Gender differences delays in initiating tuberculosis treatment among tuberculosis patients, Far-Western Development Region

CHAPTER I

INTRODUCTION

1.1 Background

Tuberculosis (TB) is a bacterial disease caused by the bacillus *Mycobacterium tuberculosis*. After TB infection occurs, most individuals carry the tubercle bacilli inside the body, but bacteria are in small numbers and are dormant. These dormant bacteria are kept under control by the body's defenses and do not cause disease. Disease occurs only when the tubercle bacilli in the body have started to multiply and become numerous enough to overcome the body's defenses (World Health Organization [WHO], 2004a). The most important source of infection is the patient with TB of the lung, or pulmonary TB (especially sputum smear positive TB), and who is coughing. Coughing produces tiny infectious droplet nuclei. An individual's risk of infection depends on the extent of exposure to droplet nuclei and his or her susceptibility to infection.

1.2 TB situation worldwide

TB remains a threat to the health and well-being of people around the world. Among infectious diseases, TB remains the second leading killer of adults in the world. Today, TB is estimated to cause about 1.64 million deaths (1.08 million men and 0.57 million women), and 8.74 million new cases yearly. Of these estimated TB cases, 3.6 million cases, of which 1.5 million were new sputum smear-positive, were reported to the World Health Organization (WHO) in 2000. The male to female ratio of reported cases in most countries is about 2:1 (WHO, 2002a; WHO, 2002b). The extremely high male to female ratio of TB patients in developing countries has yet to be explained. It is estimated that of the approximately six million women with TB at any given time worldwide, at least one-third die because they are undiagnosed or receive inadequate treatment. This means that more than 2,700 women die from TB each day (WHO, 1996).

1.3 TB situation in Nepal

In Nepal, TB is one of the major public health problems. About 60% of adults and 45% of the general population have been infected with the disease. Nearly 80,000 people currently have TB, with more than 40,000 new cases arising every year (National Tuberculosis Control Programme [NTP], 2003). About half of these have infectious (or sputum smear-positive TB) and continue the chain of transmission. Reported rates are higher in men (79/100,000) than women (40/100,000) (Ministry of Health [MoH], 2004), possibly because adult men are more

frequently exposed to infection than women, possibly because women have less access to health care services than men. About 5,000-7,000 people continue to die from TB every year (MoH, 2004). The reported death rates among new smear positive pulmonary male and female patients from TB are 5.8% and 5.0% respectively (NTP, 2003). It has been estimated that without treatment, nearly 190,000 people would have died from TB in Nepal over the next ten years (MoH, 2004). In Nepal, DOTS was initiated in 1996 and 100% DOTS coverage reached at the end of 2001 (NTP, 2003). The national case detection rate was achieved at 70% and treatment success rate was at 87% (NTP, 2005).

1.4 Statement of the problem

The goals of TB control are to reduce mortality, morbidity, and transmission of the disease, while preventing drug resistance, until TB no longer poses a threat to public health. It also aims to reduce human suffering and the social and economic burden which families and communities have to bear as a consequence. To achieve this, it is necessary to ensure access to diagnosis, treatment and cure for each TB patient and to protect vulnerable populations from TB and its drug resistant forms (WHO, 2002c).

Early diagnosis and prompt effective therapy form the key elements of the tuberculosis control programme (Enarson, et al., 1996). Delay in diagnosis results in increased infectivity in the community, and it is estimated that an untreated smear-positive patient can infect, on average, 10 contacts annually, and over 20 during the natural history of the disease until death (Styblo, 1991). Delay in tuberculosis diagnosis may also lead to a more advanced disease state at presentation, which contributes to late sequelae and overall mortality. Smear-positive cases are more likely to infect other individuals. Various studies in the different parts of the world showed that delay in diagnosis may worsen the disease, increase patient expenditure, increase risk of death and enhance TB transmission in the community (Styblo et al., 1973; Olumuyiwa et al., 2004; Zafran et al., 1994; MacIntyre et al., 1995; Bustamante-Monties et al., 2000). Factors affecting delays in diagnosis identified in studies worldwide include gender, age, education, poverty and access to health care, and low level of knowledge and awareness about the disease (Lawn et al., 1998; Sherman et al., 1999; Wandnalo & Morkve, 2000; Yamasaki et al., 2001).

Gender differences in delays

Long diagnostic delay among women has even more adverse effects, as the health and welfare of children and other family members are closely linked to that of the mothers

(Hudelson, 1996). Therefore, reducing delays in TB health seeking and diagnosis is especially important among women.

Published studies report inconsistent findings about differences between men and women in delays. The overall trend shows that delays to TB diagnosis for women are longer than men. A study conducted in Vietnam and Japan reported that the mean total delay was significantly longer among women than among men (Long et al., 1999b; Niijima et al., 1990; Hooi, 1994) but there was a report of no gender related differences in total delay in Australia (Pirkis et al., 1996).

Studies from Ghana and Japan revealed that doctor's delay was also significantly longer for women than men (Lawn et al., 1998; Sasaki et al., 1995). Several studies have shown that even settings where more women than men present for care; they experience longer provider delays (Long et al., 1999b; Needham et al., 2001, Thorson et al., 2000). Perhaps this is a reflection of different gender roles in different societies and/or differences in TB diagnostic performance of health workers between the study settings.

1.5 Rationale

In countries like Nepal, both men and women may suffer from social inequality, poverty, and deprivation, but women are even more disadvantaged. In most developing countries, women are disproportional among the poor, have a low social status, and have less access to education as well as health care. In most of the low income countries, notification rates of pulmonary TB for males are nearly always higher than that for females (Borgdorff et al., 2000). The true magnitude of male excess for pulmonary TB is very difficult to quantify, partly because case detection in most prevalence surveys is by sputum microscopy, which appears to be less sensitive in detecting TB in women than it is in men. Questions and debate persist about whether the male preponderance for TB stems more from biological/genetic gender differences or more from socio-cultural gender differences (Thorson et al., 2000; Borgdorff, Maher, 2001; Thorson, Long, 2001). Several studies suggest that women face more barriers to opportune TB treatment than men do. There may be undiscovered huge reservoir of active TB cases but due to cultural beliefs, women would be less likely to seek TB treatment than men would (Sumartojo, 1995). Very few studies have looked at the gender differences in relevant socio-cultural factors, and little evidence is found on the potential impact on improving TB control programmes by increasing access to health care for underprivileged people (Liefooghe et al., 1999).

TB is one of the most significant health problems facing Nepal, infecting over 60% of the adult population. Every year 40,000 people develop active TB, of whom 20,000 have

infectious pulmonary TB, and can spread the disease to others (NTP, 2003). Remarkable achievements have been made by the NTP by sustaining treatment success rate above 85% among those who presented voluntarily to the DOTS centres, and expanding the DOTS throughout the country. However, to our knowledge, there was no attempt to examine the help seeking behavior of the TB patients before getting into the DOTS system. Our study aim was to provide the baseline information about the magnitude and risk factors for delay in the diagnosis. This would be useful in estimating the impact of the DOTS strategy over time, as well as for developing appropriate strategies to reduce patients and health system delays.

Rates of TB are generally high across the countries of south-east Asia, where TB accounts for between 4.3% and 7.2% of total deaths (WHO, 2003a). Demographic questions here are especially concerned with a disproportionately high female mortality from TB relative to other world regions (Sen, 2003). Persisting patterns of social discrimination against women and unfulfilled social responsibilities of men underscore diverse and complex relationships between cultural values, social practices, and gender related health and social policy. Widespread stigma targeting people with TB, especially women, further complicates the interactions between this disease and normative gender roles in this part of the world (Hudelson, 1996; Balasubramanian et al., 2004). Almost everywhere, however, dealings 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 ultimate outcome. Public health professionals concerned with TB have long emphasized the role of poverty, living conditions and non-specific determinants of health. In 1921, Allen Krause, director of the TB laboratories at Johns Hopkins, noted: "The solution of the TB problem is partly dependent on the removal of other evils and inequalities which constitute, no doubt, a more fundamental problem than does TB itself." (quoted in WHO, 2004). Various extraordinary social stressors, such as war, conflict, insurgency, migration, imprisonment, and forced labour may also potentiate the spread of TB in affected countries and communities, with gender-specific effects on both men and women.

Nepal has a high TB case-notification rate, with an estimated annual incidence of TB patients of 211 per 100,000 populations (Dye et al., 1999). This is on a par with countries known to have a high burden of TB (Dye et al., 1999), and indicates that the TB burden in Nepal is very serious, as is the case in many other developing countries. According to WHO, the male to female ratio of registered TB patients in Nepal is higher for men, at 2.3:1 (WHO, 2004b). However, one study reported that a higher proportion of women with TB detected at a

temporary outreach TB diagnostic camp than at the existing government health facilities (Harper et al., 1996), while another study in Nepal reported a higher proportion of female cases found by active case finding than by self referral, with a male female ratio of only 1.2:1 (Cassels et al., 1982).

These findings suggest that women might encounter difficulties in the case detection process in developing countries, and that a substantial percentage of women with TB might consequently be missed by the existing health care systems. It can also be hypothesized that the pattern of women's utilization of health care providers differs from that of men.

Addressing the challenges of TB control, WHO has recommended the member countries to set the goals of NTP to reduce the morbidity, mortality and break the chain of transmission of TB, while preventing drug resistance, until TB no longer poses a threat to public health. Early case detection in the community is of the highest priority for WHO (WHO, 2003b). Following the WHO and International Union Against Tuberculosis and Lung Disease (IUATLD) guidelines, National Tuberculosis Control Programme of Nepal has developed 10 Year Development Plan (2002-2012) for the control and prevention of TB in the country. Several challenges have been highlighted including gender differences in case detection in the plan (MOH, 2004).

In Nepal, at least twice as many men as women are registered for TB treatment (NTP, 2003). This could be because women are less frequently infected than men, possibly because men are more often in situations where TB infection commonly occurs-frequently because of migration in search of work. It also could be because women also have more difficulty getting treatment. They may have less access to modern health care facilities, and use traditional healers more than men do. Access to modern medical care for women in Nepal is limited by many factors. The key factors would be poor education, distance, poverty, inferior social status, stigma, dependency, and discrimination, gender of health workers, and lack of decision making power, health beliefs, illness behavior and social roles.

The private sector is active and growing, and perhaps 25-50% of patients with active TB are treated by the private sector, and not registered by the NTP (MOH, 2004). Very little information is available about these numbers of patients (Dye et al., 2002). Several studies have revealed that in order to address the concern of poorly regulated private sector in TB control, their effective involvement in NTP is highly required and desired (MOH, 2004.; Rangan et al., 2003.; Hurtig et al., 2002.; Murthy et al., 2001.; Lonnroth et al., 2001a) and should be treated as

a gender issue. Gender issue is highlighted as one of the priority research areas of NTP Nepal (MOH, 2004).

Policymakers need to know which barriers to address first, and where interventions would be best targeted. For example, control programmes are often uncertain about where to target health education messages – at individual level, at families or in large communities. In order to move understanding of barriers to DOTS service utilization to a higher level, this research taps into the enabling and supporting factors within communities that provide the context in which individuals must face and deal with access issues, and ultimately act out their health seeking behavior. Thus, this research moves from an individual view of health care seeking, to an understanding of how communities deal with health system, and how individuals draw on their communities to address health problems.

Published articles have shown that local surveys on knowledge and attitudes towards TB greatly benefit the planning, health education and implementation of TB control programmes. Several health interventions have failed because they were designed without ascertaining any knowledge of the health behavior of the target population (Godin & Shephard, 1983). A serious concern has been pointed out that a great deal of attention is being given to case finding in TB services, because programmes are not yet attaining targets for case-finding in the overall strategy of TB control. Clearly, if we do not find and treat a substantial proportion of existing cases, the strategy of TB control will fail (Enarson, 2003). Therefore findings from this study are useful as evidence to develop specific strategic planning to narrow down the interval between onset of symptoms and start of TB treatment under DOTS strategy. Based on study findings, recommendations are made for countermeasures to improve early case detection and treatment, as a result and these to serve the goal of NTP to reduce morbidity, mortality and transmission of TB.

