore, a review of the literature and possibly further primary research on the attribution of blame for the origin or course of TB among those with co-morbidities, such as diabetes and HIV, would contribute to further theoretical development.

Whilst by no means perfected products and inevitably so, the causal theories which I discovered through this research and have presented in this thesis provide both a useful theoretical basis for the design of TB stigma interventions and serve as a basis for the accumulation of knowledge on TB and stigma.

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Appendix A: Interview guide for people with TB (Bangladesh)

PREPARATION

- Arrange seating
- Check recorder
- Welcome & greet respondent

INTRODUCTION

Thank you for coming

Introduce yourself

Background information: We're trying to learn about people's views and experiences of illness and how it's affected their lives. We're hoping that what we learn will help in the development of appropriate and effective programmes to improve people's lives and their experiences of illness in communities such as this one.

Procedure: I'm going to start off by asking you a few questions and I want you to speak freely and openly. It will take about 1-1½ hours.

Confidentiality and recording: This interview is strictly confidential. Your name will be kept completely separate from the information you give, so please feel free to speak openly. I have some questions written down here as a guide, but please speak freely and tell me anything you want.

If it's ok with you, I would like to use a recorder, so I don't miss anything important you might say to me, although I may make a couple of notes in my notebook as well. I'll try not to use your name in this interview, so that it's not on the recorder. Nobody except myself and my colleagues will hear this recording and after the interview we will copy down everything that was said on to paper and delete the recording. We won't include your name on that paper.

Is that ok? YES/NO

Not answering questions and terminating the interview

I am going to ask you some questions about your thoughts, feelings and experiences and because everything you say is strictly confidential I want you to feel at ease and free to speak openly. However, if there are any questions I ask you

that you don't want to answer or feel uncomfortable answering just say so and we shall move on. Also, if at any time you want to stop the interview just say so.

Whether you talk with me today or not, it will have no effect on any treatment you or anyone else gets at the clinic.

Do you fully understand?

Do you have any questions?

Is it ok to start?

(If appropriate, ask respondent to please switch off his/her mobile phone)

I'm going to turn the recorder on now and we can start our discussion.

INTERVIEW

First of all, tell me about yourself and your family.

Note down: approximate age, ethnicity, place of residence, occupation, marital status, no. of years married (if applicable), level of education and position within family/family composition. If these don't come up spontaneously, ask when appropriate.

I believe you have/had TB. How did it start?

Probe:

- What made you first suspect you were ill?
- Did you (or anyone else) suspect you might have TB before it was diagnosed? What did you think was wrong?
- What did you do when you first started feeling unwell (home remedies, treatment-seeking – what, from whom, where)

What happened when you first came to the clinic?

Probe:

- Describe your first appointment – what did you/the health worker do/say?
- How did you feel (about the diagnosis/consultation)?
- Who did you tell about your diagnosis? Who didn't you tell? Why?

How have you found the TB treatment?

Probe:

- Side effects? Perceived effectiveness
- What difficulties do/did you face getting to the clinic for your treatment? (Concealment)

How has your life changed since you got TB?

Probe:

- How has it affected your home/family?
- How has it affected your relationships with other people? (in-laws, parents, spouse, siblings, friends, neighbours, employer, colleagues)

- How have other people been towards you? Why?
- How has it affected the way you feel about yourself? Why?
- How has it affected the things you do, how you act? Why?
- How have you coped?

Do you think your experiences are typical of most TB patients?*

* We're asking the interviewee to reflect and theorise

Probe:

- Women/men like you?
- How do you think it might have been different if you were/were not married?
- How do you think it might have been different if you were a man/woman?
- How do you think your experiences might have been different if you had had asthma/cancer/paralysis/gonorrhoea instead of TB?

How do you feel about the future?

Probe:

- What worries you?
- (over the course of the treatment and beyond)

Constantly think about

- Gender, age, education differences
- Economic status / resources
- Position within family (blood & marriage)
- Social expectations and roles
- Stages/types of TB
- Change over time
- Allah imposes TB vs. other people spread TB
- Addiction
- Hygiene, cleanliness, contamination
- Inner weakness linked to TB
- Semantics / Language
- Comparisons with other diseases (asthma, cancer/paralysis, gonorrhoea)

END

Summarise. It's been really interesting hearing about your experiences and your thoughts and feelings. Thank you very much.

Before we end the discussion, is there anything else anyone would like to say?

Thank you very much for your time and for participating.

