

**Community Perceptions and Experiences
of TB in Kanchanaburi, Thailand:
A Gender Equity Analysis**

Amara Soonthorndhada
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Foreword

First and foremost we would like to thank the British Council/ Department for International Development (DFID) for granting support for our Higher Education Link between the Institute for Population and Social Research, Mahidol University and the Gender and Health Group, Liverpool School of Tropical Medicine, United Kingdom. We also thank the British Academy South East Asian Award, the DFID funded Tuberculosis Knowledge Programme at the Liverpool School of Tropical Medicine for supporting our research.

It is promising to see the increasing awareness of how gender roles and relations affect vulnerability to TB and treatment experiences. This is a challenging area that is fairly new in the Thai context but is increasingly recognised in both teaching and research. Researchers and policy makers are using gender analysis as a tool to provide important insights into equitable and sustainable disease control strategies.

Research examining sex and gender differences in the epidemiology of other tropical diseases has already yielded useful information. In the case of tuberculosis there is an estimated 2:1 male-to-female ratio of cases notified to public health authorities worldwide. A recent review examined possible socio-economic, gender and cultural factors underpinning these differences and called for further research to clarify our knowledge of how sex and gender shapes the epidemiology of tuberculosis.

The report brings together theoretical perspectives and practical research on gender and health care. This report provides an important framework and includes recommendations of novel ways to mainstream gender in communicable disease control programmes.

Most importantly, the case studies in this report examine in detail practical efforts to engender health programmes and services so that they respond directly to the needs of both men and women.

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We would like to thank the community members and health workers of Trakam-En sub-district, Tamaka District, Kanchanaburi province who generously shared with us their time, ideas and experiences. This research took place as part of a British Council/ Department for International Development Higher Education Link between the Institute for Population and Social Research, Mahidol University and the Gender and Health Group, Liverpool School of Tropical Medicine, UK. We are also grateful to the British Academy South East Asian Award, the Tuberculosis Knowledge Program at the Liverpool School of Tropical Medicine for providing additional funding to make this research possible. We are also delighted to have had the opportunity to make use of the Wellcome Trust funded data set from the Demographic Surveillance Survey, Kanchanaburi Project.

We own enormous thanks to Associate Professor Dr. Bencha Yoddumnern-Attig, Director of the Institute for Population and Social Research, Mahidol University for her insightful vision and recognition of the importance of gender and health research. Ms. Auraphan Hanchangsith, Head of Administrative Office and her staff deserve our thanks for their endless logistical assistance, which enabled the project to run smoothly. Warm thanks and appreciation go to Ms. Prathip Naiyana, Mr. Somchai and Mrs. Jutharat Supyodkaew for preparing the layout of the report with great care.

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Executive Summary

Gender analysis has untapped potential in responding to the challenge of tuberculosis (TB) prevalence in Thailand. A gender perspective is sensitive to the ways in which gender roles and relations, age, ethnicity, geographical location and socio-economic status interact to affect vulnerability to ill-health and ability to enjoy quality health care. Applying a gender analysis can enable a clearer understanding of how gender identities shape the complexity of the epidemic and inform more equitable and effective policy.

Tuberculosis is on the increase in Thailand, triggered mainly by the unfolding HIV epidemic. In an attempt to control the increasing prevalence, the Thai TB Control Programme is employing the World Health Organization Directly Observed Therapy Short course (DOTS) strategy, with an emphasis on Directly Observed Treatment (DOT) in the community. DOTS is a challenging process given the current economic climate in Thailand; economic depression has direct repercussions for the effective management of health services and impacts on health seeking behaviour and adherence to treatment, especially among the poor, who are more vulnerable to tuberculosis.

Current research in Thailand focuses largely on quantifiable indicators of TB prevalence, which do not provide adequate explanations of risk and vulnerability to TB. Exploratory studies, using qualitative methods, can help to understand how TB and TB treatment is perceived and experienced at the community level. This report presents the findings of a qualitative study that explores community and TB patients' perceptions of TB. Chapter one provides an overview of TB in Thailand and in Kanchanaburi province, and describes the study design and methods. Chapter two details key themes emerging from community based interviews and focus group discussions around perceptions and experiences of TB in Takram-En sub-district, and discusses the implications of these for stigma and treatment at the health centre and in the community. Chapter three interprets the findings, compares and contrasts the experiences from other parts of Thailand and Asia and draws implications for policy, practice and further research. Concluding comments are outlined in Chapter four.

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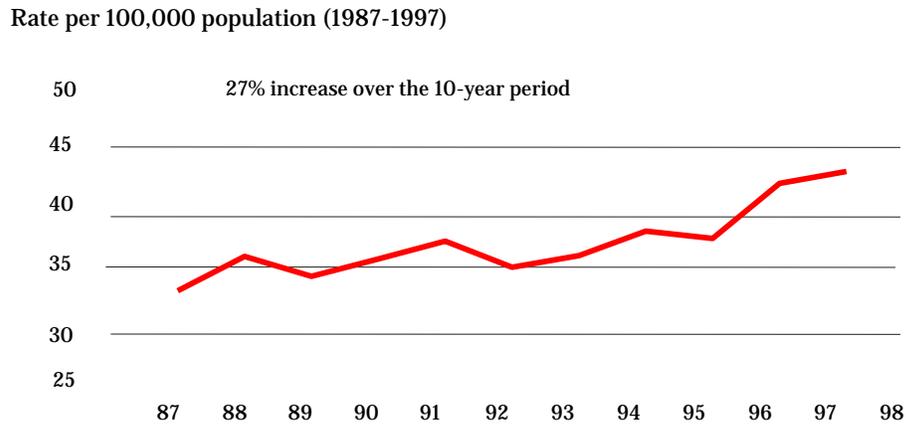
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The Changing Dynamics of TB in Thailand

1.1 Background

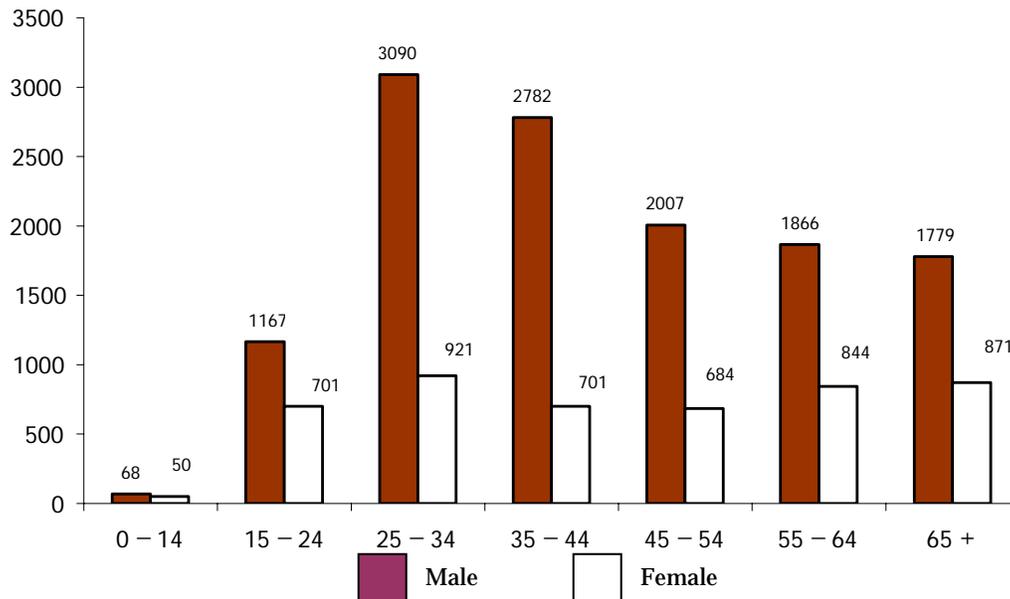
After a steady decline in TB prevalence, Thailand has experienced a recent re-emergence in new TB cases. The country experienced a continuous decline in tuberculosis incidence in the four decades following the Second World War (Ministry of Health, 1999). The reported mortality from the disease declined tenfold from a rate of 65:100,000 in 1945 to 6.2:100,000 in 1977 (Ministry of Health, 1999). The overall socio-economic development of the country, combined with activities of the National Tuberculosis Control Programme (NTP) is thought to be responsible for this decline. Continuous reports of notified cases are available since 1980. The highest reported incidence rate of 150:100,000 was observed in 1985; the rate then declined to 76:100,000 in 1991 (Ministry of Health, 1999). At the beginning of 1990s, an increase in case notifications was observed nationwide; for example in 1993 incidence rates were measured at 85:100,000, and for the year 2000 incidence rates were estimated to be approximately 160:100,000 of which approximately 20% were attributed to the impact of HIV epidemic (TB Control Programme, 2000). Figure 1.1 shows reported smear and pathologically confirmed TB illustrates the increased incidence in Thailand from 1987-1997.

