

Understanding Tuberculosis Treatment Completion in Urban Areas of Nepal

PhD Thesis

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degree of Doctor of Philosophy)**

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[I confirm that the work submitted is my own work and that appropriate credit has been given where reference has been made to the work of others]

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DEDICATION

I dedicate my thesis to those *people who lost their life* due to tuberculosis – their lives could have been saved – and those *individuals and families suffering due to tuberculosis* and continuing their fight for cure and survival.

ABSTRACT

Non-completion of tuberculosis (TB) treatment has been a major topic of debate ever since combined drug therapy started to be used. It has threatened global TB control and posed a challenge to many National TB Programmes (NTPs) especially in developing countries where the burden of TB is highest and the poor are worst hit. As a means of controlling TB, WHO advocated a strategy branded as DOTS, which includes direct observation of treatment (DOT). Many countries have implemented DOTS, so DOT has become a central component of NTPs' TB control strategy. DOTS as a comprehensive package was shown to be successful in many countries: however, this success over-credited the direct observation component, which led to a focus on the concept of TB treatment completion. The Nepal NTP implemented DOTS in the late 1990s and has achieved high treatment success rates under DOTS, but has not been exempted from the debate. There have been many studies which have identified the need to minimise non-completion as vital to controlling TB: however, few have considered how non-completion could be tackled through establishing locally feasible patient-centred care within existing TB control procedures.

The overall aim of my study was, therefore, to gain a better understanding of experiences and issues faced by People Living with TB (PLTB) during the course of TB treatment under DOTS and identify appropriate ways of addressing the issues identified in the context of the NTP in urban setting in Kathmandu, Nepal.. The study used a qualitative research approach to investigate why and how different factors hindered or facilitated successful completion of TB treatment in an urban TB control setting in Nepal. The study used semi-structured qualitative interviews (49), focus group discussions (6) and observation techniques to generate data and a content analysis approach to analyse the data. Study respondents were PLTB; family members of PLTB; health care providers, NTP officials and community members.

My study shows that, as defined by the NTP, successful completion of TB treatment was not straightforward for PLTBs. PLTBs underwent TB treatment in very difficult circumstances, as various obstacles to successful TB treatment completion complicated the treatment process and thus made PLTBs and their families further vulnerable. Obstacles arising from causes related to the health system had a greater impact on PLTBs and their families than obstacles arising from causes related to the PLTBs.

My study also shows that, in the face of mounting difficulties faced by PLTBs and their families during the course of treatment, PLTBs' families' untiring efforts and support greatly facilitated the treatment process, regardless of family circumstances. This support occurred not only during the illness but beyond the period of treatment, despite the devastating impact of TB on the entire family. This finding highlights the need to redefine the role of family members in PLTBs' treatment: this has been overlooked in many NTPs.

Arising from my findings, I identify key prerequisites for successful treatment completion: appropriate, affordable access to TB services; affordable care; appropriate responses to problems; appropriate socio-cultural responses; supervision and patient support; appropriate interpersonal communication; care with respect and dignity; individual privacy; and mutually beneficial relationships. Finally, I propose an implementation framework to establish patient-centred care. I believe that these key prerequisites would greatly reduce the burden on PLTBs' and families' experiences during TB treatment, and thus facilitate successful TB treatment completion in the context of urban TB control in Nepal.

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LIST OF ABBREVIATIONS

PLTB	People living with Tuberculosis
AFB	Acid-Fast Bacilli
AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral Therapy
ARI	Annual Risk of Infection
ARV	Antiretro Viral
BCC	Behaviour Change Communication
CBO	Community Based Organization
CDR	Case Detection Rate
CHW	Community Health Worker
CPT	Co-trimoxazole Preventive Therapy
CBD	Community Based DOTS
FBD	Family Based DOTS
D/PHO	District/Public Health Office/Officer
DFID	Department for International Development
DoHS	Department of Health Services
DHS	Demographic and Health Survey
DOT	Directly Observed Treatment
DOTS	Directly Observed Treatment Short-Course
DR	Drug Resistance
DRS	Drug Resistance Surveillance
DST	Drug Susceptibility Testing
DTLA/DTLO	District TB Leprosy Assistant/Officer
EP	Extrapulmonary
FDC	Fixed-dose Combination (FDC of anti-TB drug)
GFATM	Global Fund to fight AIDS, Tuberculosis and Malaria
GoN	Government of Nepal
HIV	Human Immunodeficiency Virus
HMIS	Health Management Information System
HP	Health Post
HSR	Health Sector Reform
IEC	Information, Education and Communication
INGO	International Non Governmental Organization
IPC	Interpersonal Communication
ISTC	International Standards for Tuberculosis Care
MDGs	Millennium Development Goals
MDR	Multidrug Resistance
MDR-TB	Multidrug Resistance Tuberculosis
MoHP	Ministry of Health and Population
NCASC	National Centre for AIDS and STD Control
NGO	Non Governmental Organisation
NHA	National Health Accounts
NTC	National Tuberculosis Centre

NTP	National Tuberculosis Programme
PHC	Primary Health Care
PHCC	Primary Health Care Centre
PPM	Public–Private Mix
PPP	Public-Private Partnership
PPs	Private Practitioners
PTB	Pulmonary Tuberculosis
SCC	Short-course Chemotherapy
SHP	Sub Health Post
STD	Sexually Transmitted Disease
STI	Sexually Transmitted Illness
SWAp	Sector Wide Approach
TB	Tuberculosis
WHA	World Health Assembly
WHO	World Health Organization
XDR-TB	Extensively Drug- resistant Tuberculosis

CHAPTER ONE

ORIENTATION OF THE STUDY

1.1 Introduction

This chapter introduces my thesis. It describes the background of the research problem and the rationale of performing the study. It also describes the key terms used in the study and presents the overall structure of the thesis.

1.2 Background to the research problem

Tuberculosis (TB) is a disease as old as humankind, and by now it should belong to the past, as it is a bacterial disease and is curable with antimicrobial drugs. Nonetheless, TB remains a unique pandemic. In 2010, there were 8.8 million (range, 8.5–9.2 million) incident cases of TB, 1.1 million (range, 0.9–1.2 million) deaths from TB among HIV-negative people and an additional 0.35 million (range, 0.32–0.39 million) deaths from HIV-associated TB globally (WHO, 2011). The vast majority of deaths occur in developing countries: the poor are worst hit by the disease (Dye, 2006).

Despite several attempts to control TB, and advances in medical science, TB remains a major threat to the global community. In the early 1990s, the World Health Organisation (WHO) declared TB to be a global emergency. As a response to this emergency, WHO recommended the use of the DOTS (Directly Observed Therapy – Short Course) strategy. This strategy consists of five key components including a standardised ‘short’ course of treatment lasting six to eight months (WHO, 2002). One of the components of DOTS is direct observation of therapy (DOT) which requires every dose of TB treatment to be directly observed, either by a health worker or someone nominated by a health worker; the person observing treatment is often known as a DOT provider or treatment supervisor. DOT is intended to help identify People living with TB (PLTB) who miss treatment and encourage them to continue treatment (WHO, 2003b), and also to help prevent the development of TB bacteria that are resistant to rifampicin, the main anti-TB drug (Enerson *et al.*, 2000).

However, the benefits and costs of DOT to health services and patients are complex, potentially causing both positive and negative effects on treatment outcomes, and thus this approach to TB treatment delivery has been the subject of much debate (Volmink and Garner, 1997; Walley *et al.*, 2001; Zwarenstein *et al.*, 1998; Newell *et al.*, 2006).

DOT has been widely used by NTPs across the developing world, and DOTS has shown high treatment success rates (WHO, 2003b). However, the question remains: is DOT essential for the success of the DOTS strategy, or would implementation of DOTS without DOT also achieve high treatment success rates? The answer is not straightforward. However, a Cochrane review of randomised controlled trials conducted in low, middle and high income countries concluded that, when all other elements of the DOTS strategy were in place, treatment outcomes (cure or treatment success) were similar whether DOT or self-administered treatment were used (Volmink and Garner, 2007).

The necessity of using DOT in TB treatment was further argued across the medical and social sciences. In many instances the debate was centred on differing beliefs in the roles of 'science' and evidence (Harper, 2006). A review by Noyes and Popay (2007) pointed that instead of prescribing DOT to all PLTBs, a focus was needed on the impact of measures (such as DOT) that cause obstacles to PLTB during TB treatment. Similarly, a review of qualitative studies on TB treatment adherence by Munro *et al.* (2007) suggested that the focus needs to shift towards establishing patient-centred interventions; and that this will require structural obstacles (which may be caused by economic, social, policy, organisational and environmental factors) to be addressed.

WHO's Stop TB Strategy, launched in 2006, builds on the foundation of DOTS. To some extent it acknowledges the DOT controversy, by introducing some flexibility on TB treatment delivery modalities. It emphasises the need for '*supervised treatment, which may have to include DOT*', (p.10; my emphasis), a move away from mandatory provision of DOT. This is a welcome shift. The phrase 'supervision and patient support' indicates a desire for patient-centred care in TB control, but is rather unclear. This may have been intentional to give more scope for local NTPs to define 'supervision and patient support' in the light of the contexts in which they operate. Questions remain, however, as to whether NTPs have properly thought about what changes they should make to their traditional practice of DOT.

Nonetheless, despite various interventions aimed at improving treatment completion, non-completion of TB treatment has been a major obstacle to effective TB control (Jin *et al.*, 1993; Chaulet, 1990). Cuneo and Snider (1989) note that up to half of all TB patients do not complete the full course of TB treatment. Failure to complete TB treatment can lead to prolonged infectiousness, development of drug resistance,

relapse, and death. Poor completion of treatment thus poses a serious risk not only for the individual but also for the community. There are various reasons why PLTBs fail to complete the prescribed course of TB treatment. Non-completion is a multifaceted issue determined by the interplay of multiple factors, which I discuss in chapter three.

There has been little research to understand non-completion that leads to strategies to improve treatment completion, as few researchers have looked at treatment completion from the perspective of TB patients, and the explanations for non-completion do not in general inform the design of strategies that could enable patients to stay on treatment (Donovan, 1995; Lassen, 1998). This demonstrates a need for greater efforts to broaden our understanding of treatment completion, which will lead to development of context-specific measures to address the complex issues affecting treatment completion (Munro *et al.*, 2007). The absence of in-depth understanding gained through appropriately designed research presents major challenges to NTPs.

1.3 Problem statement

In Nepal, DOTS implementation started in the late 1990s, and covered the nation by mid-2001, since then DOT has remained a central element of the Nepal TB control strategy. The NTP achieves high treatment success rates with DOTS: however, case detection in urban areas is far below the national figure of 70% detection of estimated new cases (NTP, 2008/09). The NTP interpretation of DOT is quite rigid in both rural and urban areas, and this can make it difficult for PLTBs to continue their treatment. Poor people, and in particular the urban poor, face a major and multiple challenges. It seems that the NTP is satisfied with the current achievement of high treatment success, and is shifting its focus towards case detection, rather than managing TB cases by establishing a patient-centred approach within the programme. However, since the NTP adopted WHO's Stop TB strategy, the International Standards for Tuberculosis Care (ISTC) and the Patients' Charter for Tuberculosis Care, it has become increasingly important to develop an enabling environment for PLTB to successfully complete TB treatment through fostering patient-centred care. These international documents place emphasis on context-specific quality delivery of TB services, with a central focus on PLTBs. However, the NTP has not properly considered the need to shift from the traditional way of delivering TB services including the mandatory requirement for institutional DOT. Experts have proposed various reasons for this: it could be that there is not sufficient knowledge on *how* to develop a patient-centred approach in the programme; or that the NTP fears changing

its practices in the light of contemporary knowledge and locally generated evidence due to lack of resources; it could be because the NTP is not yet prepared for change; or it could be the NTP feels no change is required as it already achieves high treatment success rates, or financial implications of the change to the programme. Whatever the reason, sooner or later the NTP must align its TB service delivery in accordance with contemporary knowledge towards a more patient-centred care.

In the context of the NTP's urban TB control programme, there is not yet a clear understanding of issues relating to successful TB treatment completion. Although TB treatment completion rates remain high in urban areas, it is unclear whether and to what extent PLTBs suffer during the course of TB treatment; at what cost treatment is continued; how to reduce the burden on PLTB during TB treatment; and whether there should be a context-specific patient-centred approach in the urban TB control programme to ensure current success is sustained. It is not straightforward to answer these questions. The lack of current knowledge in such areas strongly indicates the need for a study from the perspective of PLTBs which is qualitative in nature.

Thus, taking the study context into account, my problem statement is: Despite high treatment success in the study area, many PLTBs face difficulties completing the full course of TB treatment. High treatment success rates may have been achieved at high cost to the PLTBs and their families. The NTP needs to have an explicit understanding of issues that hinder successful TB treatment completion, which would then enable it to design context-specific TB service delivery measures to reduce the burden on PLTB and their family members. There is also a need for the NTP to develop a patient-centred approach, following adoption of the Stop TB strategy, the ISTC and the Patient Charter for TB Care.

1.4 My motivation in the study

I received my community health worker training in general medicine in the 1990s and worked for more than 10 years in health service delivery as a government employee, mostly in peripheral health institutions in remote districts of Nepal. As a junior health worker, I had many opportunities to work with members of different communities across the social spectrum, and understand their health needs. However, my theoretical understanding of health issues and health service delivery was initially very bio-medical, and I had limited understanding of the public health aspects. Progressively, my practical experiences in community health interventions and my close working relationship with various public health scientists inspired me to pursue

a career in public health. As a result, I started working in communicable disease control programmes as an emerging public health professional and gradually developed my career as a researcher in public health.

Prior to enrolling on the PhD programme I worked as a Research Assistant within the Nepal NTP, involved in two big research projects: action research on engaging the private sector in TB control, and a district randomised controlled trial comparing community and family based TB treatment delivery strategies in hard to access areas of Nepal. My exposure as a researcher in the NTP and interactions with people with TB and their family members, community members, programme managers and health service providers enabled me to understand issues relating to TB treatment, particularly non-completion, resulting in ongoing upheaval for families living with TB. Although the NTP was achieving a high treatment success rate overall, this seemed to be at substantial personal cost to patients. Similarly, I also observed that those failing to complete treatment were blamed for that failure, despite the 'causes' appearing to be their difficult living conditions, inappropriate TB service delivery provision under the DOTS framework and stigma and discrimination attached to TB disease and people with TB.

I therefore became motivated to do further research using a qualitative approach to gain in-depth understanding of the problems and issues that people with TB were experiencing during the course of their treatment. Moreover, my motivation in this study was to identify locally feasible strategies to address the issues and problems using a patient friendly approach. The aim was to ensure successful TB treatment completion while reducing the burden on people with TB and their families, health systems, health services and communities. I hoped that the strategy would ultimately influence the NTP to establish a patient-centred approach in TB care.

1.5 Study timeframe

I was enrolled as a part-time provisional PhD candidate in December 2001 and transferred to a full PhD candidate in late 2003. My field research work was initiated in 2004, but was delayed for a year during a period of serious political instability in the country. In 2006 my field work recommenced and was completed by 2008. I worked full time as a Health Advisor with the Department for International Development (DfID) country office Nepal whilst analysing the data part-time over two years.

1.6 Concepts and definitions

Below are some key terms and concepts that I used in the study as relevant.

People Living with Tuberculosis (PLTB): a person with confirmed TB undergoing TB treatment is defined as PLTB for the study purpose. In general, such person is known as TB patient in the programme and recorded accordingly. I used this concept after my first interview respondent rejected the idea of being labelled as ‘TB patient’ which, in general, overlooked the human role on people and saw only as an ill person with no power. I have provided an explanation on why I used the concept of PLTB in the study in chapter four.

Cured: a PLTB whose sputum smear (or culture) was positive at the beginning of the treatment but who was smear- or culture-negative in the last month of treatment and on at least one previous occasion. This definition is used in NTP to evaluate treatment outcome result of PLTB.

Treatment completed: a PLTB who completed treatment but who does not have a negative sputum smear or culture result in the last month of treatment and on at least one previous occasion. The sputum examination may not have been done or the results may not be available.

Treatment success: the sum of cured and treatment completed, the main outcome measure in national TB programmes .The distinction between cured and treatment completed is whether the patient had sputum checked at the end of treatment or not.

Non-completion: PLTB registered for TB treatment in NTP fails to complete full course of treatment as recommended by the programme known as non-complier to TB treatment thus the condition is non-completion to TB treatment. It is an undesired condition which could arise as a result of various or a cause during TB treatment.

Treatment discontinuation/interruption: a PLTB taking treatment under the programme who stops treatment or who takes TB drugs on and off. It can be difficult to differentiate between these two. However, NTP records on and off cases as ‘late patient’ and PLTB who discontinue treatment continuously for two months as ‘defaulted’.

Stakeholders or partners: In the study context, stakeholders are defined as individuals or institutions engaged in delivering TB services with a role. The concept defined here comes from an operational aspect of the programme: however, PLTB, their family members and community people should also be seen as key stakeholders

in the process of TB treatment but in the study they hold an independent identity thus not considered under the definition of stakeholders.

National Tuberculosis Programme (NTP): countrywide programme for TB control which is led by the government and supported by other stakeholders including PLTB, their family and community. It is a priority programme of the Ministry of Health and Population in Nepal.

Frontline Health Care Providers: those individuals working in TB control who interact with PLTB on a regular basis as part of their job responsibility in their working institutions. These people are the one who can provide day-to-day experience with TB and their family during TB treatment.

1.7 Organisation of the thesis

Chapter one introduces the thesis, and also gives a brief explanation of the research problem.

Chapter two provides a historic overview of global TB prevention and control, along with a global synopsis of TB control measures. It also presents progress in TB control, with a focus on DOTS and the key challenges faced by developing countries, along with an account of Nepal's NTP and the features of TB services in urban settings of Nepal.

Chapter three provides an understanding of the current body of knowledge with regard to TB treatment completion, with a focus on factors affecting continuation of TB treatment in developing country contexts. It provides the foundations of my study, analysing factors helping and hindering PLTBs during treatment and identifying gaps in our understanding of TB treatment completion. Finally, this chapter presents a theoretical understanding of the issue and a conceptual framework, which lead to the aim and objectives of my research.

Chapter four describes the research design and methods that I used in the study along with detailed descriptions of data generation techniques, data sources, data analysis, the trustworthiness of the research process and findings, as well as limitations of the study and ethical considerations.

Chapter five presents the study findings followed by initial discussions. It broadly examines the issues that hindered or helped successful completion of TB treatment from the perspectives of PLTB. The chapter is divided into two major sections: issues in successful treatment completion, and factors enabling treatment completion.

Chapter six presents further discussion of the key study findings. It also revisits the study aim and objectives, and the conceptual framework in the light of the study findings and the programme context, and concludes with further limitations of the study.

Chapter seven, the final chapter, presents the conclusions of my study along with the policy implications of my study findings with a particular focus on urban TB control in Nepal. It also discusses a possible implementation framework for the revised conceptual framework of the study. The chapter gives brief information on the uptake of interim findings during the course of the study, and the contribution of this study to the wider body of knowledge relating to successful TB treatment completion, and concludes with suggestions for areas of research that may further advance successful TB treatment completion in the context of the Nepal NTP and elsewhere.

1.8 Conclusions

This chapter provided an overview of the problems and issues in TB treatment completion as a background to the research problem. It presented my motivation in the study topic, the study timeframe and the concepts and definitions used in the study. The chapter also provided an overview of each chapters of this thesis. The next chapter provides background information on: TB situation globally; historic overview of TB control approaches; issues and challenges in TB control, and an overview of health service delivery and TB control in Nepal.

CHAPTER TWO

TB AND ITS CONTROL: REVIEW OF GLOBAL EVIDENCE AND THE NEPAL NTP

This chapter starts with a historic overview of global TB prevention and control, describes epidemiology and gives a global synopsis of TB control measures. The chapter also presents progress in TB control with a focus on DOTS and discusses key challenges in TB control in the context of developing countries. It also gives an account of Nepal's National Health System and NTP along with features of TB services in urban settings with a focus on the study area, the Kathmandu Valley.

2.1 TB: general introduction

TB is a communicable disease affecting humans around the world, but primarily in the developing world. If untreated, it is generally deadly. TB is caused by various strains of mycobacteria, usually *Mycobacterium tuberculosis* in humans. It is transmitted through the air when people who have active pulmonary TB disease cough, sneeze or spit. Primary infection occurs when a person is exposed for the first time to tuberculosis bacilli, but not all people exposed will develop TB disease. The progression from infection to disease depends on the immune status of the infected person (Wilkinson *et al*, 1997). Of those who become infected, 10% to 12% will develop TB disease, over a period ranging from weeks to decades. However, if the infected person is immuno-compromised, the risk of developing active TB is as high as 50% (Grange, 1999; Rieder *et al*, 1999). Active TB can manifest in three forms: pulmonary sputum smear positive; pulmonary sputum smear negative; and extrapulmonary. Pulmonary TB is the most frequent form of the disease, occurring in over 80% of cases. If untreated, each person with pulmonary smear positive TB can infect on average 10 to 15 people a year, of which 6% to 10% people will themselves develop active TB (Styblo and Bumgarner, 1991).

For diagnosis of pulmonary TB, use of direct sputum smear examination is considered thus generally recommended for TB control programmes. However, where resources are available, culture and drug sensitivity testing is also desirable. In addition, more high-tech molecular techniques of TB diagnosis such as polymerase chain reaction, DNA and RNA probes, are becoming available and are being tried in some developed countries.

2.2 TB and its control: historic overview

TB disease is considered as old as the human race. TB is known to have a major impact on the health and development of people in many countries. Since the seventeenth century, treatment of TB has been a major concern. On 24th March 1882, the first real breakthrough was made in the history of TB control when Dr Robert Koch isolated the TB infectious agent, *Mycobacterium tuberculosis*, also known as the tubercle bacillus. Koch's discovery helped understanding of the communicable nature of the disease and provided a new insight into detecting TB. However, despite knowing its communicability nature and transmission route, prevention measures have not been successful and TB continues to be a leading infectious disease globally, but primarily in developing countries.

In the early 20th century, treatment of TB patients usually involved bed rest, mostly in sanatoria. However, TB remained one of the most feared diseases of the human race as all efforts to control TB were ineffective and it continued to be a major public health threat in many countries (WHO, 1999). It was also widely believed that TB was associated with the supernatural, so its treatment included many superstitious practices (Davis, 2000). It is still the case and influence local ways of treating TB in some areas.

2.3 Vaccine and chemotherapy: a new hope in TB control

The development of Bacille Calmette-Guerin (BCG) vaccine in 1921 raised new hopes in TB control. The vaccine is the most widely used in humans: however, it was found to be ineffective in preventing the transmission of pulmonary TB but has been shown to be beneficial to infants, especially to prevent meningeal and disseminated forms of TB (Styblo and Meijer, 1976; Rodrigues *et al*, 1993).

Despite the poor effectiveness of all identified measures, the hope of controlling TB has never died, and the search continued to find effective ways of controlling TB. Eventually, the chemotherapy era began with the discovery of Streptomycin in 1944 which became available for wide use in 1946 (Hinshwa *et al*, 1946). However, its toxic effects, clinical deterioration, problems in completing therapy and increasing drug resistance threatened its wide use and efficacy (Medical Research Council, 1948). However, no tangible progress was made in TB treatment until new antibiotics were first used between 1945 and 1960.

In 1951, introduction of is nicotinic acid hydrazide (isoniazid) therapy was perceived as a 'miracle drug' for TB (Robitzek and Selikoff, 1954). A number of additional drug

trials during the 1950s and 1960s and their combined suggested that TB is treatable in outpatient hospital settings. Treatment was further simplified by the development of so-called short course chemotherapy (SCC) –usually nine months of treatment – in the 1970s, which became more effective with introduction of rifampicin (1963); and the duration of SCC was further shortened to six months. Experts noted that SCC was not only effective, but the most cost-effective of all therapeutic interventions (Murray *et al*, 1996). However, further challenges arose as the TB bacillus developed resistance to anti-TB drugs. The unexpected resurgence of TB cases, especially in the late 1980s and early 1990s, dashed hopes of controlling TB in the near future.

2.4 TB epidemiology: global scenario

Despite the presence of diagnostic measures and highly cost-effective chemotherapy, the TB epidemic is on the rise, and continues to pose a threat not only to health but also overall development. One third of the world's population is estimated to be infected with TB, and one in every ten of those infected carry a risk of developing TB disease in their lifetime (Kochi 1991; Raviglione *et al*, 1995). TB is among the leading infectious diseases with over nine million new TB cases worldwide each year (WHO, 2006). In 2008, WHO estimated there were 139 TB cases per 100,000 population globally.

Deaths due to TB are largely preventable; however, it is sometimes said to be the single biggest killer in the world, killing nearly two million people a year, or 5,000 every day; the great majority of deaths are among poor communities in the developing world. It is a greater cause of adult deaths in the world than any other communicable disease (Kladaut, 1994; Mc Kinney *et al*, 1998), presenting an increasing threat to country economies. TB accounts for 2.8% of global disability adjusted life years (DALYs)¹ lost in all age groups and 7% to 8% of all DALYs lost among those aged 15-49 years. TB represents 2.5% of the global burden of disease, ranking 7th among causes of global DALYs lost (Murray, 1996; WHO, 2006).

The burden of disease is largely born by developing countries where it is estimated that 98% of TB deaths and 95% of all TB cases occur (WHO, 2002). The South East Asia Region bears about 40% of the TB burden with around 5 million TB cases. Though TB deaths have declined over the years, the disease still claims more than

¹Disability Adjusted Life Years – the sum of years of potential life lost due to premature mortality and the years of productive life lost weighted by disability and specific health conditions.

500,000 lives each year in the region. Globally, the problem of TB has become more challenging due to the spread of HIV infection, and the emergence of Multi Drug Resistant (MDR) TB. Grange (1999) noted that if global TB control efforts fail to bring fundamental changes to its epidemiology, the world will see a dramatic increase in the overall incidence and prevalence of disease, which can lead TB running out of control in many countries.

2.5 Evolution of TB control approaches

The devastating impact of TB has been from when it was first notified in humans. Since then, a number of prevention and control measures have been undertaken, but control efforts have not shown great success. However, with the discovery of TB chemotherapy and its use in outpatient settings, global TB control efforts moved towards the development of vertical TB programmes– a top-down approach to controlling TB (Raviglione and Pio, 2002). By the late 1950s, it was realised that a vertical approach to TB control was not affordable by developing countries. With this realisation, global TB control actors demanded new approaches; as a result, several research studies were initiated to identify new approaches to fighting (Fox *et al*, 1999; Bayer and Wilkinson, 1995; Fox, 1958, 1962; Banerji, 1965; Raviglione and Pio, 2002). Studies showed the possibility of a countrywide national programme to deliver TB services integrated into general health services. However, there was debate around whether integration of TB services into general health services should be limited to TB service delivery or should also include other managerial components that were vertically managed. To date, this debate has led to integration of a few TB services within general health services. However, integration was not sufficiently backed up by adequate resources or technical skills. In many developing countries such shortages lowered the profile of TB control programmes within general health services, so that the benefits of such partial integration to TB control were very limited (Raviglione *et al*, 1995; Raviglione and Pio, 2002).

Gradually, the lesson was learned that new approaches and inventions in diagnostic measures and TB drugs would not make a difference to TB control in developing countries unless a good public health infrastructure was in place, and TB services were easily available, accessible and affordable to people suffering from TB. Furthermore, ensuring successful completion of prescribed chemotherapy by TB patients was a major issue in the national programmes in developing countries where medical, social and financial consequences of TB made people vulnerable to

unsuccessful treatment. The TB control community started to realise that TB is a social disease and tackling TB control only through medical advances alone was simply not possible (Zumla and Grange, 1998; Farmer, 1997; Benatar 1995).

Finally, 111 years after the causative organism of TB was identified and half a century after the introduction of effective therapy, in 1993 the WHO publicly recognised, for the first time, that TB was a ‘global emergency’ (WHO, 1994) and recommended accelerating TB control efforts globally. This announcement generated a momentum and considerations were given to tackle other external societal factors of TB.

2.5.1 DOTS: a global strategy to control TB

In 1994, WHO introduced a new TB control strategy, officially branded as DOTS (Directly Observed treatment using Short course drugs) (WHO, 2002), to serve as the cornerstone of WHO’s Global TB Control Programme.

Many observational studies in South Africa, China, Bangladesh, and elsewhere have shown successful results with DOTS (Enarson *et al*, 2000; Chowdhury *et al*, 1997; Wilkinson *et al*, 1996). Even though DOTS was accepted in principle, progress in implementation was relatively slow. In fact, almost a decade into DOTS, the percentage of infectious cases found and treated had climbed to only 23%. It became apparent by 1998 that the global targets of TB control (see Table 1) would not be achieved, so following a review of DOTS, the target year was postponed to 2005 (WHO, 2000) .

Table 1: Global TB control targets

2005: World Health Assembly:

To detect at least 70% of infectious TB cases

To treat successfully at least 85% of detected cases

Stop TB Partnership

50% reduction in TB prevalence and death rates by 2015

Millennium Development Goals (MDG) 2015

Goal 6: Combat HIV/AIDS, malaria and other diseases

Target 8: to have halted by 2015 and begun to reverse the incidence of HIV/AIDS, malaria and other diseases

Indicator 23: prevalence and deaths associated with TB

Indicator 24: proportion of TB cases detected and cured under DOTS

The DOTS strategy comprises five key elements: political commitment; quality-assured sputum microscopy for TB diagnosis; standardised short-course chemotherapy with direct observation of treatment; regular drug supplies; and monitoring, recording and reporting, and supervision. I briefly describe these elements in the following sections.

2.5.1.1 Political commitment

Lessons from past TB control efforts make it evident that in the absence of strong political will, TB control cannot achieve its desired goal. The DOTS strategy strongly advocates for sustained political commitment from the government and individuals, and seeks to increase financial and human resources for TB control. Furthermore, it emphasises the need to make TB control a nationwide activity integrated within the general health system at all levels. Despite this call for political commitment, there continues to be only limited translation of political commitment into resource allocation to address financial and human resource constraints in TB control.

2.5.1.2 Quality-assured sputum microscopy for TB diagnosis

Sputum microscopy remains the first option recommended for TB diagnosis, but where available and affordable, culture and drug susceptibility testing (DST) is also desired. People with chest symptoms seeking care from general health care facilities need to be properly screened for TB and sent for sputum microscopy. This requires sputum microscopy services to be widely available and accessible to all patients who need the service.

2.5.1.3 Short-course chemotherapy with direct observation of treatment

All patients should be administered TB chemotherapy using DOT. DOT is defined as a process of observing TB patients taking their anti-TB drugs by a health care provider or a trained person accountable to the health service (WHO, 1997). WHO considers that DOT is the cause of the success of the DOTS strategy. It is recommended as a standard of care throughout TB treatment if the treatment regimen contains rifampicin (WHO, 1999; Bass 1994; Maher 1997; Chaulk 1998; Enarson 2000). However, DOT has been a contentious element of DOTS and there has been debate on its impact on achievement of successful completion of TB treatment and on case finding (Volmink 1997, Volmink and Garner, 2003 and 2007; Walley et al, 2001; Zwarenstein et al, 1998).

2.5.1.4 Regular drug supplies

Uninterrupted availability of TB drugs at the point of TB service delivery at all levels is crucial for TB programmes. Without this, TB control is merely a dream. The DOTS strategy includes establishing and maintaining a system to supply all TB drugs to all service delivery points, driven by a system to forecast drug requirements based on case registration numbers. In many countries supply of TB drugs is being managed vertically and the introduction of Fixed Dose Combination (FDC) drugs has made the drug supply chain more effective. However, ensuring regular supply drugs across Nepal remains a major challenge, especially in remote areas with poor transport links.

2.5.1.5 Monitoring, recording and reporting, and supervision

Another important component of DOTS is ensuring effective monitoring, evaluation and supervision in NTP, with effective communication from central to periphery levels. This component requires the establishment and maintenance of a standardized recording and reporting system based on individual TB patient records to allow periodic assessment of treatment results. It is also important to have established supervision mechanisms at all levels to identify any problems arising during implementation. Many NTPs in developing countries have established a semi-vertical monitoring mechanism with routine cohort analysis of registered TB patients.

2.5.2 The Global Plan to Stop TB and Stop TB strategy

The second global stop TB plan (2006-2015), launched in 2006, primarily focuses on the actions and funding required achieving the global targets for TB control. Under the DOTS strategy nearly 20 million TB patients have completed TB treatment globally, the majority from developing countries. Despite this success story, global TB control faces several challenges. It was realised that on its own, DOTS, was insufficient to address challenges in TB control and achieve the TB-related MDG targets by 2015. WHO identified the need for a new strategy that builds on and goes beyond DOTS. As a result, in 2006 a new Stop TB Strategy was introduced (WHO, 2006), see Table 2. The new strategy emphasises equitable access to the highest quality of care for all TB patients and accelerating the progress and impact of TB control. In addition, it focuses on reducing families' and communities' suffering caused by TB and vulnerability to TB, TB/HIV and MDR-TB, and addressing health system issues that impede TB control. The aim of the strategy is to reduce deaths and disease, and meet the MDGs related to TB by 2015.

The foundation of the new Stop TB strategy remains DOTS. The strategy retains DOT, the widely-debated element of the DOTS strategy, stating that it helps to ensure treatment completion and prevent development of drug resistant TB. Although the new strategy refers to DOT along with ‘supervision and patient support’, it remains unclear what this means for TB patients and their families.

Table 2: The Stop TB strategy at a glance

<p>VISION: A world free of TB</p> <p>GOAL: To dramatically reduce the global burden of TB by 2015 in line with the MDGs and the Stop TB Partnership targets</p> <p>OBJECTIVES</p> <ul style="list-style-type: none"> - Achieve universal access to high-quality diagnosis and patient-centred treatment - Reduce the human suffering and socioeconomic burden associated with TB - Protect poor and vulnerable populations from TB, TB/HIV, and MDR-TB - Support development of new tools and enable their timely and effective use
<p>TARGETS : MDG 6, Target 8</p> <ul style="list-style-type: none"> - Halt and begin to reverse the incidence of TB by 2015 <p>Targets endorsed by Stop TB Partnership</p> <ul style="list-style-type: none"> - By 2005: detect at least 70% of sputum smear positive TB cases and cure at least 85% of these - By 2015: reduce prevalence of and deaths due to TB by 50% relative to 1990 - By 2050: eliminate TB as a public-health problem (less than 1 case per million population)
<p>COMPONENTS</p> <p><i>1. Pursue high-quality DOTS expansion and enhancement</i></p> <ul style="list-style-type: none"> - Political commitment with increased and sustained financing - Case detection through quality-assured bacteriology - Standardised treatment, with supervision and patient support - An effective drug supply and management system - Monitoring and assessment system, and impact measurement
<p><i>2. Address TB/HIV, MDR-TB, and other challenges</i></p> <ul style="list-style-type: none"> - Implement TB/HIV collaborative activities - Prevent and control MDR-TB - Address prisoners, refugees and other high-risk groups, and special situations
<p><i>3. Contribute to health system strengthening</i></p> <ul style="list-style-type: none"> - Actively participate in efforts to improve system-wide policy, human resources, financing, management, service delivery, and information systems - Share innovations that strengthen systems, including the Practical Approach to Lung Health - Adapt innovations from other fields
<p><i>4. Engage all care providers</i></p> <ul style="list-style-type: none"> - Public-Public and Public-Private mix (PPM) approaches - International Standards for TB Care (ISTC)
<p><i>5. Empower people with TB and communities</i></p> <ul style="list-style-type: none"> - Advocacy, communication, and social mobilisation - Community participation in TB care - Patients' Charter for TB Care
<p><i>6. Enable and promote research</i></p> <ul style="list-style-type: none"> - Programme-based operational research - Research to develop new diagnostics, drugs, and vaccines

2.6 TB control: issues and challenges

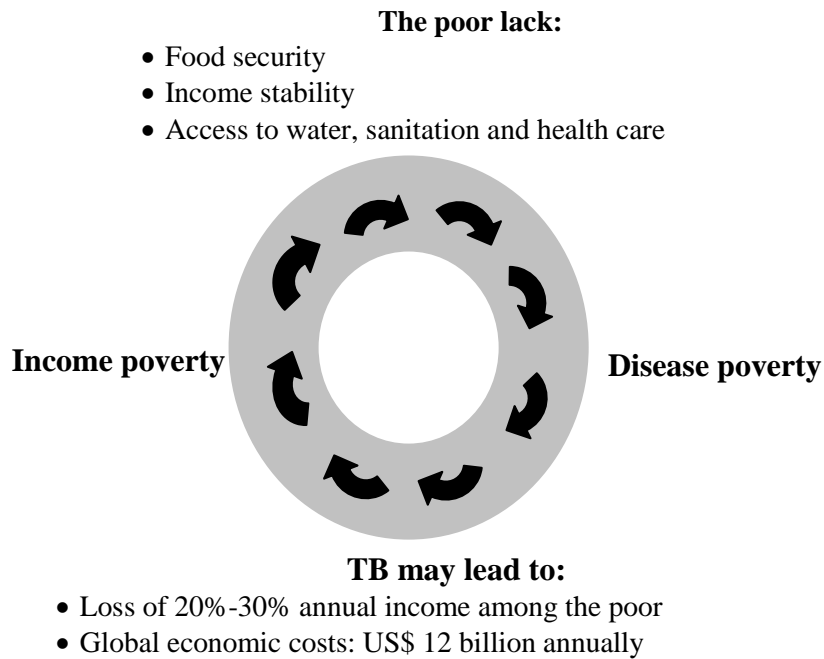
It is essential to identify and understand the key challenges in TB control and address them appropriately. Below I discuss some of the key challenges that impede TB control efforts and threaten the success of TB control programmes.

2.6.1 TB and poverty: an unbreakable association

TB can affect anyone, but there is a clear association between poverty and widespread TB. The poor and disadvantaged suffer more from TB than the more privileged. When a poor person falls sick, it is likely s/he will receive inadequate health care because of the catastrophically high cost of health care. This is true also for TB (Lui *et al*, 2007), even though TB drugs are provided free of cost by the state in many countries. There is no doubt that TB has an overwhelming financial impact on patients and their families (WHO, 2006).

Rates of TB are high among the poor, most marginalized and most vulnerable groups, and TB further traps them in a vicious cycle of disease and economic devastation. Studies have shown that people affected with TB on average lose 3-4 months of work time, and significantly longer for people with MDR-TB as they need to take treatment for at least two years. The financial impact of TB not only makes life difficult for the person directly affected with the disease but also has a devastating impact on the livelihood of that person's family, with 20-30% of a family's household income lost on average (Figure 1). If a TB patient dies the family loses about 15 years of income. In many cases, children whose parents become sick with TB face severe consequences and end up working to support the household, endangering the child's education and further hindering the family's development. TB affects the most economically productive age groups (Murry *et al*, 1993) and reduces the ability of people with TB to work. Generally, people with TB have to follow a long path of diagnosis and treatment, and even though many national TB programmes offer free diagnosis and treatment, there remain substantial costs to patients, including costs of care, transportation, food and loss of income. Such costs of accessing TB care can be more than twice the monthly income of the poorest (Kempet *al*, 2007), which makes people more vulnerable to poverty. Moreover, TB may push the non-poor towards poverty (WHO, 2005b), and a consequence is that the likelihood increases that the patient may not complete the full course of treatment.

Figure 1: Income poverty and TB



Source: Adapted from Hanson. TB, poverty and inequity: Cited from WHO, 2005b: Addressing Poverty in TB control, Options for NTP

It should be possible to control TB in developing countries but the main obstacles are disease-associated poverty and inadequate focus on the relationships between TB and socio-economic conditions (Squire, *et al*, 2006). The Table 3 presents six practical considerations addressing poverty in TB control. There is a clear need for all TB activity needs to be tailored and delivered using an equitable health system approach with universal coverage of services. Furthermore, there is a clear need to use standardised indicators in national TB programmes in order to understand the dimensions of poverty and equity in TB service delivery, to which end the participation of people affected with TB must be ensured.

Table 3: Addressing poverty in tuberculosis control: six practical steps

Step 1: Establish profile of poor and vulnerable groups <ul style="list-style-type: none">- Government or other data; Locally done surveys
Step 2: Assess poverty-related barriers to accessing of tuberculosis services <ul style="list-style-type: none">- Economic barriers- Geographic barriers- Social and cultural barriers- Health-system barriers
Step 3: Take action to overcome barriers to access <ul style="list-style-type: none">- Economic barriers: integrate services within primary-care provision, encourage pro-poor Public-Private Mix DOTS, promote tuberculosis control in workplaces, improve coverage of smear microscopy networks, avoid user fees, provide free smear microscopy and other diagnostic services- Geographical barriers: extend diagnostic and treatment services to remote regions, provide free transport to patients from such regions, promote community-based care- Social and cultural barriers: engage former patients and support groups to advocate for services and encourage community mobilisation- Health-system barriers: engage in health-service decentralisation to ensure capacity strengthening in less well served areas and by establishing tuberculosis control as a district-level priority
Step 4: Work with groups that need special consideration <ul style="list-style-type: none">- Refugee communities, asylum seekers, economic migrants, displaced populations- Pockets of deprivation in wealthier countries; ethnic minorities, homeless people- Injecting drug users- Prison populations
Step 5: Harness resources for pro-poor services <ul style="list-style-type: none">- Global Fund to Fight AIDS, TB and Malaria, poverty reduction strategies- Technologies to enhance efficiency and effectiveness of services
Step 6: Assess pro-poor performance of tuberculosis control <ul style="list-style-type: none">- Harness human and other resources through alliances with partners (such as universities)- Include socioeconomic variables in routine data collection- Include tuberculosis-related questions in district health surveys- Undertake periodic studies of care-seeking, diagnostic delay and use of DOTS- Do qualitative assessments among community members and patients about who benefits from tuberculosis services (including linked services for HIV) and who does not
<i>Source: Adopted from Squire, et al, 2006</i>

2.6.2 TB and HIV: a growing concern in TB control

The human immunodeficiency virus (HIV) epidemic and its interaction with TB has resulted in a rise in TB case numbers in many countries (Murray, 1991; Rieder, et al. 1989): this is considered to be one of the major factors for the resurgence of TB. The association between TB and HIV presents not only a massive challenge to public health but also a threat to socio-economic conditions in the developing world. TB and HIV co-infection has therefore become a global issue (Naraian *et al*, 1992; Raviglione *et al*, 1995; Raviglione *et al*, 1997). TB is the most common cause of death in HIV positive adults (Grant *et al*, 1997), accounting for about a third of HIV/AIDS deaths worldwide (UNAIDS, 2000). Considering the issues of TB and HIV co-infection and its impact in TB control, WHO clearly noted that that HIV is the primary reason for failure to meet TB control targets (WHO, 2004; WHO, 2005a).

Although sub-Saharan Africa bears the majority of the HIV-fuelled TB burden, the rapidly increasing HIV epidemic in South East Asia and countries in Eastern Europe will also increase the number of people with TB resulting from HIV infection. Moreover, the impact of the two epidemics on resource-poor countries will have significant social, economical, cultural and medical implications, and already overloaded health services will face a tremendous increase of co-infected cases; as a result, TB control could become even more difficult. Since HIV drives the TB epidemic, prevention of HIV should be a priority for the control of TB, and similarly TB care and prevention should be a priority concern of HIV/AIDS programmes.

The cost of managing TB in co-infected patients is substantially higher than the cost of care for TB patients without HIV infection (Murray *et al*, 1991). The burden of TB and HIV co-infection can be reduced through close collaboration between TB and HIV/AIDS programmes, but weak links between TB and HIV programmes present a major challenge. In response to the growing TB HIV co-infection problem, countries have started forging collaboration between these two programmes, but implementation has been slow.

2.6.3 Drug resistant TB: an issue

The term multidrug-resistant TB (MDR-TB) refers to organisms that are resistance to two or more anti-TB drugs including isoniazid and rifampicin. Development of drug resistance occurs in nature, but it is also related to human error, such as non-completion of treatment, patients not taking medication properly, incorrect or inadequate prescription of chemotherapy by health workers, weak processes of drug delivery to patients, poor case management, and many others (WHO, 1997). The presence of drug resistance in a community usually reflects a poorly managed TB control programme (Fuijwara *et al*, 2000; Shah *et al.*, 2007). If not treated, patients with resistant TB may transmit resistant strains to others in the community, so from a TB control public health perspective, for MDR-TB, no therapy is better than poor therapy.

Several countries are experiencing increasing numbers of MDR-TB cases, so the threat it poses to TB control cannot be underestimated. WHO estimates that there are about half a million MDR-TB new and existing TB cases each year, with the highest prevalence in Eastern Europe (WHO, 2006). DOTS has been promoted widely to ensure successful treatment completion and avoid resistance to TB drugs. However, access to affordable TB services including adequate first line TB drugs is difficult for many people with TB in developing countries, so the theory that use of DOTS will prevent MDR-TB may not translate into practice in many settings (Sinder and Castro, 1998). In fact, such concerns are not new in developing countries, where TB control services are still hard to reach for the majority of populations. Farmer *et al*, (2000) clearly note that if the development of MDR-TB is to be avoided, the successful implementation of the TB control programme in the public and private health sectors is essential to ensure the maximum numbers of TB cases possible are successfully treated (Farmer *et al*, 2000).

The urgency of the need to combat MDR-TB led to WHO introducing DOTS-Plus in 1999 (Farmer *et al*, 2000). Now some countries are implementing DOTS-Plus: Nepal started in 2005. The cost of second-line TB treatment is very high and treatment management is complex, and also the cure rate is 56% (Hayward, 1998), compared with 95% for non-resistant TB patients. Most importantly, countries facing difficulties implementing DOTS may not even think of treating MDR-TB through implementation of DOTS Plus.

2.7 Nepal: country context

Modern Nepal is a unification of a number of small independent former kingdoms. The democratic movement in 1990 instituted multiparty democracy with a provision of a constitutional monarchy. However, a decade-long conflict (a Maoist insurgency) led to some 13,000 deaths, many of them civilians. The conflict badly damaged the economy and development activities. Consequently, a large number of people migrated from their usual place of residence: a massive impact on local development and delivery of services, including health services. After a decade of conflict, a comprehensive peace agreement was signed. Subsequently, the monarchy was overthrown, and parliament reinstated. The country is now moving towards restoration of democracy. A constituent assembly was elected in 2007 to deliver a new constitution, although ongoing disputes among political parties have hampered the constitution-making process.

2.7.1 Population, social and economic context

Nepal has an estimated population of 29.5 million with almost equal proportions of males and females. The majority of the population (84%) resides in rural areas. The annual population growth rate is 2.25% (CBS, 2003). The literacy rate in 2001 was 54% -42% for females and 65% for males - substantially higher in urban areas (64 %) than in rural areas (36 %). The country is diverse in many ways: culturally, ethnically and religiously. There are about 103 ethnic/caste groups and about 90 languages and dialects. In addition, there are complex social hierarchies within communities. The abolition of the traditional caste systems that took place many years ago was further reemphasised in the Nepal's Interim Constitution, 2007, which stated 'the State shall not discriminate among citizens on grounds of religion, race, caste, tribe, sex, origin, language or ideological conviction or any of these.' (Nepal's Interim Constitution, 2007, clause 13.3, p.6, English translation version). However, various forms of social exclusion and discrimination based on ethnicity/caste, religion and language continue. This has not only exacerbated poverty among the lower castes, minorities and tribal groups, but also affected utilisation of public services. (The low caste groups, commonly known as Dalits, are historically linked with occupations regarded as ritually impure such as cleaning streets, latrines, waste, dead bodies of animal; assisting pregnant women during and after pregnancy; butchering; involved in leather works; metal works and many other jobs considered as low grade in the community). Dalits were considered polluted and contagious, and thus untouchable by other people

especially those from upper castes. Discrimination based on such grounds still exists but is less marked in urban than in rural areas. Recently, issue of social inclusion is given a high priority but yet to see effective implementation of strategies benefiting the excluded.

Nepal remains the poorest country in South Asia and ranks as the 12th poorest country in the world with a per capita Gross Domestic Product (GDP) of US\$270 in 2005. Although, the poverty rate (people living below the poverty line) declined by 11% – from 41% to 31% – between 1995/1996 and 2003/2004, poverty is still widespread, especially in rural areas, with almost a quarter of the total population earning less than 1 US\$ per day (MoF, 2006). The incidence of poverty in urban areas declined from 22% to 10%, while poverty in rural areas also declined from 43% to 35%, but remains high and some groups have poverty rates much higher than the national average. See Table 4.

Table 4: Poverty in Nepal

	Poverty Headcount Rate (%)	
	Fiscal Year 1995/1996	Fiscal Year 2003/2004
Nepal	41.8	30.8
Urban	21.6	9.6
Rural	43.3	34.6
Development Regions		
Eastern	38.9	29.3
Central	32.5	27.1
Western	38.6	27.1
Mid-western	59.9	44.8
Far-western	63.9	41.0
Ecological Belts		
Mountains	57.0	32.6
Hills	40.7	34.5
Terai	40.3	27.6
<i>Source: CBS, 2004</i>		

2.8 Nepal's Health Sector Programme

The Nepal National Health Policy, 1991, aims to improve the health status of the people by extending the primary health care system. Within this approach, increased access to essential health care services (EHCS) to rural poor is to be provided through decentralized primary health care delivery (see figure 2). Government (also known as public sector) is the largest service provider, followed by NGOs and finally the private sector. A comprehensive framework of health policies, plans and strategies are in place. In order to achieve the health sector aim, the *Health Sector Strategy: an Agenda for Reform 2003* was introduced. Subsequently, the *Nepal Health Sector Program – Implementation Plan (NHSP-IP) 2004-2009* was developed by encapsulating various policies, plans, strategies and lessons learned in the health sector, to serve as an implementation tool for the strategy, and became the basis for Nepal's first health SWAp (sector-wide approach) with three programme outputs and eight sector outputs.

Nepal has achieved good progress in some health outcomes: a considerable decline in child and maternal mortality over the last 10 to 15 years (NDHS, 2006), and Nepal is on track to meet child and maternal health MDGs. The government estimated that NHSP-IP saved about 96,000 deaths and nearly 3.2 million disability-adjusted life years (DALYs) at a cost of \$144 per DALY saved (MoHP, 2010).

Table 5: Selected health indicators and their change over time

Year of survey	1996	2001	2006
Under 5 mortality rate (per 1000 births)	118	91	61
Under 5 mortality net of neonatal mortality (per 1000 births)	68	52	28
Maternal mortality rate (per 100,000 births)	539	-	281
Adult mortality (% dying in age group 15-49)	11.5	-	7.9

Source: Demographic Health Surveys 1996, 2001 and 2006

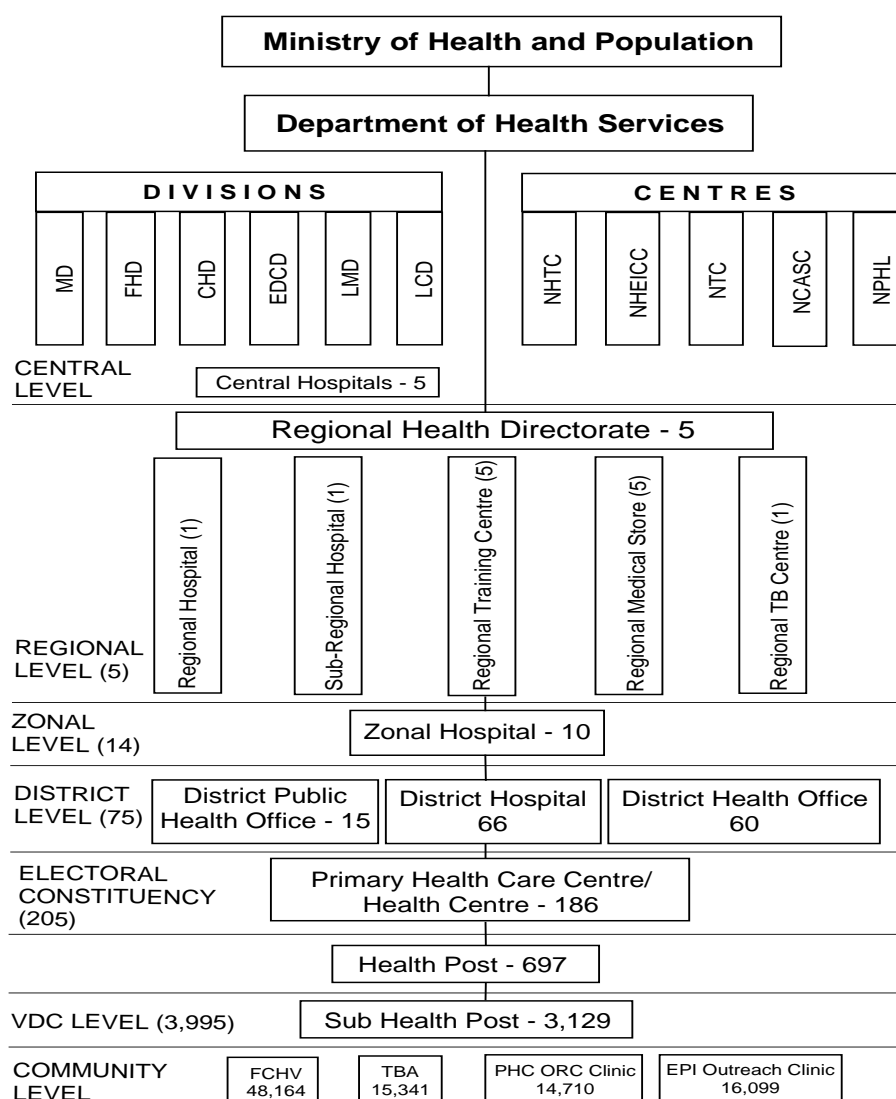
It should be noted that these health gains (including TB control achievements) were made over the last 10 to 15 years during which the country was plunged into deep conflict and delivery of basic services including health were affected, especially in rural areas. So far, there has not been any credible evidence for any factors responsible for better health outcomes during the conflict. However, two suggestions have been made: health service delivery was less affected by the conflict than other sectors, as both sides (the state and the Maoists) were aware of the need to keep health service delivery intact.

Expenditure in health remains low at 5.3% of GDP in 2006 (MoHP, 2010). The per-capita health expenditure stood at USD 19.09, a relatively low compared with other South Asian countries (i.e. Bhutan USD 44 and 29 in India) (WHO, 2008; cited from MoHP, 2010). Sharing of the total health expenditure is - Government 24% (USD 4.28), external funding from partners 21% (USD 3.75) and more than 55% from household out-of-pocket. The high household spending is an inequitable which mean the poor cannot (or find it very difficult to) afford services in the private sector, and thus rely on public health services which are often not adequate to meet their needs and not accessible by many. Government's commitment to expand essential health services has not been translated into practice thus significant barriers to access to health services remain, especially for the poor and excluded, as more than 60% of the rural population live more than one hour's walk from a public health facility.

2.8.1 Unequal distribution in health outcomes

Despite good health outcomes at the national level, health gains are not equitable but are unevenly distributed across wealth quintiles, social groups and geographic locations, and worsening disparities can be observed. For instance, infant mortality is 73% higher in rural areas than urban areas and more than 100% higher in mountain zones than in hill zones. The richest fifth spend 25 times more on health care than the poorest fifth (NDHS, 2006). Under-five mortality rates are more than twice as high for the poorest compared to the wealthiest. Similarly, infant and maternal mortality rates are significantly higher among the poor than the non-poor. The poor have the largest unmet demand for family planning, make the lowest use of maternal care, have the lowest vaccination coverage, and are least likely to seek care when ill. While the total fertility rate has declined, it remains high for Muslims, Dalits and poor women. A higher proportion of Brahmans and Newars (the so-called higher casts) receive antenatal care by a Skilled Birth Attendant than Muslims and Terai Janajatis (NDHS, 2006). The average time to travel to a health facility is more than 4.6 times longer for the poorest fifth than for the richest fifth (NLSMS, 2002/03).

Figure 2: Organisational structure of health service delivery in Nepal



Source: HMIS/MD, DoHS, Annual Report 2004/5

<i>MD</i>	Management Division	NTC	National TB Centre
<i>FHD</i>	Family Health Division	NCASC	National Centre for AIDS and STD Control
<i>CHD</i>	Child Health Division	NPHL	National Public Health Laboratory
<i>EDCD</i>	Epidemiology and Disease Control Division	FCHV	Female Community Health Volunteer
<i>LMD</i>	Logistics Management Division	TBA	Traditional Birth Attendant
<i>LCD</i>	Leprosy Control Division	PHC/ORC	Primary Health Care Outreach Clinic
<i>NHTC</i>	National Health Training Centre	EPI	Expanded Programme on Immunisation

2.8.2 The free health care policy: evolution and issues

In line with the provision stated in the Interim Constitution of Nepal – every citizen shall have the right to basic health services free of cost from the State –in 2006 the government introduced a 'free health care policy' with the aim of removing financial barriers in seeking basic health care services, especially for the poor and excluded. The policy was subsequently extended, adding more services and population groups, and now offers essential health care services up to district hospital level free for all citizens (see Table 6), along with the removal of user fees.

Initial observations of the implementation of the free health care policy suggest that utilisation of out-patient and in-patient care has increased considerably at all levels. However, management, implementation and sustainability of the policy have presented substantial challenges. Communication of the policy has been poor: a study at ten district hospitals demonstrated that most users, especially the poor and excluded (who the policy aims to benefit), were not aware that care was free and paid considerable sums for care, instead of being informed by the service provider about free care provision – although it could be the case that the provider was also unaware of the policy. However, the same study revealed that the distribution of benefits among different population groups showed that the poorer groups received a larger share of public subsidies at the district hospital (MoHP, 2009).

Human resource and health service infrastructure to deliver health free services is severely constrained – there is one nurse per 5,000 population, one doctor per 18,000 population and one hospital bed per 2,300 population (MoHP, 2010). It can be concluded that if the free health care policy is to be effective, the programme needs to increase access to services especially for the poor and excluded. There is a clear need to address inequalities in service utilisation; costs of transport and other associated costs of illness; increased workload in some facilities; poorly managed health logistics (causing drug stock outs); clarity on what is free and not free; and sustainable financing for the implementation and expansion of free health care.

Table 6: Evolution of free health care in Nepal

Date	Policy/Programme Description	Issues/challenges
December 15, 2006	Emergency and inpatient services offered free of charge to the poor, destitute, elderly, people living with physical and psychological disabilities, and Female Community Health Volunteers at district hospitals and primary health care centres (PHCCs) in 25 low Human Development Index (HDI) districts	<ul style="list-style-type: none"> - proper identification of targeted groups eligible for free care - partial implementation of policy poor orientation of health service providers on free health care policy - limited awareness of policy among people - inadequate monitoring and reporting
July 17, 2007	Outpatient services offered free of charge to same target groups at district hospitals and PHCCs in low HDI districts, and, together with inpatient and emergency services, expanded from 25 to 35 low HDI districts.	<ul style="list-style-type: none"> - proper identification of targeted groups eligible for free care - lack of clarity among providers on policy - lack of follow-up of policy implementation
Announced: October 7, 2007 Enacted: January 15, 2008	User fees removed and essential health care services (EHCS) offered to all free of charge at all health and sub-health posts, including 25 essential drugs at sub-health posts and 35 at health posts.	<ul style="list-style-type: none"> - Concern over loss of revenue by health institutions - Over-consumption of free drugs (fake illness presented to collect drugs) - lack of clarity among providers on policy - lack of follow-up of policy implementation
January 14, 2009	EHCS offered free of charge at PHCCs and to target groups in all districts at district hospitals. Institutional Deliveries (normal, complicated, and caesarean sections) free of charge at all government facilities nationwide.	<ul style="list-style-type: none"> - lack of clarity among providers on policy - big hospitals were concerned about revenue loss - management of logistics and ensuring financial flow from centre to periphery
Announced: July 13, 2009 Enacted: July 16, 2009	Essential drugs (40 in total) free of charge for all at district hospitals	<ul style="list-style-type: none"> - Operation guideline of the policy delivered late to service delivery sites disrupting implementation - Local purchase of drugs and concern over quality - Sustainability of the policy

Source: compiled from MoHP, 2010

2.8.3 Health services in urban areas: a neglected scenario

Nepal is experiencing rapid urbanization with 7% urban population growth annually, the highest amongst the South Asian countries (UN Habitat, 2007). Urbanization is largely unplanned in Nepal: a large number of slums, squatters, homeless and unemployed population in cities, resulting in a large number of urban poor living in unhealthy conditions. The urban population has risen substantially: it was 4% in 1971, 6.4% in 1981, 9.2 % in 1991 and 13.9% in 2001 (CBS, 2001). Currently the municipal population is about 16% of the total population, and a projection suggests that by 2015 it will be more than 21% of the total population. About 25% of the total urban population (about a million people) are poor. Among the urban poor, more than 60% live in slums (UN Habitat, 2005). About 46.3% of urban households have no piped drinking water; 45.6% have no sanitary system and 55% have no appropriate garbage disposal system (NLSS, 2004).

The situation described above demonstrates that urban poverty is increasing and urban development will be severely challenged by poverty. In terms of health services, provision of basic primary health care services is considerably limited in town and cities. Some big central hospitals and specialized care centres exist, but are generally inaccessible to the urban poor. Limited urban primary health care centres, ineffective outreach and referral systems, inadequate information about health service provision and low awareness of health among urban dwellers make poor people more vulnerable to ill health. Demographic health survey (2006) show that almost all health indicators are better in urban areas than in rural areas. However, absence of disaggregated health data for the urban poor severely limits overall understanding of the status of the urban poor.

Government health policy documents generally state that providing basic health services to urban population is the responsibility of the state. However, implementation of the policy has been weak despite increasing health demands of the urban poor. In urban areas there are multiple health care providers with varying statutory responsibilities, but service delivery is largely uncoordinated and unregulated as there is no well-structured and clearly articulated urban health policy/strategy to guide urban health care delivery. This poses management and implementation problems, and fragments efforts. Moreover, there is lack of clarity within policy on who is responsible for providing basic health care in municipalities – the municipalities themselves, or the Ministry of Health and Population – further

impeding the development of urban health care. Hence, a consistent and focused approach to urban health is imperative.

2.8.4 Challenges in health service delivery

Although Nepal has made good progress in some health outcomes, there are many challenges and constraints in delivering health services effectively, efficiently and inclusively. Major challenges at system, sector and sub-sector levels, together with fragile political and economic conditions, make delivery of basic health care difficult. Key challenges in the health sector include socio-economic disparities (regional-urban-rural-ethnic/caste) in service delivery and utilisation; accessibility and coverage of services; institutional arrangements, planning and management including intra- and inter-sectoral coordination and decision-making processes which are highly centralised though policies aim for decentralisation. Similarly, inappropriately located health institutions, challenging geography, poorly coordinated health programmes, lack of human resources especially in rural health institutions, social inequalities and discrimination in service provision grossly impede delivery of essential health care services especially to the poor and excluded. Moreover, concerns about the quality of services provided by public facilities are widespread, and may limit increased utilization of health services and damage achievements in health outcomes. Addressing all these problems requires an accelerated and sustained health reform process that includes effective use of financial, human and institutional resources, a clear policy and an effective and efficient delivery mechanism, equitable and socially inclusive service delivery provision, and collaborative efforts of private, public and NGO stakeholders.

2.9 National TB Programme of Nepal

TB is one of the main public health problems in Nepal. The history of the fight against TB began in 1937 with the establishment of a TB sanatorium in the Kathmandu Valley. The National TB Programme (NTP), one of the priority programmes of the Ministry of Health and Population (MoHP), was initiated about four decades ago. The NTP operates nationwide, implemented within the national general health system, especially in rural areas. However, some components of the programme such as training, drug management, microscopy quality control, monitoring and surveillance are managed vertically.

