

From the Division of International Health (IHCAR)  
Department of Public Health Sciences  
Karolinska Institutet, SE-171 76 Stockholm, Sweden

and

Umeå International School of Public Health  
Epidemiology and Public Health Sciences  
Department of Public Health and Clinical Medicine  
Umeå University, S-901 87 Umeå, Sweden



**CHALLENGES AND OPPORTUNITIES**  
**FOR TUBERCULOSIS PREVENTION AND CARE**  
**IN AN HIV EPIDEMIC AREA, CHIANG RAI, THAILAND.**

Jintana Ngamvithayapong-Yanai



Stockholm 2003

**ISBN: 91-7349-440-2**

**Printed in Stockholm by Karolinska University Press (KUP), 2003**

## ABSTRACT

**Background:** Thailand is one of the countries where TB and HIV are highly prevalent. The Human Immunodeficiency Virus (HIV) is the strongest risk factor in promoting the progression of the latent tuberculosis (TB) infection which activates the TB disease. The HIV epidemic is fuelling the tuberculosis epidemic in northern Thailand. TB and HIV/AIDS have been recognized as the diseases closely associated with social, economic and behavioral factors. Strategies for TB-control in high HIV-prevalent settings requires biomedical interventions and a need to address and incorporate people's perspectives about TB and HIV into disease control.

**Objective:** To describe the impact of HIV/AIDS on the perceptions, attitudes and behaviors of various groups of people that may effect TB transmission, prevention and care.

**Methods:** The study was conducted in Chiang Rai, the northernmost province of Thailand with some of the highest rates of TB and HIV. The study employed qualitative and quantitative methods: (i) adherence to the 9-month TB preventive therapy among people with HIV infection (PLWH) was investigated by pill count, in-depth interviews were used with poor-adherent cases while focus group discussions (FGD) were utilized with the good-adherent cases; (ii) perceptions about TB, HIV and the feasibility of implementing Directly Observed Therapy (DOT) was investigated through FGD with health providers, patients, community people, drug users and people living with HIV; (iii) health seeking behavior of HIV-positive TB patients (TB (HIV+)) and HIV-negative TB patients (TB (HIV-)) was investigated through interviews with patients using a structured questionnaire; (iv) the lifestyles before and after the TB diagnosis of TB (HIV+) and TB (HIV-) of patients were examined by conducting repeated home visits during a period of 6-8 months applying in-depth interviews and observations.

**Major findings:** (i) The adherence rate to TB-preventive therapy among PLWH, defined as the proportion of those who took more than 80% of the pills was 67.5% (n=278). Default took place at the early phase of the therapy. Females displayed a significantly higher adherent rate than males (OR 3.45; 95%CI 1.79-6.67). Major reasons for non-adherence included migration due to work, denial of HIV status and perceived medicinal side effects. Important reasons motivating adherence were the concern for children and family and good provider relationships; (ii) In general, people expressed a high awareness of AIDS symptoms and transmission causes but had an inadequate knowledge regarding TB. AIDS stigma and several misconceptions of TB-associated AIDS caused a delay in seeking TB service and a non-adherence to TB treatment in some patients who suspected they had AIDS and therefore, feared AIDS detection. Most TB (HIV-) patients were labeled as having AIDS by their family and community; (iii) The high mortality of TB (HIV+) and HIV-related complications in TB patients negatively affected the credibility of the TB treatment and influenced the attitudes of the health staff and the community resulting in perceived low priority or low motivation to treat TB for HIV infected persons expecting that the patients would eventually die from AIDS; (iv) In the HIV epidemic area, both health center-based DOT and home-based DOT have their problems. TB (HIV+) patients were usually too sick to visit a health center independently on a daily basis. These patients frequently suffered from other opportunistic infections and drug reactions. Therefore, the ability of the health center staff in clinical management during the implementation of home-based DOT was challenging. The health staff had low motivation to

implement DOT unless financial incentives were offered. However, the monetary demand could be avoided if staff are well informed about the risk of multi-drug resistant TB and to how to safeguard their own health; (v) The median patient delays for TB (HIV+), TB (HIV-) and TB (HIV unknown) were 10, 15 and 15 days, respectively. The risk factors for long patient delays (>21 days) included being HIV-negative, having no health insurance, being of hilltribe ethnicity, having had no previous visits to the hospital and needing to borrow money for the hospital visits. Provider delay was significantly longer for female patients than male patients; (vi) clinically, socially and financially, the TB (HIV+) patients suffered more than the TB (HIV-) patients. The TB (HIV+) patients suffered more complications and had more problems in drug taking. The AIDS stigma led to the discrimination of TB (HIV+) patients and their exclusion from social activities as well as the negative effect on family income including the loss of their job; (vii) Following the Grounded Theory tradition, the study developed a model presenting that the risk of TB and HIV transmissions may be attributed to the following: role and responsibility, virtue, stigma, learning for life, human bond and accepting fate.

**Conclusion:** HIV/AIDS provides a graphic and tragic example of complex interactions between the disease agent and human behavior, which further complicates the patient's care-seeking behavior, adherence to the therapy and the effort to control tuberculosis. Despite the enormous clinical and social impact of HIV/AIDS on TB, some socio-cultural interventions may improve TB prevention and care.

**Key words:** TB associated HIV, socio-cultural aspect, health seeking behavior, adherence, Directly Observed Therapy, Thailand, qualitative research.

## ORIGINAL PAPERS

The thesis is based on the following papers:

- I.** **Ngamvithayapong J**, Uthaivoravith W, Yanai H, Sawanpanyalert P, Akarasewi P. Adherence to Tuberculosis Preventive Therapy among HIV-infected Persons, Chiang Rai Thailand. *AIDS* 1997;11:107-112.
- II.** **Ngamvithayapong J**, Winkvist A, Diwan V. High AIDS Awareness May Cause Tuberculosis Patient Delay: Results from an HIV-Epidemic Area, Thailand. *AIDS* 2000;14:1413-1419.
- III.** **Ngamvithayapong J**, Yanai H, Winkvist A, Saisorn S, Diwan V. Feasibility of home based and health center based DOT: perspectives of TB care providers and clients in an HIV epidemic area, Thailand. *Int J Tuberc Lung Dis* 2001; 5: 741-745.
- IV.** **Ngamvithayapong J**, Yanai H, Winkvist A, Diwan V. Health seeking behavior and diagnosis for pulmonary tuberculosis in an HIV epidemic mountainous areas of Thailand. *Int J Tuberc Lung Dis* 2001;5:1013-1020.
- V.** **Ngamvithayapong J**, Winkvist A, Luangjina S, Diwan V. ““Love”, “Virtue” and “Let it be” ... challenges and opportunities for tuberculosis and HIV/AIDS prevention and care in northern Thailand (submitted)

The papers will be referred to by their Roman numerals I-V.

The original articles have been reprinted with permission from the publishers.

## ABBREVIATIONS

<b>AFB</b>	Acid fast bacilli
<b>AIDS</b>	Acquired Immunodeficiency syndrome
<b>ARV</b>	Anti-retro virus therapy
<b>BCG</b>	Bacille Calmette-Gue'rin
<b>CI</b>	Confidence interval
<b>DOTS</b>	WHO-TB control strategy (Directly Observed Treatment, Short Course)
<b>DOT</b>	Directly observed therapy for tuberculosis treatment
<b>FGD</b>	Focus group discussion
<b>HCW</b>	Health care worker
<b>HIV</b>	Human immunodeficiency virus
<b>IDU</b>	Intravenous drug user
<b>MDR-TB</b>	Multi-drug resistant TB
<b>MOPH</b>	Ministry of Public Health
<b>NGO</b>	Non-governmental organization
<b>OI</b>	Opportunistic infection
<b>OR</b>	Odds ratio
<b>PLWH</b>	People living with HIV
<b>PLWA</b>	People living with AIDS
<b>TB</b>	Tuberculosis
<b>UNAIDS</b>	The Joint United Nations Program on HIV/AIDS
<b>WHO</b>	World Health Organisation

## ACKNOWLEDGEMENT

The Japanese Foundation for AIDS Prevention (JFAP) financially supported my study. The Research Institute of Tuberculosis (RIT) and the Japan Anti-TB Association (JATA) technically and administratively supported the field research conducted in Chiang Rai.

My deepest gratitude to my two advisors: Prof. Vinod K. Diwan (IHCAR, Karolinska Institutet) and Prof. Anna Winkvist (Umeå International School of Public Health, Epidemiology and Public Health Science, Umeå Univeristy).

Prof. Vinod kindly accepted me as his student and arranged a formal registration for me at the Karolinska Institutet, starting in 1994 and effective in 1996. I sincerely appreciate his patience and tireless supervision during my several years of study. He was the first person to introduce me to and broaden my vision on “Gender and TB” and offered me great opportunities to learn about TB control in Vietnam. I am grateful for his visits to Chiang Rai, for supervising the field research and sharing his precious time for technical discussions on several occasions at the Bangkok airport between his travels to and from Vietnam. I appreciate his kindness and warm support whenever I was in Sweden. His research fund supported my trip to Sweden to plan and work on my thesis, and on several occasions financed my accommodations in Stockholm. I would like to restate what my Vietnamese colleagues said: “Vinod seems to be our eldest brother”.

Prof. Anna Winkvist kindly supervised my qualitative research. Over the years, I have learnt a great deal from her academic excellency and working style. My long-term memory about Anna is “efficient, critical and creative”. Anna’s way of teaching me qualitative research was unique. She provided timely and critical comments for my studies. I sincerely appreciate her kind visits and her valuable time spent with me in Chiang Rai to ensure that my field research received adequate advice. My warmest appreciation goes also to her kind support for when I was in Umeå.

Both of my supervisors provided invaluable comments for the thesis draft. They offered me an academic freedom to finalize my thesis based on my own judgement.

My first field research work in Chiang Rai started in November 1993, which has amounted to almost a decade to complete my degree. My two children were born and have grown up during my studies. My doctoral thesis was made possible through the supports of many hundreds of individuals and several organizations from Thailand, Japan and Sweden, to which I would like to acknowledge their contributions to this thesis.

### **Thailand:**

#### **Chiang Rai Province:**

*Patients, participants, informants:*

Due to an ethical reason, I cannot acknowledge the names of the patients, participants in focus groups and informants from the communities. I sincerely appreciate their kind participation and

contribution to my studies. Many patients died during the studies and I wish to extend my sincere gratitude to them.

*Chiang Rai Provincial Health Office:*

I am grateful to the health authorities and the staff from the Chiang Rai Provincial Health Office and community hospitals for their approval and coordination in conducting the studies under their responsibilities. Dr. Supachai Saisorn, Dr. Somsak Supawitkul, Dr. Surachai Piyaworawong, Dr. Surin Summanaphan, Ms. Ratchanee Mitkiti and the PLWH-volunteers at the Mae Chan HIV day care.

*Chiang Rai Regional Hospital:*

I am grateful to Dr. Renu Srismith for approving my research to be conducted at the hospital. I sincerely appreciate Dr. Wat Uthaiworavit for his kind collaboration with the study and his technical advice regarding clinical TB. The staff nurses at the Social and Preventive Medicine Department kindly collaborated with the study and offered me their warm support and friendship during my first stay in Chiang Rai: Ms. Chomnapa Kittipakorn, Ms. Yuwapa Wiwatwongwana, Ms. Pornnapa Suggaravetsiri, Ms. Busaba Chaimanee, Ms. Wilawan, Ms. Chalerm Teomtong and Ms. Metta Tullachart. The following doctors greatly contributed in the discussion of the research findings: Dr. Patcharee Kantipong, Dr. Vichai Panich, Dr. Pipat Srinoi, Dr. Juthathip Putthasorn, Dr. Jate Ajalapong, Dr. Vithaya Pongsurachet, Dr. Wiwat Ratanachai, Dr. Chaiwat Chandnuamai and Dr. Reuchukorn Teomtong. I am indebted to Dr. Supak Pitipakorn and Dr. Patchraporn Out for their kindness in providing medical care for my children, especially during my absences to Sweden

*TB/HIV Research Project (RIT-JATA)*

I appreciate the project's staff for their assistance. Ms. Piyanoot Chatchawarat for the administrative assistance; Ms. Sarnwai Luangjina for being my excellent research assistant; Ms. Oranuch Nampaisan and Ms. Dollaporn Chaisanrith for the quantitative data management and Mr. Boonchai Chaiyasiriroj for the computer management.

*Others in Chiang Rai:*

I acknowledge the information supported by the Chiang Rai Center for Developing and Supporting Hilltribe Minorities. I thank Ms. Supaporn Korattana (Pink House-HIV/AIDS Collaboration) for her kind collaboration in the first study.

**Bangkok**

*Tuberculosis Division, Ministry of Public Health:*

I gratefully acknowledge the generous support from the Tuberculosis Division from the Ministry of Public Health for the production and distribution of many thousands of copies of the Tuberculosis Home Visit Manual, which I serve as the author. The book has greatly facilitated translating my



research in to public health practice. I am grateful to Dr. Pasakorn Akarasewi for his kind technical advice. My warmest thanks to Ms. Sirinapa Jitmanee for sharing several useful TB-related articles and her kind assistance for preparing the final materials for thesis printing.

*Others in Thailand:*

My special gratitude to Prof. Chitr Sitthi-amorn for broadening my public health research perspectives, his encouragement for my studies in Sweden and for his invaluable comments of the manuscripts. Professor Chaivej Noochprayun kindly provided technical advice for clinical TB care. My warmest thanks to Dr. Petchawan Punggrassami for technical contribution and her encouraging emails. Dr. Kanchit Limpakanjanarat served as a reviewer in the Ethical Committee and provided critical comments and materials on ethical considerations for the research. Dr. Pathom Sawanpanyalert served as an excellent co-investigator for the first study. I kindly appreciate his thoughtfulness and his special tutorial sessions on epidemiology. My qualitative research and concepts in medical sociology and medical anthropology were greatly contributed by Dr. Bencha Yoddumneon-Attig, Dr. Thavitong Hongwiwat and Dr. Pimpawan Boonmongkol at the Mahidol University. My gratitude goes to Ms. Aree Wadwongtham for her kind coordination during the period in which I began communicating with Prof. Vinod for the TB research. Dr. Potjaman Siriyapon kindly shared information in her doctoral thesis. Ms. Duangkamol Wattradul and Ms. Dares Chusri provided me with their assistance to obtain literature. Dr. Ravinan Sirikanokvili kindly sent his warm wishes and information surrounding Buddhism for writing my thesis.

**Japan:**

*The Research Institute of Tuberculosis, Japan Anti-TB Association:*

I am indebted to Dr. Toru Mori for his kind permission to conduct my field research attached to the RIT's research project in Chiang Rai. I am in deep gratitude to Dr. Nobukatsu Ishikawa. He is my inspiration in devoting my social science research and training career to TB. I sincerely appreciate his generous support in incorporating social science subjects into the International TB Training course, which I have been involved in teaching since 1993. I extend my thanks to Dr. Akira Shimouchi for his support for the development of the TB Home Visit Manual. Dr. Takashi Yoshiyama provided technical advice for the clinical TB care. Ms. Yoshiko Kazumi kindly supported me with much TB literature. Ms. Sato and Ms. Okamoto provided administrative assistance.

**Sweden**

*IHCAR, Karolinska:*

I am grateful go to Prof. Goran Sterky for his first positive letter in response to my inquiry about the doctoral study at the Karolinska Institutet. I express my gratitude to Prof. Staffan Bergstrom and Prof. Bengt Hojer for supporting my student life at IHCAR. I am indebted to Prof. Hans Rosling for his leadership and for his academic contributions during the halfway control and pre-disputation.

My special thanks go to Ms. Anna-Stina Ullrich, Ms. Birgitta Linnanheimo and Ms. Bodil Hellstedt for their invaluable administrative assistance during my study at IHCAR, especially during the last period before the date of the thesis defense. I gratefully acknowledge kind contributions from Dr. Eva Johansson and Dr. Anna Thorson during the halfway control and before the defense. Eva also generously welcomed me in her home when I first started my study at IHCAR. Anna Thorson and Anders Ragnarsson helped me finalize the thesis title. Dr. Anna-Berit Ransjo-Arvidson, for her kind physical and mental support. I enjoyed staying in her home during the halfway control. In the pre-disputation, I extend my sincere thanks to Dr. Anna Mia Astrom for her contribution as my pre-opponent. Drs. Grazyna Stanczuc and Elizabeth Mathai provided me with comments to improve the final thesis. I appreciate the computer and Internet assistance from Mr. Lars Hedlund and the working space at IHCAR from Kersti Radmark. I thank Cecilia Stalsby Lundborg, Annika Johansson, Aslie Kulane and my many colleagues at IHCAR for their nice smiles and warm friendship which are helpful to fo

*Epidemiology, Department of Clinical Medicine and Public Health, Umeå University::*

I gratefully acknowledge Prof. Stig Wall for accepting me to be a doctoral student at the Epidemiology, Department of the Clinical Medicine and Public Health Sciences. His wife and his kind hospitality during my summer in Sweden will always be cherished. Drs. Ann Ohman, Maria Emmelin and Anders Emmelin for their hard work in organizing a summer course in Epidemiology and Qualitative Research and for their suggestions during the doctoral thesis seminar at Umeå. I thank Dr. Lars Dahlgren for his kind academic contributions during my halfway control and for his reader-friendly book on Grounded Theory. For the excellent student support, I sincerely thank Ms. Anna Lena-Johansson, Ms. Birgitta Astrom, Ms. Lena Mustonen and Mr. Jerzy Pilch.