1.6 Research questions

- What are the magnitudes of delay intervals, and do these intervals differ between male and female?

1.7 Objectives

General objective

- To investigate the gender differences for delay in initiating directly observed treatment, short-course (DOTS), among new pulmonary tuberculosis patients.

Specific objectives

- To investigate the gender differences for patient delay in reaching to first health provider and provider delay in receiving TB diagnosis and treatment.
- To elicit, in qualitative research, whether males and females with tuberculosis have different levels of opportunity to obtain diagnosis and DOTS treatment.

CHAPTER II

LITERATURE REVIEW

A comprehensive search in MEDLINE was conducted using the following key words tuberculosis, delay, help seeking behavior, gender, sex, equity, equality, justice, private sector, traditional healer, and Nepal. In addition, a library search was carried out.

2.1 Delay in initiating tuberculosis treatment and its impact on the community

Most of the countries in the world now apply passive case-finding approach for TB detection. The term passive case finding used here describes such methods for the identification of TB cases where the initiative for an individual patient-health provider contact is taken by the patient (Rieder, 1993). In most low and middle-income countries about two-thirds of reported TB cases are men and only one third women (WHO, 2000), this ratio (male : female) in Nepal was 2:1 (NTP, 2003), and it is not well known that whether this is due to a higher risk of developing TB among men or under notification of TB among women. Analysis of TB notification history suggests the possibility that cases of TB among women are being under-reported in developing regions (Holmes et al., 1998).

The principal reservoir of infection in the community might be the patients with undiagnosed tuberculosis. Delays in the duration between the onset of symptoms (and by proxy the onset of infectiousness) and the start of appropriate treatment will increase the risk of transmission. The contagion parameter suggests that where TB is endemic, each infectious case will result in between 20-28 secondary infections. Strategies aiming to reduce the time between the onset of symptoms and the initiation of effective chemotherapy may impact the infectious duration in the community and thereby reduce the number of new infection. Late diagnosis of pulmonary TB is likely to be associated with a worse prognosis owing to the presence of extensive disease and poor clinical condition. Additionally, and of particular importance from a public health perspective, delay in treatment for active tuberculosis is likely to be associated with a greater number of secondary cases per index case (Styblo, 1991). Research has shown that delay in diagnosis may worsen the disease, increase risk of death and enhance tuberculosis transmission in the community (Olumuyiwa, 2004). One study presented that the duration of symptoms at presentation to medical services varied from 4 days and 3 years, with a median of 2 months for patients of both sexes. They believed that they had malaria or pneumonia, depending on their symptoms (Eastwood & Hill, 2004). Patients have complex patterns of care seeking

behavior that cause diagnostic delay, involving traditional healers, pharmacies, private doctors and health centres. Published studies have shown that some patients use traditional methods and medical services simultaneously, and use more than one traditional healer before presenting to medical services (Eastwood & Hill, 2004).

One of the main objectives of any TB Control Programme is to reduce tuberculosis transmission in the community through early detection of tuberculosis cases and prompt implementation of DOTS. This is particularly important in the case of untreated smear positive patients who are the main sources of infection in a community (Enarson et al. 1996). Delay in diagnosis and start of effective treatment of tuberculosis patients result in a prolonged period of infectivity in the community and health care workers (Mathur et al., 1994). A study showed that 40%-50% death rate occurred for patients admitted to the intensive care unit. This study suggested that a delay in diagnosis and institution of appropriate anti-tubercular therapy are important predictors of mortality for patients with pulmonary tuberculosis (Paolisso & Leslie, 1995).

Long delay to TB diagnosis has adverse effects on the patients; their family members, and society, as well as TB control in general (Mathur et al., 1994). In another study, it has been reported that delay in the detection of TB was the main factor contributing to the death of TB patients (Zafran et al., 1994). A study in Australia on diagnostic delay and transmission of TB in an office concluded that delay in diagnosis was the major factor responsible for the spread of TB in the studied office (MacIntyre et al., 1995). Long diagnostic delay among women have even more adverse effects as the health and welfare of children and other family members is closely linked to that of the mothers (Hudelson, 1996). Therefore, reducing delays in TB help seeking and diagnosis is especially important among women.

There are number of delays in help seeking and diagnosis of TB and start of treatment. "Delay to first health provider" is the time interval from onset of symptoms to the first presentation to any health care provider, including self medication. "Patient's delay" is the time interval from onset of symptoms to the first visit to a hospital or a doctor or a formal public health facility where TB diagnosis is available. "Doctor's delay" or "health care personnel's delay" is the time interval from the first visit to a hospital or a doctor or a formal public health facility to a TB diagnosis. "Total diagnosis delay" is the time interval from onset of symptoms to

TB diagnosis. "Treatment delay" is the time interval from diagnosis to the start of treatment. "Total treatment delay" is the time interval from onset of symptoms until the start of treatment. "Health system delay" is the time interval from the first visit to any type of provider to the start of treatment.

Delays in health care seeking and TB diagnosis, as well as in initiating appropriate treatment have been addressed by a number of studies in different countries. The proportions of patients' and providers' delays, respectively, among total delays are different between settings. Studies suggest that the pattern of different delays is affected by country's geographical, socio-economic, demographic, socio-cultural and health systems.

Table 1: Delays in help seeking of and tuberculosis diagnosis

Place	Measurement	Patient delay	Doctor's delay	Diagnosis delay
Bostswana (Steen & Mazonde, 1998)	Mean	5.1 wks	12.2 wks	17.3 wks
Ghana (Lawn et al., 1998)	Median	4 wks	8 wks	4 mths
Malaysia (Liam & Tang, 1997)	Median	2 wks	7 wks	12.5 wks
Korea (Mori et al., 1992)	Mean	80% of total	20% of total	2 mths
Tanzania (Wandwalo, 2000)	Mean	162 days	23 days	185 days
	Median	120 days	15 days	136 days
New York City (Sherman et al., 1999)	Median	25 days	15 days	57 days
Vietnam (Long et al., 1999)	Mean	7.7 wks	4.2 wks	11.9 wks

Delay from onset of symptoms to treatment initiation from several studies

Place	Measurement	Patient delay	System delay	Total delay
Nigeria (Odusanya O. O. et al. 2004)	Mean	12.3 wks	2.1wks	14.3 wks
Vietnam (Long et al. 1999)	Median	7.7 wks	11.9 wks	11.9 wks
New York, USA (Sherman et al. 1999)	Median	3.5 wks	2.1 wks	8.1 wks
Vietnam (Lonnroth et al. 1999)	Median	3.0 wks	7 wks	9.9 wks
California USA (Asch et al. 1998)	Median			10.5 wks
Tanzania (Wandwalo, Morkve 2000)	Median	23 wks	3.2 wks	26 wks
Gambia (Lienhardt et al. 2001)	Median	0.7 wks	10.6 wks	11.5 wks
South Africa (Pronyk et al. 2002)	Median	4 wks	2 wks	
Zambia (Needham et al. 2001)	Mean			9 wks
Ethiopia (Demissie M et al. 2002)	Mean	78.2 days	9.5 days	88 days

2.2 Gender

Broadly, gender is "what it means to be male or female, and how that defines a person's opportunities, roles, responsibilities and relationships" (WHO, 2004). There is an important distinction between sex and gender as terms for describing differences between men and women, and role of gender as a determinant of health status. Specifically, sex is genetic/physiological or biological characteristics of a person which indicates whether one is female or male (WHO, 2004). Gender on the other hand refers to those distinguishing 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. Gender configures both the material and symbolic positions that men and women occupy in the social hierarchy, and shapes the experiences that condition their lives (WHO, 2004). Gender is a powerful determinant of health that interacts with other variables such as age, family structure, income, education, and social support, and with a variety of behavioural factors. These gender divisions shape the lives of both women and men in fundamental ways. As individuals with particular identities and as member of the society they are shaped and reshaped by their femaleness or their maleness. In one sense then, both women and men are constrained by their membership of particular gender group. But these variations represent more than just a difference. In most societies they are also used to justify major inequalities with those in the category female having less access than those in the category male to a wide variety of economic and social resources like obvious inequality in the distribution of income and wealth, around the world as well as in the Nepal, women make up about 70% of those who are poor (United Nation Development Programme [UNDP], 1995), unequal situation in the labour market, less favorable treatment in most social security systems, many have no access to independent income and those who do earn their own wage receive on average around three quarters of the comparable male salary (UNDP, 1995).

Devaluation of femaleness is a significant element of everyday thinking in many societies (Ussher, 1989). The cultural discrimination is expressed by low status within the household, the relatively low value placed on women and girls by individual families and by society as a whole. Women still outnumber men by two to one among the world's illiterate people and girls constitute the majority of the children without access to primary school (UNDP, 1995). Women's access to political and economic power is not also balanced with their number

and contributions as citizens and in some countries these gender inequalities in power continue to be reflected in the discriminatory nature of the law.

Traditionally, women have had to face much greater health risks; confront many more constraints and make do with much fewer opportunities in trying to resolve their health needs than men (WHO/TDR, 1996). Gender also plays a role, however, in men's health problems-their proneness to accidents, addiction and violence for instance. As they affect women, gender relations reflect power relations: which each category 'woman' and 'man' is a hierarchical ordering of status that leads to inequality in the health and well being of women in relation to men.

2.3 Gender differences in delays

While many studies have addressed delays in TB health care seeking in general, few have analyzed gender differences in delays. Although studies report conflicting findings about differences between men and women in delays, the overall trend shows that delays to TB diagnosis for women are longer than men. A study conducted in Vietnam reported that the mean total delay was significantly longer among women (13.3 weeks) than among men (11.4 weeks). The difference between men and women in total delay was attributed to the significantly longer doctor's delay for women (5.4 weeks) than for men (3.8 weeks) (Long et al., 1999b).

A study from Ghana revealed that delay in diagnosis of pulmonary TB was unacceptably high, and doctor's delay was also significantly longer for women than men (Lawn et al., 1998). Another study in Japan also reported that doctor's delay was significantly longer for female than for male patients (Sasaki et al., 1995). Several studies have shown that even settings where more women than men present for care, they experience longer provider delays (Long et al., 1999b; Needham et al., 2001). Two Japanese studies reported that total delay tended to be longer in men than in women (Niijima et al., 1990; Hooi, 1994), and there was a report of no gender related differences in total delay in Austrilia (Pirkis et al., 1996). Perhaps this is a reflection of different gender roles in different societies and/or differences in TB diagnostic performance of health workers between the study settings.

A population based study in Vietnam reported that although women did not start seeking care later than men, they often sought health care from less qualified providers, took more health

care actions, and had longer delay to hospital than men (Thorson et al., 2000). The overall help seeking pattern of men was described to mainly consist of a neglect of symptoms until a late stage of the disease, then followed by a tendency to go straight to public health services, e.g., hospitals, without an initial visit to a private practitioner or an attempt at practicing self-medication. Women were perceived to practice self medication, visit a private health practitioners or a less qualified health provider close to home first, and then see hospital services (Johansson et al., 1999; Johansson et al., 2000). A study in Catalonia, Spain presented that the proportion of women visiting a health professional was slightly greater than that for men; however, the proportion of hospitalizations was lower among women than among men (Fernandez et al., 1999).