The National TB Centre (NTC), established in 1989, is the focal point of the NTP at national level. It develops policies and strategies and provides technical support in areas of programme implementation, monitoring and supervision. It also manages the vertical components of the programme mentioned above. At the regional level, coordinating NTP activities is the responsibility of the Regional Health Directorate. A designated NTP officer oversees such regional responsibilities. At the district level, the district health office/district public health office is responsible for planning, implementing and monitoring NTP activities within the district. A District TB/Leprosy Officer coordinates overall management of TB control activities in the district. Within the district, the basic units of management for diagnosis and treatment of patients with TB are district hospitals and primary health care centres (PHCC) with microscopy facilities. At the periphery, TB suspect identification and treatment services are available at Health Posts (HP), Sub-Health Posts (SHP) and other district health institutions (NTP 2006).

2.9.1 NTP's aims, objectives and strategies

The NTP aims to reduce the mortality, morbidity and transmission of TB until it is no longer a public health problem. In order to assess progress towards these aims the NTP has set two targets: to achieve 80% case detection rate of new smear positive TB nationally by 2012; and to maintain the existing treatment success rate of 90% throughout the programme (NTP 2004).

2.9.2 TB epidemiology: infection and disease

The NTP estimates that 45% of the total population is infected with TB bacilli, of which about 60% are adults: more than 80,000 have TB. Every year, 40,000 people develop active TB, of whom 20,000 have infectious pulmonary disease and could transmit TB to others. In 2007 the reported incidence of TB cases was 173/100,000 with a total number of 48,766 cases. NTP data shows that TB is predominant among poor and marginalised groups, and the burden is highest in the urban and terai areas.

TB mortality: Deaths due to TB are largely preventable if early detection is made and successful treatment completion is ensured. Ten years ago, the NTP estimated that about 16,000 people were dying from TB every year in Nepal. Current estimates suggest 5,000 to 7,000 TB deaths per year - about 17 people every day (NTP 2008/09).

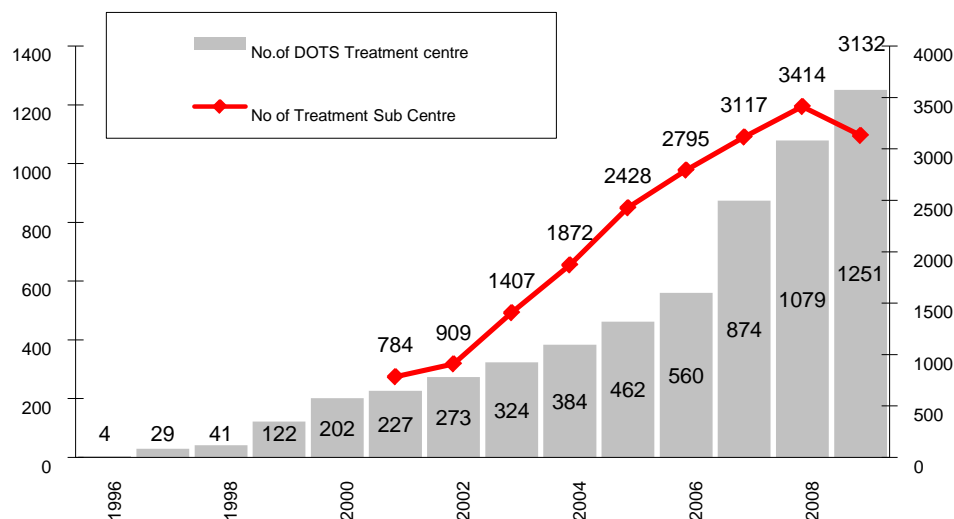
Drug Resistant TB: The most recent survey (2006/07) of MDR-TB that showed 2.9% of previously untreated TB cases had MDR-TB, an increase from 1.3% in 2001/2002, which is a cause for concern. Of even more concern for the NTP is that a recent study found a prevalence of 5% of XDR-TB among MDR-TB cases registered in the NTP (NTP 2008/09). In 2005, Nepal launched a DOTS plus pilot project to treat MDR TB cases using a standardised treatment regimen free-of-charge to patients. The first annual cohort enrolled 175 MDR-TB cases, and achieved 70% (123) cure rate with 17% (29) defaulter rate. The success of MDR-TB treatment in Nepal demonstrated that it is possible to deliver fully ambulatory-based MDR-TB care in resource-limited settings with good treatment outcomes (Malla *et al*, 2009). However, a research study conducted with MDR-TB patients in Nepal highlights that continuing treatment for two years is a problem for many MDR-TB patients due to the high cost of care (even though drugs are free), lack of social support especially when they are away from home for their treatment, and the highly toxic effects of the drugs (HERD, 2009). Recently the NTP has started providing limited financial support to MDR-TB patients. This is a good first step towards addressing patients' needs but unless adequate financial support combined with social support is provided to MDR-TB patients they will continue to face problems continuing their treatment.

TB and HIV: Nepal has the highest HIV prevalence in South Asia with 0.49% of the population aged 15-49 infected (GoN, 2009): a concentrated HIV epidemic among high risk population groups such as injecting drug users, male and female sex workers and their clients, men who have sex with men, and migrants to high risk districts in India and their partners. Increasing HIV prevalence is a concern of the NTP as numbers of HIV-related TB cases can be expected to increase as the prevalence of HIV increases. Since 1994, Nepal has conducted six rounds of HIV surveillance in people with TB. The results indicate that the prevalence of HIV among TB patients is low but increasing. The latest survey showed HIV prevalence among TB patients at 2.4% (NTP, 2008/09). This result indicates there is an immediate need to enhance TB and HIV collaboration activities, which though initiated many years ago has made only slow progress (NTP 2007).

2.9.3 National TB Programme: review of progress

Nepal is a country where the implementation of any programme nationwide appears to be difficult, because of geographic, cultural and social conditions, and widespread poverty. However, Nepal has achieved remarkable success with the DOTS strategy. The government adopted the DOTS strategy in late 1990s and observed countrywide implementation by 2001(see Figure 3).

Figure 3: Trend of DOTS expansion in Nepal



DOTS: the central strategy of NTP: DOTS is the central strategy of TB control in Nepal. There is no doubt that the NTP has achieved remarkable success using DOTS, and it continues to be the NTP's major TB control strategy within the NTP's long-term plan (NTP 2004). Under DOTS, the NTP has gained momentum, secured considerable political commitment from the government and local DOTS committees² in its effective rollout. However, political commitment in terms of domestic resource allocation for the NTP remains weak as more than 80% of NTP funding comes from external source thus the NTP relies heavily on donor funding. Lack of adequate allocation of domestic resources for essential NTP activities such as drugs, microscopy and training could be detrimental to the NTP's success if a single donor stops funding or changes its funding modality (NTP, 2004). In 2006, Nepal officially adopted the new WHO Stop TB Strategy. In line with this strategy, Nepal also adopted the International Standards for TB Care (ISTC). However, effective

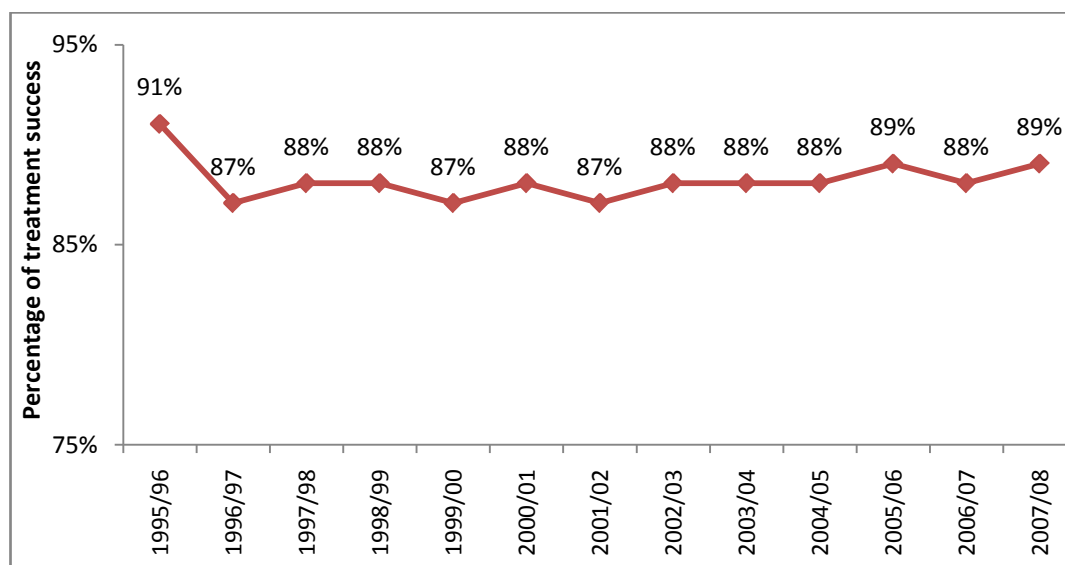
²DOTS committees were established by the NTP locally to gain community support in DOTS implementation. They also help TB patients complete treatment in their areas.

implementation of all components of the Stop TB Strategy and the ISTC is a challenge to the NTP given weak primary health care networks especially in urban areas.

DOT: All TB cases notified to the NTP are treated under DOTS and policy continues to be that conventional health facility-based DOT is used for all TB patients. The NTP promoted DOT by claiming that it ensures better adherence to TB treatment and prevents drug-resistant TB. Therefore, all TB patients taking rifampicin need to comply with the requirements of DOT regardless of whether it causes patients and their families to suffer. The effectiveness of DOT has been widely debated internationally and is infeasible for many TB patients in the context of Nepal, given its complex geography, and inappropriately located health facilities, especially in rural, hill and mountain districts where patients have to travel/walk considerable distances to reach the nearest health facility. Availability of health workers in these areas for routine DOT is also a concern. Even in urban areas, complying with DOT is difficult for many TB patients due to inconvenient opening hours of DOTS clinics, social stigma attached with TB, travel costs for DOT and distance to DOTS centres from patients' homes (Baral *et al*, 2007; Kirwan *et al*, 2009; Karki *et al*, 2007). Moreover, although the selection of treatment observer should be properly negotiated with TB patients and their families to ensure acceptance and execution of treatment plans, the programme instead uses a blanket approach for all TB patients which may not be feasible for all (Harper, 2006). Although the NTP has achieved about 90% treatment success rate under DOTS (see Figure 4), there has been little acknowledgement of the hardships that patients have to face to comply with DOT, or of its impact on their lives. Some health workers may address issues locally, but the policy remains silent on concerns about DOT raised by patients, their families and health workers (Newell *et al*, 2006, Kirwan *et al*, 2009) even though they were documented in an NTP in-depth review in 2007. Nepal conducted a major district-based cluster randomised trial comparing feasibility and effectiveness of DOT using community members and family members as treatment observers in hill and mountain districts (Newell *et al*, 2006). The trial demonstrated that both approaches attained the global target of TB treatment completion, and were thus suitable for settings where conventional DOT is infeasible for many TB patients. The study also noted that these approaches were feasible to implement in Nepal from a programme management perspective, but costs of implementing family based DOTS were found to be slightly higher than those of community based DOTS (Mirzoev *et al*, 2008). The NTP recently (2009/10) revised its guidelines and training manuals but did not shift its focus from a conventional

approach to DOT. However, the guideline spelled out the use of a community member as a treatment observer for those living a long way from any health facility, but gave a rather weak explanation in of how to use them as treatment supervisors. The guideline also mentions using family members as treatment supervisors, but only as a last resort. Thus the policy remains focused on conventional health facility-based DOT and has little consideration towards advancing patient supervision and support mechanisms in the programme.

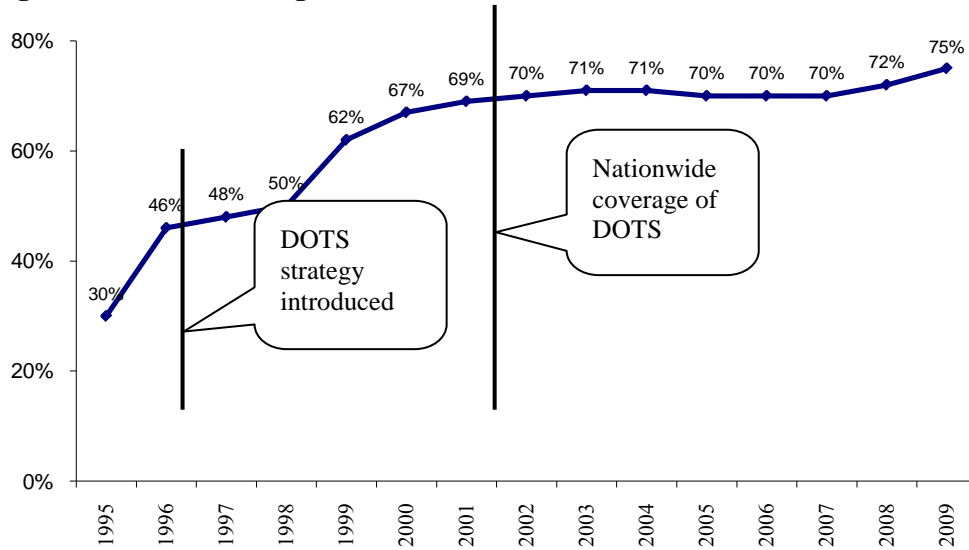
Figure 4: Trend of treatment success in NTP



Source: data compiled from NTP annual reports

Case finding: Notification of new smear positive TB cases in the NTP increased steadily from 1996 until 2001, after which the rates stabilized and further increased from 2008 (Figure 5). Similarly, the trend in age distribution among notified new smear positive cases over the period from 1997 to 2006 shows a steady shift to older patients. In the absence of other information, these two pieces of evidence suggest that the TB burden is has declined over recent years, although the data needs to be interpreted with caution, and it is too early to be certain that this trend will be sustained (NTP, 2007).

Figure 5: TB case finding rate based on actual notifications (1995 to 2009)



Source: data compiled from NTP annual reports

Monitoring and evaluation of NTP activities: NTP has a well established vertical monitoring system. Monitoring of treatment outcome relies on a cohort system, analysed on a four-monthly basis. These cohorts are followed up for the duration of treatment, their outcomes recorded, and the proportion achieving treatment success (those cured and those who completed treatment) calculated. The NTP routinely uses these data for programme management, and to identify weaknesses in programme performance. Every district prepares and analyses four-monthly case finding, smear conversion, treatment outcome and programme management reports by conducting a four-monthly district DOTS planning and monitoring workshop. Districts then submit these reports to a regional DOTS planning and monitoring workshop. Finally, a national level four-monthly planning and monitoring workshop held under the NTC's guidance prepares the national TB report. Routine supervision at all levels is a core activity of the NTP.

Partnerships in TB control: The first public-private partnership (PPP) project in Nepal was initiated in Lalitpur in 1998. This developed a successful PPP model for engaging the private health sector in TB control; however, scale-up of this model was rather slow due to resource constraints. Now, under new funding provision from the Global Fund, the NTP plans to expand the PPP model in at least 25 districts. All medical colleges in Nepal have been providing TB services by establishing a DOTS centre in their teaching hospitals. DOTS orientation to private practitioners, industrial

workers and pharmacists is one of the key regular activities of the NTP. As a result of PPP, referral of TB cases from private providers to the NTP has increased remarkably. Nepal provides a classic example of community participation in DOTS through the establishment of DOTS committees at DOTS treatment centres and sub centres. They are engaged in raising awareness in their local community and helping effective implementation of DOTS. Similarly, the NTP has established functional partnership with several private and non-governmental organizations to deliver MDR-TB services across the country. The national reference lab for MDR-TB, almost half of the MDR-TB treatment centres and close to 30% of the MDR-TB treatment sub-centres are operated by the private and NGO sectors.

2.10 Conclusion

The chapter provided an overview of global TB control status along and challenges to TB control with especial focus on developing countries. In addition the chapter also provided an account of Nepal's health sector with focus on NTP. This chapter set a background of the broader research area – tuberculosis and national status of TB. The next chapter critically examines the issue relating to TB treatment completion which sets a foundation of issues under investigation.

CHAPTER THREE

UNDERSTANDING TB TREATMENT COMPLETION

In this chapter I describe the current body of knowledge with regard to TB treatment completion with a focus on factors affecting continuation of TB treatment in the context of developing countries and resource constrained settings. It provides the foundations of my doctoral research project by analysing factors helping and hindering TB patients during their course of TB treatment. I also discuss knowledge gaps in understanding TB treatment completion, taking into account the contexts of developing countries and TB service delivery modalities. I further present an outline of different measures applied in TB programmes to address issues of non-completion. Finally, I develop a theoretical understanding of the issue and a conceptual framework leading to the aim and objectives of my research and to guide the research approach.

3.1 Defining the term 'successful treatment completion'

Various studies have examined treatment behaviour of people especially in the use of long-term treatment therapies. Different models have been used to understand the patients' behaviour and its impact on the effectiveness of treatment regimens and different terms have been used interchangeably to capture patients' treatment behaviour, including *adherence*, *compliance*, *concordance*, *cooperation*, *mutuality*, *completion*, and *therapeutic alliance*. The operational definitions of these terms vary considerably: however, most definitions contain elements relating to patients' responsibility for self-care, their role in the treatment process, their collaboration with health care providers and their obeying of prescriptions in their treatment management by health care providers.

In recent years, the use of the term compliance with treatment has been debated as it has the 'unfortunate connotation that the patient is docile and subservient to the provider' (Sumartojo, 1993). Some experts have noted that treatment is usually an independent choice of patients and can therefore best be described as adherence. Recently, practitioners have recommended the term concordance to reflect 'the active exchange of information, negotiation, and spirit of cooperation' (Mullen 1997). However, most widely used is the term *adherence*, which simply refers to how closely patients follow a prescribed treatment regimen. It includes a willingness to start treatment and an ability to take medications exactly as recommended. However, it has been realised that to be able to understand overall aspects of treatment and

effectiveness requires a full understanding of the factors that prevent people taking medicine correctly and the factors that help them complete their treatment therapy. Many of these definitions overlook these aspects, which are important as patients often take their medication under very difficult circumstances and have no control over many of the factors that prevent and help them take their treatment.

For the purpose of my study, I will use the outcome oriented term 'treatment completion'. I define 'treatment completion' as when a person with TB completes the full course of treatment as per the programme requirements. Further to this, I will use the term '*successful treatment completion*' to reflect the need for a comprehensive understanding of the overall treatment process (from start to completion) and factors that help or hinder at different stages of treatment. '*Successful treatment completion*' is where a patient completes the full course of treatment in a supportive environment with no harmful consequences of the disease to him/her and their family during and after completing the full course of treatment and, by having so, the person will be easily able to restore quality of life and productivity. In my experience as a health worker and a researcher, I have found many examples of people with TB who complete their full course of treatment despite major problems that continue to pose a threat to their well-being even after being labelled 'cured' or 'treatment completed' by the TB programme. By using this definition, I intend to foster an awareness and understanding of the suffering and consequences that are faced or will be faced by TB patients (and in the case of cured patients, former TB sufferers) due to TB, and also enabling factors that led the person to complete their full course of treatment. It is important to remember that, although TB control programmes may achieve high treatment completion rates, this might be at major cost to the patients who complete treatment.

3.2 Understanding TB treatment completion

One of the international targets of TB control is to ensure 85% of all identified smear-positive TB cases successfully complete their treatment. However, many national TB programmes are struggling to achieve this target, particularly in developing countries. Even though effective anti-TB drugs have been used since the 1940s and TB control measures have been put in place, the problem remains (Dye 1999; Netto 1999). Non-completion of TB treatment continues to be a major barrier to tackling TB control effectively, despite various interventions aimed at improving treatment completion (Jin *et al.*, 1993; Chaulet 1990). Generally, people with TB require treatment for at least six months but many TB patients find it difficult to complete treatment even when services are available (Fox 1958; Addington, 1979; Cuneo and Snider 1989). Several factors impeding successful completion of TB treatment are discussed in section 0 of this chapter. Failure to complete TB treatment can lead to prolonged infectiousness, development of drug resistance, relapse of TB, and death (Volmink and Garner, 2006). Poor completion of treatment thus poses a serious risk not only for the individual but also for the community.

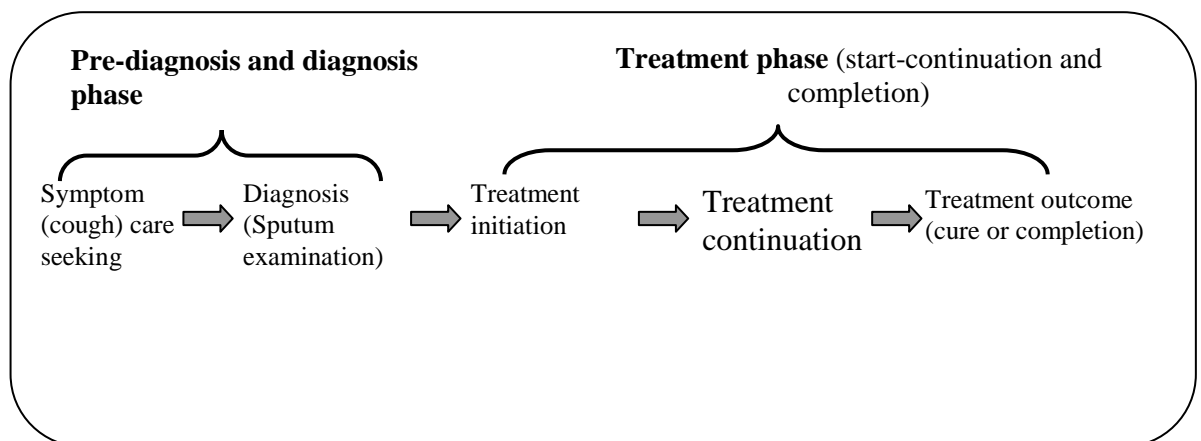
Treatment of TB requires access to appropriate health services designed and delivered with a full understanding of patients' needs. However, over the many years of the history of TB treatment, patients have experienced difficulties following treatment regimens delivered in a biomedical fashion. DOTS is a highly effective strategy promoted globally but the TB treatment delivery modality that uses direct observation has been a much debated issue. Nevertheless, difficulties experienced by patients in the process of their treatment under a strict treatment delivery protocol has raised awareness of the issue in TB control programmes and TB treatment completion is now recognised as a complex issue influenced by many factors. Advancing TB control programmes by improving treatment completion requires a comprehensive and holistic understanding of the barriers to and facilitators of treatment completion, using systematic approaches feasible for context (Munro *et al.*, 2007). It is important to gain patients' experiences of problems and coping mechanisms, but there seem to be a major knowledge gap in this area which limits developing effective solutions specific to local contexts: in response there have been calls for qualitative research that can contribute to widen understanding in TB treatment completion and help interpret the findings of quantitative studies of the effectiveness of promoting interventions (Dixon-Woods, 2004).

3.3 Pathway to TB treatment: ideal vs. reality

TB patients often face a prolonged and difficult process in order to access TB treatment under normal programme conditions. In this section, I discuss the proscribed steps that all TB patients are expected to follow to receive TB treatment in national programmes, with specific reference to Nepal's national TB programme. This section gives a description of the pathway patients must follow in accessing TB treatment (symptom appearance, diagnosis, entry into DOTS, treatment continuation and completion, leading to treatment success or otherwise), as shown in Figure 6 below. This will help develop understanding of the barriers faced by TB patients at different stages of care and their implications for TB treatment completion.

In an ideal world, all people with cough for two weeks or more, the main symptom of pulmonary TB, will seek out a formal health service provider, either private or public, to diagnose and treat their illness. Once a person with TB symptom(s) voluntarily appears to any health provider, it should be the responsibility of the provider to screen the person for TB and perform sputum microscopy to rule out TB disease. If the person is found to have TB disease, then the provider should arrange TB treatment under programme conditions, continue anti-TB treatment with direct observation for at least six months, and ensure cure or successful treatment completion. Most TB programmes in developing countries follow this approach in line with WHO guidelines.

Figure 6: General pathways to TB services under programme conditions



However, reality is very often different from the ideal and the steps outlined above (figure Figure 6) are rarely followed in a linear sequence, as many people face multiple barriers in accessing care. People may not see their symptoms as serious enough to seek care, due to lack of knowledge about TB symptoms, until it affects their routine work. People often look for a range of remedies from a variety of different providers at all stages of their illness. In a study from Malawi, for example, TB patients made an average of 5 visits to health care providers before TB was diagnosed, with women making more visits than men (Kemp *et al.*, 2007). Similarly, in Vietnam, TB patients contacted an average of 1.3 different health-care providers to seek TB care, and made an average of 2.5 visits to each provider, before contacting the designated TB services (Lonnroth *et al.*, 2001).

In Nepal, the national TB programme recommends the pathway to TB treatment as presented in Figure 6. However, several factors make it difficult to follow the route suggested by the policy. For example, as in Malawi and Vietnam, patients often visit several health care providers and make multiple visits for diagnosis, leading to delays in diagnosis of disease, and high costs to patients. Early identification and management of TB suspects is emphasised in the programme, but many patients experienced long health system delays in diagnosis. This shows the health system's inability to implement the policy of early detection of TB leading to rapid treatment. A recent qualitative study found that the route TB patients often travel to seek TB care is very complex. It involved several visits to different health care providers, ranging from traditional healers to highly qualified medical practitioners, and several factors influenced the route to treatment such as severity of complaints, ability to pay for services, availability of services and peer support for choosing a provider. Factors influencing choice of providers included perceived quality, costs and service level of a provider, and lack of provider-initiated referral (Asbroek *et al.*, 2008). The study findings and other evidence from the field suggest that TB patients have to overcome multiple obstacles to receive TB treatment under programme conditions (Harper, 2007; Newell *et al.*, 2006; Baral *et al.*, 2007). These barriers are related to economic, geographical, socio-cultural, health system and patient factors. There is considerable overlap and interdependence between the barriers in each category. I discuss these barriers later in this chapter.

3.4 Factors affecting treatment completion

Completion of TB treatment is a multifaceted issue determined by various interplays. Treatment behaviour is embedded in a complex web of psycho-social, economic, cultural, and health system factors, as well as factors associated with the quality and accessibility of TB treatment offered by TB control programmes (Liam *et al.* 1999). For many years, researchers have been accumulating knowledge about the scale of poor completion of TB treatment, its determinants and various ways of addressing it. However, there has been a widely prevalent tendency to blame patient-related factors as the cause of poor treatment completion, to the relative neglect of provider- and health system-related determinants (WHO, 2003a).

Frequent interruption of treatment, drop-out from treatment, irregular treatment, non-compliance with treatment, late patient, defaulter, non-completer – whatever label we put on people who do not complete the prescribed course of TB treatment for whatever reason – is a major concern for TB control, as it leads to programme failure and contributes to rise of MDR-TB (Borgdorff *et al.* 2002; Sharma & Mohan 2006), or even extremely drug resistant TB which is virtually untreatable. One problem cited is that it is difficult to anticipate who will comply with treatment. It has been shown that demographic factors such as age, sex, ethnicity, and education status are not accurate predictors of treatment completion (Weis *et al.* 1994; Chaulk *et al.* 1998). On the other hand, psychiatric illness, substance abuse (alcohol and drugs) and homelessness are typically associated with non-adherence (Weis *et al.* 1994; Davidson *et al.* 2000). In general, however, there are several factors that make TB patients vulnerable to discontinuing their treatment. In this section, I aim to discuss various factors that often present obstacles to patients to continue their treatment. Many of these factors are interdependent, so presenting them independently is not straightforward. I have tried to present them under separate headings but indicated some of the links that occur.

3.4.1 DOT: a tool to ensure treatment completion

As I have already described in chapter 2, DOT (Directly Observed Treatment) is one of the five elements of DOTS. The aims of DOT are twofold: to ensure patients continue TB treatment and thus ensure treatment completion (WHO, 2003b); and to ensure patients do not take rifampicin intermittently, to prevent development of rifampicin-resistant TB (Enarson *et al.*, 2000). DOT is a mandatory component of

DOTS. WHO reports that more than 30 million patients with TB have been treated using the DOTS strategy, resulting in cure rates of more than 80% and default rates of less than 10%. Many experts believe that WHO's focus on DOT has improved overall treatment TB completion rates (Frieden and Sbarbaro, 2007). However, the value of DOT itself in achieving high treatment success has been the subject of much debate (Volmink and Garner, 1997, 2003 and 2007; Walley *et al.*, 2001; Pope and Chaisson, 2003; Zwarenstein *et al.*, 1998; Newell *et al.*, 2006).

Although one of the aim of DOT is to enhance treatment completion, in many settings DOT is not feasible to implement especially in areas with poor access to health services (Newell *et al.*, 2006). DOT requires a daily visit to a DOTS centre or treatment supervisor. In many settings, TB patients have declared that six months of DOT is unfeasibly long, negatively affecting their ability to care for their children, interfering with their full-time work or study schedules, and making it difficult to provide an income for their families (Gupta *et al.* 2004; Dick *et al.* 1996); and some patients inferred supervised treatment to mean that the health system did not trust them (Hurtig *et al.* 1999). High transportation costs, conflicts between work and DOT, long waiting times at DOT centres, fear of being seen as a TB patient when visiting the DOT centre daily, and inconvenient opening hours of DOT clinics were some of the problems identified that patients face while continuing treatment under DOT (Johansson *et al.*, 1996; Khan *et al.*, 2000 and 2005; Sanou *et al.*, 2004; Joseph *et al.*, 2004; Coleman *et al.*, 1998). All these factors grossly compromised patients' ability to continue treatment with DOT (Singh *et al.*, 2002; Greene, 2004). Considering the constraints on TB patients caused by DOT, it can be said that DOT as projected and implemented by national TB programmes can have a negative impact on treatment completion, and could also reduce treatment-seeking practices thus impinging on case finding as well as treatment completion (Newell *et al.*, 2006).

Although other elements of DOTS seem to be uncontentious, the debate on DOT continues. In a Cochrane review, Volmink and Garner (2007) concluded that 'directly observing people taking their TB drugs did not improve the cure rate as compared with people without monitoring of treatment'. The authors mentioned further that DOT is expensive to implement and there is no good reason to advocate its routine use in programmes. This review provided clear evidence that there is no benefit in using DOT to achieve high cure or treatment success rates in TB programmes. The study reviewed the results of randomised controlled trials conducted in low, middle and high-income countries, and proposed self-administered treatment and treatment

observation by a family member as acceptable alternatives. Questions were also raised about the resource implications to health systems of running DOT, especially in developing countries (Volmink, 1997; Volmink and Garner, 2007). Moreover, the debate is increasing as the problem of non-completion of treatment and development of multi drug resistance becomes more apparent even though patients are treated using DOT within the DOTS strategy (Sumatajo, 1993; Van-Si, 1992).

However, Farmer and Sbarbaro (2007) have challenged the validity of these assertions saying that none of the trials reviewed by the Cochrane authors have effectively implemented the direct observation component and have not analysed the post-treatment relapse rates in trial areas. In their opinion, the absence of this latter information makes it dangerous to conclude that DOT is useless. They also mentioned that use of family members as DOT provider is only a 'feel-good' idea, as they believe rigorous monitoring of treatment will not take place, and information provided by family supervisors to the health system may be questionable. However, they also acknowledged that family members can potentially be effective treatment supervisors in certain circumstances. They also stated that there are challenges in implementing DOT, to ensure convenience and respectful interaction with patients is maximised. In conclusion, they reemphasized that the only way to achieve high cure rates on a programme basis is through DOT given by a person accountable to the health system and accessible to the patient (Farmer and Sbarbaro, 2007).

Many of these concerns about DOT emerged along with wider implementation of the DOTS strategy. In fact, the debate stimulated the development of DOTS into the broader Stop TB strategy (see chapter 2). Two other important documents were also simultaneously released in 2006: the *Patients' Charter for TB Care*, and the *International Standards for TB Care*. The new Stop TB strategy has tried to address some of the concerns raised about DOT under the heading of 'Standardized treatment, with supervision and patient support' in its 24 page strategy document. The new phrase introduced in the strategy document is 'supervision and patient support'. It demonstrates that the strategy considers patients' needs and their right to treatment and cure provided in a conducive environment. The document does not make clear what is meant by supervision and patient support and there is no guidance on how it could be implemented, and is thus rather incomplete from a programme implementation perspective. I was in Nepal when it was launched, and perhaps Nepal is one of the first few countries that adopted the strategy shortly after its launch. I was at the launch where the NTP made much of the new strategy. In my discussion with policy makers

on that day I found that they were not clear how 'supervision and patient support' was going to be delivered, and concerned that it would require additional resources to implement, while the programme was only just managing to run the routine DOTS programme with the resources available.

The most controversial element of DOTS, DOT, remains unchanged in the new strategy. However, the wording gives more flexibility than the original DOTS strategy. The strategy (WHO 2006x) reads 'supervised treatment, which may have to include direct observation of therapy (DOT)' [my emphasis]. When referring to treatment providers, the strategy states '... supervision must be carried out in a context-specific and patient-sensitive manner, and is meant to ensure adherence on the part both of providers (in giving proper care and support) and of patients (in taking regular treatment). Depending on the local conditions, supervision may be undertaken at a health facility, in the workplace, in the community or at home. It should be provided by a treatment partner or treatment supporter who is acceptable to the patient and is trained and supervised by health services' [again, the emphasis is mine]. The words underlined show flexibility in DOT for the programme: however, words may mean little or nothing for patients if programmes continue to insist on DOT as before. This confusion suggests a need for NTPs to design programme-based operational research in order to tailor supervision and patient support in their programme.

In summary, DOT has not served the aim of facilitating TB patients towards completing full treatment course. There are several contradictions around the effectiveness of DOT as it has been projected and implemented in TB control. It may or may not have been beneficial in controlling TB, but credible evidence to demonstrate the claim is missing. DOT needs to be tailored to context: a blanket approach is not appropriate. The modality of DOT needs to be sufficiently patient-friendly to ensure patients can identify their treatment supervisors; the health system should facilitate the process. However, explicit understanding on the qualitative impact of DOT in TB treatment is lacking, and this limits designing so-called 'supervision and patient support' mechanisms in TB control.

3.4.2 Socio-cultural factors

TB is not only a biomedical disease, but also a social disease, because it affects not only the person with disease but also the entire family; it affects not only the physical status of a person with disease but also their social wellbeing as it erodes social support networks and relationships; treatment of TB requires not only biomedical interventions but also support from family members and the community; and TB is prevalent in overcrowded areas and thrives in communities with low social status (Macq *et al.*, 2005; Needham, *et al.*, 2004; Long *et al.*, 2001; Hudelson, 1999; Farmer, 1999).

Socio-cultural environment, norms and practices have substantial influence on health outcomes in general, not only shaping the nature of illness but also playing critical roles in care-seeking behaviour and thus treatment completion. This is particularly true for TB, since the disease and the suffering it creates not only relates to patients, but because society carries entrenched misconceptions about its causes, communicable nature, and treatment practices, and treatment is therefore greatly influenced by socio-cultural beliefs and practices (Meulemans *et al.*, 2002). Researchers have cited the need for TB programmes and health service providers to have greater understanding of these aspects, particularly those that influence treatment completion (Johansson *et al.*, 2000; Khan *et al.*, 2000; Long *et al.*, 2001 and 2002; Meulemans *et al.*, 2002). Farmer *et al.* (1991) and Sagbakken (2003) concur, adding that structural social problems may be the most important contributors to poor TB treatment completion. Gaining wider understanding of patients' social and cultural environments is important for TB control programmes as it often influences TB treatment and completion (Grange & Festenstein, 1993, Ogden *et al.*, 1999; Sumartojo, 1993). Similarly, social scientists and anthropologists have long argued that TB control will not succeed in the absence of sufficient attention to fundamental aspects of socio-cultural dimensions (Farmer, 1997; Harper 2005; Ogden, 1999; Weise, 1974). Evidence suggests that it is vital for TB control programmes, whether in developed or developing countries, to enhance ways of understanding the socio-cultural aspects of TB that contribute to poor completion of TB treatment, and that these will be different between and within countries because of varying social groups and social settings. The current lack of focus on social indices in the management of TB treatment makes TB control programmes less effective than they could and should be (Ogden *et al.*, 1999).

There is a strong association between social support others provided to TB patients by family and others, and their successful completion of TB treatment (Barnhoorn and Aadriaanse, 1992). TB patients who receive positive encouragement from their family and friends are more likely to successfully complete their treatment. This finding is supported by other studies which add that patients who receive more social help are also less likely to be stigmatized (Khan *et al.*, 2000; Meulemans *et al.*, 2002). TB morbidity and mortality rates are also related to people's social status. Improved social status contributes to lower TB transmission and greater support to TB patients towards successful treatment completion, as was observed in developed countries during the 1950s; and at one time some TB control experts envisaged that TB would soon be eliminated (Farmer, 1997). However, due to increasing HIV infection and emergence of drug resistant TB, along with an insufficient focus on the socio-cultural dimensions of TB, the dream of making TB a disease of the past has not come true and the world continues to struggle to control it (Shah *et al.*, 2007). However, it cannot be denied that improved communities' social status helps combat TB.

The problem of TB appears to be greater in urban areas, where the social composition is diverse with multi-cultural, multi-ethnic groups, and complex community settings. Also rapid urbanization with increasing migration, homelessness, urban slums and unemployment in urban areas make TB control efforts more fragile, as these factors have considerable impacts on the spread of TB disease, its service provision and completion of its treatment. In addition, the diverse socio-cultural profile of health service providers and TB patients in urban areas has been an important factor influencing interactions and relationships between providers and patients thus affecting treatment outcomes. However, inadequate understanding of the ways urban complexity and socio-cultural structures impact on TB control programmes limits effective ways of overcoming these barriers.

In Nepal, the persistent legacy of interconnected caste, ethnic and gender-based exclusion, a complex social hierarchy and socio-cultural diversity continues to influence health, with low service utilization and poor outcomes among socially excluded groups (NDHS, 2006; MoHP 2010). For further details see chapter two, section 2.7.1. In the recent past there has been massive cultural transformation in Nepal along with rapid urbanization, migration from rural to urban areas (both within Nepal and internationally), and creation of new settlements with blends of various socio-cultural groups. This will continue to pose problems in provision of health services including for TB, especially in urban areas. TB has been a taboo and

traditional home remedies and care-seeking from traditional healers have been common practices rooted in cultural beliefs. The association of TB with various socio-cultural beliefs such as TB being a consequence of past wrong doing, association of TB with low caste, and TB being linked with impurity, dirt and bad habits like drinking and smoking, have implications for the delivery of TB services; and being required to visit a TB centre for daily treatment makes TB services more difficult to access (Harper, 2005). However, we have limited knowledge on how and why social and cultural concepts help or hinder TB services, preventing the development of effective ways of addressing negative impacts of socio-cultural beliefs and practices (NTP 2007). In the absence of such knowledge, improvements in TB control through ensuring successful treatment completion will be difficult, especially in complex urban contexts.

It has been widely recognised that socio-cultural barriers present threats to successful TB treatment completion, and thus accomplishment of TB control goals will not be feasible if the socio-cultural phenomena of TB disease are kept in isolation from the programme. Until now, attribution of the impacts of socio-cultural factors on TB treatment completion has been measured in quantitative terms, thus limiting wider understanding of how and why socio-cultural beliefs and practices help or hinder treatment behaviour of TB patients. This suggests the need for an explicit investigation rather than just reiterating issues which have already been identified. Sumartojo (1993) supports the need for further research, saying ‘social and behavioural research is particularly important at this time because of changes in the epidemiology of the disease TB’.

3.4.3 Stigma and discrimination

Although stigma can be classified as a socio-cultural issue, I discuss it separately because of its impact on successful TB treatment completion. The two words *stigma* and *discrimination* are often used interchangeably, which can lead to confusion about cause and effect. Defining stigma is not simple because explanations and concepts vary and it is difficult to establish cut-off points between what is stigma and what is not (Maco and Martinez, 2006). Goffman (1963) defines stigma as an 'attribute that is deeply discrediting' and that reduces the bearer from 'a whole and usual person to a tainted, discounted one'. Goffman classified stigma into three different types: ‘abominations of the body’ (the various physical deformities); ‘blemishes of individual character’ perceived as weakness, domination, and rigid beliefs and

dishonesty; and 'tribal stigma of race, nation, religion and castes'. In simple term stigma is a negative attitude whereas discrimination is negative behaviour resulting from stigma. Stigma is therefore important because of the way it causes discrimination (Baral *et al.*, 2007).

Fear of stigma and discrimination is a major reason why people with TB delay seeking proper care and fail to complete treatment (Meulemans *et al.*, 2002; Khan *et al.*, 2000; Kelly 1999; Nair *et al.*, 1997; Liefoghe *et al.*, 1995; Liefoghe *et al.*, 1999; Auer, 2003; Kelly, 1999; Jaramillo, 1998; Johansson, 2000). The association of TB with poverty, itself stigmatized, further increases TB stigma and makes TB control even more complicated (Johansson *et al.*, 1997; Meulemans *et al.*, 2002). The consequences of TB stigma are social isolation, rejection, shame, blame, and self-isolation, all of which can lead to severe stress, loneliness and hopelessness, which have direct implications for treatment. As a result of social stigma, discrimination against people with TB occurs in workplaces, healthcare facilities, communities and families. The consequences of such discriminatory behaviours on TB patients can be devastating as they cause feelings of isolation, disgrace and shame (Mason *et al.*, 2001; Johnson, 1995) and can eventually lead to non-completion of treatment. However, stigma attached with TB varies from country to country and therefore addressing TB stigma and discrimination requires a comprehensive understanding tailored to local contexts (Baral *et al.*, 2007).

The effects of stigma are clearly seen in the community. Women seem to be more vulnerable. Married women may be divorced by their husband and unmarried women's marriage prospects may be jeopardized because of TB (Long *et al.*, 2001; Khan *et al.*, 2000). Moreover, women TB patients' loss of physical strength, inability to perform household jobs, and financial loss are important contributors to stigmatization in the community (Meulemans *et al.*, 2002). Similar results have found in Vietnam, Pakistan and India where women TB patients are more worried about the social consequences of the disease than men, as women with TB fear they could be isolated or expelled from home (Long *et al.*, 2001; Khan *et al.*, 2000; Nair *et al.*, 1997). In India, mothers have been observed attending clinics claiming to be suffering from TB, although in reality it was their daughters that had the disease: the mothers were protecting their unmarried daughters (Nair *et al.*, 1997). This further highlights how TB stigma and discrimination can make women's lives extremely difficult.

In Nepal, issues related to stigma and discrimination provide substantial barriers to care-seeking and treatment completion. TB patients generally isolate themselves from community, friends and family for fear of transmitting TB to others (Baral *et al.*, 2007). One study suggests that because of TB stigma, a higher proportion of women than men that remain undiagnosed in the community (Connolly and Nunn, 1996). Anecdotal evidences from the field suggest that there are still many people who hide their disease due to fear of stigma, taking treatment in the private sector to avoid being seen in the DOTS programme.

In summary, TB is stigmatised for both men and women, though to different degrees, causing discrimination in the community. Such discriminatory behaviour influences TB care-seeking and treatment, leading to poor treatment completion and disrupting TB patients' positions within their societies. It is therefore vital to gain wider understanding of how stigma causes discrimination and affects TB patients at various stages of their treatment and identify ways TB control programmes can effectively address these issues.

3.4.4 Gender and TB

The term *sex* is used to distinguish men and women based on their biological characteristics whereas *gender* is used to distinguish men and women based on features that are socially constructed. Gender influences the control men and women have over the determinants of their health, for example their economic position and social status, and their access to resources (WHO, 2005c). In this section, I consider knowledge on TB and its treatment from a gender perspective.

TB researchers have looked at gender differences in infection and disease progression, health-seeking behaviour, treatment completion and many other social aspects. Interactions between society, culture and TB control raise important questions about the role of gender and discrimination in all aspects of the disease, from case finding to diagnosis, treatment and eventual outcome. In most countries, men carry more of the TB burden as the estimated male to female ratio of TB cases reported worldwide is two to one (Borgdorff *et al.*, 2000). A similar scenario is seen in Nepal. However, TB poses a major threat to women's health security: in 2008, 3.6 million women had TB and 700,000 women died from TB, making TB the third leading cause of death worldwide among women aged 15-44 years (WHO 2009). TB makes women more vulnerable than men because of their low status in society and because of relatively high stigma and discrimination by families and communities (Johansson *et al.*, 2000).

In Bangladesh, women have poorer access to public out-patient clinics and are less likely to undergo sputum examination than men (Begum *et al.*, 1994). Moreover, women see themselves and are seen by others to be more sensitive to poor service conditions (Johansson *et al.*, 2000).

Health care providers often treat women as being inferior and therefore women are hesitant to seek treatment and interact with health care providers (Vlassoff, 1994), particularly when the health workers are male. In Mumbai, India, women's household responsibilities made it impossible for them to continue TB treatment, and women kept their disease undisclosed for fear of rejection (Nair *et al.*, 1997). Men with TB seemed more worried about financial implications of TB disease, and thus paid less attention to completing their treatment (Johansson *et al.*, 1999) whereas women were more worried about social implications of TB such as rejection by their husband and in-laws and reduced chances of marriage (Nair *et al.*, 1997). Studies from other developing countries by Long *et al.* (2001) and Khan *et al.* (2000) support these findings. Most women who defaulted from treatment said concerns about interactions with health-care providers and social stigma were the main reasons for their default. Weiss (2003) reported that for 70% of women in Maharashtra, India, consuming medicines in the presence of a health-care practitioner was unacceptable. If they were forced to take their medicines under direct observation, these women preferred to do so under the supervision of a female nurse. These findings support those of an earlier study by Balasubramanian *et al.* (2000), which also indicate that women are less likely to accept DOT than men because of concerns about social stigma. These findings clearly suggest that the imposition of DOT forces people towards non-completion or prevents people from starting treatment in the programme. Getahun and Aragaw (2001) identified clinical improvement during treatment as the most common reason for treatment discontinuation, followed by long distance to the treatment facility. Support from family and community was found to be a critical element in promoting treatment adherence. It is therefore suggested that if TB programmes wish to achieve high treatment completion, the TB treatment delivery modality needs to be developed and implemented within a wider understanding of patients' needs and tailored to local context (Newell *et al.*, 2006).

In Nepal, the male: female TB case detection ratio is 2:1. More women complete TB treatment than men (NTP 2008/09). As in other countries, there are significant gender differences among TB patients, including in treatment seeking behaviour, overall knowledge on general aspects of TB, social problems faced by patients, and treatment

completion (NTP, 2008/09; NTP, 2007; Asbroek *et al.*, 2008; Yamasaki *et al.*, 2001; Baral *et al.*, 2007). Women have lower access than men to health services in both rural and urban areas. Women have been historically deprived in Nepali society, adding further complications, since women have little or no control over household resources. Women have very few decision-making roles in the family. Such unequal division of roles and responsibilities makes it more difficult for women than for men to seek proper health care. Thus, gender roles not only affect illness reporting but also decisions to choose a health care provider and how much to spend on the sick woman or man: gender affects all steps of health-care seeking behaviour (Pokhrel, 2005; Smith, 1994). A TB case-finding survey showed that health facilities were less utilized by women than men, as women continue to hide their illness until it severely affects their routine life, and mobile clinics were particularly attractive to women in rural areas (Harper *et al.*, 1993).

In summary, gender inequality is an issue in TB control influencing TB treatment completion, with women tending to have worse access to TB services than men. Women seem to be more receptive to TB treatment, but the sufferings women face due to TB is enormous. There is a need for further in-depth investigations into the impact of gender differences on TB control.

3.4.5 Economic factors

The poor are at high risk of developing TB as poverty makes people more vulnerable to ill health, and reduces their capability to cope when these illness occur. The association between TB and poverty has been discussed in chapter one. This section mainly focuses on the economic consequences of TB disease on TB patients and their households at various stages of the care-seeking process; and patients' financial ability to continue TB treatment in the context of developing countries and specifically Nepal.

TB is more common among the poor and disadvantaged, and low economic status is an important predictor of non-completion of TB treatment (Meulemans *et al.*, 2002; Barnhoorn & Adriaanse, 1992). This presents a major challenge to TB control as the disease is most prevalent among the poor. The situation is complex as TB severely affects the financial status of patients and their families because many TB patients lose their routine income, and are forced into poverty from which there is no escape (Khan *et al.*, 2000; Liefoghe *et al.*, 1999; Barnhoorn & Adriaanse, 1992; Comolet *et al.*, 1998; Khan *et al.*, 2005; Jaiswal *et al.*, 2003; Johansson *et al.*, 1999; Johansson *et al.*,

1996; Johansson and Winkvist, 2002; Liefoghe *et al.*, 1995). Although anti-TB drugs are provided free in the public sector, other direct and indirect costs born by TB patients (such as transportation for multiple clinic visits, loss of wages and opportunity costs of time spent) put these so called free services beyond the reach of many poor people (Kemp *et al.*, 2007; Johansson *et al.*, 2000; Barnhoorn & Adriaanse, 1992; Rubel & Garro, 1992; Comolet *et al.*, 1998). Nair *et al.* (1997) found that TB caused on average a loss of 60% of monthly income among wage-earning respondents in India. Similarly, Kemp *et al.* (2007) found that in Malawi the cost of TB diagnosis (direct and indirect) for poor could be as high as 574% of their total monthly income. They highlighted that the poor and women pay more for TB diagnosis. It is clear that poor people need to divert scarce resources to seek the TB care that is claimed to be free of charge for all.

For many TB patients there is a conflict: should they choose to support themselves and their family and die with disease; or attend the clinic for treatment and die of hunger? Men, as head of households and often the sole wage earner, tend to raise this dilemma more frequently than women (Liefoghe *et al.*, 1995; Greene, 2004; Khan *et al.*, 2005; Johansson *et al.*, 1999; Coleman *et al.*, 1998; Demissie *et al.*, 2003): it is a difficult choice, as many patients are not able to afford to both feed the family and attend the TB clinic (Khan *et al.*, 2000; Jaiswal *et al.*, 2003; Johansson *et al.*, 1996; Nair *et al.*, 1997). This situation forces many TB patients to abandon treatment. Many TB patients interrupt TB treatment citing an inability to afford the cost of care (Watkins and Plant, 2004; Greene, 2004; Johansson *et al.*, 1996) and express guilt that they are unable to stop TB forcing their entire family into difficulties (Sanou *et al.*, 2004; Johansson and Winkvist, 2002; Demissie *et al.*, 2003). Despite evidence of enormous financial consequences to TB patients and their families due to TB, health care providers in some settings do not acknowledge the fact, merely stating that TB treatment is provided at no cost (Greene, 2004). This shows a lack of health care providers' understanding of patients' suffering due to TB, which may contribute to poor TB treatment completion rates. However, in some cases providers did acknowledge patients' financial constraints (Sanou *et al.*, 2004).

In Pakistan, almost 32% of patients did not complete treatment due to lack of financial support during their treatment (Liefoghe, 1997). This finding is supported by a literature review of TB in India performed by Ogden *et al.*, (1999). Mull *et al.*, (1989) pointed out in their study on Pakistani leprosy patients that economic and social support appears to be a valuable tool in reducing the number of treatment defaulters.

In summary, TB pushes the poor deep into poverty and places a massive financial burden on TB patients and their families, severely damaging their likelihood of completing TB treatment. Although TB patients receive free treatment from national programmes, other costs (e.g. opportunity costs, income loss, and costs of care, transportation and additional food) give a high financial burden to patients, creating problems of TB treatment continuation. Although TB patients who successfully complete treatment may have gone through the same difficulties but overcome financial problems by applying coping strategies, there is little or no mention of this issue in the literature. The conclusion must be that national TB programmes have not paid sufficient attention to reducing financial barriers among TB patients and TB control strategies are not addressing the needs of the poor. There is a clear need for further research to better understand how to establish ways of addressing financial problems patients face.

3.4.6 Physical access to treatment

Access to health care may be examined from three major perspectives: availability (physical access); acceptability (social access) and affordability (economic access). Social and economic factors have already been discussed above (see sections 0 and 3.4.5): this section focuses on physical access to TB treatment.

Availability of TB services is generally measured using the distance from the patient's home to the TB diagnosis and treatment centre (the DOTS centre). It is an important factor that may lead to poor utilization of TB services. Studies in Pakistan, India, and many other parts of the world have reported that patients who live close to DOTS centres are more likely to complete their treatment than those who live a long distance away from the DOTS centre (Khan *et al.*, 2000; Liefoghe *et al.*, 1999; Al-Hajjaj & Al-Khatim, 2000). Comolet *et al.* (1998) found that patients who live more than half an hour away from the treatment centre interrupted TB treatment and then defaulted from treatment more often than those who live closer. A similar situation can be noted in Nepal, especially in rural areas where DOTS centres are far from patients' homes. In many settings, DOTS clinic opening times are not convenient for many patients, causing patients major problems in receiving daily DOT from DOTS centres. In Nepal this issue is mainly raised by daily wagers in urban areas who often work long hours, leaving their rented room early in the morning and not returning until late. The problem also occurs for people who have positions such as office bearers and students. However, good physical availability of TB services under DOTS does not mean that a

DOTS programme will be accessed by many patients. There may be other reasons for the low use of DOTS programmes like socio-cultural constraints, economic constraints, inappropriate behaviour of health workers, and quality of services, as discussed earlier. Studies have also pointed out that private practitioners are popular not only because of the respect shown to patients by private doctors but also the convenience of their location and opening hours (Uplekar *et al.*, 1998; WHO, 2001; Newell, 2002).

In summary, access to health facilities is an important area which determines treatment completion. Patients with easy access are more likely to take treatment regularly. However, there is limited understanding in the context of urban areas how factors such as distance, clinic opening hours, and the presence of other services in the public and private sectors contribute to non-completion, and further studies are needed that look explicitly at links between access to TB services and treatment completion.

3.4.7 Knowledge and attitudes to disease and treatment among TB patients

Knowledge of disease and treatment plays an important role in completion of treatment. Treatment interruption has repeatedly been related to perceptions about TB as a disease; some patients did not believe that they had TB, only wanting a cure for their symptoms and stopping treatment once they lessened. TB patients with poor knowledge of their disease and treatment are less likely to complete their treatment. Barnhoorn & Adriaanse (1992) found that TB patients who had an active orientation and adequate knowledge of TB and its treatment were more likely to complete treatment than patients who had less understanding about the disease and treatment approach. In contrast, Liefoghe and Muynck (2001) found knowledge of TB itself did not have a clear impact on defaulting but attitude towards treatment did. Many studies have found that after some months of TB treatment, many patients feel better or cured and discontinue their treatment due to lack of clear knowledge about their disease and treatment (Tekly, 1984; Barnhoorn & Adriaanse, 1992; Liefoghe *et al.*, 1997). In TB control, 'on and off treatment' is well known; but there is a tendency to blame patients where in reality they are unable to continue treatment due to factors outside their control.

Positive and negative beliefs of patients' regarding disease and efficacy of treatment may affect treatment continuation, as noted by Munro *et al.* (2007) in their review. The efficacy of drugs, especially pills, is normally a concern to many TB patients:

some think that injectables may do better than oral drugs. Belief in treatment efficacy appears to be related to patient confidence in the medical system (Singh *et al.*, 2002; Johansson and Winkvist, 2002). Patients ask for medicine if they feel unwell and drop out of treatment when they feel better (Barnhoorn & Adriaanse, 1992). Liefoghe (2000) observed in Pakistan that many patients want to have quick relief once they start taking drugs: if there is no significant improvement at the initial stage this may lead to dissatisfaction with treatment and medical shopping, a trend seen in most developing countries. This finding was confirmed in a second study, which found that non-satisfaction with treatment was the main reason for defaulting (Dataline Service, 1998). A similar situation exists in Nepal (author's personal experience). It has been found that many TB patients fear and deny a diagnosis of TB, and some patients do not accept their diagnosis: such feelings and behaviour could lead to non-completion. Conversely, though, some studies noted that patients' desires to be cured acted as a motivator for completing treatment (Watkins *et al.*, 2004; Marra *et al.*, 2004; Wares *et al.*, 2003).

In many developing countries TB is still perceived as an incurable disease (Liefoghe *et al.*, 1997; Khan *et al.*, 2000), and my experience from Nepal shows that patients who have little information about TB and its treatment are more likely to stop their treatment (informal consultation with TB patients and care providers in DOTS centres) and feel more stigmatized (Baral *et al.*, 2007). A study in a teaching hospital in Malaysia found that improved knowledge of TB by TB patients and families helps to improve treatment completion (Liam *et al.*, 1999). Similarly Meulemans *et al.* (2002) found in Pakistan that patients with higher professional rank and with reasonable knowledge about TB and its treatment had more belief in the curability of disease and were more likely to be compliant compared with unemployed and illiterate patients.

Completion of treatment requires the active participation of the patient. Patients' treatment literacy, and knowledge of TB disease and its treatment, therefore plays an important role. A study in the Wardha district of India found that for TB treatment to be successful, patients must see themselves as vulnerable to the illness, believe that it is of a serious nature, be convinced that treatment will be efficacious and experience external or internal motivation to complete the prescribed course of treatment (Barnhoorn & Adriaanse, 1992). For their motivation, knowledge about disease and treatment is vital. Other authors recommend further research to help understand this issue. Other factors contributing to non-adherence include language barriers and lack

of awareness about the existence of TB treatment programmes. This is especially true among migrants who have arrived in cities (Daniela *et al.*, 2009). A study conducted in New York City on Chinese immigrants enrolled in TB DOT programmes (Ho 2004) revealed that new immigrants are unaware of TB treatment programmes and consequently waste a significant amount of time and money seeking treatment from multiple providers (e.g., hospitals, general practitioners and traditional Chinese practitioners). Lack of on-going patient-provider communication, inadequate treatment supervision/support from health care workers and the perception that treatment facilities are unwelcoming are also potential barriers to treatment completion especially in urban areas where there are multiple providers and multiple users.

In summary, patients' knowledge and attitude influence treatment behaviour thus it is imperative that health care providers working in TB programmes give patients adequate information. Approaches to providing the right information at the right time within the treatment process with an appropriate approach to treatment literacy need to be well embedded in routine programme activities: health care providers need to be sufficiently equipped with relevant education materials to help communicate information to patients and address any negative attitudes to TB treatment.

3.4.8 Health care provider and patient relationships

Successful treatment requires an understanding between patients and providers in order to develop their treatment plan and mutually execute the plan. The role of health care providers is crucial from the beginning to the end of treatment: health workers who are well informed about patients' needs will help patients to implement their treatment plan to cure their TB. In this regard, health workers' behaviour and relationships with TB patients and their family members cannot be overlooked: they can contribute to non-completion of treatment by their behaviour (Grange & Festenstein, 1993). When TB patients have good knowledge of the nature of the disease, treatment requirements and effects of drugs, they are more likely to follow the treatment required to achieve cure. Success of TB treatment is related not only to biomedical factors: there is a web of social, psychological and behavioural factors which influence patients' and providers' relationships and overall treatment. The relationship developed between the patient and the provider is key to achieving success in treatment, and requires investment of time and energy from both sides (Enarson *et al.*, 2000; Liefoghe *et al.*, 1999). Studies in this area have not assessed in

depth how health care providers' behaviour and relationships influence TB treatment completion. However, some studies have found that the relationship between providers and patients performs a key role in treatment completion. The Centres for Disease Control (CDC) also echo the above statement. Furthermore, the CDC identifies other key factors that sway relationships and have direct or indirect influence on treatment outcomes: personal and social characteristics of patients and providers; culture, knowledge and beliefs of patients and providers; health care infrastructure; and quantity and quality of information available to patients (CDC, 1994). However, limited research in this area inhibits understanding of how good relationships can be developed by addressing issues related to both patients and providers.

Several studies have noted that a substantial number of TB patients seek care from private practitioners, one reason being that they have gained popularity among TB patients and their families. Most authors agree that poor relationships between patients and government sector providers is a factor in increased use of private practitioners (Uplekar *et al.*, 1998; WHO, 2001; Newell, 2002).

If patients trust health care providers, they are more likely to visit the health facility regularly and discuss their problems (Barnhoorn and Adriaanse, 1992). Trust cannot be established unless there are good relations and sharing of treatment decisions by patients and their families. Thus the problem of treatment non-completion could be reduced by improving relationships between providers and patients (Nuwaha, 1999; Meulemans *et al.*, 2002). Furthermore several authors (Khan *et al.*, 2000; Liefoghe *et al.*, 1999; Nuwaha, 1999; Meulemans *et al.*, 2002; Barnhoorn and Adriaanse, 1992) state that effective health care delivery is possible if the health care provider does not provide support, love and respect and is just concerned with providing drugs without showing any feelings or providing adequate information.

In summary, inadequate or poorly established relationships between patients and providers deters continuation of TB treatment, which is not good neither for patients nor for the health system; thus good relationships and trust are vital from both sides. Several studies have identified that mutual confidence between service providers and patients has to be established, tailored to each patient. Fears and misunderstandings differ from patient to patient, and should be considered for each individual – an issue which is not properly addressed in TB control (Nuwaha, 1999; Meulemans *et al.*, 2002).

3.4.9 Therapy related factors

The TB treatment regime is complex, including several drugs, some of which can have substantial side effects. This complexity, real, anticipated, or culturally interpreted, has often been mentioned as a common cause of treatment interruption (Liam *et al.*, 1999; Jaiswal *et al.*, 2003; Greene, 2004). The number of medications prescribed, the difficulty associated with swallowing the medication, the frequency of dosing and the occurrence of side effects (e.g., skin rash, hepatitis, stomach upset) can all contribute to higher non-completion rates. Chaulk *et al.* (1998) noted that the higher the levels of these factors, the lower the adherence to treatment.

Poor management of drug side effects can result in patients stopping taking drugs. In national TB programmes, health workers receive training on identification and management of drug side effects. However, health workers' and patients' interpretations of side effects and their severity can vary. This often results in poor management of issues reported by patients, and in many instances, patients are badly informed about side effects and their potential impacts on their illness. Patients say that health workers pay little heed when they report drug side effects: in some cases they have responded with derision (Nair *et al.*, 1997; Greene, 2004; Jaiswal *et al.*, 2003; Singh *et al.*, 2002; San & Bothamley, 2000). When side effects occur, continuing treatment can sometimes be fatal. Poor management and inappropriate responses to reports of side effects also shows a lack of responsiveness by health workers and can deter treatment continuation.

In summary, side effects during TB treatment are caused neither by patients nor health workers, but if not promptly managed can deter treatment continuation. It is important that health workers are sufficiently skilled and responsive to issues reported by patients, and provide information on potential drug side effects in advance. Cultural perceptions of TB drug effects need to be explored properly.

3.4.10 Other factors affecting TB treatment completion

Other factors also influence TB treatment completion. These include migration; patients' satisfaction with treatment; quality of service and delivery of care; ethnic differences; occupation; age differences; and floating populations. Limited information based on good research is available on these factors. Patients who are migrants have poor access to treatment. Most are not aware of the availability of treatment services (Kirwan *et al.*, 2009). Patients from low castes may have

difficulties continuing TB treatment. Some occupations may interfere with patients continuing TB treatment: such occupations include drivers, trekkers, contracted labourers, the police and the army, who often move from one place to another during their work. However, issues related to these groups have not been investigated in depth. It is difficult to predict who is going to complete treatment and who is not, based on the characteristics of the patient. However, some groups have been identified as high risk of non-completion: these include substance abusers (drug users, alcoholics), homeless people, migrants, people with mental illness, and residentially mobile people (Coleman *et al.*, 1998; Nair *et al.*, 1998; Jaiswal *et al.*, 2003).