Figure 1.1 Smear and pathologically confirmed TB in Thailand 1987-1997

Source : TB Control Programme, 2000

Post-1990 increases in TB incidence are largely attributed to the HIV epidemic (Ministry of Health, 1999). In Thailand the HIV epidemic is occurring alongside increasing urbanisation, industrialisation, migration and poverty. These processes of change affect men and women from different socio-economic groups in different ways, and arguably contribute to increasing rates of TB prevalence, although there is little supporting research. There are no national figures available that show the proportion of male and female People Living with HIV/ AIDS (PLHA) infected with TB, or the proportion TB patients who are HIV positive. Figures that break down TB prevalence by gender and age are only available at a national level, as detailed in Figure 1.2.

Figure 1.2 Age and gender distribution of the number of new smear positive patients 1994-1997



Source: TB Control Programme, 2000

The graph shows that more men than women are diagnosed with TB in each age group. The overall pattern of TB incidence by gender and age in the latter part of the 1990s is similar to HIV prevalence, although there is higher proportion of women with HIV amongst the lower reproductive age group (20- 25 years) than the corresponding TB age category. This pattern may change as co-infection with TB and HIV becomes more common.

1.2 The Thai TB control programme

DOTS history and background

Thailand adopted the international Directly Observed Treatment Short-course (DOTS) strategy as the core policy of the National Tuberculosis Programme NTP in 1996. The DOTS strategy consists of the five key

elements stipulated by WHO, namely political commitment, case detection through sputum microscopy, Directly Observed Therapy (DOT) with standardised regimen, regular drug supply and monitoring system with evaluation of treatment outcome for each and every patient by cohort analysis (Ministry of Health, 1999). Prior to 1996, supervised treatment was limited in some parts of the country due to a lack of central policy. The re-emergence of TB, associated morbidity and mortality, and increasing rates of drug resistance has prompted renewed commitment to effective treatment. The national health policy 1997 regards DOTS as a priority area.

DOTS coverage is not uniform across Thailand. The programme is very successful in some regions such as in the North-East where all districts have implemented DOTS but less so in other regions. Only 20% of the provinces in Chiangmai and Bangkok have implemented DOTS (Ministry of Health, 1999). In 1998, the DOTS programme covered 40% of districts. In these districts it has been noted that:

- ⊗ *Current conversion rate in DOTS area is 72-85% with an average of 79%*
- ⊗ *Cure rate varies from 60-81%*
- ⊗ *People co-infected with TB and HIV have a high mortality rate of 20-30%, despite DOTS.*

Source: *TB Control Programme, 2000*

Addressing the gaps in DOTS coverage and implementing the strategy country-wide is an important challenge for the Thai National TB Control Programme. WHO estimates that all districts in Thailand will be covered by 2003 (World Bank, 2000).

Organisation of DOTS services

The TB Division of the Department of Communicable Disease is responsible for policy development and planning, training health workers

and monitoring of TB control throughout Thailand. National coordinators monitor the four geographical regions (North, Northeast, Central and South) and provincial TB coordinators (PTC) operate in each province. There is considerable variation in the level of staffing for TB control between the provinces.

DOTS implementation is decentralised to the district, which is the unit of management for TB control. Doctors in district and provincial hospitals that have laboratory and X-ray facilities conduct diagnosis of TB. TB clinics (which usually reside in the Social Medicine section of hospitals) register people with TB and maintain treatment cards. There are 3 options for DOT in the national TB control guidelines:

- 1) Daily DOT at a health centre
- 2) Daily DOT by village health volunteers
- 3) Daily DOT by family members

Thailand has a policy of free care for tuberculosis patients, stating that there should be no charges for diagnostic services (follow-up sputum examinations and X-rays) or anti-tuberculosis drugs (Kamolratanakuk et al, 1999).

1.3 TB in Kanchanaburi province

Organisation of treatment

In Kanchanaburi TB treatment is organised within the DOTS framework, and there are different types of DOT providers. Table 1.1 shows the breakdown of DOT providers in Kanchanaburi over an 18-month period.

Table 1.1 Type of DOT provider in Kanchanaburi October 2000 – January 2002

	Health Care Worker	Health Volunteer	Family Member	Other	Total
October 2000 – Jan 2001	3 (6%)	5 (10%)	42 (84%)	0 (0%)	50 (100%)
Jan 2001 – Sept 2001	7 (10%)	20 (28%)	42 (62%)	0 (0%)	69 (100%)
October 2001- Jan 2002	14 (10%)	24 (18%)	95 (70%)	2 (2%)	135 (100%)
Total over 18 months	24 (10%)	49 (19%)	179 (70%)	2 (1%)	254 (100%)

Source: CDC Unit, Health Provincial Office, Kanchanaburi 2002

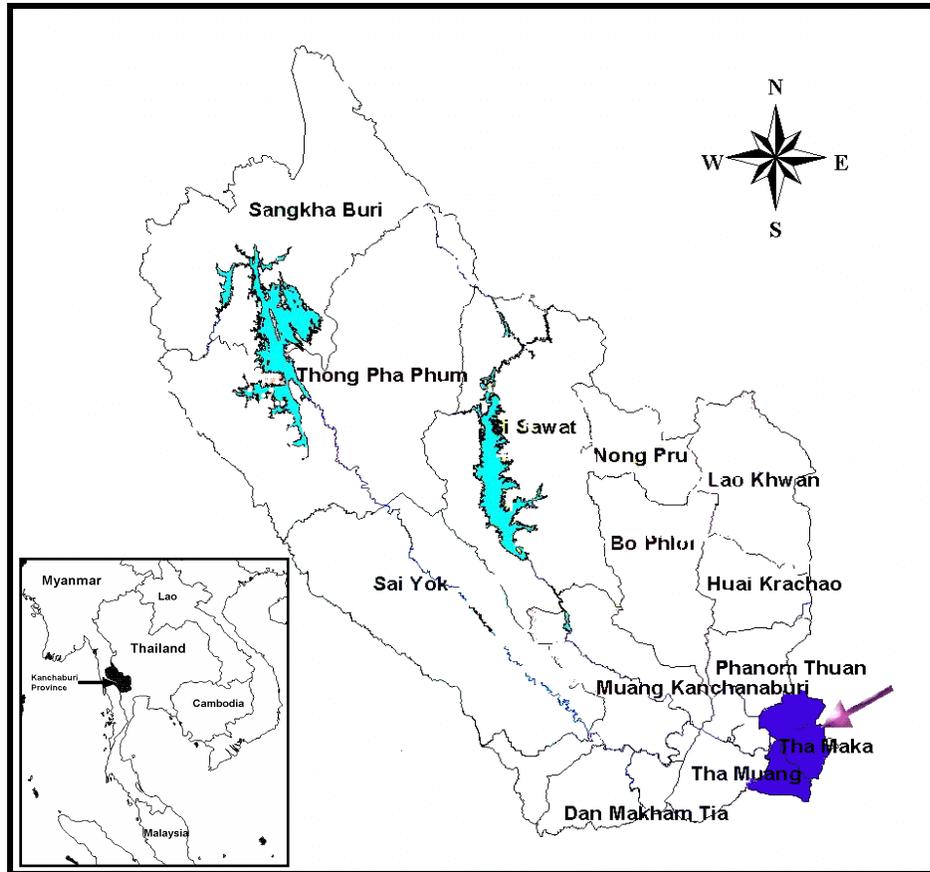
The table shows that, in each 6 month period and overall, the most popular choice of DOT provider is a family member (70%); followed by health volunteer (19%) and then health care worker (10%).

TB prevalence and selection of study site

The National TB statistics collected routinely by the National TB Control Programme. The TB prevalence rate in Kanchanaburi in 2000 was 48.01/100,000 population as compared to 70/100,000 for the whole country TB Division, 2002). There were 960 cases of confirmed pulmonary positive TB in Kanchanaburi Province in the year 2000 (ibid.).

The provincial TB control records are disaggregated by district. Of the 960 confirmed cases in 2000, the highest number (172 cases) were from Tamaka district. Scanning these data with the help of the district TB officer revealed that Takram-En sub-district had the highest prevalence (36 reported cases) (personal communication). Further disaggregation of the data by gender showed that of these 36 cases, 20 were male, 14 female and 2 had passed away.

Figure 1.3 Location of Tamaka district, Kanchanaburi province



A survey funded through the Wellcome trust and conducted by the Institute for Population and Social Research, (Mahidol University) provides another source of information on TB prevalence in Kanchanaburi. The survey is part of a five-year population platform project and socio-demographic and health data are collected annually using a stratified sample designed to randomly select 86 villages in rural areas and 14 census blocks in urban areas (IPSR, 2000). To determine the health of the population, respondents in 2000 were asked to report if members of their household had been sick. The following wording was used: *In the past month, did you have any*

disease or did you feel sick (include both minor and serious sickness as well as accidents).'