Table 2: Gender differences in delay from onset of symptoms to treatment initiation

Study place	Measure		Patient delay	Provider delay	Total delay
Queensland, Australia	Median	M (224)	27 days	22 days	
(Ward J. et al. 2001)		F (n=140)	30 days	23 days	
		M+F	29 days	22 days	
Alexandria, Egypt (Kamel	> 2 months	M (n=231)		34.6%	
MI et al. 2003)		F (n=103)		39.9%	
		M+F			
Teheran (Masjedi et al.	Mean	M	15.5 weeks	74 days	
2002)		F	10.5 weeks	112 days	
		M+F	12.5 weeks	97 days	
Tamil Nadu India (Sudha	Mean	M	10 days		
et al. 2003)		F	10 days		
		M+F	10 days		
Recife Brazil (Martinho	Median	M (n=741)			120 days
S. et al. 2005)		F (n=364)			90 days
		M+F			142 days
Turkey (Guneyliogiu D et	Mean	M (n=122)	35.2 days	19.1 days	
al. 2004)		F (82)	25.7 days	26.6 days	
		M+F	31.4 days		
Rural Nepal (Yamasaki-	Median	M (n=238)		0.8 month	2.3 month
Nakagawa et al. 2001)		F (n=98)		1.3 month	3.3 month
India (Balasubramanian et	Median	M (n=433)	14 days	30	
al. 2004)		F (n=133)	14 days	37	
Rural Bangladesh (Ahsan	>60 days	M (n=145)	29%		
G et al. 2004)	>60 days	F(n=162)	50%		
	Mean	M+F	63 days		
London, UK (Paynter S.	Median	M (n=48)	26 days	26.5 days	77.5 daya
et al. 2004)		F(n=23)	50 days	41.5 daya	93 days
		M+F		29.5 days	

CHAPTER III

RESEARCH METHODOLOGY

This chapter presents the methodology applied to investigate the gender differences in delays in initiating tuberculosis treatment under DOTS programme. This chapter addresses the study site, study subjects, size of the sample, sampling procedures, study instruments, measurement of the variables, and methods of data collection, management and analysis. Reliability and validity of study instruments are also addressed.

3.1 Study setting

Far-western development region

Politically Nepal is divided into five development regions and 75 districts. Tuberculosis is one of major public health problems throughout the country. It has been estimated that the annual risk of tuberculosis infection (ARTI) is 2.5% in the plains areas, 1.5% in the hills, 1% in the mountain and 4% in the Kathmandu valley (Ministry of Health, NTC, 1994). The reported incidence of new smear positive male and female patients are 79/100,000 and 49/100,000 respectively in the year 2004 (NTP, 2004).

Directly Observed Treatment Short course (DOTS) has been introduced in Nepal in April 1996 as a pilot in four districts; namely Bhaktapur, Parsa, Nawalparasi and Kailali. DOTS has been expanded in all 75 districts of the country. About 96% of the population are being covered by DOTS.

There are nine districts in the Far-western development region account 9.48 % of the total national population. About 9% of the national estimated new smear positive cases are covered by these districts in the year 2004 (NTP, 2004). The big gap between males and females has been seen in TB case finding. About 85% of the male estimated TB cases have been detected and enrolled in DOTS in these districts, whereas only 43% of the female estimated TB cases were identified in the year 2004. The trend is similar from last five years (NTP, 2004). About 57% the female cases and only 15% of the male cases are missing in the region. The gap is more than 40% between male and female missing cases in the region. These findings indicate that the huge amount of tuberculosis patients is still missing especially more female than men.

The collaborative approach has been taking place between NTP and local governments; between NTP and and non-governmental organization and public private partnership has also been initiated. Through this collaboration, DOTS has been expanded to all districts of the region (NTP, 2004). TB diagnosis and short course treatment therapy is freely available in all DOTS

centers to all type of TB patients. Therefore it is surprising question that why do not TB symptomatic patients visit the public health facilities?

3.2 Research Methodology

Both quantitative and qualitative methodologies were applied in this research.

3.3 Study population

New smear positive pulmonary tuberculosis patients enrolled in the DOTS centres, of Kailali and Kanchanpur districts.

3.4 Sample population

Study population for qualitative study

Four focus group discussions were carried out among the different communities. They were i) Tuberculosis patients; ii) community people with no history of TB; iii) private practitioners and iv) DOTS providers.

Study population for quantitative study

All the registered new smear positive pulmonary tuberculosis patients under 4 randomly selected DOTS centres of the Kailali and Kanchanpur districts between Mansir 2063 to Chaitra 2063 were the sample population. This was matched with the inclusion and exclusion criteria.

3.5 Sample size

Sample size for qualitative study

Six to eight participants in each group were selected. Gender balance was respected in selecting process of in each group.

Sample size for quantitative study

The minimum sample size is calculated using EPI-INFO 6.04 (Fleiss, 1981). In addition, an extensive literature search is done to understand the prevalence of delay and pattern of delay in TB care seeking. A study carried out in Ethiopia showed that the prevalence of delay more than 30 days was 50% (Demissie M et al. 2002). Published articles showed that the mean or median total delay between onset of TB symptoms and initiating of tuberculosis treatment was 8 weeks to 15 weeks (Nigeria (Odusanya O. O. et al. 2004; Long et al. 1999; Sherman et al. 1999; Asch et al. 1998; Wandwalo, Morkve 2000; Lienhardt et al. 2001; Pronyk et al. 2002; Needham et al. 2001). The annual report of the National Tuberculosis Control Programme shows that the case finding rate among females was only 43% (NTP, 2004). For this study we have calculated minimum sample size taking confidence level 95%, power 80%, estimating risk (60%) in exposed group (female) and about 35% risk in unexposed group (male) of delay for more than 30 days and taking male to female ratio 2:1. Minimum sample size is (n) = 150.

The annual report-2004 of the National Tuberculosis Control Progamme of Nepal shows that the male and female ratio of case detection of new smear positive cases is 2:1 (NTP, 2004). We have expected that this sample size will be between 150 and 180. It has been estimated based on the review of previous years' data of the region.

3.6 Inclusion and exclusion criteria

Qualitative study

i) Tuberculosis patients: Male and female new smear positive tuberculosis patients currently under DOTS treatment aged between 15 to 50 years old were included.

ii) Community people with no history of TB: Representatives from mother' group, community volunteers, and social leaders aged between 25 to 60 years old were included.

iii) Private practitioners: Male and female private practitioners who are currently treating tuberculosis patients were included in the study.

iv) DOTS providers: Male and female DOTS providers who are currently providing DOTS services at the DOTS centre level were included.

Quantitative study

New smear positive pulmonary tuberculosis patients aged ≥15 years were included. Patients who did not like to participate, new smear positive pulmonary tuberculosis patients less than 15 years old, extra pulmonary tuberculosis patients, and re-treatment positive (relapse, failure, and return after defaulter) and smear negative pulmonary TB patients were excluded from the study. It was estimated that about 5% to 10% of eligible TB patients would decline participating in the study.

3.7 Sampling Procedure

Phase I: Sampling procedure for qualitative study

i) *Tuberculosis patients:* the group consists of 6 to 8 participants, relatively homogeneous with respect to socio-economic status, but not with respect to age. Patients were purposively selected.

ii) *Community people:* this group was recruited from the representatives of community workers, mother's group, and other lay people in the community by the help of DOTS committee.

iii) *Private practitioners/pharmacists:* This group consisted of private practitioners who were treating tuberculosis patients at the point of study. The participants of this

group were selected with coordination of District Public Health Office of the study area.

iv) *DOTS providers:* This group consisted of DOTS providers working at the DOTS centre. The members of this group were selected with coordination of District Health Office of the study area.

Sampling procedure for quantitative study

Sampling Frame (if relevant) and Sampling Process including Criteria for Sample Selection

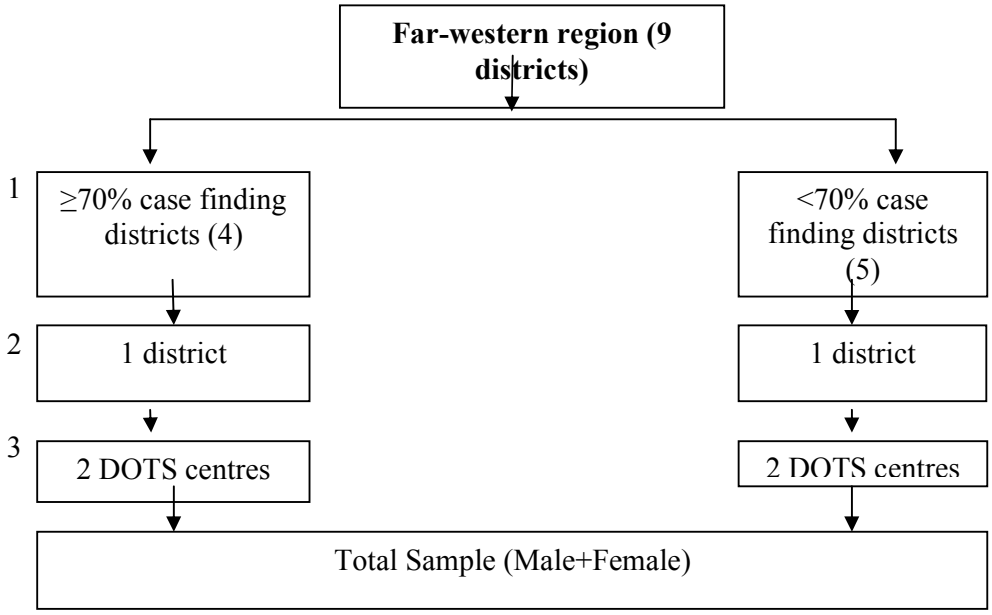

Figure 1: Sampling frame for quantitative study

1. Stratification of the districts by the proportion of the case finding of new smear positive tuberculosis patients on the basis of the case finding report of the year 2004 (NTP 2004).
2. Simple random sampling (one district from each strata was selected)
3. Two DOTS centres with high TB cased were purposively selected.
4. All the eligible new smear positive tuberculosis patients were interviewed

3.8 Data collection instruments

Phase I: data collection instruments for qualitative study

Data collection for qualitative study includes group discussion. Guidelines of focus group discussion were developed (annex 1). Some open-ended questions were presented at the beginning and during the discussion.

Phase II: Data collection instruments for quantitative study

A standard structured questionnaire was prepared in English and then it was translated by professional translators into Nepali (annex 2). The questionnaire was composed of 11 parts: the general demographic; socio-economic; recognition of symptoms and decision making; help seeking behavior; socio-cultural; knowledge about TB; perception about TB; Health system related information was also obtained by using structured questionnaire.

3.9 Validity and Reliability of the instrument

Validity

Questionnaires in this study were developed from the review of published articles and research reports. In addition, information from qualitative study provided important guidance in developing the questionnaire for quantitative study. The content validity was assessed from the experts. Most of the questions in this study were developed regarding health seeking for TB treatment, knowledge, perception, accessibility, socio-economic, stigma and delay measurement from various studies carried out in the different settings around the world (Demissie et al., 2002; Needham et al., 2001; Ngamvithayapong et al., 2003; Yamasaki et al., 2001).

Reliability

The questionnaire was pre-tested for reliability in a non-study district among 32 individuals. Revision of the words and phrases and reordering of the questions were made based on the feedback from the respondents. The whole process of interview was closely monitored to ensure clear understanding of the questions. The history given by the patient was correlated with the date of prescriptions and laboratory test results, to verify the reliability of the patient's account.

3.10 Data collection procedures

Training of the research assistants

Two research assistants were recruited for the study purposes. A two day intensive training was organized for them by the researcher. A standard data collection guideline was used. Emphasis was given on data collection methods, focusing on interview techniques. Field testing was organized and careful attention was given to field procedures. During the training, regarding research ethics and patient's confidentiality, providing the information about the study to the participants and obtaining the informed consents, right of the patients to withdraw from the study at any time were addressed to the research assistants.

Focus group discussion (FGD) for qualitative study

The researchers conducted all sessions of FGD with the assistance of a note-taker and a support staff member. The process of organizing each FGD consists in the recruitment of the participants, conducting FGD and analyzing the data. All sessions were recorded with a tape recorder.

The main focus of qualitative study was to understand the women's help seeking behavior for tuberculosis especially, in the areas of what do they think about tuberculosis, why don't they give higher priority to their health, what are the socio-cultural factors that contribute to delay in TB care seeking, what is their role in decision making in their households, where do they consult first, how do they present in DOTS centres.