3.5 Responses to lateness or non-completion in TB treatment

This section presents various responses put in place to enhance TB treatment completion in different settings. Experts have noted that even with accessible and appropriate health care, some patients still face various obstacles and do not always complete treatment (Volmink, Garner, 1997). It is well documented that establishing effective TB control is an enormous task for health systems, especially in developing countries.

3.5.1 DOT to improve TB treatment completion

DOT is seen by many as a good method of ensuring that patients continue treatment, but continues to be contentious. The Stop TB strategy emphasizes patient-centred ‘supervision and patient support’ which may include DOT but tailored to the local context. However, the strategy lacks detail on approaches to supervision and patient support, and what is meant by patient-centred. As a result, many countries have not yet come with well-designed mechanisms to translate the strategy into practice. More detail is given in section 0.

3.5.2 Support from family and community

Several studies have found that family support greatly improved treatment completion, yet in general NTPs do not appear to try to mobilise families. Instead, many programmes include various forms of community support, but the effects of this support within the social context have not been properly evaluated. Many national programmes (including Nepal) have a DOTS committee in most DOTS centres, the role of which is to address public awareness, community advocacy and education, provide treatment observers and patient tracers, identify local solutions and encourage cooperation (Macq *et al.*, 2003). These committees (where active) have helped TB

patients and their families by encouraging them and facilitating a local social environment for TB treatment. The provision of identified late patient tracer volunteers, especially in urban areas, has contributed significantly in raising awareness and helping TB patients when they are late in TB treatment (Thomas *et al.*, 2007; Newell *et al.*, 2004; Baral *et al.*, 2009; Harper, 2006). Nepal has an extensive network of female community health volunteers who provide help to TB patients by acting as their treatment observer (Newell *et al.*, 2006), removing the need for patients living in remote areas to travel long distances to get TB drugs. Munro *et al.* (2007) noted that positive community and family attitudes helped TB patients to overcome TB-related stigma and discrimination and also offered support in maintaining treatment taking. On the contrary, negative community and family attitudes can act as strong barriers to taking TB treatment. In such circumstances, community-based TB treatment programmes and stronger involvement of local social networks to support TB patients are well justified (Newell *et al.*, 2006).

3.5.3 Financial incentives

TB patients' poor financial situations and additional financial stress due to TB are two of the major barriers to completing TB treatment. In the light of this issue, financial incentives, either in cash or as vouchers, have been used to help TB patients continue their treatment. Several authors have commented on the effectiveness of financial incentives and the sustainability of these measures in different settings. A review performed by Volmink and Garner (2000) found that some forms of incentives like free food and clothes were effective. Many interventions using financial incentives performed in developed countries were effective to bring continuity in TB treatment (Bock *et al.*, 2001; Davidson *et al.*, 2000). However, there are relatively few studies investigating financial interventions in developing countries, suggesting that programmes are not sufficiently established or financed to consider financial incentives to TB patients.

3.5.4 Different forms of late patient tracing mechanisms including reminders

The term 'late patient tracing' is generally defined as any action by the programme or individuals to contact patients when they are late for their treatment. What is meant by 'late' varies from two days to several weeks. Another approach is reminders, defined as any action to inform patients to take their medication at any stage of treatment.

Reminders are commonly used when patients are late to collect drugs on their due date.

Mechanisms such as telephone reminders, reminder letters and cards, and home visits by health workers or community volunteers have been used in many programmes to enhance treatment completion among TB patients. In Saudi Arabia patients who failed to collect TB drugs for two weeks were traced using home visits by social workers and a telephone call where possible, but no data is given to assess the effectiveness of this method on increasing treatment completion rates (Al-Hajjaj & Al-Khatim, 2000). A similar tracing system was applied in rural Uganda but no measure of the effectiveness of this system was given (Nuwaha, 1999). Volmink and Garner (2000) mention that tracing of late TB patients has been a major part of many programmes applied in local settings and their effectiveness vary. In Nepal, tracing using volunteers in an urban TB programme in Lalitpur gave good results (Thomas *et al.*, 2007; Newell *et al.*, 2004 and 2005). In contrast, Lonnroth *et al.* (2001) found in Vietnam that tracing of defaulters had potentially negative effects on patients' willingness to attend DOTS clinics.

In a Cochrane review, Liu *et al.* (2008) reviewed reminder and late patient tracer interventions in the diagnosis and management of TB. The authors reviewed nine trials, six of which assessed reminder systems and three the use of late patient tracers. They concluded five of the six studies assessing a reminders system showed benefits in increasing adherence in TB treatment, as did all the trials of late patient tracers. They further noted that the use of letters appeared to be effective in encouraging patients to return to treatment who were late even in those who were illiterate. However, all interventions assessing reminder systems were conducted in developed countries (USA and Spain), so may not be relevant to developing countries.

3.5.5 Health education

Continued education of TB patients is part of national TB control programmes. Effective education provision to individuals and to society appears to be a logical solution to problems of treatment completion. All the literature reviewed agrees that health education is important in TB control. However, in many countries national TB programmes seem to focus on identification of cases to the exclusion of good management of cases through an effective health education network. Several authors (Liefoghe *et al.*, 1999; Nuwaha, 1999; Meulemans *et al.*, 2002; Barnhoorn and Adriaanse, 1992) from many countries have stated the importance of health education

in reducing problems with non-completion in TB treatment, but most have not assessed its direct impact on TB treatment completion.

A randomized control trial in Pakistan found counselling in TB treatment is effective in improving adherence if it is provided one-to-one (Liefoghe *et al.*, 1999). Several studies have recommended effective health education to help to decrease social stigma and discrimination of TB, which will lead to better treatment completion (Lonnroth *et al.*, 2001; Baral *et al.*, 2009; Harper, 2006; Jaiswal *et al.*, 2003; Frieden and Sbarbaro, 2007; WHO 2009b). In Nepal, health education for TB patients at DOTS centres and other awareness programmes is part of routine national TB programme activity. However, the effectiveness of health education in increasing treatment completion has not been assessed and concerns have been raised about its effectiveness as the programme uses conventional ways of delivering education to patients and communities. A review of the NTP in 2007 also highlighted this and recommended innovative approaches to health education in the programme; however, the programme has not yet developed an effective health education and communication strategy. The NTP recently started implementing a patient-to-patient education programme, in which successfully treated TB patients provide information to new TB patients. This programme seems likely to be effective if implemented well, but its effectiveness in improving continuation of TB treatment is yet to be assessed. A similar approach to educating TB patients and families was found to be effective in Pakistan, and also increased social and family support to TB patients (Liefoghe and Muynck, 2001). Balasubramanium *et al.* (2000) also believe that use of trained community volunteers, religious leaders, NGO members, cured TB patients and shopkeepers as treatment supervisors help to ensure treatment completion. However, identifying a gap in the current health education process, Kelly (1999) urges changes in the current system of providing information to patients. She proposes alternative ways of working with patients by replacing the current one-way flow of information from health worker to patient towards a process of negotiation between provider and patient.

Previous reviews have shown that interventions directed at staff in TB clinics rather than patients were key in improving patient treatment completion. Patients with TB attending health centres with intense staff supervision were more likely to complete treatment than those attending health centres with routine staff supervision (Volmink and Garner, 2003). A subsequent review by Volmink *et al.* (2000) provided a summary of 15 programmes with intensive and personalized management interventions to motivate staff. Interventions included lectures and role playing which

provided staff with in-depth training in various areas, including communications, confidentiality, outreach techniques, and management of TB. External funding for health education was also seen as an important and necessary component of effective DOT programmes. Salihu *et al.* (2001) remind us that factors such as adequate training and commitment by care providers and those involved in TB control programmes, as well as overall administrative efficiency, are important factors that help patients to continue their treatment.

In summary, various measures have been proposed to combat the problem of non-completion. They include increased service access, mass media campaigns, decentralization and integration of the TB programme into the primary health care system, intensive supervision of clinic staff, mailed or telephone reminders of appointments and follow-up of missed appointments, giving medicines in well-organised containers and maintaining good relationships between TB patients and care providers (Meulemans *et al.*, 2000; Barnhoorn and Adriaanse, 1992).

3.6 Successful treatment completion remains an issue

Studies have found successful completion of treatment is associated with multiple factors including social, behavioural and economic factors, health systems, and structural factors such as poverty and gender. The route to successful TB treatment completion is difficult for many patients, as studies have shown that TB patients often take their TB medication under difficult circumstances and experience significant challenges, many of which are outside their direct control (Munro *et al.*, 2007). Undergoing treatment lasting a minimum of six months, and an unbearable period of DOT, in combination with many individual constraints, compel patients and their household to take difficult decisions at various stages of the care process, sometimes at substantial personal and social cost. The factors affecting TB treatment are intricately linked: see Table 7 below for a summary of factors affecting treatment completion. To achieve successful treatment completion requires affordable, accessible and appropriate health services, designed and delivered with a greater understanding of patients' needs and the wider socio-cultural context. Progress towards successful completion of TB treatment can be seen to involve a chain of responsibilities involving various actors and factors such as patients and their behaviour, patients' families and their cooperation, health service providers and their conduct, policy makers and their understanding of issues, and the community's values and norms (Wares *et al.*, 2003).

Munro *et al.* (2007) presented a model to understand factors affecting adherence to TB treatment which involves structural, personal and health service factors, as well as the social context in which TB patients take their treatment. All but one of the studies included in the review concurred with this model. The final article reviewed envisages three layers of barrier that TB patients experience in TB treatment: attending the health care facility initially; attending repeatedly; and experiences while there. These layers were often interlinked and exacerbated by structural factors such as geographic, economic, and gender inequalities. Most importantly, patient decisions in relation to treatment taking were thought likely to shift during the treatment course, for a variety of reasons (Sanou *et al.*, 2004).

It is important that PLTB are sufficiently motivated to continue their treatment, and a range of approaches has been used to encourage patients. However, even though PLTB are sufficiently motivated, other social and structural factors may create barriers (Munro *et al.*, 2007).

There are several other factors affecting TB treatment completion which TB patients have little or no control over, such as poverty, social exclusion, gender, stigma and discrimination, organizational factors, therapeutic factors and other societal factors that influence patients' treatment-taking behaviour (Sumartojo, 2000). TB patients need to have flexibility and choice in their treatment plan including choice of treatment observer if required by the programme. However, patient autonomy in treatment taking seems to be contrary to conventional TB service delivery (WHO 2003a; Diwan & Thorson, 1999; Cuneo & Snider, 1989). It is also important to note that patient choice in taking treatment is influenced by the social and cultural structures in which the person lives and physiological and psychological phenomena of the disease (Lienhardt *et al.*, 2003). However, a common notion found among programme managers and health care providers is that completing treatment is the sole responsibility of TB patients, and care providers are only there to ensure that they follow the recommended way of completing their treatment plan. This approach puts TB patients in a difficult position, and when they fail to complete their treatment, they are the ones who get the blame. This tendency among care providers and managers can lessen patients' motivation towards treatment and fail to create a supportive environment for treatment. Health workers and programme managers therefore require an explicit understanding that beyond the patients' control there are several other factors that play important roles in determining treatment completion among TB patients; their role is to minimize those negative factors by understanding patients'

needs and providing them with support. However, there are few studies looking at this issue in depth.

There are several factors related to health system or organization of TB service delivery that pose enormous difficulties to patients and thus may prevent them continuing their treatment plan. For instance, treatment taking behaviour of TB patients is greatly affected by poor access to DOTS centres, DOT, health worker behaviour and inadequate information about the disease, treatment and TB service availability, travel distance and transportation costs, and other costs of care associated with TB treatment. Sumartojo (1993) suggested that interventions to enhance treatment completion should focus not only on the patient but also on the wider context and the health care system. A clear shift is therefore needed from a limited biomedical approach to a wider social, contextual and structural understanding of issues in TB treatment completion which will broaden knowledge and experiments in designing patient-centred pro-poor strategies in addressing this complex issue. Lienhardt *et al.* (2003) and Munro *et al.* (2007) have also noted that a shift in perspective is needed in order to give greater attention to both the social and economic environment in relation to TB infection: stirrings in this direction can be seen in the international policy arena.

Several measures have been used to address poor completion of TB treatment. Some (training, motivation and supervision) aim to change the behaviour of health staff. Others are directed at patients and include education, reminders and prompts to re-attend, financial incentives to return, contracts between patient and provider, supervision of tablet taking, and tracing of patients who are late or default. All have documented success stories but vary greatly. However, studies have also acknowledged the inadequacy of interventions to address issues of non-completion and suggested investigating new ways of interventions tailored to local contexts.

Table 7: Summary of factors affecting TB treatment completion - current knowledge

Factors	Themes	Issues
Health systems	<ul style="list-style-type: none"> - TB service delivery modality - Patient education, treatment literacy - Clinic opening time 	<ul style="list-style-type: none"> - Poor access to treatment services - Availability of drugs and quality of care - Infeasible daily DOT - Inconvenient opening hours - Long waiting hours at clinics - Unfriendly health workers, poor relationships between service providers and patients - Attitude of service providers towards TB patients - Maltreatment of patients - Poor management of patient issues - Inadequate information to patients on their disease and treatment - Poor management of drug side effects - Poor follow up - Lack of specific approach and flexibility in treatment
Social and family	<ul style="list-style-type: none"> - Stigma and discrimination - Cultural beliefs 	<ul style="list-style-type: none"> - Social and family rejection, isolation - Support from community, friends and family - Challenging traditional beliefs and practices related to TB (incurable disease; disease of poor and unhygienic people; result of bad deeds) - Women – family rejection, difficult to find husband - Weak social network and broken relationships
Economic	<ul style="list-style-type: none"> - Diagnosis cost - Cost of treatment and care - Unemployment 	<ul style="list-style-type: none"> - Loss of income and job - Financial stress to individual and household - Inability to support family – increases stress and frustration - Diversion of other resources to TB care – compromises with other family needs - Relatively high diagnosis cost affects treatment continuation - High transportation cost - Food costs – routine and additional and other cost
Individuals	<ul style="list-style-type: none"> - Knowledge - Beliefs - Behaviours - Personal motivation 	<ul style="list-style-type: none"> - Inadequate information about disease and treatment - Limited understanding about treatment duration - Lack of information about service availability - Denial of TB - Feeling good after initial treatment - Willingness to complete treatment - Substance abuse (drug users and alcoholic)

Factors	Themes	Issues
Therapeutic factors	<ul style="list-style-type: none"> - Treatment duration - Treatment regimen 	<ul style="list-style-type: none"> - Long treatment duration - Complex regimen with many tablets at a time - Side effects of drugs - Taste of drugs
Structural factors	<ul style="list-style-type: none"> - Geography - Gender - Urbanisation - Migration 	<ul style="list-style-type: none"> - Difficult geographical terrain – hard to reach health facility - Lack of gender-friendly approach in TB care - Urban complexity (slums, homelessness, overcrowding) - Increasing migration, vulnerable to ill health

3.7 TB treatment completion and gaps in current knowledge

Studies show that TB patients were burdened with a wide array of social, economical, and medical problems. Often TB patients take their medication under a complex environment and pressure, which severely affects their ability to complete the full course of TB treatment. In TB control, understanding treatment completion is a complex science as several factors hinder treatment completion, many beyond the control of individual patients. Non-completion of TB treatment is the largest issue in TB control, and is made more complex because TB is prevalent among people with low socio-economic status and TB makes individuals and household vulnerable financially, socially and physically. Considering the complexity of the issue and the relatively poor measures applied to tackle this issue, Addington (1979) stated ‘treatment completion is the greatest unmet public health challenge in TB control’, a view that still remains valid today.

Many factors affecting TB treatment completion and their responses have been identified (and have already been discussed above). However, economic burdens to patients and families, feasibility, accessibility, acceptability and affordability to TB treatment, migration, caste, support from society and families, and health beliefs among individuals, and their direct and indirect impacts in TB treatment completion have not been rigorously researched. People with TB are frequently disadvantaged members of the society and face numerous problems fighting their disease. Patients who have successfully completed treatment may have faced many difficulties during their long course of TB treatment but most studies have ignored this group and their problems. The strategies they have used to overcome the many financial, social and managerial difficulties they encounter during their treatment have not been properly addressed in any study. Most importantly, studies have not considered issues of TB

treatment completion in urban areas where TB is more prevalent and urban complexities challenge its control. Explaining the urgency of dealing with TB in urban areas, Weiss and Addington (1998) in an editorial mentioned that ‘TB definitely is an urban health penalty’. This further emphasizes the urgency of gaining in-depth insights into issues that affect TB treatment completion in urban areas especially in developing countries. In order to improve TB treatment completion, health service providers need to be well aware of the factors that affect and facilitate treatment completion for individual patients, a complex task in urban areas.

Most studies have used quantitative approaches to measure the magnitude of problems in treatment completion. Some researchers have used social science approaches applying qualitative methodologies but have not addressed in depth the issues of treatment completion from patients’ and communities’ perspectives. Dick (1998) raised the issue of the use of inappropriate research methodologies to address the problem of non-completion. She further stated that to investigate and obtain a clearer insight into the barriers to completing TB treatment and to develop a unified approach, current research has to move from quantitative to qualitative techniques. Similarly, Munro *et al.* (2007) in their review article advocated looking at wider social, economical, and structural issues. In the context of Nepal, to my knowledge, there are no published studies looking in depth at issues related to TB treatment completion. However, other studies conducted in Nepal have highlighted the need for better understanding of the interrelated factors affecting TB treatment completion (Baral *et al.*, 2009; Newell *et al.*, 2006; Newell *et al.*, 2004; Harper, 2005; Bam *et al.*, 2006).

The potential solutions to the problem of non-completion discussed above have also not been very well studied. Most of the studies reviewed in this chapter have not considered in any depth issues of patient autonomy, and the importance of patient-centred approaches to increasing TB treatment completion. Various support mechanisms have been proposed to address non-completion, but information on whether and how they were tailored to patients’ needs is not well documented. Similarly, various social networks exist in communities where patients live but there is limited understanding of how these social structures and networks influence TB treatment continuation. I found only a very few interventions that were designed to map social and family support to Tb patients, and they were not assessed using treatment completion or other outcome measure. I also found that gender inequalities in TB treatment have not been well studied despite their obvious importance. Most studies and trials have not considered the effects of DOT in TB treatment completion,

although most studies infer that DOT affects TB treatment completion in many ways and state that further investigation is required. Approaches such as late patient tracing mechanisms have not been effectively investigated. There is a gap between implementation of such processes and measurement of their effectiveness. Issues of non-completion must be addressed from a social perspective rather than purely from a biomedical standpoint. In order to do this, qualitative information must be gathered from TB patients on their definitions of treatment completion, beliefs about the consequences of and reasons for non-completion and successful completion, and explanations of how and why treatment behaviour may have changed over time. It is also important these issues need be understood within the local context and complex, day-to-day living conditions of TB patients. Some studies have investigated treatment completion using social perspectives, but rather superficially. There has been little assessment of approaches like financial incentives to patients, resource mobilization for late patient tracing, improved education and peer assistance to overcome problems of non-completion. These gaps concur with the gaps highlighted by Munro *et al.* (2007) in their systematic review of patient adherence to TB.

Most of the relevant literature I have reviewed in the area of TB treatment completion seems to be somewhat superficial in terms of identifying ways of addressing these issues effectively. Based on this literature I conclude that there is a need to gain an explicit understanding of factors associated with non-completion of TB treatment and future investigations should consider and relate their findings with the local context. Furthermore, while investigating these factors there is a need to use appropriate qualitative techniques to bring clearer insight into the problem.

3.8 Theoretical understanding of TB treatment outcomes and treatment completion

A theoretical framework is a structure that presents the theory underpinning a research study, whereas a conceptual framework (discussed in the next section) is the approach used to operationalise the theory. In this section, I present a framework to aid understanding of pathways to potential TB treatment outcomes and thus TB treatment completion in the context of national TB programmes. The framework explains the problem under study, and thus serves as a basis for conducting this research work.

As discussed at length above, not all people living with TB will be able to complete the full course of TB treatment for a variety of reasons, despite their best efforts to do so. People who complete their treatment are required to follow a difficult treatment pathway, along which many factors may help or hinder progress. This section describes the standard pathway through TB care, and the potential treatment outcomes in the context of a national TB control programme.

As shown in Figure 7, the national TB programme receives people with TB from a variety of sources who commence treatment using an appropriate treatment regimen. However, some people with TB do not come to the national TB programme for treatment and the programme will not know their treatment status. Generally, such people take their treatment from the private sector (Newell *et al.*, 2004; Uplekar, 1998; Hurtig *et al.*, 2000) or are left untreated. It is important for the programme to understand why many people do not come into the programme for treatment and know the treatment status of such people. However, this study focuses on people registered for treatment in the programme and does not include people who get treatment outside the national TB programme.

Some people living with TB registered for treatment into the programme will complete the full treatment course without any interruption and their outcome is classified as *Treatment Success* (treatment completed or cured) as shown by the straight line A in the figure. In Nepal, the national TB programme claims 85% of people fall into this category (Annual NTP report 2007) which indicates that the programme is highly successful. Although these people complete their full course of treatment, it does not mean that they did not have issues during their treatment. Some people complete treatment but with some interruption of treatment doses as shown by line B with straight and dotted lines: these people are also classified as treatment success. In terms of outcome category in the programme there is no difference in the

two outcomes shown by lines A and B. However, experience suggests that many of the treatment success cases will have experienced some irregularities during the course of their treatment. Many people in this category were at risk of discontinuing treatment if they failed to address the causes of irregularities or lateness. What is unreported, and what the figure does not present, is *how* people who completed treatment managed during their treatment; what coping strategies people applied, and what factors might have helped or hindered their treatment pathways. However, it is important for the programme to understand the critical relationships between treatment success and individual strategies that people applied in order to complete treatment. This will help the programme to develop effective ways to advance TB treatment completion.

Not all people who start TB treatment will complete their full course of treatment. Several factors that can interfere with their treatment continuation as discussed earlier in this chapter. People who start treatment, and then discontinue treatment at least for two months, classified as *Defaulters*, are shown by the straight and dotted lines (C). This is an undesirable treatment outcome for the programme. In Nepal's context, around 10% percent will default from treatment during the treatment course (NTP Annual Report 2007/8). People of this type could be late or irregular in treatment at any stage during the period during which they are taking treatment. Some such 'defaulters' will come back to treatment, either on their own or after tracing by the programme, are classified as *Returned After Default*. People who default from treatment are often difficult to identify especially in urban communities where settlements are complex and people, especially migrant workers, do not record a proper address or change their address frequently. It is crucial for the programme to understand the reasons for lateness/default in their treatment, to be able to address such effectively.

People may die during the treatment course, whether due to TB or other causes. They are classified as *Died* in the programme as shown by line D. This is another undesirable outcome and can happen at any stage of treatment. People of this type could be late or irregular in treatment before they die. The same is true for people whose sputum status is positive at 5 months of their treatment or later, classified as *Treatment Failure* in the programme. In the NTP, treatment management and allocation of treatment regimen is based on disease site, type of TB disease and history of previous treatment.

People who are on TB treatment can transfer from one centre to another as shown in line F. Their treatment outcome is categorised and recorded as *Transferred Out* at the centre from which transfer occurred. This study does not investigate this category of people and outcome, as they are difficult to trace within the study area.

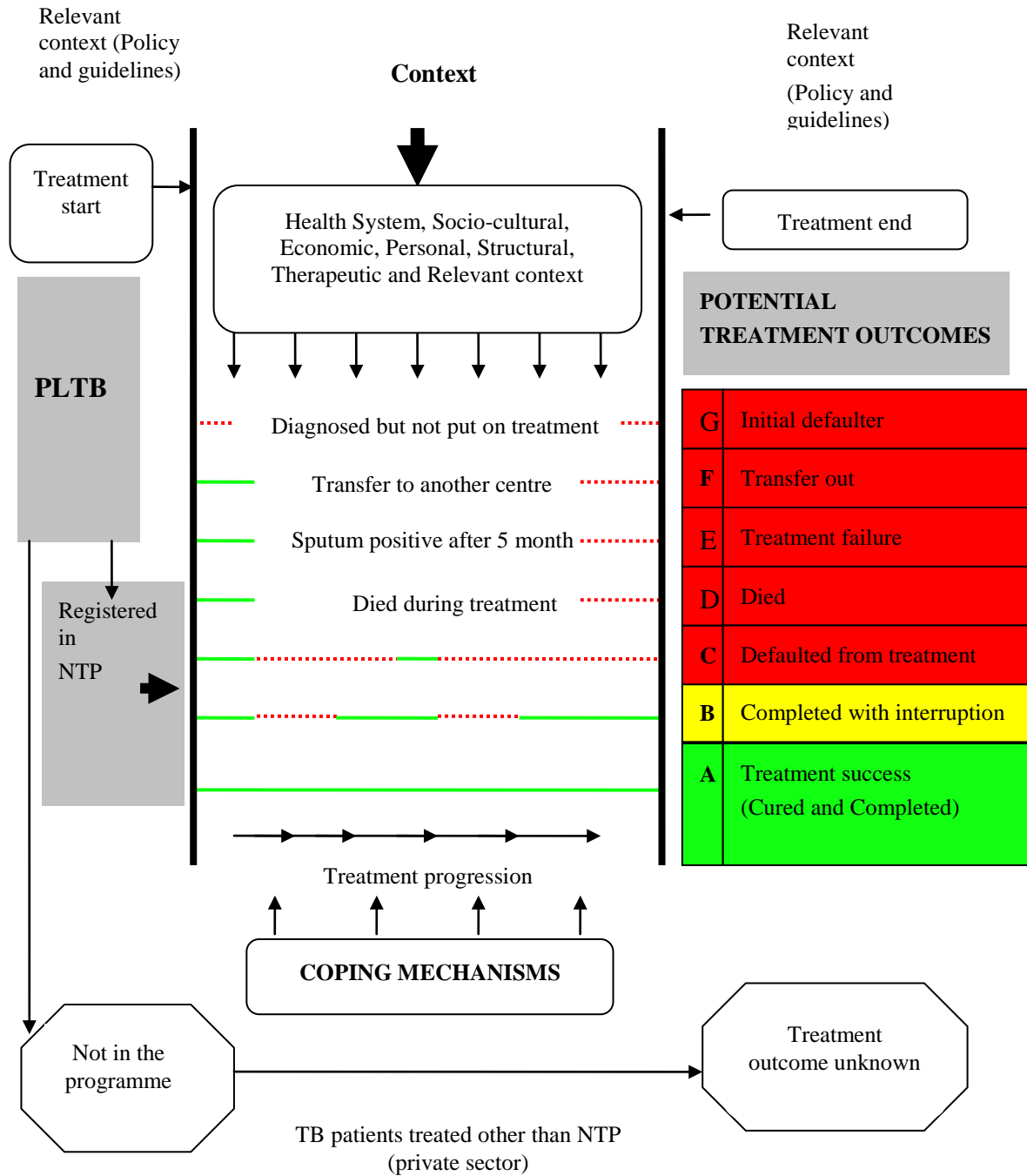
Some people have a confirmed diagnosis of TB but are not put on treatment. The programme needs to find these people and register them for treatment. People may reappear or start treatment elsewhere but this information is not available. The study assumes there are only a small number of people in this type, but this may be untrue. Line G shows such people who are diagnosed but never get into the treatment process.

Thus lines A to G depict the main potential pathways and hence treatment outcomes that can occur after being registered in the programme. In addition, the figure includes factors that affect taking regular TB treatment, and may lead to treatment disruption at any stage.

Most people with TB want to be cured – this is why they seek treatment. Studies have shown that people with TB are burdened and take their treatment in complex environments. The study assumes that while going through the treatment people apply different mechanisms to comply with defined treatment procedures and overcome barriers in treatment. These ‘coping strategies’ are included in the figure. Failure to identify and follow effective coping strategies can result in treatment discontinuation and may lead to non-completion. It is important for the programme to gain explicit understanding of these strategies in order to understand barriers and enabling factors and minimize the burden on people with TB and their families to achieve high treatment success rates. Thus, this study also intends to investigate the coping strategies that people apply during their treatment course: this knowledge will contribute to the design of patient-friendly approaches to delivering TB treatment services.

It is also important to take into account relevant context which can influence treatment completion. Relevant context includes national and international policies and TB control guidelines; the local context of each individual with TB, including where they live, their occupation, caste and ethnicity, status in society; and potential reforms in the health sector.

Figure 7: theoretical framework to understand potential treatment outcomes and treatment completion in TB



The theoretical framework (figure 7) presented the various treatment pathways and potential treatment outcomes that a person with TB could experience once enrolled for TB treatment in the NTP. The majority of those with TB are poor and live in difficult socioeconomic circumstances. They often work in an unhealthy and hazardous environment. Hence the determinants of ill health are not just biological. Evidence indicates that success in TB treatment is influenced by multiple factors. When the delivery of health services uses a 'patient-centred approach', adverse influences on treatment outcomes are diminished, suggesting that TB treatment outcomes can be improved in this way.

The basic principle of the patient-centred approach to health care promotes the concept of putting the patient at the centre of his/her health care. Definitions vary and are context specific (Stewart *et al.*, 2003; Laine and Davidoff, 1996; Mead and Bower, 2000). Stewart et al (2003) in their book *Patient-Centred Medicine: Transforming the Clinical Method* present a patient-centred model with six interacting components:

- (i) assessment of both the disease and the illness experience,
- (ii) integrating the assessment with an understanding of the whole person,
- (iii) finding common ground between the service provider and the patient,
- (iv) incorporating prevention and health promotion,
- (v) building up a long-term relationship between the provider and patient, and,
- (vi) being realistic about allocating resources in practice.

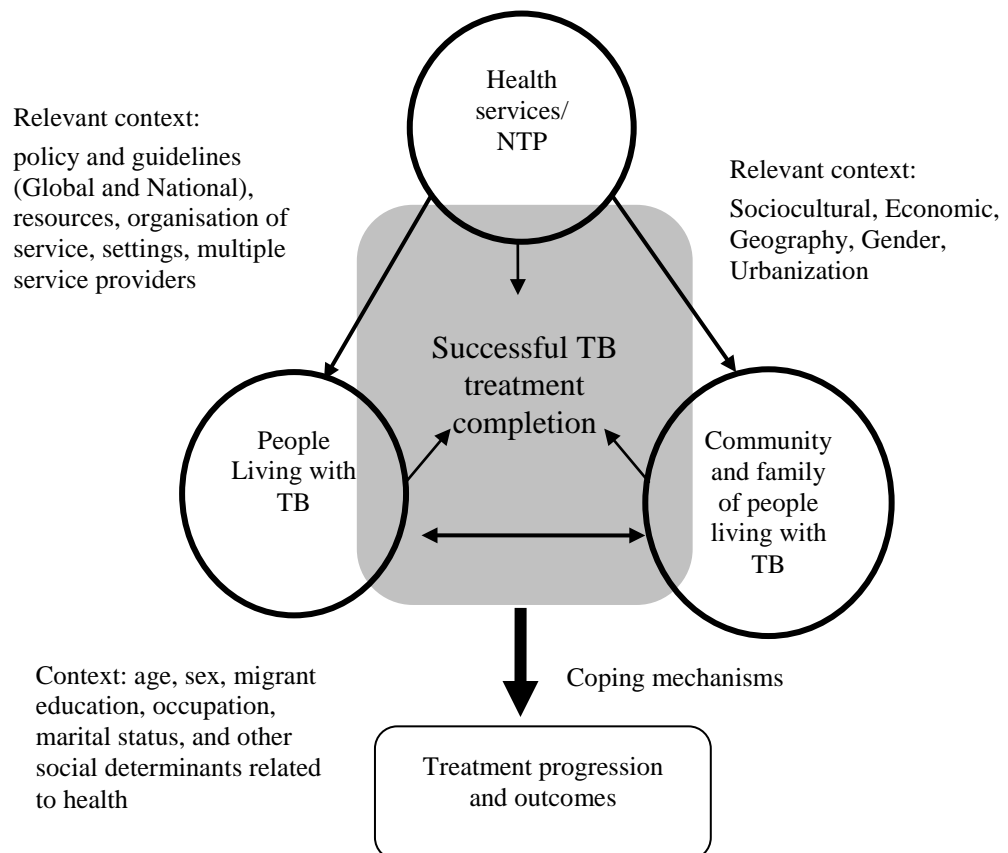
There is a growing trend away from provider-centred care towards patient-centred care in health service delivery. Although in developed countries the patient-centred care approach is increasingly viewed as a core component of the management of illnesses including long term treatment therapies, and is widely advocated (Law and Britten, 1995; Barry *et al.*, 2000; Britten *et al.*, 2000; Kennedy *et al.*, 2007), it has not been recognised to the same degree in developing countries.

Studies show that patients strongly prefer a patient-centred approach to health care (Little *et al.*, 2001), particularly when long term treatment is needed, such as for TB disease. The traditional biomedical approach fails to recognise the influence of psycho-socio-economic factors in disease and its management. TB is not merely a biological phenomenon, and hence successful TB treatment requires an accurate initial diagnosis plus an integrated patient-centred approach, support from family, relatives, community, and health care providers. I therefore developed a conceptual framework for this study putting TB treatment completion at the centre (see section 3.9).

3.9 Conceptual framework

A conceptual framework is a group of concepts that are broadly defined and systematically organized to provide a focus, a rationale, and a tool for the integration and interpretation of information in research (Reichel & Ramey, 1987). The use of predefined concepts through a conceptual framework in qualitative research is argued: however, not rejected. In my study, I used the conceptual framework in Figure 8 to outline the research approach at initial stage of my research which helped understanding the research context and also guide the research process. The framework well interacted as the research progressed, and ultimately refined in line with the study findings (Guba & Lincoln, 1989). As discussed by Smyth (2004) the conceptual framework strengthens the study in following ways: providing clear links from the literature to the research goals and questions; informing the research design; providing reference points for discussion of literature, methodology and analysis of data, and; contributing to the trustworthiness of the study.

Figure 8: Conceptual framework



I developed the conceptual framework considering a theoretical understanding of TB treatment pathways, reviewing current understanding and knowledge about factors that help or hinder people with TB taking TB treatment, potential treatment outcomes, and treatment completion in the context of a national TB control programme. My framework identifies three main actors: health services/NTP; PLTB; and the family of PLTB and community. These three actors can influence TB treatment completion by either facilitating or hindering progress towards the treatment outcomes. The framework shows relationships among these players. The framework considers that TB control programmes are guided by global and national policies and guidelines; they determine the TB treatment process under programme conditions, often designed from a biomedical approach with little consideration for the needs of PLTB and the local context. I plan to try to understand how these policies and guidelines contribute to successful TB treatment completion in local context of Nepal's NTP. Similarly, the organization of TB service delivery, resources, settings, existence of multiple service providers will also influence TB treatment completion and I plan to gain an explicit overview of these contexts.

3.10 Study aim and objectives

3.10.1 Aim

The aim of the study is to gain a better understanding of experiences and issues faced by People Living with TB (PLTB) and their responses during the course of TB treatment; and to identify appropriate ways of addressing the identified issues in a specified context. This study will contribute to the body of knowledge relating to TB treatment completion and facilitate the design and implementation of patient-centred care in Nepal's National TB Programme (NTP) and similar settings elsewhere. The study focuses on factors that influence TB treatment completion among PLTB taking TB treatment under the NTP in urban settings in Kathmandu Valley, Nepal.

3.10.2 Objectives

The following study objectives were developed;

- to understand the issues underlying the successful and unsuccessful completion of TB treatment from the perspective of PLTB in the context of the NTP in urban settings in Kathmandu, Nepal;
- to understand responses to the factors influencing the successful and unsuccessful TB treatment completion from the perspective of health systems, communities and PLTB in the context of the NTP in urban settings in Kathmandu, Nepal;
- to identify appropriate ways of addressing the issues identified leading to the successful and unsuccessful TB treatment completion in the context of the NTP in urban settings in Kathmandu, Nepal.

3.11 Conclusion

This chapter provided an understanding of the context relating to the issue of TB treatment completion considering the existing knowledge into account. Based on the understanding it set out a theoretical framework which then developed to a research tool – a conceptual framework – based on which I formulated study aims and objectives in this chapter. The next chapter describes research design and methods.

CHAPTER 4

RESEARCH DESIGN AND METHODS

I have presented the context, problem analysis, problem statement, aims and objectives of the study in previous chapters. This chapter describes the research design and methods that I used in the study. It also describes the basis for my selection of the study approach, data collection methods and analysis of data along with a description of issues that arose while conducting the field research and analysis. The chapter also describes the trustworthiness of the research process and findings along with limitations of the study and ethical considerations.

4.1 Setting up the study

Only very limited prior information on TB treatment completion in the context of Nepal's urban TB control programme was available, so my intention was to seek a greater depth of understanding. To do so, a well thought-out research design and application of methods was vital. A review of relevant literature on study approaches used by other researchers, my experience of more than fifteen years working in Nepal's health system including in the NTP, and a general overview of the study context helped me to shape my thinking as a researcher. In early days of my research, my involvement in the NTP as a research assistant, primarily working on a randomized controlled trial (Newell et al., 2006), provided an opportunity to develop concepts about TB treatment completion in Nepal and elsewhere. It also gave me opportunities to interact with various researchers involved in TB control and social sciences in Nepal and elsewhere, as well as health service providers and policy makers. I was also engaged in formal and informal discussions with the NTP and its stakeholders, including people with TB and their families, who were central to my research area. It also helped me understand the context of how TB services were delivered in urban areas of Nepal and general characteristics of urban populations, and in particular migrants. All these processes at the initial stages of my research helped me to understand major issues related to TB service delivery in Nepal and other developing countries, particularly in the context of South Asia. These initial understandings helped me to give shape to my research design and methods in line with the study aim and objectives.

4.2 Research approach and design

My research sought explicit understanding of issues in TB treatment completion in the context of urban TB control in Nepal. Considering the nature of the study, involving personal experiences of people with TB, their families, members of the community and health workers, I thought appropriate to use a qualitative research approach. I considered a research 'approach' is to help researcher to shape research at various stages to conduct research systematically in relation to its aim and objectives. Ethnography; phenomenology; grounded theory; biographical, life history and humanistic; ethnomethodology; interpretivist; conversational analysis and discourse analysis; psychoanalytic approaches are some of the key approaches to qualitative research. I do not intend to present a comprehensive explanation of various qualitative research approaches. Instead, I emphasise that the qualitative researcher can apply a range of methodological techniques and practices and present a range of philosophical underpinnings in their areas of enquiry (Mason 2002). No matter what the approach or approaches are, qualitative researcher need to engage actively in making decisions at throughout their research, which need to be grounded in relation to their research questions/objectives, and changing context (Mason, 2002).

Qualitative research is multi-method, interpretative, exploratory, flexible, analytical, and context-specific in its nature (Manson, 2002; Maxwell, 2005; Denzin and Lincoln, 1994; Flick, 2007). Uses of a qualitative research approach in health care have gradually increased; however, arguments on its theoretical underpinnings and mode of operating continue to exist (Marshall, 1996). Many researchers have used this approach in designing and validating quantitative research i.e. to inform development of hypotheses and survey questionnaires, to help wider interpretation and understanding of quantitative data, to ensure validity of data, to probe or provide different perspectives to quantitative research (Pope and Mays, 2006). Besides the use of qualitative research approach in complementing quantitative research, its independent use to unveil the varied nature and essence of things in the social world has been widely acknowledged and used in many disciplines of social sciences (Mason, 2002) including studies related to human health and well-being (Pope and Mays, 2006). I therefore thought it appropriate to use this approach in my study to allow me to be able to address the diverse social phenomena influencing the issue that I was interested in, and in which I could modify or reconsider the research design and methods as research progressed and respond to new knowledge and changes in the

study as they emerged (Hammersly and Atkinson, 1995; Mason 2002), thus allowing a greater understanding of the issue that I was investigating.

In the study, I intended to uncover social world and phenomena related to TB disease and its treatment completion primarily from the point of view of the people involved: individuals or groups including various social actors, their various behaviours and experiences, emotions, beliefs, thoughts, ideas, perceptions, knowledge, feelings, motivation, interpretations of happenings, attitudes in particular to illness and affected people, identities and views, social positions of individuals and family, cultural and social practices and constructions, and events and reactions to them. The use of a qualitative approach allowed me to understand the study respondents and their social world in their natural settings. This concurs with the use of a qualitative research approach in social sciences to gain understanding of subjects, meanings and metaphors and their causal relationships to context and knowledge (Neuman, 1997; Mason, 2002; Brink and Wood, 1998). This approach is useful to explore issues, refine research questions/objectives, conceptualize them considering the context, and to increasingly focus the study as it progresses (Hammersly and Atkinson, 1995; Creswell, 1998). Using a qualitative research approach, researchers can distinguish and develop understanding on factors behind observed behaviour (Strauss and Corbin, 1998), modify researchers' prior assumptions (which are often little explored), and provide an in-depth analysis of 'what, how and why'.

In the field of social science, qualitative research in the form of an inquiry of human behaviour was initiated in the late 1920 and 1930s (Denzin and Lincoln, 2005). Since then, various attempts have been made to define qualitative research. During the 1960s and 1970s, qualitative research was considered as an alternative to quantitative research (Flick, 2007; Strauss and Corbin, 1998). Qualitative research has a long history of use in many disciplines, especially studies related to social sciences (Silverman, 2000; Manson, 2002), as it studies people in their natural settings and focuses on understanding events and the meaning people make of their social world (Denzin and Lincoln, 1998).

Qualitative research aims to gain an explicit understanding of social phenomena. In doing so, it emphasises exploration of: peoples' experiences and perspectives; their day-to-day behaviour in the areas of investigation; social constructs of the issues under investigation; situational constraints; the reality of natural world in which people live, and intimate relationships between researchers and what was studied

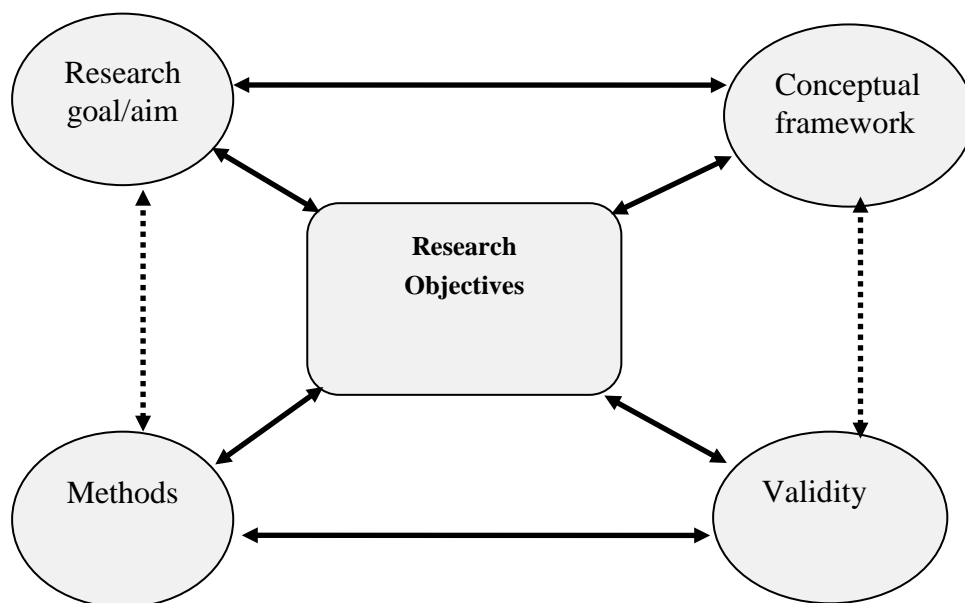
(Strauss and Corbin, 1998; Silverman, 2005; Manson, 2002; Flick, 2007). However, in designing a qualitative research study, it is important to choose appropriate research method(s) to be able to best understand the area under investigation. Denzin and Lincoln (2005) provide an initial generic definition of qualitative research in the third edition of their qualitative research handbook:

‘Qualitative research is a situated activity that locates the observer in the world. It consists of a set of interpretive, material practices that make the world visible. These practices transform the world. They turn the world into a series of representations, including field notes, interviews, conversations, photographs, recordings, and memos to the self. At this level, qualitative research involves an interpretive, naturalistic approach to the world. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them.’ (p.3)

Although my study’s research design began to take shape as I defined my research objectives, it was obviously vital to have an appropriate research design taking into account the issue(s) and context where I was going to conduct my research. However, I found there were inconsistent views among qualitative researchers as to whether or not qualitative research should have a research design (Miles and Humerman, 1994; Maxwell, 2005). Figure 9 presents the overall research design of the study. I adapted this design from Maxwell (2005), who named it ‘an interactive research design’. Maxwell further elaborated that this design captures various aspects of a qualitative research approach, retaining sufficient flexibility to allow researchers to deepen their understanding on the areas under investigation. It provides opportunities to travel back and forth in terms of refining methods and research objectives/questions along with assuring their validity and credibility. The design includes various components, all of which interact with each other. Each component has multiple reciprocal relationships, rather than being in a linear relationship with only one component. Another characteristic of this research design is flexibility to respond to emerging knowledge and changes during the course of research – thus allowing the researcher to move back and forth between, and interact with, methods and issues under investigation. The relationship between research aim and methods and conceptual framework and research validity is shown using dotted lines: interactions among these components and their implications were found to be of less importance than other components, although a certain degree of interaction was still expected during the course of research.

While adopting the research design, I fully considered the research context and findings from the literature review; both demonstrated a clear need for a flexible and interactive research design, which could enable me to understand relationships between issues by visiting and revisiting the various research components shown in the design. Thus, the research design has carefully considered details of issues of TB treatment completion, local context, and the study aim and objectives.

Figure 9: A representation of the interactive research design



Source: adopted from Maxwell, 2005, p.5

This study was unique. The nature of the data I intended to generate through discourse in the study was rich in explanations, for example knowledge of people with the disease and undergoing treatment, experiences of PLTB in natural or constructed situations during illness and treatment, how and why the social and cultural world in which PLTB and their family lived were constituted, and their interactions with TB and its treatment. I therefore concluded that the research design and methods would need to be interactive and continually refined, as informed by fieldwork (Jacobs, 1987; Goetz and LeCompte, 1984; Erlandson *et al.*, 1993).

The research design I adopted (Figure 9) not only allowed me to investigate important new issues and questions as they arose, but also helped me to drop unproductive areas of research from my original research objectives. I started with the general idea of exploring issues in areas of my investigation then gradually focused on specific issues as they emerged. A similar approach is found in other qualitative research (Silverman,

2000; Manson, 2002; Lincoln and Guba, 1985). For example, I started exploring some basic questions relating to TB treatment completion, such as ‘what happened or was happening?’, ‘why did it happen the way it did?’, ‘how did it happen?’, and ‘what was its effect?’. Then, as concepts and relationships emerged during the research process, I gradually narrowed my study focus to specific issues, developing ‘theory’ by closely understanding interactions of issues with people and context. A key characteristic of a qualitative research approach is that the researcher does not start with a comprehensive understanding of the issues under investigative at the outset of the research, but rather provides deep understanding at every step of the research, thus leading to modifications of the research design as the study progresses (Maxwell, 2005; Manson, 2002; Silverman, 2005).

4.3 Methods

This section describes the research methods I used, giving a detailed explanation of why I choose these methods and how I implemented them during the course of my study. I considered research methods as a process of identifying potential data sources, generating data from the sources, and techniques of conceptualising data and thus building a concept (Strauss and Corbin, 1998; Mason, 2002). Thus, in this section I provide a description of potential data sources, study respondents and their selection, techniques used in data generation, processes of conceptualization and data structuring to facilitate in-depth analysis of phenomena, ethical issues in research and my experiences while undertaking this study.

4.3.1 Study sites

The study was conducted in the urban areas of Kathmandu Valley. The valley consists of three cities: Kathmandu, Lalitpur (also known as Patan) and Bhaktapur. The study sites were urban DOTS centres in Kathmandu and Lalitpur. Kathmandu is the capital and largest metropolitan city of the Federal Democratic Republic Nepal, and Lalitpur is a sub-metropolitan city located in southeast of Kathmandu. More than 40 DOTS centres providing TB services in these cities including public, private and NGOs (Figure 10). Due to confidentiality reason I have not identified the DOTS centres where I conducted the study.

Categorising the potential sources was not merely a theoretical exercise; it provided an insight into whether the data sources existed and how they could be accessed as per the study requirements. It also helped me to engage creatively with the potential sources as and when relevant to the study context (Mason, 2002). The list of potential sources not only highlighted data generation options, but also helped me to define and consider ethical aspects of data generation among various sources. The categories above were indicative; thus data generation were not limited to these sources, but were extended taking into account of issues that emerged during the course of study.

4.3.3 Methods of generating data from sources

I used data generation methods to explore respondents' subjective understanding and on experiences of the issues I investigated. There are various approaches to generating data in qualitative research studies and qualitative researchers use them according to the research theme and the nature of the study, the participants involved and the context of the research. Despite differences in their use, a common focus can be seen among many researchers in the use of data, as qualitative studies focus on talk, actions, interpretations and meanings to human beings to make sense of the social world they live in (Pope and Mays, 2006). I used the following methods in my study;

- *Individual interviews*: I conducted open-ended and discovery-oriented in-depth interviews with respondents;
- *Focus group discussions (FGDs)*: involving around 6-8 people in a group, which focused on and explored in depth a specific topic;
- *Observation*: I observed interactions, actions and behaviours, and peoples' interpretation of these acts especially in DOTS centres in the study area and formal meetings of the NTP. I recorded observations as field notes;
- *Document review*: I reviewed published and unpublished literature related to my research area, including NTP policy and guidelines, and NTP training materials;

The next sections describe the process of implementation of each technique that I used in generating data, the context in which I used these techniques, and whether and how the process and the context influenced the data generating process.

4.3.3.1 *Qualitative interviews*

Qualitative interviewing is a creative art, and doing it well is a difficult task, which demands active engagement and creative work by the interviewer (Holstein and Gubrium, 1995), not only at the start but also throughout the process. Various adjectives are used to differentiate interview methods in qualitative research – in-depth; semi-structured; open-ended; and unstructured. Mason (2002) believes that the term ‘qualitative interview’ refers to an in-depth interview with a semi-structured nature. Rubin and Rubin (2005) suggest that each qualitative interview is unique, because questions are constructed in the light of the interviewee’s responses. They also termed qualitative interviewing as ‘responsive interviewing’, urging that the interviewer should consider as a person rather than merely as a research subject, so should listen to the interviewee and ask questions carefully to generate deep understanding of issue(s) being researched rather than superficial breadth (Rubin and Rubin, 2005). Rubin and Rubin (2005) define qualitative interviewing as follows;

‘Qualitative interviews are conversational in which a researcher gently guides a conversational partner in an extended discussion. The researcher elicits depth and details about the research topic by following up on answers given by the interviewee during the discussion’. (Rubin and Rubin, 2005, p 4)

I considered in-depth interviewing as the main method of generating data in the study, because it can produce rigorous and rich data through talking and listening carefully to the people being researched in the settings where they live; eliciting peoples’ perspectives, knowledge and behaviour, personal experiences and opinions, and interactions with socio-cultural contexts of the issue under investigation (Bogdan and Biklen, 1992; Burgess, 1994; Mason, 2002; Lincoln and Guba, 1995; Rubin and Rubin, 2005). In in-depth interviews, the researcher starts the conversation in a relatively informal style and listens to the interviewee’s perspective on the research topic (Burgess, 1994), eliciting the interviewee’s knowledge about the issue under investigation (Rubin and Rubin, 2005).

I used a semi-structured approach in interviews without compromising on depth and flexibility (Rubin and Rubin, 2005). For this purpose, I used an interview guide with a set of flexible worded questions to keep the conversation guided, which helped interviews to be more focused on specific issues but did not limit the emergence of new ideas (Annex 1). I found this technique appropriate to gather knowledge on how TB affected the lives of PLTB and their families, and to understand PLTBs’

interpretations of causal explanations and relationships in the context (Mason, 2002), keeping TB disease and treatment completion as a central theme.

There are different ways of conducting interviews in qualitative research, including one-to-one interactions, large group interviews, face-to-face interviews and telephone interviews. I decided to conduct face-to-face interviews in a relatively informal style, one interviewee at a time. I started interviews by posing open questions in a neutral manner, listened carefully to the responses, and asked follow-up questions and probed based on the responses and issues raised. I started all interviews with open-ended questions: during the conversation my questions became more structured or focused on specific issues raised by the interviewee (Merton et al. 1990). In subsequent interviews, I focused on issues raised by previous respondents. Interviewees were given maximum opportunity to discuss new issues as they emerged and encouraged to construct contextual knowledge by focusing on relevant specific contextual issues. For example, I asked participants to talk through their specific experiences with regard to their disease and treatment rather than framing questions about what they 'generally did' under certain circumstances.

I conducted the majority of interviews. There were a few instances where I considered using another appropriately trained researcher as an interviewer. For example, I trained two female researchers, who had already had some prior experience in qualitative research, in qualitative interviewing techniques. They interviewed some women respondents in the study. In the initial stages of my fieldwork, I thought that women respondents would feel less comfortable if they were interviewed by me, considering the Nepali cultural context where, in general, a woman would prefer to be served by a female health worker, so I thought they would be more open about their views and issues with a woman interviewer. The female interviewers performed some interviews with women respondents; at the same time, I also conducted some interviews with women respondents. I went carefully through the interviews conducted by the women interviewers and the ones conducted by myself, but did not find any differences with regard to issues explored and the depth with which they were explored. In contrast, a woman I interviewed communicated her experiences without any hesitation, even though some of the information she provided crossed my preconceptions about cultural boundaries, such as her concerns regarding her sexual relationship with her husband since she had TB. I thought women would not share such issues when interviewed by a male interviewer: however, I found this was not the case. I became convinced that using female interviewers to interview women

respondents would not maximise intellectual richness in data generation. However, in one instance, I used a female interviewer when a woman respondent preferred to be interviewed in her local language³, which I did not know. Apart from these few instances, I interviewed all respondents, regardless of sex, transcribed the interviews and analysed them.

4.3.3.2 Focus Group Discussions

Unlike one-to-one interviews, focus group discussions (FGDs) involve a group, typically 6 to 8 participants, in discussion. FGDs are useful to explore peoples' experiences, opinions, wishes and concerns related to the issue under investigation. Their use in qualitative research has enabled researchers to understand the perspectives of people as they operate within a social network, and are particularly suited to the study of attitudes and experiences around specific topics (Barbour and Kitzinger, 1999). Use of FGDs varies depending on the nature of the research. However, in general, all FGDs are used for similar purposes. Morgan (1998) presents three fundamental strengths of FGDs in qualitative research – (i) exploration and discovery; (ii) context and depth; and (iii) interpretation. Employing one or more of these strengths would further enrich data generation. I specifically focused on interpretation, for example of policy and practice of institutional DOT; opinions of participants on opening hours of DOTS centres and their convenience or otherwise; perspectives on diversity and complexity in delivery of TB services in urban areas and what they meant to PLTB; different behaviours of people with TB during the course of treatment and what that meant to PLTB and their family; and opinions of members of the community regarding TB disease and the effects of such constructed beliefs to PLTB and their family. In the above areas I primarily looked at interpretations of people on how things happened; why they happened the way they did; could they have happened differently, and if so what, how and why. Similarly, I also considered the second strength – context and depth – during FGDs.

Six FGDs were conducted, with six to eight participants each. Four were conducted with PLTB and two with frontline health workers. In each group, participants were recruited purposively. PLTB were recruited in consultation with health workers of the DOTS centres where the PLTB were taking treatment, after I described the purpose of

³Newari, a local language of Newar ethnic groups, which is commonly used among Newars.

doing FGDs with PLTB and what kind of participants I was looking for. I consulted with health workers because they dealt with the PLTB on a daily basis and I therefore assumed that they had an understanding of the background of the PLTB e.g. in one FGD I looked for migrants, factory workers, daily labourers, and identifying such PLTB without consulting health workers was difficult. However, selection bias was minimised as far as possible. Similarly, when constituting FGDs with frontline health workers who were working in DOTS centres run by public, private and NGO providers, I approached individuals who had been taking a lead role in delivering TB services, as I wanted to gain their experiences with PLTB. Each FGD lasted approximately 1.5 hours.

I moderated four of the six FGDs and a woman researcher trained in qualitative research and FGDs moderated the other two. She had conducted FGDs in a research project I had been involved in on TB stigma and discrimination in Nepal, so I had good knowledge of her skills as an FGD moderator. She conducted FGDs with women with TB and their family members. The role of the moderator was to raise specific topics and encourage participants to talk freely and spontaneously about them. In each FGD, a public health graduate working as a research officer in various qualitative research projects acted as rapporteur. In addition to her field experience as a qualitative researcher, I trained her in FGD with specific focus on the role of rapporteur. We requested permission in advance to record the discussion in all FGDs: in three FGDs there were no objections, while in the remaining three FGDs, we did not use a recorder, as the participants did not feel comfortable with their discussion being recorded. In particular, front line health workers did not want to be identified when making critical comments about NTP policy and its implementation. However, the rapporteur captured all proceedings in the form of anonymous discussion notes in each FGD. Efforts were made to create a favourable physical environment in all FGDs.

A thematic guide was used in each FGD, giving a general outline of areas to be covered as well as specific themes and questions, and potential probes (annex 2). The moderator followed the guide although allowed wider discussion, particularly when new issues pertaining to the research area emerged and were discussed and explored by the participants. All areas given in the guide were well covered in discussion, even if not precisely in the order stated in the guide. Based on the guide, all processes and roles of facilitator, participants and rapporteur were clearly explained before the actual FGD started, helping to make the FGD more informative.

4.3.3.3 *Observation method*

I used observation in the study to broaden the range of data generated (Manson, 2002; Coffey, 1999). By ‘observation’ I mean me, as a researcher, being physically present in a research setting and observing and experiencing a range of happenings e.g. actions and interactions between health workers and PLTB and their family members; behaviours and relationships; social interactions among and between PLTB and others; and management of events, in particular TB treatment management. The research setting in my study was: health institutions i.e. DOTS centres, NTP meetings and trainings, and in few instances residences of PLTB.

At the DOTS centres, I observed many routine activities. I particularly focused my observation on the process of DOT with a focus on the health worker who was providing the service (also known as a DOT provider or treatment supervisor), and the PLTB who was being served. I observed verbal and non-verbal communications, actions, relationships and behaviours of PLTB and health workers in natural settings from the sidelines. In DOTS centres, I also concentrated my observation on events related to health education/communication, which took place between health workers and PLTB at various stages of TB treatment. In a few instances I also visited residences of PLTB. My visit to their homes was mainly for the purposes of the interview: however, I also observed what was happening in the family, especially the behaviours of PLTBs’ family members. I also observed various meetings, orientations and training programmes organised by the NTP, such as meetings with urban DOTS stakeholders, and reporting and planning meetings; and various interaction events in urban TB control, such as awareness campaigns targeting communities and PLTB. I made many visits to the sites; some observation was made during visits to the DOTS centre to interview health workers and PLTB. Information obtained from various observations was recorded in the form of field notes. In many instances, I recorded my findings after I completed my observation, because in many settings it was infeasible to observe and record the observations at the same time, as in many instances I was standing in a corner or talking to people other than the actors I was observing. However, on few occasions, I did observe and record my observation, especially at events such as training, meetings and orientations. All information was recorded in the form of field notes, which were subsequently analysed.

I was equally aware of the fact that my physical presence in the observation setting could distort the naturally occurring interactions between and among the actors and

events that I observed. However, I made efforts to minimise this distortion by not taking notes while I observed the events; making friendly relationships with the actors and being part of their group instead of presenting myself as an external observer. Nevertheless, it was difficult to assume ‘zero or no influence’ due to my presence in the setting especially when I visited resident of PLTB.

4.3.3.4 Document review

I also reviewed relevant published and unpublished documents, including unofficial reports of the government of Nepal including the Ministry of Health and the NTP. I also reviewed NTP manuals, guidelines, strategies, training modules for different groups, case studies, NTP annual reports, locally published newspaper articles related to TB, advocacy and IEC (information, education and communication) materials developed by the programme as per their relevance to the study.

4.3.4 Study participants and their characteristics

Although TB affects a wide range of people in the community, I restricted my study to the participants stated in section 4.3.1: (i) people living with TB (PLTB); (ii) family members of PLTB; (iii) frontline health care providers; (iv) NTP authorities; and (v) members of the general community. Table 8 and 9 provides brief characteristics of study participants (in-depth interview and FGDs) with a focus on PLTB.

Table 8: General characteristics of in-depth interview respondents

In-depth Interview				
Participant	Approached for interview	Participated in interview		Total interviews
		Male	Female	
People living with TB	43	22	9	31
Family members (age: 22 to 55 years)	8	1	5	6
Health care providers	14	5	3	8
Community people (age: 22 to 42 years)	4	2	2	4
Total	69	30	19	49
General characteristics of PLTB participated in interview (n=31)				
Local resident		7	3	10
Migrant		15	6	21
Occupation of PLTB participated in interview (n=31)				
Housewife/Homemaker		0	3	3
Factory worker, labours		14	3	17
Unemployed		2	0	2
Student		1	1	2
Local business (e.g. small shops)		1	1	2
Others		4	1	5
Median age of PLTB respondents (n=31)		36 years		

Table 9: Characteristics of FGD participants

Focus Group Discussion (FGD)	FGD 1		FGD 2		FGD 3		FGD 4		Total	
	M	F	M	F	M	F	M	F	M	F
A. People living with TB (PLTB)										
Homemaker	1	0	0	2	0	0	0	0	1	2
Factory worker, labours	4	0	0	5	2	0	4	0	10	5
Unemployed	2	0	0	0	1	0	1	0	4	0
Student	1	0	0	0	2	0	1	0	4	0
Local business (e.g. small shops)	0	0	0	1	2	0	1	0	3	1
Others	0	0	0	0	0	0	2	0	2	0
B. Health Service Providers										
DOTS clinic staff	3	3	4	2					7	5
District supervisor	0	1	1	1					1	2
Lab technician/assistant	1	0	0	0					1	0
DOTS clinic volunteer	0	0	0	1					0	1
NTP officials	1	0	0	0					1	0

People Living with TB (PLTB): a person diagnosed with TB is normally known as a ‘*TB patient*’ in both the NTP and the community. However, I started naming them as ‘*people living with TB*’ (PLTB), because a young male patient told me that being named as a TB patient grossly undermined his position as a normal member of his family and community. Other people, and especially members of the community, (except other PLTB) who already perceived them as ‘different’, further stereotyped them by naming them as TB patients. In many instances, such stereotyping further demoralised them. According to this interviewee, members of the community (and many health workers as well) started seeing them only as a TB patient, with no autonomy, and a burden and a risk to others, thus completely overlooking their role in their family and community. I therefore decided to use the phrase ‘*people living with TB*’ in my thesis and in my work.

PLTB in the study area were from various strata of the population: however, the majority of my study respondents were migrants⁴, presented as ‘migrant’ or ‘migrant

⁴For the purpose of this study, migrants are defined as people coming to the city area (Kathmandu Valley) from other parts of the country. A majority of migrants were from rural areas of the country.

worker'⁵ as appropriate. The magnitude of TB burden among migrants in the study area was unknown as there was no official estimate available in the NTP. However, discussions with DOTS centre staff, and other anecdotal evidence suggested that a majority of registered TB cases in the study area were migrants with low socioeconomic status and very limited social networks as most had come to the city in search of work. At the start of the study, I did not plan to focus only on migrants and people with low socioeconomic status, but as I proceeded with interviews, I found many issues were related to these groups. However, I also sought information from PLTB who were local residents⁶ and other non-migrants. The occupation of respondent PLTBs varied, but the majority among migrants were workers and daily labourers in factories producing products such as carpets and bricks, and in building construction. Respondent PLTBs were from a variety of caste and ethnic backgrounds with a median age of 36 years.