Analysis of survey responses from the year 2000 survey showed that 86 cases reported that they, or their family members, were ill with TB; of these 59 were male and 27 were female. The IPSR survey data confirmed the findings from National TB statistics - that Tamaka district had the largest amount of people reporting TB (analysis of IPSR data). Hence we purposively chose Tamaka district as our study site because both the IPSR data and the National TB statistics confirmed that Tamaka had the highest number of TB cases in Kanchanaburi province. This is discussed further in the following chapter.

2.1 Study site

Both data sources (provincial TB control programme prevalence data and the IPSR survey) confirmed that Tamaka district had the highest levels of TB prevalence in Kanchanaburi. The two different data sources also confirmed that Takram-En sub-district had the highest TB prevalence in Tamaka District. We therefore purposively selected Takram-En as the study site, since community members were more likely to have come into contact with TB, either personally or through family and friends. In-depth enquiry into community and individual perceptions about TB would therefore be more meaningful.

2.2 Study design

We used an exploratory design with qualitative research methods. The goal of qualitative research is ‘to understand social phenomena in natural (rather than experimental) settings, giving due emphasis to the meanings, experiences, and views of all the participants’ (Pope and May, 1995). This design is appropriate for understanding in depth community perceptions and experiences of different groups within a particular context.

2.3 Objectives:

The following objectives were explored using a gender–equity framework, that is focusing on the inter-relationships between gender, age, socio-economic status.

- 1) To explore community perceptions about TB, particularly language, aetiology, and associated stigma amongst different groups.
- 2) To explore TB patients experiences and perceptions of TB.
- 3) To develop recommendations for training, health promotion and community supported treatment strategies.

2.4 Methods and participants

Table 2.1 shows data collection methods used to obtain data for each objective. Methods are described in detail below.

Table 2.1 Data collection methods

Objective	Methods	Data collected
1. To explore community perceptions about TB.	Focus group discussions - Community members: Male and female, young and old - Village Health Volunteers	Knowledge about TB causes, symptoms; language used to describe TB; perceptions of stigma.
2. To explore TB patients' experiences and perceptions of TB.	In-depth interviews with four TB patients	Knowledge about TB causes, symptoms; language used to describe TB; perceptions of stigma, and support from family and community; treatment seeking and barriers to adherence
3. To develop recommendations for training, health promotion and community supported treatment strategies.	As above plus in-depth interviews with health workers	As above

Objective 1 - To explore community perceptions about TB

We conducted 4 *focus group discussions* with community members in village one (village identity confidential):

- ⊗ Men under 30 years of age
- ⊗ Women under 30 years of age
- ⊗ Men over 30 years of age
- ⊗ Women over 30 years of age

In village two we conducted a Focus Group Discussion with:

- ⊗ Village health communicators (VHVs), who were all female

Each group comprised 5-8 participants. The group discussions took place at the village meeting place. We started group discussions with a body mapping exercise; we provided pens and flip charts and asked the participants as a group exercise to draw what they saw when they thought about TB. This was a useful starting point from which to explore issues around community perceptions of TB and understandings of TB aetiology. Language and stigma associated with the disease were also discussed. The group discussion with the VHVs also focused on their roles and responsibilities regarding the health of their village, and in particular suspected or confirmed TB patients. The focus group discussions enabled us to have an understanding of how the interactions between participants shaped their perceptions and understandings of TB.

Objective 2 - To explore TB patients' experiences and perceptions of TB.

We conducted four *in-depth interviews* with TB patients identified by the health workers in Takram-En (2 men and 2 women). The in-depth interviews were conducted at the homes of three TB patients and at the work place of one. We explored individual patients perceptions of symptoms, aetiology; their experiences of TB, support from family and community and barriers to adhering to treatment.

Objective 3 - To develop recommendations for training, health promotion and community supported treatment strategies.

In addition to the above methods, we conducted *in-depth interviews* with the following key informants:

- ⊗ 2 male health workers from Takram-En Health Centre
- ⊗ 1 female nurse

The interviews with the health workers took place at the health centre. The interviews elicited information about TB incidence and processes of treatment seeking and referral in Takram-En.

2.5 Data analysis

With the consent of participants, all interviews and focus group discussions were recorded. All tapes were then transcribed in Thai by one researcher. Each transcript was then translated into English. Analysis of the narrative data was conducted according to the framework approach (Ritchie and Spencer, 1994). Themes were developed from the original topic guides and additional issues raised during interviews and group discussion were considered within the framework. All authors took part in the analysis process – identifying key themes, coding transcripts, and comparing and contrasting experiences between age groups and gender; there was general consensus over the key themes that emerged.

2.6 Quality Assurance

The following mechanisms were used to enhance to quality of the study:

- ⊗ Participant triangulation—comparing the findings from the different participant groups (community members, VHVs, health workers and TB patients)
- ⊗ Methodological triangulation—comparing the responses from different methods focus group discussions and in-depth interviews
- ⊗ Respondent validation—at the end of each interview or FGD the facilitators sense of the key issues discussed were fed back to the participant(s) for comment and discussion
- ⊗ The interviews and focus group discussions were conducted in Thai by experienced qualitative researchers

- ⊗ With the consent of participants all discussions were recorded
- ⊗ All the focus group discussions and interviews were transcribed
- ⊗ An experienced translator translated the transcripts from Thai to English and the translation was checked by one of the qualitative researchers
- ⊗ All authors took part in the fieldwork and were involved in the analysis process

2.7 Ethical considerations

We worked closely with health workers and community leaders to facilitate access to participants from the villages. To maintain anonymity of TB patients we asked health workers to approach participants for interview, explain the purpose of the study and seek informed consent. Interviews were held at the homes of people living with TB in other villages in the district. This was to ensure confidentiality amongst participants. To maintain confidentiality, villages, interviewees and focus group discussion participants are not referred to by name in this report.

3.1 Perceptions and experiences of TB in Takram-En sub-district

Talking about TB: Language and connotations

This section details findings from focus group discussions with community members; then contrasts these findings with the views of individuals with TB (from in-depth interviews).

We asked the five different groups (older and younger males and females from the community and the village health communicators) to describe TB. Younger women and men were only familiar with the term TB (wanna-rok); whereas the older generation and particularly the older men used a range of descriptive terms to describe TB (see Box 1).

Box 1: Words used to describe TB

<i>Older male:</i>	damp lung (pod-chune) infected lung (pod-tid-cha) inflamed lung (pod-ak-sep) lung disease (rok pod) TB (wanna rok)
<i>Older female:</i>	TB (wanna rok) lung disease (rok pod) bumpy diaphragm (tung lom pong)
<i>Younger male and female: VHV (this group was all female in the age range 30-60 years)</i>	TB (wanna rok) TB (wanna rok) Boiled lung (pod pen phae)

Source: Focus group discussions

Most of the older participants felt that there was very little difference between TB and lung disease. However, the connotations of TB (wanna rok) were seen as particularly problematic by older men, for example:

*'Lung disease sounds better. It is not a very fearful name.
Tuberculosis sounds horrible'*
(older male, FGD)

*'TB sounds ugly, nobody would wish to get close to him [a TB patient].
It seems OK with lung disease'*
(older male, FGD)

Older men also referred to how previous generations talked about TB, suggesting that they often linked TB with asthma:

'They called it asthma or laboured breathing, or something like that'
(older male, FGD)

'Some people were sick of asthma, but did not understand it. They thought it was tuberculosis when their breathings would cause them panting symptoms and make them easily'
(older male, FGD)

3.2 The symptoms of TB: What does TB look and feel like?

During the body mapping exercise in the focus group discussions, the younger females drew a 'text book' picture of the lung and the diaphragm. One woman took the lead in the drawing and she was assisted by her peers who discussed the proportions and what colour should be used to depict a lung which is infected with TB. The women all thought that it should be a dark colour although there was some

discussion about whether it should be black, a dark colour, purple plus black or dark green. On probing about why it should be dark one woman responded that:

'The germ enters the lung and make it impossible to purify blood...the lung has to work harder so its colour changes'

(younger female, FGD)

The younger males also talked about the idea of 'black lungs' being linked to TB and one respondent in this group linked TB to:

'the breathing system not bones'

(younger male, FGD)

The older groups talked more about the effects of TB on the external appearance of a TB patient rather than the effect of TB in the internal body organs. This was also reflected in the body mapping exercise with the older groups both drawing an image of a person with TB rather than a diagrammatic picture of the lungs. For example following on from discussion of the body mapping exercise the older males said that TB patients were more likely to be thinner, darker have a pale face and be predisposed to coughing, especially different types of coughing. For example:

'TB would erode inside and [those afflicted] become pale and thin'

(older male, FGD)