Turn recorder off

Reimburse expenses/Provide refreshments (if applicable)

Appendix B: Interview guide with health workers (Pakistan)

PREPARATION

- Arrange seating
- Check recorder
- Welcome & greet respondent

INTRODUCTION

Thank you for coming

Introduce yourself

Background information: We're trying to learn about people's views and experiences of illness, and in particular TB, and how it's affected their lives. We're hoping that what we learn will help in the development of appropriate and effective programmes to improve people's lives and their experiences of illness in communities such as this one.

Procedure: I'm going to start off by asking you a few questions and I want you to speak freely and openly. It will take about 1 hour.

Confidentiality and recording: This interview is strictly confidential. Your name will be kept completely separate from the information you give, so please feel free to speak openly. I have some questions written down here as a guide, but please speak freely and tell me anything you want.

If it's ok with you, I would like to use a recorder, so I don't miss anything important you might say to me, although I may make a couple of notes in my notebook as well. I'll try not to use your name in this interview, so that it's not on the recorder. Nobody except myself and my colleagues will hear this recording and after the interview we will copy down everything that was said on to paper and delete the recording. We won't include your name on that paper.

Is that ok? YES/NO

Not answering questions and terminating the interview

I am going to ask you some questions about your thoughts, feelings and experiences and because everything you say is strictly confidential I want you to feel at ease and free to speak openly. However, if there are any questions I ask you that you don't want to answer or feel uncomfortable answering just say so and we shall move on. Also, if at any time you want to stop the interview just say so.

Do you fully understand?

Do you have any questions?

Is it ok to start?

(If appropriate, ask respondent to please switch off his/her mobile phone)

I'm going to turn the recorder on now and we can start our discussion.

INTERVIEW

First of all, tell me about your job and your role in this community. What is it you do?

Note down: approximate age, ethnicity & caste, place of residence, place of employment and occupation. If these don't come up spontaneously, ask when appropriate.

If a patient comes to see you, what would make you suspect he or she might have TB?

→ What would you do or ask to confirm it?

Describe to me a typical consultation with a suspected TB patient?

→ What do you say to him/her?

→ How might they act?

→ How much time do you have for the consultation?

Sometimes the term "TB" is used, sometimes the terms "sokhma" and "tapedik" are used. When do you use which term?

→ What other terms do you use?

→ In what circumstances would you use one term and not the other?

→ Why do you choose to use one term rather than the other?

→ What do you think the terms mean to your patients?

When you tell someone they have TB, how do they react?

→ How do you think they feel?

→ What worries them?

As a health care provider, you have probably known more people with TB than most. How does TB typically change someone's life?

→ Is it different for men and women, married and unmarried, old and young?

→ (If it is different), why do you think it's different?

→ Does TB ever change the course of someone's entire life, or are the changes just short-term? Please explain.

Sometimes when people are ill, they don't visit a health worker right away for all sorts of reasons. Why do you think your patients don't always come to see you right away?

→ (If anything relating to stigma/shame/fear is mentioned, ask) What do you think is behind this stigma/shame/fear?

→ What do you think could be done to encourage people to see a health worker straightaway?

Once a patient has been diagnosed with TB they don't always come regularly for treatment. Why do you think that is?

→ What do you do if a TB patient hasn't come for their medicine?

Sometimes we instinctively feel things, even if our jobs or heads tell us not to. After all we're only human. As a researcher I know I mustn't show fear of catching TB, but deep down sometimes I fear anyway. It must be the same for you.

→ How do you feel when someone with TB comes to see you?

→ How do you show or hide these feelings?

→ What do you do to make sure you don't get TB?

What about your family and friends. How do they feel about you working with TB patients?

→ Are they fearful? (If so, why?)

→ Do you feel that anyone has ever treated you or those close to you negatively because you work with TB patients?

We're hoping that what we learn will help us to identify things that can be done to improve the lives and experiences of TB patients, their families and the health workers who treat them. What do you think could be done?

→ We can't expect anyone ever to be *happy* with a TB diagnosis, but how can we reduce the sadness and fear that some people feel?

→ What would make patients feel happy to disclose their TB disease to anyone? (even to their fiancé or prospective in-laws)

Constantly think about

- Comparisons with other diseases
- Stages/types of TB
- Gender / position within the family
- Social status
- Semantics / language
- Emotions, attitudes and behaviours
(Interviewee's feelings, thoughts and actions)
- Who, when, how, what and why

END

Summarise. It's been really interesting hearing about your experiences and your thoughts and feelings. Thank you very much.

Before we end the discussion, is there anything else anyone would like to say?