*Nordic School of Public Health:*

I extend my thanks to Ms. Rose Wesley Lindahl and Ms. Birgitta Bohm for their kind coordination and assistance between Prof. Vinod and myself. Dr. Knut Lonnroth for his interesting TB thesis and his hospitality. Dr. Bo Eriksson for his kind support during my stay at the Nordic School.

*Others in Sweden:*

I am grateful to Dr. Inger Julander for her kind support with finding literature regarding TB and its association with HIV and for serving as an examiner for my TB clinical knowledge. She kindly introduced me to an infectious ward of the Huddinge Hospital where I had an opportunity to visit and talk with a Thai AIDS victim who was hospitalized there at the time. My warmest thanks to Mr. Andres Orjuela for his English-language assistance.

**Other countries:**

My warmest thanks to the following experts for their critical review, advice and revision of the manuscripts before submitting for publication; Drs. Richard Chaisson, Mark Nichter, Tim Mastro, Kevin De Cock and Christopher Murray. I am grateful to the anonymous reviewers of the AIDS Journal and The International Journal of Tuberculosis and Lung Disease. Their comments and

questions sharpened my brain. Drs. Pual Nunn and Dermot Maher supported me with useful literature. I appreciate the advice for the general examination, thesis preparation and friendship of Dr. Nguyen Hoang Long, Dr. Nguyen Thi Kim Chuc and Dr. Thanh Vupham.

Lastly, my deepest gratitude to my family in Thailand and Japan. To my late grand mother and my parents for their hard work in supporting their children's education. Their concepts of sharing, social justice and virtue influence my public health perspectives and my life. My Japanese in-laws and my sisters greatly contributed to my children's care, especially during my absences to Sweden. I thank my kids, Eri and Takumi for their patience and encouragement while writing my thesis. Hideki Yanai for his endless support for my doctoral study and my research career, for his academic assistance and for sharing love, happiness and hard times with me since 1992.

**I dedicate this thesis to all the persons that I acknowledge. I alone bare comments and criticism on this thesis.**

## TABLE OF CONTENTS

<b>Abstract</b> .....	iii
<b>List of original papers</b> .....	v
<b>Abbreviations</b> .....	vi
<b>Acknowledgement</b> .....	vii
<b>1. INTRODUCTION</b> .....	1
1.1 Tuberculosis and HIV/AIDS: The Global Health Issues.....	1
1.1.1 Global situation of tuberculosis.....	1
1.1.2 Global situation of HIV/AIDS.....	2
1.1.3 Global situation of tuberculosis associated with HIV.....	3
1.2 Tuberculosis and HIV/AIDS in Thailand.....	4
1.2.1 Thailand country profile.....	4
1.2.2 Tuberculosis in Thailand.....	5
1.2.3 HIV/AIDS in Thailand.....	6
1.2.4 Tuberculosis associated with HIV in Thailand.....	8
1.3 The clinical aspect of tuberculosis and HIV/AIDS.....	9
1.3.1 The interaction between tuberculosis and HIV/AIDS.....	9
1.3.2 Clinical patterns of tuberculosis associated with HIV.....	9
1.3.3 Interventions for tuberculosis control in the HIV epidemic area.....	11
1.4 Soci-cultural and behavioral aspects of tuberculosis and HIV/AIDS...12	
1.4.1 The medical systems and the explanatory model.....	13
1.4.2 Health seeking behavior.....	14
1.4.3 Adherence to the therapy.....	15
1.4.4 Stigma.....	19
<b>2. OBJECTIVES AND CONCEPTUAL FRAMEWORK</b> .....	20
2.1 Objective.....	20
2.1.1 General objective.....	20
2.1.2 Specific objective.....	20
2.2 Conceptual framework.....	21
<b>3. METHOD</b> .....	24
3.1 Study setting.....	24
3.2 Research methodology.....	26
3.2.1 Foundation of qualitative research.....	27
3.2.2 Validity, reliability and generalizability in qualitative research..29	
3.3 Study design, study population and data collection.....	30
3.3.1 Data collection methods.....	32
3.3.2 Data collection procedures.....	34
3.3.3 Researcher's bias.....	36
3.4 Definitions and measurements.....	38
3.5 Data analysis.....	38
3.5.1 The statistical analysis.....	39

3.5.2	Qualitative data analysis.....	40
3.6	Strength and limitations of the studies.....	41
3.6.1	Limitations of the studies.....	41
3.6.2	Strength of the studies.....	42
3.7	Ethical considerations .....	43
<b>4.</b>	<b>MAIN FINDINGS.....</b>	<b>45</b>
4.1	The impact of AIDS epidemic on the perception and practice regarding tuberculosis.....	45
4.1.1	The explanatory model of tuberculosis and HIV/AIDS.....	45
4.1.2	Impact of high AIDS awareness on tuberculosis.....	46
4.1.3	Attitudes and value associated with HIV and tuberculosis transmission.....	47
4.2	Health seeking behavior before and after the tuberculosis diagnosis...50	
4.2.1	Health seeking behavior before the tuberculosis diagnosis.....	50
4.2.2	Health seeking behavior after the tuberculosis diagnosis.....	52
4.3	Adherence to tuberculosis preventive therapy and tuberculosis treatment.....	53
4.3.1	Reasons for non-adherence.....	53
4.3.2	Reasons for good adherence.....	54
4.4	HIV infection and life style of tuberculosis patients.....	57
4.4.1	Impact of HIV infection on patients' life style.....	57
4.4.2	Impact of HIV infection on the family.....	57
4.5	TB and AIDS stigma.....	60
4.6	Health care providers: knowledge, perspectives and practice regarding TB .....	64
4.6.1	Knowledge about TB.....	64
4.6.2	Financing incentives versus intensive education for health staff.....	65
4.7	Feasibility of home-based and health center-based directly observed therapy (DOT) in the HIV epidemic setting .....	66
<b>5.</b>	<b>DISCUSSION.....</b>	<b>69</b>
5.1	The role of knowledge, perception and behavior in tuberculosis and HIV control.....	70
5.2	The role of stigma in TB and HIV transmission.....	71
5.3	Poverty, equity and gender.....	74
5.4	The role of fatalism and lack of virtue in TB and HIV transmission.....	76
5.5	Tuberculosis prevention in an HIV epidemic setting.....	78
5.5.1	Tuberculosis preventive therapy for people with HIV infection.....	78
5.5.2	Preventing TB by detecting and curing TB patients.....	79
5.6	The role of health care workers.....	81
<b>6.</b>	<b>CONCLUSION.....</b>	<b>83</b>
6.1	Challenges for TB control in HIV epidemic areas.....	83

6.2 Opportunities for TB prevention and care in HIV epidemic area.....84  
6.3 Recommendations for social and behavioral research.....85

**REFERENCES.....87.**

**APPENDIX: Tools for data collection.....103**

**ORIGINAL PAPERS I-V**

## **CHAPTER 1**

### **INTRODUCTION**

The alarming global crisis of HIV/AIDS, tuberculosis (TB) and malaria epidemics in the new millennium has prompted the United Nations and the international community to set a global target to reduce the burden of these three priority diseases. Thailand is one of the countries where TB and HIV are highly prevalent. This chapter describes background information about TB and HIV/AIDS globally and in Thailand, as well as the background on the clinical and socio-cultural aspects of TB associated HIV/AIDS.

#### **1.1 Tuberculosis and HIV/AIDS: The Global Health Issues.**

##### **1.1.1 Global situation of tuberculosis**

In 1993, the World Health Organization (WHO) declared TB a “Global Emergency” and created a framework for effective TB control. The targets for global TB control by the year 2000, ratified by the World Health Assembly were to successfully treat 85% of the detected smear-positive TB cases, and to detect 70% of all such cases (WHO, 1994). However, these targets were not achieved as planned, the target year has been re-set to 2005 (WHO, 2002a). From the public health perspective, TB is a high priority disease because of its tremendous burden and the existence of interventions of proven efficacy that are some of the most cost-effective (Murray, Styblo, Rouillon, 1990). Since 1994, WHO has recommended and up scaled the TB control strategy, brand name as “DOTS” (Directly Observed Treatment Short-course), which includes the five major components, namely; political commitment; accurate TB diagnosis using microscopy; regular drug supply; recording and reporting and directly observed therapy (DOT) by trained persons. Other global initiatives, which have recently emerged in response to the global TB crisis, are Global Alliance for TB Drug Development, TB Diagnostic Initiative and TB Vaccine Initiative (WHO, 2002b). 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 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).

From the global perspectives, TB is perhaps the greatest infectious killer of all time. Over centuries, it has taken over one billion lives (WHO, 2002b). WHO estimated a total of 1.86 billion people were infected with *Mycobacterium tuberculosis*, or 32% of the world population in 1997. New cases of TB were estimated at 7.96 million cases, including 3.52 million (44%) cases of infectious pulmonary TB cases (smear-positive). Eighty percent of all incident TB cases were found in 22 countries, with more than half the cases occurring in 5 Southeast Asian countries. Nine of 10 countries with the highest incidence rates per capita are in Africa (Dye, Scheele, Dolin, & Pathania, Raviglione, 1999). Tuberculosis caused more than 26% of avoidable adult (15-59 years of age) deaths in the developing world, which resulted in tremendous social and economic costs (Murray, et. al., 1990). Mortality due to TB is estimated at 1.87 million in 1997 and the global case fatality rate was 23%, however it has exceeded 50% in some African countries with high HIV rates (Dye et al. 1999). In 2000, an estimated 273,000 of the 8.7 million new TB cases (3.2%) were multi-drugs resistance (MDR). In drug resistance surveys carried out in 64 countries, the highest MDR proportions among new cases have been found mostly in Eastern Europe, Russia and China. An estimated 70% of new MDR cases were found in only 10 countries. Thus, MDR, and resistance more generally, are problems of local rather than global importance. By far, the majority of TB cases remain treatable (i.e., cure rate 85%) under standard short-course chemotherapy (SCC) with cheap and safe first line drugs (Dye, Williams & Espinal, Raviglione, 2002).

### **1.1.2 The global situation of HIV/AIDS**

The most explosive spread of HIV epidemics in the world is occurring in the young adult population. Transmission through sexual contacts, mother-to-child and unsafe blood transmissions remain the most significant methods in which the disease is being spread in most parts of the world. The Joint United Nations Program on HIV/AIDS (UNAIDS, 2002) reported that globally, over 40 million adults and children were living with HIV/AIDS at the end of 2001. About 5 million people were newly infected with HIV, 3 million people died due to AIDS and 14 million children (0-14 years) are orphaned due to AIDS in the same year. Sub-Saharan Africa continues to be the region hardest hit by HIV/AIDS, followed by South and Southeast Asia (14%). According to the latest UNAIDS estimates, over 71 percent of people living with HIV/AIDS live in the African region. Within Sub-Saharan Africa disparities by region remain great. In most countries of Western and Central Africa, the HIV prevalence among adults still remains below 10% the populations of East and Southern Africa are more heavily affected. In Southern Africa, including Zambia, Zimbabwe, Botswana, Namibia, Lesotho, Swaziland, and South Africa, the prevalence among adults exceeds 20%. The size and diversity of the Asia-Pacific region continues to be reflected in multiple distinct patterns of the HIV occurrence. Encompassing some 60% of the global population, the region still has a very low overall prevalence, but contains some sub-populations which register the highest and most sharply-increasing prevalence seen worldwide. The majority of industrialized countries have concentrated HIV epidemics with most infections occurring among homosexual men and injecting drug users. Approximately 75,000 new HIV infections occurred in industrialized



countries in 2001. These new infections, combined with the reduced mortality that has been observed since 1995/96 due to the introduction of Highly Active Anti-retroviral Therapy (HAART), have resulted in an increasing number of people living with the HIV infection in these countries. This increasing trend in survival will have a significant impact on the burden of disease for costs of treatment, care and support. Anti-retroviral drug resistance is increasingly becoming a problem as individuals experience difficulty complying with complex drug regimens.

### **1.1.3 The global situation of tuberculosis associated with HIV**

The HIV infection is considered the most significant risk factor for progression of latent infection with *Mycobacterium tuberculosis* to active tuberculosis (Reider, 1998). Several studies have shown the relevance of an endogenous mechanism for the manifestation of active TB among HIV-seropositive clients. TB incidences may increase dramatically as immunodeficiency occurs among HIV-infected people who also have a latent TB infection. Furthermore, recent evidence in the US shows that HIV seropositive individuals are highly susceptible to progressive primary TB, i.e., there is rapid progression in primary infections (Edlin, Tokars, Gireco, Crawford, & Williams, Sordillo, et al., 1992; Small, Schecter, Goodman, Sande, & Chaisson, Hopewell, 1991). In addition, re-infection of TB can occur in the advanced stage of the HIV-infection (Small, Shafer, Hopewell, Singh, & Murphy, Desmond, et al., 1993).

Globally, TB is a leading cause of HIV-related morbidity and mortality. In developing countries, HIV-infected people run an annual risk of 5-15% of developing TB; at least one in three PLWH will develop TB (WHO, 2001). The escalating TB-case rate over the past decade in many countries in sub-Saharan Africa and in parts of South East Asia (e.g. northern Thailand) are largely attributable to the HIV epidemic (Bleed, Dye, Raviglione, 2000). In 1997, prevalence of *Mycobacterium TB* and HIV coinfection worldwide was 0.18% and 640,000 incident TB cases (8%) had the HIV infection. It was estimated that in the year 2000, the global incidence of HIV-positive TB cases was 12 percent. The number of people living with TB and HIV coinfection was 16.3 million. Of the estimated 2 million TB deaths in the world, about 0.5 million deaths were HIV-positive TB cases (WHO, 2001). Sub-Saharan Africa bears the highest burden of HIV-positive TB cases, followed by South East Asia. In the HIV epidemic settings, the rising annual TB case notification rates have been observed even in well-organized TB control programs (successful DOTS program) such as Botswana (Kenyon, Mwasekaga, Huebner, Rumisha, & Binkin, Maganu., 1999). In order to reduce the burden of TB-related HIV, other novel public health interventions beyond DOTS are needed.

## **1.2 Tuberculosis and HIV/AIDS in Thailand**

### **1.2.1. Thailand Country Profile**

Thailand is a low middle-income country in Southeast Asia, with an area of 513,115 square kilometers. Its neighboring countries are Myanmar, Laos, Cambodia and Malaysia. In terms of population size, Thailand is the fourth largest country in Southeast Asia headed by Indonesia, Vietnam and the Philippines. Thais form the majority, though the area has historically been a migratory crossroads, and thus strains of Mon, Khmer, Burmese, Lao, Malay, Indian and most strongly, Chinese stock produce a degree of ethnic diversity. However, culturally and socially there is enormous unity. About ninety five per cent of the population is Buddhist. The official language is Thai. People living in the north, northeast and south have different local dialects. Administratively, Thailand has 76 provinces, 795 districts, 81 sub-districts, 7255 tambols and 69,866 villages in 1999 (The National Statistical Office, 2002).

The national population and housing census conducted on April 1, 2000 reported the population of Thailand at 60,606,947 (49.24% men and 50.76% women). There were 15,660,667 households with an average size of 3.9. The population density in the same year was 106.3 persons per km<sup>2</sup>. Thirty one per cent of the population lived in municipality areas. As a consequence of the extended family being replaced by the nuclear family the sense of community and traditional forms of co-operation and safety nets has been weakened, increasing the vulnerability of disadvantaged groups. Drug addiction and crime are on the increase. Approximately 68% of the population lives in rural areas and the majority are farmers with incomes reliant upon subsistence agriculture. Rapid change has had a disruptive effect on social structures. Urban migration to Bangkok, the capital city, has led to serious problems of congestion, land shortage and water and air pollution. During the last three decades, Thailand has significantly improved the socio-economic and health status of the population. Infant mortality rate per 1,000 in 1970 was 74, which was reduced to 26 in 1999. The life expectancy in 1970 and 1999 was 59.5 and 69.5, respectively. The Human Development Index (HDI) of Thailand in 1999 was 0.757, and the country was ranked as 66th. Gender-related development index ranked 58<sup>th</sup> (UNDP, 2001). Traditionally, the parents' attitude is to give priority to their sons' education. At present, limited access to education is not obvious although gender differences still exist (UNIFEM, 2000).

**Table 1.** Selected health and social development indexes of Thailand in 1999 (UNDP Report 2001. New York: Oxford University Press, 2001)

Under one year old fully immunized against TB (BCG vaccine)	98%
Maternal mortality (per 100,000)	44
Infant mortality (per 1,000)	26
Birth attended by skilled health care staff	95%
Life expectancy at birth	Male 67.0 yrs., Female 72.9 yrs.
Population growth rate	1.0
Health expenditure as % of GDP 1998	1.9
GDP	6.132 US\$
Adult literacy rate	Male 97.0%, Female 93.5%

### 1.2.2 Tuberculosis in Thailand

Like many countries in the world, TB became an important public health problem in Thailand after the Second World War. TB was the major killer, second to malaria at that time. The National TB Program (NTP) in Thailand was formulated during 1966-1967 following the recommendation of WHO. At the beginning of Thailand NTP, TB services were delivered to people through specialized TB clinics such as Bangkok chest clinic, Anti-TB Association hospitals, chest hospital and zonal TB centers in major provinces of each region. Until 1982, TB services were fully integrated into general health services, i.e. community hospitals. The use of short-course chemotherapy started in Thailand in 1983 but became systematically and widely provided to TB patients in 1991 (Sriyabhaya, Payanandana, & Bamrungtrakul, Konjanart, 1993).