Data collection procedures for quantitative study

Record review

A standard recording and reporting system is developed and applied by the National Tuberculosis Control Programme of Nepal. All the recording tools; Tuberculosis register, Tuberculosis laboratory register, TB treatment card and Patient card are developed as per the WHO and IUATLD guidelines and applied throughout the country. The details of diagnosis and treatment information of each patient are recorded in these tools. Therefore, diagnosis and treatment information were obtained reviewing TB register, TB Laboratory register, and TB treatment cards.

Face to face interview

Interview was carried out at the DOTS centre by using a structured questionnaire. All new smear positive pulmonary tuberculosis patients who were enrolled for DOTS treatment between Mansir 1, 2063 and Chaitra 30, 2063, were interviewed by trained research assistants. Nearly all patients were interviewed within a month after initiation of anti-TB treatment at DOTS centre.

3.11 Measurement

Dependent variables

Median delays were used to measure all delay intervals i.e. patient delay, provider delay and total delay.

Patient delay; It is an interval between onset of symptoms and first contact to any type of health provider.

Provider delay (Diagnosis + Treatment); It is an interval between first presentations to health care provider until the start of anti-TB treatment with DOTS.

Total delay; It is an interval between onset of symptoms and commencement of anti-TB treatment under DOTS.

3.12 Data analysis

Qualitative data analysis

Modified grounded theory

A modified grounded theory technique (Glaser & Strauss, 1968) for analysis of data was used. The FGDs was tape recorded, transcribed in Nepalese and then it was translated into English. Translation was made by the independent translators in order to maintain the accuracy of the records. Data were analyzed inductively, i.e. raw data were transformed into categories. During the analysis, open codes were applied to segments of the text by the researchers. Constant comparison among open codes was made between men and women. Data were reorganized accordingly and categories were created from the open codes.

The cut and paste technique

The cut and paste technique is a quick and cost effective method for analyzing the transcripts of focus group discussion. Before starting the analysis, the recorded tapes of FGD were transcribed verbatim by the note taker and were verified by the researchers and experts. The recorded information in the tapes was transcribed in handwriting and then the texts were typed into word processor. This method was used because the sophisticated transcribing machines would not be possible to make available in the resource poor settings like Nepal. The researcher carefully read the transcript and identified the sections that would be applicable to the research questions. The researcher classified the major themes and the topic related to each theme. Each theme was coded related to research topics and highlighted by different colors. Each piece of the coded materials was sorted and all materials relevant to a particular topic were collected together for the explanation.

Quantitative analysis

The statistical analysis

Every data form was checked by the researcher. Data validation was done twice; by the research assistants first and then by the researcher. All the data was coded and the codes were verified.

All analyses were conducted using the SPSS statistical package, version 13. Median delays associated with all covariates were calculated separately by gender, and for both

genders combined. The specific delays considered were as follows: (1) patient delay; (2) provider delay; (3) total delay

In bivariate analyses, the Mann-Whitney and Kruskal-Wallis tests were used to compare delay times across different levels of individual independent variables, because these times were not normally distributed. (In chapter IV, results of bivariate analysis are presented only for patient delay and provider delay). Multilevel analysis was performed for total delay.

3.13 Ethical consideration

The study was approved by the Ethical Review Committee of Nepal Health Research Council before initiating the field work. In addition, the researcher strictly adhered to the ethical guidelines for researchers, issued by the Nepal Health Research Council. The following general ethical considerations were applied including training for the research assistants regarding research ethics and patient's confidentiality, providing the information about the study to the participants and obtaining the informed consents, all participants were made aware of their right to withdraw from the study at any time, the patient's right not to respond to those questions which they don't wish to respond to as well as the confidentiality of the individual's data and information. The study participants were identified by clinical records (TB treatment card and tuberculosis register), not by name. These records were available in each DOTS centres.

The participants were assured of confidentiality and the possibility to withdraw at any time. In fact, participants of each FGD expressed considerable interest in taking part in the discussions.

3.14 Biases

The result of the study could be affected due to the recall bias. Due to their long period of time before accessing DOTS services and large scale of shopping for seeking treatment, they might have forgotten some important events such as exact date or interval of beginning of symptoms and first contact to the any type of providers. Therefore, to help with accurate recollection, some additional questions were asked regarding local festival, harvesting time, birth day, wedding ceremony of the relatives or neighbors, or any special events happened in community, during the vacation period of the children and so on to make recall easy of the time of symptoms onset. These attempts would help to minimize the recall biases.

Interviewer bias was reduced by using a structured, standardized questionnaire administered by trained interviewers. Interview guidelines were provided to all the research assistants. There would be little possibility that some respondents might not respond due to not

understanding of the question, but interviewers were instructed to follow the guidelines if such situation happened.

Confounding was controlled by using multivariable linear regression and multilevel analysis.

3.15 Scope of the study

Since this study was conducted in the high burden districts of Nepal among new smear positive pulmonary tuberculosis cases (highly infectious), the findings would not be generalized to the whole population of the country due to difficult terrain and multiple ethnic groups with multiple socio-economic situations and cultural value structures.

The patient delay among male and female was calculated as the difference between the duration of first symptom and the time of first consultation. This delay is of major importance; it is the window when people wait while sick, putting off a visit/consult for whatever reason. If we could cut that shorter, fewer people would get so ill and fewer would die once on treatment. The real problem unfortunately is that I think this study's subjects represent only the "tip of the iceberg," and that the majority of new smear positive pulmonary tuberculosis patients never show up at all. The study was not conducted on a larger scale because of time and resource constraints.

3.16 Budget support

This study was financed by Nepal Health Research Council, Kathmandu.

Chapter IV

Results

Results of quantitative study

Background

This cross-sectional study was carried out in Kailali and Kanchanpur districts of Far Western Development Region between Mansir 2063 and Chaitra 2063. Almost all the subjects were interviewed within two months after starting treatment. Face to face interviews were made with the study subjects using a structured questionnaire. The study included 176 tuberculosis patients, of whom 118 (67.1%) were male and 58 (32.9%) were female, enrolled in the selected DOTS centres.

Gender differences in patient delay, provider delay and total delays

Table 3 summarizes the lag time from reported symptoms onset to treatment initiated. The delay from onset of symptoms to commencement of treatment, and its components, is subjects of considerable public health attention. Patient delay is defined as time interval from the appearance of the symptoms until the first visit to any type of provider. Provider delay is defined as interval between first visit to any type of provider and start of treatment. Interval between onset of symptoms and start of treatment is regarded total delay.

Patient Delay

The mean patient delay was 2.71 months in females and 2.64 months in males. This difference was not statistically significant ($p>0.05$). The mean patient delay in all patients was 2.67 months.

Provider Delay

Provider delay consisted of diagnosis delay and treatment delay. The mean provider delay was found longer in both males (2.86 months) and females (7.58 months). Moreover, it was significantly longer among females than males ($p <0.05$).

Total delay

The mean total delay was 5.51 months in males and 10.21 months in females. This difference was highly significant ($p<0.001$).

Table 3 Gender differences in delays between symptom onset and start of DOTS treatment among

Types of delay	Male	Female	Total
Patient's delay (month)**	Mean = 2.65 Median = 2.00	Mean = 2.72 Median = 2.00	Mean = 2.67 Median = 2.00
Provider's delay (month)*	Mean = 2.92 Median = 1.00	Mean = 7.63 Median = 1.65	Mean = 4.47 Median = 1
Total delay (month)*	Mean = 5.57 Median = 3.18	Mean = 10.34 Median = 3.05	Mean = 7.14 Median = 3.12

***p-value <0.05, **p-value >0.05**

Patient's profile

Demographic factors by gender

Of the 176 people interviewed, 118 (67.1%) were male and 58 (32.9%) were female. The greatest proportion (67.6%) of the patients (72.0% in male and 58.6% in female) was rural residents. The median age in years was 36 for male and it was 34 for female. It was observed that most of the respondents were with productive age. About two thirds of the respondents in both groups were Janajati followed by Chhetri. More than half (58.6%) of the female participants were illiterate, while the corresponding figures for their male counterparts was 41.5%. Regarding occupation, the male and female patients comprised 19 (16.1%) and 24 (41.4%) self-employed, 42 (35.6%) and 19 (32.8%) laborer respectively and the rest belonged to different occupational groups. The median household size was 6 for male respondents and it was 5 for female. Details were presented in table 4.

Table 4 Socio-demographic characteristics

Characteristics	Male n (%)	Female n (%)	Total n (%)	P-value
Age				0.020
<34	52 (44.1)	37 (63.8)	89 (50.6)	
35-54	42 (35.6)	17 (29.3)	59 (33.5)	
>54	24 (20.3)	4 (6.9)	28 (15.9)	
Median, max,min	36, 13, 81	27, 13, 70	34. 13. 81	
Resident				0.074
Rural	85 (72.0)	34 (58.6)	119 (67.6)	
Urban	33 (28.0)	24 (41.4)	57 (32.4)	
Ethnicity				0.381
Janajati	77 (65.3)	38 (65.5)	115 (65.3)	
Chhetri	14 (11.9)	10 (17.2)	24 (13.6)	
Brahmin	15 (12.7)	8 (13.8)	23 (13.1)	
Dalit	12 (10.3)	2 (3.4)	14 (8.0)	
Educational status				0.033
Illiterate	49 (41.5)	34 (58.6)	83 (47.2)	
Literate	69 (58.5)	24 (41.4)	93 (52.8)	
Marital status				0.839
Married	92 (78.0)	46 (79.3)	138 (78.4)	
Unmarried	26 (22.0)	12 (20.7)	38 (21.6)	
Occupation				<0.001
Self-employed	19 (16.1)	24 (41.4)	43 (24.5)	
Daily wages laborer	42 (35.6)	19 (32.8)	61 (34.7)	
Farmer	36 (30.5)	11 (19.0)	47 (26.7)	
Services (govt./pvt)	12 (10.2)	3 (5.2)	15 (8.5)	
Others	9 (7.6)	1 (1.7)	10 (5.7)	
Households				0.029*
Median, max, min	6, 30, 2	5, 12, 2	6, 30, 2	

*Mann-Whitney test

Table 5 shows cough was the main reporting symptom (male 97.5%, female 93.1%), followed by chest pain (male 87.3%, female 87.9%), and fever (male 81.4%, female 75.9%).

Table 5 Presentation of first clinical symptom of TB by sex

Characteristics	**Male (n=118)**		**Female (n=58)**	
	No.	%	No.	%
Cough	115	97.5	54	93.1
Chest pain	103	87.3	51	87.9
Fever	96	81.4	44	75.9
Loss of appetite	75	63.6	37	63.8
Blood in sputum	64	54.2	32	55.2
Loss of weight	103	87.3	49	84.4

Table 6 showed that more women (91.4%) than men (82.2%) did visit to any type of provider at some time prior to diagnosis**.** More women (27.6%) than men (19.5%) made an initial visit to traditional healers. But it was observed that more male (28%) than female (22.4%) made their first consultation with private pharmacy.

Table 6 Health Care providers visited first or visited at some time prior to diagnosis

Type of health care providers	Visited first		Visited at some time prior to diagnosis of TB	
	Male n (%)	Female n (%)	Male n (%)	Female n (%)
Traditional healers	23 (19.5)	16 (27.6)	31 (26.3)	21 (36.2)
Private practitioners	29 (24.6)	15 (25.9)	31 (26.3)	15 (25.9)
Private pharmacies	33 (28.0)	13 (22.4)	51 (43.2)	28 (48.3)
Government facilities	9 (7.6)	7 (12.1)	10 (8.5)	8 (13.8)
Others	3 (5.1)	2 (3.4)	10 (8.6)	6 (10.3)
No visit	21 (17.8)	5 (8.6)		

Patients were asked to report reasons for delay in help seeking. About one third of the female patients and 39.8% of the male patients told their delay reason was lack of money. Of the 58 female patients, 22.4% reported that they thought as simple coughing, while this proportion for

male patients was only 15.3%. Reasons like lack maintaining secrecy, and frequent consultation with private sector were more strongly associated with female sex (Table 7).