'I think it is thinness, paleness and darkened skin'

(older male, FGD)

During focus group discussions, all groups (male, female, older and younger age groups) described coughing as a symptom of TB. Older males and females described coughing with blood present as a definite symptom of TB; typical comments from older groups included:

'Blood coming out while coughing sometimes'
(older male, FGD)

'When coughing heavily, blood would come out in lumps'
(older female, FGD)

Older women also associated frequent coughing with TB:

'If his coughing stops, it is all right, but if he keeps coughing lengthily for months or years he has to get his body examined...'
(older female, FGD)

'If one has TB he will keep coughing continually to the point of almost losing his breath'
(older female, FGD)

Younger men and women also talked about the frequency of coughing and associated it with TB. Comments from younger groups included:

'A person with cold would cough normally, but a person with TB would cough continually'
(younger female, FGD)

'Light coughing such as while having irritation in the throat can be cured, but heavy and frequent coughing could have the assumption that he is a TB infected person'
(younger male, FGD)

When asked about the distinction between heavy and light coughing, the respondents described light coughing as that which derives from a cold. When asked whether people with frequent and heavy coughing were suffering from TB, most of the younger females agreed *'it must be tuberculosis'*. In describing the way a person with TB would cough, one participant suggested:

'He would be coughing a lot with force, throughout the day and night'

(younger female, FGD)

Unsurprisingly TB patients were more familiar and more expressive about the range of symptoms experienced with TB during treatment. Table 3.1 outlines the types of symptoms described by this group.

It is difficult to extract common experiences of TB symptoms and side effects of medication by age and gender with such a small sample of interviewees. However, it is apparent that coughing, pain and fever were common symptoms of TB; some patients' experienced particular side effects, including hair loss (31 year old female) and blurred vision (78 year old male). All TB patients interviewed except the youngest female, found taking TB medication problematic and challenging; many comments related to appetite and relationship with, and enjoyment of food. Responses that clearly illustrate the particular challenges that TB patients face when taking medication, include:

'During the first 2 months of medication it was hard to take medicine, I always threw up, and had pains in the joints'

(31 year old female)

Table 3.1 Summary of TB patients expressed symptoms, side effects, and effect of medication

	Physical effects: pain, coughing and fever	Other effects	Medication/ effects and attitudes towards
Female (age 23)	<ul style="list-style-type: none"> - Coughing for two months; couldn't lie down prior to treatment. - Dry cough, no blood. - More coughing at nighttime. - Fever/headache. 	<ul style="list-style-type: none"> - Couldn't work or get around as usual. 	<ul style="list-style-type: none"> - Appetite returned after starting medication. - Seafood and pickle food should be avoided as they neutralise medication. - No side effects.
Female (age 31)	<ul style="list-style-type: none"> - In knee joints. - Severe pain in stomach for 4 months prior to treatment. - Pain in hands and joints. - Coughing continuously for 3 weeks; coughing and panting. - Coughing especially when cold. 	<ul style="list-style-type: none"> - Weight loss. - Hair loss. - Couldn't wash clothes. - Needs a walking stick. - Tired. - Feels cold. 	<ul style="list-style-type: none"> - Could not eat well. - Cannot take medicines with water, as feel nauseated. - Have to take medicine before bedtime to avoid nausea. - Could eat and sleep more after 3 months of medication.
Male (age 65)		<ul style="list-style-type: none"> - Stopped smoking. - Swollen spots (like shrunken skin) all over body in first 2-3 months of medication. - Eyes became awkward or blurred. - Coarse hands. 	<ul style="list-style-type: none"> - Burning pain in tongue when taking medicine. - Very determined to continue taking medication. - Cannot eat spicy food; food becomes tasteless; eating a meal becomes painful and difficult, and get a numb tongue.
Male (age 78)	<ul style="list-style-type: none"> - Very severe pain the bones, shoulders, lower, upper and middle parts of the left arm. - Has massages to help alleviate pain. - Could not breathe easily. - Panting and coughing, tired and exhausted. 	<ul style="list-style-type: none"> - Blurred vision and itchy skin. - Weight loss. 	<ul style="list-style-type: none"> - No nausea. - It's boring to take medicine and couldn't eat much.

Source: In-depth interviews

'After eating medication for 10 tablets I became thoroughly restless and felt so heated to the point of not being able to empty my bowel. My body was full of heat and slightly jerked all over'
(65 year old male)

3.3 Who is more vulnerable to TB and why?

This section explores the main themes that emerged from focus group discussions with community members about the causes of TB and why particular groups might be more susceptible to acquiring TB. The main themes discussed here include: gender roles and relations (with a focus on social behaviour and working environment); poverty; links with other diseases and biological causes.

3.3.1 Gender roles and relations

All focus group discussion participants and most of the TB patients said that men were more vulnerable to tuberculosis than women; a trend confirmed by indicators of national, provincial and district prevalence. On probing why this is the case participants' responses clustered around two main themes – social behaviour and type of employment:

Social behaviour: 'more men suffer from TB because of smoking and drinking'

Most focus group participants felt that more males than females are infected with TB as they are more likely to drink, smoke and go revelling outside the household. For example:

'men are more likely to have TB because they drink whisky and smoke cigarettes'

(young female, FGD)

Some participants in the younger female group discussion disagreed with this analysis and said that women also drink and smoke so this probably isn't the main reason.

One older woman also pointed out that one person's smoking can make others vulnerable too:

'Women can be vulnerable to TB because the husband smokes...anyone who is around the smoker will be vulnerable to TB as well'

(older female, FGD)

Participants of the older FGDs perceived monks as particularly vulnerable as the public frequently gives them cigarettes:

'Monks would be the first class sufferers, because people like very much to give them cigarettes. They don't know what to do with those cigarettes so they keep smoking. So a lot of monks have been infected with TB. Nowadays they told us not to offer cigarettes to monks when making merit'

(older female, FGD)

Both male TB patients made the link between catching TB and smoking; whereas smoking was not mentioned by either of the female TB patients as a potential risk factor. For example, this was mentioned as a risk factor by a male TB patient:

'I have been smoking palm leaf cigarettes for forty years, since my ordination. I was ordained more than 40 years ago, and I kept smoking ever since'

(male TB patient, 65 years old)

Drinking was also discussed as a risk factor and as a response to the tensions' one can face in life. For example:

'tensions can mean that you turn to drinking, especially amongst the poor, and hence vulnerability to disease'

(older female, FGD)

Working environments: 'Men are more vulnerable because they work harder'

Analysis of focus group discussions revealed that both older and younger males regarded males as more vulnerable to TB as they are more likely to be doing paid work and working 'hard'. When asked who was more vulnerable to TB, responses included:

'More men, the labourers who are working hard'

(young male, FGD)

'More men are working, that is why'

(young male, FGD)

Additionally the male focus group participants made a close link between the increased likelihood of men getting TB and working in polluted or dusty environments rather than in agricultural jobs, outside in the open air:

'Men who work in places with bad air being dusty and polluted'

(young male, FGD)

'It is related to working in heavily polluted places'

(young male, FGD)

'I think the agricultural areas are more transparent. Their environments are not congested. If there is anything to spread it will produce only little impacts, not enough to cause us to get TB'

(older male, FGD)

'I think it is type of factories, not every factory. Some factories have activities that could cause this disease – such as metallic work and polishing'

(older male, FGD)

The older male group agreed that farmers have less vulnerability to TB as they work in the open air; although there was a general feeling that insecticide can also cause inflamed lungs.

'Farmers working in the farm won't catch TB because the environment is not congested, but spreading insecticide could cause inflamed lung'

(older male, FGD)

Finding from the in-depth interviews with TB patients either undergoing TB treatment or cured from TB also revealed links between occupations and TB status. For example the two males both related it to working too hard and working in dusty environments (one as a carpenter). One of the women said that she thought she had worked too hard, and that this had made her body weak and therefore vulnerable to TB.