Family members of PLTB: For the purposes of the study, family members were defined as those who had biological and cultural relationship with PLTB and were living as co-residents. In general, the family consisted of a father, mother and their children (i.e. a nuclear family). Some PLTB had an extended family structure (a joint family). In joint families, at least two generations of family members were living together in one house: members often comprised grandparents, their sons and their sons' families. Generally, the oldest man headed the family. I found that family members of PLTBs were important sources of information who could provide a depth of understanding on experiences of TB and its treatment, and their management of consequences at home and in the community, because family members were with the PLTB from the start of illness to treatment completion, and shared the journey of sorrow and happiness together. My interviews with PLTB clearly demonstrated the crucial role in their treatment of family members as supporters, not only accompanying them to DOTS centres, but also assisting them at home and work, and in financial and social areas. In the study, I interviewed the husband, wife, mother or father of the PLTB as I found these were the family members who generally assisted the PLTB during their treatment. However, in some cases, where appropriate I also interviewed brother and sisters of PLTBs.

⁵In the study, migrant workers were those who had temporarily migrated to the city and were working in factories and small private firms or were daily labourers.

⁶For the purpose of this study, local residents were defined as indigenous people living permanently in the study area.

Frontline health care providers: In the study, frontline health workers were those working in DOTS centres who had direct interaction with PLTB on a regular basis as part of their role in TB service delivery. They included government, NGO and private health sector employees who were working in one of the identified urban DOTS centres in the study area. I wanted to explore their practical experiences in implementing TB services in the local context and their first hand experiences with PLTB during their treatment. It was important to investigate their understanding of TB treatment policy, feasibility of implementation of policy options, policy relevance and awareness of problems in the urban TB control programme. Their knowledge and behaviour towards the TB disease and PLTB, and their opinion regarding patient centred TB service delivery were crucial components of the study. All frontline health workers working in TB had received five days basic TB training provided by the NTP.

NTP authorities: NTP officials were defined as government officials working for the NTP in various roles at central, regional and district level. These officials were staff of general health services under the Ministry of Health and Population. Many, particularly those working at central level, were involved in policy development and providing technical and operational guidance to front line health care providers involved in TB control. Those interviewed included the Programme manager, senior officials, regional TB officers/coordinators, district health officials including district TB officers, and programme supervisors. TB programme supervisors in districts, also known as District TB and Leprosy Assistants/Officers were responsible for ensuring effective implementation of TB control policies including DOTS in the districts. Other major areas of urban TB control they were engaged in included monitoring and capacity development. Issues discussed included their roles and areas of engagement in urban TB control. I had several formal and informal interactions with these people during the course of the study while enabled me to understand NTP policy and implementation aspects related to TB treatment management.

Community members: For the purposes of the study, I considered members of the community to be people who were living in the community and were not directly affected by TB: such people had roles in shaping support or otherwise to PLTB and their families. I did not include any PLTB or their families in this group, even though they were also members of the community in which they were living.

Evidence showed that the socio-cultural understanding and perceptions of community members regarding TB disease and PLTB greatly affected PLTBs' lives, including

their treatment continuation. It was therefore important to document such perceptions and understand how differing knowledge and perceptions affected the social lives of PLTB and their treatment behaviour. The community included various people and groups, but I focused on community volunteers who had a degree of involvement TB control in various roles such as late TB tracers and members of DOTS committees. The late TB tracers were volunteers identified by the programme who had mostly received orientation on TB including DOTS. They were not salaried. Their involvement in DOTS was visiting PLTBs when they were late coming for treatment, educating them and their families, and providing support to the DOTS centre in delivering TB services in their local area. The DOTS centre coordinated these volunteers. As one focus of the study was to understand why PLTB are late for or discontinue treatment and how this is managed, it was important to better understand the experiences and practical understanding of late TB tracers. Likewise, it was important to gain insight on whether and how the late tracing mechanisms worked in different contexts. These people also interacted with PLTB and their families during the course of their treatment so it was important to document their perceptions and behaviour towards them.

The DOTS committee is a voluntary community group formed to gain community support in implementing DOTS. Formation of committees was perceived as a means of community participation in TB control in Nepal, the NTP encouraged all DOTS centres to do so when DOTS was established. Most of the DOTS centres in urban areas had formed a DOTS committee comprising members from the local community including local political leaders. However, their level of involvement in DOTS varied greatly thus their knowledge of and opinions in the study.

4.3.5 Sampling strategies

Unlike quantitative research, which aims to generalise study findings to a larger population, the purpose of qualitative research is to provide in-depth insight into the issues under investigation, eliciting human experiences and interactions and illuminating meanings, rather than making general statements (Glaser and Strauss, 1968). Although use of qualitative research in health care has increased over the years, it faces some challenges, including in particular how to justify sampling strategies and recruitment of study participants (Marshall, 1996). See Table 10 for some examples of sampling in qualitative research. Marshall suggests that the use of various complex terms in qualitative research, frequent changes in views and interpretation of these terms and ambiguous sampling strategies in qualitative research have fuelled confusion, especially among quantitative researchers who question the generalisability of findings from qualitative studies. Patton (1990) recommends that qualitative studies focus on understanding the conceptual links between the issues under investigation, emerging themes from the data, and research subjects and their selection process, instead of numerical considerations in selecting research subject and size.

Table 10: Examples of qualitative sampling

Scholars	Proposed sampling strategies
Strauss & Corbin (1990)	Theoretical sampling – three stages <ul style="list-style-type: none"> • open sampling • relational and variational sampling • discriminate sampling
Patton (1990)	All sampling is purposeful – 15 strategies <ul style="list-style-type: none"> • extreme or deviant case sampling • intensity sampling • maximum variation sampling • homogeneous samples • typical case sampling • stratified purposeful sampling • critical case sampling • snowball or chain sampling • criterion sampling • theory-based or operational construct sampling • confirming and disconfirming cases • opportunistic sampling • purposeful random sampling; • sampling politically important cases • convenience sampling
Morse (1991)	Four types: (i) purposeful sample, (ii) nominated sample, (iii) volunteer sample, and (iv) total population sample
Sandelowski et al. (1992)	<ul style="list-style-type: none"> • selective sampling • theoretical sampling
Sandelowski (1995)	All sampling is purposeful – three kinds <ul style="list-style-type: none"> • maximum variation • phenomenal variation • theoretical variation
Marshall (1996)	Three types <ul style="list-style-type: none"> • Convenience sample • Judgmental sample • Theoretical sample
Ulin et al. (2005)	<ul style="list-style-type: none"> • theoretical • priori

Source: Adapted (with some additions) from Coyne 1997

Overall, however, there are three broad approaches in qualitative sampling strategy: convenience sampling; purposive sampling; and theoretical sampling (Rubin and Rubin, 1995; Marshall, 1996; Silverman, 2005).

Convenience sampling refers to the selection of research subjects who are easily accessible to the researcher. In this technique the researcher puts comparatively little effort into finding research subjects, either individuals or groups. In contrast, *purposive sampling* is the recruitment of research subjects guided by their relevance to

specific research objectives/questions. This is one of the most commonly used sampling techniques in qualitative research. Patton (1990) considers that the broad term 'purposeful sampling' can define all types of sampling in qualitative research. *Theoretical sampling* is based on a continuous interplay between the researcher, the ongoing data gathering process and its simultaneous analysis, which guides the researcher in selecting the next research subject, to help further examine and elaborate emerging concepts (Ulin *et al.* 2005). When the researcher decides the next research subject according to emerging codes and categories, this is described as a theoretical sampling process (Coyne, 1997). This sampling technique is particularly used when research focuses on an explicit construction of theories grounded in real circumstances (Strauss and Corbin, 1990).

There is considerable overlap between these sampling strategies, and especially between purposive and theoretical sampling, and in fact the phrases purposive sampling and theoretical sampling are often used interchangeably in the literature. In practice, qualitative researchers are generally guided by their research objectives/questions as well as the theoretical framework of the research when it comes to identifying sampling techniques and recruitment of study participants (Ulin *et al.* 2005), and use of such techniques usually demands a flexible approach. Silverman (2005) suggests that all methods are acceptable as long as the researcher takes a flexible approach, considering the study objectives, context, research subjects and emerging concepts in data, and provides a deeper understanding of social phenomena related to the issue under investigation.

In the study, I used a mix of convenience and purposive sampling strategies. Study participants were drawn from the various groups discussed in section 4.3.4. It was important to identify study participants who could candidly explain their experiences with TB and its treatment, perspectives, and behaviours and their consequences in successful completion of TB treatment. I therefore focused on a specific subset of people who had direct experience with TB and its treatment and who could talk openly. I developed an initial plan to recruit potential study participants: however, at the start of data collection, I was unclear about *who* to recruit and *how many* participants would be sufficient to best answer my study objectives. I therefore initially used convenience sampling: however, study participants were identified in consultation with frontline health workers in DOTS centres. Once I had interviewed some study participants, issues started to emerge. In the light of the study objectives and issues emerging from the data, I identified subsequent participants to broaden my

understanding on the issue emerged. For instance, once it emerged that the fixed opening hours of DOTS centres hindered many PLTBs' treatment, I chose some participants who had jobs with fixed hours, to understand whether and how the centre's opening hours influenced their treatment continuation and their coping strategies. In deciding sampling strategy, I not only took the research participants into account, but also considered the local context, willingness to participate, trustworthiness, my relationships with key informants, interview location and many other factors that could influence data generation. I also looked for participants who could be critical of ideas emerging from the data, to elicit opposing views if they existed. For example, in my sampling I sought health workers who were critical of the DOT policy and of overall service delivery in urban areas. I stopped collecting data once no new issues emerged and no additional insight was forthcoming.

4.3.6 Recruitment of participants

This section describes the process that I followed in recruiting study participants, with special focus on in-depth interviews, as recruitment for FGDs has already been discussed in section 4.3.3.2. First, I considered identifying PLTB who were willing to be interviewed and to detail their experiences with regard to TB disease and their treatment processes, the central focus of the study. The following steps were performed in selecting PLTB for in-depth interviews.

First, I visited each DOTS centre and met the frontline health care providers there. I explained about my study area, aim and objectives, potential study groups and methods. I sought their verbal approval for the study to be conducted in their centre. I assumed that frontline health care providers would have an idea about general characteristics of the PLTB who they were serving: i.e. social, cultural and financial background; occupation; behaviour during treatment; openness and willingness to talk about their experiences etc. The visits helped me to understand the basic characteristics of PLTB who were undergoing treatment at the centre; the feasibility of conducting in-depth interviews there; the willingness of the service providers to cooperate in the study; and the feasibility of recruiting PLTB into the study.

Next, I went through the main TB register of all PLTB taking treatment from the centre. I obtained the details of the PLTB available there: registration and treatment start date, full name, age, sex, address, disease classification and registration category, and result of sputum examination (initial and follow-up). I also reviewed the TB

treatment cards of the PLTB and obtained information about their treatment history i.e. whether there was any lateness and retrieval; side effects of drugs; and history of disease (current and previous). After a rigorous process of information collection, I selected some names and discussed them with the service providers.

Finally, I individually approached the PLTB who I had identified. I briefed them about my identify, the study purpose, their expected role in the study and voluntary participation, any implications to them and their treatment if they chose to participate/not participate in interviews, use of information and its confidentiality and the interview process. After a few interviews, I pursued issues raised in previous interviews and identified appropriate participants who would provide greater insight into the issues identified. I also selected participants who had specific characteristics and experience in order to understand typical conditions and their influence in TB treatment completion, such as people who were frequently late in their treatment; people who had stopped TB treatment due to side effects of TB drugs; people who frequently had to travel as part of their occupation; migrants; people residing in slum areas and daily labourers. I did not take this approach to generalise knowledge gained from specific cases, but to enhance understanding of various characteristics.

In total, I approached 43 PLTB for interview, of which 31 agreed to participate. It was a very time consuming process. Reasons for non-participation included lack of time for interview; did not get approval from household (especially women and young girls); not willing to talk about their disease; did not want to participate because this was the first time they had talked to an interviewer; did not see any benefit of talking to an interviewer; did not think they have anything special to tell.

During the process of identifying PLTB for interview, I considered potential selection bias: however, I was interested to know the issues in-depth rather than trying to cover all groups in the study. It was likely that service providers suggested those PLTB that they thought easy i.e. people with whom they had a good relationship, who would not talk negatively about them and the services they were receiving from the centre; and people who had never complained about their treatment. I was concerned about such potential bias, so used not only discussions with service providers but other approaches when selecting study participants. My multiple visits to the centres and careful observation of the services provided helped further to minimise bias.

Another group I recruited for in-depth interviews was family members of PLTB. For convenience, the majority of family members selected were accompanying PLTB to

the DOTS centre either for daily DOT or follow-up. In some cases, PLTB were also present during the interview with family member, as the context did not make it easy to ask PLTB to leave the family member. However, responses were obtained from the family members and by making clear that I wanted to interview the family member about their experiences, possible interferences in the interview were minimised. In such conditions I also assumed that the family member who accompanied PLTB to the DOTS centre had a good relation with PLTB and provided support. However, on a few occasions during interview family members were critical about the PLTB, especially on their personal habits i.e. smoking, dietary habit, and negligence in taking TB drugs. Such comments confirmed my assumption that I had created an environment where family members could air their views openly. Not all family members were interviewed with the PLTB. I also visited PLTBs homes and interviewed the family members there, in agreement with PLTBs. In some cases, I interviewed a family member who went to the DOTS centre to collect drugs without the PLTB. In most cases, family members were spouse (in the case of a married couple), or a parent of the PLTB (in the case of children). Young unmarried girls were mostly accompanied to the DOTS centre by their mother, who was thus identified for interview. However, I could not interview PLTB who did not support the PLTB in their treatment, or those family members who discriminated against the PLTB in the family, as gaining access to them was not feasible.

I also interviewed frontline health care providers. I mainly approached service providers working in identified DOTS centres, because their role was to facilitate TB treatment; hence, I assumed that they had frequent interactions with PLTB throughout the various stages of care seeking. According to NTP policy, their role was identified as a DOT provider, which means they were the one implementing the NTP's DOT policy at service delivery level thus had firsthand experience in DOT and its feasibility in the context. The service providers were also an important source of information to PLTB regarding TB disease and treatment management, which had a big role in TB treatment completion. Moreover, most of the providers were local residents and were aware of the complexity of the urban environment, especially regarding essential health care services. I conducted in-depth interviews and FGD with this group (see more on FGD in section 4.3.3.2). The service providers were purposively selected for in-depth interviews. Fourteen frontline health care providers were approached for interview, of which 8 (5 men and 3 women) agreed to participate. The reasons given for non-participation were: no prior experience of giving such interviews; concerns

about jeopardising their job by describing differences between policy and practice; no approval from organization; and personal unwillingness to participate. Interviews were conducted in DOTS centres.

Similarly, NTP officials were identified as key informants, because NTP senior officials, in particular at national level, were involved in policy formulation, providing technical assistance to districts including to the urban TB control programme and overseeing overall implementation along with engagement in monitoring of NTP activities. TB programme supervisors also worked in district public health offices. They played a key role in setting up and managing the urban TB control programme in collaboration with other stakeholders in the study area. The purpose of key informant interviews with NTP officials was to gather information as they had particular knowledge and understanding about the NTP policy and its implementation, especially in TB treatment management, thus I assumed that they could provide insight on the issues identified from field data collection, from policy and programme implementation perspectives. NTP officials were identified purposively based on their roles and responsibilities in the NTP. I also interviewed senior members of the public health division of the municipality in Kathmandu as they were the key partners providing TB services in collaboration with the NTP in the study area.

Another group I interviewed in the study was community members. DOTS committee members and volunteers (late TB tracers) were identified for the interview after discussion with DOTS centres staff. Lists of volunteers were obtained from the DOTS centres, from which I identified volunteers who had experience of tracing late PLTB. (Not all tracers had traced PLTB, nor were all of them actively involved in TB control activities.) I did not consider interviewing non-active TB tracers, even though they could have provided reasons of not getting involved, because the focus of the study was to understand their experiences with TB and PLTB while performing their role as TB tracer. However, it could be an area of further research to understand how and why TB tracers engage or do not engage in TB control. I recruited members of DOTS committees to gain community perceptions towards TB disease and PLTB. Participants from this group were identified after discussion with staff members of the DOTS centre with which the DOTS committee was associated. As with the tracers, I only identified DOTS committee members who had had involvement in TB control.

4.3.7 Interview location and context

The purpose of in-depth interviewing was to gain a clear understanding from individuals regarding their experiences during treatment, how and why those situations occurred, and their relationships to the study aim and objectives. It was important to ensure interviews occurred in places where participants could feel comfortable to talk openly. However, in the study setting, it was hard to find good locations where all external disturbances could be prevented. Nevertheless, I made a considerable effort to find the best environment for interviews. I initially discussed with frontline TB service providers and obtained ideas about the context and possible locations where interviews could take place. Below, I describe how I worked with the participants to find interview locations.

PLTB and their family members: Once a participant had agreed to be interviewed, we discussed the location and time for the interview. I made it clear that I could be available at any place and time they proposed, at their convenience. Initially, I did not propose any location and time but it was not easy for them to suggest a preferred location and timing. For the ease of participants I then suggested some potential locations i.e. participant's home or rented room, their work place, and the DOTS centre where they were taking treatment, but made it clear that I could be available at any location they chose. Some participants proposed a different location. Preference of location and time varied among individuals: the most common were DOTS centres where they were taking treatment; their home or rented place; a restaurant; and public places such as parks, temples, and other holy premises.

The majority of PLTB and their family members choose DOTS centre where they were taking treatment. Their preferred time was when they visited the centre for DOT or drug collection. First, they took or collected their drugs, then started the interview. Many DOTS centres in the study area had limited rooms, so it was difficult to find a good location there for interview. DOTS centre staff made a room available for the interview (e.g. office room or drug store room). No interruptions occurred.

Three participants chose their home or rented room for interview. People who preferred to be interviewed at home lived 15 to 20 minutes from the DOTS centre. (I recorded the travel time when I walked with the participants from DOTS centre to their home for interview: participants perceived this as nearby.) All participants I interviewed at home had rented one or two rooms for them and their family or friends

and relatives. People who were living with friends choose a time when others were not in the room; most were out for work or visiting their village.

Three young men with TB, all migrants living with friends, identified a restaurant near the DOTS centre for interview. The restaurant owner or worker was a friend of the participant or from the same village and knew about their disease: some provided support for their treatment. I found that they had a good trusting relationship, which was the reason they preferred that place for interview. The restaurant was open to everyone but we sat in a corner and did the interview with a cup of tea. There was some external interference such as movement of people and talk, but the participant did not seem bothered.

Five participants choose public places, four inside the temple premises, and one in a public park near the DOTS centre. I found that these people often visited these places to rest on the way to and from the DOTS centre, and were familiar with surroundings.

All family members chose to be interviewed at DOTS centres, except one who chose to be interviewed at home.

Frontline health care providers and NTP authorities: All interviews with health service providers took place in their office, in accordance with their preferences. The environment appeared conducive during the interview, as the participants were open to frank discussion about the issues that arose. Similarly, NTP officials were interviewed in two locations: their office premises and at DOTS centres when they visited for supervision or monitoring purposes.

Community members: Participants from this group also given the option to choose the location of their interview. All preferred to be interviewed at the local DOTS centre.

4.3.8 Data management and storage

Qualitative data often consists of a collection of unorganised notes, transcribed conversations, audio-taped interviews, documents, matrices, hunches of ideas, maps and diagrams, photographs, field notes, etc (Mason, 2002). It is a difficult task to organise the data and use them to generate theory in line with the study objectives. In my study, I gathered a great deal of data as discussed in section 4.3.3. In this section, I describe my data management, referring specifically to primary data which I collected in the form of recorded interviews, transcripts, field notes and discussion notes.

Regarding recording of **qualitative interviews**, three different ways are commonly used: notes written at the time of the interview; notes written after the interview; and an audio recording of the interview. There are pros and cons to all these methods. A researcher who writes notes at the time of interview needs to do two things at once, which can interfere with the process of interviewing and thus compromise the quality of the interview. A researcher who writes notes after completion of the interview is likely to miss out details of the conversation, as remembering a long interview and documenting information afterwards is a challenge for most researchers. In many cases researchers prefer audio-taping, but not all respondents will be comfortable with this, especially when the topic under investigation is sensitive (Britten, 1995): some respondents do not speak openly when their interview is recorded, limiting the quality of data obtained.

In the study, I used two ways of recording qualitative interviews that were appropriate to the context: audio recording and note taking during the interview. I clearly explained the recording options to respondents before the interview started. The majority of interviews were audio recorded. Interviews with those respondents who preferred not to be audio-recorded were recorded using notes taken at the time of interview. Reasons given by respondents who did not agree to use audio recorder included feeling uneasy; first time to be interviewed; concerns about confidentiality; unwilling to be recorded because some interview questions and answers critical of policy and practice could be related to other people in the team; did not want to be recorded as voice is not good (one woman respondent commented, *'my voice is like a buffalo cry, I don't want to be recorded'*). Most people with a formal role in the NTP were reluctant to use audio recording. Similarly, women including unmarried girls were hesitant to record their conversation. I found that despite ensuring confidentiality some respondents did not seem to be comfortable to be recorded, but still consented to be interviewed. All interview records, interview notes and audio recordings were given a code and kept locked away in a place only I had access to.

The audio-recordings of the initial fifteen interviews were transcribed and then translated into English, as the interviews were conducted in Nepali. For the remaining interviews, I only translated the major concepts and issues, because in the initial full translations, I found much of the information was not relevant or had already been covered and did not bring additional insights. However, in this process, there was the possibility of missing some relevant information, so decisions on relevancy were carefully considered.

Data generated from **observation** was recorded in the form of field notes. I recorded notes in Nepali and then translated them into English during analysis. I used my notepad to record field notes in brief, depending on the context and time available and kept the notes separately.

Data generated from **FGD** was recorded in writing, as the group participants did not agree to audio-recording. A trained rapporteur took discussion notes, which were then translated into English. Consideration was given during translation to maintaining the originality of the data; I later checked this myself.

4.3.9 Qualitative data analysis

Qualitative data analysis is a rigorous process. In many qualitative studies, data collection and analysis complement each other, with analysis occurring in parallel with data collection (Silverman, 2005; Huberman and Miles, 1994). Data collection and analysis is a cyclical process: collecting, noticing, thinking, rethinking and inferring in qualitative research (Jorgenson, 1989; Krippendorff, 2004; David and Sutton, 2004). In his book *Doing Qualitative Research*, Silverman (2005) identified four ways to develop the analysis of qualitative data within a context where data analysis and data collection go hand in hand: (i) focus on data which is of high quality and easiest to collect; (ii) look at one process within that data; (iii) narrow down to one part of that process, and (iv) compare different sub-samples of the population (p. 173). He encourages qualitative researchers to develop provisional ideas of analysis and comparison categories between groups in order to maximise depth of data collection focusing on high quality data.

It is clear that qualitative data analysis requires a rigorous process of critical thinking at various stages of the research process on whether and how the data could be used to construct meaningful themes, common and/or divergent ideas and relationships relating to the phenomena under investigation. Scholars have defined various methods of qualitative data analysis e.g. grounded theory, narrative analysis, conversation or discourse analysis, and content analysis along with use of inductive or deductive approaches – either independently or using a mix of approaches (David and Sutton, 2004; Silverman, 2005). In their book *Social Research* David and Sutton (2004) suggest that two forms of qualitative analysis dominate: content analysis and discourse analysis. These two approaches complement each other and may be combined.

4.3.9.1 *Process of analysing data*

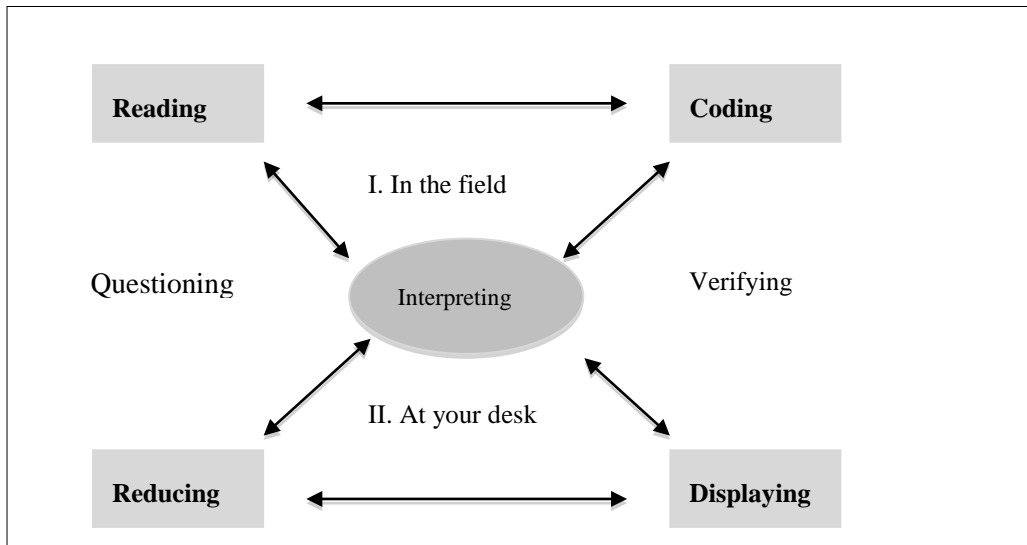
I used a content analysis approach. This is a scientific tool to analyse textual data. Krippendorff (2004) presents a definition of content analysis as: ‘Content analysis is a research technique for making replicable and valid inferences from texts (or other meaningful matters) to the context of their use.’ (p. 18)

In this definition the word *technique* emphasizes active engagement of the researcher in data analysis through application of appropriate scientific tools thus gaining greater insight of the context and issue under investigation. The use of specialised technique(s) in research is expected to be *reliable*: hence, findings derived using scientific procedures are *replicable* regardless of circumstances, when researchers apply the same technique to the same data. Application of scientific procedures in research studies including analysis of data should yield evidence that is *valid* and independent. Similarly, the use of word *text* in the above definition is not limited to written scripts only, but covers unwritten forms of data e.g. photographs, art, signs, symbols etc. However, eventually all qualitative data become text when they come to the analytical stage. In defining content analysis in qualitative research, researchers have configured their definition within three essential points: content to be inherent in a text; content to be a property of the source of a text; content to emerge in the process of a researcher analysing a text relative to a particular context (Krippendorff, 2004).

However, use of content analysis is questioned by some qualitative researchers, who see it as the imposition of arithmetical quantification in qualitative research. Researchers who reject content analysis prefer to use discourse analysis; thus the debate seems to revolve around content analysis versus discourse analysis (Silverman, 1993; David and Sutton, 2004). However, some qualitative researchers believe in the value of content analysis to maximise depth of analysis of qualitative data (Berg, 1998; Huberman and Miles, 1994), and urge that the researcher using content analysis needs to construct a context within which the text makes sense and can answer the researcher’s questions relating to social phenomena.

I used content analysis within which I applied detailed and inductive approach. Figure 11 outlines the components of my interactive approach to data analysis, which I adapted from Huberman and Miles (1994).

Figure 11: Qualitative data analysis- steps-by-steps



Source: Adopted from Huberman and Miles 1994, p. 429.

In the figure, I focus on the process that I used in data analysis in parallel with data collection, and the interactive relationships between data collection steps and analysis: reading; coding; reducing; displaying and interpreting. I emphasise that I did not precisely use a grounded theory approach in the study as defined by Glaser and Strauss (1967).

Interim analysis: I considered data analysis as an ongoing and frequentative process. I made an interim analysis (not in-depth and explicit at this stage) during and after each event of data collection, based on reading the content of the data. Reading through data helped me to understand whether the responses were full and detailed, or superficial. At this stage I also reviewed whether other aspects, such as context, location of interview, selection of study participants, and broadmindedness of participants and health care providers influenced the study: I also gave these aspects repeated consideration throughout data collection. At this stage of interim analysis I also looked at new issues emerging from the data and started to assess linkages. I continued doing this until I had understood the issues or areas emerging during data collection. The interim analysis helped make sense of the data and focus subsequent data collection events on emerging themes and the study aim and objectives. This also helped me avoid being overwhelmed by data as my data collection was guided by issues arising from the data, thus omitting unrelated data which were outside my study area, while permitting widening of the scope of data collection to admit new issues. My continue reading of data as they were collected helped me to assess the quality of

my notes and transcripts, the data collection process, my observation methods and my interactions with study respondents.

Although there are several software packages for qualitative data analysis, I chose to record and analyse data manually, as my previous experience as a qualitative researcher gave me a degree of confidence in this approach.

Coding: Coding is a process where codes (key words, themes or phrases) are applied to textual data which highlight similarities and differences within and between text (David and Sutton, 2004). I found that coding was a major step in data analysis as it starts the data analysis and prepared me for further in-depth analysis. Although most qualitative researchers use some form of coding exercise in qualitative research, no standard rules exist on how coding should be done. It is up to the researchers to decide what types of code to formulate and how they should be used (Ulin et al., 2005): however, coding in line with research objectives/questions helps researchers to see the association of data with the objectives and thus advance further analysis. I assigned a code to each meaningful segment of text as it occurred: I call this first level coding. I used an inductive coding approach: codes were generated after initial reading of data, known as open coding. While selecting codes, I primarily considered original ideas, concepts, and words used by study participants during the interview. In doing so, I found it appropriate to generate various codes keeping the original concepts within the conversation recorded in the data. Reoccurring segments of data were coded several times (but with the same code) as they appeared and eventually clustered under one theme after verification. It was unmanageable to have too many codes, so after the initial coding I reviewed the coded data and reduced the codes to a manageable level without losing data and keeping the original sense intact. I personally coded all data.

Data grouping, categorization and theme identification: After coding each segment of data, I clustered the codes and used them to develop themes and categories. Extracting and combining of information from the data under various themes allowed me to look at the data more closely and examine them separately and jointly. I repeatedly referred back to my study objectives. This also helped me to identify linkages between and among categories to deepen my understanding of issues identified.

Data reduction: The data reduction process started when I fully finalised coding and grouping of data under themes. Before reduction, I was well acquainted with all major themes and subthemes and various categories that I generated from the data, and had an understanding of various links and meanings of themes and sub themes (Ulin et al.,

2005). In the data reduction stage, I carefully considered the identified themes and their linkages to the research objectives. I also looked at why some unrelated themes occurred, and hence whether they had any connection to other themes. I found some interesting things in the data that were not related to my study objectives: such irrelevant segments were dropped during the final analysis process. I used handwritten flow charts and matrices to understand whether and how the data segments I wanted to drop from the final analysis had any association with the study objectives.

Comparisons: After clustering data segments under various themes I extracted commonly understood meanings, then used constant comparison of features of the evidence emerging from the data analysis process. This helped me to understand patterns of similarities and differences, and enablers and barriers. It also helped me to understand the robustness of issues and to avoid misleading interpretations of data. However, comparison was often not easy as multiple themes were derived from the data and comparing them to events and features of certain groups or individuals was a challenge. I also found various commonalities as well as differences in responses, so that in a few instances comparisons and their interpretations were rather mystifying.

Interpretation: Interpretation is considered to be the establishment of a concept through identification and appropriate explanations of the core meaning of data (Ulin et al., 2005). In the study, I considered interpretation not just as an act of providing interesting notions about the data: I was more interested in explaining what all the identified themes and subthemes in the data meant and how they related to individuals or groups of individuals and their social interactions under different circumstances. In the study, interpretation was not made only at the end of study (i.e. after collection of all data): but at various stages including during observation and interviews and while reading interview transcripts. Essentially, my interpretation of the data was based on: the categories and themes produced from the data and their originality; concepts and ideas that emerged from data grouping; contextual meaning of data relevant to the study setting and the people studied; my best judgment related to the issues that emerged without manipulating the essence of issues; previously documented knowledge on issues in the local context and elsewhere; and the study's aim and objectives. However, before arriving at the final interpretation of the data's core meaning I frequently revisited the data, the concepts that emerged from the data and their relevance to the context and the study objectives. Similarly, I also considered the key questions put forward by Silverman (2005), which he suggested that qualitative researchers should take into account before they actually plunge into data analysis and

revisit them during analysis: what are appropriate method(s) of data analysis? Do the analysis methods suggest interesting questions? Is the analysis method likely to generate interesting generalisations? Do previous research findings seem to apply to the study data? How do particular concepts from the preferred social research model apply to the study data? Which concepts work best and are likely to be most productive? (p.152)

Nevertheless, in some instances it was difficult to make appropriate interpretations, particularly when respondents were reticent about an issue, either due to perceived risk of being explicit or lack of understanding of the issue. I also experienced challenges while interpreting core nuances from the data when there were multiple dimensions in the data indicating multiple meanings of an issue or finding – either in similar or in different contexts. This happened generally when contradictions were observed on the same issue with the same group. However, I found that further thought and comparison between themes and subthemes and emerging concepts, with greater understanding of the context, helped my interpretations in such circumstances.

4.3.10 Contribution of different data sources

The purpose of this study was to develop an in-depth understanding of TB treatment completion – problems, issues, responses and ways to address them in the specific contexts in which they arose – mainly from the perspective of PLTB. I used the following qualitative research methods: (i) in-depth interviews, (ii) FGDs, (iii) observations, and (iv) document review, which are discussed above. These methods were equally important and complementary in the study, enabling information to be triangulated and validated. It is not appropriate to quantify the relative contribution of different data sources when judging the merits of the study findings, developing arguments and building theory. Comparative weighting of methods used in evaluating qualitative research is complex (Elder and Miller, 1995; Krik and Miller, 1986), especially when multiple methods are used. However, considering the frequency of methods used and adequacy of responses gained on the issues and complexities of the phenomena that I researched, I found that in-depth interviews, FGDs, field observation and document review all contributed substantially to the study findings.

4.4 Validity and reliability

The definition of *validity* varies among qualitative researchers since there is not a single, fixed or universal definition of the term. Hence, use of the term in qualitative research paradigm is often subject to controversy, unlike in quantitative research. However, many qualitative researchers have given their own concepts of validity and presented terms that they considered appropriate, such as: ‘trustworthiness’, ‘worth’, ‘quality’, ‘rigor’, ‘plausible’, ‘representative’, ‘confirmable’, ‘credible’, and ‘relevant’ (Denzin & Lincoln, 1998; Guba & Lincoln, 1989; Hammersley, 1987; Mishler, 1990; Wolcott, 1990).

Hammersley (1990) relates his concept of validity to the account of truth that a researcher needs to represent correctly while interpreting phenomena in his/her study. He stated; ‘By validity, I mean truth: interpreted an account is valid or true if it represents accurately those features of the phenomena, that is the extent to which an account accurately represents the social phenomena to which it refers.’ (p. 57).

Hammersley (1992: 67) also defines reliability from the point of view of consistency in the research: he notes, ‘reliability refers to the degree of consistency with which instances are assigned to the same category by different observers or by the same observer on different occasions.’ In contrast, some researchers do not use the term reliability, stating that the term is not applicable in qualitative research. Rejecting the concept of reliability in qualitative research, Stenbacka (2001) stated; ‘the concept of reliability is even misleading in qualitative research. If a qualitative study is discussed with reliability as a criterion, the consequence is rather that the study is no good’ (p. 552). Thus, the understanding of reliability among qualitative researchers is found to be as complex as the understanding of validity. Table 11 is a summary of Hammersley’s (1987) reviews of reliability and validity as defined by various authors from different methodological positions.

Table 11: Hammersley’s review of validity and reliability - definitions by various researchers

Validity	<p>‘An agreement between two efforts to measure the same thing with different methods’ – Campbell and Fisk (as cited in Hammersley, 1987)</p> <p>‘The measure that an instrument measures what it is supposed to’ – Black and Champion (1976, pp. 232-234)</p> <p>‘Accuracy’ – Lehner (1979, p. 130)</p> <p>‘Degree of approximation of ‘reality’ – Johnston and Pennypacker (1980, pp. 190-191)</p> <p>‘Are we measuring what we think we are?’ – Kerlinger (1964, pp. 430, 444-445)</p> <p>‘to the extent that differences in scores yielded ... reflect actual differences’ – Medley and Mitzel (as cited in Hammersley, 1987, p. 150)</p>
Reliability	<p>‘An agreement between two efforts to measure the same thing with the same methods’ – Campbell and Fisk (as cited in Hammersley, 1987)</p> <p>‘Ability to measure consistently’ – Black and Champion (1976, pp. 232-234)</p> <p>‘Reproducibility of the measurements ... stability’ – Lehner (1979, p. 130)</p> <p>‘Capacity to yield the same measurement ... stability’ – Johnston and Pennypacker (1980, pp. 190-191)</p> <p>‘Accuracy or precision of a measuring instrument?’ – Kerlinger (1964, pp. 430, 444-445)</p> <p>‘To the extent that the average difference between two measures obtained in the same classroom is smaller than ... in different classrooms’ – Medley and Mitzel (as cited in Hammersley, 1987)</p>

Source: adapted from Winter G. (2000). Retrieved from www.nova.edu/ssss/QR/QR4-3/winter.html

Expectations of highly consistent ‘high reliability’ in qualitative studies can result a systematic bias in data generation and interpretation, as reality is dynamic in social phenomena and changes constantly, so that attempting to attain high reliability will grossly compromise validity. Therefore, in qualitative research, many researchers focus on validity and some of them also consider validity as the combination of ‘validity’ and ‘reliability’ (Hammersley, 1987). Mason (2002) argued that the terms validity, reliability and generalisability, which he named ‘scientific criteriology’, often do not fit comfortably with the essence of qualitative research – the way qualitative research conceptualises, designs, implements and interprets – and thus discussion on how qualitative researchers measure the significance of ‘scientific criteriology’ should not be the primary debate; instead, researchers should focus on the bigger picture of qualitative research; that is quality and rigor.

In my study, I looked at two aspects of so-called validity: *data generation methods* and *interpretation* (Manson, 2002).

In general, validity in research is largely determined by the use of research instruments based on which interpretations are made. As Patton (2001) pointed out, in qualitative research ‘the researcher is the instrument’ (p. 14), thus the validity and credibility of qualitative research depends largely on the ability and effort of the researcher.

Threats to the validity of the research techniques that I used emerged from the outset of my research; I constantly addressed these threats through rigorous thinking at various stages of my research. An important approach that I instigated at the beginning of my research was – who could contribute to answer my research objectives; how I could recruit them into the study; what alternatives did I have in identifying potential data sources and methods of generating data from the identified sources; and how and whether the context was conducive for the kind of research I was conducting. Such thinking forced me to learn more about methodological stances that I took in the study. In the overall design of my research approach (see section 4.2), including selection of study participants and data generation methods, I consistently looked at the relationships between selection of methods, potential study participants, selection of research sites such as DOTS centres and my research objectives and the kinds of theory and explanations that I sought in the study. I put every effort into generating trustworthy data in the field. I conducted the great majority of qualitative interviews and moderated all FGDs, constantly checking and verifying data, asking myself questions such as: Does this data make sense? Can I trust the data source? Does this segment of require verification from the source? Was the respondent fair in his/her answers? Had there been any pressure on the respondent to answer questions in a particular way? It was not easy to get answers to all these questions but I constantly retained my stand to search for the best through understanding of the context and establishing a good rapport with the respondents. In a few instances, I used other researchers in qualitative interviews, but I judged their skills as researchers to be good and I provided training to further enhance their skill before they actually commenced fieldwork. Similarly, a well-trained rapporteur in FGDs also ensured quality of FGD discussions.

Interpretation of data and inference were achieved through content analysis using a flexible approach in which constant comparisons and triangulations were ensured.

Comparisons of categories to understand similarities and differences between two constructs were important to enhance richness of data interpretation and thus trustworthiness. Comparisons were made not only between categories of data, but also between study participants and their responses to the issues emerging from the data. Broadly, triangulation refers to the combined use of more than one method of investigation to look at the study findings – that is, methodological triangulation. However, in qualitative research, triangulation is not limited to methodological triangulation, but is also used to seek explanations for similarities and differences and record the construction of reality, considering respondents, theories, investigators, and data generation (Denzin, 1970). The purpose of triangulation in qualitative research is to enhance confidence and credibility of data interpretations and thus reduce uncertainty and increase the plausibility of inferences. The use of multiple methods in data generation, such as qualitative interviews, observations, FGDs and key informant interviews further helped to yield more valid, reliable and diverse construction of realities in the study.

Similarly, during data generation, especially in qualitative interviews and FGDs, a probing strategy was adopted which helped to avoid misleading conclusions during data analysis. At the end of each interview I verified with respondents the key issues that emerged during conversation. I considered performing a full validation of data interpretations with the study respondents but concluded this was not feasible because of problems accessing respondents, especially PLTB and their family, as they were not in touch with the DOTS centres after they completed treatment and many of the respondent PLTB were migrants and thus mobile.

Chapter 6 touches further on validity and reliability related to the generalisability of my findings.

4.5 Ethical issues and considerations

I obtained ethical clearance for the study from the Ethical Review Committee of Tribhuvan University, Institute of Medicine, Nepal. As per my research proposal and the guidance of the ethical review committee, I used an information sheet and consent form (see annex 3 and 4) written in Nepali (Nepali was the common language of all participants). The ethical review committee reviewed and cleared the form. Obtaining written consent from participants was explored and rejected, as it was not deemed feasible within the Nepali culture and the local context where people had reservations about signing any documents. Thus, I decided to gain verbal informed consent from all research participants, an approach approved by the ethical review committee. The information and consent form was read out to the participants before the interview started. All participants were clearly informed about their right to withdraw their consent at any time during the study and assured that a decision to withdraw would not affect the treatment that the PLTB was receiving. All participants were also informed if they did not wish to answer any question(s), they had the right to do so at any stage of the research process. I also informed the participants that data generated from interviews would be used for my doctoral thesis and publication as seen relevant but no identification of participants would be made. Before each interview, potential study participants were clearly informed about the purpose of the study and the interview, and their role in the study.

In addition to the information and consent form, I developed an information sheet containing other related information regarding the study and provided it to the participants. Sometimes I read the consent form and information sheet, while in other cases I helped participants to read them. Some study participants took the information sheet with them after the interview. I encouraged participants to ask any questions they had regarding their participation and the study.

I was fully aware of the need to preserve the anonymity and confidentiality of participants' identities and information. All information obtained from individual participants was recorded using either audio taped or written notes, only for the purpose of the study, and no names were used on these recordings, as code numbers were used instead of participants' names. I or my team (the additional interviewer and the rapporteur) did not and will not disclose names or any other information that could be used to identify study participants, either in this thesis or in any other circumstances.

It was also explained to participants that all data would be destroyed after the purpose of the study was achieved: a completed PhD thesis and associated publications. I also mentioned to study participants that I would provide feedback of the major findings to participants through using available means. Considering the context I thought it appropriate to use local radio stations to provide this feedback. I will also use the DOTS centres and staff members involved in the study to communicate findings to PLTB and their families. I did not take any biological samples of any kind in the study. I also obtained permission from the NTP to conduct the study in their programme setting, having presented how I was going to maintain ethics standards and protect the rights of study participants throughout the study.

4.6 Limitations in data collection

In this section, I focus on limitations that I experienced in the data collection process. Limitations were observed during data collection: however, throughout the process I made efforts to understand limitations and then overcome or minimize their implications as the study progressed.

One limitation was that I planned to interview some specific groups of people as guided by the issues emerging from the data, but could not do so. For instance, there were some young unmarried girls receiving TB treatment under DOTS in the study area. I approached them but most refused to participate in the study because their parents did not give permission for them to be interviewed, mainly because of concerns about being identified as a TB patient by the community.

Data collection may have been affected by external factors such as interview locations. Although the interview location was decided after discussion with research participants, there were not many options available where interviews could be conducted without external interference. In some instances, I noticed that research participants were not willing to share specific information, such as how they were treated in health institutions, and especially health workers' behaviour towards them. Such reluctance was mainly observed when the interview took place in a DOTS centre. Considering this limitation, I encouraged PLTB to choose an alternative interview location but had limited options available.

Some women participants from the Newari ethnic group preferred to talk in Newari, a common language among Newar community in Kathmandu, but at the initial stage of data collection, I was not able to address this issue. Once I became aware of this issue, I trained a female researcher who then did interviews in Newari.

There was a perception that women would not talk openly when interviewed by a male interviewer. Initially, I interviewed a few women, and then used a trained female researcher to interview female respondents. I found that there was no difference in openness about issues experienced during TB treatment. However, I used both to avoid limitations. Use of an audio recorder was not acceptable to some study participants and it was difficult for the researchers to note all conversations, so some important points from conversations may have been missed. Similarly, one interview was not properly recorded due to a problem with the recorder, and had to be excluded from analysis, as it was not possible to redo the interview.

Selection of research participants for interviews and FGD may have had some limitations as it was done largely in consultation with DOTS centre staff. It can be assumed that they may have proposed research participants who they thought would respond favourably when asked about their experiences with TB service providers.

One of the tools that I used in data collection was observation. My physical presence during observation at the DOTS centre may have influenced the service delivery environment and the behaviour of health care providers and PLTB. However, I tried to minimize this limitation by creating a good relationship through several visits and interaction with health service providers, so as they could see me not a 'quality assessor' of services they provided to PLTB and others.

One limitation in data collection could be the cultural understanding or perception of the Nepali people. In Nepali culture, people often try to please by not saying negative things even though there could be many negative issues that occurred. This might have happened in this study: however, I considered this and tried to avoid it by developing informal relationships through many meetings and visits before obtaining data from participants.

Wider limitations observed in the study are described in chapter 6.

4.7 Conclusion

This chapter described the research approach and design, and approaches to ensuring validity and reliability of the study findings, along with a rationale of the methods and approaches used during the various stages of my research. The chapter further discussed ethical considerations throughout the research process and some observed limitations in data generation in the study. The next chapter presents my study findings and initial discussions.

CHAPTER FIVE:

STUDY FINDINGS AND INITIAL DISCUSSIONS

The previous chapter described the research design and methods used in the study. This chapter presents the study findings and initial discussions. The chapter broadly examines the issues that hindered or helped TB treatment completion from the perspectives of PLTB. I have divided the chapter into three major sections inline with my study objectives: issues in successful and unsuccessful treatment completion; organisation of TB service delivery as a response to the issues related to successful and unsuccessful treatment completion; and, factors enabling successful treatment completion. The third objective of my study - identify appropriate ways of addressing the problems and issues identified – is discussed in chapter seven.

To broaden understanding of successful and unsuccessful completion of TB treatment, I have primarily considered perspectives gained from the three major stakeholders: PLTB and their family members; the health system (which includes the NTP and health workers); and the community (general members of communities, and friends and colleagues of PLTB). However, the perspectives of PLTB and their family members have been my priority, because I wanted to gain first hand experiences of PLTB to understand whether and how TB service delivery in urban areas hindered or helped TB treatment completion.

I found that the many issues relating to TB treatment completion were interrelated. Objectively understanding their impact on TB treatment was complex. Hence I have presented the study findings, initial discussions and my interpretation as they emerged during data analysis. However, I considered the following areas while making my interpretation: the original views expressed by various study respondents; local context including organisation of TB service delivery in the study area; my observations throughout the study, in particular during field research; information obtained by reviewing relevant documents; and my experience as a researcher during the research process. I note at the outset that there were multiple health care providers providing TB services in the study area. The findings and initial discussions presented in this chapter are within the context of Nepal's NTP in an urban area: thus I have presented implications of findings considering this local context. I fully acknowledge that many people with TB receive treatment outside the NTP (i.e. in the private sector) but this was not the focus of my study.

5.1 Understanding pathways to TB diagnosis and treatment

Although the study focused on problems and issues arising during the treatment period (the period from the start of anti-tuberculosis treatment until treatment outcome was available), many PLTB stated that they experienced barriers before they embarked on treatment (i.e. in the period between the start of illness until diagnosis of TB), causing considerable suffering. I found that some such issues started in the diagnosis phase and continued into the treatment phase, thus affecting TB treatment completion. I therefore also discuss major issues that arose during diagnosis in this section.

5.1.1 Health care seeking among PLTB

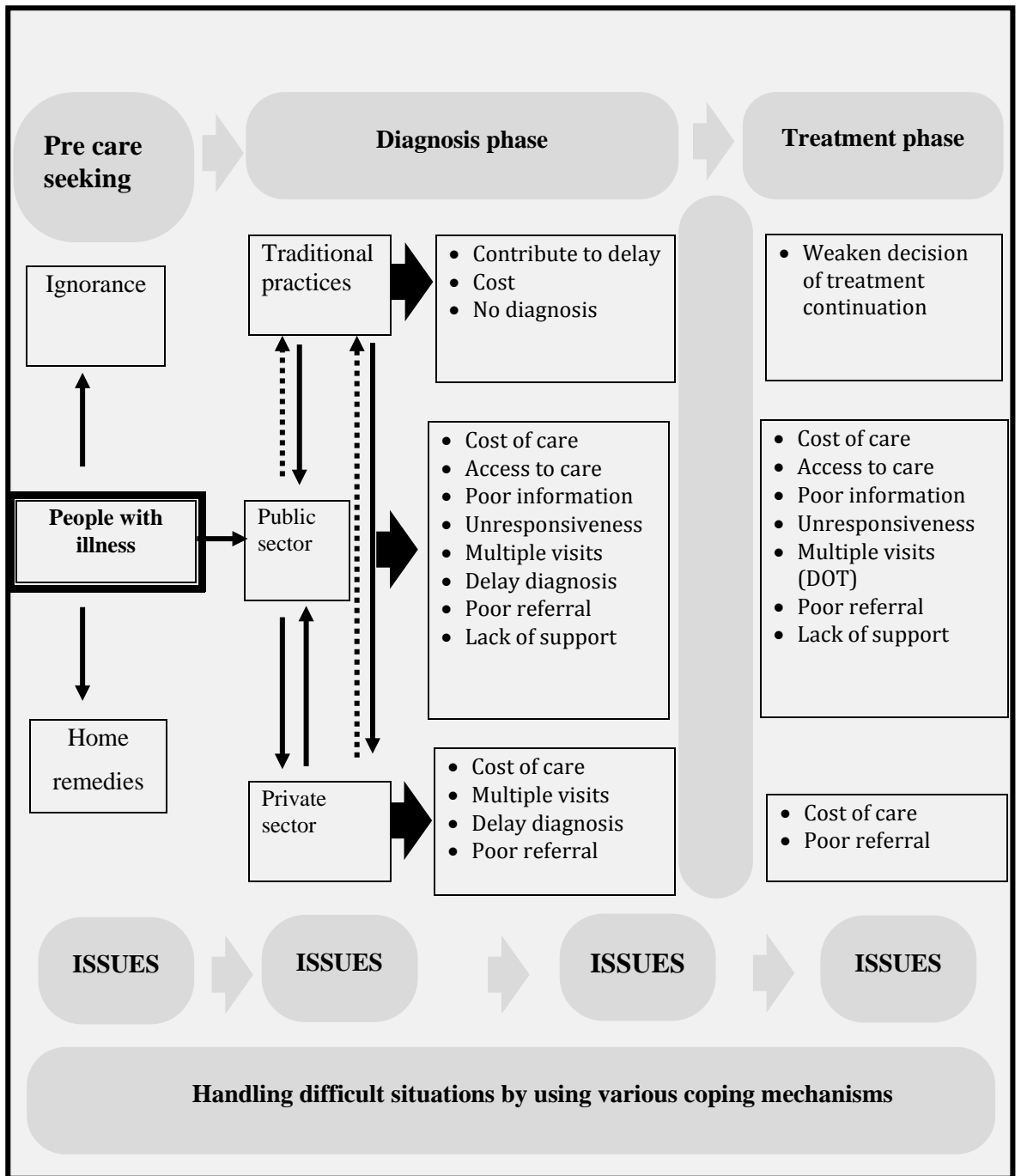
Health care seeking behaviours among PLTB varied, making it difficult to identify a unique pathway through TB diagnosis to appropriate care. Figure 12 compiles the main TB care seeking pathways, and major issues that PLTB experienced before and during diagnosis including continuation during treatment phase. I found that many PLTB decided to seek initial care only when symptom(s) disrupted their routine work: this was especially prevalent among people with limited knowledge about health care and low socio-economic status. Similarly, a tendency to ignore illness for as long as possible was found among some PLTB. People describing this behaviour gave several reasons: PLTB did not suspect TB when they noticed symptom(s); cough and fever were considered as symptoms of mild common cold; PLTB used home remedies to address the symptoms; PLTB were unable to seek care from formal health care providers/institutions for financial reasons, or because they believed costs of care would be unaffordable; their illness was tolerable as it did not disturb routine activities; and because they were not aware of health service availability in the city.

I found that ignoring illness till it disturbed routine activities was a common phenomenon which was supported by a culture of practicing home remedies, for instance, using hot water with turmeric powder to treat cough. Another major reason PLTB delayed care seeking was the cost of care: this was more common among those facing difficulties to maintain their livelihood. I discuss costs of diagnosis of TB in section 5.1.5. In addition to the high cost of care, I found that not knowing the cost of care was another reason for delaying care seeking, as many PLTB were not sure how much it would cost them to seek care from formal health workers and feared it could be so high that they could not afford it.

I found that delayed care seeking by PLTB was often linked to their knowledge and perceptions about the disease and its symptoms, and use of traditional practices to overcome their illness and cost of care. Although initially related to care seeking, these issues continued further into the treatment phase and had consequences for continuation of TB treatment.

In conclusion, Figure 12 provides an understanding on pathway to TB treatment. During the pre-care seeking phase I found that many PLTB either ignored their illness or used home remedies to treat their illness. Only when illness started disrupting PLTBs' routine work did they seek care from a health care provider. Many PLTB switched care provider during diagnosis as discussed in 5.1.3. As shown in Figure 12 I found some issues that hindered care seeking during diagnosis: for instance, cost of care; access to care; lack of support; poor referral mechanisms among care providers; and poor information of service availability. These barriers contributed to diagnosis delay, which ultimately increased cost of care to PLTB and households. As shown in the figure, some issues experienced during diagnosis continued to hinder TB care during the treatment phase: to address them, PLTB and their families used various coping mechanisms in order to stay in TB treatment. In subsequent sections I discuss the major issues that delayed TB diagnosis that had implications for TB treatment.

Figure 12: Pathways of TB care seeking and issues



5.1.2 Use of multiple care providers during diagnosis

I found that the providers most often visited by PLTB during the initial stages of illness, were private health care providers, especially pharmacies or drug retailers. The reasons stated were that they were trustworthy, easily accessible, were the same providers used for other illnesses, were thought to provide good quality care, were recommended by family members, relatives and friends and were easily accessible (i.e. close to home and convenient service hours). I also found that many PLTB were unaware of availability of health services in the city. Migrants had difficulties locating health facilities as they were new in the city and information about health facilities was not readily available, so they simply visited the nearest health workers, mostly pharmacies, as advised by friends, relatives and neighbours. A male migrant with TB said;

'I arrived a few months ago and the city is new to me. I did not know where to go for a health check-up. I looked for clinics nearby then found a pharmacy, which I visited first.'

On the other hand, not initially seeking care from the public sector was due to poor access to services; perceived poor quality of care in public sector and inconvenient opening hours of health institutions. Some PLTBs stated that the lengthy care seeking process in public hospitals was another reason why they sought services from private providers. I found that the decision to seek care from a specific provider was not only guided by costs or physical access, but also by types of information about providers and the health care process that PLTB would receive. Such information was generally obtained from people around the PLTB, mainly family and friends. Thus, family members, friends and relatives played a major role not only in selecting the health workers during the diagnosis phase but also in choosing treatment services and continuation of treatment.

In contrast, some PLTB directly went to public hospitals. PLTB who choose this approach had suspected their symptom(s) could be related to TB and preferred visiting the specialized centre i.e. the NTC. In addition, some PLTB who had problems affording the cost of private care visited government hospitals. Similarly, people who had been affected by TB in the past sought care from the government hospital where they had previously been treated.

I found that some PLTB also sought care from traditional healers before they used allopathic health workers. This was more common among migrants when they became ill while in their village home. The reasons they cited were that they preferred traditional practice; were advised by family members especially elderly member of the family; had seen improvements in other people with similar symptoms who sought help from traditional healers; and felt there was no harm in visiting them. I found a tendency among some PLTB to visit traditional healers at the same time as using modern health services: this happened frequently when other forms of care were not making an impact on their illness. Information and advice PLTB received from traditional healers was influential: in some cases, it led them to change their care seeking practice including treatment prescribed by the health workers. A 22-year old unmarried girl with TB said;

'I had feeling that my disease was not TB and so did my parents. We went to a faith reader. He gave me a religious ring and some herbal medicines and asked me to stop other medicines because the medicine he gave would not work if the modern medicines continued.'

5.1.3 Switching health workers during care seeking

PLTB often switched from one provider to another (see Figure 12). The main reasons stated were: no improvements in health; unaffordable cost of care; suggestions from others (relatives, friends and colleagues); behaviour of service providers; negative effects of drugs prescribed by the provider; delay in diagnosis of disease; moved house; and to find a more qualified provider. However, shifts from private to public providers were due largely to financial constraints such as inability to pay the cost of care – the doctor's fee, and investigation, drug and other charges.

I found that switching from one provider to another was more common during the diagnosis stage than in the treatment phase. The PLTBs who switched more often during diagnosis were also likely to seek alternative providers during treatment. This was more likely when the PLTB was not making a quick recovery or the health worker was not trusted by the PLTB. Advice from family members, relatives and friends also played a vital role in whether PLTB switched providers during the diagnosis and treatment phases. Importantly, I found it was common that the decision of the PLTB was greatly influenced by those who were close to them: in such cases, the knowledge of the PLTB had little role to play in decision-making.

5.1.4 Referral for TB diagnosis and treatment

I found there was relatively poor referral linkage from the private sector to the public sector and vice versa. My interaction with care providers revealed that private health care providers had little trust in the quality of services provided in the public sector and were thus not interested in referring their clients. Although some PLTB stated that private pharmacies referred them to the TB hospital when their medications did not work and they suspected TB, it was not the case with private practitioners, who almost never referred people to public hospitals for diagnosis.

Some referral practices were found within the public sector. A few PLTB stated that when doctors in public hospitals suspected they had TB, they referred them to the NTC. I found that PLTB rarely mentioned referral by public hospitals for TB diagnosis, whereas referral for treatment after diagnosis was common practice, with many big hospitals referring PLTB to DOTS centres for treatment.

5.1.5 Cost of TB diagnosis

Although the NTP has a policy of free TB diagnosis nationwide, many PLTB stated that they had to pay fees for diagnosis that were high relative to their individual and family income thus being unaffordable for many. I found that the cost of diagnosis varied among individuals, ranging from 1000 to 150,000 Nepali rupees⁷ (US\$ 14 to 2,142). The upper end of this range was an extraordinarily high cost for diagnosis of pulmonary TB. The PLTB who spent that amount said that his diagnosis took more than a year and involved visiting several places including India. I found that spending such a high amount for the diagnosis was rare: other PLTB who I interviewed had spent approximately US\$ 40 for diagnosis. However, this exceptionally high cost of diagnosis cannot be overlooked as many PLTB stated that the cost of diagnosis was a problem that also affected TB treatment, as money borrowed for diagnosis had to be repaid during the treatment period.

I found that the NTP's free provision of TB diagnosis was only for sputum examination in some DOTS centres and public hospitals. Many PLTB stated that the high cost of care affected timely care-seeking as they did not have savings and depended largely on daily wages or monthly salary. For many PLTB it was difficult to

⁷US\$ 1 was equivalent to Nepali rupees 70 (2007/2008)

pay even nominal costs of care so that they remained untreated for a long time. A woman with TB said;

'I did not have money. My husband took loan and went to Qatar for work but he was not able to send money back. I was ill but did not go to hospital because had to pay charges. I stayed at home for 2 month without consulting any doctors. My husband sent some money then only I sought care.'

Not knowing the approximate cost of TB diagnosis in advance was an issue which delayed PLTBs' decision to seek care.

In contrast, PLTB who visited the NTC paid relatively low costs and were rapidly diagnosed. Those whose first point of contact with a health care provider was the NTC had suspected their cough as a symptom of TB. This clearly showed that community awareness of TB led to choice of a proper health care provider: thus TB was diagnosed early with low cost to the PLTB and their household. Although the cost of diagnosis varied among individuals, managing the cost was a problem for many PLTB, and a cost that adversely affected their TB treatment.

5.1.6 Motivation for TB treatment in NTP

PLTB stated several reasons why they chose treatment under DOTS even though their diagnosis was made in the private sector. One major reason stated was the provision of 'free antiTB drugs' in NTP, which seems to be an encouragement for many PLTB to start treatment in the NTP. This encouragement was more appealing to the people with low economic status (especially migrants and daily wage labourers) and the people who spent a considerable amount of their income and savings for TB diagnosis, whether in the public or the private sector.

Information about 'free drugs' seemed to be widely known. PLTBs' sources of knowledge of free drug provision varied: they included family members and relatives, friends, colleagues, television, FM radio and health service providers where PLTB sought diagnosis. The most common sources of information were family, friends and relatives.

PLTB mentioned that before treatment they knew very little about the process they needed to go through to get the 'free' drugs in the DOTS programme, or about other hidden costs associated with free treatment. Some PLTB stated that if they had known that they would be required to spend a considerable proportion of their income to

access the free drugs, they could have chosen another provider. A 46-year old man with TB (a shopkeeper) said;

'Before I came here [the DOTS centre] I was not aware that I need to come daily. I pay twelve rupees every day to get to this clinic. Sometime I think that with the money I am spending on travel I could have brought drugs from medical hall with less hassles every day.'

Another reason PLTB used the NTP for treatment was because they had seen other persons cured after taking DOTS treatment. However, they were unaware of issues that these cured persons faced while undergoing DOTS. Some PLTB perceived the free drugs in the public sector to be of low quality, though they were continuing their treatment as they feared using the private sector due to the high cost of drugs there. I discuss the issue of quality of care and drugs in subsequent sections.

In conclusion, there were multiple health care providers and users with differing characteristics in the study area, so that pathways to TB diagnosis and treatment varied. Although PLTB initially sought care from a variety of providers, eventually, many of them were diagnosed in the public sector and started DOTS in the NTP. However, delays in diagnosis occurred whether the provider was private or public. Although the diagnosis of TB sounds simple as described by the NTP, in reality, not a single PLTB I spoke with had gone through a smooth process of diagnosis, regardless of whether they used public or private providers. Issues during the pre-treatment period had an enormous impact on successful completion of TB treatment. The next section provides an in-depth analysis of the issues experienced by PLTB during treatment which affected the TB treatment completion.

5.2 Issues in TB treatment completion

In this section and subsequently, I discuss issues and problems that hindered TB treatment completion. Since there is substantial overlap and interrelations between issues, some overlap in the analysis and discussion is inevitable.

5.2.1 Understanding of TB disease: knowledge and perception

Among PLTB I found mixed knowledge and perceptions about TB and its treatment. People used various synonyms, described in **Error! Reference source not found.**, for TB disease. This indicated that TB is a complex social phenomenon, and understanding of the disease was greatly influenced by social and cultural beliefs, most of which contradicted ‘scientific’ evidence. It also reflected general community views of TB and people with TB. It is clear that developing an understanding of TB and its effects using only a biomedical lens could misrepresent social consequences of the disease and its control, thus undermining successful TB treatment completion.