Table 7 Main reasons for delay seeking treatment

Main reasons for delay	Sex	
	Male (n=118) n (%)	Female (n=58) n (%)
Lack of money	47 (39.8)	19 (32.8)
Thought simple coughing	18 (15.3)	13 (22.4)
Busy with work	21 (17.8)	9 (15.5)
Treatment from traditional healers	4 (3.4)	1 (1.7)
Treatment from private sectors	7 (5.9)	5 (8.6)
Maintain secrecy	6 (5.1)	5 (8.6)
Hospital is very far	1 (.8)	1 (1.7)
Carelessness	13 (11.0)	2 (3.4)
No idea/don't know	1 (.8)	2 (3.4)

Former TB patients were seen to be an important source of influence in seeking treatment in 36.2% of the female cases whereas the corresponding figure for male counterparts was 42.4%. Drug sellers and relatives were also found to be an important source of information in both male and female (Table 8).

Table 8 Sources influencing to visit DOTS centre for TB treatment

Sources	Men (n=118) n (%)	Women (n=58) n (%)
Former cured patients	50 (42.4)	21 (36.2)
Drug sellers	16 (13.6)	12 (20.7)
Relatives	14 (11.9)	7 (12.1)
Friends	5 (4.2)	5 (8.6)
Self	11 (9.3)	4 (6.9)
Local health post	7 (5.9)	3 (5.2)
Hospitals	2 (1.7)	2 (3.4)
Private physicians	5 (4.2)	2 (3.4)
Neighbors	5 (4.2)	1 (1.7)
Traditional healers	3 (2.5)	1 (1.7)

Very few (3.4%) female patients reported their perception as TB is a really dangerous disease, whereas it was 18.6% for their male counterparts. It was also significantly different between males and females. About a quarter (24.1) of female respondents perceived risk of acquiring TB as everybody could get TB easily while this figure for males was 17.8% .

Table 9 perception about tuberculosis by sex

Characteristics	Male	Female	Total	P-value
Perceived tuberculosis				0.013
Really dangerous	22 (18.6)	2 (3.4)	24 (13.6)	
Quite dangerous	42 (35.6)	16 (27.6)	58 (33.0)	
Slightly dangerous	32 (27.1)	19 (32.8)	51 (29.0)	
Not dangerous	8 (6.8)	8 (13.8)	16 (9.1)	
Don't know	14 (11.9)	13 (22.4)	27 (15.3)	
Perceived risk of acquiring TB				0.450
Could get TB easily	21 (17.8)	14 (24.1)	35 (19.9)	
May get TB	58 (49.2)	23 (39.7)	81 (46.0)	
Probably would not get TB	11 (9.3)	5 (8.6)	16 (9.1)	
Definitely would not get TB	4 (3.4)	5 (8.6)	9 (5.1)	
Don't know	24 (20.3)	11 (19.0)	35 (19.9)	

Table 10 presents, approximately 61% of the female and 59% of the male respondents knew TB is a communicable disease. One third of the male respondents and a quarter of the female respondents knew that TB is transmitted through droplets and it was not observed significant differences between male and female (p=0.369). More females (22.4%) than males (12.7%) knew that bacteria caused TB.

Table 10 Knowledge about TB and its treatment

Characteristics	Male (n=118)	Female (n=58)	Total (n=176)	P-value
TB is a communicable disease				0.843
Yes	69 (58.5)	35 (60.3)	104 (59.1)	
No	16 (13.6)	9 (15.5)	25 (14.2)	
Don't know	33 (28.0)	14 (24.1)	47 (26.7)	
Mode of TB transmission				0.369
Droplets	39 (33.1)	15 (25.9)	54 (30.7)	
Utensil	31 (26.3)	21 (36.2)	52 (29.5)	
Don't know	48 (40.7)	22 (37.9)	70 (39.8)	
TB is a curable disease				0.239
Yes	88 (74.6)	44 (75.9)	132 (75.0)	
No	4 (3.4)	5 (8.6)	9 (5.1)	
Don't know	26 (22.0)	9 (15.5)	35 (19.9)	
Cause of TB				0.112
Bacteria	15 (12.7)	13 (22.4)	28 (15.9)	
Others	89 (75.4)	35 (60.3)	124 (70.5)	
Don't know	14 (11.9)	10 (17.2)	24 (13.6)	

Bivariate analysis of patient delay, provider delay, and total delay

All analyses were conducted using SPSS statistical package, version 13. Median delays associated with all covariates were calculated separately by gender, and for both genders combined. The specific delays considered were as follows: (1) patient delay; (2) provider delay; (3) total delay.

Patient delay

Bivariate analysis

Female patients aged more than 34 years had longer patient delay than younger patients ($p = 0.05$) but patient delay did not differ with age in males. Patient delay was significantly longer in rural males than urban males but it was not observed among females. Patient delay varied by ethnicity and education in both sexes but not reached statistical significant ($p > 0.05$). Patient delay was observed varied by types of occupation and it was found statistically significant in males ($p=0.013$).

Table 11: Patient delays (month) in males, females, and all subjects: bivariate analysis by socio-demographic and economic characteristics

Demographic factors	Male		Female		All	
	No. (%)	Median	No.	Median	No.	Median
Age						
≤34	52 (44.1)	2	37 (63.8)	1	89 (50.6)	1.5
>34	66 (55.9)	2	21 (36.2)	3	87 (49.5)	2
P-value		0.719		0.05		0.399
Resident						
Rural	85 (72.0)	2	34 (58.6)	2	119 (67.6)	2
Urban	33 (28.0)	1	24 (41.4)	1	57 (32.4)	1
P-value		0.007		0.526		0.015
Ethnicity						
Janajati	77 (65.3)	2	38 (65.5)	1	115 (65.3)	2
Chhetri	14 (11.9)	1	10 (17.2)	4	24 (13.6)	2
Brahmin	15 (12.7)	3	8 (13.8)	1.5	23 (13.1)	2
Dalit	12 (10.3)	2	2 (3.4)	1.75	14 (8.0)	2
P-value		0.653		0.198		0.951
Educational status						
Illiterate	49 (41.5)	2	34 (58.6)	2.5	83 (47.2)	1.33
Literate	69 (58.5)	1.5	24 (41.4)	1	93 (52.8)	2
P-value		0.353		0.257		0.148
Marital status						
Married	92 (78.0)	2	46 (79.3)	2	138 (78.4)	2
Unmarried	26 (22.0)	1	12 (20.7)	1	38 (21.6)	1
P-value		0.061		0.330		0.041
Occupation						
Self-employed	19 (16.1)	1	24 (41.4)	1.66	43 (24.5)	1
Daily wages laborer	42 (35.6)	2	19 (32.8)	2	61 (34.7)	2
Farmer	36 (30.5)	2.5	11 (19.0)	2	47 (26.7)	2
Services (govt./pvt)	12 (10.2)	0.6	3 (5.2)	1	15 (8.5)	0.66
Others	9 (7.6)	2	1 (1.7)	0.33	10 (5.7)	1.45
P-value		0.013		0.745		0.032

Longer patient delay was observed in those females who reported TB is not a dangerous disease than those who reported as dangerous disease, however, we could not detect statistically significant ($p>0.05$). Similarly, patient delay was found longer in female patients who perceived TB would not get easily. (table 12).

Table 12: Patient delays (month) in males, females, and all subjects: bivariate analysis by perception about TB

	Male		Female		All	
Perception	No. (%)	Median	No.	Median	No.	Median
Perceived TB						
Dangerous	96 (81.4)	2	37 (63.8)	1	133 (75.6)	2
Not dangerous	22 (18.6)	1.75	21 (36.2)	2	43 (24.4)	2
P-value		0.810		0.655		0.798
Perceived risk of acquiring TB						
Would get TB	79 (66.9)	2	37 (63.8)	1	116 (65.9)	1.5
Would not get TB	39 (33.1)	2	21 (36.2)	3	60 (34.1)	2
P-value		0.571		0.141		0.165

The patient delay was significantly shorter in males (p=0.026) and females (p=0.05) who knew TB is a communicable disease. Overall, patients who knew TB is transmitted through droplets had significantly shorter delay than those who did not, however, it was not observed significantly by sex specific. Other knowledge related factor such as cause of TB, and knowledge about cure did not reach statistically significant in all and sex specific (table 13).

Table 13 Patient delays (month) in males, females, and all subjects: bivariate analysis by knowledge about TB

	Male		Female		All	
Knowledge	No. (%)	Median	No.	Median	No.	Median
TB is a communicable disease						
Yes	69 (58.5)	1.33	35 (60.3)	1	104 (59.1)	1
No	49 (41.5)	2	23 (39.7)	3	72 (40.9)	3
P-value		0.026		0.05		0.003
Mode of TB transmission						
Droplet	39 (33.1)	1.5	15 (25.9)	1	54 (30.7)	1
Else	79 (66.9)	2	43 (74.1)	2	122 (69.3)	2
P-value		0.060		0.169		0.018
Cause of TB						
Bacteria	15 (12.7)	1	13 (22.4)	2	28 (15.9)	1.25
Else	103 (87.3)	2	45 (77.6)	2	148 (84.1)	2
P-value		0.167		0.667		0.498
TB is a curable disease						
Yes	88 (74.6)	1.58	44 (75.9)	1.66	132 (75.0)	1.58
No	30 (25.4)	2	14 (24.1)	2.5	44 (25.0)	2
P-value		0.113		0.956		0.175

Factors affecting provider delay

Provider delay

Table 14 shows the relationship between help seeking factors and diagnosis delay in male and female patients. The median diagnosis delay varied by the choice of first health care providers between male (p<0.001) and female (p.0.030) patients. For female, the shortest median diagnosis delay was reported by patients who first visited to government facilities and the longest median diagnosis delay was reported by patients who first visited to traditional healers and drug store. For male, the shortest median diagnosis delay was reported by patients who did not visit any type of providers and made visits directly to DOTS centre and the longest median diagnosis delay was reported by the patients who first visited either private doctors or traditional healers.

Table 14 Provider delay (month) in males, females, and all subjects: bivariate analysis by providers they met first

	Male		Female		All	
Items	No. (%)	Median	No.	Median	No.	Median
First visit to any Providers						
No visit	23 (19.5)	0.2	6 (10.3)	0.1	29 (16.5)	0.17
Traditional healers	23 (19.5)	2	16 (27.6)	2.8	39 (22.2)	2
Private doctors	29 (24.6)	2	15 (25.9)	1	44 (25.0)	1.7
Govt. facility	10 (8.5)	1.2	8 (13.8)	0.08	18 (10.2)	1.1
Drug store	33 (28.0)	1	13 (22.4)	2	46 (26.1)	1.3
P-value		<0.001		0.030		<0.001

Total Delay

Factors affecting total delay

Multilevel analysis was performed for total delay to investigate factors that were simultaneously related to delay and to determine the strength of the relationship.

Factors as shown in the table 15.were included in the model. It was found that female sex was found as one of the significant risk factors with lengthened total delay (p=0.011). Other factors i.e. knowledge about the cause of TB (p=0.050), and perceived TB as a communicable disease (p=0.017) were found significantly associated with total delay.

Variables such as rural residence (p=0.015), and perceived TB may not get completely cured (p=0.027) were associated with increased likelihood of total delay for male patients, while caste Janajati (p=0.056), poor knowledge about the cause of TB (p=0.030) and perceived TB is not a communicable disease (p=0.016) were found increased likelihood of total delay for female patients.