Thank you very much for your time and for participating.

Turn recorder off

Reimburse expenses/Provide refreshments (if applicable)

Note down:

- **Date**
- **Venue and location of interview**
- **Your name (facilitator)**
- **Whether anyone other than facilitator and interviewee were present**
- **Interviewee characteristics**

Age:

Ethnicity:

Place of residence:

Place of employment:

Occupation:

Appendix C: Interview guide with family members (Nepal)

PREPARATION

- Arrange seating
- Check recorder
- Welcome & greet respondent

INTRODUCTION

Thank you for coming

Introduce yourself

Background information: We're trying to learn about people's views and experiences of illness and how it's affected their lives. We're hoping that what we learn will help in the development of appropriate and effective programmes to improve people's lives and their experiences of illness in communities such as this one.

Procedure: I'm going to start off by asking you a few questions and I want you to speak freely and openly. It will take about 1-1½ hours.

Confidentiality and recording: This interview is strictly confidential. Your name will be kept completely separate from the information you give, so please feel free to speak openly. I have some questions written down here as a guide, but please speak freely and tell me anything you want.

If it's ok with you, I would like to use a recorder, so I don't miss anything important you might say to me, although I may make a couple of notes in my notebook as well. I'll try not to use your name in this interview, so that it's not on the recorder. Nobody except myself and my colleagues will hear this recording and after the interview we will copy down everything that was said on to paper and delete the recording. We won't include your name on that paper.

Is that ok? YES/NO

Not answering questions and terminating the interview

I am going to ask you some questions about your thoughts, feelings and experiences and because everything you say is strictly confidential I want you to feel at ease and free to speak openly. However, if there are any questions I ask you that you don't want to answer or feel uncomfortable answering just say so and we shall move on. Also, if at anytime you want to stop the interview just say so.

Whether you talk with me today or not, it will have no effect on any treatment you or anyone else gets.

Do you fully understand?

Do you have any questions?

Is it ok to start?

(If appropriate, ask respondent to please switch off his/her mobile phone)

I'm going to turn the recorder on now and we can start our discussion.

INTERVIEW

First of all, tell me about yourself and your family.

Note down: approximate age, ethnicity & caste, place of residence, occupation, marital status, no. of years married (if applicable), level of education and household composition (i.e. who does the respondent live with). If these don't come up spontaneously, ask when appropriate.

I'm interested to learn about how TB patients, their family members and others in the community feel about TB, so I'd like to begin by telling you a story about a woman. Then I'd like to ask you some questions about how you think she feels and what you think she would do, and also how you would feel if you were in her situation. Is that ok?

Vignette

The woman lives in Lalitpur. Her son has been feeling unwell for a while and has tried some home remedies and some medicine from a pharmacy, but it hasn't helped. He's been to see a doctor who has done a test and has told him he has TB.

How do you think the woman might have reacted when she found out her son has TB?

Probe:

- How do you think she would feel? Why?
- How do you think she would have found out that her son has TB?
- How do you think the rest of the family and others would feel?

Vignette

The woman is worried. She's worried about her son's health, but she's also worried about other things.

What else do you think the woman might be worried about?

Probe:

- What do you think worries her most (in the short-term and long-term)?
- Have you had similar experiences as her? Does someone in your family have TB?
- How did you find out your [family member] had TB?
- How did you react when you found out?
- How did you feel? (Did you feel the same way as the woman?)
- What were you worried about?
- Did you talk with others about your [family member's] diagnosis? How would you feel if people in your neighbourhood found out?

Why do you think the woman's son got TB?

Probe:

- Why do you think your [family member] got TB?
- Do you think the reasons why someone gets TB makes a difference (e.g. to how family and friends feel about the diagnosis or to their recovery?)

Do you think TB can be cured?

Probe:

- Do you think everyone with TB can be cured?
- Do you think there's anything that may make the treatment less effective (alcohol? pregnancy?)
- Does the TB go *completely* with treatment?
- Once someone has had TB and has been cured, do you think they're more likely to get it again? Why? (Can a man/woman pass it on to their child even if they were cured a long time ago?)

Vignette

The woman used to get a lot of visitors - friends and neighbours coming by to visit. Since her son has been ill, there have been fewer visitors. She wonders whether this is because people don't want to burden or disturb the family, but also wonders whether it might be for other reasons.

Why do you think people might not be coming to visit the woman and her family?

- From your own experience, what do you think the most likely reason is?
- Once the woman's son has been cured of TB, do you think things will go back to *exactly* how they were before? Why? In what ways?