The TB national prevalence surveys in Thailand were conducted in 1962, 1977 and 1991. The surveys consisted of Mass Miniature Radiography (MMR), sputum examination and PPD tuberculin test in the multi-stage cluster sampling of the Thai population. The sample size of the third survey was 35,800 (>10 years age: 32,069). MMR and sputum examinations were used to calculate TB prevalence. The results of these three surveys show that TB radiological prevalence (MMR) was 2.1%, 1.4% and 0.92% and the bacteriological prevalence (sputum smear positive and culture) was 0.5, 0.3 and 0.23, respectively (Payanandana, Bamrungtrakul, & Sareebutra, Na Songkla, 1992). Studies of the annual risk of TB infection (ARI) performed in 1962, 1977 and 1983 reported the ARI rates as 3.8%, 4.9% and 2.3%, respectively. (Tuberculosis Division 1992). The first and second national epidemiological surveys show the decline of infectious TB morbidity from 500 per 100,000 in 1960-1964 to 300 per 100,000 in 1977 (Sunakorn, 1969; Daramas, Konjanart, Sunakorn, 1981). The tuberculosis mortality rate (per 100,000) had steadily declined over the years amounting to 35.2 in 1960, 21.4 in 1970, 14.3 in

1980 and 6.8 in 1990. However, during 1995-1996 the mortality rate started to increase reaching 7.0 and 7.7 per 100,000 (Payanandana, Kladphuang, & Somsong, Jittimanee, 1999). The overall TB notification rate in Thailand markedly decreased after the introduction of highly effective short-course chemotherapy in 1985. The overall TB notification rate in 1985 was 150/100,000 as compared to 79/100,000 in 1994. Although the national average figure declined in 1990s, the trend towards higher incidence rates continues in the areas most afflicted by the emerging HIV epidemic such as the northernmost part of northern Thailand, where the increasing annual rates of the case numbers is 10% (Payanandana, et al., 1999).

In 2000, Thailand was ranked 16<sup>th</sup> of twenty-two high TB burden countries, (WHO, 2002d). In 1997, WHO estimated TB incidences (all cases) in Thailand at 142/100,000 and infectious TB (smear positive) incidences at 63/100,000; the death rate was 29 per 100,000; and the estimated multi-drug resistance (MDR) for new cases was 2.1%. The TB and HIV coinfection rate per 100,000 was 561 and HIV infection rate in TB patients was 10% in 1997 (Dye, et al., 1999). The country commenced the DOTS strategy in 1996 in eight pilot districts (of about 800 districts). The coverage of DOTS in 2000 was 70% (WHO, 2002d). The national TB control guidelines listed three options for directly observed therapy (DOT); 1) daily DOT at health center; 2) daily DOT by village health volunteers; 3) daily DOT by family members (Ministry of Health, 1998). Prior to the DOTS initiative, most public hospitals in Thailand provided TB patients with one-month supplies of TB medicine free of charge. Health centers were not involved in providing TB care, except by referring suspected TB cases to the hospital. A health center is a unit of first-line health service covering approximately 1,000 to 5,000 inhabitants, staffed by 2-5 nurses and health workers.

### **1.2.3 HIV/AIDS in Thailand**

There are two major HIV-1 subtypes found in Thailand, E and B (previously named Thai-A and Thai-B). Subtype E is most commonly found in the heterosexual group (more than 80%) while subtype B is commonly spread among injecting drug users (75%) (Ruxrungtham & Phanuphak, 2001). Approximately 96% of the nationwide HIV-1 isolates from Thai men in 1992 and 1995 were HIV-1 subtype E. Although Thailand was among the first 3-4 nations in the Asia and Pacific region to experience the explosion in HIV infections, it was considered a recent origin compared to the epidemic in Africa (Weninger, Limpakarnjanarat, Ungchusak, Thanprasertsuk & Choopanya, Vanichseni et al., 1991). The first case of AIDS in a Thai patient was reported in September 1984. However, the actual epidemic transmission of HIV in Thailand did not commence until 1988. There have been five major epidemic HIV waves in Thailand; the first wave started in 1984-1985 within male homosexuals; the second wave started in 1988 within the intravenous drug users; the third wave, in 1989, within female commercial sex workers; the fourth wave started in 1990 within males who had sex with HIV-infected sex workers and the fifth wave started in 1991 within housewives and the newborn (Ruxrungtham & Phanuphak, 2001). The latest wave indicates that HIV/AIDS transmission is not limited to specific groups of people but rather involves the general public.

Currently, the major route of HIV transmission in Thailand is heterosexual transmission, although homosexual men and intravenous drug users were the main groups at the very early period of the epidemic (Weninger, et al., 1991).

From June 1989, the Ministry of Public Health (MOPH) instituted the HIV sentinel sero-surveillance system in order to monitor the trends of the HIV epidemic in six high-risk groups (Table 2).

**Table 2.** Median HIV sero-prevalence rate (%) in high risk groups in Thailand June 1989 – June 2000.

Month and Year	HIV Risk Group Category					
	Blood donor	IDU	ANC	Male STD	CSW	ICSW
June 1989	0.28	70.09	0.00	0.00	3.12	0.00
Dec 1989	0.20	45.00	0.00	2.00	6.27	1.45
June 1990	0.43	29.71	0.00	2.50	9.30	2.00
Dec 1990	0.36	37.81	0.00	4.17	11.43	2.57
June 1991	0.45	34.04	0.68	5.00	15.24	4.34
Dec 1991	0.82	37.04	0.71	5.67	22.72	5.41
June 1992	0.81	37.00	1.00	5.71	22.97	4.46
Dec 1992	0.95	36.40	1.00	5.63	24.14	6.31
June 1993	0.78	35.21	1.39	8.05	28.00	7.69
Dec 1993	0.80	35.53	1.50	6.83	29.52	7.69
June 1994	0.68	34.27	1.80	8.50	27.64	8.00
Dec 1994	0.90	30.56	1.61	8.60	33.15	9.48
June 1995	0.63	37.00	2.29	8.08	17.79*	17.79*
June 1996	0.57	40.00	1.82	8.00	28.17	10.14
June 1997	0.59	40.00	1.68	6.79	26.14	8.26
June 1998	0.39	47.46	1.53	8.50	21.05	6.67
June 1999	0.44	50.77	1.74	9.09	16.00	6.55
June 2000	0.31	41.17	1.46	5.92	18.46	5.51

Source: HIV sentinel surveillance system, Ministry of Public Health, Thailand.

IDUs: Injecting drug users, ANC: Ante natal care, CSWs: direct commercial sex workers, IDCWs: indirect commercial sex workers. \*CSW and ICSW were not differentiated in June 1995. STD: sexually transmitted diseases. Survey of male prostitutes has been conducted in only 5 major provinces.

The HIV epidemic is particularly advanced in upper Northern Thailand (Weninger, et al., 1991; Brown, Sittitrai, & Vanichseni, Thisyakorn, 1994). In 1993, HIV prevalence in military

conscripts at the national level was 4%, while the prevalence in Chiang Rai, the northernmost province, was 16.5% (66 of 401) in the same year. The prevalence was reduced to 1.4% in 2000. Thai Working Group on HIV/AIDS Projection estimated that in the year 2000 the number of HIV infections in adults and children amounted to 984,000, the total deaths were 289,000, those living with HIV/AIDS reached 695,000 and there were 34,372 AIDS orphans. Sexual transmission accounts for 83.3% of the reported AIDS cases, IDU 4.9% and the transmission of HIV from mother to child accounted for 4.7%. More than 78% of the cases were registered in the age group of 20-39 years. The male to female ratio is 3.3 to 1. The top five opportunistic infections reported in 1984-2000 were Mycobacterium tuberculosis (27.6%), Pneumocystis pneumonia (19.7%), Cryptococcosis (16.8%), recurrent bacterium pneumonia (3.6%) and Cerebral Toxoplasmosis (2.9%). The manifestations as well as the clinical course of HIV infection among patients in developing countries may differ from those observed in western countries. AIDS patients at the early phase of the epidemic in Bangkok had much shorter survival times than patients in developed countries (Kitayaporn, Tansuphaswadikul, Lohsomboon, Pannachet, & Kaewkungwal, Limpakarnjanarat, et al., 1996). A recent study with Thai male soldiers of 21-23 years of age found that median time since seroconversion to CD4+ <200 cells was 6.79 years (Rangsin & Chiu, Sirisopa, 2001).

The Thailand national guidelines for the clinical management of HIV infection in children and adults (MOPH, 2000) classified the primary prophylaxis for opportunistic diseases into 3 categories; 1) recommended as a standard care, e.g., PCP, toxoplasmosis, cryptococosis and penicillosis prophylaxis; 2) inconclusive and requires special caution, i.e., TB prophylaxis; 3) recommended but the cost may be unaffordable, e.g., CMV and MAC (Ruxrungtham & Phanuphak, 2001).

#### **1.2.4 Tuberculosis associated with HIV in Thailand.**

Results from HIV surveillance among TB patients from twelve TB zonal centers in Thailand indicate the increasing HIV seropositivity from 3.1% in 1989 to 9.3% and 15.8% in 1994 and 1998, respectively (Payanandana, et al., 1999). In the six provinces of the upper northern part of Thailand, the epicenter of HIV epidemic, the number of reported newly detected TB patients clearly revealed a steady upward trend. Approximately 40% of all TB patients are infected with HIV, furthermore, there is a high mortality rate (10-35%) (Akarasewi, 2001).

**Table 3.** Percentage of HIV seropositivity in new TB patients in Thailand and in a zonal TB center in the upper north region of Thailand (1990-1998).

Period	1990		1991		1992		1993		1994		1995		1996		1997		1998
	1	2	1	2	1	2	1	2	1	2	1	2	1	2	1	2	1
Country	3.8	6.3	2.7	5.4	4.2	7.3	5.8	8.6	10.0	8.6	12.9	15.0	15.3	22.3	18.2	15.4	15.8
Zonal TB Center 10	6.5	10.5	6.7	9.3	14.8	25.8	25.6	39.7	39.7	40.6	34.3	45.7	40.4	34.0	42.1	35.8	41.2

Source: Payanandana, et al., 1999, p.34

Note: 1 = May-June; 2 = November-December; Zonal Center 10 = six provinces in upper north of Thailand

In 2001, the Ministry of Public Health in Thailand published the national recommendation guidelines to integrate TB/HIV strategies for the control and prevention of tuberculosis in the country (Akarasevi, 2001). The recommendations include seven strategies to improve the TB-related HIV care and prevention:

1. Strategy to improve the quality of TB care and promoting access to TB care
2. Strategy to improve DOTS implementation in HIV-positive TB patients
3. Strategy for screening TB among PLWH through HIV counseling
4. Strategy to mobilize resources and collaborations from public, private and non-governmental organizations for comprehensive and continuity care
5. Strategy to improve and collaborate with TB and HIV surveillance and to support the information for research
6. Strategy to provide preventive treatment of latent TB infection with isoniazid
7. Strategy to strengthen prophylaxis treatment for other opportunistic infections

### 1.3 The clinical aspect of TB and HIV/AIDS

#### 1.3.1 The interaction between TB and HIV/AIDS

HIV is the most powerful known risk factor for reactivating latent TB infections into TB diseases (Rieder, 1998). Several studies consistently demonstrated the association between HIV and TB. All studies reported the increase risk of developing TB among HIV-infected persons, compared to those not infected by HIV. The lifetime risk of developing TB in HIV-negative persons is 5-10%, while the risk is 50% in HIV-infected persons (Harries & Maher, Uplekar, 1997). The annual risk of developing TB in a PLWH, which is co-infected with *M. Tuberculosis*, ranges from 5-15% (Raviglione, Harries, Msiska, & Wilkinson, Nunn, 1997). The interaction

between the TB and HIV epidemics is particularly lethal. During the course of HIV infection, PLWH suffer at different times from a number of different HIV-related illnesses, including TB. TB enhances HIV replication and might accelerate the natural progression of the HIV infection as well as shortening their life expectancy (UNAIDS, 1997). Case fatality rates for TB in HIV-infected patients are much higher than in nonimmunocompromised patients (Hopewell, 1993). Case fatality rates by the end of TB treatment in HIV-infected patients was 20% among new sputum smear-positive cases and 50% among sputum smear-negative cases (Mukadi, Maher, Harries, 2001). Moreover, HIV-positive TB patients who were cured from TB had a higher rate of recurrent TB than HIV-negative TB patients (Fitzgerald, Desvarieux, Severe, Joseph, & Johnson, Pape, 2000).

### 1.3.2 Clinical patterns of tuberculosis associated with HIV

The clinical pattern of TB in PLWH depends on the stage of the HIV infection and its associated degree of immunodeficiency. Even in HIV-infected patients, pulmonary TB is still the most common form of TB. In early HIV infection with mild to moderate immunodeficiency, the features are characteristics of post-primary TB (due to reactivation or re-infection), which are similar to the pre-HIV era (WHO, 2002e). As the HIV infection progresses, CD4 lymphocytes decline in number and function. The immune system is less able to prevent the growth and local spread of *M.tuberculosis*. Therefore, the disseminated and extra-pulmonary disease is more common in the late stage of HIV infection (Harrie et al., 1997).

Table 4 summarizes the clinical pattern of TB in HIV-infected patients. Table 5 compares the clinical characteristics when pulmonary TB occurs at the early and late stage of the HIV infection.

**Table 4** The clinical pattern of TB in HIV-positive patients (Crofton & Horne, Milller, 1992; Harries et al.,1997; Hopewell, 1993)

	Pattern
Form of TB	-More common form of extra pulmonary, especially TB lymph nodes -More common of miliary disease.
Sputum smear result	-Higher proportion of sputum smear negative patients
Chest X-ray appearance	-Atypical chest x-ray, x-ray can look normal in TB (HIV+) patients -Often large mediastinal lymph node masses; -Lower lobe disease and less frequent of cavitation -More frequent pleural effusion



**Table 5.** Clinical characteristics and investigation results among persons with pulmonary TB during the early stage and late stage of HIV infection

Investigation for pulmonary TB (PTB)	Stage of HIV infection	
	Early stage	Late stage
Clinical picture	Often resembles post-primary	Often resembles primary PTB
Sputum smear result	Often positive	Often negative
Chest X-ray appearance	Often cavities	Often infiltrates with no cavities

Sources: Harries, & A., Maher, D., Uplekar, M. (1997). *TB: A Clinical Manual for South East Asia*. Geneva: WHO. p.93.

### 1.3.3 Interventions for TB control in the HIV epidemic area

The basic components of TB control, including case finding and case holding, have been in place with little modification for decades (Hopewell, 1993). Regardless of the HIV prevalence, TB control strategies in all countries with high TB burden include DOTS and BCG vaccinations (WHO 1994). However, in settings with high a HIV burden, additional control strategies are needed. In order to reduce the burden of TB, it is important to reduce the HIV burden. Therefore, the interventions to control TB in HIV-epidemic areas include interventions directly against TB and the interventions to reduce the burden of HIV. These are summarized in table 6.

**Table 6.** Interventions for TB control in the HIV epidemic settings (Summarized from WHO (2002e). *Strategic Framework to Decrease the Burden of TB/HIV*. Geneva: WHO. pp.17-23.)

Categories of the interventions	List of interventions
Interventions directly against TB	<ol style="list-style-type: none"> <li>1. Earliest and intensified case-finding and treatment to ensure cure rate. The case finding can be done with people having respiratory symptoms at general health service; people attending HIV voluntary testing, prisoners, household contacts of the indexed TB (HIV+) cases.</li> <li>2. Preventive tuberculosis treatment aiming to decreasing the risk of first ever episode of TB and aiming to decreasing risk of a recurrent episode of TB</li> <li>3. BCG immunization</li> </ol>
Interventions against HIV (Interventions indirectly against TB)	<ol style="list-style-type: none"> <li>1. Interventions to decrease HIV transmission (promotion of condom use, treatment of STIs, reduction in number of sexual partners, safe injection behavior, drugs to prevent mother-to-child transmission, safe blood</li> <li>2. Antiretroviral therapy</li> <li>3. Interventions against other HIV-related diseases to decrease morbidity and mortality in HIV-infected TB patients (such as cotrimoxazole prophylaxis against bacterial causes of pneumonia and diarrhea and their complication).</li> </ol>

#### 1.4 Socio-cultural and behavioral aspects of TB and HIV/AIDS

One of the main objectives of this thesis is to research the socio-cultural and behavioral aspects of TB associated HIV prevention and care. Are studies on social and behavioral aspects relevant for TB and HIV control? In a traditional model of epidemiological triad (agent, host and environment), which is a causation model for all infectious diseases, the social and human behaviors are involved a great deal with host and environment components and therefore are determinant of disease occurrence. In brief, “agent” in this model refers to microorganism; “host” is the individual who is exposed, susceptible or response to a causative agent; “environment” refers to condition, which effect the agent and the opportunity for exposure (U.S. Department of health and human service, 1992).