Box 1: Synonyms of TB disease in the community

- a disease of poor: poor are more affected
- a distant making disease: makes relationship fragile
- a wasting disease: makes people skinny
- a disease of cough: person coughs persistently
- a killer disease: it kills people
- a communicable disease: people can infect others
- a disease of bad doings: it affects person who does unsocial behaviour
- a disease of divine cruse: it affects people who disobey god, a punishment of disobey
- a disease of dirty people: it affects people who are unhygienic and work in such conditions
- a disease of pollution: dust and air pollution cause the disease
- a disease of malnutrition: it affects people who eat less
- a simple and curable disease: disease is treatable with drugs
- an incurable disease: once person gets the disease it stays lifelong

In general, PLTB regarded TB as a communicable disease. This is for two major reasons: they heard that TB can transmit from one person to another; and they perceived that their disease was transmitted from others. Some PLTB who had been exposed to a known TB case before they were diagnosed, strongly believed that they

got the disease from that person, thus strongly believing that TB is a communicable disease. A young man working in a carpet factory mentioned:

'When doctor told me I have this disease [TB], I got surprised and later I came to know that a colleague working in the factory had TB but he never mentioned to me. I think I got the disease from him.'

I found that PLTB who believed in the communicability of TB thought that they could transmit TB to others until they were cured. Consequently, most of them kept a distance from others in the household, and especially children and spouse, throughout the course of treatment. Many, and especially women, stated that keeping a distance from their love ones was painful, and influenced continuation of their treatment. A woman with TB who had two children said;

'I may transmit my disease [TB] to children thus I have sent them to my parents' home since I was diagnosed with this disease.'

On the other hand, some PLTB were uncertain whether their disease was transmittable. Although they had heard that TB is a communicable disease, their experience did not correspond with this, as they had been living with their family and none of their family members had TB. I found varying understanding among PLTB of the causes of TB, including germs; smoking; hard physical work; unbalanced and spicy food; excessive consumption of alcohol; not enough sleep at night; the worst consequence of pneumonia; frequent sex with sex workers; sex with multiple partners; and not enough food. I found a link between such understanding and continuation of TB treatment as some of them thought that their disease would be cured if they avoided such causes: thus they focused on avoiding the causes they thought relevant to them, rather than organising regular TB treatment. A primary school teacher in the hills but who was staying in Kathmandu for TB treatment said;

'The doctor told me that my disease was due to less eating so I am trying to eat more food with protein but it costs a lot of money.'

I found that PLTB often construe their understanding about the disease based on what they experienced in the real world: but in many instances knowledge and experience conflicted, and experience dominated over knowledge. However, not all PLTB experiences were the same leading to differing understanding. In several instances, I found that the PLTB who were suspicious about the communicable nature of TB had

problems accepting their TB diagnosis (although they were continuing their treatment): most PLTB were curious to know how they got the disease. It is therefore important to understand misunderstandings and negative experiences that influence PLTBs' knowledge and determine treatment behaviours. However, I found that the health system had little consideration of such practical aspects of health communication: PLTB were often not satisfied with the responses to questions that they put to the health workers. See section 5.2.4 for further analysis of communication.

In addition, I found some common beliefs that PLTB, health service providers and community members often stated when describing their understanding about TB as a social disease. The sections below describe such beliefs and their link to TB treatment completion.

5.2.1.1 TB: a disease of poor and marginalised

I found that many people associated TB with poor people and conditions of poverty. The health workers very often stated that the majority of PLTB undertaking treatment in the NTP were from poor and marginalised groups. In this context, the poor and marginalised groups were defined as people working in factories (producing for example carpets, bricks, metalwork and garments), vegetable sellers (people who fetch vegetables and sell them door to door by bicycle), daily labourers, porters, construction workers, people working in motor garages, garbage collectors, transport workers (drivers and helpers), and slum dwellers. People living in such conditions were not only vulnerable to TB, but also to other illnesses for which they required care from other health care providers, and the cost of care was unaffordable for many people. It was found that TB was often not the only illness PLTB (and especially poor PLTB) were dealing with, as TB invited other illness, which further reduced the ability of PLTB to stay on TB treatment. A DOTS clinic staff mentioned:

'We receive many poor people suffering from various illnesses and TB is the most common among others. Sometime TB patients get seriously ill due to other illness which creates further problem for them to visit the DOTS centre.'

PLTB confirmed that their TB treatment became more complicated when combined with other illnesses. They often associated their TB with their poverty, which they described as not having enough to eat; hard physical labour and long working hours; working in poor environments such as brick factories; and performing low-grade

jobs⁸. They also thought that the illnesses accompanying TB were largely due to poor socioeconomic conditions and their inability to seek proper care, which was precipitated by TB. A young man who had undertaken three months treatment said;

'I was well and doing my work, since I was diagnosed with this disease [TB] one after other illnesses made my conditions [financial and physical] worse.'

While there are obvious links between TB and poverty, PLTBs were generally subsequently labelled as of low status, further disadvantaging them, and affecting their morale and ability to live as a normal member of the community. Consequently, not only the individual with TB, but the family suffered with psychosocial problems such as anxiety, feelings of guilty and depression. A spouse of a PLTB revealed how she felt when she discovered her husband had TB:

'When doctor said he [her husband] had TB I felt like the land I was standing on has gone down. I felt helpless because he is the only hope of our family wellbeing. People think TB is not a simple disease, how can I survive with two children, how to respond questions from people if they know about his TB.'

In a similar vein, an educated young local resident, maintaining a decent job but who had been diagnosed with TB three months previously, said: *'I know TB can be cured. I can convince myself but it is very hard to convince others such as relatives and friends as TB is known as a disease of low status people and holds bad reputation in the community.'*

In contrast, a few PLTB stated that TB does not only affect poor people and nor was it only the result of hard physical labour and limited food. This belief had two roots: TB affected the PLTB even though they were eating well and had a decent job without much physical hardship; and they had seen other people affected by TB who they thought were not poor. Some PLTBs further stated that the disease was more visible among the poor because they could not afford to hide their disease as rich people did by taking treatment in confidence, generally from the private sector. It was felt by many PLTBs that only poor people accessed DOTS and those who could afford to pay took treatment in the private sector unnoticed by others. Some PLTB also mentioned that TB treatment under DOTS was of poor quality. They thought so because the main

⁸In this context, PLTB referred to low-grade jobs which required heavy physical work such as portering, and other jobs that many people in the community did not want to perform such as metal working, garbage collection, cleaning safety tanks etc.

users of DOTS were poor people who had no alternative (i.e. treatment in private sector) and there was a feeling that the poor generally accept anything, even of low quality, when provided free of charge. In contrast, some PLTB whose health had gradually improved after taking TB treatment did not question the quality of drugs and services they received under DOTS. Similarly, some PLTB stated that their perception that TB only affects the poor had gradually changed after they saw other people (who they thought were not poor) taking treatment under DOTS.

5.2.1.2 TB: a disease of sin

Respondents reported that there was a belief in society that TB disease was a consequence of wrong doings⁹ and a divine curse. Many PLTB stated that they feared revealing their disease to others as people with TB generally had bad reputations in the community especially among elderly people. This perception has considerable implications in Nepali society where culture, religion and livelihood are strongly embedded and interlinked. A woman homemaker continuing her second month of treatment mentioned:

'I visited a temple during the second day of my menstruation, may be the God became unhappy and as a curse I was caught with this disease [TB].'

She thought this because in the past she had heard women (mostly elderly) referring to such incident happening to a girl in her neighbourhood who had TB. Because of fear that she could be labelled as uncivilized, the women did not disclose her disease to others: this was not easy for her.

PLTB also stated various other common community beliefs about causes of TB, including not fulfilling secret promises¹⁰ that people made to God; engaging in socially unacceptable behaviour; and sexual relationship within the extended family relations. Many PLTBs were afraid that people who hold such beliefs would link them to one of these behaviours if they knew they had TB. Although PLTB did not experience any direct impact from such beliefs, they affected their treatment seeking behaviour, as some PLTB did not go to the nearest DOTS centre for fear that local

⁹ In the study context wrong doing referred to an act that violates the moral norms of the community

¹⁰ In Nepali society, there is a practice of making secret promises – if as a result something happens, something will be offered to god.

people would see them visiting the TB clinic and link them with such behaviours. It was clear that such negative cultural beliefs prevented PLTB seeking care from the nearest TB centre and forced them to take medications in fear and isolation.

In contrary, some PLTB stated that, although such beliefs regarding TB existed in the community, they did not take them seriously. Young men with TB in particular were less bothered by such beliefs. However, the majority of PLTB stated that TB-related stigma existed in the community, and that this was often linked to such beliefs; on the basis of such beliefs, people with TB were discriminated against in the community thus creating a barrier to accessing TB treatment. I give more analysis of TB-related stigma and discrimination in section 5.2.2.1.

5.2.1.3 TB: a lifelong disease

One of the most common beliefs among PLTB was that once a person has TB, the disease remains in their body forever. This belief arises from doubts about a complete curability of TB – some PLTB thought that TB gets partially cured but not completely; and they saw the disease reoccurred in some people who had been cured in the past; a belief that TB badly damages the lungs and healing damaged lungs without surgery was not possible. Such beliefs further worried PLTB when friends and community members mentioned that TB could reoccur anytime as it remains in the body and weakens human.

Many PLTB also had a belief that the reduction in physical strength caused by TB could not be recovered even when the TB was cured. PLTBs' main reasons for this belief were that TB can severely damage the lungs, which will not heal even after the TB is cured; TB makes people vomit blood as a result of permanent damage inside the body that will remain forever; TB can become chronic and untreatable; and powerful anti-TB drugs damage body cells while killing the TB bacilli. It is important to note that the belief about damaged lungs and oral TB drugs was closely linked to TB treatment, which often made PLTB question continuation of treatment. PLTB continued to take their treatment but seemed to be at greater risk of discontinuing treatment when these concerns were not well addressed.

Many PLTB further believed that TB drugs are so powerful that they can make both men and women sterile by weakening their body cells - this made some PLTB vulnerable to discontinuation of treatment. An educated young man who had been

continuing treatment for one month was seriously concerned when he heard from his friends that TB drugs could cause impotence.

'When I think the consequence [impotence] that TB drugs can have on me, I cannot concentrate on my work and can't sleep too. My friend told me about the bad effect of the drugs that I'm taking. Though it is hard to believe but I'm worried.'

Similarly, a woman with TB mentioned that she and her husband were worried that she may not be able to bear a child as consequence of the powerful drugs. Health workers also mentioned that PLTB, especially young people, often asked questions about the effect of anti-tuberculosis drugs, concerned about their fertility. It was found that such beliefs among PLTB sometimes caused them to consider discontinuing treatment. Such PLTB were taking their treatment under very difficult and fearful circumstances. PLTB stated that health workers did not take these concerns seriously, even though they were raised several times during their treatment, and responses were not convincing. A lack of good information presented in a convincing manner put the PLTB caused fear and uncertainty

I further discuss communication between PLTB and health workers and its effectiveness in subsequent sections.

5.2.2 Socio-cultural issues in TB treatment

This section is closely related to sections 5.1 and 5.2.1 above and overlaps with some of the issues that I have already discussed, because the issues are interdependent. This section describes how societal and cultural context and practices influenced TB treatment completion. I discuss social and cultural issues independently considering the roles of the community and culture, and their impact on PLTB and his/her household during TB treatment. I have configured this section under three major themes: stigma and discrimination; gender related issues in TB; and the social system, including caste and ethnicity.

5.2.2.1 *Stigma and discrimination due to TB*

A majority of PLTB stated that they experienced some level of stigma and discriminatory behaviour based on their disease. According to them, stigma and discrimination existed at multiple levels: among the community; at workplaces; in institutions such as hospitals, DOTS centres, schools and colleges; and at home. Stigma and discrimination not only prevented PLTB seeking care for diagnosis but also affected their ability to continue TB treatment in many ways. However, the magnitude of stigma and discrimination varied among PLTB, depending on individual discriminator's and sufferer's knowledge, and local contexts such as social status, financial well-being, treatment duration, and severity and visibility of disease. The discriminators were defined as people who had negative attitude and behaved unfavourably towards PLTB and their family members on the grounds of TB whereas sufferers were those who affected by discriminatory acts of people.

In the study, I focused on the causes of stigma and discrimination and their impact on treatment completion rather than merely a description of what happened to PLTB and their family due to TB in general. However, it was complex to pin down the causes of stigma and discrimination as they varied amongst PLTB and understanding of individuals had a significant role to play. Stigma and discrimination can be described in many ways. Here, I present findings and discussions in the ways which PLTB and their family members perceived and experienced them. Considering the study findings and the nature of stigma and consequent discrimination, I have grouped them under four major themes: (i) stigma and discrimination in community, (ii) self-stigma (iii) stigma and discrimination in family, and (iv) stigma and discrimination in institution.

I considered presenting stigma under these themes based on respondents' experiences and their perceptions in line with the study aims and objectives. However, although all these themes are interrelated, for simplicity I have attempted to describe them independently as I thought appropriate, based on the data that I gathered in the study.

(i) Stigma and discrimination in community:

In this section, the word 'community' refers to general members of the community who may or may not be directly associated with PLTB and their family: neighbours, friends, and colleagues of PLTB and their families. I found various reasons why stigma existed against TB, PLTB and their families. The major reasons were:

- associated social and cultural beliefs on the causality of TB;
- fear of disease transmission;
- TB disease often being linked to people with 'low-grade' in the community;
- immoral behaviour of a person and association with TB disease in the community;
- association between poverty and TB.

As consequence of the reasons mentioned above, many PLTB and their family members were frightened to disclose their disease status, as they thought that the reasons above were enough to humiliate them if community members behaved unfavourably as a result of knowing their disease status. Below I describe the reasons and experiences of PLTB and their families due to TB in the community.

I found that one of the causes of stigma and discrimination against PLTB and their family was linked to the causality of TB and associated social and cultural beliefs, which I have discussed in section 5.2.1 of this chapter and will not repeat here. The strongly held socio-cultural beliefs on the causality of TB, which were often scientifically unverified, have made TB a taboo subject within the community, putting many PLTB and their families in difficult positions, although such beliefs varied among individuals. As an example, there is a belief in the community that a person who visits sex workers and frequently has sex with them could get TB. A male college student, who had been taking treatment for two months, and was victimized on the basis of this misbelief, said;

'I disclosed my disease to friends and they asked with negative deed whether I visited prostitute women because they thought that maybe my disease is a consequence of that act. I was so upset to hear such allegation then I stopped visiting friends and did not disclose my disease to others.'

PLTB stated that another reason why they and their family members were seen and treated differently in the community was due to the widespread fear of transmission of infection. They gave this as the reason community members kept a distance from PLTB and their family members. People with children in the community were the one who often kept a distance from PLTB as they perceived that children would more easily get infected than adults. Some PLTB perceived the distance kept by community members was reasonable, as they might have done similarly to protect themselves. However, the unfavourable behaviour associated with fear of disease transmission was seen as discrimination by some PLTB. Consequently, PLTB hid their disease because of fear of being seen as '*an unwanted social element*' in the community where they live. PLTB and their family members thought this was not only linked to fear of infection but also that community members often saw TB as a disease of 'low-grade' people and thought such a label could damage their social status.

According to PLTB, 'low-grade' was defined considering the PLTB's social status including caste and ethnicity; financial status; occupations perceived to be physically demanding and in an unhealthy environment; poor education shown by poor manners; physical visibility indicated by wasting; engagement in immoral social behaviour such as unsafe sex, alcoholism and drug use; and poor housing and living standards. In many instances, I found that PLTB and their family members had a strong apprehension that people in the community would link them to one or many of the above-mentioned 'low-grade' statuses if they knew they had TB: thus disclosing their disease to others was a concern for many PLTB. I found that, due to such beliefs in the community, PLTB see themselves as vulnerable – socially, financially, physically and psychologically – which had an impact on treatment continuation. A few PLTB stated that not all community members would think this way; but it was hard to ascertain who would think differently. A migrant worker, a woman who had been undergoing treatment for one month, with a small child, said;

'We live in a rented room. I am worried if my neighbours come to know my disease, especially women living in the same flat because I heard them talking bad things about other person affected with TB in the past. I'm worried that they could think the same on me if they know my disease.'

Some PLTB stated that not disclosing their disease was the only way they could avoid being linked with such negative community-held beliefs. However, they also stated difficulties in doing so as TB was visible with cough and wasting so people in the community could easily guess they had TB. Living with TB in the face of such

negative beliefs in community was even harder for woman, which not only prevented them disclosing their disease but also made them psychologically vulnerable and abashed, severely affecting care seeking. A young woman respondent who decided to take treatment far from her local community said;

'I am afraid I could be perceived as a bad girl in the community thus I have not disclosed my disease to others. There is a DOTS centre nearby my house but I came to this place because local people do not know me here.'

PLTB also stated that there was widespread feeling in the community that poor people get TB and disclosing their disease to others would make them be seen as inferior within their community and group. A young male respondent said; *'People think TB only affects poor people. Sometime people call me kshayarog birami [TB patient], it hurts me and I feel so embarrassed.'*

This issue had particular implications for people living in slum areas, migrant labourers, vegetable sellers and factory workers as they were perceived as threats to the community, consequently increasing stigma among the poor. Health workers in DOTS centres also mentioned that poor people were the ones most affected by TB and they often hide their disease from others as they thought the community would avoid them. The care providers further stated that other people (perceived by them as wealthy local residents) who were visiting the clinic with their children for immunization complained about PLTB taking treatment from the same clinic, as they feared bringing their children to a place where people with TB were being treated. I discussed with members of the community to understand how they perceived links between poverty and TB. A local community resident said;

'We have a slum near to our community where many poor people reside. They suffer from many health problems and I heard that TB is a common disease. They could be a threat to local people.'

Some PLTB also commented on differences in TB related in urban and rural areas. In focus group discussions most PLTB stated that people with TB and their families were more stigmatised in rural areas than in urban areas. Consequently, some PLTB came to an urban area for their treatment. PLTB thought there would be less stigma and discrimination in urban areas because in urban areas PLTB had less contact with other members of the community; urban people were unconcerned about others; in urban areas there are many people with mixed cultures so it is easy to keep a low profile; in urban areas people were well educated and aware. In contrast, in rural villages everyone could easily guess that a person has TB as such people lose weight and have

a continuous cough. A few PLTB stated that because of these reasons they came to Kathmandu for their treatment. However, some PLTB had different experience. They found no difference in rural and urban area regarding the way people thought about PLTB and TB-related stigma. A young migrant male said;

'I find no difference in terms of what people think about me in my village and here [urban] as people I know here did not like me visiting their room and no one comes to see me. I want to go to village but I was told by health worker TB drugs were not easily available in the village.'

Similarly, an old man who came to the city for his treatment and was staying with his son said in a focus group discussion;

'People in city are not welcoming and have less sympathy to people like us. We know we have TB but when someone says unpleasant it touches our heart. If someone say good such as take medicine and get cured we feel so good but in the city it is difficult to find people with good heart.'

On the contrary, a few PLTB stated that they had positive experiences when they disclosed their disease to others, as people subsequently helped them. Community members helped them in several ways, encouraging them to continue their treatment; assuring them that taking regular treatment would cure their illness; said TB is a normal disease; demonstrated sympathy towards them and their illness; and supported them financially when they were in difficulties.

In many instances PLTBs felt older people held stronger negative beliefs than the younger generation. They also stated that some young people who behaved badly towards PLTB were influenced by older people with negative beliefs. However, this should be interpreted with caution, as the study did not find stigmatising behaviour only among the older generations. Nevertheless, cultural beliefs about causes of TB seem to be changing gradually: people of younger generations had less belief in scientifically unproven arguments.

I found that many PLTB had problems due to TB such as physical weakness and financial hardship. TB-related stigma and discrimination added yet another challenge. However, many PLTB stated that their family members and some relatives, friends and colleagues supported them in difficult situations, which helped them to boost their morale and stay on treatment. For example, a young woman homemaker said she was worried when she was diagnosed with TB and did not disclose her disease to her

neighbours but after two weeks she became very weak and her neighbours came to see her and they came to know her disease. She described her experience thus;

'I was wrong that I did not discuss my illness to my neighbours earlier as I was not sure how they would react but they know many things about TB and showed sympathy towards me and said that TB occurs to all people, no need to worry.'

Although some PLTB stated positive responses from friends, and relatives, a few experienced avoidance after disclosing their disease. A young woman said;

'We used to share many things with friends when I was well and our children used to play together. I called my friend a few weeks ago and she said she does not want to come to my house because I have TB. I felt so embarrassed. My daughter wants to go to her house but I afraid how they will behave her so I didn't send.'

I got a mixed response when I asked what PLTB thought about such behaviour from friends. Some PLTB thought the behaviour was legitimate if they did so to protect themselves and their children, whereas others thought it was discrimination because in their experience, some relatives and friends used this as an opportunity to claim PLTB were inferior on the basis of their disease. However, not everyone had the same experience.

I found a contradiction between what PLTB interpreted as the perception of TB in the community (mostly stated negative perceptions), and positive experiences of some PLTB who gained support from friends and relatives after disclosing their disease. PLTB who received support or were not stigmatized in the early days of their treatment were encouraged to share their disease status with others and they were likely to receive support from friends and community. On the other hand, PLTB who did not receive support in early days of treatment were more inclined to hide their disease, where possible they wanted to hide throughout the treatment period, which affected their treatment continuation as often they had to continue treatment under perceived social pressure, even though sometimes such pressure did not actually exist.

I also found that the sharing of support received during treatment was not common practice among PLTB even though they frequently met in the DOTS centres. Rather, they often talked about problems and negative experiences they had during the treatment. When I asked them why they did not share the support they received, their responses were: they had many more experiences of problems and concerns than of receiving support; they felt relieved sharing problems with other PLTB; PLTB listened well to each other, unlike others in the community; and PLTB felt free to share

problems which they fear sharing with other community members. However, not all PLTB had shared their experiences, positive or negative, in their group. Some mentioned that they did not find the environment in DOTS centres conducive to talking freely with other PLTB, as there was limited space, waiting rooms were small and only few of them knew each other, although they were taking treatment from the same DOTS centre. Although it could take long time for the NTP to change cultural disbeliefs through interventions, a way forward could be to address negative thoughts of PLTB by providing an environment in DOTS centres that enabled sharing good experiences and support provided to PLTB by friends, relatives and community members. However, I found that the programme had not taken such opportunities to a great extent in DOTS centres.

(ii) Self stigma

I found that often PLTB felt undeserving and had lack of self respect which often led them to depression and self isolation from others – a determinant of self stigma and discrimination. Many PLTB isolated themselves from others, especially family and friends. The reasons behind self-isolation were to avoid disease transmission to others; fear of discrimination; fear of losing their identity among friends; concerns about relationships; and feelings of guilt and depression. I found that beliefs of individuals played a major role in isolating them from others and the major reason cited was fear of transmitting disease to others. For example, a recently married young female stated that she wanted to protect her husband thus had kept her distance since she noticed her disease. She did so despite her husband telling her she was no longer infectious as her sputum had become negative.

Most PLTB were struggling to continue their treatment as they had to manage not only the treatment but all other problems. Inability to do so made them psychologically weak and damaged their confidence. Many of them felt lonely and depressed, except some who had good support from family and friends. Due to their disease condition other responsibilities were grossly compromised: many felt guilty and some PLTB had a tendency to self-blame. A young migrant worker said;

'I have two small children and wife has no job. I am not able to feed them well, sometime they ask me to bring meat but I cannot afford as I lost my job and have no savings. I feel so embarrassed and sometime do not want to live life anymore seeing my family in difficult situation.'

I found that PLTB who isolated themselves were self-stigmatised and had difficulties to maintain relationships within the family. This led to self-imposition, social and physical distance, and restricted participation in the family and in society. A young woman with TB said she sent her children to her parents' house when she was diagnosed with TB and had hardly seen them during her treatment. Similarly, self-isolation was an issue in husband and wife relationships. A young woman said;

'I was told that my disease transmits while breathing so I don't share bed with husband. He [husband] asked several times but I avoided. I fully understand his desires and one day I told him I don't mind if he fulfils his desire with others because I'm ill at the moment.'

I also found that some PLTB were worried that they would face an identity crisis if they disclosed their TB to others. They feared that they could become known as a 'TB patient' rather than their original identity as a businessman, teacher, social worker, a nice woman, etc. The fear that TB would erode their existing status in society was another reason PLTB hesitated to disclose their disease. A school teacher who was taking TB treatment expressed his concern;

'I know TB is a normal disease and it will cure but community people do not think so and often call Mr ...with TB or that person with TB, thus I am also concerned that people in community and my mates will call me Mrwith TBa teacher with TB, which I feel awkward.' He further said that this was not only his judgment: he had seen other people who were labelled with TB.

PLTB also stated that they preferred to be in isolation because they thought if community members became aware of their disease then the family would have a taboo in the community and they would be victimised. Such feelings were especially found among PLTB who were local residents of the city.

It was evident that self-isolation and thus self-stigmatisation existed, which often decreased morale of PLTB, thus putting them in a difficult situation. I found that such low morale affected the confidence of PLTB, and thus their individual power to negotiate with service providers on their treatment protocol, so they became passive recipients throughout the duration of treatment. It was found that even though PLTB had knowledge about their disease and treatment, translating this into practice was difficult due to low morale.

Similarly, PLTB stated that they could have received support from others if they had disclosed their disease to friends and relatives, but they feared negative consequences.

I found that self-isolation was used as a coping mechanism by many PLTB in order to protect their family from infection and stigmatisation in the community. Although they had a difficult journey to travel, many remained in isolation throughout the treatment period. It was clear that some PLTB who disclosed their disease, either knowingly or by accident, had less suffering from isolation phobia than non-disclosers. I also observed that the individual contexts were different as some did experience discriminatory behaviour when their disease was disclosed and some discrimination had a direct impact on their treatment such as job loss, broken relationships, or rejection from community and family. A young male factory worker said;

'I disclosed my disease to supervisor as I thought he will allow me some time to visit DOTS centre but he dismissed me from the job.'

(iii) Stigma and discrimination in family

PLTB participating in the study came from two different family structures: small and big families. For convenience, in the study, I have defined small families as those with two to five members, generally comprising husband, wife and children; and big families, commonly known as joint family as those comprising more than six blood relatives.

I found that many PLTB were supported by their family at different stages of their treatment, which gave a strong indication that stigma and discrimination within the family was less strong than in the wider community. However, a few PLTB had a different experience: they reported stigma and discriminatory behaviour by some family members. This was mostly observed in big families and was often linked to some other dispute with family members before the TB developed. In such cases the family members who had disputes with PLTB used the TB to demoralise the PLTB within the family. Similarly, some elderly family members discriminated against the PLTB; in-laws were the most common discriminators.

In most cases, I found that family members asked PLTB to stay in isolation, guided by fears of disease transmission. Although isolation was intended to protect other family members from infection, the act was hurtful to the PLTB, although not in all instances. In many cases, PLTB themselves wanted to be isolated from their family members, reasons cited being to avoid transmission of disease to others; fear of discrimination by other members especially in a big family; concern about relationships; fear of being blamed if things go wrong in the family (mostly in big families); and avoiding

burdening the family. PLTB therefore found various ways to keep at a distance from family members, even though there was no stigma and discriminatory behaviour in the family. A young man with two children staying in a big family said;

'I use separate utensils and do not give contaminated food [jutho] to my children and wife. I do not watch TV together with my family as I fear of infecting others.'

However, most PLTB who isolated themselves from the family stated that it was a difficult experience. Although a fear of infecting others was found to be the main concern among PLTB at home, a few PLTB also had a fear of being seen as inferior within the family if they disclosed their disease to other members. Some members of the family insisted they be isolated and not disclose their disease even within the family. A young woman from a big family stated;

'My husband took me to hospital and I was found TB then he [husband] asked me not to disclose my disease to his parents and brothers. He was worried that I may be treated differently in family because of my disease.'

The woman also stated that she was suffering to maintain such conditions as she had to find suitable times to visit the DOTS centre so that others would not notice her disease.

A few PLTB stated that they could have received more support from the family members during their treatment, but did not, because some family members especially in-laws perceived that TB is a dangerous disease and incurable. I found that compared with men, women with TB were more stigmatized within the family and discriminated against by other members and especially in-laws. A female respondent said;

'My mother-in-law always gets angry with me because I have TB and she mentioned with other women that I am a witch in her family.'

Similarly, another woman respondent stated that her husband behaved well in the early days of her disease, but his behaviour had changed and he had started to hate her. Because of her husband's behaviour she did not get good support from other members of the family. Another woman respondent also stated that her husband physically assaulted her because she had TB. The husband blamed her for ruining his life. Since then, she had gone to her parents and was staying apart from husband. Similarly, another female respondent stated that her family members including her husband became disloyal once she was diagnosed with TB.

I found that some PLTB were reluctant to talk openly about having no support and discriminatory behaviours they received within the family: they thought talking about

their own family was insulting their own position in society. However, I found some PLTB talking about their family problems with other PLTB who they trusted in the DOTS centres. Many PLTB found stigma and discrimination from family members difficult to cope with, even though the family stigma was relatively minor compared with what they experienced in the community. However, it was clear that support from the family was a strong determinant of their treatment outcome and stigma in family had reduced the support thus make the PLTB vulnerable in their TB treatment. This was particularly the case for women in big families. It is to be noted that the majority of PLTB stated that they received good support from their family during the course of their treatment.

(iv) Stigma and discrimination in institution

Institutional stigma and discrimination occurs when the PLTB and their family members are labelled or linked to undesirable stereotypes resulting in unfair treatment by an institution or person(s) affiliated to an institution on the grounds of TB. PLTB gave examples of institutional stigma and discrimination at the workplace, and in health institutions, college and schools. I found that migrants with TB and PLTB working in factories often experienced institutional stigma, and as a consequence some stated that their job was vulnerable. Consequently, their TB treatment was affected, as it not only reduced their financial ability to continue treatment but also damaged their social network. A young man, a migrant worker in a factory, narrated his experience as;

‘The disease made me so weak but my friends were helping me thus I was continuing my treatment. It was hard for me to come everyday to this [DOTS] centre as I had only half an hour break. I thought my supervisor would allow me more time if I tell him my condition. I talked to him but after two days I was dismissed from the job.’

Other respondents stated similar experiences. Institutional stigma occurred more for poor PLTB who were less empowered to claim their rights and had weaker social networks outside their workplaces. A young unmarried woman who had worked about six months in a factory said that she was doing well in her job and her owner promised to increase her salary. Since she developed TB her work had been compromised. She had to disclose her disease as it was difficult to continue the job and visit the DOTS centre daily and in consequence she was dismissed from her job. She regretted that she had disclosed her TB to the owner. She thought that she could have managed her treatment with help from friends and kept her job.

Similarly, a young woman working in a travel agency said; *'My job was to help the clients. My boss did not like me continuing the job since I had TB. Now I'm jobless.'*

Apart from job loss due to stigma linked to TB, PLTB had faced other consequences in the institutions where they were working, such as reduced pay, inferior treatment, and undermined capacity to perform tasks. However, not all PLTB had similar experiences. Some PLTB mentioned that they received support from the employer during treatment including time off work to visit the DOTS centre for treatment; salary advances; leave to rest when they were weak. A young man working in a private shop said; *'My owner gave me leave for a week when I was very weak. It helped me to continue my treatment.'*

Similarly, a female respondent working in a factory said she had received good support from her employer when she disclosed her disease status.

I also found that children with TB were treated differently in school because of their disease. A mother of a girl with TB said; *'My daughter was asked to leave the classroom because she had TB. The teacher asked my daughter not to come to school until her TB is cured.'*

Similarly, a young woman respondent who discontinued her study due to TB shared her TB status with her teacher and was told not to disclose the information to others.

It was found that PLTB were given a label that set them apart from other normal people in various institutional settings. PLTBs' experiences revealed that they were treated unfairly on the grounds of their disease, affecting their social and financial well being, and thus their continuation of TB treatment.

Stigma and discrimination in health institutions

I found that some PLTB experienced discrimination in health care settings on the grounds of their disease. Since health institutions are the place where PLTB seek care and hope to cure their disease, any forms of stigma and discrimination in these institutions would directly affect TB treatment. I found that a few PLTB were treated unfavourably in health institutions compared with people with other general illnesses. The unfavourable behaviour that PLTB experienced included;

- Ignorance by care providers: for example, in some cases PLTB felt that they were ignored by health workers as they did not respond well to their concerns during treatment, whereas they saw health workers engaging well with other (non-TB) patients;

- Health workers behaved in a hostile way while serving PLTB: PLTB observed health workers being aggressive and irritated while serving them although this was not the case when they served other (non-TB) patients;
- Health workers maintained a distance with PLTB: for example, in some instances PLTB stated that the health workers asked them to keep at a distance while providing TB care although their sputum had converted to negative;
- PLTB were asked to wear a mask all the time in the DOTS clinic: I found that some PLTB did not like wearing a mask as they thought it would identify them as a TB patient in the community.
- Health workers directly asked PLTB not to cough during communication and while injecting: this demand was embarrassing for many PLTB who became fearful while in the DOTS centre. A woman said; *'I pray to god not to produce cough while I'm in front of health worker.'*
- In some instances, health workers asked PLTB to leave the clinic as soon as they had taken their drugs, whereas other clients were not asked to do so.
- A few PLTB stated that they were treated badly because of their origin (local or migrant) and language they speak: for example, some PLTB noted health workers employing different behaviour (in terms of politeness and caring) to PLTB who migrated to the city compared with that shown to local people who spoke the local (Newari¹¹) language;

The points mentioned above illustrate some PLTBs' experiences in DOTS centres. However, despite this, a majority of PLTB stated that they received good care in DOTS centres.

With regard to the language and discriminatory behaviour, a young migrant working in a factory said; *'The Nurse is a Newar and she behaves well with people who talk in Newari. I can't speak Newari language thus I felt that she often ignored me.'*

I found that the use of Newari among Newars was common both in the community and in institutions. However, when I asked Newari-speaking health workers to comment on the issues raised by PLTB, they did not agree. They denied any discrimination to PLTB based on the language they used in DOTS centres. However,

¹¹Newari is a local language used by the Newar ethnic group in Kathmandu and some other parts of the country

they stated that Newari-speaking PLTB preferred the use of local language in communication. Some Newari-speaking health workers did say that the PLTB who did not know Newari may have felt uneasy seeing us communicating in Newari. A health worker working in DOTS centre said;

'So far we are doing our best to help TB patients, sometime their concerns may not have been well addressed as we often have busy work schedule but it was not due to the language they used in communication.'

Despite some issues with regard to stigma and discrimination in health institutions, many PLTB stated that they had support from health workers: I discuss this in subsequent sections. During my fieldwork I also discussed with senior NTP officials to get their views on the stigma and discrimination that PLTB experienced in health institutions, and especially in DOTS centres. It was hard for them to agree that institutional stigma exist in DOTS centres. However, they did mention that in spite of the NTP's best efforts there were some issues, as in urban areas, DOTS centres were run by multiple stakeholders and they had not been able to provide support to these centres to maximise TB service delivery and effectiveness.

In conclusion, I found various forms of stigma and discriminations against PLTB and their families, with varied consequences. Socio-cultural beliefs about TB, especially about causation of the disease, which was often based on little or no scientific evidence, had a major role in stigma and discrimination. Although incorrect cultural beliefs were changing as TB control measures became widely available, they still exist in the community and contribute to stigmatisation of PLTB and their families. Varying understanding of the disease influenced the perceptions of PLTB and their families and determined their behaviour with regard to their disease and treatment. PLTB often took into account the cultural beliefs and anticipated attitudes of community members towards them, and modified their behaviours in response, for instance hiding their disease, isolating themselves, feeling unworthy, having a lack of trust in others and feeling ashamed. So stigma worked as a chain which affected PLTBs' treatment behaviour and PLTB and their family used various coping strategies to tackle the stigma and discrimination. It was clear that the sets of factors causing or influencing stigma against PLTB were interconnected. However, it was evident that PLTB who perceived TB as a normal disease were often less influenced by cultural beliefs and experienced less stigma and discrimination compared to PLTB who followed traditional socio-cultural beliefs.

5.2.2.2 *Gender inequality in TB treatment*

This section presents findings on how the wide variety of socially and culturally constructed roles and responsibilities of women and men influenced their treatment behaviour. I found that gender-related inequalities affected TB treatment completion in many ways in the Nepali cultural context. In this connection I found four major themes occurring in the study related to gender inequality in TB treatment:

- socio-economic position;
- culturally defined values and customs;
- stigma and discrimination;
- health beliefs and the health service delivery model.

These themes often determined differences in the treatment experienced by women and men with TB. However, it should be noted that gender inequality appeared in the study as a crosscutting issue as it affected TB treatment in many ways. Thus, where relevant I have discussed gender and its influence on TB treatment in other sections. Stigma and discrimination has already been discussed in section 5.2.2.1 and will not be revisited here.

Regarding socio-economic status, there were differences among and between women and men. The impact of TB was found greater on women as they were the most deprived members of the household and community, both economically and culturally. I found that almost all men were involved in some economic generation activities outside the home before, during and after diagnosis with TB, whereas women were mostly confined at home doing household chores such as cooking, cleaning, and washing. In addition, they were also looking after their children and helping other family members, a further responsibility of a homemaker. Thus men were working outside the home, doing 'proper' money-earning jobs, while women worked inside the home, doing jobs not considered to have financial value. I found that women had little or no power to access financial resources within the family as they were not directly generating money. The implications for women were massive, as in many cases women were compelled to put other things first and make their treatment a low priority. I also found differences within the group of women and men as their characteristics varied. Therefore I realised it would not be reasonable to present issues of gender inequality in TB treatment as though they were homogenous.

I found that most women respondents considered household work as their assigned duty and intended to continue despite illness and physical inability. They thought that failure to continue household jobs would make them more vulnerable in the family and would have a negative impact on their treatment. I found that in the face of mounting pressure of household chores, a big problem that many women with TB faced was finding time for treatment. Although men also stated similar constraints, it was even hard for women, especially in joint family. A woman respondent described her difficulties;

'I am the only one handling kitchen work at home. My family is a big family in size, I need to start early in the morning to prepare everything in kitchen, sometime even harder when there is no water supply. I only come here [the DOTS centre] after finishing all my work and need to do the same when I go back in the afternoon.'

I found that it was even harder for many women to manage their treatment and household chores when the DOTS centre had short, inconvenient opening hours. Section 5.2.5.2 further analyses the effects of DOTS centres opening hours on both women and men.

I found that men were somehow better off than women as they received support from other family members, especially parents and wives. Women were compelled to continue their job inside or outside the home despite their physical inability to do so. Women respondents stated that there were few ways to cover work at home when they were ill, whereas men's jobs could be covered by women by finding another job outside the home. A young migrant man with TB said;

'I have not been able to go to work since I got this disease [TB]. My wife had to find a job and now she is working as housecleaner and taking care of children and me. Sometime she comes here [DOTS centre] to collect drugs for me. I feel so repent as she is taking a trouble.'

In contrast, a woman with TB said; *'I am very weak but have to do job at home as there is no other person to help, my husband goes for work and comes late evening.'*

Fears and worries were major reoccurring themes in interviews and FGDs. Women were found to be more psychologically distressed and thus more vulnerable during their treatment, than men. A few women stated that their in-laws often assaulted them due to their disease. In some cases, husbands disliked them and fear of rejection

further contributed to their distress. A married woman with two children, a local resident, said;

‘It has been three months since I was diagnosed with TB, my husband and in-laws do not behave as before, they talk to me very less. Recently my in-laws took all my jewelries that I received in wedding. I have a feeling that she [mother-in-law] wants me to go out from home.’

Similarly, relationships between husband and wife can become fragile due to TB. A woman from a village who migrated with her husband to the city and was undergoing treatment said;

‘My husband scolded me many times. He thinks all wrong happenings in the family is because of me. We did not have good relation since last one year which became further worst since I was diagnosed with TB. He always blames me and dislikes me at home.’

I found that many women who did not receive support and were discriminated against by family members struggled to continue their treatment. They stated that they could tolerate and fight against discrimination by others but when it happened within the family, their spirit was completely broken, affecting their ability to continue treatment. However, despite such difficulties women continued their treatment, and were more compliant than men. I discuss more on stigma and discrimination in the family in section 5.2.2.1.

I found that unmarried girls and women had more support from their parents and were thus less troubled than married women who had a big role in looking after their family. A 22 - year-old student said; *‘All my family members are very helpful, my mum comes along with me when I come to this centre. They always remind me to take drugs.’*

However, unmarried women had other worries due to TB. I found that their parents were restless and had put every possible effort to hide their daughter’s TB, as they stated a fear of having difficulties arranging their marriages.

Although I found both married and single women had issues, women with small children faced more difficulties continuing treatment than single women. Most women with children stated that despite their worries they were not able to care for their children properly, because of fear of infection and physical inability. It is likely that things would have been even more difficult for lactating mothers with TB but I was

unable to find any to interview. However, my discussion with health workers who served lactating women in the past revealed that they often had difficulties continuing their TB treatment. Such women not only feared infecting their babies but also thought TB drugs that they were taking would cause physical deformity in their children.

Many women with TB stated that their children had to suffer more than others in the family as a consequence of their illness. In several instances, their children were forced to work to generate money for the household, deeply affecting their study. In many cases, their children replaced them in their work when they were unable to attend due to TB. This situation was found mostly among poor women who were working in small factories, and especially migrants. A woman migrant worker said;

'Sometime when I feel very weak I send my daughter to replace me in my work. This is how I am managing to keep my job in the factory. I feel sorry that she missed her school but will continue her studies once I feel better.'

In this case, I asked the woman whether she would send her daughter if her husband was ill. She said that she would do the work instead of her daughter to help her husband to continue treatment. Such findings clearly indicated that the impact of TB on women not only affected the individual but others in the family, especially children.

I also found an array of issues among migrant women with TB which affected their ability to continue treatment. Most migrant women arrived in the city with their husband and children and did household chores as well as working outside. They already had problems to earn and live in the city. TB further damaged their economical and social ability as the disease made them jobless and spoiled their social networks in the city as well as in the village.

I found that, in addition to concerns about the harmful effects of TB drugs (see section 5.2.1.3), women and men who were single and married with no children were more distressed about their fertility than women and men who had children. Their apprehension was not only whether they would be able to bear children but also the risk of not finding a marriage partner and being rejected by the family. The effects of such emotions in their treatment were clear as they often visited different health workers during their treatment and even thought about discontinuing treatment. A mother of an unmarried girl with TB who visited the DOTS centre with her daughter

said; *'We consulted several doctors to find whether these [anti-tuberculosis] drugs causes impairment on her.'*

She further stated that she heard in the community that TB drugs are very powerful and they dry and shrink the uterus, and cause infertility. Similarly, a young single man studying in college asked me during an interview whether the TB drugs that he was taking really affect his ability to be fertile. In contrast, married women and men with children found to be less concerned about this issue: however, some male respondents mentioned that the TB drugs have reduced their sexual strength. A lady health worker also stated in her interview that a woman who had her pregnancy test positive after diagnosis of TB was extremely concerned about her pregnancy status and had fears about negative impact on her foetus due to TB and TB drugs.

I found that the TB services were not gender friendly. Most women respondents stated various inconveniences in receiving TB treatment from designated DOTS centres. Such as women had difficulties sharing their problems with health workers due to lack of privacy in DOTS centres. Many women respondents stated that they had to wait for a conducive environment in the centre to discuss their concerns with health workers. It was more difficult when they had some personal and family issues hindering their treatment. I also found that women with TB were more inclined to visit the DOTS centre when there were fewer men there. Women also stated that they wanted to be served by woman health workers instead of man but there was no choice in many DOTS clinics. The reason they stated was they could discuss their problem openly with female care providers; in contrast, whereas men stated they saw no difference in the service provided by men or women care providers.

Similarly, I found that, unlike men, women tend to visit faith healers during TB treatment. I also found that health workers believed women were more stable and continued treatment from the same centre where they initiated treatment whereas men were more mobile. The mobile nature of men was mainly due to their job and family responsibilities. Health workers also stated that women were more compliant to advice given by them and more committed to their treatment despite hardships.

In several instances, I found that wives accompanied husbands to the DOTS centre but husbands hardly accompanied wives. This indicated that women and their illness were less of a priority for husbands. It could be also that men did not want to be seen with women, as this is not common in Nepali society. However, in interviews men stated that it was due to their busy schedule as they do care about the illness of women.

In conclusion, I found that gender differentials exist in TB service delivery and treatment: thus gender inequality was an issue in the NTP. Both men and women face difficulties continuing their treatment. However, women with TB were more vulnerable to TB treatment due to their positions in the family and society, which are further determined by socially constructed roles, and a wide variety of behaviours and expectations. Women faced several barriers at home, in the society and in health institutions. Despite such hardships, women tend to follow TB treatment better than men. I also found that the existing TB service delivery mechanism was not gender sensitive: thus revisiting the existing modality needs to be a priority to address the gender-based inequalities in TB services. However, despite gender differences both men and women continued their treatment.

5.2.2.3 Social system, caste, ethnicity and TB

Nepal has a multifaceted social structure with a number of traditionally defined social layers generally based on caste, ethnicity and language as described in section 2, section 2.7.1. The study area was not untypical, as it included people from different ethnic origins, castes and languages, so that my respondents were mixed (see chapter 4, section 4.3.4). In this section, I discuss findings related to people with TB from the socially disadvantaged classes (so called lower cast groups known as Dalits) as I found them to be more vulnerable. I present their experiences with TB and TB treatment with a view to understanding whether there were caste and ethnicity differences in factors affecting TB treatment completion.

Most of the Dalits with TB I interviewed shared concerns about whether their caste identity would be disclosed, even despite my initial guarantees of confidentiality within the study, because they thought that the community perceives Dalits as low caste people, and disclosing their caste identity would make them further vulnerable in accessing TB services from the DOTS centre. They also stated that in DOTS centres so called higher caste PLTB may not like them, and they may receive poor behaviour from health workers, who mostly belong to the higher castes. A young man, working in a factory said;

'I don't mind letting others know that I'm from a Dalit but not all people in the community have same respect to all castes therefore sometime I fear whether people would treat me differently knowing that I am a Dalit.'

In the Nepali social system, caste can be identified from a person's surname. According to health workers, Dalits with TB, especially women, often hesitate to give their surname during registration for treatment. I found that Dalits with TB were anxious about unfavourable behaviour from people in the community and at the DOTS centres, over and above fear of discrimination on the grounds of TB. Consequently, some Dalits with TB had changed their surname when they registered for treatment in a DOTS centre. I found that Dalits' intention to hide their caste identity was nothing more than to avoid situation of discrimination against themselves and their family on the ground of their caste and the disease.

I found that the false names and addresses given by Dalit TB patients during registration had implications for treatment, if they missed treatment doses and health workers tried to trace them to encourage them to continue treatment, they could not be found at the address given. In addition, health workers stated that some Dalits with TB often carried drinking water themselves, as they were reluctant to use the water jar provided in the DOTS centre. They were worried whether others would say something unpleasant because they thought that PLTB from higher castes would not use the water touched¹² by them. This showed that Dalits with TB wanted to avoid any situation of potential discrimination by others, but doing this throughout treatment caused them additional problems.

I found that Dalits often had a perception of being less empowered to demand services; and this was exacerbated when Dalits had TB. A young woman who migrated to the city with her husband said;

'People do not care our problems because we are Dalits and having TB is a suicide for us.'

Identifying clear links between TB and specific caste groups was hard: I found that the socially disadvantaged groups, especially the Dalits, saw an association between their TB and the job they were performing, which was generally considered a low-grade job. Dalits also said that their perceptions of association between TB and the kind of job they were engaged in became stronger when health workers told them that the

12 Historically Dalits were considered to be untouchable and were therefore culturally restricted in many ways. In many instances, food or water touched by Dalits was considered to be contaminated and therefore unacceptable by so-called higher castes. However, things are changing since the government reinforced anti-discrimination legislation

causes of their TB was very much associated with their job. (It should be noted that not all Dalits were engaged in the type of work that was perceived as low-grade.) Although TB flourishes in conditions of hardships and poverty, it made Dalits with TB feel that their disease was a consequence of the work they were involved every day, which further humiliated them, and their feeling of being inferior in the society became stronger. I found that such perceptions among Dalits affected continuation of treatment as they often isolated themselves and blamed themselves for being Dalit and having TB. In addition, the poor social and economic status of Dalits made them more vulnerable to the disease and created further hurdles to treatment continuation.

On the other hand, a Dalit with TB working as a teacher stated that there was no discrimination against low caste TB patients in the DOTS centre where he was treated. In addition, he said; *‘Things have changed a lot in the society as these days people do not take caste business seriously.’*

I found that people in urban areas perceived caste as less high profile and less important for them in their public life, clearly indicating a changing scenario. A health worker said;

‘It is not much important in cities as many people do not care whether a person is from lower or upper castes, the only matters is how people behave with each others.’

From my findings it can be said that the caste issue is no longer taken seriously in the cities whereas it still exists to a certain degree in rural areas. However, from the point of view of Dalits with TB, unfavourable behaviour against Dalits based on caste still exists, which in some instances was made worse by TB.

I then interviewed NTP officials to obtain their opinion on the matter of discrimination based on caste. First, they denied that there was any form of discrimination in TB service delivery. Second, they perceived that TB was common among socially marginalised groups, although they said that the NTP has no specific evidence for this opinion, but has planned research on this topic. Third, they mentioned that the NTP has been considering designing some specific interventions taking into account the TB burden among socially marginalised groups and their difficulties accessing TB services, especially in urban settings.

Box 2: Case study of a Dalit woman with TB

A 28-year Dalit woman arrived in the city with her husband and two children in search of financial improvement. She had no big dream in the city being an uneducated Dalit woman, so she started a job in a brick factory. She started earning 95 rupees (US\$1.3) per day. She registered in the factory with a non-Dalit surname and enjoyed her new social identity. While in the city, she wanted to avoid prejudices based on her Dalit status. Such prejudices had caused her substantial suffering in her home village: for instance, she did not have privileges to access the temple, water sources, eating places and other public places.

Unfortunately, the joy of being away from discrimination did not last for long as within two months another tragedy hit her life when she was diagnosed with TB. Diagnosis cost her all her savings. Survival in the city became difficult for her due to financial constraints and access to the distantly located DOTS centre. Consequently, she had to return to the village. Her brother helped to get drugs from a health post, which was 6 hours distance from her home. Despite several efforts to hide the disease, other women in village became aware of her illness. The prejudice mounted after her disease became public. It was more difficult to continue treatment when her brother had to come to the city to earn money.

These consequences weighed heavily on her and she stopped treatment for a month. She thought life had come to an end. Meanwhile her husband came and rescued her back to the city. She had to go through all the TB tests again and restarted her treatment at a new DOTS centre. Now her nine-year-old daughter helps her at home, her husband has a job and her little boy stays with her. She is getting help from her brother who came to the city to earn money. She has regained her hope in life but is worried whether she can continue the treatment. Now she has left everything to God.

(The woman was a participant of focus group discussion)

5.2.3 Attitudes and behaviour of health workers

In this section, I present my findings about attitudes and behaviour of health workers, as a follow-up to a question I asked to most PLTB: *'how do you think you have been treated by health workers during the process of your TB treatment?'* The initial answer most respondents gave was in line with the statement; *'most health workers were good but they generally keep their distance'*.

In the interviews, I sought further explanations of the word 'distance'. I found that it did not mean only the physical distance between PLTB and health workers during TB service delivery, but also the distance in the DOTS centres in everyday practice such as behaviour, communication, providing TB drugs, and examining PLTB. In most cases, PLTB were disinclined to discuss the attitude and behaviour of health workers, despite my assurances of confidentiality, because many PLTB feared that negative comments about aspects of health workers' behaviour would endanger their treatment; they assumed there would be no change in health workers behaviour towards them so what was the point of raising the issue; many PLTB were unclear on the role of health workers towards them and what should they expect from a health worker, so they could not comment on whether what they received from health workers was good or bad; PLTB had a feeling of so far, so good, as things were moving despite problems thus why comment on health workers. However, not all PLTB had the same feeling and fear: I found a few were critical of health workers' attitude and behaviour. A woman with TB who had also volunteered in a DOTS clinic in the past said;

'Health workers in this centre are good. It is not to blame them but often they consider us only as a patient then a human thus they have difficulties to understand our situations. This makes me to feel that they do their job but not serving us from their heart. I feel sometime they may have ill feeling towards us or some kind of fear with TB disease, but they don't show in general'.

Similarly, a few PLTB stated that their health care workers were not friendly towards PLTB and in many instances did not respect them. Examples they gave included: PLTB were scolded by workers during the course of their treatment, especially when PLTB were late, even by a few hours, in collecting TB drugs; uncooperative behaviour of health workers such as not supplying TB drugs even for a few days when PLTB were in desperate need; responding with an insolent tone of voice when asked questions; and unresponsiveness to PLTB shown when health workers sometimes

asked PLTB to wait while they chatted with friends. A young migrant with TB working in a factory, who used his lunchtime to visit the DOTS centre said;

'I wish I could have money to buy drugs in pharmacy as the health workers here [DOTS centre] are so unresponsive to my needs. I told them I have limited time to come for drugs, despite so, they keep me waiting and they engage in chat with each other. Seeing their behaviour makes me so upset but nothing I can do as they don't like if I complain.'

On several occasions, PLTB stated that they felt uneasy discussing problems, especially personal and social issues, with health workers, because health workers often did not show any interest in listening to problems other than those directly related to health; health workers did not encourage PLTB to share their problems; and in a few instances health workers said to PLTB that they cannot help. A rural woman who migrated to the city in search of work but who developed TB, and who tried to share her problems with her care providers, said;

'Staff here [the DOTS centre] are nice but they were often not interested to listen issues other than treatment and I feel odd when I wanted to talk about my other problems. I thought she [a nurse] would not listen to me, as she never asked how I was managing my treatment. She may not like if I push her to listen my problems.'

A tendency was seen among some health workers to view PLTB as a 'TB patient' rather than a human being with roles in the community and family; and thus such health workers treated TB, not people. PLTB said that health workers did their routine duty but were less sympathetic to PLTB as they viewed them differently from other people in the community. A young man said;

'I missed drug for a day as my father came from village and he was ill. My wife took him to hospital. I was very weak and not able to come here. I was waiting my wife to return home and get drugs from the centre but it was too late by the time she arrived home. Next day I came to this centre she [a Nurse – the respondent pointed to her] scolded me as if I am not a human and only an ill desired person. I tried to explain my situation but she did not listen to me.'

However, most health workers said that they did listen to PLTB and tried to understand their difficulties, but were unable to help PLTB in addressing non-medical issues such as financial and social problems. A health worker working in an NGO clinic said;

'We are aware that TB patients have concerns other than medical. We listen them but cannot address the especially their financial inability, accommodation needs and so many others. Although we listen them, not able to provide help may have annoyed TB patients thus they may have felt that we do not consider them seriously but it is not what we think.'

There was therefore a mismatch between the health workers' and PLTBs' perceptions regarding non-medical support. PLTB thought most of the problems they suffered during TB treatment were as a consequence of TB, and therefore it was legitimate to ask for advice and support from health workers; while health workers believed that the PLTBs' non-medical problems, had nothing to do with them, as they could only address medically related issues such as drug side effects.

In contrast, some PLTB stated that they had a good relationship with health workers, who supported their treatment continuation in various ways. Examples included: health workers accepted PLTB and put them on treatment; they tried to be flexible in DOT as they supplied drugs when requested; they provided assurance that their disease would be cured; they opened the DOTS centre on time and called PLTB when they were late for treatment; they were polite and informative in their dealings with PLTB. A woman with TB who had family problems which meant she faced difficulties continuing her treatment said;

'I shared my problem with the nurse and she suggested me how to deal with problems. She presented like my sister and worried that I may discontinue my treatment. All her support and encouragement helped me a lot.'

I observed that, in general, health workers attitudes and behaviour towards PLTB were good; and when health workers respected PLTBs, this provided considerable motivation to continue TB treatment.

5.2.4 Information and communication

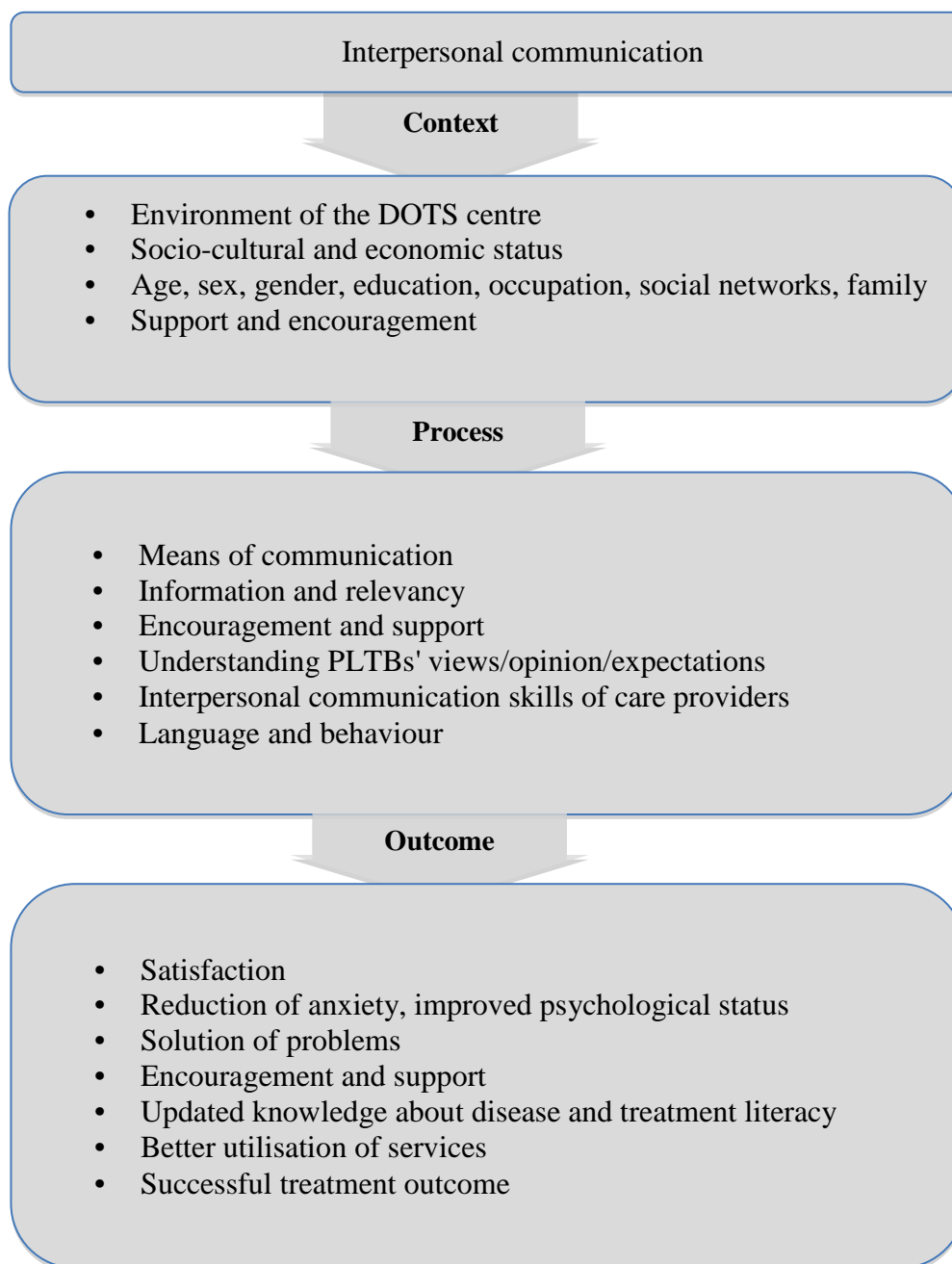
I have already discussed my finding that TB-related knowledge and perceptions among PLTB, their families and the community played crucial roles in proper diagnosis and treatment of TB. The knowledge, perceptions, attitudes and behaviours of both health workers and PLTB were closely linked to information and information communication. Information communication was an important activity of the NTP, the main examples being:

- **Interpersonal Communication (IPC) between health workers and PLTB during treatment**, where appropriate including family members, friends or relatives of PLTB.
- **Programme communication to communities**: aiming to change socio-cultural norms, thus improving community understanding of TB and perceptions of PLTB, expanding community support and solving social problems at community level.
- **Communication with politicians and policy makers** to advance policies and guidelines and secure required financial resources.

In this section, I mainly focus on IPC between health workers and PLTB (and where appropriate PLTBs' family members), because information and communication, when delivered effectively, can have a profound impact on changing individuals' attitudes and behaviour. I will not discuss the other communication activities explicitly as the focus of my study is on health workers and PLTB.

In this section, I discuss my findings on IPC with a specific focus on information as a 'resource' and communication as an 'activity'. I developed a framework (Figure 13) to aid understanding of IPC based on the three major themes that emerged in the study: context, process and outcome. Context refers to the physical and socio-cultural environment; process to information relevancy, means of communication, understanding and respect for each other's views; and outcome to satisfaction, problem solving and knowledge enhancement and hence to successful treatment outcome.

Figure 13: Framework for understanding interpersonal communication in successful completion of TB treatment



I found that a various elements had a role in shaping the IPC. The subsequent sections focus on context for IPC, its process and outcomes.

5.2.4.1 Context for interpersonal communication

In this section, I mainly focus on the following areas that influenced IPC: the environment of DOTS centres, the cultural diversity of PLTB and health workers, and socioeconomic differences of PLTB and health workers.

5.2.4.1.1 Environment and other context for communication

I found that IPC between health workers and PLTB was influenced by the atmosphere at the DOTS centres (external and internal); institutional settings and service delivery; privacy; comfort; and support and encouragement provided. The DOTS centres in the study area were heterogeneous in terms of infrastructure, internal settings and services they provided. A few centres were located within the premises of a general hospital and offered a wide range of TB services, but the majority operated in a limited physical setting with no designated room for communication services (although a few centres had a general consultation room, which was also used for TB services). Generally, communication took place in an area where other services¹³ were being delivered, so that frequent interruptions occurred. Health workers commented that limited physical facilities at the DOTS centre, especially rooms, not only affected communication but also challenged delivery of basic TB services and quality of care.

I found that communication events were also often interrupted by frequent phone calls (and particularly mobile phone calls) to the health worker involved in communication; lack of concentration by health workers; untidy rooms and disorganized and cluttered working environments (e.g. the health worker's desk was messy with papers and drugs); external noise such as pressure horn of cars and loud music from nearby shops; and frequent comings and goings of people in the room during communication. Moreover, many DOTS centres were poorly equipped with furniture and other essentials such as water supply, power, curtains, toilet etc. The absence of a minimum standard in the centre not only affected IPC but also lowered the motivation of PLTB. A woman respondent said,

'This centre even does not have provision of drinking water and sufficient chairs to sit and, how can they provide good service to us.'

¹³ In the study area, many DOTS centres were also providing other health services such as general health check-up, immunization, antenatal and post-natal care, family planning services, child health etc.

Likewise, the majority of PLTB stated that confidentiality was an issue in DOTS centres: a lack of privacy meant many of them did not discuss important issues with health workers and affected trust and curtailed relationships between both parties. I found only a few centres that had good physical facilities with a separate consultation room. However, PLTB receiving treatment in the centre stated that health workers were often busy and thus had little time for communication. This indicated that PLTB required more than merely good physical facilities.

On the other hand, I found that a few PLTB were not concerned with the environment of DOTS centre when it related to information and communication. This was not because they did not require information, but because they did not consider the DOTS centre as an information source, because they had not been satisfied with communication at the DOTS centre; because they satisfied their information needs from other sources (e.g. family members, friends, colleagues, books and the internet); and exceptionally because as they did not want to look for additional information.