What differences in your everyday life have you noticed since your [family member] got TB?

Probe:

- Do you think you feel or act differently towards your [family member]?
- Do you think other people feel or act differently towards your [family member]?
- Do you think other people feel or act differently towards you?

Once your [family member] has been cured of TB, do you think things will go back to *exactly* how they were before?

Probe:

- Why or why not? In what ways might things be different?
- How do you feel about the future? What worries you?

Constantly think about

- Gender/position within the family!
- Social expectations and roles
- Age (old age and children) & risk
- Pregnancy/risk
- Addiction (smoking/drinking)
- Sexual contact/proximity
- Social status / caste
- Stages/types of TB
- Comparisons with other diseases
- Semantics / language
- Change over time
- Emotions, attitudes and behaviours
(Interviewee's feelings, thoughts and action)

END

Summarise. It's been really interesting hearing about your experiences and your thoughts and feelings. Thank you very much.

Before we end the discussion, is there anything else anyone would like to say?

Thank you very much for your time and for participating.

Turn recorder off

Reimburse expenses/Provide refreshments (if applicable)

Appendix D: Focus group discussion guide (Nepal, rural site)

PREPARATION

- Arrange seating
- Check recorder
- Welcome & greet participants

INTRODUCTION

Thank you for coming

Introduce yourself / Introductions of participants

Background information: We're trying to learn about people's views about illness, especially TB or chayarog. We're not trying to test your knowledge – it's your opinions and views we're interested in. We're hoping that what we learn will help us understand how people's lives and their health can be improved.

Procedure: I'm going to start off by asking you all a few questions. The idea is that we get a discussion going, that everyone participates in, so you don't have to wait for me to let you speak. If you want to say something, please go ahead and just say it. Try to speak one at a time though and speak clearly. The discussion should take about 1 hour.

Confidentiality and recording

If it's ok with you, I would like to use a recorder, so I don't miss anything important you might say and I may make a couple of notes in my notebook as well. Nobody except myself and my colleagues will hear this recording and after the interview we will copy down everything that was said on to paper and delete the recording. We won't include your names on that paper.

Is that ok? YES/NO

Withdrawal: Your participation in this discussion is voluntary, so you can withdraw at any time and that will be perfectly ok. However, I really appreciate you being here.

Language: If there's anything you don't understand or anything you haven't heard clearly, feel free to ask me to clarify or repeat it.

Please feel free to speak openly and comfortably. There are no right or wrong answers; I'm interested in what you all think and how you feel, so I hope everyone joins in the discussion.

Is everyone happy with it so far?

Does anyone have any questions?

(If appropriate, ask participants to please switch off their mobile phones)

I'm going to turn the recorder on now and we can start our discussion.

DISCUSSION

VIGNETTE 1

... so I'd like to begin by telling you a story about a woman called Radha. Then I'd like to ask you some questions about Radha's situation, how you think she feels and what you think she should do and so on. Is that ok?

Vignette 1a

Radha lives in a village in Lalitpur. Her son has just got married. His new wife is almost 25 years old – older than Radha had hoped (in fact Radha wonders why she isn't already married) – and she doesn't come from the best family but at least her son is now married and so Radha hopes they will give her lots of grandchildren.

After a few months, Radha notices that her daughter-in-law, Kamala, has been working less in the home and has seen her son, Syam, take her to the clinic. She is concerned because Kamala looked thin and her skin was dull. Even Syam's skin is looking a bit dull. Radha wonders whether they have been eating properly.

What do you think Radha should do?

How do you think Radha feels about her daughter-in-law?

What do you think might be wrong with Radha's daughter-in-law, Kamala?

If Kamala was unwell before she got married, do you think she would still have got married?

Radha is hoping for grandchildren, but will this be possible if it turns out Kamala has TB?

- How long will she have to wait?

Vignette 1b

Kamala seems to get better quickly and it's not long before she falls pregnant and when the child is born everyone is very happy, especially Radha. But it's not long before Kamala seems thin again and this time she is coughing a lot. They take her to the clinic, where they do some tests, and the health worker tells them that Kamala has TB.

What do you think might have caused Kamala's illness?

How do you think Radha is feeling? What do you think is going through her mind?

→ What do you think worries Radha most (in the short-term and long-term)?

What do you think will happen now? Especially as Kamala has just had a baby that needs looking after and breastfeeding?