Tuberculosis and HIV/AIDS have been well recognized as diseases which are closely associated with social and behavioral factors. AIDS seems to be the most apparent today providing a graphic and tragic example of complex interactions between the disease agent and

human behavior within varying ecological contexts (Brown, & Inhorn, 1990). TB is frequently referred to as a disease of poverty. People living in overcrowded and poor environments have a higher risk of becoming infected by TB, developing the disease and assuming a lack of access to care. The improvement of socioeconomic conditions decreased the TB prevalence in most industrialized countries (Comstock, 1993). Within an industrialized country like the United Kingdom, TB morbidity and mortality was much more prevalent in lower social classes. The increased rate of TB is also significantly associated with political turmoil and war, AIDS epidemics, injection drug use and homelessness (WHO, 2001). It has consistently been proposed that TB and AIDS are social diseases whose patterns of transmission must be understood, not only through the clinical or laboratory studies of bacteria and virus, but also equally through the study of attitudes, behavior and social organization (Ankrah, 1989; Campbell & Mzaidsume, 2002; Dubos and Dubos, 1992; Ford, & Koetsawang, 1991; Grange, 1997; Ogden, Rangan, Uplekar, Porter, & Brugha, Zwi, et al, 1999; Rubel & Garro, 1992).

This thesis addresses the issues of TB associated with HIV, and its prevention and care from socio-cultural perspectives. Some important sociocultural concepts that are applied in the thesis are medical systems and the explanatory model, health seeking behavior, adherence to therapy and stigma. These are discussed below.

#### **1.4.1 The medical system and the explanatory model (paper II, III, V)**

From an anthropological perspective, a cultural system is the way of life composed of several cultural sub-fields, e.g., religious, economic, kinship and medical systems. A medical system is a coherent of beliefs, norms, arrangements, institutions and patterns of interaction in response to health and diseases. During the course of human life, disease is an inevitable experience and coping with disease is a universal aspect of the human experience. However, the particular diseases that afflict people, as well as the way in which symptoms are interpreted and acted upon, vary greatly (Brown & Inhorn, 1990). According to Arthur Kleinman (1980), a medical system is composed of three sectors, namely i) medical professional sector, ii) popular sector (self-care, family and community based care) and iii) folk sector (e.g. traditional healer, faith healer). Each sector may have different beliefs, explanations and actions regarding illness, which are distinguished or may partly overlap. The framework of the medical system is important for the health-seeking behavior study of the individual, as well as for the disease control and health planning in the community level.

Moreover, in order to improve the effectiveness of patient care and to provide culturally appropriate care, Katon and Kleinman (1981) suggest that the initial step a clinician should take is to elicit the patient's perception of his/her illness, or what Kleinman named "patient's explanatory model". The explanatory model is the way that patient believes, interprets and reacts upon the disease in various aspects, i.e., belief about the cause of the disease (disease etiology); disease pathophysiology; expected course and prognosis; and treatment method which the patient

believes should be administered. The notion of “explanatory model” can also be applied to studies at a community level. It is important to recognize that patients, families and communities have their own beliefs, perceptions and information regarding the disease and their health that may or may not coincide with those of medical professionals (*Kleinman, 1980*). It is important to investigate the belief and attitude of the targeted population/community before launching any educational or informational interventions.

#### **1.4.2 Health-seeking behavior (paper IV, V)**

Health-seeking behavior is a decision process undertaken by an individual or family and friends to cope with illness. The process involves complex sociocultural, psychological and economic factors. Several models have been developed to study health-seeking behavior and health service utilization from different disciplines and perspectives (Tipping, & Segall, 1995). Health economists study the utilization of health services through perspectives of equity and fairness in which researchers investigate the interaction of the risks of illness across different social groups, the availability and use of services for the illness and the ability of different groups to pay for the health services (Bogg, 2002). Anthropological studies have chosen “accessibility” (defined as geographical, economic and psychosocial accessibility) to the service as a main criterion for people when making their choice of treatment. Other anthropological studies have correlated people’s choice of treatment (modern versus traditional medicine), their belief regarding the cause of the illness (“natural” versus “supernatural” causes), and patients’ qualities (e.g. age, sex, ethnicity). An anthropologist named Jame C. Young (1981), proposed four criteria that determine patients’ choices of treatment which include: perceived severity of the illness, knowledge about the illness and remedy, perceived efficacy of each treatment choice and the cost of the treatment.

Noel Chrisman (1977) and Arthur Kleinman (1980) view therapeutic choices as a component in the health-seeking process. There are five components in the health-seeking process namely, symptom recognition, sick role, lay referral, treatment action and evaluation and compliance to treatment.

(1) Symptom recognition: The first step in the health-seeking behavior is whether a patient recognizes the symptoms as a health problem. If the symptoms are not recognized, the subsequent steps will not take place. In this step, the patient also identifies the cause and assesses the severity of the symptoms.

(2) Sick role: After the symptoms are recognized as problems, patients may consider themselves as “sick persons” and will need to take a further step by consulting with their family, friends or neighbors regarding the management of the illness.

(3) Lay referral: Family members, friends, neighbors and other social networks help patients define the symptoms and guide them to treatment action.

(4) Treatment Action: Patients, family and their social networks make decisions regarding the treatment action which may include taking no action, conducting self-medication,

or visiting a drug store, health center, hospital or traditional healer within the public or private sector. This step also includes beliefs and practices about foods, drinking, bathing, exercise, rest, etc.

(5) Evaluation of treatment efficacy and adherence to treatment: In this step, patients and their social network evaluate the symptoms and treatment efficacy with common questions. Have the symptoms improved? Are the treatments effective? Should patients adhere to the treatment or should they switch to other treatment options? If the treatment action yields an unsatisfactory outcome, patients and their social network will make further decisions into other treatment options.

### **1.4.3 Adherence to the therapy (paper I, V)**

Non-adherence or non-compliance to the therapy is a common problem in the treatment of most chronic diseases as the patients have to take medicine for several months or, in some cases, for life. The consequences of non-adherence to treatment are treatment failure, relapse, increasing drug resistance and mortality. Sumartojo (1993) described the difference between “compliance” and “adherence”. She referred to "compliance" as those patients who are submissive and are influenced by the health care providers. Patients are supposed to obey and to comply with the medical guidance. However, the completion of the treatment requires the patients' independent initiative in taking the medicine, especially when the patient has to take medication in his own setting without the presence of health care providers. Sumatojo suggested that adherence is the better word for representing the active role of the patients in the treatment management and the importance of the cooperation between the patient and the health care providers.

#### **Measuring the adherence**

Table 7 summarizes the strength and limitations of several methods for measuring patient adherence to treatment. Not a single method is completely accurate, therefore, the use of combined measurements is recommended.

**Table 7.** Strength and limitations of methods for measuring patient compliance\*

Measurement for patient adherence.	Strength	Limitation
Providers' estimates	-High accuracy if the patients are known to be alcoholic and the provider is familiar with the patient, or the provider considers the relationship with the patients are not satisfied.	-In general, accuracy is less than 50%
Patient self-report	-High accuracy if patients have agreed to share the responsibility for their treatment. -It provides quantitative and qualitative information which is not provided by other measures.	-Seems to be less reliable due to patients' forgetfulness, unwillingness to admit not taking medication, and fear of the providers.
Measure of appointments kept	-High accuracy if medications are administered at the health facilities.	-If the patient keeps the medical records, they may be lost and therefore the appointments cannot be measured.
Pill counts	-Reliable if only one drug, and taking medicine once a day is prescribed.	-Does not provide information on dosage, drug administration, and time.
Presence of drugs in urine	-Can be easily identified, particularly rifampicin because it turns the urine red-orange, and INH can be identified through use of paper test strips.	-The results may be influenced by the patients' rate of metabolism of the drug. The tests only indicate last medicine dosage taken but do not provide information on the regularity of taking medicine.
Microelectronic devices of drug box or bottle recording time and frequency of extracted pills from the container.	-When the devices are effectively used, they measure both the daily frequency and long term duration of box or bottle opening.	-The devices do not verify whether medicine is actually taken by the patients. -The patients may open frequently due to curiosity, or may leave the devices open.

\* Summarized and adapted from Homedes, N., & Ugalde, A. (1993). Patients' compliance with medical treatment in the third world. What do we know? *Health Policy and Planning* 8, 291-314.

### **Reasons for non-adherence**

Non-adherence to treatment is a complex behavior involving multi-faceted factors. Table 8 summarizes factors associated with non-adherence to treatment including patients' related factors, disease and clinical factors and health service factors.

**Table 8.** Factors attributing to non-adherence to treatment\*

Factors attributing to non-adherence
<p style="text-align: center;"><u>Health policy and health service factors</u></p> <ul style="list-style-type: none"><li>-No policy to ensure adherence to treatment</li><li>-Inappropriate treatment guideline, insufficient training and supervision</li><li>-Irregular supply of drugs</li><li>-Poor quality of service (poor reception, long waiting time, inconvenient opening hours)</li><li>-Inadequate counseling and poor health education</li></ul>
<p style="text-align: center;"><u>Disease and clinical factors</u></p> <ul style="list-style-type: none"><li>-Seriousness of the symptoms</li><li>-Side effects and drug allergies</li><li>-Poor response to treatment, drug-resistant TB</li></ul>
<p style="text-align: center;"><u>Socio-cultural and economic factors</u></p> <ul style="list-style-type: none"><li>-Poor socioeconomic status, gender inequity</li><li>-Poor accessibility to health service (high cost, time consuming)</li><li>-Availability of treatment alternatives (traditional healers, quacks, drug stores)</li><li>-Poor knowledge about the disease, treatment and the negative consequence of non-adherence.</li><li>-Social stigma</li><li>-Poor social support (family, relatives, community, employer)</li></ul>

\* Ngamvithayapong-Yanai, J., Puangrassami, P., Yanai, H. (1998). Compliance with TB treatment: a gender perspective. In V.Diwan, A.Thorson, A.Winkvist (Ed.) *Gender and tuberculosis: An international research workshop*. (pp.127-148). Gothenburg: Nordic School of Public Health; Varkevisser, C.M., Pathamanathan, I., Brownlee. (1991). *Health Systems Research Training Series*. IDRC and WHO. Module 4, p. 9.

### **Strategies for enhancing adherence**

In response to the complexity of non-adherence to treatment, enhancing the adherence also requires various strategies. These are presented in table 9.

**Table 9.** Strategies for enhancing adherence to treatment\*

Strategies for enhancing adherence to treatment
<p><u>Improving health service systems</u></p> <ul style="list-style-type: none"> <li>• Providing directly observed therapy</li> <li>• Hospitalization may prevent non-adherence among patients exhibiting the profile of defaulter (e.g. homeless, alcoholic patients)</li> <li>• Health education and counseling service should be offered by using linguistically and culturally appropriate messages.</li> <li>• Active follow up system</li> </ul>
<p><u>Improving attitude of health care providers</u></p> <ul style="list-style-type: none"> <li>• Good relationship between health providers and patients significantly improves patient adherence.</li> <li>• The providers should render service with courtesy and respect for the patients.</li> <li>• The providers should understand patients' needs and constraints, understand patients' cultural differences in attitudes to disease.</li> <li>• The providers should spend more time listening to the patients.</li> </ul>
<p><u>Facilitating patient medication</u></p> <ul style="list-style-type: none"> <li>• Providing special packages of TB medicine such as a daypack for easier medication.</li> <li>• Prescribing medication once a day and fixing a time such as before breakfast or before bed.</li> <li>• Providing calendar for medicine reminding system.</li> </ul>
<p><u>Providing incentives to the patient, community and provider</u></p> <ul style="list-style-type: none"> <li>• Providing transportation support to attend TB clinics, shelter support for homeless people, offering meals and assistance with job skills.</li> <li>• Giving rewards to patients who complete the treatment.</li> <li>• Paying a deposit at the start of their treatment, which entitles the patient to cheaper drugs and is refundable on completion of the prescribed course.</li> <li>• Involving the community leaders in the planning of tuberculosis control in the community and giving incentives to the community development fund when treatment is complete</li> <li>• Giving rewards to health provider when a patient completes treatment.</li> </ul>

\* Ngamvithayapong-Yanai, J., Puangrassami, P., Yanai, H. (1998). Compliance with TB treatment: a gender perspective. In V.Diwan, A.Thorson, A.Winkvist (Ed.) *Gender and tuberculosis: An international research workshop*. (pp.127-148). Gothenburg: Nordic School of Public Health; U.S. Department of Health and Human Services. (1994). *Improving patient adherence to tuberculosis treatment*. Atlanta: CDC.



#### 1.4.4 Stigma (paper II, V)

Erving Goffman (1963), a prominent sociologist, in his pioneer work on stigma provided important understanding into the socio-cultural construction of illnesses associated with social deviant behaviors. Goffman defined stigma as an attribute that is deeply discrediting. There are two types of stigma, i.e. enacted stigma and felt stigma. Enacted stigma refers to actual discrimination or unacceptability. Felt stigma refers to the fear of such discrimination (Scambler, 1998). Alonzo and Reynolds (1995) defined stigma as a broad and multidimensional social concept essentially focusing on social deviance. Stigmatized people are devalued, shunned by society and therefore have less of a chance to receive humanizing benefits in addition to participating in less social interactions. Several diseases and ailments such as TB, AIDS and leprosy are stigmatizing, while diseases such as the common cold and hypertension are not. Whether or not a disease is stigmatized, depends on the following criteria: Is the disease associated with deviant behavior? Is the disease perceived as a contagious disease? Is the disease incurable and life-threatening? Does the disease cause an unpleasant physical appearance? Is the disease perceived as a heredity disease? AIDS involves almost all the above criteria and therefore, is considered as one of the most serious and most stigmatized disease of this era (Alonzo & Reynolds, 1995; Goldin, 1994; Helman, 1990).

Prior to the HIV/AIDS era, several socio-cultural factors including misperceptions about TB, delay in seeking care, non-adherence to treatment and TB stigma had already undermined effective TB control in most developing countries. The HIV/AIDS epidemic further complicates the effort to control TB because of serious stigma surrounding AIDS, clinical and social complex interaction between the disease agents and human behaviors. These are challenging issues that have driven the research agenda and research questions for this thesis. These issues will be presented in the following chapter.

## **CHAPTER 2**

### **OBJECTIVES AND CONCEPTUAL FRAMEWORK**

This thesis synthesizes the social and behavioral research conducted between 1993-2000 in Chiang Rai, the province which records some of the highest rates of TB and HIV in Thailand. This chapter describes the thesis' objectives and includes a conceptual framework presenting the clinical interactions between TB and HIV and how each study (paper I – V) applied social and behavioral concepts located within this framework.

#### **2.1 Objectives**

##### **2.1.1 General objectives**

This thesis aims to describe the impact of HIV/AIDS on perceptions, attitudes and behaviors related to TB of people in northern Thailand, as well as the consequences of TB transmission, prevention and care.

##### **2.1.2 Specific objectives**

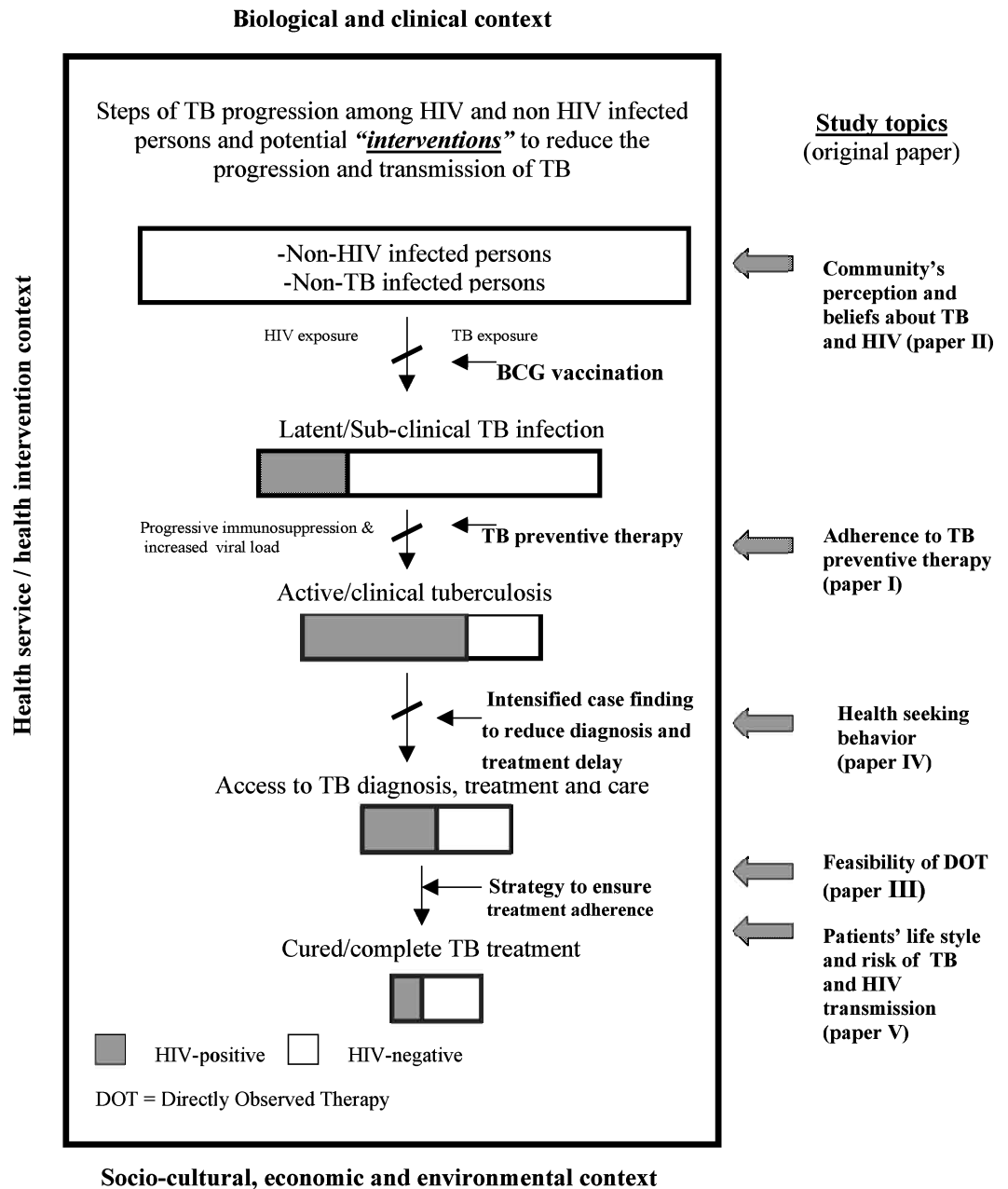
1. To elicit the community's perception about tuberculosis in regards to the local terminology, etiology, symptoms and choice of treatment, the role of traditional medicine, stigma and the association between TB and AIDS (Paper II).
2. To explore the attitudes surrounding the Directly Observed Therapy (DOT) for TB treatment among health care providers and various groups of clients, and to investigate the feasibility of implementing home-based and health center-based DOT in the HIV epidemic area (Paper III).
3. To describe the health-seeking behavior among TB patients (with or without HIV infection), to measure patient and provider delays and to analyze factors determining these delays (Paper IV).