Exploring information from various sources, especially the internet, was common among young PLTB with a good educational background and who are familiar with modern information technology.

Despite insufficiencies in physical environment and other contexts, I found that a degree of communication between PLTB and health workers was happening. Most health workers felt that they delivered effective communication within the limited resources provided to them. I found a strong feeling among health workers that high treatment success rates indicated that PLTB were satisfied with the services provided by them: thus they thought communication with PLTB was effective and contributed to good results. A health worker said;

‘Despite the resource constrains, we have been providing good services to patients as a result we have achieved a high rate of treatment success which indicated that TB patients were satisfied with our services.’

Such understanding among care providers did not acknowledge that, despite completing treatment, PLTB suffered greatly due to TB. The claim of health workers directly contradicted with what PLTB experienced, as many PLTB stated that the environment in DOTS centres did not allow them to discuss their issues and problems with health workers.

To summarise, a degree of communication took place between health workers and PLTB in DOTS centres, despite communication hurdles due to inadequate physical and other environments of DOTS centres and other contextual issues. Although the environment in the DOTS facilities is hard to change, there are opportunities which could minimize the effects of some contextual factors on IPC if health workers take the trouble to take them; but many health workers seen unbothered.

5.2.4.1.2 The need to understand socio-cultural diversity

I have already discussed in sections 5.2.1 and 5.2.2 my finding that PLTB had varied understandings and interpretations of their disease and treatment, most of which were influenced by locally-held cultural norms and the socio-economic status of the PLTB. In addition, the varying socio-cultural, economic, and occupational status of PLTB greatly influenced the support and barriers encountered during their treatment. It is therefore important to assess knowledge, attitude and beliefs of PLTB, and where applicable their family members, regarding TB and its treatment. Better understanding of PLTBs' knowledge, attitudes and beliefs would enable health workers to understand their views and information needs, and tailor information and communication accordingly. However, in many instances, health workers started communication without assessing the views of the PLTB, hence ignoring their views and failing to respect the PLTB's beliefs during the communication process.

For example, a woman strongly believed that taking drugs on an empty stomach would cause stomach erosion, but her health worker asked her to take all her TB drugs on an empty stomach. This information that conflicted with her beliefs not only confused her but made her worried whether the drugs would work for her, because she decided to take the drugs after a meal. I found many instances where beliefs of a PLTB and information given by a health worker were contradictory, and as a consequence the PLTB became anxious, fearful, or distanced him/herself from the health worker.

Such contradictions/mismatches often occurred when health workers gave generalised information to all PLTB without being aware of their views and information needs, so that the information was not tailored to the PLTB's needs. I found in many instances that the health workers started communication with a set of pre-determined information discussed in largely bio-medical, with little or no consideration of the PLTB's social and cultural background. It was often the case that TB messages were technical rather than contextualised to locally-held socio-cultural beliefs.

For example, the first information provided to PLTB was about the requirement for DOT, in line with national policy. Health workers could have communicated the policy after assessing the status, knowledge and behaviour of PLTB and motivated them by detailing the importance of DOT in treatment. Similarly, health workers often emphasized the need for continuation of TB treatment. Clearly, this was important information that all PLTB needed to know, but PLTB perceived that health workers focused only on treatment continuation without understanding the problems that prevented the PLTB continuing treatment. For example, a young migrant worker working as a carpenter was told to come daily for his treatment without the health worker having sufficient understanding of whether and how he had any issue that was affecting his treatment. He said;

'I know continuation of my treatment is very important for me and not doing so my disease will not be cured but there are other problems preventing me to do so. They [health workers] do not understand how much pain I am carrying due to this disease [TB].'

I found that only providing important information to PLTB would not change their behaviour as desired: it was equally important to know how and when to provide such information, to ensure that their knowledge was enhanced and they changed their behaviour to that needed to ensure cure.

I found that many PLTB had a difficult journey getting to the treatment stage. Notification of the disease itself was a shock for many PLTB, and by the time they arrived at the DOTS centre for treatment, they had many personal and family problems and frustrations in addition to TB. A woman running a small street shop said;

'I know TB is curable, sometime I feel it is better to die instead of facing hardship in life. It [TB] is not only the problem that I am facing, there are many others but who is going to listen them.'

Although to some extent health workers seem to be aware of the fact that PLTB were living with many other difficulties, they were rarely considered during communication. In absence of such considerations, exchanging information through IPC was often ineffective.

5.2.4.1.3 Socioeconomic differences between health workers and PLTB

I found that the difference in status, and especially socioeconomic differences, between health workers and PLTB played an important role in shaping the context for IPC. I often found that PLTB saw the health workers as being in a high position in the community, because of the respect they commanded and the power they held. Respect was largely due to the health worker's social position (they were often high caste people with education), economic well-being (having a high standard of living compared to the PLTB), their identity as a health professional, all influenced by a traditional mindset (health workers, especially doctors, save lives and are thus respected in the community). I found this respect often helped establish good relationships, contributing to good communication. On the other hand, power often hindered effective communication. Many PLTB strongly felt that health workers 'control' their treatment in many ways, because health workers make the decisions with regard to their treatment and PLTB have to comply. Consequently, many PLTB thought that the health workers were less approachable to them because of the power they hold translated into control during TB treatment. I found that the health workers further dominated the communication when they used their power to control the treatment process by showing no flexibility, especially in implementing DOT. Although DOT was mandatory in DOTS, it could have been properly explained and discussed with PLTB and their family members before being imposed; PLTB would then have seen the health worker as a facilitator, rather a 'treatment controller'. The power of control and such non-negotiated decisions often meant that PLTB were unable to challenge health workers. A teacher with TB said;

'Coming here [the DOTS centre] every day is like visiting the court as if I have done a crime. Several times, I asked health workers to supply drugs for a week but they say it is restricted by the policy.'

Some PLTB believed that decisions made by health workers were unquestionable. Such perceptions not only restricted PLTB from challenging the decisions but also made them reluctant to seek the health worker's advice on other issues. A woman who had continued treatment for two months said;

'I do not question them [health workers]. I simply try to comply with their decision. I fear that asking many questions would annoy them and I may get problem getting treatment from this centre.'

Similarly, I found that the words that health workers used to address PLTB during communication indicated less respect to PLTB. For instance, 'timi' is a Nepali word which indicates 'you' in English but when pronounced with more stress, it is considered as less respectful. I found that many health workers used such words, which devaluated the PLTB in several ways. A young man working in a private firm had a bad experience with a health worker when he asked for drugs for few days. He said;

'The doctor behaved me so badly. He said you (timi) all people [PLTB] are uneducated thus, you do not understand us [health workers]. He said angrily that it is not possible to educate people like us, if I wanted to cure my disease I should listen what he said if not I should buy drugs from private.'

This was an extreme example and I did not find any other examples of health workers behaving in such a grossly intolerant way towards PLTB. There were other examples which indicated that PLTB were scolded by some health workers during their treatment but not to the same extent.

I also found that many PLTB were not comfortable to talk about negative experiences that they had with the health workers from their DOTS centre, indicating that PLTB were worried whether their treatment would be affected if they talked about bad experiences they had with care providers. Such feelings were prevalent despite my reassurances about the confidentiality of information in the study. It was clear that there was a lack of mutual trust in the relationship between PLTB and health workers. Despite this PLTB showed respect to care providers.

Of course, not all health workers had negative attitudes and behaviour towards PLTB. I found health workers respecting PLTB on many occasions: some health workers did help PLTB during their treatment because of a strong commitment to make the treatment a success. In doing so, some helped address non-medical problems, leading to good relationships throughout the treatment. A young migrant worker working as supervisor in a carpet factory described the help he received from a health worker, which enabled him to continue treatment without losing his job;

'I had problem to come every day to the centre which I discussed with health worker. She [nurse] phoned the factory owner and asked him to support my treatment.'

I also found that gender differences between care providers and PLTB affected information exchange. This was more common among women PLTB, who were often

reluctant to share their problems with male providers. Similarly, age and literacy status also affected communication. However, NTP TB training modules clearly state that such factors must be taken into account by health workers when communicating with PLTB. However, not all health workers put into practice the theoretical knowledge that they gained during basic TB training.

I also found that PLTB acquired information from their social networks – relatives, friends, neighbours, and colleagues – which played an important role in determining their treatment behaviour. The information that PLTB received from their social networks was of mixed reliability: some of them were incorrect, for example ‘TB drugs cause impotence’. Such misconceptions could reduce PLTBs’ ability to continue treatment if not properly addressed by the health system. However, I did not see health workers carefully considering information that PLTB received from their social networks. Likewise, I found that many PLTB received encouragement and support from family members. However, health systems did not pay sufficient attention to engaging PLTBs’ family members despite many opportunities to bring family members into the treatment process.

5.2.4.2 *Process of information and communication*

In this section, I define *process* as a particular course of action in communication intended to achieve a desired outcome. Although the process of information communication started when PLTB sought care, in this section, I only consider communication during the course of TB treatment.

I found four major actors/agents that shaped the information and communication process: health systems (the NTP and its policies); health workers (who though part of the health system are also individuals); PLTB and their family; and members of the community such as friends, relatives and colleagues. Although all four were important, I focus on two major actors: health workers; and PLTB along with their family where applicable, because these actors were more often engaged in communication during the treatment phase than the other two. Important areas influencing the communication process and thus its effectiveness were: information content and relevancy; means of communication; and involvement of PLTB and their family members in the communication. Below, I describe each independently.

5.2.4.2.1 Information content and relevancy:

The NTP had a pre-defined information package, designed for all PLTB. This focused mostly on the technical aspects of the disease and treatment with less consideration of socio-cultural implications of the disease (see Box 3). Although this technical information was important for the PLTB, it was hard to expect successful treatment completion when socio-cultural aspects of the disease were ignored. During interviews, many PLTB raised concerns regarding their disease and treatment which I have discussed in subsequent section. I found that most of the specific concerns (Table 12, the second column) were not fully addressed in the NTP's information package. Examples of such issues include TB-related stigma and discrimination; the impact of TB drugs on fertility; dietary restrictions during treatment; relationships between TB and poverty; life-long implications of TB; and physical relationships between husband and wife during TB treatment. Such issues are discussed in section 5.2.4.3. It is clear that the NTP information package did not fully address the concerns PLTB had during TB treatment. However, health workers had a strong feeling that they addressed needs of PLTB because they observed high treatment success rates.

Box 3: NTP's predefined TB information package

All PLTB must know that;

- i. they need to take the full course of prescribed drugs under the direct observation of a treatment supervisor
- ii. treatment should not be interrupted throughout the treatment period

Information that health workers should inform PLTB at the start of TB treatment

- iii. PLTB need to take their treatment everyday under DOT;
- iv. The duration of TB treatment;
- v. TB will not be cured if treatment is interrupted;
- vi. Information on minor side effects of drugs (e.g. red urine). If PLTB have other difficulties they should contact health facility as soon as possible;
- vii. TB drugs are available free of charge;
- viii. About TB: cause; regular treatment cures the disease; once treatment is completed the disease will not infect others etc;
- ix. Cover mouth while coughing, where possible use handkerchief or use hand

Source: Translated by author from the NTP training module 'treatment management, health education and skill development' page 48 and 49. NTP Nepal

The DOT element of DOTS is emphasized in the information package. Although use of DOT was part of policy, it was not suitable to all PLTB as discussed in section 0. It was stated by a majority of PLTB that the emphasis placed on the requirement for DOT overshadowed other information needs that were equally important to PLTB. I found that selection and individualisation of information taking into consideration the PLTB's personal circumstances was not common practice, and greatly affected communication.

Some information in the NTP information package was outdated (Box 3). The Box 3 point number VII says a PLTB becomes non-infectious only after completion of TB treatment, whereas evidence suggests that PLTB will be non-infectious within two weeks of starting regular TB treatment. Such unverified information provided to PLTB compelled them to be in isolation from family and friends throughout the treatment period, which was difficult for many PLTB. Similarly, I found that in some cases, although information was correct, how and when it was delivered to PLTB had a big impact on whether the information contributed to its purpose. For instance, point V in the box says that the disease will not be cured if treatment is interrupted. The information is technically true, but the way it was communicated to PLTB created unnecessary fear among those who missed only one or two doses of TB drugs during the course of treatment. A woman with TB said;

'I missed two days treatment because the DOTS centre was closed due to bandh [a strike caused by political instability]. Health worker told me at the start of treatment that I should not miss even a single dose. I am worried whether my disease will cure.'

It was important that health workers needed to understand the context and the relevance of information to each individual, instead of generalising to all PLTB. However, it was rarely considered during communication, so that information provided to PLTB often conflicted with their individual beliefs.

Table 12: Information needs of PLTBs

Areas of general concern	Specific concerns of PLTBs
<p>Disease-related</p> <ul style="list-style-type: none"> - Symptoms - Communicableness - Cause of TB - Types of TB 	<ul style="list-style-type: none"> - Is my disease really TB? - I have no bad habits (smoking, drinking alcohol): how did I get TB? - When will I stop being infectious? - Will TB remain in my body for life? Does it permanently damage my lungs? - Does TB reduce physical ability even after cure? - Misbeliefs regarding the cause of TB: e.g. I got TB because secret promises to god were not addressed; TB was a result of bad deeds. - Can my TB turn into a chronic disease?
<p>Treatment- and drug-related</p> <ul style="list-style-type: none"> - Treatment duration - Side effects of drugs 	<ul style="list-style-type: none"> - Why does treatment take so long? - Some people have said TB needs to be treated for at least 2 years: why will my treatment only take 6 months? - Can my TB actually be cured? Why does TB treatment fail? - How do these drugs work on me? Why do I need to take a lot of drugs? - Should take supplementary drugs (e.g. vitamins) during treatment? - Will TB drugs affect my fertility? Will TB drugs make me physically weak? - TB drugs are very powerful: will they damage my body? - Can TB drugs be taken after meals? - Are TB drugs of quality - Will TB drugs damage body cell while killing TB bacilli
<p>DOT and treatment management-related</p> <ul style="list-style-type: none"> - DOT 	<ul style="list-style-type: none"> - Is DOT compulsory for free TB treatment? - Why am I forced to undergo DOT? - Should DOT happen only at the DOTS centre? - Can the treatment be supervised by family or friends at home? - How long is DOT required? - If sputum is positive in 2 months, should DOT extend for another month? - Can I travel out of town during treatment: if so, how can I get my drugs? - Can I be referred to my village for TB treatment? - If I take TB treatment at my village, should I come to the city? - Are TB drugs the same and the same quality in the city and the village?
<p>Food habits</p> <ul style="list-style-type: none"> - Diet 	<ul style="list-style-type: none"> - I can't afford additional nutritious food: will this affect my treatment? - If I am vegetarian should I switch to a non-vegetarian diet? - What shouldn't I eat? - How frequently should I eat meat?
<p>Disease precautions</p> <ul style="list-style-type: none"> - precautionary measures 	<ul style="list-style-type: none"> - Should I be in isolation? How long should I be in isolation? - Can I share a bed during TB treatment? - Should I use a mask all the time? How can I protect others from being infected?

Social, cultural and financial aspects of TB

- Why is TB perceived as a dangerous disease in the community?
- Why do people avoid PLTB? Is TB only a disease of the poor?
- Can PLTB transmit their disease to others?
- Why do people discriminate against PLTB?
- Will people marry a person with TB?
- Will TB and TB drugs shrink the uterus?
- Is TB is a disease of people who do bad things?
- Does TB occur when a person engages in sexual relations with other family members?
- Does TB often occur in people who have had sex with prostitutes?
- Does TB only affect people who do low grade job e.g. garbage collector?
- Are women who visit a temple during menstruation at risk of TB?

Source: Compiled by the author from interviews and FGDs with PLTBs and their family members

5.2.4.2.2 Techniques used in communication:

I interviewed some PLTB along with their family members immediately after interaction with health workers, I found that they had several concerns that they wanted to discuss with the health workers but had no opportunity to do so. The PLTB said that;

'He (the health worker) could have given drugs as I'm very weak and coming every day is a problem for me'.

Similarly, his (the PLTB) wife stated; *'I am not sure how he will come every day. Now I'm worried how we will protect our children as his disease transmit to other. We have only one room where we all stay. He [husband] is not working since he got ill, it's difficult for me to come along with him every day as I need to go to work. I wanted to ask whether we can go to our village and take drugs from nearby health post.'*

It indicated some important shortcomings in the communication process: it was very much one-way; the health worker did not acknowledge the fact that PLTB was unable to come to the centre every day because of his physical inability although this was the PLTB's and his wife's main concern; several messages were given to the PLTB and his wife all together; and the health worker did not ask whether the PLTB had any concerns. Although the health worker communicated important messages, some of them worried the PLTB e.g. isolating himself from his children and wife.

I also verified my observation during interviews with PLTB who had been through the communication process in DOTS centre once or several times. Some stated that they often listened to health workers but had little opportunity to ask what they wanted to know about their disease and treatment. For example, a woman continuing TB treatment who was a local resident of the city said;

'The health worker said many things about my disease but I hardly remember few of them'. When asked whether she had opportunity to ask any questions to the health worker, she said; 'I wanted to ask what precautions I should take, what can I eat and what should I avoid but I did not have time.'

Other PLTB had a similar experience. I observed that many communication events in DOTS centres were poorly organised as the process followed was rather traditional and largely dominated by health workers. In many instances, I found that the health workers did not consider the physical and psychological ability of PLTB to acquire information, and the environment where communication took place, so that communication was not very effective in achieving its purpose.

In contrary to what was stated by PLTB, and my observations, the health workers thought that their communication was effective, as they believed that they applied a good process and ensured active participation of the PLTB. A health worker who had recently communicated with a woman with TB while I observed, said, when asked what he thought about how the communication went;

'It is my duty to make TB patients aware about their disease and treatment. I told [my emphasis] what she needed to know about her treatment.'

However, I hardly noticed any two-way interactions. The health worker did not ask the woman whether she understood or had any questions. I found similar occurrences in my observations and discussions with PLTB.

I found that most health workers were aware of the technical facts of TB. However, the context of the PLTB and his/her needs were rarely considered during the communication process. Issues included: how the health workers communicated facts to PLTB; whether the facts were understood by the PLTB in absence of a two-way dialogue; whether, in the absence of proper response to queries of the PLTB, the communication helped to change the knowledge and behaviour of PLTB to make successful treatment completion likely; whether the health workers considered the status of the PLTB and made adjustments to enable communication; whether a relationship and trust was developed before and during the process of communication; whether the PLTB had opportunities to share his/her opinions and ask questions. I found that none of these issues were taken fully into account.

In some instances, I found that the health workers often assumed an educated person would already have good knowledge about his/her disease and treatment and thus have less need of information. However, this was not always the case. Some well-educated PLTB I interviewed knew some information about their disease and treatment, but not enough to help them during treatment. For example, a health worker considered a well-educated young man working in a government office to be a person with sufficient knowledge about his disease, so she felt no need to provide detailed information to him. The young man narrated his experience;

'In my first meet with her [the nurse] she said that I am well educated thus I must have known many things about my disease thus no need to repeat them again. But it was not true, I did not know many things about TB. When asked whether the educated person asked the nurse any questions, he said; 'It was hard for me to ask her again as I did not feel comfortable. I simply listen her and walk out.' He stated that asking questions to the nurse again would undermine his image of being a well-educated person, so he did not do so.

In contrast, PLTB with little or no education felt overloaded with information provided by the health workers, especially in the early days of treatment. They stated that the care providers told them many things at once, making it difficult for them to remember everything. A male migrant worker said;

'The nurse told many things about my disease but I hardly remember few of them. Recently a sir [health worker] in the lab told me several things about my result and asked to bring another sample but it was hard for me to understand all information provided.'

I found that it was important to individualise the content of communication taking into account the educational level, information needs and ability to understand information. However, the findings demonstrated that there was little consideration of choosing an appropriate communication process and the status of the PLTB while exchanging information, consequently the purpose of communication was not fully achieved.

In addition, the relevance and prioritization of information according to needs of PLTB at various stages of their treatment was another important area that determined the effectiveness of communication. However, it was often the case that health

workers were more inclined to provide a set of pre-defined information to the PLTB regardless of its relevance to individual needs. During interviews, health workers often said a lack of sufficient time for communication limited their ability to understand the needs of PLTB and prioritise information accordingly. However, I observed that the majority of PLTB visited the clinic on a regular basis, and there were ample opportunities that health workers could have used to educate PLTB. In response to a question regarding how frequently PLTB were educated in the DOTS clinic, a woman respondent visiting the clinic every day said;

‘The nurse gave me several information when I started my treatment. Then after she provides information when I ask questions.’

This and other experiences did not match what health workers said about limited time. Since PLTB visited the clinic on a regular basis, health workers could have prepared a list of PLTB who they could communicate with at each visit. However, this did not happen in many DOTS centres as communication was not a routine activity delivered in an organized fashion.

I found a lack of communication tools in DOTS centres. Most of the communication events between care providers and PLTB were based on verbal discussions or lectures with little or no use of audio-visual tools. Health workers also raised the lack of communication tools as a barrier in exchanging information. I also looked at the basic NTP TB training module used to train health workers. The combined module had a section on ‘Health Education, Communication and Skill Development’. The section contained exercises, role-plays, games, some examples of good communication, pictorial exercises and communication theory. Communication was a half-day course within a five day training package. During interviews with health workers, I asked about the training they received with regard to communication. Responses were mixed. Some health workers said that a half-day course was insufficient to enhance their skills in communication whereas others said that the content and exercises were sufficient, but they were insufficiently focused on during the training course.

In the central store of the NTP I found some educational materials related to TB (see Table 13). I found that most of the communication materials were developed considering the programme perspective with limited understanding on the needs of PLTB. In addition, the materials were also limited in quantity so that they were not available in many DOTS centres in the study area. In my discussion with NTP

officials they also highlighted the lack of educational materials in the programme. A NTP official said; *‘We have developed few communication materials and realized that these are not sufficient thus we are in process of developing new materials considering the needs of the programme.’*

Table 13: Communication materials of NTP for various target groups

Tools	Contents	Target groups	Comments
TB leaflet	TB in general (cause, symptoms, treatment and prevention)	General population	- Too much information with no prioritisation - Lack of content to address misconceptions about TB - Not useful for illiterate people
TB poster	TB general	General population and PLTB	- Traditional design - Unfocused messages
Banner	TB in general DOTS	General population and PLTB	- General TB messages - Only used during certain occasions i.e. world TB day
Flip chart (cloth)	TB in general, diagnosis, treatment, DOT	Community health workers, PLTB	- Designed with focus on DOT (institution and community) - Useful to educate PLTB on disease and treatment - Limited availability
Pamphlets	TB in general	Community people, volunteers, PLTB	- Too many messages - Hard to read - Not useful for illiterate people

5.2.4.2.3 Involvement of family members of PLTB in communication:

I observed that PLTB were often accompanied by a family member, friend or relative while visiting the DOTS centre. This was more common during the initial two months of TB treatment when PLTB were asked to visit DOTS centre daily and when the PLTB was physically weak. In several instances, the family members wanted to know more about the disease and treatment. Thus, a woman who accompanied her husband to the DOTS centre showed her desire to know more about the disease and treatment;

‘I want to know more about his [her husband’s] disease. Since he started taking drugs he became very weak and sometime vomits blood. This makes me so worried and seeing him in such condition, I feel helpless. It may be due to these strong drugs or may be due to other disease he may have. I wanted to know whether the treatment he is currently taking is correct for his disease.’

In DOTS centres, I often observed that the family members who accompanied the PLTB were present during discussions with health workers. However, family members' participation in communication process was passive. In discussion with the family members, I found that they were unclear about their role in treatment, as it had not been clearly explained by the health workers. PLTB and their family members commented that although health workers ensured family members were engaged in discussions on the requirement for DOT in TB treatment, otherwise their engagement was overlooked. Regarding the requirement for DOT, family members were mostly seen as witnesses to ensure that the PLTB visited the DOTS centre every day. A family member who accompanied her daughter to the DOTS centre said;

'I come here with my daughter every day. It has been few weeks I have been doing so. I asked the nurse whether I can take drugs and feed at home but she said my daughter needs to come every day for initial two months then after she can supply drugs for a week.'

In my discussion with the health workers, they clearly stated the importance of engaging family members in the treatment process. They believed that without the help of family members many PLTB would have difficulties continuing their treatment. However, they also stated that lack of a clear understanding in the programme on the role of family members, especially during DOT, limited opportunities to engage family members in the treatment process. Despite this, the health workers thought that they often appropriately engaged family members of PLTB. The health workers also stated that some family members proactively engaged in discussion with them. However, not all family members of PLTB were the same.

It was clear that the family members of PLTB had been playing an important role in TB treatment. However, a lack of clearly defined roles and responsibilities was an issue. This clearly demonstrated a need to maximize involvement of family members in the treatment process by engaging them at various stages of TB treatment.

5.2.4.3 Outcomes: unresolved concerns of PLTB

I found that a degree of communication was taking place between the health workers and PLTB at various stages of TB treatment. However, it was not an easy task to measure its contribution to enhancing PLTBs' knowledge and changing their behaviour as the responses varied among PLTB and information needs were

different. I also found that the amount and type of information communicated to PLTB differed, however, to a certain extent, the NTP's set information package was communicated to all PLTB.

I found that some PLTB and their families were not fully aware of the treatment regimen, the reasons for the long duration of TB treatment, potential side effects of drugs and what to eat and avoid during the course of treatment. Similarly, some PLTB had strong personal or cultural beliefs about the disease and treatment, and who they could turn to for help. In some instances, I found that the treatment process that PLTB were asked to follow in DOTS conflicted with those beliefs. As a result, PLTB and their family members became fearful and anxious, and distanced themselves from their health workers, negatively affecting communication and thus the desired outcome. Such incomplete knowledge and unchanged traditional thoughts resulted in an inability or lack of motivation to stay on TB treatment. A young woman with TB said;

'It has been more than three months I'm taking drugs but the drugs are not responding well. Instead, my health is getting worse as I'm losing my weight, my head spins all the time and I can't sleep as I see dreadful dreams. I think it is happening on me due to Boksi [she-devil], she may have been following me all the time. If it was a disease then these drugs should work on me.'

Despite such conflicting thoughts, she was continuing her treatment.

In contrast, I found that some PLTB were happy with the basic information they had received. They stated that the information they gained greatly helped them to enhance their knowledge. Some also said that the communication they had with care providers helped to reduce their psychological stress and motivated them to stay on treatment. A woman with TB said;

'It gave me a pain when my children used to cough though the cough was simple. It made me to feel that I may have transmitted disease to them. I discussed with health worker and he told me that chance of transmitting disease is rare once I started taking TB drugs. He also checked my children and their sputum was negative. I was a big relief to me.'

I found that the NTP set of information was communicated to PLTB despite hindrances in the communication process. Some PLTB stated that the communication

helped them to understand technical aspects of TB treatment, as the majority of them said they were aware of basic information of the disease and treatment. However, most of them were also concerned about other than technical aspects of TB and its treatment which were taken less into account during communication: information needs with regard to socio-cultural aspects of the disease and its treatment were poorly addressed. Table 14 presents a summary of concerns frequently raised by PLTB during interviews and FGDs. I found that some if not most of them remained as concerns of PLTB throughout the treatment process.

Table 14: Frequently raised concerns by PLTB during data collection

Key questions	Areas of concern
Is it true my disease is TB? How did I get this disease? Can it be transmitted to others? What happens if my sputum remains positive after two months? What makes me vomit blood? Why it does not stop?	Disease related
Why do I need to come here every day? How do these drugs work? Are there other options available for TB treatment? I cannot sleep at night, is it due to these drugs? How long do I need to take drugs? I missed drugs for a day; do I need to restart drugs from the beginning?	Drugs and treatment related
How long do I need to be in isolation? What should I eat and what not during treatment? How frequently should I eat meat?	Precautions and other concerns
How long should I not conceive after completion of my treatment? My job requires taking heavy boxes from one place to another; can I restart my job while on treatment? Will I be cured after six months? Do these drugs reduce my sexual potency forever? People say once a person has TB it stays in the body forever; is it true? Will my disease really be cured? Will my disease relapse? Can I establish a physical relationship with my husband/wife while I am on treatment? Do these drugs affect my fertility? Will I regain my health?	Psychological stress, anxiety

I also found that PLTB did seek information from various other sources such as family, friends, relatives and the internet and updated their knowledge about the disease and treatment. In such a context it was hard to pin down the effectiveness of the communication events which PLTB had in DOTS centres.

5.2.5 Access to TB services in DOTS

NTP policy clearly states that TB diagnosis and treatment should be as close as possible to PLTB. However, I found conflicting views among study respondents including NTP officials in what was meant by access. NTP officials at national, regional and district level generally defined access to TB services by geographical coverage only – the distance from PLTBs' homes to DOTS centres – whereas I found that the access to TB services, especially treatment services was not merely limited to physical access to DOTS. Many PLTB and some frontline health workers stated that other factors presented barriers to access TB services as they hindered day-to-day TB treatment under DOTS. The study respondents, especially PLTB and their family members, noted the following barriers that curtailed access to TB treatment services in the given context;

- **Geographical:** inequitable distribution of health services including TB
- **Health care systems:** poor infrastructure supporting TB control activities; long care taking process; long waiting hours; inconvenient opening hours of DOTS centres; provision of mandatory DOT for all PLTB; non-availability of basic services for other illnesses in DOTS centres; no provision of follow-up sputum examination in DOTS centres; complex referral mechanism; attitude and behaviour of health care providers towards PLTB
- **Financial:** poor financial status of PLTB; high cost of TB diagnosis resulting in high financial burden during TB treatment; opportunity costs; job loss resulting in difficulties living and continuing TB treatment in the city especially for poor migrants; unemployment; other associated costs to TB treatment; other priorities such as survival opportunities perceived to be more important than TB treatment; lack of savings resulting in a lack of money for TB treatment;
- **Social and cultural:** cultural misbeliefs; stigma and discrimination; traditional practices (see section 5.2.2)
- **Educational, information and knowledge:** lack of information among PLTB on TB and its treatment (see section 5.2.1); poor information on availability of TB services; lack of information on location of DOTS centres;

- **Environmental:** external environment such as frequent strikes;
- **Personal habits:** alcoholism, lack of motivation for TB treatment; drug abuse.

Some of the barriers stated above have been discussed in earlier sections (see 5.2.1, 5.2.2, and 5.2.4). In this section I therefore focus on barriers related to geography, health systems, finance, environment and personal habits.

5.2.5.1 Geographical barriers to access to TB treatment services

The number of DOTS centres in the study area has increased over the years. NTP officials' view was that since the coverage of TB services had increased, the problem of limited physical access had been addressed in the programme. A District Health Official said;

'Over the years we have increased the number of DOTS centres fourfold thus TB services is widely accessible in urban area therefore service utilisation has increased.'

In contrast, the frontline health workers in DOTS centres stated that they had been receiving PLTB from a far distance in their centres, and dealing with their problems regarding long distance travel was an issue for them. I found that the geographical expansion of TB services in the study had been prioritised by the NTP, and as a result, a number of new DOTS centres were established. Although expansion had taken place, it was inequitable, as it did not consider the distribution of populations who had poor access to TB services. I found that migrants and factory workers faced more difficulties accessing TB services from designated DOTS centres than other PLTBs, as they lived and worked far away from the nearest centre. This was especially the case for those working in factories such as those making bricks and carpets. A migrant woman who was helping her husband continue TB treatment, and who lived in a slum, said;

'There is no health institution in our area, we need to travel far even for minor illness. It takes about an hour [one-way] to reach to this centre and coming everyday here with an ill person sometime it takes longer as he [her husband] cannot walk as I do.'

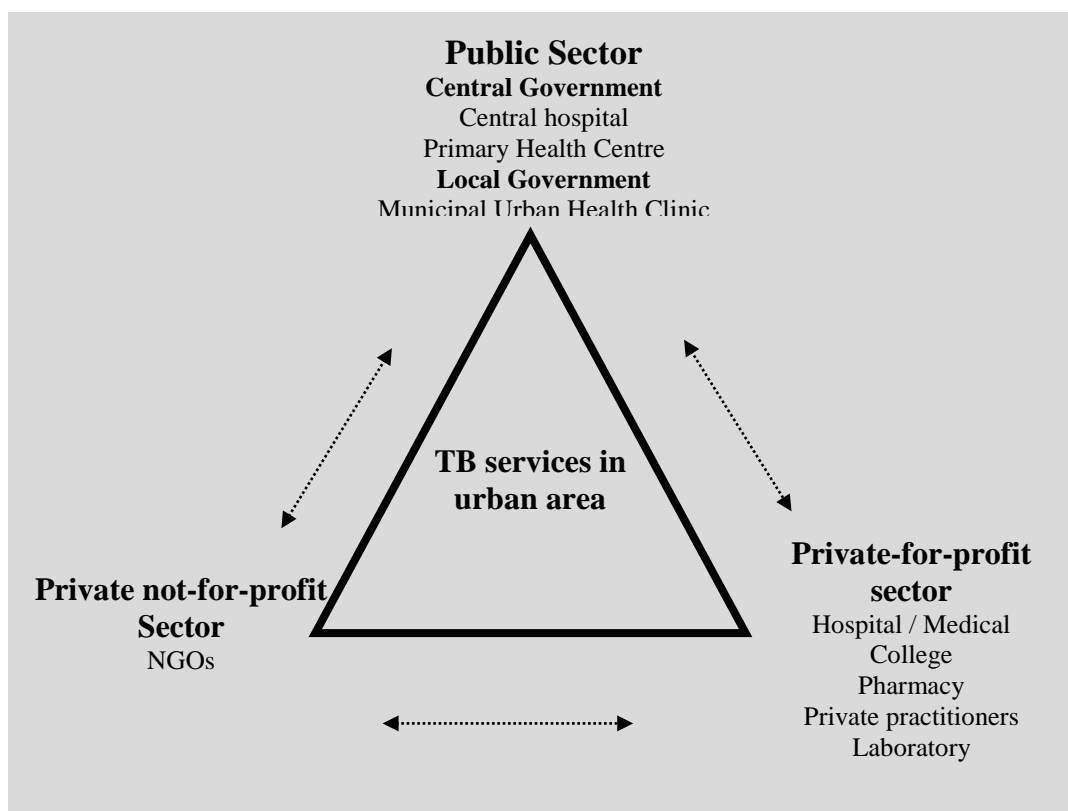
I found that access to the DOTS centre on a daily basis during the initial two months of TB treatment was a major problem. Although this problem did not resolve

completely after the initial phase of TB treatment, it was reduced as the PLTB were given a weekly supply of TB drugs. Likewise, women with TB and students also cited the distance they had to travel everyday to the DOTS centre was hampering their other routine activities. It demonstrated that had the TB drugs been supplied to PLTB during initial months, it would have greatly reduced access barrier to PLTB.

5.2.5.2 Health systems barriers to access to treatment TB services

I found only limited public health infrastructure available for implementing essential health care services (EHCS) including TB care in urban areas. There were three major health care types of provider delivering EHCS in urban areas as described in Figure 14, the public sector (central and local government); the private for-profit sector (mainly private hospitals and medical colleges, private pharmacies and private practitioners); and the private not-for-profit sector (Non-Governmental Organisations). Unlike the other health services in the study area, I found that the NTP had established a level of partnership with non-governmental organisations and a few private health institutions as presented in the figure. The public sector comprised central and local government was the main TB service provider under the NTP. I found that the private sector, both for-profit and not-for-profit, was relatively large in terms of services and numbers in the urban area. However, only limited providers were engaged in providing TB services under the NTP. Although a level of collaboration existed, TB service coverage was limited in areas where most of the urban poor and marginalised groups lived (slums and peri-urban areas). I also found that coordination among these providers was poor (shown by dotted lines in the figure), because it was unclear whether these institutions had any responsibility to provide EHCS including TB services, so that services were uncoordinated and unregulated. Similarly, inadequate institutional setup and human resources in existing DOTS centres provided only limited TB service delivery. Health services provided by the private for-profit health sector were not readily accessible for many urban poor due to the high cost of care.

Figure 14: TB services under NTP – an example of urban area



I found various other institutional barriers that hindered TB services. They included no DOT: no TB treatment (if PLTB was unable to comply with DOT requirements, s/he was not eligible to start TB treatment under the NTP); inflexible opening hours; limited information available on the location of DOTS centres; long waiting hours in DOTS clinics; unavailability of basic health care for other minor illness in DOTS centres; limited number of care providers in DOTS centres; no facility for follow-up sputum examination in some DOTS centres. These barriers particularly prevented migrants from accessing TB services from the designated DOTS centres.

Particularly important among these institutional barriers, were the inconvenient opening hours of DOTS centres. The normal working hours of government offices is 10 am to 5 pm, except Friday, which is 10 am to 1 pm. However, most of the DOTS centres opened from 10 am to 2 pm with the exception of a few which opened from 9 am to 4 pm. The DOTS centres' opening hours conflicted with the work schedule of many PLTB, resulting in difficulties continuing work and treatment simultaneously. The unsuitable service hours particularly affected jobholders, job seekers, homemakers and women with children: many PLTB fall in such categories. I also found that a few PLTB left their job because they had to attend the centre for DOT; and some PLTB who wanted to start job could not do so because of inappropriate

opening hours of the DOTS centres. A male respondent who was working as an electrician said;

'I did not work for two months as I had to come here daily. Now I get week supply, even it is not enough as I need to start my work at 6 in the morning and it lasts till 7 in the evening.'

A young man with TB who left his job because he had to visit the centre daily said; *'There should be provision in the programme, either they need to extend service hours or supply drugs to patients who are not able to come daily.'*

I found that migrants who had come to the city for work and were mostly working in factories and surviving on daily wages suffered a lot. Most had working hours from before 10 am until late in the evening, conflicting with the opening hours of DOTS centres: managing time in between was a problem for most if not all. A migrant worker with TB said;

'My major problem is time as I am obliged to come here leaving my work. It is not possible to take two hours leave everyday from my work, need to take whole day off as my work is far from this centre. If the centre had opened early I could have taken drugs first then go to work but who is going to listen our voice here.'

Some PLTB stated that they requested the care providers to open the centre early as the majority of people who were receiving TB treatment from the centre wanted it. However, the care providers refused their request by citing official policy.

I found that it was not only opening hours that hindered PLTB: some PLTB also said that they needed to spend a considerable time in the centre to be served. Similarly, some PLTB said that the DOTS centres did not open on time and sometimes they closed early. A student who had taken treatment for one month said;

'Every day I come here at 10 am then I go to college but they [the health workers] take so long time to give drugs. Once I asked the nurse here to serve me a bit quick but she did not like my saying.'

Some PLTB said that they had to take the day off from work when they had to go for follow-up sputum examinations, as some DOTS centres did not have provision of sputum microscopy. Similarly, PLTB were sent to either National TB Centre or other

hospitals to seek advice from doctors when they noticed drug side effects: even minor side effects were not well managed in the DOTS centres. I also found that PLTB had to visit other health care providers for other illnesses, even minor ones. Lack of comprehensive delivery of essential health care from DOTS centres caused difficulties for many PLTB taking TB treatment, especially for migrants who had limited knowledge about other health care providers in the city.

I found that some PLTB, especially migrants, wanted to be referred to a DOTS centre near their village for the course of TB treatment, mainly because they could not afford to stay in the city. However, health workers were reluctant to refer them. As PLTB stated, at the time of registration for treatment they were strictly scrutinized by health workers and asked to commit to completing the entire treatment from the centre where the initial registration took place. Because of such conditions, PLTB feared asking health workers to be referred to other places. I also found that the health workers were not fully aware whether TB drugs were available in the village where PLTB wanted to be transferred to, as they did not have a list of DOTS centres providing TB services across the country. This issue affected not only PLTB who wanted to be referred: PLTB who needed to travel out of the city for a few days also had difficulties, so their mobility was restricted due to the complex transfer process in the NTP. In a few instances, I found that PLTB were transferred to other centres in their district during TB treatment but did not get drugs from the health facility nearest to where they were transferred. Although the NTP treatment guideline gave clear procedures for transfer/referral during TB treatment, it was poorly managed in practice.

5.2.5.3 Financial barrier to access TB treatment services

The poor financial status of PLTB appeared to be a major problem in accessing TB services: it was a particular issue among migrants and factory workers who had come to the city for economic opportunities. I found that existing poor financial status became catastrophic due to the appearance of TB, and consequently many PLTB became engulfed in a vicious cycle of abject poverty. Major causes were that many PLTB had to pay a lot for TB diagnosis (see section 5.1.5); loss of opportunity costs¹⁴ many PLTB stated that they had to discontinue their work due to TB; and job loss due

¹⁴The opportunity cost is the cost incurred because of inability to do other activities due to TB or the engagement of the PLTB and family members in the TB treatment process. This is not restricted only to monetary or financial costs.

to TB resulted in difficulties living and continuing TB treatment in the city especially for poor migrants. A health worker working in an NGO-run DOTS centre said;

'I have seen many TB patients in this centre who have been facing difficulties to continue their treatment. Most of them are factory workers and labourers. Some of them left job due to their disease and often tell us that they have problem to pay the rent, buy food, travel to the centre and look after their children. Despite such financial difficulties they have been taking TB treatment.'

Although TB drugs were free of charge in the NTP, managing other costs associated with TB treatment such as travel to the DOTS centre, additional food and accommodation was an issue for many PLTB. I found that many PLTB had spent a considerable sum on travel compared with their monthly income, especially during the initial intensive phase (the initial two months) of TB treatment when PLTB had to visit the DOTS centre at least six days a week for DOT. A migrant worker told me his income was around US\$ 70 per month and he spent around US\$ 8 in travel for DOT, which was around 12 percent of his monthly income. Many other PLTB described similar problems regarding travel costs to the DOTS centre. Only a few PLTB lived in walking distance of the DOTS centre.

I also found that some PLTB had difficulties to cover basic costs for other illness such as diarrhoea, dysentery, gastritis, fever of unknown cause etc. during the course of TB treatment. Although the government had a policy of 'free health care' under which essential health care services were provided free from government institutions, it was not the reality in urban areas as there were insufficient government institutions delivering essential health care services. PLTB therefore had to seek care from private health care providers even for minor illnesses, which was expensive for many PLTB. This placed an additional financial burden on PLTB and their household during the TB treatment.

I found in many cases that TB was not only a disease of one individual in the family: rather, it destroyed the entire household financially and put other family members in jeopardy. This was mostly observed among migrants who had come to the city to earn money and help their family. It was even more devastating when TB attacked the head of the household, when all members of the household were affected, especially the children who then had to search for a job or accompany their parents in their jobs. The

wife of a migrant with TB who started seeking a job once her husband was not able to continue work due to TB said;

'We had problem to manage our day-to-day life, which became complicated from the day he stopped working due to the disease. Since then, I started searching job but I am not educated and hard to find a job. My friend helped me and I worked for few days and managed some food and travel for him [travel costs for the husband to visit the DOTS centre] but there was no work after a few days. I got some work but not everyday. When I had no work, many days we lived in absolute dry with no food, we had only water to drink. We are adult; we can manage somehow but cannot see children suffering. Now my daughter [aged 12] started working as a house cleaner. It is not good for her future but instead of keeping her hungry we thought sending her for work.'

5.2.5.4 Environmental and personal barriers to access TB treatment services

On the environmental context, I found that frequent unplanned strikes in the city, largely due to political instability, hindered access to TB treatment, especially to those who needed to visit DOTS centres daily during initial intensive phase of TB treatment. A man with TB said;

'I was in the clinic but it was closed, later I came to know that there was general strike and it lasted for four days. I went to a medical hall to buy drugs but I did not know which drugs I was taking.'

Similarly, I found that the personal habits and behaviours of PLTB influenced their TB treatment. Health workers told me that some PLTB often failed to keep appointments thus missing some doses of their TB treatment. This often happened for alcoholics. I also found that a few PLTB who had a weak social network and support from family and friends were poorly motivated to complete their TB treatment.

5.2.6 Supervision and patient support: an issue in TB treatment

Supervision and patient support emerged as a key issue in TB treatment as it deeply influenced the treatment process and outcome. This section describes various ideas that study respondents had on the meaning of *supervision and patient support*, and how and whether it facilitated the successful completion of TB treatment.

As per the Stop TB strategy, supervision and patient support refers to helping PLTB to identify and address issues in TB treatment through developing a partnership and mutual understanding between health care providers and PLTB (WHO 2006). However, in the study context, the various understandings among NTP officials, frontline health workers and PLTB about supervision and patient support contradicted each other and the essence of supervision and patient support as envisaged in the Stop TB strategy.

In general, I found that the NTP viewed supervision and patient support as two separate elements: *'supervision'* and *'patient support'*. Supervision was defined as supervision of health workers and supervision of PLTB during treatment. Supervision of health workers was considered as a routine activity of the NTP where senior programme officials supervise their subordinates. Supervision of PLTB was largely linked to daily DOT, in which treatment supervisors often asked PLTB what they were supposed to do, regardless of their needs and contextual feasibility. I observed some instances of supervision at the DOTS centres where NTP officials and district supervisors performed their routine supervision. The visits largely focused on cohort recording and reporting and verification of TB treatment cards to see whether the DOTS centre had been providing DOT to all PLTB. Although the PLTB were present in the centre during the time of supervision, supervisors did not have any meaningful interaction with them. This clearly showed that the views of PLTB were not taken into account during programme supervision, although the NTP supervision checklist encourages supervisors to do so. Box 4 presents a summary of the NTP supervision checklist; every supervisor should have discussed relevant points with PLTB during their supervisory visit to DOTS centre.

Box 4: Summary NTP supervision checklist

[This box presents on the patient section in the NTP supervision checklist]

Interview with patients

- Distance of the treatment centre from home
- Attitude of family member/community people having TB
- Awareness of treatment and medicine
- Time between the first symptom and contact with the health services
- How long between the first contact with the health services and diagnosis
- Family history of TB patient
- The types and colour of prescribed drugs
- The duration of the treatment
- Common side effects of drugs
- The importance of directly observed treatment
- Any payment for treatment
- Any home visit by the health workers
- The importance of sputum examination
- Does anyone observe them taking their medicine
- Which disease were they suffering from?

Source: NTP supervision checklist

I found that the NTP considered supervision largely from the clinical aspect of treatment management. Although clinical management was important, on its own it was inadequate to achieve the desired outcome of successful treatment completion without also addressing the social and cultural aspects of the disease and treatment. The NTP's emphasis on clinical management often encouraged health workers to control the treatment process rather than facilitating it. Hence, they often overlooked other important aspects of the social and behavioural context in treatment management which ultimately contributed to creating a distance between the health workers and PLTB, and hindered development of trust and good relationships.

Similarly, the NTP viewed free diagnosis and free drugs in the programme as sufficient means of patient support. The provision of free TB drugs was welcomed by a majority of PLTB. However, it was evident that they had to pay a considerable sum for diagnosis (see section 5.1.5), treatment and unnecessary additions such as vitamins, other investigations (e.g. routine blood tests), which was difficult for many PLTB. Moreover, I found that the PLTB linked the free drugs with DOT, as they thought that the DOT was compulsory because the programme provided free drugs to them.

It was clear that the understanding of supervision and patient support varied. The PLTB had relatively little power so simply followed instructions, whereas health workers were in control and regulated the entire treatment, often without providing facilitation and support to PLTB. However, neither was the NTP able to convince the PLTB what the treatment supervision meant in the programme, nor could the PLTB challenge the NTP despite mounting difficulties posed by inappropriate policy regarding their treatment, especially mandatory DOT. Taking into account the views of the NTP officials and health workers and the PLTB, it was clear that the ‘supervision and support’ component was ill-defined in the NTP. Moreover, the NTP’s perception of DOT and availability of free anti-tuberculosis drugs as sufficient supervision and patient support was limiting and eventually, in several instances, it failed to facilitate treatment thereby negatively affecting the treatment process.

I found that DOT had enormous implications for defining supervision and patient support during TB treatment. Understanding and implementation of the DOT policy varied between NTP officials, health workers and PLTB, as some DOTS centres applied it as per the NTP policy and some applied a degree of flexibility. However, DOT was seen by many PLTB as a major barrier to continuing TB treatment. In subsequent sections, I analyse and discuss DOT with a focus on its implementation, acceptance, convenience, and whether and how it helped or hindered successful treatment completion in the local context. In doing so I consider the views expressed by the NTP authorities, front line health workers and PLTB.

5.2.6.1 NTP’s guideline and views on DOT

The NTP’s long term plan states that TB diagnosis and treatment services should be fully integrated into general health services and all PLTB taking rifampicin should receive DOT (NTP, 2004). DOT was therefore regarded as a major operational policy of NTP, and was considered an adequate tool for both treatment supervision and patient support. A NTP official said;

‘DOT is to ensure that patients take drugs regularly thus applicable to all TB patients at least during the initial two months of TB treatment.’

Figure 15 presents the NTP guideline on implementing DOT in the programme. Hospitalization of PLTB for DOT is the first option, but was not applicable in the study area, as the majority of DOTS centres did not have in-patient facilities and hospitalisation was not deemed a requirement for the majority of PLTB. Talking to

NTP officials, I found that the NTP never encouraged hospitalization of PLTB unless the person was seriously ill and required treatment in hospital. A NTP official said.

'NTP does not encourage health workers to admit TB patients for DOT which is not the programme's strategy. It is in the guideline just to make sure that seriously ill patients get admitted in the hospitals.'

However, the instructions in the NTP guideline and understanding among NTP officials and health workers were contradictory. My observation was that since implementation of DOTS, I did not find PLTB hospitalized for DOT, except in a few in rural areas.

The second option in the guidelines was DOT by health worker, under which PLTBs had to visit a health facility. Following the guideline, health workers stated that they ask all PLTB to attend the DOTS centres on a daily basis (except holidays and weekends) during the initial two months, after which they supply drugs for a week. A majority of PLTB were treated under this option.

The guidelines further state that, if a PLTB had problems visiting the DOTS centre for DOT, the health workers should identify a trained person in the community and start treatment under direct supervision. However, I found that health workers were unclear what 'trained person in the community' meant, as no such people were identified. In this situation, health workers assumed that the 'trained people' could be community volunteers; but I did not find any PLTB receiving DOT by community volunteers in the study area. A health worker said;

'We do not have people in community trained as treatment supervisor except some TB volunteers who generally used for late patient tracing but not as DOT provider.'

The last option given in the guidelines was to identify a reliable person and provide them with training as a treatment supervisor, and then administer treatment through the trained person. I found this option was rarely used, because the programme had not clearly defined what type of person was seen by the NTP as 'reliable'; how the person could be identified and trained; the role of the trained person in treatment; how the treatment should be observed and where; who should be accountable to whom; how long drugs could be supplied to the trained person; who should come to collect the drugs from the centre to give to the supervisor; and how long the trained person should supervise the treatment. I therefore found that health workers were not sure

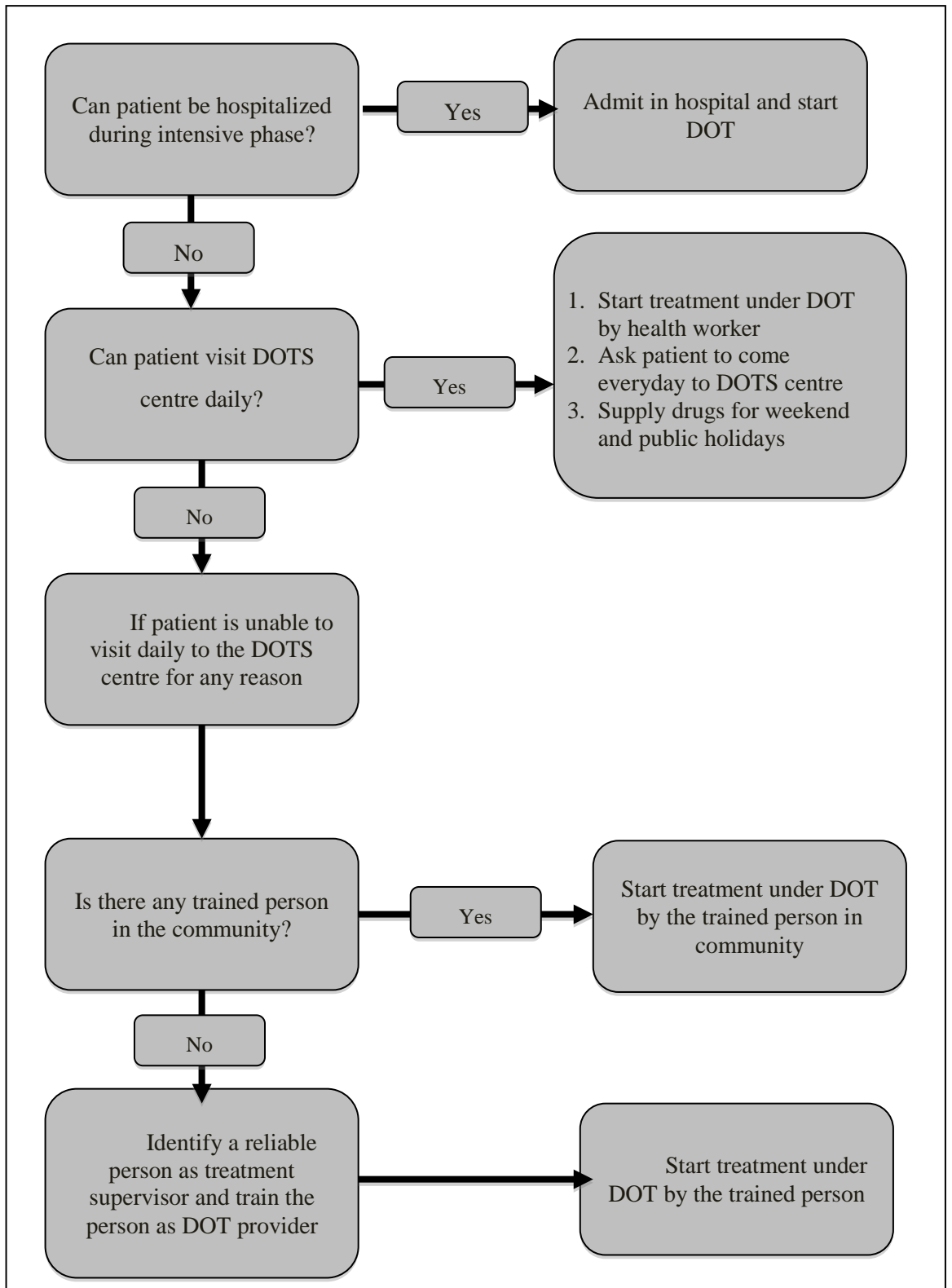
how to identify a treatment supervisor. When I asked health workers how they managed PLTB who had problems attending daily DOT at the centre, many said that they simply asked PLTB to manage daily visits to the centre despite their difficulties. A health worker said;

'We have many people who cited difficulties in visiting the centre every day but we ask them to manage visits for their treatment. We face problem to start treatment for such cases but the guideline is not clear how we should be managing such patients and they are many.'

The health workers stated that finding a reliable person other than a family member of PLTB was difficult in their settings but the programme did not encourage them to use family members as treatment supporter.

Although I did not find a clear statement in the programme guidelines which prohibited using a family member as treatment supervisor, my discussions with NTP officials and frontline health workers clearly revealed that the use of the family members as treatment supervisor was not considered appropriate by the NTP, as it always promoted institutional DOT and unofficial communication from the NTP authorities on various occasions (e.g. during supervision and reporting and planning meetings) discouraged the use of family members as treatment supervisor despite a large number of PLTB saying visiting the centre for daily was a problem hindering their treatment. This unofficial policy not only created additional difficulties for PLTB but also failed to make the most of the opportunities created by engaging family members in treatment process. Such notions and practice in the NTP contradicted the provision made in the Stop TB Strategy that DOT could be done at home, which meant a reliable family member could supervise treatment at home.

Figure 15: NTP guideline to identify DOT provider



5.2.6.2 DOT: views of frontline health workers

The previous section described NTP's guidelines on DOT. Although frontline health workers are also part of the programme, in this section I present their views separately because, in some instances, I found policy and practice were confused or contradicted. The illustrations in this section were derived from my conversation with frontline health workers working in various DOTS centres (government, non-government and private). I found in my initial conversations that people were disinclined to express critical opinions about the DOT policy, although it was obvious they had some reservations. However, after several discussions, they opened up and elaborated on their experiences. I have anonymised the illustrations as the respondents did not want to be identified when being critical about the DOT policy.

As briefly discussed above, there were two different views among frontline health workers on DOT linked to supervision and patient support: DOT was a sufficient means of treatment supervision thus should be provided for all PLTB; and DOT could be a means of treatment supervision but should be implemented with a degree of flexibility depending on the context of the PLTB. These views contradicted so implementation differed.

Some frontline health workers perceived that the success of the NTP was largely due to DOT (i.e. institutional DOT supervised by health workers), so that DOT was seen as the cause of success of the DOTS strategy as the other components of DOTS were ignored. As some frontline health workers stated;

'DOT is a national policy therefore it should be implemented to all TB patients.'

'TB patients do not take drugs if supplied to them at home thus DOT is essential.'

'Today DOTS is successful because of DOT. If had no DOT, DOTS would not have achieved high success.'

Although the NTP adopted the ISTC and showed commitment to implementing it nationwide, I found the standards for TB treatment were barely considered when it came to implementing DOT. ISTC standard nine clearly states the need to establish a patient-centred approach in TB treatment through understanding the needs of PLTB and tailoring TB treatment to individual circumstances; but I found that the NTP had

not communicated this ISTC standard to health workers or ensured effective implementation of a patient-centred approach in TB treatment.

‘As a person, I disagree with the DOT policy. I would not accept it if I were a TB patient because it undermines patients and simply increases other problems such as travelling everyday to the centre and increased cost. I think we are becoming irresponsible to patients’ needs and problems by forcing them to visit the centre daily but as a health worker we are bound to follow the government policy.’

‘DOT may be required for some patients but not for all. I feel embarrassed to force patients to come everyday after knowing their problems.’

‘DOT is a national policy and the programme demands strict implementation but it is unwise to think that all TB patients can adhere to it, as TB patients have several other issues and the programme should consider them if the success of the programme need to sustain.’

‘The DOT at health facility restricted many TB patients to commence their treatment under DOTS. We the health workers face problems implementing it because of inappropriately designed policy.’

‘We understand the DOT policy and ask patients to come every day but they raise many questions and ask drugs at least for a week citing their problems. It is difficult implementing DOT to all TB patients.’

‘I think the NTP communicated DOT as the important component of DOTS thus there is big emphasis on DOT among us [health workers]. The increased emphasis on DOT actually deterred the other important components such as sputum microscopy and drug supply. Similarly, coordination among DOTS centres is another issue but these are less discussed in the four-monthly programme meeting.’

These illustrations clearly show that some health workers had disagreements with the blanket provision of institutional DOT for all PLTB. However, these disagreements were rarely raised in public. Some felt compelled to follow the DOT policy despite difficulties and infeasibility for the great majority of PLTB.

In contrast, some health workers stated that DOT was important but it should be tailored to the needs of PLTB, and implementation required exploring a full range of alternative options that were acceptable to the PLTB. I found that a few frontline

health workers implemented a flexible approach to DOT taking the context into account. Some health workers supplied TB drugs for a week to fifteen days even during the initial two months. They did so after a few weeks of treatment when the health worker and the PLTB started to get to know each other and developed a level of trust between them. I also found that they engaged family member of PLTB to ensure the PLTB took the drugs regularly. The health workers strongly believed that this flexibility helped PLTB in their treatment, and as a result PLTB continued treatment supported by good relationships and an atmosphere of trust. I also found that some health workers provided some financial support to a few PLTB using money from their own pocket to provide food, cost for travel, clothes etc. However, these were individual initiatives, as I did not find such practices across the programme. However, the practice of flexible DOT and individual support provided to PLTB was not officially documented. A health worker said;

‘Although it was intensive phase [initial two months of treatment], I supplied drugs for a week to ten days as some patients were unable visit daily. If drugs had not been provided, they would have problem to manage their work and treatment.’

Some care providers did not like DOT at all because it increased their workload. They stated that their job had become difficult since the institution started DOTS, as they were supervising several PLTB, so daily DOT resulted in them having more work and needing to stay for longer hours at the centre. Consequently, some health workers did not implement the DOT policy.

‘The increased number of TB cases every year resulted more work to us but number of staff remained the same. If we call all TB patients daily we cannot manage them so we provide drugs weekly. It reduced our workload and may have helped TB patients.’

When asked whether the increased caseload of PLTB in their centre was due to the flexibility in DOT implementation that they practiced, the health workers did not disagree. They also stated that there were other DOTS centres that also supplied drugs to PLTB on a weekly basis but would not discuss the practice publicly.

I also found that some health workers were unsatisfied with the NTP and its officials, as some health workers in the study area stated that they were not receiving adequate support from the NTP and opportunities were not provided to frontline health workers. Some of them felt exploited as acknowledgement of their contribution in DOTS was

not linked to other benefits such as higher-level training, international visit, incentives etc. As a result, health workers did not implement the DOT policy to indicate their dissatisfaction to the NTP.

'We do the hard work in the field and people at National TB Centre enjoy all benefits of the programme, when opportunity arise we do not get informed.'

I found that some health workers did not feel comfortable implementing DOT due to lack of basic infrastructure at the centre. For instance, they stated that lack of a water supply in the centre made them embarrassed to ask PLTB to visit daily for DOT. I also observed that at some centres PLTB had to bring their own water as there was no provision of drinking water. PLTB also complained about lack of drinking water in the centres.

Some health workers stated that DOT was not easy to deliver to all PLTB as their contexts were different. They said that the people who need to go to work were the ones who often had problems complying with the requirement for DOT. They also said that if DOT is required for PLTB, it could be implemented in several ways and the programme was not exploring other ways of supervising TB treatment. They had raised the issue of the difficulties with DOT in their four-monthly meeting but did not get a clear answer from the NTP officials. Given this situation they thought that they could apply some flexibility taking the local context into account. However, they also blamed the NTP for not being clear on the issues they raised.

'It is difficult for us to implement the DOT as it stands because in the clinic we face lots of questions from TB patients and it is true that many of them are genuine as they have problems. I raised this issue with the NTP but they simply asked to implement DOT citing the policy document. They were not very clear when I said the implementation of the policy was an issue. Since then I look at the patient and do as appropriate to them.'

'I heard that family members can be a treatment supervisor but the programme does not talk about it thus not sure whether it can be considered.'

When I asked health workers about alternative ways of ensuring DOT, most stated that family members of PLTB could be used as a treatment supporter at home. They recommended use of family member as DOT provider because the family accompanied the PLTB during their treatment; they often visited the DOTS centre to

collect TB drugs; and some family members had regular discussions with health workers and showed their concerns. Health workers thought the family members could do a good job of supervision if they were properly informed of the importance of taking regular treatment. When asked whether family members could be considered as treatment supervisors, health workers said;

'They are the one we should trust because they are member of their family.'

'We cannot ignore their role in treatment.'

'If I had TB I would expect the same, to be looked after by my family member.'

'It is important that we need to monitor them [the family member] effectively. We need to change the training manuals and have more information on how to use the family members to make sure that they do the business as a responsible person.'

'There are several other problems every family faces these days such as financial, social, unemployment and when a person diagnosed with TB it is a pain in the family but we are bound to follow the policy which restricts to supply drugs. I think we require to change our approach and use family members in TB treatment.'

The above illustrations clearly indicate that the health workers acknowledge the potential role of family members as potential treatment supporters. However, health workers commented on a lack of clear policy on the use of family members as treatment supporters. Despite this, a few health workers stated that they had been using family members of PLTB as treatment supervisor.