Vignette 1c

Radha tells Kamala that she will look after the baby and that Kamala should not go too close to the baby while she is ill. She says even breastfeeding is dangerous. Kamala is very upset about this and thinks that her mother-in-law hates her.

Who do you think is right, Radha or Kamala?

- Why?

What else do you think Kamala should and should not do now that she knows she has TB?

- Probe: Housework, preparing meals, eating certain foods ?
- For how long?

Vignette 1d

Syam tries to reassure his mother that TB is a simple disease that will get cured with medicine, but Radha wonders why, if TB really is such a simple disease, it requires taking medicine for such a long time.

Can an illness that requires taking medicine for 8 months really be simple?

- Should Radha be worried?

VIGNETTE 2

... Ok, now I'd like to tell you another short story, this time about a man called Ram. His story is a little bit different to that of Radha.

Vignette 2a

Ram lives in a rented house in Lalitpur district with his wife and three young children. A year ago he had TB/chayarog and took medicine for 8 months. When he discovered he had TB his wife told him to stop drinking alcohol and since then he only occasionally drinks. A month ago Ram started coughing and although he took some cough syrup it didn't help. He was worried so he went to the clinic to get tested. The doctor told him that he has TB ... again.

How do you think Ram must be feeling about what the doctor has told him?

Do you think it might be the same TB he has before that has come back?

- Why/why not?
- Last time he had TB and took medicine for 8 months. He seemed to be cured. Why do you think he has TB again?

If Ram doesn't want to tell anyone, is that ok?

- If Ram's wife sees the doctor in the market and asks him what is wrong with her husband, should the doctor tell her?

Vignette 2b

Ram has not been able to work for weeks and Ram and his wife have been arguing. Some days, especially when Ram isn't feeling well, he feels like everyone hates him because of his TB. Other days he feels like he will get cured soon and will return to work, so he is happier. His wife is finding his changing moods difficult to cope with.

Ram sometimes feels positive about the future and at other times he feels really down. Why do you think that is?

What do you think Ram and his family are finding most difficult about his illness?

- Ram lives in a rented home and has three young children. Do you think his experience of TB would be very different if he was in his ancestral village with his relatives around him? Would it have been easier or more difficult for him?

- Do you think Ram would feel different if his children were older?

Ram has not been able to work for weeks. How long do you think he should wait before he goes back to work?

END

(If there is a separate note taker, ask if anything has been missed)

Summarise. It's been really interesting hearing about your thoughts and feelings. Thank you very much.

Before we end the discussion, is there anything else anyone would like to say?

Thank you very much for your time and for participating.

Turn recorder off

Reimburse expenses/Provide refreshments (if applicable)

Appendix E: Letters of ethical approval



National Bioethics Committee (NBC) Pakistan



Ref: F. 4-87/NBC/ASD-Project /10/ 5404

Dated: 14 June, 2007

Patrons

Federal Minister Health
Federal Secretary Health

Chairman

Director General Health

Secretariat

Pakistan Medical Research
Council

Members Ex-Officio

President
College of Physicians and
surgeons of Pakistan

President
Pakistan Medical and Dental
Council

Executive Director
Pakistan Medical Research
Council
(Member/ Secretary)

WHO Country Representative

President
Supreme Court Bar Association

Members

Prof. Dr. Zulfiqar A. Bhutta
(Chairman REC)
Maj. Gen. Masood Anwar
Prof. Dr. Anis Ahmed
Dr. Anwar Nasim
Dr. Mohammad M. Amin
Dr. S. Qasim Mehdi
Dr. Maqbool H. Jafary
Dr. Shariatullah Siddiqui
Mrs. Faiz Alam Zeb
Mr. Shaukat Ali Jawaid
Dr. Asmatullah
Prof Dr. S. Haroon Ahmad
Dr. Farid Khan
Prof. Dr. Abdul Jan Jaffar
Dr. Aasim Ahmad

Mr. Muhammad Amir Khan
Chairman
Association for Social Development
House No. 12
Street 48
Sector F-7/4
Islamabad

Subject: Research Proposal "Stigma and discrimination associated with tuberculosis in Asia"

Dear Dr. Amir Khan,

I am pleased to inform you that the above mentioned project has been cleared by "Research Ethics Committee of National Bioethics Committee".

Kindly keep the National Bioethics Committee Secretariat update with the progress of the project and submit the final report on completion.

A separate letter will be sent indicating details of fee regarding the ethical clearance of this project.