4. To determine the level of and reasons associated with the adherence to tuberculosis preventive therapy among asymptomatic HIV-infected individuals (Paper I).
5. To describe the change of patient's lifestyles after being diagnosed with TB (with and without HIV infection) (Paper V).
6. To identify the opportunities and challenges in reducing the risk of TB and HIV transmission (Paper V).

## **2.2 Conceptual framework**

Figure 1 depicts the population dynamic and interaction between HIV and TB and the contexts to which individuals are exposed (Chaisson, 2000; Corbett & De Cock, 2001). The progression and transmission of TB is determined by the biological, clinical and health service factors, health interventions and the socio-cultural and economic factors.

**Figure 1** The population dynamic and the interaction between human immunodeficiency virus (HIV) infection, tuberculosis (TB) and the contexts leading the individuals' exposure to the diseases. (Modified from: Chaisson, 2000; Corbett, & De Cock, 2001; Rieder, 1998; WHO, 2002e)



According to figure 1, the study framework begins with non-TB and non-HIV infected persons; paper II elucidates perceptions about TB and HIV from the perspective of various groups of people. The study explores the aspects surrounding the beliefs and perceptions regarding TB and HIV, which might influence the TB infection. Following is a figure representing the population infected with TB and HIV at a TB-latent infection stage and asymptomatic HIV-infection stage. From a clinical perspective, the purpose of TB preventive therapy is to prevent PLWH who have latent TB infection to develop the active TB disease. From a social and behavioral perspective, adherence to therapy is one of the most challenging issues, i.e., how will persons without symptoms adhere to the 9-month therapy? What are the reasons for adherence or non-adherence? Paper I addresses these issues. The next step in the framework represents the persons who have active TB disease (both HIV positive and HIV negative). The questions addressed are whether there was a delay of the patients seeking care and whether health services were delayed in diagnosing TB. Paper IV investigates these issues. Following, DOT is considered as a strategy to ensure treatment adherence for patients who have been diagnosed with TB and have initiated the treatment. Since implementing DOT is a new approach in the study setting, paper III investigates the feasibility of DOT implementation from the clients' and health care providers' perspective. The last study (paper V), investigates the last step of the framework: whether or not the patients complete the TB treatment or if they become successfully cured and whether or not patients' lifestyles are associated with the transmission of TB and HIV.

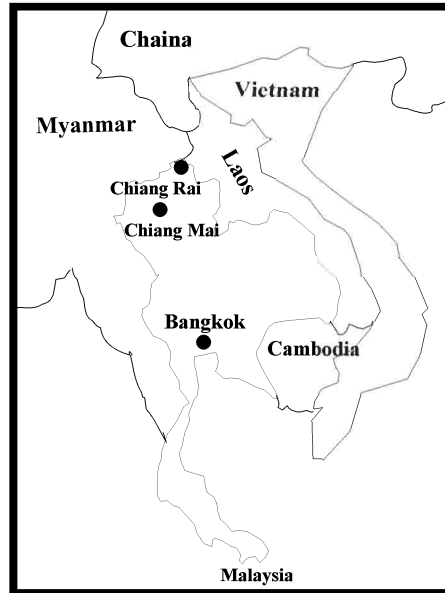
Details of the study design for each paper are presented in the following chapter.

## **CHAPTER 3**

### **METHOD**

#### **3.1 Study Setting**

The studies were conducted in Chiang Rai, the northernmost province of Thailand, about 830 kilometers from Bangkok. Myanmar, Laos and “the Golden Triangle” border the province. Geographically, forests and mountains cover about 33% of Chiang Rai. The provincial statistics in 2000 reported that the population in Chiang Rai reached 1,287,018 (20.9% were <15 years; 60.9% were 15-49 years and 17.5% were over 50 years of age). Infant mortality rate the same year was 4.45/1,000 (Chiang Rai Provincial Health Office, 2000). About thirteen percent of the Chiang Rai population were hilltribe people with eleven different ethnicities, mostly living in highland and mountainous areas. The quality of life of the hilltribe people, measured by a basic minimum-need survey, was lower than that of the Thai people in areas such as the availability of latrines, literacy rate and their access to essential drugs (Center for Development and Support for Chiang Rai Hilltribe People, 1999). The average income per capita per year of Chiang Rai in 1997 was 29,682 baht (1 US\$ = 40 baht). Almost 93% of the children complete the compulsory education (6 years of study in school). There is 1 provincial hospital, 15 community hospitals, 212 health centers and 4 private hospitals.



**Figure 2: Map of Thailand and location of Chiang Rai**

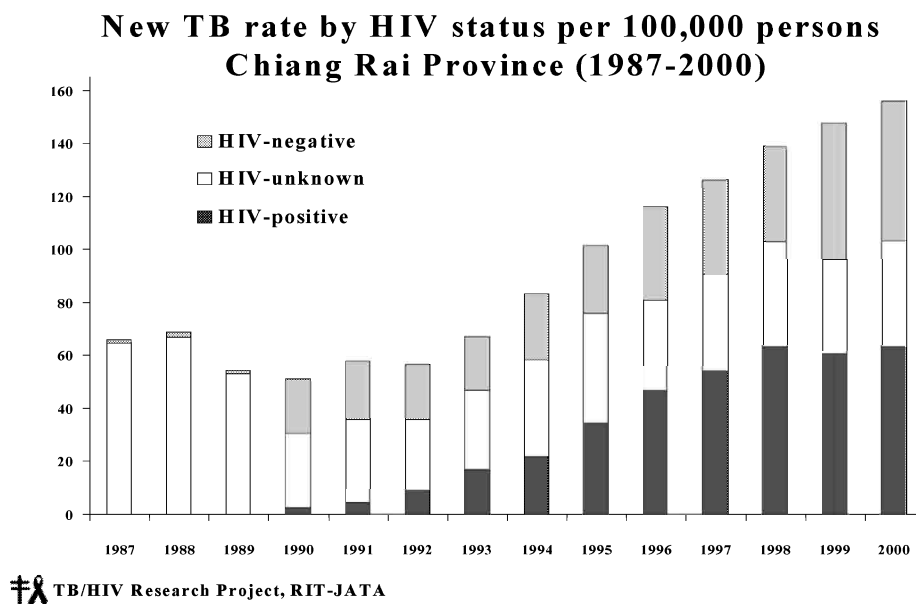
### **The TB and HIV/AIDS situation in Chiang Rai**

The first AIDS case in Chiang Rai was reported in June 1988. Up to November 25, 2000, the accumulative number of AIDS cases in Chiang Rai was 11,376. AIDS is the leading cause of death in the province (164.4/100,000). Respectively, sources of HIV transmission were sexual intercourse (92.3%), mother-to-child (6.22%) and intravenous drug use (3.2%). The provincial HIV surveillance reported trends of HIV prevalence in several groups as being stable or in decline. In 2000, HIV prevalence among pregnant women was 3.7% (community hospital) and 4.4% (provincial hospital), blood donors 0.06% and military conscript 1.8%. Every public hospital in Chiang Rai offers voluntary counseling for HIV testing. During the study period, antiretrovirus therapy (ARV) was not available for general PLWH although some hospitals provided ARV for pregnant women who participated in the clinical study.

The impact of the HIV/AIDS epidemic on TB prevalence is obvious. TB has re-emerged as a public health problem in the province. The incidence rate of new TB per 100,000 inhabitants increased from 63 in 1987 to 140 in 1999. TB was the 12<sup>th</sup> cause of death in the province (9.87/100,000). The primary multi-drugs resistant TB (MDR-TB) and secondary MDR-TB (1996-1997) were 6.3% and 33.8% which declined to 2.4% and 16.7%, respectively (1999-

2000). HIV prevalence among TB patients in 1999 was 43%, while 32% were HIV-negative and 25% were of unknown HIV status. About half of the HIV-infected persons died due to TB. During the study period, TB drugs were provided free of charge to all patients in public hospitals, and patients covered by health insurance received free investigations such as X-rays and sputum examinations. All the hospital doctors were allowed to examine patients for TB, diagnose TB and prescribe TB drugs. Serological testing for HIV among TB patients is not routinely done; it was based on the doctor's decision and the patient's consent. Since late 1997, the Chiang Rai provincial health office adopted the DOTS strategy. However, actual DOTS implementation depended on the decision of each district's health authorities.

**Figure 3. The incidence of TB and the HIV status in Chiang Rai Province**



### 3.2 Research Methodology

The research presented in this thesis applied both quantitative and qualitative methodologies. The choice for research methodology was driven by the research questions. Both qualitative and quantitative methodologies are tools, and their utility depends on their power to bear upon the research questions asked (Kvale, 1996; Starrin, Dahlgren & Larsson, Styrborn, 1997). Most of the studies in this thesis are based on qualitative research; therefore, this part will



focus on the qualitative methodology with special emphasis on the foundation of qualitative research and its validity, reliability and generalizability.

### 3.2.1 Foundation of qualitative research

Qualitative research methods have a long history in the social science research, however the methodology is new to many health professionals who are usually familiar with randomized controlled clinical trials or experimental studies (Pope & Mays, 1995). The nature of qualitative research differs from quantitative research. The term “quality” refers to what kind, to the essential character of something, while the term “quantity” refers to how much, how large, the amount of something (Kvale, 1996). Qualitative research aims to seek a deeper understanding of the social phenomena; studying things in their natural setting; attempting to make sense of, or interpret, phenomena in people’s meaning. Qualitative research uses holistic perspectives and usually uses more than one data-collection method (Greenhalgh & Taylor, 1997; Janesick, 1994). The qualitative research is an appropriate method for the study, which needs to understand the cultural value and social behavior, because the method is sensitive enough to capture the nuance of the human being (Guba & Lincoln 1994; Strauss & Corbin, 1998).

Table 10 compares various aspects of the positivistic paradigm and naturalistic paradigm, which obviously differ. “**Paradigm**” refers to a worldview, assumption about the nature of reality and the basic belief systems based on **ontological questions** (what is the form and nature of reality; what can be known?), **epistemological questions** (what is the nature of the relationship between the knower and what can be known?) and **methodological questions** (how can the inquiry go about) (Ford-Giboe & Campbell, Berman, 1995; Guba & Lincoln, 1994). The quantitative research is influenced by the positivistic paradigm, while the qualitative research is guided by the naturalistic paradigm.

**Table 10** Differences of the basic beliefs and associated principals between positivistic and naturalistic paradigms. (Summarized from Lincoln & Guba, 1985)

Positivist Paradigm	Naturalistic Inquiry Paradigm
<p><b>Simple:</b> All entities are tangible, concrete, and can be identified easily.</p>	<p><b>Complex:</b> The world has tremendous diversity of entities and systems, which are complicated and mutually related to each other.</p>
<p><b>Hierarchy:</b> The objects are simply organized in orders, or centralized.</p>	<p><b>Heterarchy:</b> The objects and entities are organized in a sophisticated way and have never been in a single order. All things are inter-related or decentralized.</p>
<p><b>Mechanical:</b> The way people view and explain the world and its entities is quite rigid. They believe that everything can be simply organized and controlled like an engine.</p>	<p><b>Holographic:</b> The way people view and explain the world and its entities is flexible and dynamic, but comprehensive. The systems and organism are interrelated along with the dynamic process. A single object can be seen and interpreted from various angles.</p>
<p><b>Determinate:</b> Following the mechanical view, the positivists believe that everything is "<i>certainty</i>". Therefore, they believe that they can <i>predict</i> or determine the future.</p>	<p><b>Indeterminate:</b> The naturalist believes that "<i>the certainty is uncertainty</i>". The future cannot be known or cannot be predicted precisely. The inquirers can only report the <i>probability</i> of the future.</p>
<p><b>Linearly causal:</b> Again, following the mechanical view, the positivists believe that they can actually predict what causes what because of the one to one relationship. Cause and effect can be simply identified.</p>	<p><b>Mutual casual:</b> The nature is uncertainty. Systems and organisms are complex, dynamic and interconnected. There is no point in trying to identify what is the cause and what is the effect. Changes occur because of the simultaneous interaction of the systems and the organisms.</p>
<p><b>Assembly:</b> As the system is simple, the components are not inter-related. The individual element can be segregated. The total is the sum of the components.</p>	<p><b>Morphogenesis:</b> A total is not the sum of the parts, as every component cannot be separated. It is a dynamic network consisting of a variety of elements, which are inter-related and spontaneously interact. We cannot look piece by piece we must look at the whole.</p>
<p><b>Objective:</b> Inquiry can be tangible and neutral. All things can be known. The reality can be identified through a single method of inquiry.</p>	<p><b>Perspective:</b> It is impossible to completely know the reality. What we partially know is determined by several factors, including the inquirer's belief and judgement. To minimize bias, we need multi methods of inquiry and need to incorporate as many perspectives from various disciplines as we can.</p>

### 3.2.2 Validity, reliability and generalizability in qualitative research

The common criticisms surrounding qualitative research are its lack of scientific rigor, the research findings may represent the personal impressions of the researchers, researcher bias, lack of reproducibility (different researchers may have different conclusions) and a lack of generalizability. However, it is not justified that the merit of qualitative research should be regarded in the same way as quantitative research as various strategies are available within qualitative research to protect against bias and enhance the reliability of the findings (Mays & Pope, 1995a). Using quantitative terms tends to be a defensive measure and is not congruent with or adequate to qualitative work (Creswell, 1998). Re-definitions are required to fit the realities of qualitative research and the social phenomena that researchers seek to understand (Eisner, 1991; Janesick, 1994; Lincoln & Guba, 1985; Strauss & Corbin, 1998).

Lincoln and Guba (1985), the prominent leaders in qualitative research proposed the term “**trustworthiness**” as an appropriate overall term for both quantitative and qualitative research. The terms **credibility** and **transferability** are used for qualitative research instead of internal validity and external validity. Prolonged engagement, persistent observation and triangulation of methods and triangulation of researchers will enhance the credibility of the study. Transferability refers to the findings being transferable between researchers and those being studied. The transferability can be improved by thick description. It is a qualitative researcher’s responsibility to provide sufficient information about the contexts to which a study is carried out so that anyone else interested in transferability has a base of information appropriate to the judgement. Creswell (1998) summarizes eight procedures that enhance the “trustworthiness” of the qualitative research, from the five research traditions that are often used in social sciences. These methods include prolonged engagement, triangulation, peer review or debriefing, negative case analysis, clarifying researcher bias from the outset of the study, member check, rich thick description and external audit. Creswell recommended that the researcher should engage in at least two of these methods in any given study. Whether or not a qualitative research is trustworthy depends on how the qualitative researcher persuades the audiences that the findings from qualitative research are worth paying attention to or worth taking into account (Lincoln & Guba, 1985).

Generalizability implies such an important value in quantitative research. The sampling method and sample size must be well calculated and designed in order to achieve representative samples. This obviously differs from qualitative research in which the study samples are recruited by purposive sampling with the intention of discovering a wide range of realities. Therefore, the study samples usually cover a variety of characteristics. The naturalistic inquiry (Lincoln & Guba, 1985) believes that there is no generalization. Uniqueness found in each new situation and the complexity and dynamics of the system and the entities make it impossible to generalize. The naturalistic inquiry believes that there are always differences in context from situation to situation, and even a single situation differs over time. The thesis author however believes that although qualitative research may not generalize the research findings, the theoretical framework developed in each study may be generalized to other settings (Morse, 1999).

### **3.3 Study Design, Study Population and Data Collection**

Table 11 and table 12 summarize the study design, study population and data collection used in the studies.