Table 15 Multilevel analysis for all cases: type III tests of effect

Total delay (month)	
Variables	P-value
Intercept	.873
Sex-female	.011
Caste	.407
Age	.197
Education	.666
Occupations	.672
Residence	.685
Marital status	.433
Perceived TB dangerous	.483
Perceived risk of getting TB	.600
Bacteria is the cause of TB	.050
Perceived TB is a communicable disease	.017
Perceived TB is transmitted disease	.545
Perceived TB may completely cured	.193
Visit providers at first	.356

Qualitative study results

Themes were introduced and questions were asked by the moderator of the focus group discussions (FGDs). The results presented below mainly describe participants' own views and experiences of TB. Four FGDs were organized separately among tuberculosis patients, private practitioners, community people, and DOT providers. The views, feelings, opinions, and experiences were summarized by key themes as follows:

Gender differences in knowledge and perception of TB

TB patients in focus group discussions perceived that knowledge about TB varied considerably between men and women. Most of the participants pointed out that TB is a dangerous disease which affects particularly poor people. Few of the participants thought that TB is an incurable disease and it is caused by the evil things done in the past life. This perception was held predominantly by elderly and illiterate people. One female TB patient expressed her feelings as:

"I had a cough for a year. I thought it is due to cold and smoking. After six/seven months I went to private pharmacy and bought the medicines. I felt there was slight improvement of my symptoms. One day while I was taking medicines, I had vomiting and I saw there was some blood stain. I suspected I might have Sukuterog (TB). I went to Maiti (Parent's home) asked the mother for my treatment. My mother took me to the temple of Kali (Goddess) to pray for me and sacrificed a black hen in the temple in the name of Goddess Kali. My mother told me that your Sukuterog (TB) will be cured very soon by the Goddess Kali. My cough was not improved. I was losing my weight, although I did not see the blood stain in my cough anymore. After one year my sister-in-law took me to the private clinic. I was examined there. Three sputum specimens were tested. She (female doctor) referred me to Friends of Shant Bhawan (an NGO DOTS clinic). I am taking medicine for a month but I don't know what was wrong with me." (female TB patients currently under DOTS treatment)

Different types and causes of TB were discussed in the FGD. In the view of some of the female TB patients, TB is caused by worries, social pressures, smoking/drinking, and too much thinking. Mainly it affects the females after they get married. Different views were highlighted by male participants; they believed that TB is caused by hard work, poor diet, and frequent sex with their wives, too much drinking alcohol and smoking, as well as the heredity mainly affecting the men.

"I worked in the garment factory for 3 years. I smoke about 10-15 cigarettes every day and I drink whisky once a week. I got married in January (last week) i.e. it was two months before. I felt weak. I lost my appetite and weight for a month. I went to Bir Hospital to see the doctor. I was asked for chest x-ray and sputum test. After two days I was referred to DOTS centre to take TB medicines. Now I am taking medicines for a month. I think I got TB due to hard work in the factory, lack of sufficient food and smoking too much." (male patients currently under DOTS treatment).

Knowledge and perceptions regarding TB also influenced patients' health care seeking behavior and tendency to have someone accompany them. The DOTS providers said that they (women) could not present their symptoms, illness, and other things related to TB as strongly as men. It could be due to their poor education, language barrier (most of the TB patients attending DOTS clinic come from a minority ethnic group; i.e. Tamang and their mother-tongue is not primarily Nepali), fear, shyness and hesitation. That explains why they (especially women) need someone accompany to them.

One of the participants noted a very interesting point that "*women are unwilling to go to health services for their own health and they hide their illness because they think their absence will disturb household and economic activities, that's why male has to accompany them."*

Gender differences by socio-cultural aspects

TB patients during the discussion raised the issue of fear of social consequences of the TB disease. It might be the isolation of the individual in the family and in the community. Both male and female patients expressed this fear. The fear of social isolation, the tendency of hiding the TB disease and fear of breaking the relationship between wife and husband was most common among women.

Hiding disease is a serious matter in delay in care seeking. Hiding the disease, knowing about it, but not initiating treatment, is a serious matter where the TB cause problems individual remains a serious source of infection and where others may not be aware of the risks. Some participants (TB patients) described that they were afraid of disclosing the truth out of a sense of shame at being diagnosed with TB. The fear of losing friends and neighbours and not being able to socialize with others were also mentioned as strong contributing factors to reactions of concealment of the disease. Women expressed a fear of losing the opportunity for unmarried sons and daughters to get married and themselves losing their husbands. Participants generally thought that women were most likely to hide their diagnosis.

"I had a fever and night sweats for last six months. I did not tell anybody in family in this regards. I together with friend went to the public hospital (Bir Hospital) for examination after 4 months. I had no idea about TB symptoms. Doctor told me I had TB. I was afraid. I became sad. I did not take medicines as he (doctor) prescribed. I did not tell anyone in the family about it. I knew I would have problem in getting married. After three months I got married. I lived about one month with my husband in his home. Then I went back to my parents' home. I told my mother about my health. She told my father. They became very afraid that I would get divorced from my husband if he knew about my disease. They took me to private physician. He made all the examinations and told me I got TB. I did not tell him about

my previous history of TB diagnosis. He prescribed the medicines. I started to buy medicines from his pharmacy. It costs 60 rupees per day. It was so expensive. My parents were not able to afford. After one month, the pharmacist advised me TB drugs available free of charge in the DOTS centre. I felt hesitation to go there. My parents went there and requested to the doctor of the DOTS centre to maintain the confidentiality of my TB medication. Now I am eight months of treatment. My husband and other members of his family hopefully do not know about my disease. I am going back to my husband's place after one month as doctor advised me." (Female TB patients, aged 26 currently under DOTS treatment)

DOTS providers felt that negative perceptions of TB were rampant. People usually did not want to talk and to share the things with TB patients. They always tried to avoid them. These negative statements were more common among female patients. To avoid these negative feelings, patients hid their diagnosis from friends, community, and family members. Cases of husbands leaving their wives were reported by health workers: 'I asked the lady, what was the cause of your staying with your parents, she said my husband said any woman who is having TB might have HIV/AIDS' (female DOTS provider). They also reported that they were some cases, especially among unmarried girls, who faced marital difficulties resulting from their illness. Health providers believed that women felt more stigmatized than men as they were more likely to hide or concealment of TB diagnosis and treatment.

It was discussed in the FGD with the community people that females are not allowed to travel long distances alone. A male member of the family, even the youngest brother or son, is required to accompany a woman. These types of cultural norms delay TB diagnosis. Shame and embarrassment can lead to reluctance on the part of women to share disease conditions with family and health providers and this may prevent them from reporting to health services for the diagnosis and treatment of TB. An unwillingness to tell others is due to the stigma associated with TB.

Gender differences in their role in the family

All focus group discussions participants described: Men were characterized as hard working, as being independent, as being the pillar of the family, as having extensive social networks, as having decision making power, as having access to resources, as having good education, as being more respected in the family and community than women, and as having less responsibility towards their children and housework.

Women were characterized as being dependent on husbands and their families, as thinking a lot and always worrying, as being patient fear of social isolation, always being at home taking care of her children and senior members of the family, being less status in the

family, community and in the workplace, as being lack of decision making power, as having poor access to resources, as being pressure to hide illness and as having poor social network and movements.

The family would make sure that the man was diagnosed and treated before other family members. A wife was expected to care for her husband, while the husband was not subjected to the same expectations. The following metaphor demonstrates the importance of the pillar of the family.

"Individuals, who are pillars of the household, should be taken care of by the family. If the head of the household is strong enough, he can drive the family very well and he can take care all of the members of the family. If he is weak and suffering from the illness, the whole family will come into a difficult situation" (Man who is under DOTS treatment).

DOTS providers acknowledged that women needed to ask permission from their husbands or elders to attend treatment. One health worker expressed it was an important problem: *'even if she is dying, she has to abide by that advice.' (male DOTS provider).*

Gender differences in seeking care

Gender difference was described by both males and females patients. The typical health seeking pattern of men was said to mainly consist of neglecting symptoms until the disease was in an advanced stage.

One of the most most common choices of care seeking was the private sector, including private pharmacies, private practitioners, and traditional healers (Dhami-Jhankri). This was more common among women. Easy access, convenient time, possibility of keeping the disease a secret, and possibility to have more healers' attention once they pay the money for consultation.

"I had a cough for a long time and went to public hospital (University Hospital) for check up. I visited the doctors after 7 hours, a long waiting time. He sent me for x-ray and asked to come next day. I went to X-ray section and waited 2 hours to get it. I find their behavior was not friendly. And he (the doctor) did not listen my voice carefully. I lost my whole day and I did not go for work. I decided not to go to that hospital anymore. I visited private doctor at the evening. Everything was done within an hour. I was told I got TB. I am taking medicines as he prescribed from one of the DOTS centres established in private sector. I am very satisfied with getting TB treatment from that centre." (Women TB patients, working as a teacher in public school)

Patients expressed a need for prompt communication about test results of their sputum. They stated that they often worried when they did not hear back from their providers. They often get informed after a long waiting about 4 to 6 hours.

One of the female participants said

"My husband took me to TB hospital for check up. We spent whole day and got nothing. We were asked to come back next day early in the morning. We went early morning next day got chance to see doctor (a man with white coat) after 6 hours. Again I was sent to laboratory for sputum test. I was asked to come back next day with sputum collecting in the sputum container which was given to me. If this was the case why should I have to lose my work for two days? Why didn't they make a communication with me that I would have to come with early sputum collection and just sent to laboratory? I did not visit the hospital anymore. My husband went there and brought the results of sputum after 2 weeks. I would not like to refer any people to there. I found people working there not friendly and not supportive.

Patients valued being treated with respect and dignity by providers. They wanted providers to respect their needs and individuality, and to extend respect to family members as people who can provide additional information and improve patient-provider communication. Patients defined showing courtesy as displaying a warm and welcoming manner. They valued providers with whom they were able to establish a trusting relationship. One of the female TB patients noted her feelings as

"We feel like they (doctors) are truly the good mothers who give good care to their children. If we have someone who just does not care us a lot, maybe we would not have good TB treatment and maybe we would die".

Female patients often described being more worried than males as the women are often socially and economically dependent on their husbands and in-laws. *"I think when women have this disease; it will affect their spirit more. They are often afraid and worried that other people will keep away from them. Especially those women who are not primarily bread-winners of the family, or who cannot earn money or who live with the husband's extended family are often much more affected by other family members like me" (women TB patient).*

As mentioned above, male patients more easily accepted to eat and live normally with the whole family when they were so requested by family members. On the contrary, female patients often wanted to protect other family members from the disease. Thus, even when they were requested by family members to eat together with them, female patients more commonly continued to isolate themselves. *"I always used to eat last. I pretend them (other family members) I had no hunger right now. I used to keep myself busy outside work (taking care of cattle) especially when they sat to eat either dinner or lunch. I tried to keep myself isolated. It was because my friend (a former cured TB patient) said to me it (TB) could be transmitted to others during the treatment period as well (first two month of treatment). Therefore, I was afraid of spreading the TB to my children, husband, and*

other family members. Even they asked me to eat together, I always avoided them, and I wanted to see my family healthy" (women TB patient).

One of the private physicians highlights her views as *"the TB patients usually come from very poor families, and they usually live under poor conditions. As practiced in the community that the man should get treatment before the woman since he is the pillar of the family. In the countryside, the status of the women is much lower than of men. When men get TB or any type of disease, all the family resources may be spent and, moreover, financial resources from the relatives may be collected, but this is not the case for women. So they hide their illness and it leads to delayed TB diagnosis and treatment." (Female doctor, working in the private clinic)*

In general, women were described as shy and hesitant which was thought to have a negative effect on their care seeking behavior and their interaction with the doctor. They were perceived as delaying seeking medical care, and when finally seeing the doctor, being reluctant to and ashamed of talking about their symptoms. Compared to men, they were said to have a greater fear of TB associated stigma. Women were also thought to have limited knowledge in care seeking matters. The care taking role of women was emphasized as one of the factors limiting women's access to time. Overall resources for women in terms of time and money were considered scares, due to their inferior position in the household as well as the fact that they were busy taking care of their family and children.

"Nepalese women are very shy, they have a character of their own. You know they are afraid when they make contact. They consult me about their health, and after examining them I asked for chest x-ray and sputum examination. They come back to me after 10 days with chest x-ray and result of sputum examination. I asked, "why did you wait such a long time?" They said that they were very busy taking care of their children and the family. They further replied that school examination was going on of their children. Maybe this is how the TB diagnosis gets delayed." (Male doctor)

The delay mentioned here was understood as being caused by the patients delaying these analyses by simply not attending to them promptly. The gender characteristics such as shyness among women, causing them to avoid medical examinations, or lack of decision making power to a need to ask for permission before seeking care could be performed.