3.3.2 Poverty

All focus group participants agreed that everyone, regardless of social or economic status, can catch TB. The following quotes illustrate typical responses:

'TB does not discriminate between the rich and poor'

(older male, FGD)

'People of every status could be infected with it'

(older female, FGD)

However, some participants said that poorer people could be more vulnerable either because of the work they do; or as they are less likely to be able to access quality health care, for example:

'Poor people have to go somewhere to works hard, rich people do light work in or around air conditioned offices'

(young male, FGD)

'Rich people could get TB, but they would have better chances of getting cured'

(older male, FGD)

3.3.3 Is TB linked with other diseases?

Many participants connected TB with other diseases. Older men made an association between TB and asthma:

'Asthma could be similar because people who have those diseases have difficulty in breathing—Asthma could develop to TB'

(Older male, FGD)

There was much discussion around whether there is a link between HIV and TB with some differing views. Some of the younger men saw no link between the two:

'No association -TB is caused in the breathing system but AIDS is caused in blood vessel and sexual relationship'

(younger male, FGD)

'AIDS is caused by sexual relationship but not TB'

(younger male, FGD)

Some of the younger females said there is no relationship between AIDS and TB; but others thought that there was an association with immunity:

'TB comes first and then AIDS because one become weaker and no immunity'

(younger female, FGD)

'If men infected with AIDS have sex with women with TB then they will be infected with both diseases'

(young female, FGD)

'TB and HIV should be related...it concerns the immunity in their body'

(younger female, FGD)

3.3.4 Biological causes

Hereditary disease: 'Sharing the same name'

A few focus group participants in the older age groups felt that TB was hereditary:

One TB patient in particular was convinced that the disease is hereditary:

'I think it's hereditary because many people who bear this last name have suffered from it'

(female, 23 years old, now cured of TB)

Although this was also dismissed as a link people made in former times by an older male TB patient and other participants from the older female focus group discussion. None of the younger focus group participants made a connection between heredity and TB.

Immunity: a weapon against germs!

The older focus group participants made a clear link between health status, immunity and TB, for example:

'And if we have enough immunity, it [TB] won't have any chance to catch us. If at any time our immunity recedes and if we go into a dusty area that is poisonous, we may catch it. It depends on our physical health. Anyone with good health I think won't catch it'

(older male, FGD)

'It is likely, when our health is not strong, we have not enough immunity to resist such an intercalater [opportunistic infection] that always tries to enter our bodies'

(older male, FGD)

Older females also mentioned immunity and health status as important factors in causing one to catch TB:

'He did not have enough immunity once he started to cough, and kept coughing chronically'

(older female, FGD)

'It depends on immunity. If his immunity is good, that disease won't be communicable'

(older female, FGD)

The younger groups also made an association between health status and immunity saying that without immunity all kinds of disease can affect you and this is also the case for TB.

'TB is not related to hard working or light working, it depends more on the extent of immunity in our bodies'

(young female, FGD)

'The old person would have more chances because he has less immunity'

(young male, FGD)

3.4 Is TB a stigmatised disease?

Many focus group participants perceived TB as contagious and easily transmitted through exhalations, food and drinks and being in close proximity to TB patients. The majority of participants generally felt that TB was not a particularly stigmatised disease, although many did point out that if they knew somebody had TB they would try and protect themselves from being infected, but without discriminating against them. For example older males suggested:

'If we already know some body is infected with the disease we should try and stay a little away from them...not that we dislike them. We just want to prevent ourselves from catching TB by staying away from the infected persons, if we know their conditions'

(older male, FGD)

'If we face with TB infected persons, as we know them, we should try our best to avoid them...that is to stay away from them as far as it should be in order not to have our breath mixed with theirs...suppose someone is infected with this disease and we know it, we would not go near him because we would not have any reasons, purpose or necessity to associate with him closely. But we don't discriminate against them'

(older male, FGD)

'I would say we would still talk to them, but we would avoid being associated with them any closer than that, and would also try to avoid receiving any symptomatic impacts of their conditions, such as trying to stay in the position that the wind blows from us to them, not from them to us'

(older male, FGD)

Older females gave similar accounts of trying to protect themselves from catching TB, but avoiding discrimination:

'When he talks with us we should turn our faces away. We should not dislike them, sometimes they are good people, they became infected unintentionally'

(older female, FGD)

'When he coughs we should stay away, or turn our faces away'

(older female, FGD)

The health care workers were generally unsure about the level of discrimination TB patients were facing; but said that TB patients do not go out much for social activity:

'It is difficult to judge whether TB patients isolated themselves because of stigma'

(Health care worker, in-depth interview)

There seemed to be gender differences in how male and female TB patients' perceived support from their family and community throughout their TB treatment. The male patients both felt that the support you receive is not related to your age or your sex, but rather the sort of person that you are.

'Visits depend a lot on the goodness of a person. Good persons usually earn more credit than the rogues. People would consider the rogues as useless for them. They would rather come to visit good persons. For me I used to patronize many. They have good lives because of me. So they came to visit me. I used to have some relations with them.'

(male TB patient, 65 years old)

One of the female patients' spoke about her fear of passing the disease on to others:

'I was afraid of passing the disease to other people, it would be a sin, and I really thought that way. During the first 1-4 months I did not go anywhere. But when I got better I felt ashamed of letting my mother work in the farm alone while I stayed home. I really felt shamed of myself. I am afraid I would pass the disease to other people. My friends and neighbours did come and visit me. Nobody showed any feelings of dislike. But when talking I kept a distance from them, telling them that I got this disease. If they felt uncomfortable they should not come at all. If they think it would be all right I would be glad to welcome them. They said I was crazy to have said like that. Everybody knows how this disease is contracted. They did not shun, if so they wouldn't keep coming. People at my workplace also came if they got free time. Those who were not free did not come.'

(Female aged 31 years, currently in her fifth month of treatment)

The other female interviewee (aged 23) who had now been cured of TB perceived that female TB patients were more stigmatised than their male counterparts.

Participant: 'I think more women will have to face the problem if people will associate with us or if they will shun us.'

Facilitator : 'So more female patients will be shunned. Why is that?'

Participant: They look upon men as natural for them to get it but it's different for women. When we get sick, it's not reasonable why we get it since we don't smoke, we have never done anything but we get it....Fewer women will associate with us because they despise us for contracting this disease. Here people are nice. They remain in contact'

This participant alludes to the idea that if TB is associated with smoking and revelling, behaviour, which is often seen as male, then women TB patients are more likely to be stigmatised as they are perceived to have transcended appropriate female behaviour.

During the focus group discussions, both male groups and the younger female group felt that men and women with TB would be treated the same and receive the similar support. Although one of the participants from the older female FGD group had a different perspective that was largely shared by her peers, as illustrated by this extract:

Participant: 'Probably the women would be more disliked because they have to do the cooking. Men are good only at eating (laughing). Women have to improve everything'

Participant: 'Because men usually don't pick or touch anything'

Participant: 'Oh when men got infected their wives have to look after them'

Participant: 'Yes'

Facilitator: 'Then if we are infected, who would look after us?'

Participant: 'Probably our neighbours would come to visit. Most women could help themselves, They do everything by themselves. Suppose we got infected, our husband would dislike and stay away from us.'

From this group one could translate that women may suffer more adverse effects of the disease as it would interfere with their perceived gender role (preparing food and cooking). The discussion also highlights women's caring role, for example women are expected to care for their husbands but not the other way around.

3.5 Perceptions of TB and TB patients: Implications for DOT provision

DOT choice

It appears that choice of DOT provider is the result of a process of negotiation and discussion between the TB patient and the health care worker. Health care workers explained that the choice of provider:

'Depends very much on family support those who are old tend to have someone to take care of them. We have one case he is very poor working as daily labourer—hard for him to take care of himself and to receive regular medications'

(in-depth interview, health worker)

So the choice of provider depends on family situation, as well as the distance between their house and the health centre:

'It would be a relative of the patient or an official. If the patient lives nearby we would know his/her circumstances, we would take the medication to him/her at their place every week. Those who live further I would advise their relatives to supervise their medication by arranging timetables for them to check each time the medication is taken'

(nurse, in-depth interview)

The nurse went on to explain how the procedure for the appointments will also depend on the distance the patient has to travel and the support

she/he has access to from family and community members. VHVs are in close contact with health workers, so can be called upon to act as a provider if necessary.

Supporting patients through a lengthy treatment process

The role of health workers

TB treatment involves taking a lot of medication regularly over a 6-8 month period. Failure to continue taking the drugs can mean that the TB is not cured and can also lead to multi-drug resistance. Physically swallowing all the drugs on a daily basis is a large challenge for most TB patients and is the main rationale behind the idea of having an 'observer' or 'provider' that is central to the concept of DOT. Health workers said that new patients were optimistic about taking their drugs, whereas patients that had been sick for a while, and on and off TB treatment were less so:

'Many [TB patients] hardly believe health care workers' advice - not many of them especially those who have been sick for a long time they have been saturated with medications, New cases are more eager to have treatment'

(in-depth interview, health worker)

The role of village health volunteers (VHVs)

There are 15 villages in Trakam-En, and on average about 5-10 VHVs per village. Generally about 30-40 VHVs attend meetings in Takram-En. Each village headman holds a meeting about once a month to give a talk, which often includes a focus on health programmes. Health Workers often join these meetings and give health education sessions on, for example, dengue fever and TB. Some villages don't hold meetings; this depends on how active the headman is.