**Table 11.** Summary of study designs of paper I -V

Study (Period of data collection)	Study population	Study design and data collection
<p><b>Paper I</b></p> <p>Adherence to TB preventive therapy (November 1993-August 1994)</p>	<p>a) 412 HIV-infected persons</p> <p>b) 72 HIV-infected persons who failed to collect medicine for more than 1 month</p> <p>c) 28 HIV-infected persons who achieved a 95-100% adherence rate</p>	<p>a) A prospective cohort study with a 9-month follow-up to measure the “adherence rate” by pill count and analysis of the medical records.</p> <p>b) Patient interview to investigate the reasons for non-adherence.</p> <p>c) Five sessions of focus group discussion were organized to examine reasons for good adherence and technique to achieve high adherence rate.</p>
<p><b>Paper II</b></p> <p>Perceptions of TB (May – June 1998)</p>	<p>23 Health center staff, 12 community members, 24 persons having HIV, 9 TB (HIV+) patients, 12 TB (HIV-) patients, and 5 male injecting drug users.</p>	<p>Eleven focus group sessions (five female groups and six male groups) were conducted to elicit community perceptions about TB in relation to HIV/AIDS from various groups of people.</p>
<p><b>Paper III</b></p> <p>Feasibility of Home-based and health centered-based DOT (May – June 1998)</p>	<p>23 Health center staff, 12 community members, 24 persons having HIV, 9 TB (HIV+) patients, 12 TB (HIV-) patients, and 5 male injecting drug users.</p>	<p>Eleven focus group sessions (five female groups and six male groups) were conducted to elicit community perceptions about the feasibility and preference for implementing DOT.</p>
<p><b>Paper IV</b></p> <p>Health seeking behavior and diagnosis for pulmonary TB (April 1998-May 2000)</p>	<p>-557 sputum positive, new pulmonary TB patients aged over 15 years.</p> <p>-10 internal medicine doctors from Chiang Rai Hospital (8 males and 2 females).</p>	<p>-A prospective study.</p> <p>-Patients were interviewed by using structured questionnaires to examine the process of health-seeking behavior and to measure patient and provider delays.</p> <p>-Reviewing medical records to investigate other complications and the date TB treatment was started.</p> <p>-Presentation of the preliminary result of patient delays and discussion with a group of doctors to obtain their feedback on provider delay.</p>
<p><b>Paper V</b></p> <p>Life style and risk of TB and HIV transmission, prevention and care (January 1999-May 2000)</p>	<p>-Seven pulmonary TB patients infected with the HIV virus and six TB patients without HIV infection (aged 16-45 years).</p> <p>-Spouses and caregivers of every patient and community person.</p>	<p>-A prospective study.</p> <p>-Repeated visits were made to each patient’s home for a period of 6-8 months.</p> <p>-Data was collected by in-depth interview and observation to understand the life style, risk of TB and HIV transmission, prevention and care from the perspectives of patients, family and the community.</p>

**Table 12.** Summary of data collection and study population

Data collection	Review patients' medical records	Face to face interview by structured questionnaire	In-depth interview	Focus group discussion	Observation
Study population					
Health care worker				Paper II, III, IV	
TB (HIV+)	Paper IV, V	Paper IV	Paper V	Paper II, III	Paper V
TB (HIV-)	Paper IV, V	Paper IV	Paper V	Paper II, III	Paper V
Asymptomatic PLWH	Paper I		Paper I	Paper I, II, III	
IDU				Paper II, III	
Community people			Paper V	Paper II, III,	Paper V
Spouse and caregivers of the patients			Paper V		Paper V
Data collection period: Paper I: Nov. 1993 – Aug.1994; Paper II and III: May-June 1998; Paper IV: Apr.1998 – May 2000; Paper V: Jan.1999 – May 2000.					

### 3.3.1 Data collection methods

Table 13 summarizes the data collection methods used in this thesis. The advantages and limitations of each method are also presented.

**Table 13.** Summary of the method of data collection used in the studies: the advantages and limitations of each method (from the literatures and the field experiences).

<b>Methods of data collection</b>	<b>Advantage</b>	<b>Limitation</b>
<p><b>Review of medical record</b></p> <p>The standard patient's medical record in the study hospital include personal information (name, sex, date of birth, address, nationality, occupation, type of payment or insurance), date of contact with the hospital, information on illness complaints, physical examination, laboratory results, diagnosis and treatment information.</p>	<p>-Provides some information which was missing from the interview -It can serve as another source for data triangulation</p>	<p>- Incomplete record, missing information</p>
<p><b>Interview by structured questionnaire</b></p> <p>The interviewers are trained to ask questions in the questionnaires (mostly fixed choice) in a standard manner (Britten, 1995)</p>	<p>-Can be applied with a large sample group -Easy to train the interviewer</p>	<p>- Only provides data available in the questionnaire</p>
<p><b>In depth interview</b></p> <p>Face to face conversation with the purpose of exploring issues or topics in detail. The method does not use pre-set questions. The researcher will start with one or two major questions and the subsequent questions will be based on the responses received from the interviewee. (Britten, 1995; Pope &amp; May, 1995)</p>	<p>-The method allows the interviewees to express their view and opinion in their own words (Kvale, 1996) - The method can produce deep information with holistic perspectives (Greenhalgh &amp; Taylor, 1997; Janesick, 1994)</p>	<p>-The quality of data depends on the quality of researchers (Lincoln &amp; Guba, 1985; Kvale, 1996; Starrin, et al., 1997) -Difficult to train a researcher who has both experiences in the study subject and interviewing skills.</p>
<p><b>Focus group discussion</b></p> <p>A form of group interview composing with 4-12 participants. The researcher does not ask each participant to respond to the question but encourages each participant to talk to one another, to ask questions, and to exchange experiences and perspectives. (Kitzinger, 1995; Stewart &amp; Sharmdasani, 1990).</p>	<p>-Provides data from a group of people quickly and with less cost - Allows the respondents to react to and build upon the responses of other group members (Stewart &amp; Sharmdasani, 1990)</p>	<p>-The results from FGD may be biased by a very dominant or opinionated member; the recruitment of the participants may limit the finding if they are only from places where it is convenient to attend the discussion ((Stewart &amp; Sharmdasani, 1990)</p>
<p><b>Observation</b></p> <p>-Systematic and detailed watching and recording of what people do and say (Mays and Pope 1995b)</p>	<p>-Allowing investigators to learn how people actually behave in a variety of contexts (Edgerton, 1984; Mays and Pope 1995b)  -Offer the possibility of providing data that may not be available through other methods (Taylor, Stephen, Bogdan, 1984)</p>	<p>-Expensive and time consuming (Edgerton, 1984) -Having a researcher observing actions may stimulate modifications in behavior or action (Hawthorne effect) (Mays &amp; Pope, 1995b)</p>

### **3.3.2 Data collection procedures**

#### **3.3.2.1 Face to face interview:**

(a) Interview by using a structured questionnaire (paper IV): One research assistant was posted in the laboratory section to conduct interviews with the patients using a structured questionnaire which consisted of patient-informed consent and six questions including i) patient's general information; ii) history of TB contact and TB risk factors; iii) present illness (a check list of TB and HIV-related symptoms); iv) health seeking behavior; v) medical and laboratory information; vi) TB diagnosis and treatment. Data for part I-IV was obtained by interviewing the patients and part V-VI was extracted from the medical records.

#### **(b) In-depth interview (paper I, V):**

- The study (paper I) identified the participants of the TB preventive therapy who missed appointments for more than 1 month but subsequently returned to the clinic. The researcher conducted the in-depth interviews in order to know the reasons for missing the appointment and non-adherence to the therapy. The in-depth interviews were conducted in a private room without the presence of health staff.

-During the home visit (paper V), the researchers conducted in-depth interviews with the patients, spouses, caregivers and family members. The interviews covered several issues, i.e. life styles, health-seeking behavior after diagnosis of TB, adherence to TB treatment, TB/HIV stigma, social relationship, etc. The interviews were recorded with a tape recorder and notes were taken to represent the non-verbal language.

#### **3.3.2.2 Focus group discussion (paper I, II, III, IV)**

Five sessions, eleven sessions and one session of FGD were organized for paper I, II+III, IV, and I, respectively. The thesis author conducted all sessions of FGD with the assistance of a note-taker and a support staff member. The process of organizing each FGD consisted in the recruitment of the participants, conducting FGD and analyzing the data. All sessions were recorded with a tape recorder.

#### **FGD (paper I)**

Thirty HIV-infected persons who achieved 95-100% adherence rate with TB preventive therapy were identified by computerization. These participants were classified into five groups according to their marital status and sex. The groups included single and divorced men, married men, widowed men, married women and a widower group. Two weeks before the dates set for FGD, an invitation letter and a reply post card were mailed to each person. Only one person was unable to participate in the discussion. The five FGD sessions were organized within five days in the same hospital rooms without the presence of hospital staff.



#### FGD (paper II, III)

The study identified eleven groups of participants (five female groups and six male groups). Recruitment methods of each group were slightly different.

*Health center staff:* Four districts were purposively selected and three health centers from each district were randomly selected. Twenty-four health staff members were identified and were invited to participate in the discussions. Twenty-three staff members (12 in the female group and 11 in the male group) participated in the discussions, which were held in a hotel on different days.

*Community people:* A congested urban community was purposively selected, and twelve participants (6 females and 6 males) aged 20-45 years were randomly identified and invited a week before the meeting. The two sessions of FGD were conducted in the community center on different days.

*Asymptomatic HIV-infected persons:* A community hospital with a well-established HIV club was purposely selected. Twenty-four HIV-infected persons (a group of 12 females and a group of 12 males) were consecutively recruited and invited to participate in the discussions, which were held in the HIV club meeting room.

*TB patients:* A hospital was purposively selected. Four groups of TB patients were classified according to sex and HIV status, i.e., a group of HIV-positive TB males, one of HIV-positive TB females, one of HIV-negative TB males and one for HIV-negative TB females. About 6-8 participants in each group were identified in the hospitals TB clinic. The patients were individually invited to participate in the FGD two weeks before the dates set. Four sessions of FGD were held in a special activity room of the hospital without the presence of hospital staff.

*Drug users:* A community hospital with a good harm-reduction program was purposively selected. Eight male intravenous drug users clients (most clients were men) were consecutively invited to participate in the FGD 2 weeks before the meeting, however only five attended. The discussion was held in the hospital's special activity room. No hospital staff members were present.

#### FGD (paper IV)

The preliminary analysis of paper IV revealed that the provider delay was significantly longer in female patients than in male patients. The investigating team organized a meeting with a team of internal medicine doctors (10 persons) of Chiang Rai Hospital to present the study results and obtain their feedback regarding longer provider delay in female patients. The meeting lasted for 2 hours where an active discussion took place with the participation of the doctors.

### 3.3.2.3 Home/community visits and observations (paper V)

Two investigators jointly performed home visits. The investigators drove an ordinary car, dressed casually and visited the patient's home with or without previous appointments. According to Spradley (1980), types of observation are classified by the degree of the researcher's involvement with others and in the activities they observe. The continuum of involvement ranges from nil to high and observations can be from nonparticipation observation to complete participation observation. In paper V, most observations were nonparticipation observations. The observations were simultaneously conducted by two investigators at the patients' home and in the community, such as funeral services, community festivals, etc. The observed subjects included physical appearance and health conditions, living conditions (location of sleeping place, eating, living space, condition of ventilation), medication behavior, coughing and spitting behaviors, sputum disposal, the interaction between patients, family members, neighbors and friends and other lifestyle habits (work, recreation, smoking, drinking, rest, food). The investigators observed, took note and discussed after each visit.

### 3.3.3 Researcher's bias

There is no value-free or bias-free research. Therefore, clarifying researcher's bias is important information for readers, this is especially so for qualitative research papers. Here, the human is the primary data-gathering instrument, therefore qualitative research underscores the fact that research is ideologically driven and that researchers cannot separate themselves from the topic and people they are studying. The qualitative research process is the interaction between the researcher and researched people and it is here that the knowledge is constructed (Lincoln & Guba, 1985). Thus, the researcher's bias enters into the picture even if the researcher tries to stay out of it (Mehra, 2002).

In the following paragraphs, I provide background information about myself and briefly discuss how this might have biased this research study.

I started my professional career as a registered nurse at a university hospital in Bangkok and an urban health center of a rural province. I was interested in community health and social medicine and achieved a Master's Degree in Medical and Health Social Sciences. Studying social sciences and conducting a Master's Degree thesis was a critical point for me, where from blaming the victims (patients) I gained knowledge for understanding the victims. Prior to studying social sciences, I was frustrated when I saw how some mothers did not bring their babies back for further vaccinations. I was upset when the patients told me that they sought care with traditional healers who place herbs over infected wounds to cure them, among other examples. I blamed the patients for their ignorance. What made my view change? Studying the theoretical concepts in sociology and anthropology in medicine and health was helpful for me in understanding people's perceptions and behaviors. However, having experiences in field research substantially influenced my view on people's health behavior. My first experience in qualitative research was in 1987 when I conducted my Master's Degree thesis on diarrhea in

children. I lived in a congested community for three months in order to learn how mothers defined diarrhea symptoms in their young children and the actions they took. It was a gratifying experience for me to live in the community as if I were a member. I learnt about what anthropologists call “emic” (perspective of the people – Hahn, 1995). By conducting this study, I was enlightened by the role of socio-cultural factors and the social context that influences people’s behaviors. I recognized the important role of qualitative research, which helped me understand the health problems from a holistic point and from the people’s perspectives. My subsequent experiences in qualitative research were gained while I worked as a researcher in a health system research project and when I served as a faculty at the Collage of Public Health. I applied qualitative research in several areas, including the rational use of drugs, health care workers behaviors in delivering health service, as well as tuberculosis. My first research on TB started in 1992 and I have been involved with TB research and teaching in the international TB training course since then. Having a nursing background has driven the direction of my social science research on TB and TB-associated with HIV to focus on cultural knowledge and behaviors of patients and health care workers with the ultimate aim that research can help improve knowledge and change behaviors.

With respect to this thesis, what did the study participants understand about the researcher? How might the researcher influence the participant’s knowledge and behaviors? In this work, I introduced myself as a student in public health, I was not a doctor and I did not have any influence on their treatment. My role was to learn from them by listening to them and observing their behaviors. All participants were instructed that I was willing to share my views and I would answer the questions raised by the participants by the end of the FGD (paper I, II, III) and at the end of each home visit (paper V). Despite repeatedly informing the participants that my role as researcher was as a student not as a doctor, several participants called me “moar” (doctor). My experiences from field research in several settings in Thailand found that lay people usually called every health staff (nurse, pharmacist, laboratory technician, medical doctor), including nursing and medical students “moar”. Several patients call medical doctors “moar yai” (big doctor) to differentiate the medical doctor from other health professionals. When I asked the participants why they called me doctor, they replied that they were unsure as to how to address me. The consecutive home visits along with observation, anti-TB medicine pill-counting and information sharing may stimulate modification in behavior or action or encourage introspection or self-questioning among those being researched (May and Pope, 1995b).

As mentioned above, once the home visit had been concluded, I opened an opportunity for the patient to ask questions; nevertheless many times they asked questions during the in-depth interview. I usually replied, “firstly, please allow me to learn what you think and I will share my view before I leave your home”. Most of them asked questions about their disease and health problems. They also asked about my personal information such as age, family and work. My nursing background served as a benefit in responding with questions about health. On the other hand, because of my health-related background, other issues beyond health may be underestimated. However, in this thesis, my co-investigator for the fieldwork, a resident of Chiang Rai, has a training background in community development. Her characteristics were helpful for some issues that I did not see. Moreover, I also discussed my work with two Swedish supervisors who have different professional backgrounds. All investigators involved in the study

have extensive experiences in international health research, including research on gender and TB. These characteristics may minimize the possible bias involved in the research process.

### 3.4 Definitions and measurements

Paper I: *Adherence* (paper I): The adherence rate was measured by pill count. The clients were instructed to bring their leftover medicine and packet whenever they contacted the hospital for TB preventive therapy service. The level of adherence is high if more than 80% of the pills were taken during the 9-month period. *Default* referred to the failure to take isoniazid in more than 60 consecutive days during the 9-month period. *Complete the therapy* represents those clients who successfully completed the 9-month preventive therapy without defaulting.

Paper III: *Directly Observed Treatment Short-course (DOTS)* is the global strategy for TB control which is composed of five major components, namely, political commitment, use of microscopic for TB diagnosis, a good system of drug supply, a treatment supervisor and a good recording and reporting system. *Directly Observed Therapy (DOT)* is one of the five elements of DOTS, which represents the procedure where a health care worker or other trained person watches a TB patient swallow every dose of the anti-TB medicine. *Home-based DOT* is a service where health staff bring anti-TB medicine and watch the patient swallow the medicine at home, *Health center-based DOT* is the treatment method that requests TB patients to visit the health center everyday and take the medicine under the observation of health staff.