'It was not possible for some TB patients to visit the centre on a daily basis. I asked patients to bring their family member and I supplied drugs for a week. They have been taking care of patients and had not missed a single dose of treatment.'

'I believe on practical things. We, the field worker, know better than the NTC people as we interact with TB patients everyday. It is true that many TB patients have problem to visit daily this I supplied TB drugs after explaining all procedures to their family member, mostly head of household as I found they were trustworthy.'

'It was nonsense not to use family members in TB treatment process as I found they were very concerned and always worried about their beloved.'

In contrast, some NTP officials and health workers were of the opinion that using family members as treatment supervisors instead of a person accountable to the health system would jeopardise the current achievements of the NTP in achieving high treatment success rates. In a question about engaging family members of PLTB in treatment they said;

'Before we had DOTS, the programme used to supply TB drugs to patients and result was not good, many TB patients stopped taking treatment. But it is not the case since the programme introduced DOTS. The DOT provided by the health workers is the way to achieve the success in TB control.'

'The family members can be involved in the treatment but giving responsibility to supervise everyday treatment at home would ruin the success of the programme.'

'In our culture family is important but they do not watch actual drug taking. Since TB patient need to take many tablets at once, sometime they do not take all which can be dangerous for them and develop resistant to drugs.'

'Out past experience tells that using family member as DOT provider will increase default rate and may invite drug resistant TB.'

However, before DOTS the programme did not have adequate focus on providing appropriate guidance, training and supervision to the family members of PLTB when the drugs were supplied to them, so that comparisons before and after DOTS may be misleading. Nevertheless, some officials still hold traditional thoughts when it comes to using family members as treatment supporters.

Similarly, some people were of the opinion that, instead of family members, the programme should involve community volunteers as treatment supervisors. Some stated that the TB is deeply rooted in the community and myths about TB had put PLTB in difficulties, so the use of community volunteers could not only help PLTB continue treatment but also help address unsocial behaviour towards PLTB. In contrast, some care providers stated that although using community members as DOT supervisors was a good idea, it would not be sustainable.

'People are busy always and most of them search for paid work these days. Community people can volunteer on certain occasion but DOT provider requires everyday task and volunteer will not do this role without money.'

Considering the views of the frontline health workers I found that institutional DOT was controversial, as it was impractical for many PLTB in the local context, but programme policy enforced its implementation. Similarly, health workers experienced difficulties due to lack of clarity by the programme on the use of people other than health workers as treatment supervisors, especially the family members of PLTB. However, despite being bewildered due to obscure explanations about DOT, some health workers applied a degree of flexibility and engaged family members as treatment supporters. However, some health workers and NTP officials were unsympathetic to using family members as treatment supervisors and were concerned that the achievement of NTP would be limited.

5.2.6.3 DOT: views of people with tuberculosis

In this section, I analyse views of PLTB and their family members on institutional DOT and its convenience or otherwise in TB treatment. PLTB and their family members often used phrases such as the following when expressing their experiences with DOT: an obligation; a non-negotiable option; an imposed task; an additional burden; no obvious reason for it; a symbol of lack of trust; no choice; an act inflating the costs of care; the health system's negligence of their needs; the health system's control in treatment; unsympathetic to PLTB. Many other terms were also used which reflected PLTBs' concerns that DOT was burdensome for them and greatly affected their treatment continuation. Below I looked at some specific areas in order to gain an in-depth understanding on the impact of DOT on PLTB and their treatment.

- ***Lack of clarity on DOT requirement in TB treatment***

I found that almost all PLTB were unclear why DOT was required. Although PLTB were adhering to DOT requirements, they were unaware why they had to do it, which made them dissatisfied. It was clear that the reason for DOT was not fully explained to PLTB. Despite a lack of clarity on why DOT was mandatory in TB treatment, the programme expected all PLTB to comply with its requirements irrespective of the difficulties it caused PLTB. I found that many PLTB regarded DOT as a indication of the health system's lack of trust in them. This further contributed to creating a distance between health workers and PLTB. A migrant worker with TB who was continuing his second month of treatment said;

'Health workers said it [DOT] is a policy thus we need to comply....what kind of policy is this which complicates life of a patient who is facing a lot of trouble already....this is nothing other than no trust of health workers on patients.'

- ***DOT was a compromise for free treatment***

I found that a majority of PLTB thought that DOT was imposed on them because the drugs were given free of charge. PLTB considered it as non-negotiable if they took treatment under the programme. PLTB often said that DOT was a burden they had to undergo to obtain free TB drugs. A migrant worker with TB recently completed his two months treatment said;

'I could have taken drugs at home if I had been given. Despite problems I had to come to this centre daily because I had no other options as I could not afford to buy drugs in private.'

I found that by the time PLTB started treatment they had faced several other problems, which often made them socially, psychologically and economically vulnerable. In addition, the severity of the disease made them physically and mentally very weak. Many of them said that they wanted to start treatment as early as possible after their diagnosis, so they accepted DOT without realizing the difficulties it might cause during the treatment process. A migrant man with TB described his experience thus;

'When I came here [the DOTS centre], the very first day, he [the health worker] asked whether I can come daily to the centre. I simply accepted it as I wanted to start my treatment. After two weeks I had difficulties to continue everyday visit and requested drugs for few days so I could do other things and seek some light job but he [the health worker] did not give drugs. I have no other choice and managing my treatment anyhow up to this point.'

- ***DOT an additional burden to PLTB***

The DOT requirement in TB treatment compelled some PLTB to leave their job, and consequently their financial conditions worsened, making them more vulnerable to discontinuing their treatment. A man who had completed two months DOT said;

'At the beginning health worker asked me to come everyday for initial two months. I felt it would be difficult then I asked the doctor right there to arrange me giving medicines for a week or 15 days. He told me that he couldn't give me drugs then I discontinued my job for treatment, since then my financial problem has increased. The

company hired another person in my position and now I am not finding any job. I regret why I left my job.'

Some PLTB found that DOT was manageable at the start of treatment. They simply accepted it because their priority was to recover from the disease. As treatment progressed, people started feeling better and wanted to resume their work. Then they realized that coming every day to the centre interfered with their ability to work, and wanted drugs to be supplied to them. A respondent said;

'It has been a month I am having treatment. I want to start my work but cannot do so because I need to come here daily for another month. I do not want to discontinue my treatment even a single day but I am not sure how I can continue my treatment without earning money. I am in problem.'

Similarly, another respondent who had been taking treatment for one month said;

'I used to work for a trekking agency which I stopped due to this disease [TB] as I was very serious and coughing all time. Now I have recovered and want to go back to work but the doctor asked me not to go to work as I need to come here every day.'

- ***DOT and increased vulnerability***

I found that DOT was a difficult choice for many PLTB, especially migrants, daily labourers and women. In many instances, it increased vulnerability of PLTB and their family, because daily travel to the centre for DOT was such a problem. Although travel distances varied, some PLTB had to travel a long distance every day. Some PLTB said that the DOTS centre and their workplace were in opposite directions and continuing DOT and getting to work on time was a matter of concern. The long travel distance meant they had to use public transport, which they needed to pay for every day and the costs increased their economic vulnerability, particularly for those who had lost their job due to TB and had no other income. Similarly, some PLTB said that they had difficulties accessing daily DOT at the centre due to their physical weakness.

Women with TB were vulnerable in many ways, because they had to take care of other tasks at home and thus faced difficulties finding time for DOT. I found that they had to compromise with other work in order to allocate time to visit the centre. Women often stated in interviews that DOT affected not only them but also other members of the family, especially their children, because women had to visit the

centre every day and could not give time to their children. I also found that sometime children were used for collecting drugs for their parents. A woman respondent said;

'I don't want coming here everyday anymore. For this [DOT] I need to leave other things. I have other things to do, I need to prepare my children for school, need to go to vegetable market, buy vegetables, and sell them. Then I have to carry other household activities, which makes my day busy. Before I was very ill and was not able to do all work but now I need to work to survive but not able to sell vegetables for long time because I need to come to this centre.'

Women with small children had more problems coming to the centre every day, as they had to find a carer for their children while they visited the centre. This was especially true among migrant families with only two adults, husband and wife, one of whom was working. Finding a carer was not easy and taking the children every day to the centre was problem as the PLTB were physically weak and often worried whether their children would catch TB.

'The health worker asked me to come here everyday but I have no other caretaker at home. It is difficult for me leaving child alone at the time of visiting DOTS centre. Sometime I leave her with my neighbours but often I carry her.'

Another woman who had been taking treatment for two months said; *'I have a small child and faced difficulties visiting this centre due to nobody at home to look after my child when I need to come for drugs. I used to leave my child at the working place of my husband at the time of visiting treatment centre but it was difficult to do so everyday.'*

Similarly, a woman who was a local resident of the city who had been taking treatment for one month said; *'On the one hand I need to go for work and other hand I need to fulfil the daily household work and look after my children and their basic needs.'*

In various cases, I found that the vulnerability created by DOT was addressed with the help of family members and friends of PLTB. The support PLTB had from family members and friends PLTB made a great contribution in helping to continue TB treatment.

5.2.7 TB treatment therapy related

I found that PLTB often complained about the long duration of TB treatment. Problems were exacerbated when the programme gave only a week's supply of TB drugs even during continuation phase, as PLTB needed to make frequent visits to the DOTS centres and increased the costs of care, especially travel costs. It also restricted PLTBs' mobility, which was problematic, because some of them needed to travel away from home during their treatment. Although the NTP reduced the treatment duration (switching from eight to six month treatment regimen) during the study period, the long duration of treatment and weekly supply of TB drugs remained an issue for PLTB. Similarly, many PLTB complained about the requirement to take multiple drugs together.

A majority of PLTB also reported side effects of TB drugs which added further complexity to their TB treatment. The most commonly reported side effects were joint pain, anorexia, nausea, abdominal pain, and burning sensations. These were classified as minor side effects by the NTP. Some PLTB spoke to health workers about these side effects, but not all received a good response or symptom management, and became worried. A few PLTB also reported jaundice, dizziness, loss of hearing, and skin rashes, symptoms which the NTP classified as major side effects which required immediate attention. According to NTP treatment guidelines, PLTB with major side effects should stop TB drugs and seek specialist care. I found that all PLTB who reported side effects could not differentiate whether their side effect was minor or major, causing them distress. A majority of PLTB stated that they notified their problem to health workers. However, in many instances the health workers did not pay sufficient attention to manage the problems that the PLTB reported. Consequently, the problem became worse and in some cases PLTB stopped taking TB drugs. Because of this inadequate management at the DOTS centre, some PLTB sought help from other care providers, which had cost implication for the PLTB. A woman with TB who suffered from dizziness during her third month of TB treatment said;

'I was not able to balance my body, my head was spinning all the time. I reported to the nurse but she said it was a minor problem and will go away after a week. I waited a week, instead of healing it got worse. Again, the nurse told me to take drugs after meal and said I will be fine after a week. My problem got worse and I stopped taking drugs. After two weeks, my husband took me to a private doctor and the doctor gave drugs. Now I'm fine but worried that I stopped drugs for two weeks.'

I also found that the side effects of drugs were not known by some PLTB, mainly factory workers.

PLTB also stated that their appetite increased once they started TB treatment: lack of food and inability to buy food was an issue for them, especially poor people who even in normal circumstances had problems managing to get basic food for themselves and their household. Similarly, health workers often asked PLTB to take drugs on an empty stomach but TB centres opened normally at 10 am, so not eating before they came for DOT was an issue. Moreover, for some PLTB, taking TB drugs on an empty stomach caused abdominal problems.

5.3 Organisation of TB service delivery in the study area

This section provides an understanding on how TB services under the NTP were being delivered and synchronized over the study period in the study area as response to the problems and issues. I have structured this section in line within the relevant components of the DOTS framework and relevant elements of the new Stop TB strategy. However, the new strategy was not fully matured in its operational form in the NTP despite almost four years of official endorsement. The section also presents responses to the problems and issues identified during TB treatment from PLTBs and their family and community members. There are of course substantial overlap and interaction between these factors.

5.3.1 Commitment and partnership for TB service

5.3.1.1 Commitment

‘Commitment’ was a component of DOTS that was commonly cited in interviews, especially by NTP officials and health care providers. However, its meaning and interpretation varied. Most respondents stated that ‘commitment’ in DOTS applied only to the ‘higher level’: that is, to government commitment to the NTP in implementing the DOTS strategy. Only a few respondents said that it was equally important to secure commitment from programme implementers; frontline health workers; PLTB and their family members, and community members.

Government commitment was clear, since TB control is one of the priority programmes of the Ministry of Health and Population (MoHP). The majority of respondents stated that one of the indications of government commitment to TB control was allocation of resources to the NTP. I found that the urban TB programme was grossly under-resourced. For example, the study area was the biggest urban area of Nepal, where the TB burden was almost four times the national average. In the last three years, it had 10% to 12% of the total TB cases registered in the NTP, whereas resource allocation was less than 1% of the total NTP budget (see Table 15). In addition, within the resources allocated to urban TB control the domestic contribution was negligible. Thus government commitment in terms of resource allocation was not enough to advance TB service delivery in urban area. A senior official of the municipality said;

‘Inadequate resources to the urban TB programme raise a big question on government’s commitment. Urban TB control programme should be considered as a top priority with adequate allocation of resources otherwise the commitment remains in words only.’

Table 15: Budget allocation and burden of TB in the study area

Fiscal Year	NTP Total		Kathmandu and Lalitpur (study districts)	
	Total budget (US\$ million)	Total registered cases (National)	Percentage of total NTP budget	Percentage of total registered cases
2066/67	6.2	35111	0.83%	12%
2065/66	3.2	35407	0.93%	11%
2064/65	2.6	33419	0.90%	10%
2063/64	2.7	33439	0.66%	11%

Source: data compiled from National TB Centre annual source book

Commitment to DOTS at the service delivery level varied. In general, it was found to be weak, both at organisational and individual levels. Many respondents, especially frontline health workers, did not see the relevance to themselves of the word ‘commitment’, as they generally assumed it referred the higher level. Such understanding could weaken service delivery at local level. A frontline health service provider said;

‘We are simply here to deliver services. Commitment should be at the higher level to make TB control effective.’

However, some respondents stated that individuals need to have ‘commitment’ towards their responsibilities: only then could DOTS be effectively implemented. A district official said; *‘I think we all need strong commitment to make DOTS a success.’*

Although people acknowledged difficulties in delivering commitments, in the meantime they thought it would help overcome difficulties if individual and service delivery institutions knew and had strong commitment to their responsibilities. In an urban TB control stakeholders meeting, a senior NTP official said;

‘Urban TB control is a shared responsibility and all stakeholders should have strong commitment to make the services available to people in need.’

Nonetheless, it was found that the tendency of referring to commitment as the responsibility only of higher levels was an issue, as it distanced people from their responsibility of delivering effective services. This tendency had implications regarding creating an environment that was conducive to PLTB to successfully complete treatment.

Likewise, community commitment to DOTS varied, as it was largely associated with individual DOTS centres' initiatives in engaging the community in DOTS. DOTS Committees were formed, but were inactive in many places. According to DOTS centre staff and district health officials, community support to TB control was difficult in urban settings due to the complex composition of urban communities. However, this was not the case in all DOTS centres, as some urban DOTS centres recruited late patient tracer volunteers who were active in helping TB service delivery and PLTB. A volunteer said;

'I come here [DOTS centre] everyday for two hours and help drug distribution and patients. I go for home visit if some patient do not turn for drugs.'

Partnership and coordination

Partnership for TB service delivery in the urban areas was initiated by the NTP under the name of '*Kathmandu Valley Collation Against TB (KV-CAT)*' with the aim of engaging various health care providers in urban TB control. However, some respondents believed that KV-CAT could not survive long as it suffered a lack of leadership, undefined roles and responsibilities among stakeholders, inadequate resources and a lack of collective responses to the issues. However, it instigated a momentum in urban TB; in particular, it helped bring public sector providers together in one forum. A senior official of NTP said;

'TB control in urban area was organised with establishment of KV-CAT. Unfortunately, it failed to continue as urban area is complex in many ways thus controlling TB requires a greater effort with a sustained partnership from all concerned.'

Consequently, a public-private partnership (PPP) model for TB was developed, based on a PPP initiated in Lalitpur urban area, which demonstrated high treatment success rates over several years. However, according to NTP officials, scale up of the model was constrained due to lack of adequate resources and a well-designed, costed action plan of TB services for urban areas. Despite these constraints, a degree of partnership in TB service expansion has been observed in the last few years in the study area.

About forty organisations, a small proportion of the total health service providers in the area, have been providing TB services in partnership with the NTP. They include government-run health facilities; private-for-profit providers such as private hospitals, nursing homes, polyclinics and private pharmacies; urban health clinics run by local government municipalities; private not-for-profit; and some faith-based organisations. I found that a range of TB services was provided depending on the nature of institutions and their capacity. A senior NTP official said;

‘In the last few years with support from various organisations we have managed to expand DOTS in urban area. We have good example of partnership and we plan to expand further under the new funding arrangement.’

I found that coordination among and between the DOTS centres was relatively weak. It was unclear who was responsible to enhance coordination in the urban TB programme, so most stakeholders seemed to be working independently with relatively little coordination with each other. This was an issue highlighted by health service providers including district and municipal health authorities, indicating that coordination suffered due to undefined roles and responsibilities of stakeholders and inadequate resources. It also affected access to services in the programme. A district health official said;

‘Coordinating DOTS centres in urban area is a big task for us because various stakeholders have their own institutional boundaries. Sometime difficult to fit with each other but we keep on saying that making it [urban TB control] a success is responsibility of all.’

Although a level of commitment among stakeholders was found, functional partnership and coordination in delivering TB services in urban areas was constrained due to inadequate resources and unclear roles and responsibility, which was further challenged due to the complexity of the urban setting. Such constraints have limited programme ability in many ways. Along with institutional commitment, it was also found important to secure individual commitments for effective implementation of TB services. However, despite insufficiencies, the NTP had made efforts to secure long-term commitment in the urban TB programme by engaging various service providers.

5.3.2 TB service delivery in urban area

In urban areas, basic health service delivery had relatively weak foundations in the public sector. Although the primary health care approach was the main focus of the National Health Policy, it was poorly existed in urban areas as there was no defined urban health strategy. Access to basic health care including TB services was therefore limited, particularly for the urban poor. In addition, I found other complexities in urban settings such as multiple health service providers including a large and unregulated private sector; multiple users ranging from the rich to the poorest of the poor; a rapidly growing urban population and increased unplanned urban settlements such as slums; growing social inequalities, and; unhealthy lifestyles among urban dwellers.

I found that within the government framework there was a lack of policy clarity on who was responsible – the Ministry of Health or the Municipality – to ensure basic health services in urban areas, an issue poorly discussed in policy documents. As a consequence, basic health care including TB treatment service delivery was affected.

District health officials – government employees – stated that because of a lack of clear roles and responsibility regarding health service delivery in urban areas, they found it difficult to expand TB treatment services to cater the needs of the people. An official said;

‘In rural area we have an established health care network whereas in urban areas we lack such provision. Most importantly, there is less clarity on institutional responsibility to provide basic health care including TB in urban area.’

The study findings make it clear that there is a need for expansion of DOTS as access to services constantly emerged as a major barrier among PLTB, only not limiting service utilisation but increasing the cost of TB care, thereby affecting treatment continuation (see section 5.2.5). However, I found that the district health authorities were concerned about their increased workload and said that they were having problems maintaining regular supervision and supplies to existing DOTS centres. District health officials revealed that they were concerned about the quality of TB treatment in the absence of proper supervision and support to DOTS centres. Moreover, increasing workloads of district health officials had led to very slow expansion of DOTS centres.

It was evident that rapid urbanisation in the study area resulted an increased number of slum dwellers, factory workers and homeless people, who were often vulnerable to ill health. However, the organisation of TB service delivery under the DOTS framework was designed to address the need of the general population and had no focus on groups vulnerable to TB such as slum dwellers, factory workers, migrants, homeless people, internally displaced people and daily wage labourers. I did not find any specific attempt by the NTP to reach these groups apart from some sporadic awareness activities.

Consideration of existing TB service delivery in the study area showed that the implementation of the DOTS strategy there was not tailored to the local context. The TB service delivery structure used a general approach, which ignored socioeconomic and other contextual aspects of society. I found that DOTS services were unequally distributed; as a result, many poor people faced difficulties. Although it has been nearly four years since the NTP adopted WHO's new Stop TB strategy, which advocates increasing access to services among vulnerable populations, I found no change in the approach or in services for these groups.

5.3.3 Logistic management in TB service delivery

Logistic management under DOTS was a responsibility of the District Public/Health Office (D/PHO). District health authorities stated that the programme was experiencing difficulties maintaining uninterrupted supplies of TB drugs, laboratory reagents, recording and reporting tools, and other items necessary to run DOTS effectively. Lack of resources (transport vehicle, cost and human resource) was cited as the major barrier. Although the NTP had a logistic management policy that included TB drugs, implementation of the policy was a major concern which sometimes resulted in stock outs of TB drugs at the DOTS centres, DOTS centre staff told me. In contrast, district health authorities did not agree that any centre experienced stock outs of TB drugs. They claimed that if they were informed about a drug stock out, they could immediately rectify it. However, they agreed that following the NTP policy of drug supply and management had been an issue in urban areas, and had hampered TB service delivery thus affecting TB treatment completion.

In conclusion, I found that the current approach towards TB service delivery requires considerable attention to respond problems and issues faced by PLTB during TB treatment especially required to improve access to services, particularly vulnerable population groups such as the urban poor and excluded people. However, this issue

does not seem to be prioritised by NTP authorities, because a constant achievement of high treatment success rates in urban areas conceals issues of service delivery and PLTBs' needs. It can be seen from the findings that, in line with new Stop TB strategy, there was an urgent need for the NTP to design a patient-friendly approach within which components of supervision and patient support need to be tailored towards greater understanding of local contexts and needs of PLTB. It also became clear that poor coordination among various service providers and a weak logistic chain, caused by lack of clearly defined roles and responsibilities among stakeholders and limited availability of resources, were issues which further weakened the programme.

During my project work I persuaded and engaged with the NTP, in developing an urban TB control guideline, which has been piloted in some cities in Nepal. Although the guideline exists, it does not negate the need for a fully costed urban TB control strategy and operational plan along with adequate resources.

Remarkably, however, despite many insufficiencies in TB service delivery in urban areas, most PLTB continued their treatment under DOTS, and the programme had scaled up its services to a limited extent and was achieving high treatment success.

5.4 Responses to factors that hindered TB treatment completion

Various interacting factors were found to influence successful treatment completion. As a consequence, many PLTB had faced difficulties during their treatment. Nevertheless, the majority of PLTB continued their treatment and completed the full course of treatment. Thus, the overall treatment success rate in the urban TB control programme remained high. This section describes factors that facilitated PLTB to continue their treatment, thereby helping to secure successful treatment completion. In subsequent sections I analyse enabling factors in the process of TB treatment in regard to the three main stakeholders: PLTB and their family; health systems; and the community.

5.4.1 PLTB and their family

5.4.1.1 Strong personal commitment and motivation

Almost all PLTB respondents stated factors that hindered their treatment. Consequently, their treatment process was challenged in many ways. However, I found that almost all respondent PLTB were highly committed and dedicated to their objective of completing TB treatment: this commitment ultimately enabled them to overcome many obstacles. A migrant woman with TB said;

‘Coming to the centre for drugs is a problem as I need to manage my household tasks and look after my children. I understand that it is for few months only. If I continue my treatment I will be in better condition to do my job thus for me treatment is important it is therefore I wake up early and complete my job at home and come for treatment.’

I found that PLTBs’ levels of personal commitment and motivation did not remain constant throughout the treatment period as the context in which they lived played a vital role. In such instances, I found that support from others, and especially family members, made a big difference and in several cases I found that PLTB considering discontinuation gained support from family members which reinforced their commitment to continue their treatment. A migrant worker staying with his family in the city and taking treatment of five months said;

‘I was frustrated because the disease has not only damaged my physical strengths it has placed several difficulties to my family. But my wife always says that there will be happy days after these sad days will over which makes me to feel that I should complete my treatment.’

I found that the knowledge of PLTB regarding their disease and treatment played an essential role in making their commitment stronger and motivating treatment continuation. PLTB who believed their disease was curable were more motivated in their treatment while those who were less convinced or had less knowledge about their disease and treatment had much less motivation. Despite this, I found that PLTB from both groups continued treatment.

5.4.1.2 *Strong desire of family wellbeing*

I found that a majority of PLTB were concerned about the well-being of their family, and especially about their children and their children's futures, since the majority of PLTB I interviewed had been playing an important role in their family, most of them being a breadwinner for the family. They therefore had a feeling that the welfare of the family had been jeopardized by their disease, as their illness made them unable to look after their family, which in turn had destroyed the happiness of the family. Such feelings led to a strong desire to continue treatment and regain the lost happiness in the family. Such feelings occurred particularly among PLTB who had children: they repeatedly stated that their children would face difficulties if they continued to be ill. A young man with TB said;

'My childhood was a misery in my village but I don't want the same happening to my children. I need to cure my disease anyhow for the sake of my children.'

I also found that many PLTB thought that their family was suffering because of their illness. Continuing treatment and curing their disease was the only thing they could achieve to lessen the stress and burden on the family. Clearly, having such thoughts was not sufficient, as tackling the many challenges were difficult, but I found that support from family members boosted PLTBs' hopes and was therefore important at all stages of TB treatment. Similarly, I also found that there was a cultural bond between illness and family wellbeing: the family would not take part in cultural events or other social gatherings if someone was ill in the family. This bond made PLTB feel uncomfortable that they were hampering the whole cultural happiness of the family, and thus motivated them to complete treatment.

5.4.1.3 *Desire to know more*

I found that many PLTB had a strong desire to know more about their disease and treatment which led them to seek more information from the health system, family and friends, and other sources. This desire not only encouraged them to gather more information, it also led them to disclose their disease to close relatives, friends and

colleagues. I found in many instances that disclosure of their disease to others helped PLTB to gain support during their treatment: people were sympathetic and provided assurance, provided financial support when they were in need, advised them to continue treatment, and visited them at home when they were ill. Such kinds of direct and indirect support to PLTB and their family enabled them to focus on treatment continuation and helped to address the loneliness and psychological stress which they experienced due to the disease. A woman with TB said;

‘Since I was diagnosed with this disease [TB] I was not sure whether to tell about my disease to friends. One of my friends relative also had this disease and I thought she would know more about the disease then I sought more information about my treatment. She was very helpful and she actually suggested me to consult with health workers when I had other difficulties. She has been very supportive throughout.’

Although some PLTB stated that they received support from others after disclosing their disease, a few experienced some level of avoidance from their friends. However, a majority PLTB who disclosed their disease had experienced either some form of support, or, if no support was gained, at least no avoidance.

A desire to know more helped PLTB to gain more support from health workers, and then decisions they made during treatment were well facilitated by health workers. Some PLTB who frequently discussed their problems with health workers stated that they had established good relationships and trust between them and health workers. Such conditions promoted some flexibility in DOT, as health workers trusted them and supplied drugs for a few days.

5.4.1.4 Acceptance of disease and treatment

Although PLTB were taking TB treatment, a few had doubts whether they actually had TB, so acceptance of the diagnosis was an issue for them. In contrast, PLTB who accepted the diagnosis were found to be more committed to their treatment. I found that the acceptance of diagnosis gradually increased as the treatment progressed and they started to feel less unwell. Good progress in treatment greatly increased many PLTBs’ enthusiasm to continue and complete treatment. I found that such enthusiasm was well supported by family members, further helping them to continue their treatment. In contrast, I found only one respondent who was de-motivated to complete the full course of treatment by improvements in his health as treatment progressed, because he thought his disease was cured. I found that the link between feeling better and motivation to continue treatment was largely determined by how health workers

responded to the treatment progress and communicated with individual PLTB – a positive and timely response resulted in increased motivation. A young woman who was seriously ill and had been hospitalised for a week, said;

‘I thank health workers who brought me to this stage as now I can walk and do my household work. I had lost my hope as my condition was severe but the health workers kept on telling me that drugs have responded well and I felt better after a week treatment. Now I fully believe that my disease will be cured with full course of treatment.’

I also found that when PLTB felt better as treatment progressed, they were constantly reminded by family members to keep their treatment going. This took place because the family members were happy seeing the improvement, and wanted to avoid any interruption during treatment that could cause the disease to reoccur or become chronic. A wife of a PLTB who accompanied her husband for his treatment said;

‘When he [the husband] started treatment he kept on saying that his disease will take him away from family but now I’m happy to see the treatment has made a difference as he started eating well and put some weight. It is really good to hear positive talk from him about his illness. Now I fully believe that he will be all right. I keep on telling him not to neglect treatment as it has made good progress.’

5.4.1.5 Increased support from family in treatment

I found strong feelings and acts of families of PLTBs’ togetherness throughout their illness, regardless of their socioeconomic conditions and cultural norms. Although there were a few exceptions where PLTB were isolated in the family, the majority of respondents had greater support from the family than from others. I found a variety of support and supportive behaviours from family members that helped PLTB to continue their treatment. Box 5 below provides key areas of support that PLTB had from their family during their illness.

Box 5: Examples of family support to PLTB during illness

- Togetherness throughout the illness
- Encouragement and psychological support
- Financial support
- Good acceptance at home
- Help to fight against social discrimination
- Sacrifice of other family priorities to support PLTB in treatment
- Help as treatment supporter: e.g. treatment supervision, drug collection, accompanying care seeking and treatment, reminders to take drugs, help with information
- Provision of nursing care at home
- Replacement of PLTB in work, to protect employment
- Help to PLTB to regain lost social identity due to TB
- Taking on PLTB's responsibilities in the household
- Searching for other opportunities during illness and after cure

The majority of PLTB respondents stated that continuation of TB treatment without support from the family was an impossible task, because it would not be possible for this support to be provided by any other people.

5.4.1.6 *Management of other priorities*

As discussed in previous sections, PLTB had other priorities which were largely determined by their role in the family and by the jobs they were engaged in. In the case of women, most held responsibility both as homemaker (managing household chores) and for other employment outside the home (mostly income generation work). Making TB treatment a priority was not a simple task for many PLTB, and especially women, as it compromised other equally important tasks, particularly jobs directly related to their livelihood such as income generation. A young man said;

'I come here exactly the time this centre opens then I go to my work. But I lose an hour in the morning which I don't get paid, it is ok because if I'm not well, I will lose more than what I'm losing now.'

I found that some PLTB had postponed travel to their traditional home because of TB treatment. They told me that doing so was difficult for them, but since keeping TB treatment was their first priority, they managed.

5.4.1.7 Individual tendency of seeking support

I found that some PLTB had sought help from others when they were in difficult times, not considering what others would think about their disease. This was particularly true among migrants, who sought help, often financial support, from other friends who had come to the city from the same village. However, I also found a reluctance among some PLTB to seek help from others when they were dealing with their problem anyway, because they feared disclosing their disease. When PLTB had no other options they were less concerned about what others would think about their disease, and shared their difficulties. In many cases, respondents said the people to whom they requested help were positive and supported their treatment. A young man who had been receiving treatment for five months said;

'I would not be able to continue my treatment more than four months because I was in big financial need as I had no money to pay my rent and food. I went to a friend as were from the same village, he lent some money and I'm now continuing treatment.'

5.4.2 Health systems

I found many issues related to health systems that generally hindered access to TB treatment and thus affected treatment continuation, which I have already discussed in previous sections: 5.1, 5.2.3, 5.2.4, 5.2.5, 5.2.5.2, and 5.3. Despite these issues, I found some key factors related to health systems and TB service delivery that helped PLTB to continue their treatment, some of which I have already discussed. Here I focus on a few key factors.

- **Commitment of frontline health workers:** Although this was an issue as PLTB stated that they did not have good experiences with a few health workers, I also found that some health workers were committed to providing good care to PLTB and facilitated their treatment. For details see sections 5.2.3 and 5.3.1.
- **Visibility of the programme:** I found that the NTP had expanded its services nationwide and its visibility among the general population was generally good, as most respondents knew that TB drugs were free and DOTS existed. In interviews many PLTB stated 'DOTS' to indicate TB treatment by the government, although they hardly knew its meaning.
- **NTP's partnership and service expansion:** Although TB services did not extend to all populations in need, their gradual expansion in

partnership with the private sector, NGOs, local government and communities (see sections 5.3.1 and 5.3.2) resulted in increased access to TB services, so that a majority of PLTB had come to government-provided DOTS services and started TB treatment. This is not to say that all PLTB had good access to TB services, but I found that a sizable proportion of PLTB were utilising TB services under the NTP. In addition, service hours of some NGO run DOTS centres found convenient to PLTB as they opened early morning where PLTB could take treatment before they head to their work.

- **Free drugs and regular supplies of logistics:** Although I found that PLTB had paid a considerable sum for diagnosis, the provision of free drugs helped PLTB in TB treatment (although, other associated costs during TB treatment were an issue for many). Apart from a few exceptions, logistics in TB service in the study area were found to be intact, helping TB services to be provided for PLTB during TB treatment.

- **Context-specific treatment supervision:** Although supervision of PLTB during treatment and provision of DOT appeared to be controversial issues in the study, I also found that some health workers were flexible and tailored treatment according to needs of PLTB, especially a level of flexibility in DOT. However, this flexibility was applied by individual health workers, as it was not a mechanism contained within policy and guidelines. Furthermore, some health workers considered the role of family members of PLTB in treatment, and engaged them in treatment supervision. Section 5.2.6 has already provided a detailed discussion on treatment supervision and patient support.

- **Friendly behaviour and positive attitudes of health workers:** Although section 5.2.3 discussed issues related to health workers' attitudes and behaviour towards PLTB, some PLTB described good partnerships with health workers which enabled them to continue TB treatment. Some health workers recognised problems that PLTB were facing and tried to modify treatment to address them. In many occasions health workers acted as supportive friends of PLTB through good understanding of the needs of PLTB.

5.4.3 Community support to PLTB

I found that PLTB were somehow linked with their own social network either by choice or default. PLTB trusted such networks and gained some support from them during treatment: examples included moral support, financial support (lending money), information provision, accompanying PLTB to treatment centres, providing shelter, and helping in the workplace. All these forms of support were vital for PLTB, and especially for migrants who had limited social support in their new urban settings.

I also found that TB volunteers working as late patient tracers provided help to PLTB by visiting their homes when they were late to collect drugs and helped them in DOTS centres. Similarly, employers helped PLTB by being flexible while attending DOTS centres for DOT (although this was not the case for all employers).

5.5 Conclusion

In this chapter I have shown that PLTB had to undergo treatment under very difficult circumstances, affected by multiple factors. The interplay of these factors made TB treatment complicated for many PLTB. The main issues found affecting TB treatment were socio-cultural understanding and practices with regard to TB and PLTB; a TB service delivery process that had limited consideration of the contextual reality and needs of PLTB; costs of TB care during treatment; inadequate provision of supervision and patient support during TB treatment; poorly tailored information and communication system in the TB programme; poor organisation of TB service delivery in the study area; and little or no consideration of the TB service needs among special populations.

Despite complexities and difficulties in TB treatment, many PLTB were continuing TB treatment and completing their prescribed course of TB treatment under the NTP's DOTS framework. The chapter also discussed on various responses to the issues and problems that PLTB experiences during TB treatment. However, I found that support from PLTBs' families was crucial in encouraging successful treatment completion.

The next chapter presents further discussion on the major issues identified in the study and investigates the possibility of developing context-specific TB treatment delivery services in urban areas to maximise successful treatment completion by reducing the burden on PLTB and their households (addressing the objective 3 of the study).

CHAPTER SIX

FURTHER DISCUSSION ON KEY STUDY FINDINGS

This chapter presents further discussion on the key study findings: barriers and supports to successful TB treatment completion. In this chapter, I also revisit the study aim and objectives in the light of the study findings and programme context. Finally, I discuss limitations in the study and validity and generalisability of the study.

6.1 The research objectives revisited

The aim of the study is to gain a better understanding of experiences and issues faced by People Living with TB (PLTB) and their responses during the course of TB treatment; and to identify appropriate ways of addressing the identified issues in a specified context. This study will contribute to the body of knowledge relating to TB treatment completion and facilitate the design and implementation of patient-centred care in Nepal's National TB Programme (NTP) and similar settings elsewhere. The study focuses on factors that influence TB treatment completion among PLTB taking TB treatment under the NTP in urban settings in Kathmandu Valley, Nepal.

The following study objectives were developed;

- to understand the issues underlying the successful and unsuccessful completion of TB treatment from the perspective of PLTB in the context of the NTP in urban settings in Kathmandu, Nepal;
- to understand responses to the factors influencing the successful and unsuccessful TB treatment completion from the perspective of health systems, communities and PLTB in the context of the NTP in urban settings in Kathmandu, Nepal;
- to identify appropriate ways of addressing the issues identified leading to the successful and unsuccessful TB treatment completion in the context of the NTP in urban settings in Kathmandu, Nepal.

My study findings suggest that various factors and their interplay affected TB treatment completion. I was surprised that, despite persisting hindrances and difficult circumstances, a majority of PLTB continued treatment: hence the NTP consistently achieves a treatment success rate of more than 85% in the study area (NTP 2008). This apparent contradiction was an interesting phenomenon, but was largely unexplored. I therefore felt it was important to explore *why* and *how* PLTBs were continuing TB treatment despite the circumstances. The use of a qualitative research

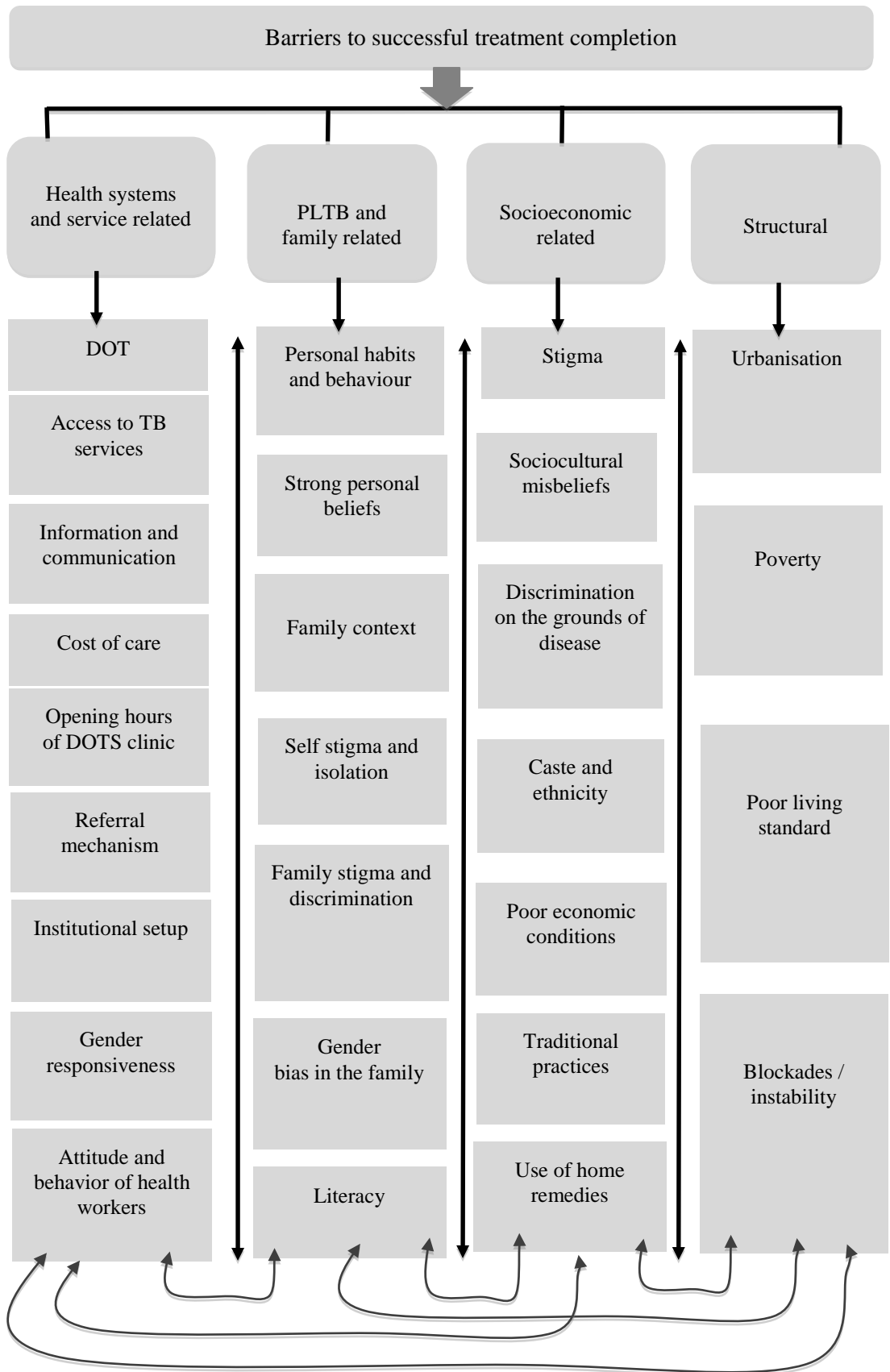
approach and an interactive research design allowed me to revisit the research objectives and methods as the study progressed (Hammersly and Atkinson, 1995).

6.2 Summary of key findings of the study

An understanding of TB as merely a biological phenomenon would misrepresent the complexity of the disease and its treatment management. The study findings suggest that an interplay of a set of factors (biological, health systems and service delivery; PLTB and family; socio-cultural; financial; and structural) had endangered PLTB and their families by stopping them addressing difficulties that arose along with TB. This finding is consistent with the findings from a study in an urban setting in India (Jaiswal *et al.*, 2003) and with what Munro *et al.*, (2007) reported in their systematic review of qualitative studies on patient adherence in TB. Although the disease affected only one person biologically, it pushed the entire family into great difficulties, and their suffering had immediate, mid- and long-term implications throughout and beyond the PLTB's treatment, and especially economic and social implications (Hane *et al.*, 2007; Kemp *et al.*, 2007; Harper, 2006; Courtwright and Turner, 2010; Gandy and Zumla, 2002; Marra *et al.*, 2004)

Figure 16 presents an understanding and interplay of factors that hindered PLTB during the course of treatment, based on my study findings. In the figure, I summarise barriers in TB treatment under four major areas – health systems and service delivery; PLTB and family; socioeconomic; and structural – and various sub-areas (presented below the major areas), which negatively contributed to successful TB treatment completion. However, it is important to be aware that the degree of hindrances and complexities and their impacts on TB treatment varied among PLTB, depending on their individual status (knowledge and beliefs; disease conditions; severity and presence of diseases other than TB); the socio-cultural context (cultural norms and practices, community beliefs and perceptions); their economic status (financial ability; costs incurred for TB diagnosis) and other local contextual factors (environment, other social determinants and urban complexities). The arrows in Figure 16 indicate interactions of factors and consequent complexities in TB treatment management. The findings suggest that, in many instances, the barriers that PLTB faced became more complex as they developed and interacted with each other. The following sections summarise and further discuss the key findings in the light of the study findings and initial discussions presented in earlier chapters.

Figure 16: Factors affecting successful treatment completion and their interplay



Note that I have presented the key findings and further discussions based largely on the context of urban TB control provided by the NTP, so that I mainly consider my findings within the context of the NTP's existing policies, strategies and guidelines including the Stop TB Strategy, the International Standards of TB Care and the Patient Charter for Tuberculosis Care. Where applicable, I also discuss the relevance of the findings in the South Asian context.

6.2.1 Key barriers to successful treatment completion

6.2.1.1 Poor access to essential health care including TB services

Although my study focused on TB service delivery, my findings demonstrated that viewing TB control in isolation from other health care services – essential health care services (EHCS) in the context of Nepal's health system – would grossly underplay the reliance of the success of the TB control programme on a functioning general health system and services, and the suffering PLTB underwent due to limitations in the general health system. The lack of government primary health care setup to deliver EHCS in the study area resulted in not only inadequate provision of basic health care, but also TB services. This finding indicates that many people living in urban areas, especially the urban poor – slum dwellers, migrants, labourers, women, children and other people residing in poor urban settlements – were having difficulties accessing the EHCS that includes TB care. Consequently, many of the urban poor were forced to seek health services including TB care from the private sector, although private sector services were unaffordable to many, as noted elsewhere (Uplekar *et al.*, 2001; Newell *et al.*, 2004; WHO, 2001). There has been a longstanding issue as to whether the responsibility for providing EHCS in urban areas falls to the MoHP or local government (i.e. municipal corporations). Although the government of Nepal's Ministry of Health and Population (MoHP) recently introduced an urban health care policy (MoHP, 2010), it has not yet taken effect, and it remains unclear who has the responsibility to deliver EHCS in urban areas.

PLTBs were concerned not only about access to TB treatment. I found that many also suffered from other illnesses while undergoing TB treatment and the absence of basic EHCS in many DOTS centres forced them to seek care for those illnesses from private health care providers. In addition to this causing a considerable delay in seeking care for other illnesses, it also affected PLTBs' TB treatment continuation, a major issue being the cost of care incurred for other illnesses, in addition to the costs of TB care. Although the government has a 'free health care policy' (MoHP, 2010a), it was

implemented through the government health institutions under the MoHP, and a lack of a government institutional network in urban areas meant the urban poor were deprived of free health care provision. According to the MoHP's definition, the EHCS package includes TB care (MoHP, 2010a, p. 18), but implementation of TB services has yet to be well coordinated within the comprehensive EHCS package in urban areas, unlike in rural areas where TB services are largely being delivered through the MoHP's EHCS network (NTP, 2006/07). The lack of EHCS in urban areas raises an important question relating to TB service delivery modality within the existing health service delivery context: whether TB services could and should be delivered or linked to the EHCS package; and if so how.

My findings also show that the TB services were delivered in partnership with some service providers – public, private for-profit, and private not-for-profit – in the study area. The partnership to some extent increased coverage (Newell *et al.*, 2004), juxtaposed with other components of EHCS. However, the partnership suffered due to lack of a mutually agreed urban TB control strategy; unclear roles and responsibilities among partners; lack of stewardship; inadequate resources; and a lack of an appropriate TB service expansion plan tailored to the needs of people. This resulted in a suboptimal partnership and an ad-hoc expansion of services in the study area. A study by Newell *et al.* (2005) in Nepal also documented a similar finding in terms of understanding among health care providers with regard to TB control; however, the study was not limited to urban areas. Consequently, TB service was not accessible to many vulnerable groups, thus having a profound negative impact on treatment continuation (in addition to financial, social and environmental constraints). Many of these constraints in partnership and TB service expansion could be addressed through scale up of a locally developed PPP model (Newell *et al.*, 2004 and 2005; Hurtig *et al.*, 2002).

Access to existing TB services was also limited by the fixed opening hours of DOTS centres. This caused great inconvenience to many PLTB, in particular migrants, daily wage workers, students, job holders and job seekers. It was also an issue among women PLTB who had a major role in the family as homemaker. A similar finding has also been noted in studies elsewhere (Walley *et al.*, 2001; Khan *et al.*, 2002; Sanuo *et al.*, 2004; Coleman *et al.*, 1998). I also found that some DOTS centres run by NGOs had longer opening hours (early morning to late evening): PLTB taking treatment from those centres did not raise opening hours as an issue. However, only a few centres made such provision. Extending opening hours of DOTS centres would

reduce access barriers and could be done without a major modification in the way the centre was run.

6.2.1.2 No DOT no treatment

The NTP provided free TB drugs, but contingent upon institutional DOT. There was a strong view in the NTP that DOT is the vehicle for TB control and the major pillar of the current success of the NTP. This arose from a perception that non-completion is caused by PLTB. Another strongly held belief in the NTP was that DOT is a must do activity and is designed to support PLTB to complete their treatment, as many of them do not take their drugs if given them to take at home. In contrast, PLTBs' perception and practical experience was otherwise – a majority of PLTB criticised DOT and felt that the NTP was truly insensitive to the needs of PLTB, and then had to make a difficult decision between the public sector's offer of free anti-TB drugs with DOT and the private sector's offer of expensive anti-TB drugs but no DOT. The NTP and PLTB had completely different views and interpretations of DOT, leading to controversy (see Table 16). The need for compulsory one-size-fits-all DOT for all PLTB was found to be at odds with evidence from Nepal and elsewhere (Newell *et al.*, 2006; Harper, 2006; Volmink and Garner, 2007), and in addition a majority of PLTB viewed DOT negatively (Singh *et al.*, 2002; Jaiswal *et al.*, 2003; Estcott and Walley, 2005). A large district-randomised controlled trial by Newell *et al.* (2006) which compared treatment outcomes using family DOT and using community-based DOT in ten districts of Nepal concluded that family member and community member DOT providers were as equally effective as institution-based DOT. Family members were found to be accountable as treatment supervisors when the programme engaged them appropriately, providing proper education and clarity about their roles and responsibilities. The study also found that PLTB preferred family member DOT.

Table 16: Differences in understanding of DOT between NTP and PLTB

Area of understanding	NTP's understanding of DOT	PLTBs' understanding of DOT
Perceptions, Opinions about DOT	<ul style="list-style-type: none"> • A mechanism of support to PLTB • Ensures PLTB completes treatment • PLTB forget to take drugs • Success dependent on DOT • Prompt management of drug side effects • Helps solve problems when they occur 	<ul style="list-style-type: none"> • Insensitive to PLTB needs • Punitive act imposed by programme • Non-negotiable option • 'Trade-off' with free drugs • A result of lack of trust by programme • Unnecessary scrutiny • Many problems created by DOT • Labour-intensive
Feasibility of DOT	<ul style="list-style-type: none"> • There are designated DOTS centres in urban areas that PLTB can access • DOTS centres have been expanded • PPP approach has been adopted 	<ul style="list-style-type: none"> • Unaffordable • One-size-fits-all, thus infeasible in many ways • time consuming • high travel costs (time and cost) • high opportunity costs • compromises other priorities
Implications of using DOT	<ul style="list-style-type: none"> • High cure rate and low drug resistance • Needed to sustain the NTP's achievements • A core element of the NTP's success 	<ul style="list-style-type: none"> • Discourages PLTB in treatment • Increases individual and family vulnerability • Increases financial burden • Lost opportunities • Treatment completion but with major hardship • Treatment non-completion • Increased stigma in the community
Practice of using DOT	<ul style="list-style-type: none"> • Policy must be strictly followed • Mixed practices with some flexibility depending on individual health worker • Some proxy collection of TB drugs for PLTB (i.e. family members) • No standard practice across the programme 	<ul style="list-style-type: none"> • No direct observation at DOTS centre • No drinking water supply, so no DOT • Drug collection by family members in a few cases • Received 2-5 days supply but no standard practice
Alternatives to DOT	<ul style="list-style-type: none"> • Use of community volunteers • In a few cases, use of family members • In a few cases, supply drugs to PLTB 	<ul style="list-style-type: none"> • Trust PLTB and supply drugs • Use family members as treatment supporter • Adequate education essential • Get treatment in private (unaffordable to many PLTB)

Source: Compiled by the author from study findings

The coercive model of treatment management with compulsory DOT does not comply with ISTC Standard 9 for TB treatment (ISTC, 2009, p. 38) which calls for a patient-centred approach to administration of TB drugs based on each PLTB's needs, and based on mutual respect. DOT practice in the study area also contravenes the 'supervision and patient support' element of the Stop TB strategy (WHO, 2006, p. 10) and the latest WHO TB treatment guidelines (WHO, 2009, p. 77) which state that supervision may have to include DOT but is not mandatory. The documents further state that when DOT is used it should be delivered within a broader package of supervision and patient support tailored to the needs of PLTB in a context-specific and patient-sensitive manner. However, neither document is explicit on what constitutes a supervision and patient support package.

Complying with the requirement of DOT caused huge inconvenience, including increased costs for care due to daily travel to and from the DOTS centre; other routine activities being compromised; a lack of privacy that exposed PLTB to others, increasing fear of stigma and discrimination; restrictions to PLTBs' mobility; increasing the hardships experienced by PLTB and their family members; and loss of opportunity costs, since in some cases PLTB had to stop working to be able to comply with the requirement for DOT. These findings are consistent with those of other authors elsewhere (Thiam *et al.*, 2007; Walley *et al.*, 2001; Khan *et al.*, 2002; Garner and Volmink, 2003; Harper, 2006; Newell *et al.*, 2006). Furthermore, the 'control' caused by DOT made PLTB become passive recipients of treatment (Lienhardt and Ogden, 2004), not only making them vulnerable in decision-making and reducing their confidence, but also prevented them exerting their rights to receive equitable care, to be treated with respect and dignity, and to choose alternative care: a majority of PLTB perceived DOT as non-negotiable, causing some to want to start treatment in the private sector after facing difficulties due to DOT but being unable to do so due to the high costs of private care. This finding was consistent with a study by Johansson *et al.* (1999) in Vietnam. I also noted that DOT was infeasible for a majority of PLTB because it grossly compromised other routine activities; in particular it affected job continuation and limited employment opportunity, which had a major negative implication for treatment continuation. A similar observation has been made in other studies (Singh *et al.*, 2002; Gleissberg, 2001; Greene, 2004; Harper, 2006). I also found that the initial two months treatment was a difficult period in TB treatment for a majority of PLTB; and a major factor was DOT. Difficulties occurred not only for PLTB but also for other family members. The study findings demonstrated that family

members supported PLTB in many ways to fulfil the requirements of DOT; children were most vulnerable as in many instances they were forced to take on a role of the PLTB, either by collecting TB drugs from the centre or by replacing the PLTB in work.

6.2.1.3 *Supervision and patient support – a need within a state of confusion*

Provision of treatment management along with needs-based supervision and patient support heavily influenced the treatment process. However, the programme's supervision and support component has suffered due to varying understanding and practices among key stakeholders along with an ill-defined scope, which failed to cater for the basic needs of PLTB. There has been speculation on the interpretation and practical use of this term since WHO included it in its new Stop TB strategy (2006). I have deliberately used the word speculation because I have not seen an agreed definition of the approach (if it is seen as an approach) or a set of clearly elaborated component(s) (if it is seen as a package). There is a need first to define what the supervision and patient support entails, and second, what it implies. However, attempts have been made to develop a broad conceptual or theoretical understanding of the approach, including helping PLTB to take their TB treatment regularly and complete a full course of TB treatment; a different form of treatment supervision tailored to the needs of PLTB taking context into consideration; a context-specific approach to TB treatment; a patient-centred approach to TB treatment developed between PLTB and provider based on a mutual trusting relationship; encouraging and facilitating a positive partnership between service recipient and provider; an approach in which the PLTB and provider work together to improve treatment completion by addressing critical factors that hinder TB treatment (WHO, 2009; WHO, 2006; ISTC, 2009; Raviglione and Uplekar, 2006).

Although the Nepal NTP has adopted WHO's Stop TB strategy, ISTC and Patient Charter for TB Care, no programmatic understanding has been formed relating to supervision and patient support taking the country context into consideration. This lack of understanding in the NTP has had implications, as PLTB have had to comply with traditional DOT practices. Surprisingly, in several instances, NTP authorities, including some health workers, have interpreted the ongoing DOT practice as supervision and patient support. This highlights a need to define a patient-centred approach within which the role of family members needs to be well defined, taking into consideration the results of the trial of family member DOT in Nepal (Newell *et al.*, 2006). In the programme, clarity is needed on modes of treatment supervision and

support mechanisms to facilitate the overall treatment process. Essential basic support mechanisms should not be restricted only to DOT and free drugs; thus a careful definition of the scope of various supervision and support mechanisms needs to be well explored, with a clear focus on PLTBs' needs. In subsequent sections, based on the study findings, I will attempt to define a patient-centred approach in the context of Nepal's urban TB programme, and develop a revised conceptual framework.

I note that WHO's Stop TB strategy (WHO 2006) has also been adopted by NTPs in other countries: however, replacing more than a decade-long practice of DOT as an essential element of the TB programme by a 'patient-centred approach' as a proxy of 'supervision and patient support' – which is yet to be defined – will be a big challenge and will require considerable effort to change practices and behaviours of TB service delivery authorities.

6.2.1.4 Health communication exists but is poorly tailored to the context

Communication between health care providers and PLTB was found to be essential as it is an important contributor to successful treatment when provided effectively (Liefoghe *et al.*, 1999; Harper, 2006; Jaiswal *et al.*, 2003). Successful completion of TB treatment requires a long-term commitment from health care providers, PLTB and their family members. The study found that effective communication through a meaningful conversation within an established partnership between care providers and PLTB provides an opportunity to maximise commitment to successful treatment completion. Simply transmitting information from providers to PLTB cannot be counted as effective communication. I found that there was a general feeling among health care providers that non-completion was due to PLTBs' poor understanding about the importance of TB treatment. This established notion largely shaped the interpersonal communication between the care providers and the PLTB, including the process of communication, the information content, behaviour of care providers and the relationship with PLTB during communication. Communication was shown to be an activity genuinely embedded within the programme culture as all PLTB had gone through a communication process, starting from the day they registered for treatment. However, the effectiveness of communication in relation to empowering PLTB and changing socio-cultural beliefs to facilitate TB treatment was an issue (Kelly, 1999). I found that it was vital to be able to achieve communication objectives, an understanding of PLTBs' needs and the socio-cultural context within they operated: other studies have drawn similar conclusions (Lienhardt *et al.*, 2003; Munro *et al.*, 2007; Sumartojo, 1993). However, my findings suggest that the communication

process was poorly aligned with PLTBs' needs and socio-cultural contexts. The preconceived notions of health workers towards PLTB as non-compliers contributed to establishing communication in a top-down and one-way process, as care providers fed much information with little or no consideration of the needs and context of PLTB: although the information provided was important, the methods used and lack of considerations of the contextual facts in communication was an issue, that I repeatedly observed and verified with PLTB during interviews.

In the face of their mounting difficulties – physical, psychological, financial, and social – it was ambitious and unrealistic to assume that PLTB would absorb and assimilate all the information provided by the care providers. In the study, I also found that health care providers did not fully engage family members of PLTB in the communication process, even though they were generally present at the event. I consider this as a missed opportunity, which could be well utilised with no additional cost to the programme; particularly given that PLTB found family members' support to be crucial in TB treatment (Sagbakken *et al.*, 2007; Newell *et al.*, 2006). However, it is important and health service providers should obtain consent from PLTB before involving family members in communication.

6.2.1.5 Other key barriers related to health system and services

The initial two months of DOTS was noted as a difficult period in TB treatment because of the need for daily visits to a DOTS centre for DOT (although PLTB living nearby DOTS centres did not have the same experience). The long waiting hours in DOTS centres due to late opening, long queues, and absent providers also influenced treatment continuation. Health providers needed to know as much as possible about PLTBs' needs, preferences, socio-cultural context, beliefs, knowledge and attitudes to be able to offer help and facilitate their treatment. There was no provision to carry out a detailed assessment of PLTB apart from filling in the TB treatment card, in which limited information was recorded (and most of them had data missing). I did not find health workers using open-ended questions by which they could understand PLTB and see the differences between PLTBs' and their own beliefs. This practice had negative implications for creating an enabling environment for PLTB at the centre. In many cases, the attitude of health workers towards PLTB hindered effective communication. In some occasions I observed that the frustration of health workers with the programme or higher level authorities was clearly reflected in their behaviour to PLTB: this did not help at all. It is equally important that health workers always make interactions with PLTB a positive experience: thus institutional or personal issues of

health care providers should not lead to victimisation of PLTB regardless of circumstances. I also found that health workers' positive attitudes and behaviour helped PLTB to stay on TB treatment: a good relationship and openness between PLTBs and providers minimises the burden on PLTB and thus contributes to success.

Health workers and district TB supervisors raised issues of supply of logistics in the programme including anti-TB drugs. However, at the point of service delivery PLTB did not mention unavailability of anti-TB drugs, as has been found in other studies (Khan *et al.*, 2000; Watkins and Plant, 2004). Likewise, I did not find evidence of PLTB being charged for anti-TB drugs, or being asked for under-the-table payments in the programme as reported in other studies (Sanou *et al.*, 2004).

Notwithstanding the evidence of various obstacles in TB treatment, the NTP has achieved high treatment success rates among those registered in the programme (NTP, 2006/07). The NTP uses the term 'successful treatment completion' to label PLTB who successfully complete the full course of TB treatment: however, it is questionable whether this is successful completion in line with the definition I have used in the study. The evidence is contradictory: high treatment success rates are achieved despite relatively poor access to TB services. This contradiction raises some important questions: what proportion of PLTB were treated in the NTP; what were the long-term costs to PLTBs of the programme to gaining the benefit of high success rates; and did numerical success overshadow the prodigious sufferings of PLTB and their families during TB treatment? I will discuss the latter two questions in subsequent sections. The first question was not a focus of my study: however, consistently low TB case detection rates in urban areas (NTP, 2009/10) suggests that many PLTB are not receiving treatment under the NTP, although a public private partnership in TB control demonstrated an increase in TB case detection in urban areas (Newell, 2004).

6.2.1.6 Socio-cultural beliefs, perceptions and knowledge related barriers:

My respondents came from a variety of socio-cultural backgrounds – a majority were migrants who had come to the city from different parts of the country and thus had mixed social backgrounds. I found that each respondent, regardless of socio-cultural background, displayed culturally constructed beliefs relating to the causality and treatment of TB, and to the efficacy of TB drugs. Their behaviour was affected by these beliefs, even though the beliefs often conflicted with biomedical understanding of the disease and its treatment: similar findings can be found in other studies (Ho M, 2004; Khan *et al.*, 2000; Long *et al.*, 1995; Courtwright and Tunner, 2010). For instance, a community understanding of causes of TB (such as disobeying socio-

cultural norms; visiting prostitutes; engaging in sexual relation with relatives; wrongdoing in the past; TB as a disease of dirty people) often prevented people seeking care for fear of being labelled, if they were found to have TB. As a consequence, many PLTB continued to hide their disease during TB treatment, causing major problems for many PLTB. In particular, women and unmarried girls were found to be more vulnerable to such beliefs due to their socially constructed positions in the community. Such vulnerability was further compounded when they had to comply with requirements for DOT by making daily visits to the DOTS centre. I found that the repercussion of such beliefs was greater for local residents of the city than for migrants, because local PLTB were often worried that such negative labelling would jeopardise their social status; as a consequence, some chose to take their TB treatment from DOTS centres located a long way from their local community, with implications for costs and treatment continuation. I found a mismatch between PLTBs who feared disclosure of their disease, and the support and encouragement provided by members of the community including friends and colleagues to PLTB who disclosed their disease status. Another study conducted in a similar setting produced similar findings (Baral *et al.*, 2007). It will be useful for the programme to document such experiences of support given after disclosure of the disease and use them as evidence in health communication aimed at PLTB who continue to hide their disease from others.

TB-related stigma and discrimination appeared to be high in the study context; women with TB were affected the most. Although health communication included the message that after two weeks of treatment TB is no longer infectious, a fear of transmission in the community or the family was found to be a major cause of stigma towards PLTB. As a consequence, a majority of PLTB practiced self-isolation not only for the initial few weeks but throughout treatment. This was particularly difficult for women with children and migrants who lived with their family in one room. I found evidence that remaining in isolation reduced support from family members and close friends. In the cases of drug-resistant TB, multi drug-resistant and extremely drug-resistant TB, the practice of isolation may be justified: however, for drug-sensitive TB, beliefs about the need for isolation need to be addressed through effective health communication. There is also a discussion to be held regarding whether avoidance of a person with active TB on the grounds of self-protection is actually discrimination (Baral *et al.*, 2007), since it is highly unlikely that they pose any risk once they start treatment. My findings also suggest that stigmatisation and discriminatory behaviour towards PLTB are found more in joint families than in

nuclear families; this was particularly the case for women with TB, who tended to be discriminated against by their in-laws. However, there was less stigmatisation and discrimination by family members than from general members of the community. Nevertheless, the findings further emphasise the need for a critical assessment of PLTB with regard to their social, cultural and family background to be able to address stigma-related concerns that often prevent PLTB successfully completing TB treatment.