One of the VHVs explained the challenges facing her in VHV role:

'We have to do many things - go to the forest, look after the family. Sometimes it is difficult to choose the right word to communicate with people. We divide the households by cluster, so if they live in a close cluster you will have more households to be responsible for. The number of households is not equal among VHVs. Some people have the feeling that you are the same as me – a farmer, with low education, why do you have to advise me. This can mean I feel discouraged, as well as having no time for family'

(VHVs, FGD)

Community and family support

All TB patients spoke of the importance of family and community support in their quest to adhere to treatment: This support could be emotional, psychological and financial.

One TB patient spoke of the concern his family showed him:

'Both mother and child having concerns for me. They kept asking whether I have eating medications so frequently. I told them I have eaten the medications already whenever they asked. I could go for my business or for my reveling anywhere'

(male TB patient, aged 65 years old)

This interviewee also mentioned how he receives support from neighbours who he either sees at the local coffee shop or who come and visit him or ask him about how he feels.

The opportunity to continue working during treatment was seen as very important from the perspective of TB patients. The 65 year old male TB patient said that he was pleased that he was still able to work selling sticky rice as he still looks healthy.

'I help my wife to sell 'kao lam' (grilled sweetened sticky rice mixed with coconut milk). Our business runs quite good. It is good for us because we have something to do and we enjoy spending time in this way. We can talk with friends and other people. We have a small shop nearby the highway so people stop by and buy my stuff. My wife is also not in a good health. She went for operation last year. I am not so sure whether she has a cervical cancer or not'.

(male TB patient, aged 65 years old)

Similarly the 31 year-old female TB patient said she was happy to be able to continue to work with community members packing corn, and that working for an income is vital for poor people:

'Poor people need to work for income and so can take less rest and have less interest about the illness they have'

(31 year old TB patient)

Further interpretations of the findings in the light of the wider literature and implications for Thai TB research, policy and practice will be discussed in chapter four.

Chapter

Discussion and Recommendations **4**

This chapter interprets the findings in the light of the wider literature and suggests implications for Thai TB research, policy and practice.

4.1 The importance of language and perceptions of TB symptoms

4.1.1 Main findings

There were differences in the language used to describe TB; particularly between the older and younger generations. All the younger groups just had one term to describe TB 'wannarok'; whereas the older groups, and in particular the older men used a range of descriptive terminology to refer to TB. The older male TB patient never used the term TB once during an interview that lasted an hour; and instead discussed his chest disease. The man's family however, after the interview and whilst he was out of hearing talked openly about their father's TB. It could be that the father was not comfortable with the label of TB; or that he had been protected from this label by health staff and his family.

All focus group participants associated TB with coughing and regarded coughing with blood as a sure sign of TB. Younger groups in particular discussed coughing over a long period of time as indicative of TB. During the body mapping exercise younger groups drew 'text book' pictures of lungs and tended to talk about TB using more biological and medical terms than older groups. This probably relates to the fact that most of the younger focus group participants had only recently left secondary school or were still involved in education. Older groups used the body mapping exercise to discuss more generally the impact of TB on a person's

appearance; illustrating that they are normally coughing, skinny and often have dark skin and a lighter face.

4.1.2 International comparisons

There are many examples from the international literature of communities using a wide range of descriptive terminology to discuss and describe TB. For example Lal Karn's (2001) qualitative research in rural and peri-urban Malawi revealed how there many different terms used to describe TB and that some of these had implications for the perceived link with HIV. For example communities and health staff referred to 'bone TB' as TB that was not linked to HIV. There were some difference in terminologies between men and women and also peri-urban and rural communities. Similarly Nichter (1994) used focus group discussions to identify a whole spectrum of terms communities in the Philippines used to describe TB; many of which centred around constructions of 'weak lungs'.

4.1.3 Implications

It is clearly important to understand the different terminologies and expressions communities use to discuss TB; this can be useful in designing research tools and health promotion strategies. For example questionnaires that just use the term 'TB' may miss responses from participants who are familiar with broader or different terminology; as was the case for many of the older participants from Takram-En. In our analysis of IPSR population data in Kanchanaburi we only counted respondents who used the term 'wannarok' to estimate TB incidence and hence the figures may constitute an underestimate. It is important to start by using qualitative research tools to explore communities' understanding(s) and use of TB related terminologies and feed this into the design of questionnaires that aim to measure reported prevalence of TB and hence increase their internal validity.

It is also important to take into consideration the language used by different groups in health promotion strategies and communication between communities and health providers. Many of the younger groups in Takram-En had received information about TB from school and college. There is a need to think creatively about the language and strategies used to raise awareness about TB with older generations. Each VHV has a number of households to give health education.

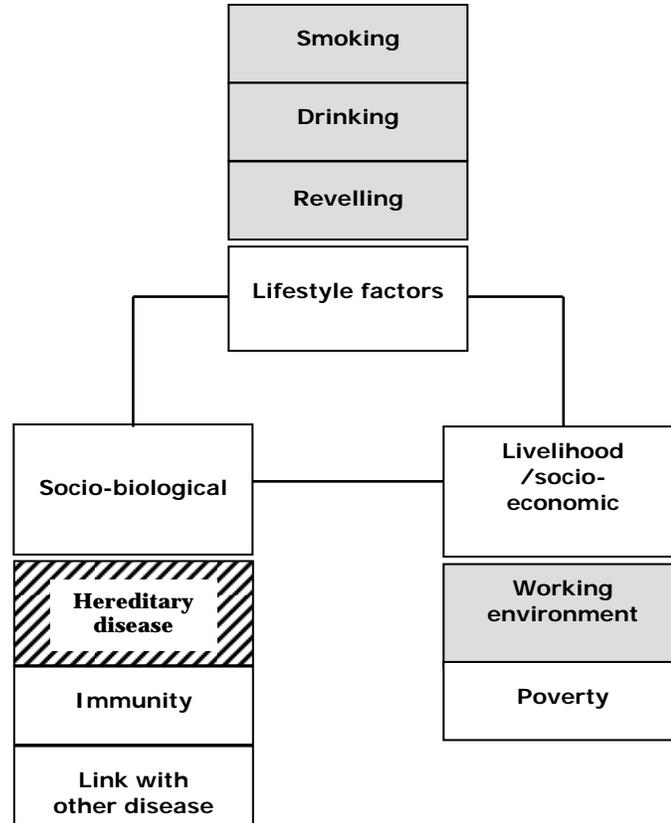
During the FGD with VHVs, they mentioned that they were closer to female members. This is because they were assigned by health workers to assist them in the collecting health records and to follow-up activities such as postnatal cases and immunization, which largely involved female community members. They seldom talked to male members because men are not perceived as having major health problems, with the exception of drinking problems and car accident. They preferred to talk with the housewives when they visited them at home. They also seldom associated with young community members because they thought that they have enough knowledge from school or college. However, they occasionally talked with them about HIV/AIDS and condom use. Strategies to develop communication strategies between VHVs and different community members (by age and gender) are central to our follow-on research project 'Building capacity for gender analysis of tuberculosis in Kanchanaburi, Thailand' which is reported elsewhere.

4.2 Issues related to vulnerability to TB

4.2.1 Main findings

The main factors that were perceived as making people vulnerable to TB were (1) being male and what this means in terms of life style; (2) being male and what this means in terms of working environment/livelihood strategy, (3) poverty; (4) links with other disease and (5) biological causes. These are summarised in diagram illustrated in Figure 4.1.

Figure 4.1 Linkages between the main factors perceived as making people vulnerable to TB



Key: Particularly associated with male vulnerability
 Particularly discussed by older generations

The diagram highlights the factors that older and younger men recognised as important in terms of vulnerability to TB. However, some of the younger women thought this was changing; as women were increasingly likely to be engaging in activities that are seen as mainly male – smoking, drinking and reveling.

4.2.2 Sex and gender – a complex and contested picture

Globally there are 1.7 times as many male pulmonary TB cases reported annually as female cases (WHO, 2001). The gender breakdown of nation wide tuberculosis figures in Thailand also shows that there are more men than women with TB (for every age group). Patterns of higher TB prevalence amongst men are found in studies that document adherence to TB treatment. We found several studies on TB adherence that disaggregated results by gender (Bam, 1991; Hussain, 1995; Kandel, 2000; Shresth, 1991; Silak, 1994). These were all conducted in the Central region (the Bangkok chest clinic, a hospital in Saraburi and a zonal TB centre in Nakhon Sawan). In these studies the proportion of males in the sample ranged from 70-75%. The findings are mainly quantitative and offer little exploration of why there is a higher proportion of males infected with TB/seeking care for TB, or how gender, or socio-economic status may affect vulnerability to TB or patterns of health seeking behaviour.

Although global notification rates of TB have been predominantly higher in males than females this may be set to change as new infections of HIV/AIDS appear to occur disproportionately in women and are set to alter TB prevalence and epidemiology (Hanson 2002). In Kenya the male-female TB ratio is steadily moving towards 1:1 due to the impact of HIV/AIDS in the female population, where previously it occurred more often in men (UNAIDS, 2000).