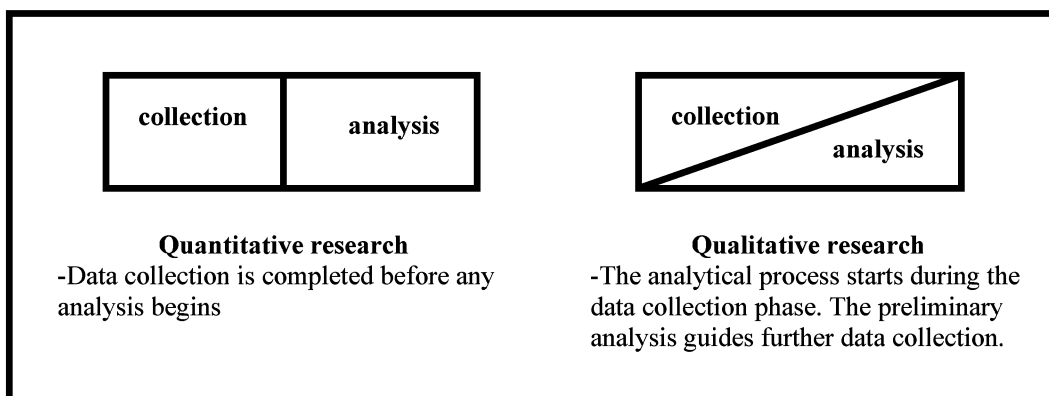
Paper IV: *Patient delay*: This represents the time from the onset of the cough or other symptoms (if there was no cough) until the first visit to a doctor or health staff in a private or government health facility. *Long patient delay* represents the patients delay > 21 days. *Provider delay* is the time from the patient's first visit to a doctor or health staff to a TB diagnosis. *Long provider delay* is provider delay > 7 days. *Health insurance* refers to patients receiving free medical services or patients whose medical charges are reimbursed from other sources. *Insured persons* include government staff, private employees under a social security scheme, health or military volunteers, monks, those holding a government health card, low income cards, cards for the elderly or those with private health insurance.

### 3.5 Data analysis

The statistical analysis was applied to the quantitative data in paper I and IV and the analysis of qualitative data were applied to all studies (paper I-V). The aims and processes of the statistical analysis and the qualitative data analysis are different. The aim of the statistical analysis in this thesis is to measure the level of association between the outcome variables and their predictors or exposures. Furthermore, the qualitative data analysis aims to understand the social phenomena in the natural setting, paying particular attention to the experiences and perspectives of the people who are studied (Pope and May, 1995). Figure 4 illustrates the process of data collection and data analysis in quantitative research and qualitative research. In quantitative research studies, data collection and data analysis are respectively conducted. Before

analyzing quantitative data, researchers finalize the data collection and proceed to the analysis. In the qualitative studies, one important characteristic is the “**emergent design**” (Lincoln and Guba, 1985), which indicates that the data collection and data analysis are not independent steps. The study design for a qualitative study cannot be preordainedly constructed (a priori) because it is inconceivable what the result of the interaction between the researcher and the researched subjects will be. Therefore, the researchers, as a critical tool in data collection, simultaneously analyze the data and further collect data which correspond to the emerging inquiries.

**Figure 4.** Process of data collection and data analysis in quantitative and qualitative research (adapted from Mays & Pope. (1995b). *BMJ* 311, p.184.)



Details of data analysis in quantitative and qualitative research are described below:

### 3.5.1 The statistical analysis (paper I, IV)

One research assistant coded the data and another assistant then verified the codes. Data was doubled-entered and validated. The statistical software used in the studies was Epi-Info version 5.01B (paper I), version 6.1 (paper IV) (CDC, Atlanta, GA, USA), EGRET version 0.26.61 (Statistics and Epidemiology Research Corporation, Seattle, Washington, USA) (paper I) and STATA release 6 (Stata Corporation, Collage Station, TX, USA) (paper IV). Descriptive statistics, uni-variate, multi-variate analysis and logistic regression analysis were performed. Odds ratio (OR) and associated 95% confidence intervals (95%CI) were used as measures of strength of the association between the outcome variables (adherence and delays) and their predictors.

### 3.5.2 Qualitative data analysis (paper I-V)

Two major analysis approaches were applied for the qualitative data analysis in this thesis. Data from the focus group discussions (paper I-IV) applied the cut-and-paste technique (Stewart, 1990). Data from in-depth interview and observation (paper V) were analyzed following the Grounded Theory tradition (Strauss and Corbin, 1998).

#### 3.5.2.1 The cut-and-paste technique

The cut-and-paste technique is a quick and cost-effective method for analyzing the transcripts of a focus group discussion. The results from this technique share many of the characteristics of more sophisticated and time-consuming analysis approaches. Before starting the analysis, the recorded tapes of FGD were transcribed verbatim by the note-taker and verified by the moderator (i.e. the thesis author). For paper I, an ordinary tape player was used and the texts were transcribed in handwriting. For paper II – IV, a transcriber machine was used and the texts were transcribed by typing into a word processor. The moderator (analyst) carefully read the transcript and identified those sections that were relevant to the research questions. Based on the initial reading, the analyst classified the major themes and the topic related to each theme. Color-coded brackets were used to mark different topics. After the coding process was completed, the coded copy of the transcribed interviews was cut apart. Each piece of the coded material was sorted and all materials relevant to a particular topic were placed together for the interpretation.

#### 3.5.2.2 Analysis of data through the Grounded Theory (Paper V)

What is the Grounded Theory?

“Theory” in the general understanding of people is a standard explanation about facts or events, which are truly universal, unrestricted to time and space and can predict a phenomena. The quantitative researcher usually starts the study by having a theory and a hypothesis, by collecting data, analyzing data and reporting the result by accepting or rejecting the hypothesis. “Theory” in grounded theory refers to the different meanings and processes of inquiry. Barney G. Glaser and Anselm Strauss founded the Grounded Theory in 1967.

The Grounded Theory refers to a specific methodology on how to move from systematically collecting data to producing a multivariate conceptual theory (Glaser, 1998). Emergence is the foundation of the grounded theory approach to theory-building. A researcher cannot enter an investigation with a list of preconceived concepts, a guiding theoretical framework or a well thought design. Concept and design must be allowed to emerge from the data. For arriving at a theory, such a task calls for sensitivity to the nuances in data, tolerance for ambiguity, flexibility in design and a large dose of creativity (Strauss & Corbin, 1998). The researcher starts with vague queries but must be sensitive to the events and be capable of observing and recording the data. The researcher constructs a new local theory based on the data,

which they systematically gather and analyze. The researcher does not claim that a newly constructed theory is universally applicable. Instead, the intention of constructing a theory is to give people an insight into truly understanding and producing a meaningful guide to action for that particular setting. After obtaining the theory, the researchers will compare their theory with the existing theories and appraise if his or her theory has coincided with the others (Starrin et al., 1997; Strauss & Corbin, 1998).

In the grounded theory, there are two common theory related-terms i.e., “theoretical sampling” and “theoretical sensitivity” which are important concepts in building a theory. “**Theoretical sampling**” is a specific of non-probability sampling in which the objectives of developing the theory or explanation guide the process of sampling and data collection. The researcher collects data, analyzes the data and produces a preliminary theoretical explanation before deciding which further data to collect and from whom. The relation between sampling and explanation is iterative and theoretically led (Mays & Pope, 1995b). “**Theoretical sensitivity**” is a desirable attribute of any researcher in qualitative study. Being “theoretical sensitive” means that a researcher must be sensitive to events and be capable of observing and recording them without filtering them through premeditated suppositions (Starrin et al., 1997). Theoretical sensitivity has namely two sources, technical and professional literatures and the personal experiences and skills of the researchers (Strauss & Corbin, 1998).

In paper V, a typist using a transcriber device and word processor transcribed all recorded tapes of the interviews verbatim. Field and observation notes were incorporated into the transcribed text. Two investigators verified the transcribed texts along with three participants, who could correctly verify the texts transcribed from their interviews and provided feedback. The two investigators performed open coding separately, following the grounded theory tradition (Strauss & Corbin, 1998), and negotiated the coding if some discrepancies existed. The other two investigators verified the open coding for some of the interviews. The open codes were entered into the computer and the lists of coding were obtained. Groups of open codes with similar themes were combined into larger categories and their properties and dimensions were identified. A core category, that was central to the emerging themes and linked to most other categories, was selected. Thereafter, a final model was formulated.

### **3.6 Strengths and limitations of the studies**

#### **3.6.1 Limitations of the studies**

Paper I: Although one of the objectives of the paper was to examine the reason of non-adherence to TB preventive therapy, the reasons of 59 defaulters (out of 412) were unknown. The investigators tried to follow up by sending letters up to two times without response, unlike the other 50 defaulters who resumed their contact with the hospital. We could not aggressively follow up with these 59 defaulters by home visits, as we were not allowed to do so based on the patients’ informed consents.

Paper II and III: The TB patients, PLWH and IDU group participants were recruited from the hospitals. The TB patients who were recruited went to TB and TB/HIV clinics for the follow up visits; IDUs to the methadone clinic and PLWHs attended an HIV club. In other words, these participants were health service users and therefore, their views might not reflect the views of “non-users” or “non-adherence” groups.

Paper IV: The study intended to consecutively recruit all new cases of over 15 year olds with pulmonary TB and sputum-smear-positive patients. However, the study could not interview 124 patients during the data collection period due to various reasons: 41 prisoners did not show up at the hospital, only the sputum was submitted (for ethical reasons, these persons were not followed into the prison); 44 patients left the hospitals before knowing the sputum results; 14 patients were seriously ill and died; 3 hilltribe people could not speak Thai or the northern Thai language and finally, the inability to locate another 12 patients. The other limitation is that the health-seeking behaviors in this study were the behaviors of the patients who sought health services. The behavior of the patients who sought care with private health services is unknown.

### **3.6.2 Strength of the studies**

#### **3.6.2.1 The qualitative studies (paper I-V)**

In a qualitative study, the researcher is the essential instrument for data collection. The quality of the data is determined by the quality of the researcher (Britten, 1995; Mays & Pope 1995a; Lincoln & Guba, 1985). The quality of the study can be enhanced by experienced and skillful interviewers who are interested in the study subject (Starrin, et al., 1997; Strauss & Corbin, 1998). In this thesis, all 17 FGD sessions (5 in paper I, 11 in paper II and III, 1 in paper IV) were conducted by the thesis author. Therefore, the core issues discussed in the different groups were consistent allowing the researcher to incorporate emerging findings from previous groups in subsequent group discussions. Moreover, the thesis applied the following procedures to enhance “trustworthiness”:

- Prolonged engagement: The researchers had longitudinal home visits with the patients for a period of 6-8 months which enhanced the participants’ trust (Paper V).
- Triangulation: Four different modes of triangulation exist, namely the use of multiple and different sources, methods, investigators and theories (Lincoln & Guba, 1985). The thesis applied three modes of triangulation to various parts of the studies.
  - Multiple data sources: Knowledge, perception and behaviors regarding TB-associated HIV/AIDS were investigated with different groups of people, e.g. patients, health workers and community people (paper II, III, V).
  - Multiple methods of data collection: To increase the credibility of the data obtained by the in-depth interviews and FGD, other methods were employed, i.e. pill count (paper I, V), observation (paper V) and the review of medical records (paper I, V).



The study result obtained through the structured interview by questionnaire was discussed with a group of medical doctors (paper IV).

- Multiple investigators: In paper V, two experienced investigators (including the thesis author) jointly performed the data collection with the two field supervisors having different backgrounds and professions. The open coding was conducted separately by these two investigators and subsequently checked for consistency.
- Member check: In the subsequent home visits, the researchers summarized the results of the last visit and asked the patients if the summary was correctly performed. Moreover, the interview transcripts were verified by the participants who could read correctly (Paper V).

#### 3.6.2.2 The quantitative studies (paper I, IV)

Paper I: Adherence was measured by pill count along with the patient interview and the review of medical records for the follow-up rate. The validity of each measurement was increased by the use of multiple data sources.

Paper IV: Each patient was interviewed immediately after the sputum smear results were diagnosed as positive reducing the recall bias. The same interviewer conducted most interviews; therefore, the interview manners were consistent and could aid in reducing interviewer bias (Last, 1995).

### 3.7 Ethical consideration

The studies presented in this thesis were approved by the Research Committee's Ethical Review Committee, from the Ministry of Public Health, Thailand (ref. no. MOPH 0229/81). The research adhered to the Ethical Principles for Medical Research Involving Human Subjects, adopted by the 18<sup>th</sup> World Medical Association General Assembly, Helsinki, June 1964 (The World Medical Association, 2002). In addition, the researcher strictly adhered to the ethical guidelines for researchers in all fields, issued by the Thailand National Research Council.

Paper I-V applied the following general ethical considerations including: training for the research assistants regarding research ethics and patient's confidentiality, providing the information about the studies 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 did not wish to respond to as well as the confidentiality of the individual's data and information. The study patients were identified by hospital numbers (HN), codes or by their nicknames.

Specific ethical considerations were applied to paper I, II-III and V.

Specific ethical considerations for paper I:

One of the study's objectives was to investigate the reasons for non-adherence, however, the patients' confidentiality was of paramount importance, especially for the HIV-infected persons. During the TB preventive therapy enrollment, each participant was given a follow-up in the event that the participant defaulted or missed an appointment for more than 1 week. The follow-up methods included by mail, telephone, home visit or "not allow for any follow-up". In the event of mail follow-up, the hospital would send a letter in an ordinary envelope written by hand so that the neighbors or the family members would not associate the letter with hospital matters. The follow up letter did not contain any content related to HIV.

Specific ethical considerations for paper II-III:

In the HIV-infected participants' focus group, a specific question was asked in order to ensure the confidentiality regarding the individual patient's HIV status. Before the focus group discussion each participant was carefully identified. The individual HIV-infected participants were asked whether they were willing to participate in the discussion and whether they would mind disclosing their HIV status to other HIV-infected persons.

Specific ethical considerations for paper V:

Data was obtained through home visits, which might have caused TB and/or HIV/AIDS stigma during the visit. Several measures were applied in order to avoid stigmatization. Home visits were only made with the patient's consensus. The researchers visited the patients wearing casual clothing and driving an ordinary car (no health/hospital related marks). The major objective of this study was to elicit the attitude, belief and behavior about TB from the patients' perspectives. The researcher should avoid manipulating the data during the interview and observe the patients. However, when the observed behaviors or perceptions were harmful to the patient, to the family or to public health, the researcher took protective measures.

## CHAPTER 4

### MAIN FINDINGS

Based on the thesis' conceptual framework and the socio-cultural and behavioral concepts presented in chapter 2, this chapter presents a synthesis of the main findings from the five original papers (I-V) and an additional analysis of data with a particular focus on the impact of HIV/AIDS in TB treatment-seeking behavior, adherence to therapy and the perceptions and attitudes of various groups, which affected TB transmissions and the prevention effort.

#### 4.1 The impact of the AIDS epidemic on the perception and practice regarding tuberculosis (paper II, V)

##### 4.1.1 The explanatory model of tuberculosis and HIV/AIDS

Table 14 presents the explanatory model of TB and HIV/AIDS from the perspectives of the community, PLWH, drug users and TB patients. High AIDS morbidity, mortality and the intensive program for AIDS information, education and communication apparently influenced public awareness about AIDS etiology and AIDS transmission. Regarding TB, people confused the etiology and symptoms with those of other diseases. Several participants stated that they recalled being given information about TB a long time ago at school.

Although most participants stated to have been educated by health staff regarding TB being a communicable disease, not all believed the information. Findings from FGD (paper II) and the in-depth interview (paper V) showed that several men (husbands) did not adhere to the health staff recommendations regarding isolation from TB patients during the first two weeks of treatment. These individuals believed that if TB were contagious, they would have developed the disease as they remained in contact with their spouses during months, even years, as they showed evidence of infection through coughing. These men interpreted "communicable disease" (in Thai – rok tid tor) as a disease that should be transmitted within a short time period, within one week or one month.

*"My husband does not believe that TB is transmittable. Aka people (one hill tribe ethnicity) believes that TB is transmitted through family blood (gene). He still ate remaining foods of mine...drank water from my cup. He asked me if TB is really transmittable, why*

*he does not have TB. He said I have coughed for years if he should get TB infection from me, it would have happened a long time ago and not right now”.*

*(A TB (HIV-) female patient)*

Most participants (paper II and V) believed that sharing spoons or cups with TB and AIDS patients was strongly associated with the risk of becoming infected. Accordingly, the most common preventive behavior among TB patients, regardless of their HIV status, was separating their eating utensils. For the TB (HIV-) patients, this TB preventive behavior lasted until the coughing ceased, while most TB (HIV+) patients maintain this behavior throughout their life.

#### **4.1.2 The impact of high AIDS awareness on TB**

The result from FGD (paper II) revealed that community consciousness about AIDS is high and that the AIDS epidemic is recognized to be a major health problem in the community. This finding is consistent with the result from the in-depth interview (paper V) presented in figure 5, which indicated that before TB diagnosis became widespread, the patients, the families and the people in the community believed that these patients were infected with AIDS or another disease. Not one case proved to have associated the illness with TB. A common notion was to associate weight loss, chronic fever, chronic cough and dark and unhealthy skin with AIDS rather than TB. Some patients who suspect that they are infected with AIDS delay seeking care for what many cases turns out to be HIV-negative TB. Some patients who had been suffering from a cough for longer than one year hesitated to consult the health service, as they were afraid of being diagnosed with HIV. These patients normally presented a history of high HIV-risk behaviors, such as brothel users or engaging in sexual activity with AIDS patients (who were already dead). Inability to cope with their HIV/AIDS caused these patients to seek care only once their symptoms became serious. In some cases, patients died from TB despite being HIV negative.