Discriminatory behaviours on the grounds of TB in institutions such as schools, workplaces and health institutions appeared to be an important barrier to treatment continuation. Migrants suffered more than others, because migrants (generally with a poor economic status) mostly ended up working in factories, and factory owners were often reluctant to continue to employ an ill person, on top of which they believed keeping PLTB at work risked infecting others. As a consequence, PLTB were dismissed from their jobs, with catastrophic effects as the PLTB found it almost impossible to survive in the city and continue TB treatment without a job; a similar conclusion was drawn from another study in the same area (Baral *et al.*, 2007). Since a majority of PLTB in the study area were migrants, my findings indicate an urgent need to develop a strategy aimed at factory managers and owners to address discriminatory actions in workplaces (Kirwan *et al.*, 2009). However, not all PLTB working in factories had the same experience, as some factory owners supported PLTB during their treatment thereby reducing their burden. This suggests that there is a possibility to address the issue of institutional stigma in factories. This would require a joint approach from local government (municipalities), the office of small business industries, garment factory associations, local health authorities, the NTP and others. I was particularly surprised to find discrimination on the grounds of TB in health institutions. Health institutions provide the last chance for PLTB to be cured, and discrimination could seriously hamper PLTB in seeking and continuing TB treatment. This suggests there is an urgent need for the NTP to design and implement measures to ensure people-friendly TB services in health care settings.

Similarly, there was a perception that TB remains forever in the body, closely associated to the perception that TB damages the lungs and normal physical strength can never be restored. These perceptions became stronger when PLTB relapsed or TB reoccurred. Such perceptions led to beliefs that TB could not be cured with oral medication alone without surgery to repair lung damage, affecting PLTBs' motivation to continue TB treatment, although they continued treatment despite this confusion.

Many PLTB were concerned about the potential consequences of TB, especially development of chronic TB. They became further worried when they saw some people failing to get cure, again affecting their motivation. I was surprised that the health system took this issue lightly and in some instances health workers ignored the fact that such beliefs existed among PLTB, stating merely that people receive health education and TB is now a simple disease to treat.

My findings suggest that PLTBs' personal knowledge, attitude and experiences played a role in determining their treatment behaviour. PLTB who had a fear of becoming impotent as consequence of TB drugs were in a stage of confusion whether to continue TB treatment. Likewise, people who were unconvinced that TB is communicable had doubts whether they had TB. Such beliefs caused PLTB to have psychological dilemmas, some of which persisted throughout treatment. This suggests that health communication was poorly tailored to correcting misconceptions. I also found that social stigma relating to TB appeared to be more common among local resident PLTB than among migrants. Being relatively new in the city, migrants had very limited social networks (Kirwan *et al.*, 2009) compared to local people, and were thus less bothered being labelled with TB: this however does imply that migrants were unaffected by stigma and discrimination. Almost all migrants I spoke in the study raised many issues that hindered their treatment continuation: the issues most commonly raised were social and financial constraints, on top of which the requirements of DOT caused further social, physical and financial problems. Other authors also highlight the need to explicitly address the requirements of migrants in TB control (Tang and Squire 2005; Long *et al.*, 2008; Wang *et al.*, 2008). The impact of stigma and discrimination among respondents varied, depending on the PLTB's knowledge, interpretation and cultural context: importantly, the level of suffering experienced was also determined by the level of support the PLTB received from the family. The more support PLTB received from the family, the less was the impact of community stigma: when stigma existed in the family, support was greatly reduced.

Gender roles are also important factors in TB treatment. Nepal's complex social structure and culturally defined gender roles influence health care seeking, especially when the duration of care is long. I found that women with TB disease were more vulnerable than men during treatment. However, women tend to cope better with difficulties, whether at home or in the community, and thus stay on treatment (Uplekar *et al.*, 2001). Women were more concerned about their children's future when they perceived they were at risk of TB. For example, a woman with TB decided to isolate

herself from her children throughout her treatment because she feared that the children may get infected; but this isolation caused her substantial and continuing distress. In addition, the requirements of DOT made women further vulnerable as it was problematic to comply with DOT as well as carrying out household duties with no additional help.

Regardless of socio-cultural beliefs and traditional practices, a great majority of PLTB managed to continue treatment. It should not be assumed, though, that PLTB were not affected by the difficulties they encountered; rather, the support they obtained from their families and their coping strategies enabled them to stay on treatment. I found that many PLTB had a strong desire to be cured, despite all the problems they faced. They continued to struggle against the barriers, in the hope that their disease would be cured and the problems would end. However, although PLTB were committed to their treatment, they continued to worry about what they would do after completing treatment. Their worries were mainly related to the debts they had incurred to pay for treatment, whether they would find a job, and whether TB would reoccur in the future if they engaged in hard physical labour, this last concern being particularly prevalent among migrant workers engaged in hard labour. Despite the fact that a large number of migrants were taking TB treatment in the NTP, no specific strategy exists to address their problems in the urban TB control programme.

6.2.1.7 Therapy related barriers:

Many PLTB found the long duration of TB treatment and multiple drugs to be taken were real problems and led to demotivation. This was further compounded by drug side-effects and poor side-effect management by health services: as a consequence, some PLTB stopped taking their drugs. Other studies have shown similar findings (Jaiswal *et al.*, 2003; Green, 2004; Wares *et al.*, 2003; Watkins *et al.*, 2004). In some instances health workers did not pay sufficient attention to the side effects of anti-TB drugs that had been brought to their attention by PLTB (Green, 2004): I also found disparities in perceptions of the seriousness of side-effects between health workers and PLTB, which further hindered the process of side-effect management. PLTB also found that once they started TB treatment their appetites increased: lack of food became an issue, especially among poor PLTB who anyway had problems managing to obtain basic provisions for themselves and their households. This problem was further aggravated when health workers suggested that PLTBs needed additional nutrition to help cure their disease. Health workers often told PLTB to take TB drugs on an empty stomach to improve their efficacy, but this was inconsistent with the

opening times of DOTS centres: being unable to eat until after receiving DOT caused concerns to PLTB. This further demonstrates the need for health communication models tailored to the context, needs and abilities of PLTBs, which are currently lacking in the programme.

6.2.1.8 Structural barriers:

Sumartojo (2000) defines structural barriers or facilitators as related to organisational, economic, social, policy and environmental issues. I have presented other barriers in earlier sections; here I focus on urbanisation, the political and organisational contexts and poverty-related issues. The infrastructural setup of DOTS centres varied in the study area: some had a relatively poor institutional setup with many services delivered from a single room. Such arrangements demotivated many PLTB in taking treatment from the centre and also raised concerns about the privacy of treatment and the quality of services. In addition, PLTB sometimes had to climb multiple flights of steps to get to the DOTS centre, causing daily problems to those who were physically weak. Some DOTS centres were located within holy premises, causing mixed responses: some PLTB who did not want to be seen visiting the DOTS clinic said it was good as they could say that they had been to the temple; while others were concerned that people visiting the temple could see them entering the TB clinic every day, potentially revealing their disease status. It is thus difficult to conclude whether having DOTS centres in such premises is good or bad, as preferences depended on individuals and contexts. However, in both cases, it is important to ensure the provision of adequate space to be able to deliver quality TB services.

Growing urbanisation has not only resulted in high population growth but also in increased unplanned settlements, increased numbers of urban poor and increased conditions of poverty in which TB flourishes. In such circumstances TB control is a challenge, as it is difficult to provide accessible services to the people residing in such areas, hindering not only TB treatment but also TB case identification. There is a proliferation of evidence suggesting direct links between poverty and TB (Gandy and Zumla, 2002). Archbishop Desmond Tutu's declaration that 'TB is the child of poverty – and also its parent and provider' emphasises the vicious link between TB and poverty. It has been shown that TB has a disproportionate impact on the poor, especially in developing countries. It is estimated that 94% of TB cases and 98% of TB deaths occur in developing countries, signifying an imperative need for NTPs to address poverty-related barriers in TB control. I was surprised by the complete lack of strategies in the Nepal NTP specifically addressing the needs of the poorest population

groups, given that in urban areas of Nepal the TB burden is estimated to be four times the national average, and TB case notification remains consistently low and default rates high. Despite enduring dreadful conditions of poverty, PLTB continued TB treatment, applying various coping strategies: selling family possessions; sending children to work; borrowing money; and reducing food intake within the family.

I also found that the ongoing political instability, and frequent unplanned strikes across the city, made life difficult for PLTB, not only because they were not able to visit DOTS centres but also because they were hampered in their routine work, which was the only means of earning enough to stay in the city. These structural factors were beyond the control of health workers and PLTB, but health workers could discuss such issues with PLTB to find ways to minimise the effects on TB treatment.

6.2.2 Key factors enabling successful TB treatment completion

6.2.2.1 Family support:

Support from family members during the course of TB treatment was one of the key factors that helped PLTB to continue treatment. The support gained not only during the treatment but from the start of illness greatly helped PLTB overcome barriers in care seeking and treatment. Other studies have also found family support to be crucial in TB treatment (Newell *et al.*, 2006; Khan *et al.*, 2005; Johansson *et al.*, 1999; Harper *et al.*, 2003; Edginton *et al.*, 2002; Nair *et al.*, 1997). For many PLTB a positive and accepting home environment was essential. PLTB were generally well accepted at home and gained support throughout treatment, with the exception of a few who experienced discriminatory behaviour at home, especially in joint families. The acceptance of the PLTB within the family not only created a conducive environment, but also helped to fight against stigma and stigma-related discrimination in the community (Khan *et al.*, 2000; Meulemans *et al.*, 2002).

Families provided PLTB with various forms of support. The main help was financial support during the course of their illness. A majority of PLTB had rather poor financial status, even before they contracted TB, so living was a challenge (Liefoghe 1997), especially for the urban poor and migrants. TB disease further increased these challenges, and consequently the large costs associated with treatment weakened the PLTB's ability to continue treatment. Several studies have demonstrated that PLTB interrupt TB treatment because of financial pressures (Watkins and Plant, 2004; Greene, 2004; Johansson *et al.*, 1996). However, the financial support given by family members proved vital in the TB treatment process and helped the PLTB continue to

stay on treatment. Another vital form of support from the family was staying with the PLTB throughout their illness. This act of togetherness profoundly helped PLTB in reducing their psychological stress, empowered them and increased their confidence. (Meulemans *et al.*, 2002; Barnhoorn and Aadriaanse, 1992).

In many instances, family members provided good nursing care at home, regardless of the severity of the PLTB's illness. They often prioritised care for the PLTB, not only at home but also accompanying them to the DOTS centre, collecting drugs from the centre, and reminding them to take drugs regularly. Family members often compromised their other work to ensure that the PLTB continued with treatment. In many instances, they replaced PLTB in their jobs and took over responsibility for the PLTB's household chores. It came as a surprise that despite ample evidence of the crucial role of family support in TB treatment in Nepal and elsewhere (Newell *et al.*, 2006; Khan *et al.*, 2005; Johansson *et al.*, 1999; Harper *et al.*, 2003; Edginton *et al.*, 2002; Nair *et al.*, 1997) the formal NTP guidelines relating to TB treatment management do not give serious consideration to engaging family members in the treatment process (NTP, 2006), despite the fact that family members often come to the DOTS Centre with the PLTB during the process of seeking care.

Although family support played a vital role in determining successful TB treatment completion, it was often the case that women with TB had less family and community support than men. This observation was also made in other studies: in many societies, especially male-dominated societies in developing countries, women are given lower priority (Long *et al.*, 2001; Khan *et al.*, 2000; Johansson *et al.*, 2000). However, it was noticeable that families provided more support to young unmarried women than to other (married) women in the home (Khan *et al.*, 2000).

6.2.2.2 *Personal commitment of PLTB:*

Almost all PLTB found the journey to TB treatment was not straightforward, as unfavourable circumstances hindered them at various stages. Despite mounting difficulties, PLTBs' personal commitment and motivation remained strong, greatly facilitating successful TB treatment completion. However, I also observed that their motivation did not stay constant throughout treatment: other support and encouragement, in particular from family members, played a central role in ensuring continuing commitment to treatment. Note that not only personal motivation facilitated PLTB to remain on treatment, and individuals' motivation varied, an issue also identified in other studies (Harper *et al.*, 2003; Khan *et al.*, 2005; Menegoni, 1996).

To be able to stay on treatment, it seemed important that PLTBs had adequate knowledge regarding their disease and treatment: however, in the majority of instances, I found that despite limited knowledge of TB and its treatment and unanswered concerns, PLTB continued treatment. This was because many PLTB understood that the disease not only affected them but the entire family, so that the happiness of the family, and especially the future of their children, relied on their cure – a strong motivational spur to PLTB. It was also found that regardless of their knowledge about the disease and its treatment, PLTBs accepted their treatment: however, there were a few occasions when PLTB seriously questioned whether their disease was TB.

6.2.2.3 Flexibility in TB treatment management and positive attitude of health workers:

My study findings suggest that some health workers applied flexibility in TB treatment management and in particular the requirements of DOT, against the NTP policy of institutional DOT. However, this flexibility went unrecorded because of fear that they might be reprimanded by senior authorities. This flexibility greatly helped PLTBs continue their treatment, but raised genuine questions why health workers had to fear when they were flexible in response to PLTBs' needs and the local context. There was a strong understanding among some health workers that institutional DOT was infeasible for all PLTBs, and therefore they chose to be flexible to achieve the NTP aim of successful treatment completion. However, they did not forget the need for quality treatment. They educated a reliable family member and often developed a good partnership before supplying drugs to the PLTB. The positive attitude of such health workers helped further a supportive conducive environment for PLTBs. I found that health workers who had a positive attitude towards PLTBs often developed a good relationship and adjusted the treatment plan to address the context and the PLTB's needs: such health workers were the ones who practiced flexible DOT. I found that 'flexible DOT' did not compromise the quality of care: nor did the PLTB interrupt treatment, despite the NTP's assumptions that supplying drugs at home would encourage PLTB to miss drug doses. Given such flexible practices secured good results, it was a surprise that the NTP has not yet considered documenting such practices and revisiting policy in the light of lessons learned in the field. It is especially relevant to do so since the NTP has adopted the Stop TB strategy, the ISTC and the Patient Charter for TB Care.

6.3 Limitations of this study

In addition to the limitations relating to data generation and analysis discussed in chapter 4, I now present further limitations of the study in two broad areas: effects of the researcher on the overall research process; and methodological limitations of data analysis.

Effects of the researcher on the overall research process: I consider it important to discuss the effect of the researcher on the research process, as in qualitative studies the researcher works as an instrument in the research (Patton, 2001). The researcher is closely engaged in generating data; performing analyses in parallel with data generation; seeing patterns and issues and deciding on respondents to widen understanding on particular issues; and reinterpreting issues; all while constantly engaging with the data and the process of data generation. Therefore, the validity and credibility of qualitative research depends largely on the ability and effort of the researcher.

In the last fifteen years of my professional career, I have worked with the NTP at district, region and national level. I was closely involved in setting up TB services in urban areas in my capacity of a government employee of the NTP and more recently as a researcher providing technical assistance to the NTP. I am therefore well acquainted with the TB services in the study area and have a good working relationship with the NTP and other key stakeholders. However, it was possible that study respondents, in particular health workers and NTP authorities, may have treated me primarily as an 'expert in TB control' instead of a researcher. Such a label may have given some respondents, and in particular health workers and key NTP officials, the feeling that I have substantial knowledge about the issue I was investigating which may have prevented them discussing some issues in depth. During data generation I wondered whether respondents were treating me differently from a researcher, as during interviews respondents used phrases such as 'as you well know', 'you are the one who faced such issues while working in government', 'what's the point of me saying more, as you know more about it than I do'. After realising this fact, I spent a considerable time clarifying my stance as a researcher before each interview. I made them clearly aware of the purpose of the conversation and the importance of their participation in my research, and emphasised their freedom to openly express their views. I believe this approach helped them to speak their mind.

Methodological issues: In the light of the research aim and objectives, I chose to use a qualitative approach, as I discussed in chapter 4. Limitations were observed during data collection: however, throughout the process I made efforts to identify and understand them and overcome or minimize their implications.

One limitation was that, guided by issues emerging from the data, I wanted to interview some specific groups of people, but I was unable to do so. For example, there were some young unmarried girls receiving TB treatment under DOTS in the study area. I approached them but most refused to participate in the study because their parents did not give permission for them to be interviewed, mainly because of concerns about being identified as a TB patient by the community.

Data collection may have been affected by external factors such as interview locations. Although each interview location was decided in discussion with the research participant, there were not many options available where interviews could be conducted without external interference. In some instances, I noticed that research participants were not willing to share specific information such as how they were treated in health institutions, and especially health workers' behaviour towards them. Such reluctance was mainly observed when the interview took place in a DOTS centre. In the light of this limitation, I encouraged PLTB to choose an alternative interview location, but there were limited options available. However, I discussed confidentiality of information in depth with respondents, and assured them of their anonymity, before I started the interview. Most, but not all, interviews were recorded, because some respondents felt uncomfortable recording their interviews. Reasons varied: some perceived risks of being recorded being critical of policy and practice; for some this was the first time they were interviewed, and thus they felt uneasy in front of a recorder; some felt their voice was not good so did not want to be recorded. Such interviews were documented by taking detailed written notes. However, I found that it was difficult to take detailed notes of the conversation and simultaneously fully interact with respondents, maintaining eye contact, listening, moderating the conversation and probing (Green and Thorogood, 2009). However, I have had substantial experience in qualitative interviewing and used all my skills to maintain the conversation without compromising quality interaction with respondents. For those interviews where use of an audio recorder was not acceptable it was difficult to note all conversations, so it is possible, but unlikely, that some important points from conversations may have missed. One interview was not properly recorded due to a

problem with the recorder, and the written notes were not comprehensive. It was not possible to redo the interview so this respondent was not included in the analysis.

In some instances, the participant had limited time, so the interview was completed at a subsequent time convenient to the respondent. A common limitation of using interviews is that they only give accounts of what the respondents say, rather than what they do in reality. I addressed this concern by creating an environment for conversation in which respondents could describe the practical experiences that they faced. I also used observation, which helped to achieve practical understanding, and compare findings with what was said in interviews.

Some women participants from the Newari ethnic group preferred to talk in Newari, a language common among the Newar community in Kathmandu, but at the initial stage of data collection, I was not able to address this issue. Once I became aware of this issue, I trained a female researcher who then did interviews in Newari.

There was a perception that women would not talk openly when interviewed by a male interviewer. I initially did a few interviews with women myself, and then used a trained female researcher to do some subsequent interviews with female respondents. I found that there was no difference in the respondents' openness about issues experienced during their TB treatment.

There may have been some limitations in my selection of research participants for interviews and FGDs, as it was largely done in consultation with DOTS centre staff. It is possible that they may have proposed research participants who they thought would respond favourably when asked about their experiences with TB service providers. However, in addition to consultation with DOTS centre staff, I also used TB registers to identify respondent PLTBs, which may have mitigated this limitation to a certain extent.

One of the tools I used in data collection was observation. My presence during observation at the DOTS centre may have influenced the service delivery environment and the behaviour of health care providers and PLTB. However, I tried to minimize this influence by creating good relationships by making several visits and interacting with health service providers, so they would not see me as a 'quality assessor' of the services they provided to PLTB and others.

One limitation in data collection could be the cultural behaviour of the Nepali people. In Nepali culture, people often try to please by not raising negative issues.. This might have happened in this study: however, I considered this and tried to avoid it by

developing informal relationships through many meetings and visits before obtaining data from participants.

I collected too much data, which may have compromised depth as I could have probed further if I had used fewer respondents. However, I did do substantial amounts of probing; and respondents might not have been prepared to spend even more time with me. Although I tried to interview PLTB who defaulted from TB treatment, I was not successful. This is unfortunate, because getting defaulters' views could have increased my knowledge on the 'why' component of non-completion of treatment.

In FGDs, some researchers have raised concerns about the influence of the moderator's views on the group (Morgan, 1997); and concerns that some participants feel uncomfortable presenting their own views (Rice and Ezzy, 1999). As the FGD moderator, I was well aware of these possibilities and addressed them by being careful not to express my views or influence the group in any other way, and by creating an environment where all participants could openly express their views. To keep the discussion focused and gain quality data I used a FGD guide and moderated all FGDs.

6.4 Validity and generalisability

I have already discussed validity in qualitative research in chapter 4. In this section, I discuss how I maximised validity in the study, and to what extent my findings are generalisable to other contexts. The comprehensiveness of my data, and the repeated inspection of my data that I carried out until I reached in-depth explanations of issues suggests my work is credible and trustworthy (Silverman, 2000). I sought to gain in-depth understanding of successful TB treatment completion in a specific context among a limited number of study respondents, so it is difficult to claim that my findings are generalisable, except perhaps to broadly similar contexts.

During the overall design of my research approach (discussed in chapter 4), I repeatedly looked at the relationships between selection of methods, potential study participants, selection of research sites, my research objectives and the kinds of theory and explanations that I sought in the study. I put every effort into generating trustworthy data in the field. I interviewed different groups of people, which further strengthened my study's trustworthiness by using multiple data sources to the issues under examination. I conducted the great majority of qualitative interviews myself, and moderated all FGDs, and constantly checked and verified data, asking myself questions such as: Does this data make sense? Can I trust the data source? Does this segment require verification from the source? Was the respondent fair in his/her

answers? I constantly retained this questioning stance to search for the best through understanding of the context and establishing a good rapport with the respondents. In a few instances, I used other researchers in qualitative interviews, but I judged their skills as researchers to be good and I provided training to further enhance their skill. Similarly, a well-trained rapporteur also ensured quality of FGDs.

Interpretation of data was achieved through content analysis using a flexible approach incorporating constant comparison and triangulation. Issues arising from the data were investigated among all study participants as appropriate, rather than relying on subgroups, which I believe helped to maximise the internal validity of the study. Comparisons of categories to understand similarities and differences between constructs enhanced the richness of my data interpretation and thus the trustworthiness of my study. Broadly, triangulation refers to the combined use of more than one method of investigation to look at the study findings – that is, methodological triangulation. However, in qualitative research, triangulation is not limited to methodological triangulation, but is also used to seek explanations for similarities and differences and record the construction of reality, considering respondents, theories, investigators, and data generation (Denzin, 1970). The use of multiple methods in data generation, such as qualitative interviews, observations, FGDs and key informant interviews further helped to yield more valid, reliable and diverse constructions of realities in the study.

Similarly, during data generation, especially in qualitative interviews and FGDs, a probing strategy was adopted which helped to avoid superficial and misleading conclusions during data analysis. At the end of each interview I verified with respondents the key issues that had emerged. I considered performing a full validation of data interpretation with the study respondents but concluded this was not feasible because of problems accessing respondents, especially PLTB and their family, as they were not in touch with the DOTS centres after they completed treatment and many of the respondent PLTBs were migrants and thus mobile.

The NTP could argue that my findings are not relevant to the programme as I did not follow the NTP definition of successful TB treatment completion. However, I believe that my definition of successful treatment completion encouraged me to look at human suffering rather than only numbers; thus I did not disagree with the NTP's definition, but looked at its meaning in the real world. I believe that my study findings can provide insight that will encourage the NTP to look beyond numbers and help to facilitate TB treatment by reducing the suffering of PLTB and their households.

6.5 Conclusion

In this chapter, I have made further discussion of the key study findings in the context of Nepal's urban TB control programme. The discussion suggests that successful TB treatment completion was not straightforward, as many obstacles posed threats to the PLTB and their families during TB treatment. Against all the odds, despite mounting difficulties faced by PLTB and their families during the course of treatment, a majority continued TB treatment: this seemed essentially to be because of support from their families. Obstacles with causes related to the health system had a greater impact on PLTB and their families than obstacles with causes related to the PLTB. It is therefore essential that the health system establishes patient-centred care with adequate provision of supervision and patient support: the proposed key prerequisites would greatly reduce the burdens PLTB and their family experience during TB treatment, and thus facilitate successful TB treatment completion. The next and final chapter of this thesis presents the revised conceptual framework and a policy framework for implementation of the revised conceptual framework within the context for urban areas of Nepal.

CHAPTER SEVEN

STUDY CONCLUSION: THE REVISED CONCEPTUAL FRAMEWORK AND ITS IMPLEMENTATION

This final chapter focuses on conclusions of my study. It presents the revised conceptual framework and a policy framework for implementation of the revised conceptual framework with a particular focus on urban TB control programme in Nepal. This chapter addresses the third objective of my study - identify appropriate ways of addressing the problems and issues identified. In addition, I also discuss the implications of my study findings and my contribution in influencing the adoption of the findings into policy and practice in the Nepal NTP during the course of my research. I conclude the chapter with suggestions for areas of research that may further advance successful TB treatment completion in the context of the Nepal NTP and elsewhere.

7.1 The conceptual framework revisited

I have shown that a series of interacting hurdles occurred during the management of TB treatment. Despite the infelicitous circumstances that repeated occurred throughout treatment, PLTBs continued to fight the threats to their successful treatment. The definition of 'successful TB treatment completion' I used in the study is 'completion of the full course of treatment in a supportive environment with no harmful consequences to the PLTB and his/her family during and after treatment, leading to cure and restoration of the pre-existing quality of life and productivity'. Although most PLTBs completed the treatment course (and were recorded as 'treatment successes' by the NTP), their treatment was not successful according to my definition of 'successful TB treatment completion', because no single PLTB I spoke with had completed treatment without experiencing harm both to them and to their family.

Taking into account my study findings, the local context and my definition of successful TB treatment completion, I revised the conceptual framework (Figure 8) to widen understanding of successful TB treatment completion, see the revised framework Figure 17. The essence of the revised framework is to promote patient-centred care in existing NTP services which will reduce (and ideally eliminate) the sufferings of PLTBs and their family during TB treatment, thus helping achieve successful completion of TB treatment. The revised framework presents the major

prerequisites needed to facilitate successful treatment completion in the context hence promoting patient-centered care. The prerequisites identified are:

7.1.1 Appropriate, affordable access to TB services

The essence of access is ensuring PLTB are able to receive TB services from diagnosis to completion of treatment. It requires that TB diagnosis and treatment services are easily physically accessible. My study findings suggest that, more than any other cause, access to TB services during treatment was limited by the requirement for institutional DOT; thus, the health system needs to give more emphasis to finding appropriate ways of delivering TB services, which may or may not include DOT, specific to the context and to needs-based treatment management (Maher et al., 2003; Adatu *et al.*, 2003; Thiam *et al.*, 2007; Garner and Volmink, 2003; Harper, 2006; Newell *et al.*, 2006). When DOT is required, the modality needs to be agreed with PLTB and must not limit access to TB care. Other major contributors to improving affordable access to TB care would be: reducing waiting times in DOTS centres; providing alternatives to requiring PLTB to be physically present at the clinic to obtain drugs, when the PLTB's physical and social mobility make attendance difficult; providing easy access to information on service availability in the city (addresses and maps of existing DOTS centres to allow PLTB to identify convenient clinics); and extending TB service delivery hours in DOTS centres to help PLTB align work and TB treatment. The availability of basic health care for other illnesses also adversely affected PLTB during treatment. It is therefore important to better integrate TB services within basic primary health care (in Nepal, the free essential health care service package).

7.1.2 Affordable care

This prerequisite addresses the findings that highlighted the negative impact of various costs – direct and indirect – born by PLTB and their households. Direct costs entail fees for diagnosis and treatment (other than TB drugs); indirect costs are other costs associated with TB diagnosis and treatment: costs of e.g. travel, food, an accompanying person; opportunity costs; costs of living in the city; etc. The findings suggest that both direct and indirect costs were unmanageable as the expenses PLTB incurred for diagnosis and treatment exceeded their and their households' incomes, even though TB drugs were provided free of charge – Hane *et al.* (2007) drew similar conclusions. I did not estimate monetary values of income and expenses, but PLTB

highlighted the high costs of care as major barriers to continuing treatment, with catastrophic impacts on PLTB and households. Similar conclusions have been drawn in other studies in Nepal (Kirwan *et al.*, 2009; Karki *et al.*, 2007) and elsewhere (Jaiswal *et al.*, 2003)

7.1.3 Appropriate responses to problems

Timely identification of problems and appropriate response to them helps overcoming barriers to successful treatment completion. It is imperative that health workers do a proper assessment of problems, not only at the start of treatment but throughout, and understand the extent to which problems present barriers to successful treatment completion. A simple problem diagnostic tool can be used to identify the root cause of problems and engage PLTB and their family members or others as appropriate in developing a problem-solving plan during treatment. The cause of problems vary; however, my study findings suggest the following were common – DOT at a DOTS centre; PLTBs' lack of knowledge; poor interpersonal communication between care provider and PLTB; physical inability due to severity of disease; conflict between work and DOTS Centre opening times; long waiting times at DOTS centres; transportation to DOTS centre; stigma and discrimination associated with TB in the community and workplaces; jobs requiring mobility; side-effects of TB drugs; health workers' lack of understanding of PLTBs' needs; lack of family and social support; unaffordable cost of care; socio-cultural beliefs; poor relationships with care providers; psychological fear of TB disease; PLTBs' lack of motivation; loss of job and income; etc. The purpose of this prerequisite is to identify which problem or problems present barriers to the PLTB continuing TB treatment, and, jointly with the PLTB and his/her family, to find a way to address them. To do so, the health worker and the PLTB need to develop a partnership and mutual trust. Although it may be that not all problems are resolved by the health system, as they vary in their nature – social, financial, behavioural and structural – joint attempts to understand and overcome them greatly contribute to the PLTB developing a positive attitude towards treatment.

7.1.4 Appropriate socio-cultural responses

PLTB come from varying background, so it is imperative that health workers discuss their cultural, religious, and other personal beliefs with regard to TB. The beliefs held among the community and individuals including the PLTB and his/her family

members often present barriers in TB treatment, and in many instances huge disrespect to PLTB and their family in workplaces and the community, which can be deleterious to successful treatment completion without appropriate responses. I also found that health workers tried with good intentions to address some of these beliefs, but in doing so often failed to respect the long-held beliefs of the PLTB, and consequently no positive change occurred. I also found that an understanding of the PLTB's socio-cultural background helps to predict social and family support provided to PLTB during TB treatment. Other studies have drawn similar conclusions (Sagbakken *et al.*, 2007; Kirwan *et al.*, 2009).

7.1.5 Supervision and patient support

In the light of my findings and the local context I see supervision and patient support as an approach to patient support that identifies and tries to address barriers that hinder successful TB treatment completion. This approach requires mutual respect between the PLTB and provider and should be implemented in ways that permit supervision and patient support to be tailored to the needs of PLTBs in the context where treatment is being provided. To develop and implement the approach, it is imperative to establish a mutually acceptable partnership between the health worker(s) and the PLTB which will then facilitate identification of barriers that could hinder successful TB treatment completion, and of appropriate solutions. During my study I identified various issues which could be addressed using this approach: for example, where context-specific treatment supervision is appropriate, the programme can use a reliable family member or community volunteer supervisor, or self-administered treatment, after ensuring that the PLTB understands the importance of treatment continuation and that monitoring measures are in place. Where necessary, based on the needs of the PLTB, the programme should consider provision of other support: e.g. nutritional supplementation during TB treatment; support for travel costs; social support to the PLTB during and after completion of TB treatment; or child care during the treatment period.

7.1.6 Appropriate interpersonal communication

That is health information tailored to the PLTB's needs and context. For this, a mutually acceptable relationship between health worker and PLTB is crucial. It is important to assess information needs at different times. For example, a majority of the PLTBs who participated in the study were in shock when they heard that they had

TB, and imparting detailed information on TB and treatment at this stage may not be useful. Understanding the different information needs at different stages of treatment is essential. There is ample evidence suggesting that PLTB generally comply with information provided if the health communication is tailored to the information needs, is provided in participatory manner and the PLTB helps make the decisions and chooses the solutions to problems rather than being told what to do. To do this, health workers need to create a conducive environment where communication can take place with no interference.

7.1.7 Care with respect and dignity

I found that for successful treatment completion it is vital to provide quality TB care in a dignified manner irrespective of resources, gender, caste, ethnicity, age, language, religious beliefs, sexual orientation, culture, or having another illness including HIV. TB services need be delivered without stigma and discrimination in health care settings, communities and workplaces. It is equally important to extend this respect to family members, as they are very often the main providers of support to the PLTB.

7.1.8 Individual privacy

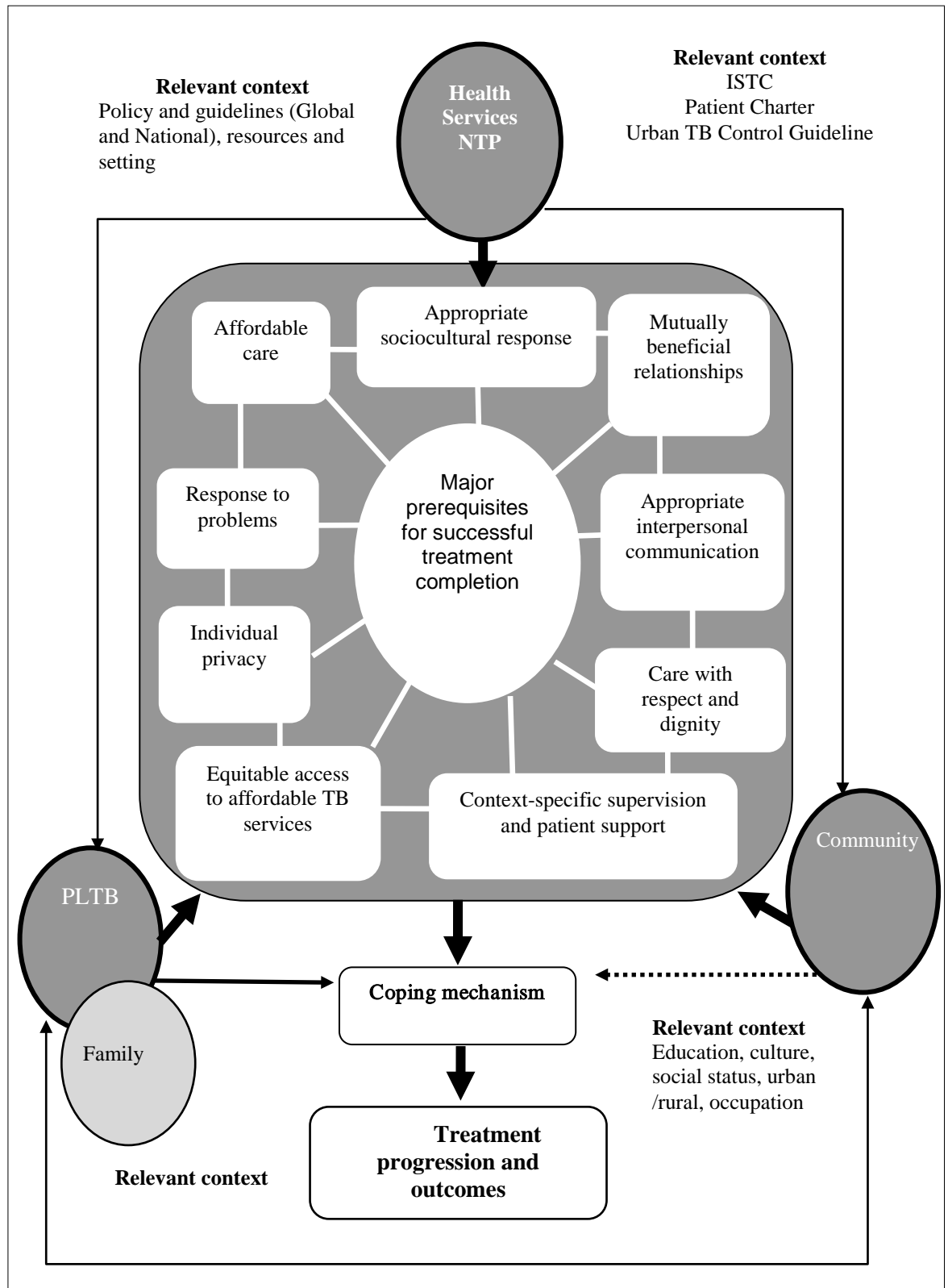
I found poor confidentiality of information about PLTB in DOTS centres and elsewhere. In the face of stigma and discrimination, health workers need to consider the privacy of each PLTB. Any information collected that may be disclosed for public health reasons must be with the PLTB's consent: in obtaining consent, the purpose of gathering the information and its potential use needs to be properly explained to the PLTB. Many PLTB would not like personal information to be disclosed: this wish needs to be respected by health workers and should not affect PLTBs' treatment. Health workers therefore need to keep all medical records confidential.

7.1.9 Mutually beneficial relationship

I found that successful treatment completion will not be achieved in the face of a poor relationship between the health care provider and the PLTB. In my study, it was often the case that PLTBs were passive recipients and health workers always controlled the overall treatment process. Health workers need to think innovatively about how a partnership can be established so that the PLTB and health workers can benefit from achieving successful treatment completion. In developing partnerships with PLTBs,

health workers should also consider engaging family members of PLTB so relationships are strengthened and continued.

Figure 17: The revised conceptual framework



The revised framework brings the family member close to the PLTB – a big change from the original framework - as support from the family appeared to be crucial at every stage of TB treatment. Likewise, a vital role is played by context such as national and international policy and guidelines, and in particular, the NTP urban TB control policy, the ISTC, the Stop TB strategy and the Patient Charter for TB Care. Three key players, the NTP, the community and the PLTB and his/her family play vital roles in establishing the major prerequisites for successful treatment completion, so meaningful contributions are needed from all three players. To do so they need to interact and be engaged in designing the implementation plan. The major prerequisites presented in the framework are interdependent. I found that the absence of any of these prerequisites will affect successful treatment completion: so effective implementation of all prerequisites is needed to help reduce the burden on PLTB and their families, thus maximising the likelihood of successful treatment completion.

In conclusion, there is a strong case for putting PLTBs at the centre of TB service delivery to achieve successful treatment completion and patient satisfaction. The identified prerequisites in the revised framework (Figure 17), when implemented effectively, should help develop more patient-centred care in the NTP. It will increase access to affordable care and motivation of PLTB, promote shared decision-making practices and ownership of the decisions made, foster a mutual partnership with service providers and enable development of more responsive TB service delivery in addressing PLTBs' preferences during TB treatment. However, there are many challenges to successful implementation of patient-centred care in the current NTP setting: limited resources and capacity; increasing numbers of urban migrants from various parts of the country and lack of familiarity among TB service providers of different cultural beliefs relating to TB across different social statuses; language barriers in communication; and unclear roles of stakeholders engaged in urban TB control programmes. In addition, practicing a patient-centred approach in TB clinics also requires development of a locally feasible guideline, not only for health service providers, but also for PLTBs and their families, to empower them to ensure appropriate care. I do not therefore suggest a fundamental transformation of TB service delivery operations in the existing NTP. Instead, I suggest, a carefully planned phase-wise move towards patient-centred care through implementation of the identified prerequisites. It is however, important that perceived freedoms under a more patient-centred approach should not compromise the service quality and fundamental

essence of TB control such as the use of microscopy in diagnosis and follow-up; the use of standard drug regimens; regular intake of TB drugs; and other standards of care. In TB control globally there is a strong desire to promote standards of TB care, emphasised through publication of the ISTC which sets 21 standards of TB care, of which 7 are standards for treatment. This has initiated a debate within the NTP: whether the NTP should focus on the standards or the targets or both equally. The Nepal NTP has adopted the ISTC in principle thus committing to the standards; but existing service delivery is not well focused on the standards of care. On the other hand, the programme is guided by its targets and strives to achieve them, an approach which often undermines the standards of care. Both standards and targets are important, but it is however difficult for the NTP to immediately shift its intervention development from a focus on targets to a focus on standards of care. Making a shift will require considerable planning backed up by adequate resources.

7.2 Implementation framework

The implementation framework that follows aims to implement the revised conceptual framework within the contexts of urban TB control in Nepal and of the existing policies of the Nepal NTP. The implementation framework may also be relevant to other settings with similar contexts: however, the aim of my study was not to identify a generalised model.

It is fundamental that public health programme policies and interventions aimed at improving people's health and wellbeing need to be supported by effective implementation frameworks that take into account the local context; the broader social determinants of population relating to health; the target beneficiaries and their needs; the availability of resources; the socio-cultural context; health system structures and health service delivery strategies; existing policies and practices; and frameworks to monitor the effectiveness of intervention implementation. Only then can an implementation framework be implemented effectively. Note that by 'implementation framework' I mean an approach to help translating study findings into policy and practice. It is not, however, a fixed implementation design, but rather should be seen as an interactive and flexible framework that may change as implementation progresses and lessons are learned.

The proposed implementation framework, Figure 18, has four key parts: their features are described below.

7.2.1 Policy

It is imperative to revise the existing NTP policies and guidelines, and in particular those that relate to TB service delivery; TB treatment management; and the urban TB programme. Revision of the policies and guidelines need to be in line with contemporary national and international policies and guidelines and the findings of this study. Policy revision should also consider lessons learned during the ten year course of the urban TB control programme and the local context of urban areas: growing urbanisation, increasing inequalities in health service delivery and utilisation in urban areas, increasing urban poverty and various social determinants of urban health. It is also important that the policy revision reflects the essence of the Nepal Health Sector Programme Implementation Plan, which calls for effective EHCS delivery with a focus on poor and socially excluded groups, regardless of (urban/rural) location. To best improve TB services for currently unreached population groups, the policy revision should incorporate the ideas included in the recently developed Gender Equality and Social Inclusion Strategy in Health. The policy revision should also take into account the multiple stakeholders in urban areas, including the local PPP model (Newell *et al.*, 2006), and health care providers who provide services to the poor and excluded (Malmberg *et al.*, 2006), and define their roles and responsibilities in the light of their institutional and individual roles as health service providers. As I stated earlier, policy revision is not a one-off process, but should reflect lessons learned as implementation progresses; thus the arrows in figure 17 suggest the interactive and reflective features of the implementation framework. My study findings suggest that in the past PLTB and community members have not been involved in the policy development/revision process. However, it would be a mistake not to get their input into future policy revisions as they will bring insights into developing locally feasible approaches based on their first hand experience dealing with TB diagnosis and treatment.

7.2.2 Implementation plan:

Another key step in the framework is to develop a detailed implementation plan in line with the policy revisions. The following steps should be included in the process of developing the implementation plan, to ensure the plan is feasible and effective.

(a) map existing and potential health service providers in the area, including providers of services to the urban poor and excluded (Malmborg *et al.*, 2006) to guide the development of a feasible plan.

(b) map available resources, including existing and potential resources (including locally identified resources) to ensure the plan is fully funded. A cost sharing health financing approach with a focus on reaching the poor and excluded should be considered in this exercise if appropriate in the context.

It may not be feasible to implement the plan across all urban areas simultaneously, so stepwise implementation should be considered, along with an explicit process of incorporating lessons learnt from each step. It is worth repeating that it is essential to fully engage PLTB and community members in each step.

7.2.3 Service reform:

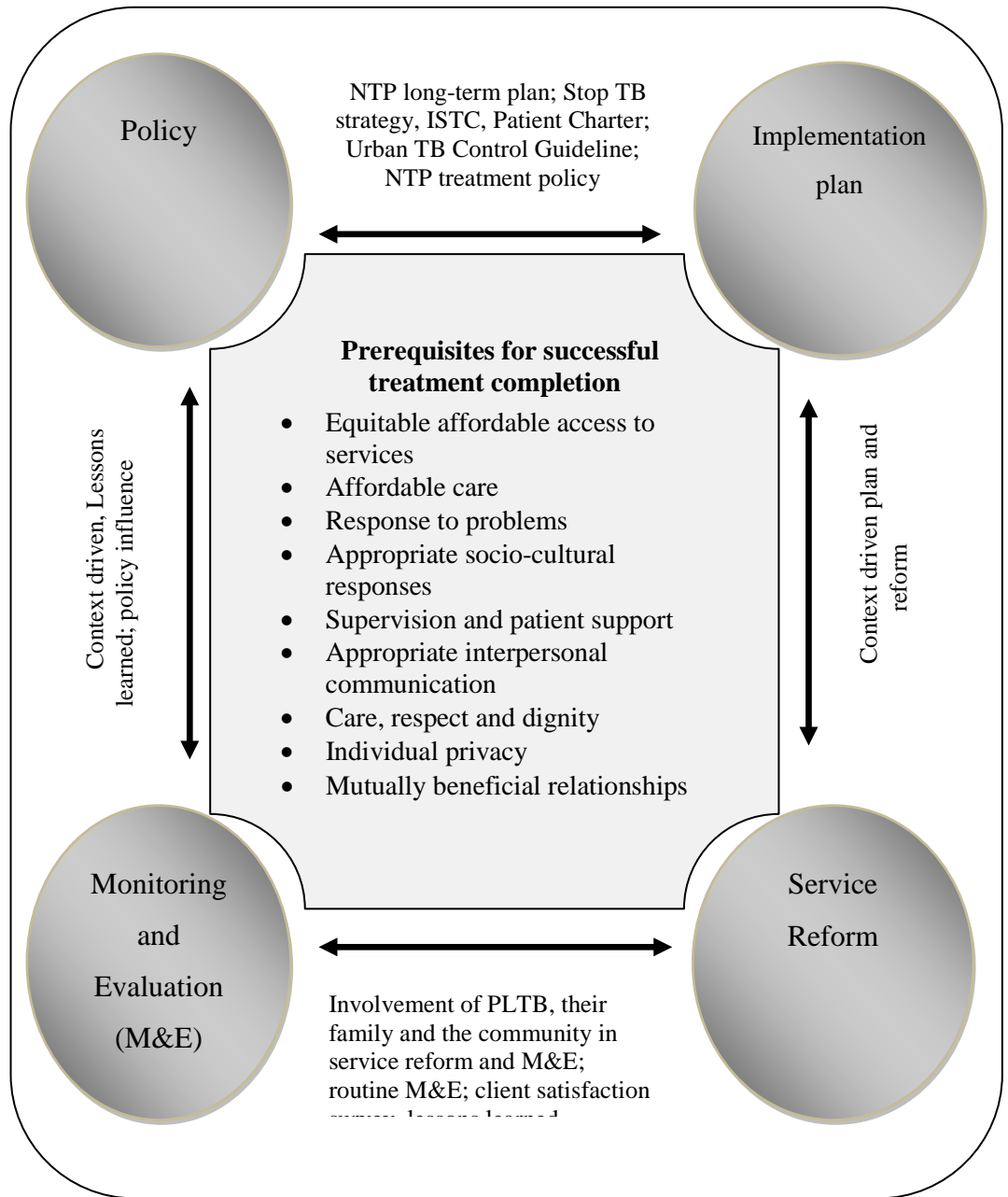
At the outset, I should make it clear that I do not foresee a major health service reform as envisaged by the MoHP in Nepal and elsewhere: rather I suggest a simple modification of existing TB service delivery in urban areas which has been there for many years, largely unchanged despite the emergence locally of better information and elsewhere of innovative approaches. Before actually planning a reform, there must be a clear understanding of what people want from health service providers, health service mechanisms or the broader health system, as appropriate. My study suggests that what people want is the best possible standard of affordable care, accessible to all, regardless of individual characteristics or any conditionality. Although my study focused on TB and PLTB, this may also apply to other programmes. I therefore suggest TB service delivery reform needs to be aligned with the prerequisites identified and discussed in 6.3, the revised conceptual framework, and the revised policy as discussed earlier in this section. Simple changes to existing TB service delivery mechanisms would reduce the burden on PLTB and their families, and in many cases health care providers, thus contributing to successful treatment completion. For instance, the relationship between health care providers and PLTB could be redefined, and appropriate ways found to develop partnerships through

strengthened relationships. This would not create substantial additional costs for the programme. In this service reform area, I suggest the programme looks at the existing barriers that hinder PLTB in diagnosis and treatment and find possible ways to address them by changing services as appropriate taking the local context into account. The service reform should be seen as a series of ongoing, routine improvements in the programme, rather than one off reform or reform at fixed intervals. Small changes in service delivery mechanisms to improve TB service delivery need not wait a long time. As I mentioned previously, when planning even simple TB service reforms, involvement of PLTB and community members is vital.

7.2.4 Monitoring and evaluation:

It is important that any intervention is periodically and frequently assessed with effective monitoring and evaluation measures: this must be properly embedded in the programme so that lessons learned during monitoring can be used to improve the intervention. Since monitoring and evaluation not only describes outputs and outcomes, but also guides further improvements, it is vital to ensure the participation of PLTB, their families and community members in the process of evaluating the intervention, so that any resultant changes are acceptable and affordable to PLTB. I believe that findings from evaluation of the intervention would inform policy revision, so that the programme could further advance in developing patient-centred care in TB service delivery.

Figure 18: Proposed implementation framework for successful TB treatment completion



7.3 The study's contribution to the body of knowledge

My study area was not novel and unexplored, as there have been many studies relating to treatment completion for TB and other diseases. However, the context in which my study was performed was different: to my knowledge, there has been no such study of Nepal's urban TB control programme previously. Thus my findings have contributed to the knowledge base on urban TB control.

Several studies have identified the need for further research in this area, to deepen understanding on *why* and *how* poor treatment completion presents a continuous threat to modern TB control. This need has intensified in the light of the increasing emergence of drug resistant TB (Shah *et al.*, 2007) and its association to poverty. My study may be seen as a response to this call.

My study findings demonstrate that successful completion of TB treatment in the context of urban Nepal was not straightforward for many PLTB. Despite ongoing difficulties, PLTB continued their treatment and a majority of them completed the full course of treatment according to NTP policy. The issue of *why* and *how* PLTB were able to overcome the difficulties that arose during TB treatment was investigated in depth. It became completely clear that PLTBs' families' untiring efforts and support greatly facilitated the treatment process, regardless of the socio-cultural, financial and education status of the family. I also identified that this mutual support occurred not only during the illness but beyond the period of treatment, despite the devastating impact of TB on the entire family. I believe this finding highlights the need to redefine the role of family members in PLTBs' treatment: this has been overlooked in many NTPs including the Nepal NTP, despite evidence of the effectiveness of properly involving family members in treatment (Newell *et al.*, 2006).

There have been many studies which identify non-completion as a pressing issue in controlling TB: however, very few addressed *how* this issue could be tackled through establishing locally feasible patient-centred care with no major modification in existing TB control procedures. My study presents a framework which aims to reduce (and ultimately eliminate) obstacles encountered by PLTB and their families during treatment through establishing basic prerequisites in NTP. In the setting where I conducted my study, the prerequisites could be implemented through simple modifications to the existing TB service delivery setup.

My study also demonstrated that the problems encountered by PLTB include not only access to TB services, but also the absence of essential health care

services to address minor illnesses that occurred during TB treatment. Thus, the study gives evidence that it is essential to integrate TB care and comprehensive essential health services in urban areas, if TB control programme is to achieve its aim of reaching the unreached, and in particular the urban poor including migrants.

7.4 Uptake of research findings during research

During my doctoral research, I worked closely with the Nepal NTP. My involvement ranged from writing funding proposals for the entire programme to providing technical support in policy development and research. My ongoing involvement provided me with opportunities to disseminate some interim findings from my research, and encourage their adoption into policy. I note here some specific contributions I made to the Nepal NTP that arose from my doctoral research, which facilitated not only the urban TB control programme but also the entire NTP.

- Development of urban TB control programme guidelines: In collaboration with the NTP I took an active role in conceptualising and developing the guideline which have been adopted by the NTP and used throughout the programme. The stakeholders welcomed the urban TB guidelines and have started using them as appropriate to their local contexts. Following insightful comments from stakeholders after initial implementation, I am engaged with the NTP in ongoing revisions of the guideline.
- Revision of NTP manuals and training materials: I took the opportunities presented by period revisions to ensure my research findings were incorporated. Despite a degree of reluctance among the NTP authorities to move from a conventional TB control approach, my engagement in revision of the NTP policy and educational materials influenced incorporation of local learning. Although not all the local knowledge was included, this was a welcoming shift towards an approach to address PLTBs needs.
- Scaling up of TB services in urban areas of Nepal: Although the focus of my study was in the urban setting of Kathmandu, my involvement with the NTP contributed to scale-up TB services in other cities of Nepal.
- Securing patient support in NTP funding: During the study period, I actively contributed to developing funding proposals for the NTP to the Global Fund, which were successful. In the proposals, I influenced the NTP authorities to

consider financial support to people with MDR-TB for transportation and accommodation, which is now being implemented for all MDR TB cases.

My experience over the years tells me that long-term, meaningful engagement is essential for researchers to be able to influence policy through research. Note that long-term engagement and support to the NTP would not have been possible if I had only been a doctoral research student. Research uptake to policy and practice would have stopped had I not received support for further research and development from other sources. During the time of my doctoral research I therefore set up a research and development NGO primarily focusing on TB research in Nepal, through which I was able to work with researchers from the Nuffield Centre for International Health and Development, University of Leeds, UK, who in particular facilitated guidance and funding for other related research. Thus, although it would be unfair to attribute all research uptake to my doctoral research project, there is no question that it provided a significant opportunity for me to influence policy through my research findings.

7.5 Further research

During the course of my research, a number of possible areas for further extensions to my research have emerged.

One such research area is to assess the intervention suggested by the revised conceptual framework and the proposed implementation framework and deepen understanding of its effectiveness in reducing barriers to successful treatment completion. Evaluation, using mixed quantitative and qualitative methods, would further aid understanding of obstacles to successful treatment completion.

The study findings demonstrated that the urban poor, and especially economic migrants, had major difficulties overcoming the many obstacles they encountered, due to their poverty and the complexity of their positions in society. Further research focusing on the poverty dimension of successful TB treatment completion would provide additional insight to help the urban TB control programme reach the poor and vulnerable.

Finally, the study found that health service delivery in urban areas is complex due to multiple providers, and undefined roles and responsibilities. Further research is needed that looks at how the burden of all PLTBs' illness (including but not restricted to TB) could better be tackled in the context of this complex but incomplete web of basic health care delivery in urban areas.

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ANNEXES

Annex 1: In-depth Interview Guide (PLTB)

Preparation

- Arrange interview location and seating as comfortable to the respondent
- Check recorder if the respondent consented to record the interview
- Read the context, if any external interferences seen try to avoid them
- Welcome & greet respondent and say thank you for participating in the interview

Introduction of interviewer: I am Sushil Chandra Baral, a PhD student at the Nuffield Centre for International Health and Development, Leeds Institute of Health Sciences, University of Leeds, UK. I live in Kathmandu.

Background information: I am conducting my PhD research on “Tuberculosis treatment completion in urban areas of Nepal”, in urban areas of Kathmandu Valley: Kathmandu and Lalitpur. I am trying to understand views and experiences of people with TB about their illness and treatment and whether any problems or issues have affected their treatment and their lives. I hope that what I learn from you will help in the design of a patient-friendly TB service delivery to improve TB treatment with no or reduced problems to people with TB and their families.

Confidentiality and recording: Your participation is completely voluntary and this interview is strictly confidential. Your name will be kept completely separate from the information you give, so please feel free to speak openly.

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. Nobody except myself and my supervisors will hear this recording and after the interview I will write down everything that was said on to paper and delete the recording.

Is that ok? YES/NO (ask respondent)

If you do not wish your interview to be recorded, it is also fine. I will take notes but the interview time may be extended by 10 to 15 minutes.

Terminate the interview if the respondent does not want to be interviewed or not feeling comfortable, or not answering the questions asked.

If the participant agreed to take part:

Procedure: Explain that - you have agreed to participate in the study by giving an interview. Now I am going to start with a few questions about your experiences, feelings and thoughts regarding your illness and treatment. The interview will take about 45 minutes to an hour. Everything you say is strictly confidential so 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 I shall move on to next. 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? (ask respondent)

KEY INTERVIEW QUESTIONS

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

(Note down: age, ethnicity & caste, place of residence, occupation, marital status, level of education and household composition. If these don't come up spontaneously, ask when appropriate)

- Tell me about your illness.
- Tell me what you experienced while seeking care and diagnosis of your illness.
- Tell me about your treatment process.
- Tell me how you experienced your treatment.
- Tell me how you were treated, perceived by health workers, family members, community members, relatives, friends, colleagues, employer etc.
- Tell me about any support that you received during your treatment and your views on why they supported you, if any.
- Tell me how you find TB services in this DOTS centre.
- Tell me what concerns or worries you have regarding your TB treatment.
- Tell me about the major problems/difficulties that you are facing in your treatment.
- Tell me how you have been managing problems or difficult situations in order to be able to stay in treatment.
- Tell me if you have any suggestions to the programme to make your remaining treatment easier.

Ask other questions on the issues raised by the respondent.

Note: always remember to ask probing questions such as why things happened so; why she/he thought so; why he/she did so; what happened as consequence of what; why this why not that – in asking probing questions constantly think of the issues raised by the respondent and put questions appropriately as relevant to the topic of discussion.

In the end of interview: 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.

Annex 2: Focus Group Discussion Guideline (PLTB group)

Research Title: Tuberculosis treatment completion in urban areas of Nepal

Selection of team

FGD team will include a maximum of 3 members: Facilitator, Rapporteur and a supporter. The facilitator will facilitate the discussion, rapporteur will help recording the discussions and observations, and a supporter will help with registration and arranging refreshments.

Selection of participants

FGD will be conducted with people with TB who are continuing treatment from urban DOTS centers of Kathmandu and Lalitpur districts. Efforts will be made to make the group homogenous i.e. male group, female group, migrants.

Location, Time and Date

Participants will be well consulted about the FGD location, time and date. Appropriate locations will be identified taking into consideration the local context, distance for participants, feasibility and external interferences. Efforts will be made to identify a training hall nearby the DOTS centre. If a training hall with adequate space exists in respective DOTS centre, which can be considered for FGD venue. Seating arrangements will be informal. Each FGD will take about 1-2 hours.

Conduction of FGD

The following steps should be considered while conducting FGD:

- Rapport building and introduction: set up group at ease, introduction between participants and FGD team, explain the purpose of FGD;
- Phrase the questions carefully. Ask open ended question e.g. what problems did you face during your treatment? And why, when?
- Use probing techniques such as: repeat the question, give some clues to understand the issues and ask in details, pause for the answer, repeat the reply- it helps to stimulate conversation, ask why-questions for more detail information, use neutral comments- anything else? Why do you feel in this way?
- balance the discussion: in groups some participants can dominate the discussion. Therefore to balance out the participation and discussion the following measures could be applied: address questions to individuals who are not participating in the discussion; give non verbal clues; summarize the points and refocus the discussion; give thanks for giving ideas/sharing experiences and move to another topic with their consent.

- Consider the following activities at the time of discussion: Coding of each participants like 01, 02...and so on; note taking regarding what was said by which code no. of participant etc
- Rapporteur will be placed at visible place so that he/she can identify what is missing as per discussion guideline and will indicate to the facilitator.

Major areas discussed

The following topics will be discussed, but not limited to: experience of participants with illness; issues that hindered or helped PLTB during their treatment; stigma and discrimination related to TB in community, family and institution; self-motivation and feelings about their illness; support gained from – health workers, family, relatives, friends and colleagues, and community members; provision of existing TB treatment delivery modality especially on DOT and their experiences; information and communication with regard to their disease and other causes; behaviour of service providers, family members and community people; factors that hinder PLTB in continuing their treatment; what could be done by the programme to reduce the burden on PLTB during the TB treatment.

Recording of discussion

The following activities will be carried out to record the FGD:

- Note taking will be done reflecting the discussion as well as non verbal behaviour like facial expression, hand movement etc.
- After finishing each FGD, information and team's expression will be summarized
- Discussion will be reported in participants' language including their phrases

End: discussion will end by giving a big thank you to the participants for their participation and time. Refreshments will be served after the formal closure of the discussion.

Annex 3: Information Sheet

Research Title: Tuberculosis treatment completion in urban areas of Nepal

Introduction

I am Sushil Chandra Baral, a PhD student at the Nuffield Centre for International Health and Development, Leeds Institute of Health Sciences, University of Leeds, UK. I am conducting my PhD research on “Tuberculosis treatment completion in urban areas of Nepal”, in urban areas of Kathmandu Valley: Kathmandu and Lalitpur. This information sheet will tell you about my research. Please take your time reading it or if you prefer I can read out for you. This information sheet may contain words that you may have

difficulties to understand. Please ask questions and I can explain you. If you wish you can talk the information sheet over with others.

What is the purpose of the study?

The study is to understand experiences, problems and issues faced by People Living with TB during their treatment. It also looks at the various coping strategies and responses to the problems in order to be able to identify better ways of addressing the issues in the given programme. The study aims to contribute to the National TB Programme to design and implement a patient-friendly TB service where people with TB can continue and complete their treatment with fewer problems.

Why have I been chosen for the study?

You have been taking TB treatment from this DOTS centre and you can more easily explain problems and issues that you are experiencing during your TB treatment.

What happens if I agree to take part?

If you agree to participate, you will be asked to give an interview, which will take about 45 minutes to an hour. I will conduct the interview. You can choose the interview location as you like. If you do not wish to answer any of the questions during the interview, you may say NO and I will move on to the next question. No one else but you and I will be in the interview unless you would like someone else to be there.

What happens if I refuse to take part or withdraw?

Your participation in this research is completely voluntary. It is up to you whether you take part or not. You are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not in any way affect the services you receive from this and any other DOTS centres.

What are the benefits of taking part?

If you participate in the study, you will help us to understand effective ways of addressing problems and issues that may have been hindering or helping people with TB during their treatment. There are no direct benefits to you but this study hopes to improve the care of people with TB like you in the future.

What are the possible disadvantages and risks of taking part?

There are no added risks involved in participating in this study. However, there may be a risk that you may feel uncomfortable talking about some of the questions. You do not have to answer any question or take part in the interview if you feel talking about them

makes you uncomfortable. Whether you agree or not to answer the question it will make no difference to the services that you have been receiving.

Will my participation in the study be kept confidential?

Yes. Your participation in this study will be kept private and confidential and any information you share with us will also be kept private and confidential. Any information about you will have a number instead of a name to maintain confidentiality.

What will happen to the findings of the study?

The study findings will be published in my PhD thesis. The findings will also be published in journals but you will not be identified or identifiable in any publications. I hope the findings will help to design and implement a people-friendly TB care in the National TB Programme.

Who is paying for the research?

I am paying the cost for this study. No additional funding has been received for this study.

If you have any questions at any time please contact: Mr. Sushil Chandra Baral, PO Box: 24133, Kathmandu, Nepal. Tel: 977-01-4238045, Fax: 977-01-102016.

Email: sushilbaral@hotmail.com

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Annex 4: Consent Form

Research Title: Tuberculosis treatment completion in urban areas of Nepal

The following should be read by or read to the participant and the participant should indicate whether they agree with each part of the consent form.

- I understand the purpose of this research
- I have had the opportunity to ask questions or raise any concerns about the research
- I am satisfied that my questions and concerns have been answered adequately
- I understand that I will participate in an interview that will last for about an hour
- I understand that my participation in this research is completely voluntary
- I understand that I am free to withdraw from the research without repercussions
- I understand that I can halt the interview at any point if I feel uncomfortable
- I understand that all information I give will be kept confidential
- I give consent for this interview to be tape-recorded
- I agree to take part in this research

Participant signature

If verbal consent obtained

Signature of witness.....

Witness name

Date and time consent given