The available literature suggests that in most countries, notification rates among males are higher than among females (Holmes et al, 1998). Whether this reflects a true disparity in TB incidence, or is complicated and possibly negated due to confounding factors such as access to treatment (Rieder 1999) is hotly debated, especially in developing country contexts. Hanson (2002) suggests these differences may reflect true

epidemiological differences between sexes rather than gender related inequities in access to care as has previously been suggested (Hudelson 1996).

In light of this ongoing debate, much of the discussion about TB from a gender perspective has focussed on access to TB treatment and how gender roles and relations may limit the opportunities of women and men in different contexts to access and concord with TB treatment (Liefoghe, 1998). In direct contrast to gender analysis of HIV, there has been less discussion about how gender roles and relations may impact on the vulnerability of girls, boys, women and men to TB infection.

4.2.3 Lifestyle factors, TB and gender: What evidence is available?

Epidemiological studies have identified a link between TB, alcohol consumption and smoking. Both alcohol and drug use has been associated with an increase incidence of TB and other infectious diseases (Rieder 1999, Acevedo-Garcia 2000). A link was identified between TB and injecting drug users even before the discovery of the HIV/AIDS link (Reichman et al. 1979). A causal relationship has been difficult to prove as studies are plagued by many confounding environmental factors that occur with drug and alcohol misuse, especially from studies in industrialised countries (Rieder 1999). It has been found however that the immune system is affected by alcohol and therefore this could increase the risk of TB and other diseases (Rieder 1999). The risk of tuberculosis has also been shown to increase with the number of cigarettes smoked (Yu et al. 1988).

4.2.4 Working environments, TB and gender: What evidence is available?

There is limited debate on the relationship between occupation and vulnerability to TB. For example, in a study conducted over 40 years ago TB was found to be more common among miners and patients with silicosis,

with miners with silicosis being most at risk (Paul 1961). Additionally those people working in the mining industry or industries where they are consistently exposed to dust are more at risk of developing TB (Medical Dictionary, 1987).

Factory workers' vulnerability to TB is also not very widely debated in the literature. However, we can hypothesise that factory workers could be more vulnerable to TB infection due to overcrowding, as the degree of physical contact between infected and non-infected individuals is a key factor in transmission of TB. The extent of overcrowding and lack of ventilation at home or in the workplace are therefore likely risk factors in TB transmission (Acevedo-Garcia 2000).

Analysing working environments from a gender perspective necessitates exploring both paid and unpaid work. There is evidence in Thailand that caring work may have implications for vulnerability to TB. In many contexts informal carers at the household and community level are female – as this is seen as women's work (Panos Dossier, 1990). Concern or love for family members may also contribute to vulnerability to infection for carers as Ngamvithayapong (2001) argues 'despite having knowledge, Being a good mother or good wife, Love and Let it be could dilute efforts to prevent TB and HIV among senior HIV infected caregivers' (Ngamvithayapong, 2001). For example, a mother may feel that caring for her son or daughter with TB takes precedence over protecting herself from the TB; or a wife may feel that closeness to her HIV/TB infected husband is more important than protecting herself from disease. Policy makers and health workers need to be aware of how social and gender roles, relations and responsibilities are constructed in interpersonal dynamics as they greatly affect preventive behaviour amongst caregivers.

4.2.5 Poverty and TB: What evidence is available?

While TB is not exclusively a disease of the poor, the association between poverty, and TB infection rates is well established and widespread. Identifying the relationship between poverty and TB is complicated by the range of possible indicators of poverty and the confounding relationship between these and other socio-demographic variables (Fenton, 2002). Studies from different contexts reveal different findings. A study conducted in South Africa found no differences in socio-economic status, including household assets and living conditions, between TB patients and non-TB patients living in the same community (Schoeman et al, 1991 in Hanson, 2002). However, a study conducted in the US (1987-93) found that the poorest 25% of the population had a relative risk of developing TB of 2.3 with compared with the richest 25% (Cantwell 1998, in Hanson, 2002).

The literature shows that there is a link between poverty and vulnerability to TB. This is a two-way relationship and evidence from Thailand shows that having TB can make patients more vulnerable to poverty; especially for those who are already living at or near the poverty line. A study by Kamolratanakul et. al, documents the economic impact of tuberculosis at the household level and highlights the need for an equity perspective. The study analysed the direct and indirect costs faced by 673 adult tuberculosis patients who completed treatment across Thailand.

The results are stratified for 3 levels of patients' household income: above national average, below national average but above the poverty line, and below the poverty line. It was found that for the latter group, the economic consequences of tuberculosis can be devastating; out-of-pocket expenditure for the diagnosis and treatment of disease amounted to more than 15% of annual income. In this group living below the poverty line, 15% of patients

had to sell some of their property and more than 10% had to take out loans to cover the cost of treatment (Kamolratanakul et. Al, 1999). No analysis by gender, age or ethnicity was conducted. This study was carried out in 1996/1997. The economic crisis began in mid-1997 and it is likely that the economic consequences of TB will have intensified in today's climate.

The same study reports that the average delay from the onset of illness until diagnosis of tuberculosis was 61-76 days. It is during this period that a large proportion of costs occur. All diagnostic services and anti-tuberculosis drugs should be free in Thailand. However, the survey shows that some patients were paying for follow-up sputums; there is a need for stricter enforcement of national regulations. Costs associated with transport were also high across the 3 different groups.

4.2.6 Biological causes and relationships with other diseases:

What evidence is available?

There is clear link between compromised immunity and vulnerability to TB. This is illustrated by the indisputable link between TB and HIV. The presence of HIV infection is among the strongest risk factors for the progression of latent TB infection to active disease (De Cock et al. 1995). Developing TB is associated with an increased likelihood of death in those with HIV infection (Msamanga & Fawzi 1997, Antunes & Waldman 2001).

4.2.7 Community perceptions of vulnerability to TB:

Implications for health promotion strategies

Figure 4.1 illustrates the linkages between the main factors perceived as making people vulnerable to TB. It is important to explore each factor in order to understand community beliefs and perceptions, and therefore be able to develop health promotion campaigns that are

applicable, relevant and appealing to particular community members. As De Koning points out, it makes sense to begin with people's own perspectives and beliefs, which facilitates campaigns that are grounded in a community's reality (De Koning, 2001). Qualitative research methods can facilitate this process, by understanding social phenomena in natural (rather than experimental) settings, and giving due emphasis to the meanings, experiences, and views of all the participants (Mays & Pope, 1995).

Our study suggests that community members perceive a link between smoking, drinking, revelling and vulnerability. While these activities are primarily regarded as 'male' activities and hence a greater vulnerability for men, behaviour of younger generations is changing; younger females are also likely to partake in smoking, drinking and revelling! Again, these findings have clear implications for health promotion/preventive strategies – which should target both young men and young women.

The community members who participated in our study also perceived men working in factories at risk of catching TB. Community perceptions that men are more vulnerable correspond to national prevalence figures (see figure 1.1). This has direct implications for promoting awareness about TB in ways that are accessible to both older and younger men. The work place would be a good place to start, but it is as yet unclear what method would be most effective to deliver health information to men in their work environment; this needs further research. It is possible that peer education strategies may be useful in this setting.

4.3 The stigma surrounding TB

4.3.1 Main findings

Most focus group participants perceived TB as contagious and easily transmitted through closeness to TB patients. The majority view from community members was that they would try not to discriminate against

friends and neighbours if they know they had TB; although they would try and protect themselves, for example by standing at a distance. The stigma associated with TB was perceived as less serious than that associated with HIV and AIDS or leprosy; although more than malaria. Most participants perceived that there would be little difference between any disease related stigma between men and women of different ages. However, most of the older women and female TB patients thought that women were more likely to be stigmatised for having TB. For this group the way in which stigma is perceived or experienced was found to be related to gender roles and relations, either because TB is seen as a male disease and linked with smoking, drinking and revelling or because having TB will interfere with what is constructed as women's work in the household.

4.3.2 The international perspective

Literature focusing on South Asian contexts demonstrates a link between gender and stigma; and a growing body of work that illustrates this is also the case in Sub-Saharan Africa. In India, there is evidence that the way social stigma is experienced varies by gender and marital status. A study of the effects of TB on the lives of patients in Bombay found that married men and single women perceived a greater level of family support to initiate and complete treatment, but married women often tried to hide their symptoms for fear of blame or rejection, and many dropped out of the treatment process due to the pressure of keeping their illness secret (Hudelson, 1996). Having, or having had TB is perceived as a threat to the possibility of marriage in young unmarried Pakistan women (Liefoghe et al, 1995). Whilst both male and female patients face social and economic impacts from TB, it appears females are more affected in certain cultures especially as divorce and broken engagements occur more often (Liefoghe et al. 1995). Additionally, as women are more likely to be economically dependent on their husbands and family-in law they need their co-operation to get treatment, which may result in reduced access (Liefoghe et al. 1995).