DOTS providers thought women initially consulted pharmacies more in urban areas and traditional healers in rural areas. It is because confidentiality is more important to them. They thought that most TB patients could not afford the fares to attend treatment clinics, and felt women experienced more problems due to lower income and characteristic of dependency. It was acknowledged that this reduced care seeking. Some patients stopped work. It was due to inconvenience of opening and closing time of the DOTS centre. They had to go early

in the day for work, but our DOTS centres usually open at 10 in the morning and close at 2 in the afternoon. They expressed that male patients who were still working did not feel that treatment interfered with their work; however, women whose work, if any, was usually in a garment factory, were inconvenienced by the time demands of the treatment. Discussion came up that medical facilities are perceived as more time consuming and less confidential.

DOTS providers expressed that even if a women notices symptoms of TB, she may completely ignore these symptoms because of competing demands. Women may believe that they cannot afford the luxury to take time out to visit a health centre because this would represent time and effort lost to other essential and possibly more important, activities such as child care, food production and farm work. We have seen patients working in factory attending our clinics mostly temporary or daily paid. It makes it difficult for them to leave their work to attend to their health problem.

"*When women suffer from conditions such as tuberculosis, they often deny their symptoms until they are too severe to ignore because of heavy competing workloads." (Female DOT providers)*

They said that before a woman decides to seek care, she must be able to recognize the signs and symptoms that indicate the need for care. However, a lack of educational opportunities and poor understanding of health related matters that many women are not familiar with different diseases and their presentations. It leads to delay in seeking help. For example,

"Some women assume that coughing for a long time is due to cold and personal smoking or think that chest pain is normal because they used to carry heavy pots full of drinking water daily from far and because they have suffered from it for as long as they can remember. Moreover, as a result of cultural taboos, women may be unable to interpret symptoms of illness, particularly as they relate to the chest. (Female DOTS provider)

A leader of the community reported that *"woman here does not take care of herself at all. The husband or the children always come first, for the family and children she does have time, but for her own health, she has never"*. (a male community leader)

Women are less likely than men to consult modern health services, wait longer than men to seek treatment when ill, are reluctant to spend limited resources on their own needs, and often cope with illness by self treatment, by consulting traditional healers, or by simply living with the condition and its resulting discomfort.

Women associate the use of a dispensary, clinic, or hospital services with the health of their children and generally attend health centres primarily to obtain care for their children, although they may also be suffering from a health problem like TB.

"To take care of her own health, a woman must recognize herself as an individual, find herself worthy, strengthen her self-esteem, and have the power to decide about own health." (a female community volunteer)

Regarding the access issues, the community people pointed out that people should be able to receive reliable care close to where they live. However, health facilities are often poorly distributed poor presence of the health personnel, and lack of laboratory facilities for sputum examination. Difficulties in reaching health facilities, lack of traveling costs and receiving poor support from the family, community, and workplace are the major barriers for women to get TB diagnosis in time.

Suggestions for improvement

When discussing various aspects of gender differences, some of the discussion pointed out the problems with the existing public health programmes run by the government, including the TB control programme. It appears that there was poor co-ordinations and collaboration between NTP and the private sector, no role in the policy making process of TB control, DOTS strategy and other activities of the physicians working in the private sector. Thus it is needed to develop a strong public private partnership mechanism ensuring referral of the patients to DOTS centres, their respect ensures full course of TB treatment, and regular feed back of the treatment to the private physicians of their referred patients from the DOTS centres (public sector). Doctors in the private sector were considered to have less knowledge about tuberculosis diagnosis and treatment as per the National guidelines developed by the NTP. Therefore they are more likely to prescribe antibiotics or other medications irrationally. Improved knowledge of the doctors who work in the private sector through regular training and orientation from NTP, easier referral to TB diagnosis were mentioned.

Participants of our focus group discussions expressed that social support from others, such as relatives, friends, and neighbors can play an important role in fostering the physical and psychological health of women, and can greatly influence the care seeking behavior to TB treatment of women. Many women, particularly poor women, and those solely responsible for the care of their households, lack the support of the family, someone to tell her to go to the doctor, to take care herself, no one worries about her. Less importance may be placed on the health of female members of the household, compared with male members, and consequently, a woman's TB illness may receive little attention from others. Although men are

strongly pressured by other family members, particularly from mothers and wives, to seek medical treatment for TB and other types of diseases, women are unlikely to receive such back-up. *"A woman's role is to nurse, not to be nursed."* (female community volunteer)

- TB awareness activities should be carried at the community level through DOTS centre
- Contact tracing at least those who are close contact of infectious TB cases should be strictly followed up.
- To increase the chances of working women and men receiving TB care, DOTS services might also be established near to working place or at working places (factory and industries).
- Public and private partnership activities need to be ensured both in rural and urban settings, not only at district or national level but also at the DOTS centre level.
- Women need to be broadly educated about the importance of regular health care for themselves, as well as for their children. Because women tend to place great importance on their children, it may be useful to present health educational messages and awareness activities that instill the notion that it is important that a mother be healthy to maintain her child's health.
- Health service must be sensitive to the shame and embarrassment. If the stigma associated with TB is recognized, health services could improve the prospects of involving mothers' groups, as community volunteers in the DOTS system.
- Health facilities must be made more accessible to improve their use in the prevention and control of diseases like TB, leprosy and others. Mobile clinics or the provision of collection of sputum samples and transportation to the microscopy centre might greatly improve timely diagnosis of TB especially for women.
- A women centred strategy would be required such as encouraging and involving community female health volunteers to visit homes or organizing TB educational advocacy meeting at the community level. This would promote identification of TB suspects and referral to TB diagnosis centre.
- Health personnel should educate TB patients of contacts' examinations and the value of contact tracing. In this way delays in TB diagnosis and treatment could be reduced and the chain of transmission would be cut down.

Chapter V
Discussion and summary findings

Help seeking behavior of tuberculosis patients

Cough followed by chest pain were the main symptoms reported by both male (97.5%) and female (93.1%) patients. These findings are consistent with reports from India 98% (Rajeswari, et al. 2002), Egypt 96%, Iraq 94%, Pakistan 100%, Somalia 98%, Yemen 98% (World Health Organization. Regional Office for the Eastern Mediterranean [WHO-EMR], 2006) and Vietnam male 94.7% and female 90.7% (Long et al. 2002) where tuberculosis patients presented with cough while 61% of patients in Malawi presented with cough and 16% with fever (Salaniponi, et al. 1991). By contrast, weight loss (82%) was the most frequent symptom reported from the Islamic Republic of Iran followed closely by cough (80%) (WHO-EMR, 2006). It is worth mentioning that sputum smear positive pulmonary tuberculosis is usually initially suspected by the cough symptom. It might be that more missed cases occur among those who have other symptoms.

About 27.6% of the female and 19.5% of the male patients entered the DOTS system by first accessing the traditional healers as their entry point. Most female patients acknowledged accessibility (near, convenient and cheap) of traditional healers and greater opportunity to keep disease secret as the main reasons for seeking initial care from the traditional healers. These findings suggest that the choice of health care provider is not only determined by socio-cultural and economic factors, but also by gender. The health seeking behavior differed significantly between males and females with TB suggestive symptoms. Comparable findings reported in a previous study from Nepal that women were more likely to visit a traditional healers first, invoking easy access to them (<30 minutes) (Yamasaki et al., 2001). Other studies in developing countries reported that women in particular reach DOTS treatment through a more circuitous route than men, preferring to seek help first from traditional healers or private practitioners (Ogden, et al. 1999; Thorson, et al. 2000; WHO-EMR, 2006).

In this present study, only 22.4% of the female and 12.7% of the male patients correctly knew that TB is caused by bacteria. About 25.9% of females and 33.1% of males knew that TB is transmitted through droplets. A better finding was reported in the study of Pakistan where 38.2% of the patients knew that TB is contagious disease and much better findings were reported in Egypt, Iran, Yemen, Iraq, Somalia, and Syria where the majority (about 75%) of the

patients knew that TB is a contagious disease (WHO-EMR, 2006). This is key information that should be well communicated to the community to cut the chain of transmission of the disease. A significantly lower level of knowledge about TB disease was reported in our study population that could lead to delay in seeking of health care, compared to other developing countries. This highlights the need for better community health education in Nepal.

Patient delay

Patient delay can occur during the process of recognizing symptoms, determining if one is ill, assessing the need for medical help, and overcoming personal, social, and physical barriers to obtaining care (Eastwood & Hill, 2004). The median duration between onset of symptoms and help seeking behavior were not significantly varied between male and female patients. The median patient delay was 2 months for male and also2 months for female patients. Corresponding findings were reported in Vietnam 7.9 weeks for women and 7.6 weeks for men (Long et al., 1999), and in United Kingdom it was 26 days for males and 50 days for females (Paynter et al., 2004). Nevertheless, studies from Teheran (15.5 weeks for male and 10.5 weeks for female) (Masjedi et al., 2002), and Turkey (35.2 days for male and 25.7 days for female) (Guneyliogiu et al., 2004) reported that patient delay tended to be longer in men than women, while in South India (14 days for male and 14 days for female) (Balasubramanian et al., 2004) and Australia (median 27 for male and 30 for female) (Ward et al., 2001) there were no gender differences in patient delay. It suggests that patient delay is influenced by gender (rather than sex) and gender related roles in different settings and societies. It is also a reflection of how the health system treats the issue of gender equity and equality to health in different county.

Provider delay

The median duration between the first help seeking and receiving diagnosis and treatment was 1.65 months for female and 1 month for male patients. A previous study in a rural district in Nepal reported similar results i.e. 1.3 months for female and 0.8 month for male (Yamasaki et al., 2001). Studies in other developing countries reported similar findings to ours. Turkey 19.1 days (mean) for male and 26.6 days for female (Guneyliogiu et al., 2004), South India 30 days (median) for male and 37 days for female patients (Balasubramanian et al., 2004) and United Kingdom 26.5 days (median) for male and 41.5 days for female patients (Paynter et al., 2004). However, longer health system delay was reported in Teheran,74 days for male and 112 days for female (Masjedi et al., 2002), while in Australia there were no gender differences in health system diagnosis delay (22 vs. 23 days) (Ward et al., 2001).

Total delay

The median duration between onset of symptoms and treatment started was significantly longer in both sex (3.18 for males and 3.05 months for females). It was found similar for females and quite different for males in the previous study in Nepal (99 days for females and 69 days for males) (Yamasaki et al., 2001). It was reported longer total delay among female than male (93 vs. 77.5 days) in the study carried out in United Kingdom (Paynter et al., 2004), while significantly shorter total delay was mentioned among female than male (90 vs. 120 days) in the study from Brazil (Martinho et al., 2005). Various mean delay durations were reported from different countries: 60 days from India (Rajeswari et al., 2002), 87.5 days from Malaysia (Sherman et al., 1999), 100 days from Pakistan (WHO-EMR, 2006), 79.5 days from Somalia (WHO-EMR, 2006), and 127 days from Iran (WHO-EMR, 2006).

Summary findings

The median patient delay was similar in both sexes. But it was observed that provider delay was significantly longer in female than male patients.

The DOTS strategy has been successfully implemented in Nepal with the financial and technical support of WHO, IUATLD, LHL, JICA and other donor partners. However, longer delay in diagnosis under-detection of women found in our study highlights a need for a discussion on gender equity aspects of the internationally recommended DOTS strategy. Gender equity should be the guiding principle for the TB patient-provider encounter, and interventions seem urgently to be needed in order to increase the gender sensitivity of all aspects of the health care seeking journey leading to TB diagnosis and treatment.

The risk factors for patient delay and provider delay identified in this study should be the area under discussion of future interventions in order to reduce delay in delivery of DOTS treatment to tuberculosis patients in general and female TB patients in particular, and hence transmission of the disease in the community.