Yours Sincerely,

Dr. Zulfiqar Bhutta
Chairman
Research Ethic Committee

NBC Secretariat:

Pakistan Medical Research Council, Shahrah-e-Jumhuriat, Off Constitution Avenue, Sector G-5/2, Islamabad.
www.pnrc.org.pk pnrc@ish.consats.net.pk Tel: 92-51-8207386, 9216793, 9205480, Fax 9216774.

त्रिभुवन विश्वविद्यालय
चिकित्सा शास्त्र अध्ययन संस्थान
डीनको कार्यालय, महाराजगंज
पो.ब.नं.: १५२४, काठमाडौं, नेपाल ।
फोन नं.: ४४१०९११, ४४१२०४०, ४४१३७२९



Tribhuvan University
Institute of Medicine
Office of the Dean
Maharajgunj, P. O. Box: 1524
Kathmandu, Nepal
Ph. No. 4410911, 4412040, 4413729

पत्र संख्या / Ref. No.:-

Patel (444)

मिति / Date.:-

13 February 2007

Prof. James N. Newell (International Public Health),
Nuffield Centre for International Health & Development,
Institute of Health Sciences and Public Health Research,
University of Leeds, UK

Email: j.n.newell@leeds.ac.uk

Dear Professor James,

The submitted research proposal entitled "Understanding stigma and discrimination associated with Tuberculosis in Nepal" was ethically reviewed by Institutional Review Board (IRB) of the Institute of Medicine, Tribhuvan University. On behalf of the IRB, I am pleased to inform you that the IRB of the Institute of Medicine, Tribhuvan University, has approved your proposed research.

You are advised to get the informed consent from each study subject and need to be properly documented for each participant or the participant's legally authorized representative. You are also requested to follow the ethical principles for health and biomedical research. I would like to take your attention that Institutional Review Board (IRB) of the Institute of Medicine should receive written notice from researcher upon the completion of the research as well as the final summary or full report of the research study.

If you have any query please don't hesitate to contact us

Sincerely Yours

Puspa Raj Sharma

Professor Puspa Raj Sharma
Chairperson,
Institutional Review Board

Cc:

Dr. Anand B. Joshi
Co Investigator
Associate Professor (Epidemiology)
Department of Community Medicine and Family Health,
Institute of Medicine, Tribhuvan University, Nepal
Email: researchi@healthnet.org.np

Mr. Sushil C. Baral
Co Investigator
Executive Chairperson
Health Research and Development Forum (HERD)
PO Box: 24133, Kathmandu, Nepal
Email: sushilb@herd.com.np

Fax No. 4413186, E-mail: iomdean@healthnet.org.np / website: www.iom.edu.np

Govt. of the People's Republic of Bangladesh
Directorate General of Health Services
National Tuberculosis Control Program
Mohakhali, Dhaka -1212

Memo No: 5-15/TB-LEP/TB Research/04-07/10253

Date: 22-3-07

To
James Newell
Professor, University of Leeds, UK
Nuffield Centre for International Health & Development
Institute of Health Sciences & Public Health Research

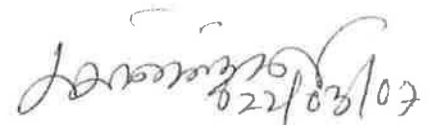
Attention:
Dr. A N Zafar Ullah
Fellow, University of Leeds, UK
And
Principal Investigator
PPP Project, the National TB Control Programme, Bangladesh.

Sub: Approval of Stigma and Discrimination Associated with TB Project

Dear James

In reference to your letter dated Jan 21, 2007 I would like to inform you that the above Project :
STIGMA AND DISCRIMINATION ASSOCIATED WITH TB PROJECT is approved for your
necessary action. This has approval of competent authority.

Thanking you



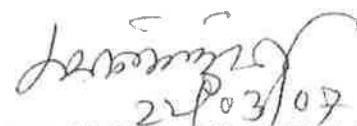
Dr. Md. Mahaboob Kamal Siddiqui
Director MBDC and Line Director TB/LEP in charge
DGHS, Mohakhali, Dhaka -1212

Memo No: 5-15/TB-LEP/TB Research/04-07/10253/1(4)

Date: 22-3-07

Copy forwarded for information and necessary action to:

1. Director General of Health Services, Mohakhali, Dhaka,
(Attn.- Asstt. Director, Coordination).
2. Programme Manager TB, DGHS
3. Salma Akter Research Coordinator-PPPP
4. Office copy



Dr. Md. Mahaboob Kamal Siddiqui
Director MBDC and Line Director TB/LEP in charge
DGHS, Mohakhali, Dhaka -1212