Qualitative research from Chiang Rai in northern Thailand also identified gender differences in perceptions of stigma. In this context, where HIV is more prevalent, there was much more awareness of the link between TB and HIV that further complicated how different groups (those who were co-infected with HIV and TB; and those who had TB but were HIV negative) perceived stigma. Gender differences in felt stigma were found amongst HIV negative groups. HIV-negative women with TB were especially likely to say that they had 'pneumonia' or a 'lung disease' and perceived a high degree of stigma associated with TB (Ngamvithayapong, et al.,2001). In contrast, HIV negative men were often relieved to receive a diagnosis of TB and not HIV and openly revealed their TB status. HIV positive women perceived fewer stigmas associated with TB than HIV. It is argued that unlike other Asian contexts (Pakistan, India) differences in enacted stigma in Northern Thailand were not obvious. This is explained in Northern Thailand by the linearity, affinity and inheritance of authority in a family is through females rather than males. This is unusual and in most of Thailand a patriarchal system is in place.

4.3.3 Implications

Stigma whether felt (perceived) or enacted (real) can pose barriers to accessing a TB diagnosis and adhering to treatment. This is an area that could benefit from further research. It would be useful to explore whether the view expressed by women TB patients and some older members of the community are common. There is also anecdotal evidence that ethnic minority groups in Thailand face disease related stigma, and that this may become increasingly so with growing numbers of Burmese people moving to the border areas. The discrimination felt and often faced by many people living with HIV presents means that the increasing co-infection between HIV and TB presents further challenges to health promotion messages that address TB related stigma.

4.4 Challenges for the provision of equitable TB care: towards flexible and accessible Directly Observed Therapy

4.4.1 Main findings

The majority of our small sample of TB patients had a fairly positive experience of accessing TB treatment and were satisfied with the quality of care received, although one female patient spent a lot of time and money before getting a TB diagnosis. In all cases family members acted as observers as is the norm in Kanchanaburi (See Table 1.1). All informants were themselves very disciplined and motivated to adhere to their treatment regimens, despite experiencing a wide range of difficult side effects. It would be useful to conduct a larger study to explore the experiences and priorities for DOT of a wider group of patients.

4.4.2 Comparisons with experiences elsewhere in Thailand

A qualitative study in Chiang Rai explored the extent to which community members would find different DOT strategies acceptable. The feasibility of home-based DOT (with a daily visit from a health worker to supervise the treatment) versus health centre based DOT was assessed (Ngamvithayapong et al, 2001). The majority of community members preferred the option of home-based rather than health centre-based DOT. For this group health centre based DOT was regarded as impractical because of:

- 1) Sickness or being too old to make the daily journey
- 2) Busy with daily work (female participants stated that it would be very difficult for them to bring their small babies daily)
- 3) Inconvenience and high transport costs.

However, it was found that over half of the HIV negative female TB patients strongly rejected the idea of a health worker visiting them at home (home-based DOT) on a daily basis due to unease and fear of stigma of TB. Health staff were also resistant to home based services due to higher workloads. Female health staff also mentioned the difficulty and inconvenience of travel.

A study of 779 TB patients in Yasothorn Province compared TB outcomes of patients who opted for DOT (over the initial 2-month period of the treatment) and those who did not. Patients choosing to forgo DOT attended their nearest health care facility once a month to collect their tablets. Of the 347 patients who opted for DOT, the observer was a family member in 299 (86.2%) of the cases. In new smear positive patients, cure rates were 184/216 (85.2%, 95% Confidence Interval [CI] 80.5-89.9) with DOT versus 78/110 (70.9%, 95% CI 62.4-79.4) with self-supervision (Akkslip et al, 1999).

Akkslip et al concluded that the implementation of the new DOTS strategy, including the use of a supervised family member in observing treatment, resulted in improved programme performances in Yasothorn. Allowing the TB patient to choose the DOT strategy, which is most convenient and accessible, would further enhance the success of the TB control programme. There is also a role for Community Health Workers, who were not trained in this study and acted as the observer in the case of only one patient. The authors recommend that a further study would be useful to investigate patient preference of different types of family member.

4.4.3 Implications

Barriers exist to accessing and adhering to TB treatment and these are often related to costs, opportunity costs, accessibility of health services and stigma. The ways in which these barriers are experienced

will vary between males and females of different ages, ethnic groups and socio-economic and health status. The challenge for the Thai National TB Control Programme is to provide TB services that are responsive to these issues and which enable more people infected with TB to seek prompt care, receive swift diagnoses and concord with care without too much interruption to patients' livelihoods. The focus on DOT in the community should facilitate this process. There is a need to further explore the opportunities and challenges of involving community health workers and families in TB health promotion and in supervising DOT to enable a more flexible regime that reduces the costs and opportunity costs associated with health centre or hospital based treatment strategies. However, this needs to be negotiated and discussed with Village Health Volunteers who are often over-stretched in their work. There is a need to think about training and support for VHVs in their new role.

Family members can also face challenges in being a DOT provider coupled with the emotional, financial and time consuming burdens associated with being an all-round carer. In some cases this role can expose carers to TB infection. Caring is a gendered activity and this research and other studies from Thailand (Ngamvithayapong et al, 2001) and elsewhere (Panos Dossier, 1990) that it frequently falls to women. A challenge for the immediate future appears to be – how can we support DOT providers in the family who often double up as carers?

All the patients we interviewed spoke at length about the range of varied side effects experienced with TB drugs. Some of these were anticipated but others took them by surprise. To be effective, health care workers needs to provide good information about treatment, the possible side effects that may be experienced and advice for adhering to treatment. If the patient is forewarned about side effects then they are

more likely to trust the provider and be prepared for any adverse outcomes. Health care volunteers and DOT providers in the community and the family also need to be thoroughly briefed on the importance of adherence and the possible side effects of the drugs. Lessons can be learnt and applied from innovative strategies to support patients to adhere to drugs from other contexts. For example in the Western Cape in South Africa photo novellas that present personal testimonies of the challenges faced by TB patients to adhere to treatment and encouraging stories and letters have been successfully evaluated (Dick 2002, personal communication). These also contain tick box calendars so patients can chart their own progress in drug taking and count down the days and months. We have developed similar approaches in our subsequent action research 'Building capacity for gender analysis of tuberculosis in Kanchanaburi, Thailand', which will be reported elsewhere.

4.5 Concluding comments

4.5.1 Research approaches to studying TB

⊗ Qualitative methods, in particular in depth interviews, are useful for gaining insight and understanding of how TB patients perceive their illness and the process of care and treatment. With sufficient time and funds, the study could be expanded to explore and compare the perspectives of other ethnic groups within Thailand.

⊗ Survey data are useful for estimating TB prevalence, but, survey data can be flawed since the questions asked to community participants do not adequately account for local language and terminology associated with TB.

⊗ Action research is a useful method for experimenting with strategies for promoting TB awareness and capacity of community

members. The benefit of action research approach is the ability to engage in cycles of activity and reflection and therefore track change in behaviours over time. Plans for action research that emerged from this study include: involving youth groups in promoting awareness about TB; VHV training about TB and how gender roles and relations affect vulnerability to TB; and using the experiences of former TB patients to promote adherence to TB treatment.

4.5.2 Research priorities:

At present there is a dearth of literature on the possible link between working environments and TB vulnerability. Further research should focus on factory workers and the environment in which they are exposed everyday. This is especially important in Thailand, given the climate of industrial expansion and growing numbers of factory workers, which is in turn shaped by gender. Men are more likely to work in metal and automobile factories, where as women predominate in electronics and garment factories.

International migrants and workers may be particularly vulnerable as they may lack the official registration cards needed to 'officially' remain in Thailand and access care and treatment. For example for Burmese migrants along the Thai-Burma border in the North Thailand, barriers to accessing medical care are recognised and believed to include stigma, financial costs, employment considerations, language difficulties and a fear of deportation (Medecins Sans Frontieres, 1999). There is a need for further action research to delineate these barriers and design interventions to address them.

4.5.3 Practice

⊗ Gender equity analysis has the potential to contribute to the future shape and effectiveness of the National TB Programme in Thailand.

⊗ The findings from this research suggest that the TB Control Programme should promote a flexible approach to treatment and DOT so that it is more likely to meet the needs of women and men of different ages and socio-economic status.

⊗ The role and training needs of VHVs and DOT providers both within and external to the family need to be addressed if the TB Control Programme is to take a more flexible approach to the care and treatment of people with TB.

The priority is to develop a coherent body of research on how different groups experience vulnerability to TB, access to quality care and treatment processes and outcomes. The challenge is to build channels to integrate research findings in practice, and use research findings to develop strategies for maintaining and evaluating a gender equity perspective into all layers of the TB Control Programme.

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