Female patients aged more than 34 years had longer patient delay than younger patients ($p = 0.05$) but patient delay did not differ with age in males. Patient delay was significantly longer in rural males than urban males. Patient delay was observed varied by types of occupation and it was found statistically significant in males ($p=0.013$). The patient delay was significantly shorter in males ($p=0.026$) and females ($p=0.05$) who knew TB is a communicable disease

For female, the shortest median diagnosis delay was reported by patients who first visited to government facilities and the longest median diagnosis delay was reported by patients who first visited to traditional healers and drug store. For male, the shortest median diagnosis delay was reported by patients who did not visit any type of providers and made visits directly to DOTS centre and the longest median diagnosis delay was reported by the patients who first visited either private doctors or traditional healers.

Recommendations and policy implications

- To address gender inequalities in access to DOTS centres and to increase case detection among women, NTP should have to put more efforts by integrating DOTS services with other existing health services at all levels.
- Efforts should be made to increase public awareness about the symptoms of tuberculosis and about the importance of early care seeking behavior, by including development of behavior change communication audio, visual, and print materials, especially targeting women.
- Efforts should be made to increase public awareness about the availability and location of free TB diagnosis and treatment services.
- Efforts should be made to educate both public and private physicians, and other paramedics, about the need to maintain a high index of suspicion of tuberculosis and rapidly performing appropriate tests or immediately referring to DOTS centres. Sputum must be examined in all patients with persistent cough, and negative investigations should be repeated.
- Patients must be counseled on the importance of sputum tests and production of quality sputum.
- Effective collaboration should be developed between private and NTP providers to ensure an effective public private partnership.
- Training and retraining of both private and public health care providers about tuberculosis at regular intervals should be instituted.
- Efforts should be made to involve private medical establishments in DOTS monitoring and evaluation process at regular intervals.
- Efforts should be made to develop a network of former cured TB patients at all DOTS centres, and to utilize them as DOTS advocators/ambassadors at the community level.
- The various delay durations identified in the present study should be incorporated into routine surveillance reports. Date of symptoms onset and date of first contact to any type of

providers would be recommended to incorporate in the TB treatment card as well as TB register. This would allow monitoring of the effectiveness of the interventions and control measures in reducing the duration of delay, hence reducing the transmission and burden of tuberculosis in the community.

- Improve quality of care at public health facilities, focusing on reducing waiting times and better inter-personal quality of care, in order to attract patients from the private to public sector and reduce direct costs. Building community and patient trust in lower level public facilities is a key challenge.
- Invest in health services that are closer to clients (WHO, 2001), to reduce excessive transport and time costs, and also to reduce the direct medical costs incurred at private providers including traditional healers.
- Decentralization of DOTS services may reduce patient costs substantially, but range of service delivery capacities need to be in place before decentralization can be implemented effectively.

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Appendix A

Qualitative study

Guidelines for focus group discussions

- **Introduction:** Introduce name of the facilitators and participants.
- **Objective of the study:** To elicit perception, etiology, symptoms, belief, stigma, treatment seeking behavior, treatment practices among various groups.
- **Length of the Discussion.** The discussion session lasted approximately 1 and 1/2 hours.
- **Confidentiality:** Participants were assured of confidentiality and the possibility to withdraw at any time.
- **Tape recorder.** The sessions were tape recorded.
- **Refreshments.** Refreshment was served during the discussion.

FGD 1, Key questions: Tuberculosis patients both for men and women
• Is there a gender difference in perception about TB? (Probe: how and why?) • Are there any differences in interpretation of cause of TB between men and women? (Probe: how and why?) • Who does normally make decision for care if somebody gets sick in the family? What is a gender role in the family? • Is there a gender difference in seeking care? Why? • In your opinion, how your group can do in reducing the gender gaps in health seeking behavior in TB?

FGD 2, Key questions: Community members
• Believes one sex is inferior to another. What is your opinion? • Believes being a man/woman prevents them for discussing health problem. What is your opinion? (Probe: why?) • Being a man/woman they need permission to go to health facilities. What is your opinion? (Probe: why?)

- Is there a gender difference in knowledge about TB? (Probe: how and why?)
- Is there a difference in delay help seeking behavior between men and women? Why?
- In your opinion, how the community group can do in reducing the gender gaps in health seeking behavior in TB?

FGD 3, Key questions: private practitioners

- Do you think there is gender difference in help seeking behavior?
- More female/male tends to seek care in private sector than public sector. What is your opinion? Why?
- Is there a gender difference in delay presenting to seek care? (how and why?)
- Why do the patients seek care in private sector even though DOTS treatment is free in public sector? Any gender differences in this? (Probe: how and why?)
- In your opinion, how your group can do in reducing the gender gaps in health seeking behavior in TB?

FGD 4, Key questions: DOTS providers

- There is gender difference in accessing DOTS services. What is your opinion?
- There is gender difference in concealment of TB diagnosis. What is your opinion? Why?
- Being a man/woman they need companion to go to DOTS centre. What is your opinion?
- Why do the patients seek care in private sector even though DOTS treatment is free in public sector?
- In your opinion, how the NTP or government can do in reducing the gender gaps in health seeking behavior in TB?

Quantitative study

QUESTIONNAIRES

Gender differences in delays in initiating directly observed treatment among new sputum smear-positive pulmonary tuberculosis patients in Far western region of Nepal

The main objective of this study is to investigate gender differences in delays in initiating DOTS treatment among smear positive pulmonary patient. Face to face interview was carried using structured pre-tested questionnaires by trained interviewers. The right of the participants to decline to participate or to reply specific questions was respected. The confidentiality was maintained throughout the study.

Date of interview: dd/mm/yy: _____

Name of interviewer: _____

Name of the DOTS centre: _____

Part I: Diagnosis and treatment information:

The following information was obtained from TB laboratory register, TB register, referral note, TB treatment card, and TB patient card.

1. Name of the patients: _____
2. Address:_____
3. Sex: □ **1=** Male □ 2= Female
4. Age: _____years old
5. Date of diagnosis : _____(dd/mm/yy)
6. Date of registration for TB treatment: _____(dd/mm/yy)
7. TB registration number: _____
8. Date of treatment initiation:_____(dd/mm/yy)

Part II: Socio-demographic and socio-economic

Socio-demographic factors:

9. What is your marital status?

   ( ) 1 = Unmarried ( ) 2 = Married

   ( ) 3 = Widowed ( ) 4 = Divorced

10. What is your residence?

    ( ) 1= urban ( ) 2= rural

11. What is your highest educational status?

( ) 1 = Illiterate ( ) 2 = Primary (1-5 grade)

( ) 3 = Lower secondary (6-8 grade) ( ) 4 = Secondary (9-10 grade)

( ) 5 = Higher secondary and more ( ) 6= Simple read and write

12. What is your main occupation?

( ) 1 = Farmer ( ) 2 = Daily laborer

( ) 3 = Housewife ( ) 4 = Government service

( ) 5 = Private service ( ) 6 = Student

( ) 7 = Merchant ( ) 8 = No work

( ) 9 = Others (specify) _____

Onset of symptoms:

13. What was/were your first symptom (s)? (may check more than one)

( ) 1 = Cough ( ) 2 = Chest Pain

( ) 3 = Coughing up blood ( ) 4 = Fever

( ) 5 = Weight loss ( ) 5 = Loss of appetite

( ) 6 = Night sweats ( ) 7 = Weakness

( ) 8 = others (specify) _____

14. What month and year did your first symptoms start?

_____Day _____Month, _____Year

_____days before, _____month before, _____years before

15. When these symptoms started as you mentioned above?

( ) 1 = Exact date _____day _____month _____Year

( ) 2 = Early days of the month ( ) 3 = Middle days of the month ( ) 4 = Late days of the month ( ) 5 = Not sure

If response is 1, go to question 17

16. Was there any special occasion or festival or other important event when your first symptom started?

( ) 1 = Yes specify_____( ) 2 = No ( ) 3 = Unsure

17. how did you suspect them as the TB symptoms?

( ) 1 = Self ( ) 2 = friends

( ) 3 = family members ( ) 4 = former TB patients

( ) = newspaper ( ) 5 = radio

( ) 6 = television ( ) 7 = Health provider

( ) 9 = No idea ( ) 8 = others specify _____

Help seeking behavior

18. Did you seek any treatment before coming to the DOTS Centre for TB?

( ) 1 = Yes ( ) 2 = No (If no go to question no. 26)

If yes, what are pattern, frequency of visit, cost paid to the provider, reasons to visit, and interval between onset of symptoms and visit made (multiple answers and order in time starting with earliest, moving to latest as follows,

Treatment seeking patterns: 1= Self medication, 2 = Traditional healers, 3 = Private physician, 4 = Private pharmacy, 5 = Nursing home, 6 = Public hospital, 7 = Ayurvedic centers, 8 = Spiritual centers

Reasons to visit (why): 1 = to keep disease secret, 2 = nearer, 3 = convenient time, 4 = Cheap, 5 = Referred by family member, 6= others (specify) _____

Treatment seeking pattern	Frequency of visit	Cost paid to provider (NRS)	Reasons to visit	Interval between onset of symptoms and visit (days)	Did sputum examine?

19. How long after onset of symptoms did you visit to DOTS center?

Days _____, or Month _____, or Year _____

20. Did any of the following cause you to delay seeking DOTS treatment? (Check more than one)

( ) 1 = DOTS center too far ( ) 2 = Lack of money

( ) 3 = Lack of awareness of DOTS services ( ) 4 = Could not go alone

( ) 5 = Fear of isolation ( ) 6 = Don't like to label as TB ( ) 7 = Blockade of road ( ) 8 = Unfriendly health worker ( ) 9 = Treatment from private providers ( ) 10 = Busy with work

( ) 11 = taking care of children ( ) 12 = Busy with housework

( ) 13 = No

21. Did any of the following sources of information help you decide to visit DOTS Centre? (Check more than one)

( ) 1 = Television ( ) 2 = Radio

( ) 3 = Former/current TB patient ( ) 4 = Friends

( ) 5 = Family members ( ) 6 = Pharmacy

( ) 7 = Traditional healers ( ) 8 = Private doctor

( ) 9 = Newspaper ( ) 10 = Public health facility

( ) 11 = Others (specify) _____

Psycho-social factors

Knowledge about TB and its treatment

22. Do you know TB is a communicable disease?

( ) 1 = Yes ( ) 2 = No ( ) 3 = Not sure

23. What is the most important symptom of TB? (Check only one)

( ) 1 = Fever in the evening and night sweat ( ) 2 = Chest pain

( ) 3 = Cough with blood ( ) 4 = Loss of weight

( ) 5= Loss of appetite ( ) 6 = Cough for 2 weeks/more

24. What is the cause of TB? (Check only one)

( ) 1 = Smoking ( ) 2 = Alcohol drinking

( ) 3 = Heredity ( ) 4 = Hard work

( ) 5 = Bacteria ( ) 6 = Cold

( ) 7 = Poor diet ( ) 8 = Witch

( ) 9 = Don't know ( ) 10 = others (specify) _____

25. How does TB transmit? (Check only one)

( ) 1 = Inherited ( ) 2 = sharing same utensils

( ) 3 = Contact with a TB patients ( ) 4 = Hand shaking

( ) 5 = Don't know ( ) 6 = Others (specify) _____

26. What is the most important method of TB diagnosis? (Check only one)

( ) 1 = Chest X-ray ( ) 2 = Sputum examination

( ) 3 = Blood examination ( ) 4 = Stool examination

( ) 5 = Others (specify) _____ ( ) 6 = Don't know

27. Is TB a curable disease?

( ) 1 = Yes ( ) 2 = No ( ) 3 = Not sure

28. What is the most important benefit of DOTS? (Check only one)

( ) 1 = DOTS can completely cure the TB disease

( ) 2 = DOTS can make good relationship with health staff

( ) 3 = DOTS treatment is free

( ) 4 = Don't know

Perception about TB disease

29. Perceived TB as

1= Really dangerous, 2= Quite dangerous, 3= Slightly dangerous

4= Not dangerous, 5= Don't know

30. Perceived risk of acquiring TB

1= Could get TB easily, 2= May get TB, 3= Probably would not get TB

4= Definitely would not get TB, 5= Don't know

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Profile

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