*“My uncle was 59 years old. He coughed severely for months, had fever, severe loss of weight and appetite. He thought he had AIDS. He refused to go to the hospital until he could not get out of the bed. We took him to hospital. The doctor said he has got TB. His HIV status was negative. He was too sick to accept any medicine or foods. Eventually he died...”*

*(A female, community member)*

High AIDS awareness also affected the TB (HIV-) patients psycho-socially. In every case, the patient expressed to have been labeled as having AIDS by their neighbors and community people, including family members such as their wife and mother. The TB (HIV-) patients became aware of the gossip and the various rumors regarding AIDS. The high AIDS

mortality rate also discredited the efficacy of the TB treatment as the community witnessed the death of those AIDS victims who died from TB even though TB treatment had been administered. Therefore, people believed that TB was incurable if the patients were infected with HIV. The established evidences of incurable and fatal AIDS cases in the community embraced “fatalism” among the patients and the community people, which reduced their demands of health services as they simply accepted to die. Several TB (HIV +) patients admitted to have had suicidal thoughts because of the suffering caused by clinical symptoms and their feelings of discrimination and as a result did not want to add taking care of them as a burden on their elderly parents.

*“My relatives said, “Going to hospital does not help, you will not be cured. Don’t go. If you can live...you just live. If you can not live, just prepare for the next birth in the next world. Whatever will be will be. Let it be.” Many of my siblings and relatives (seven) have died of AIDS. I am the only remaining person. My cousin died despite of spending huge money for hospital care. His parents sold their car for the treatment but finally he died anyway. I accepted not to go to the hospital. Just die...just die.”*

(A TB(HIV+) male patient having major TB drug reactions but nobody brought him to the hospital.)

#### **4.1.3 The attitudes and values associated with HIV and TB transmission (paper V)**

The studies conducted (paper II and V) revealed that most people were aware of the transmission and prevention of HIV. Despite this knowledge, some HIV-infected persons remarried without notifying their HIV status to the new partner; after their husbands had deceased due to AIDS, some HIV infected women became prostitutes in other provinces and outside Thailand. Most caregivers (mothers or wives) knew that TB is a transmittable disease and that they should avoid close and lengthy contact with the patients, especially during the first two weeks of the treatment. However, most caregivers (including asymptomatic HIV-infected caregivers) took care of the patients closely for a lengthy period of time.

In addition to the clinical knowledge about the disease transmission and prevention, the following attitudes and values also involved the risk of HIV and TB transmission behaviors.

Social role : Women who strictly adhered to their social role and norm of being a “good wife” would intensively take care of their husbands and therefore, became highly exposed to TB.

Virtue: Lack of “virtue” caused the HIV-infected persons to further transmit the HIV virus to others taking in consideration their personal benefit, without considering other people’s suffering.

Accepting fate: The caregivers' of over 50 years of age tended to accept "fatalism" as their only option. They felt that, once over 50 they had completed their life cycle (getting married, having children, raising the children and having the children marry). Therefore, they were not afraid of being exposed to TB or AIDS if they could provide their best care to the one they loved. This attitude and value also applied to the caregivers who were HIV-infected and did not have children. These individuals were determined to die because of HIV and were not concerned about becoming infected by TB.

*"...At the hospital, nurses told me to sleep outside the patient's room. When the nurses left the room, I just lied down on the floor, under my daughter's bed. I was worried, she was terribly sick. When she went to toilet, nobody helped her. Who would help her? Well...whatever will be will be. I accept that I may get TB. Let it be. She is our child. Wherever she is, she is our child. We are already old, not so many years that we will live. If we have to die, we just die."*

(A 53 years old mother of a TB (HIV+) female patient.)

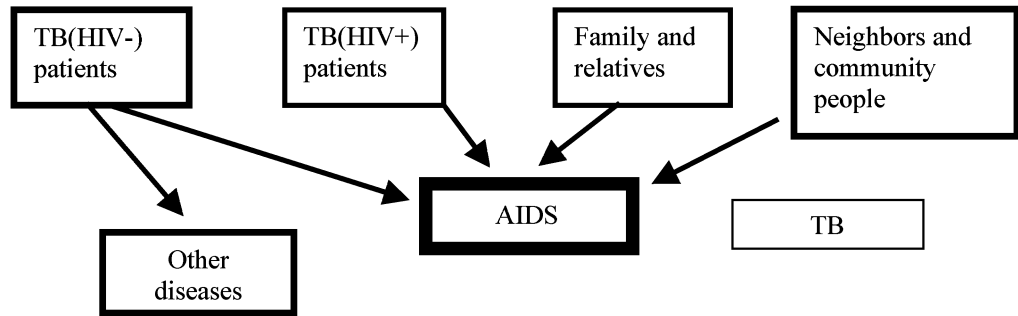
*"I will protest if the hospital will issue a regulation not allow the family to look after the patients over the night. I don't care...what ever will be will be if I will have to get TB. Who will take care the patient as good as us? Who will care which part of body that the patient is suffering? Who will care if the patient wants to eat or wants to void? P (husband) complained that once a hospital staff changed clothes for him, he was so hurtful because the staff quickly changed. They were not aware that P had severe body ache and joint pain".*

(HIV-infected woman, wife of a TB (HIV+) patient)

**Table 14.** The explanatory model of TB and AIDS (paper II)

Explanatory model	TB	AIDS
Terminology	-wanna roak -roak pod (lung disease) -ki koo (asthma)	-AIDS -roak nun (that disease) -roak parn yarng waa (that kind of disease)
Etiology	-close contact with TB patients -heavy smoking and drinking -dust and polluted air -spread by dog, cat, mice and flies -living in dirty environments -virus -genetic disease	-promiscuity -having sex, sharing needles with persons carrying the AIDS virus -virus
Symptoms	-ai hang hang (dry cough), ai knug (massive cough), more than one month-cough -diarrhea and vomiting	-fever, weakness, cough -dark skin, weight loss, loss of appetite
Diagnosis	-chest x-ray	-blood test for virus AIDS -lumbar puncture
Perceived severity and treatment Efficacy	-incurable if infected with TB and virus AIDS -curable if early diagnosis and treatment	-incurable -dead only
Transmission	-TB is transmittable through coughing, sneezing, exhalation, -sharing eating or drinking utensils with TB patients -TB is a heredity disease	-AIDS is transmittable through sexual intercourse, sharing needles with persons having AIDS

**Figure 5.** Diseases which TB (HIV-), TB(HIV+) patients, families and neighbors think about? (paper II and V)



## 4.2 Health-seeking behavior before and after the tuberculosis diagnosis (paper IV, V)

### 4.2.1 Health-seeking behavior before the TB diagnosis (paper IV)

An interview with 557 TB patients (66.3% male and 33.7% female) with different HIV status (46.9% HIV-positive; 38.1% HIV-negative; 15% HIV-unknown) revealed that the TB (HIV+) patients suffered more serious symptoms when the TB was diagnosed, indicated by a higher hospitalization rate and more symptoms, especially diarrhea and oral thrush. More than 80% of the patients reported having a cough or other respiratory-related problems, which prompted them to visit the hospital. Approximately 73% of the patients had health insurance. Nevertheless, in order to visit the hospital, 16% of these insured patients had to borrow some money from their relatives or neighbors. The proportion of those borrowing money was higher among the patients who did not have insurance (42.5%). Among the HIV-positive TB patients, higher proportions reported borrowing money and selling their assets than the HIV-negative and unknown-HIV-status patients. Half of the patients spent 30 minutes or less travelling to the hospital; 55% traveled on their own or in relative's vehicles; the remainder reached the hospital by bus or hired car. About 72% of the patients were current or previous hospital visitors.

The steps taken in care-seeking among the different types of HIV status was similar, 3.7 steps on average. Compared to other sources of treatment, private clinics were used mostly by the patients regardless of their HIV status (35.2%), while the use of traditional healers was rare (1.6%). The overall use of private hospitals was low (8.2%). The proportion of HIV-positive and HIV-negative patients visiting drug stores (31% and 27.4%) was two times higher than the HIV-unknown patients. HIV-positive patients utilized health centers least, while the use of district hospitals among different HIV status groups was similar. Before the diagnosis of TB, only 6.6% of the patients thought they may have contracted TB, and half of these patients had come in contact with family members who recently had TB.



The proportions of patient delay  $\leq 7$  days, 8-14 days, 15-21 days, 22-29 days, 30-60 days and  $\geq 60$  days were 43.3%, 10%, 13.7%, 2.4%, 21.8% and 8.8%, respectively. Median patient delay for the 557 patients was 11 days. The median patient delay for HIV-positive, negative and unknown patients was 10, 15, and 15 days respectively. The median patient delay for men and women was 14 and 7 days, respectively. Patients having the following characteristics had a statistically significant longer patient delay: outpatients, aged 46-60, hilltribe people, non-previous visitors to the hospital, those with no health insurance and those borrowing money from relatives or neighbors for hospital visits. HIV-positive patients proved less delay than HIV-negative patients, and those with an unknown HIV status. The adjusted OR for patient delays based on logistic regression model showed that hilltribe ethnicity, those borrowing money for hospital visits and non-previous hospital visitors were independently associated with a long patient delay. The analysis revealed an association between their marital status and HIV-status. The HIV-positive patients who were married or widowed had the lowest adjusted OR of 0.42 (95%CI 0.22-0.83) after controlling the other potential confounding factors.

**Table 15.** Factors associated with long patient delay

	N	Long patient delay %	OR (95%CI)
Sex			
Male	369	32.8	1
Female	188	31.9	0.96 (0.66-1.40)
Marital status			
Single	92	37.0	1
Married	335	31.9	0.80 (0.49 – 1.40)
Divorced	51	33.3	0.85 (0.42 – 1.75)
Widowed	79	29.1	0.70 (0.37 – 1.33)
Ethnicity			
Thai	483	29.6	1
Hill tribe	74	51.4	2.51 (1.53 – 4.12)
Current/previous visitor to the hospital			
No	157	41.4	1.75 (1.19 – 2.57)
Yes	396	28.8	1
Had health insurance			
No	153	39.9	1.57 (1.06 – 2.31)
Yes	404	29.7	1
Borrowed money for hospital visit			
No	457	30.4	1
Yes	100	42.0	1.67 (1.07-2.61)
HIV status			
Negative	212	41.5	1
Positive	261	23.4	0.43 (0.29 – 0.64)
Unknown	84	38.1	0.87 (0.52 – 1.46)

#### 4.2.2 Health seeking behavior after the tuberculosis diagnosis (related to paper V-unpublished data)

The consecutive home visits for 6-8 months found that during the TB treatment course, half of the patients, especially TB (HIV+) patients, sought additional treatment and care from other sources including their neighbors, drug stores, health centers, private clinics and private hospitals. The common reasons for seeking additional help was to obtain medicines which were

not prescribed by doctors in the TB clinic. Some symptoms (including symptoms caused by drug reactions) were recent and emerged when the patients came home. The private hospital was chosen because of perceived effectiveness, while the other treatment sources were chosen due to accessibility, i.e. close to their house and having convenient hours. Visits from the neighbors, sharing medicine as well as sharing opinions regarding the treatment choice was common in the study setting.

*“After taking only one dose of TB drugs in the evening, at night I had body ache, severe itching, awful rash appeared on my face. I could not sleep at all. I went to a group of neighbors to seek advice. All of them suggested me to stop medicine. They said I would die because of medicine not because of AIDS. One senior neighbor said, “No need to take medicine. Throw them away!!!”.*

(A TB (HIV +) male patient)

The home visits showed that the TB (HIV +) patients not only used anti-TB medicines but also other medicines (ranged between 3-18 items). The TB (HIV-) patients used 0-5 other medicines. Use of other medicine during TB treatment course included antibiotics, anti-cough medicines, anti-fungus, antihistamine, anti-dermatitis, pain killers, antacid, anti-hemorrhoid, anti-stomachache, vitamins, traditional medicines, as well as home-made herbal medicines. The observations and the interviews showed that some TB (HIV +) patients overused the medicines, for example, they took double doses of anti-histamines and analgesic drugs which they received from different sources (private clinics and drug stores).

### **4.3 Adherence to tuberculosis preventive therapy and tuberculosis treatment (I, II, V)**

Table 16 summarizes various aspects of adherence to TB preventive therapy and adherence to TB treatment. Although patients' characteristics and the regimens for TB preventive therapy and TB treatment differed, reasons for good adherence and medicine reminder systems among good adherent patients of the two programs were comparable. During the study period, the directly observed therapy was not formally implemented in the study hospital. The participants and the patients took medicine by themselves or they were taken care of by family caregivers.

#### **4.3.1 Reasons for non-adherence**

About 62% of the 412 HIV-infected persons enrolled in the preventive therapy program did not have TB or HIV-related physical symptoms at the time of starting the therapy. The fact that they were in the non-symptomatic stage, allowed them to be strong enough to work as usual. Accordingly, a major reason for non-adherence to isoniazid preventive therapy for TB (missed at

least one month of medicine) was due to migration to work outside the province. Another significant reason was denial of HIV infection and therefore, refusal of taking HIV-related medicine. The refusal of the HIV status was caused by namely two reasons, inaccurate knowledge about the natural history of HIV infection and the inability to cope with the HIV/AIDS stigma. Some participants believed that once they had become infected with HIV they would soon develop AIDS-related symptoms. The following qualitative data illustrates the denial of HIV status, which resulted in non-adherence to TB preventive therapy (related to paper I - unpublished data):

A 41-year-old male government worker participated in the TB preventive therapy program for 4 months then defaulted. He reported to the researcher that he missed the scheduled appointment because he did not believe that he had the HIV infection.

*“Look! I am so healthy, I do not have any weight loss and I still look handsome. Doctor just told a lie that I had AIDS virus. Doctor may not want men to visit the brothels? How can I believe that I have AIDS? If I really have AIDS, I should die soon ...say within 3-4 months like what I saw many men died ”*

A seventeen-year-old female commercial sex worker who also participated in the TB preventive therapy program for one month and defaulted. She withdrew from the program because she could not cope with the stress due to having HIV/AIDS.

*“Whenever I take the medicine (isoniazid), it reminds me that it is because I have “AIDS”... I have AIDS... I have AIDS. After I took the medicine I usually could not sleep until 4 o'clock in the morning. When I finally slept I had bad dreams. I wanted to die... I wanted to suicide. I had to stop taking the medicine or I would go mad!”*

In table 16, “death” was reported as one of the reasons for non-adherence to TB treatment. Consecutive home visits (paper V) showed that 3 out of 7 TB (HIV+) patients died during the course of the TB treatment (3 weeks – 3 months). Noticeably, the two dead patients strictly adhered to TB treatment until the day they died, while the other patient suffered with drug reaction and decided to quit all kinds of modern medicine, including anti-TB tablets. Psychological distress due to HIV/AIDS stigma was also reported as a reason for non-adherence to TB treatment in some TB (HIV+) patients (paper II).

#### **4.3.2 Reasons for good adherence**

About a quarter of the total 28 participants who demonstrated good adherence to preventive therapy (adhered to 95-100% of the 9 month-therapy) were not aware of the effect of

isoniazid in preventing clinical TB. Despite lacking knowledge about the medicine, these persons strictly adhered to the medication because they trusted in the recommendations given by the doctors and nurses. Good adherence to preventive therapy was not associated with age, educational level or the distance from their home to the hospital. Females were more likely to adhere to the medicine than males (adjusted odds ratio-95% confidence intervals was 3.00; 1.56-5.88).

As for TB treatment (paper V), all thirteen TB patients (seven HIV positive and six HIV negative; table 16) correctly reported about their treatment duration for TB. They were also aware that non-adherence to TB treatment might cause a drug resistance problem. Of the seven TB (HIV+) patients, three patients were not eager to treat the TB for the benefit of their own health. They were determined to die due to HIV/AIDS. Love and concern about transmission of TB to their family significantly motivated these patients to adhere to the TB treatment. Health staff told them that taking TB medicine was the best way to prevent TB transmission. A common cause for good adherence reported by the participants and the patients in TB preventive therapy and in TB treatment was the need to prolong their life in order to take responsibility for their children and the care of their family.

*“My husband died. I have two children and they are very young. My mother is old... 70 years. If I die who will feed them? Therefore, I must do everything that doctors said good. I must live long to take care my kids and my mom.”*

(Stated by an HIV-infected female participant of preventive therapy program (paper I); similar expressions repeatedly revealed in paper II and V.)

Without staff instruction, good-adherent participants and patients (paper I, V) developed their own medicine reminder systems. Family caregivers played important roles in ensuring adherence to TB treatment for most TB (HIV+) patients. Perceived love and concern from the family motivated the TB (HIV +) patients to adhere to the TB treatment.

A caregiver-mother of a TB (HIV +) female patient reported that every night between 19:00 - 20:00 hr. (about one hour), she sat next to her daughter to cheer her up and encourage her to take the anti-TB pills. It was the first time in her daughter's life to take such amount of the medicine (9 tablets at one time). In addition to pulmonary TB, the patient also suffered from oral candidiasis and a throat ulcer, which stimulated vomiting whenever the patient swallowed a pill. The patient swallowed the tablets very slowly one by one. After swallowing one tablet, the mother gently hugged the patient for support. The mother also encouraged her daughter with these words;

*“Do you love me? If you truly love mommy please take medicine for mom. You must be cured and stay with mom”* (related to paper V – unpublished data).

**Table 16** Aspects of adherence to TB preventive therapy and adherence to TB treatment

	Adherence to TB preventive therapy (paper I)	Adherence to TB treatment (paperV)	
Study participants	412 HIV-infected persons	6 TB (HIV-) and 7 TB (HIV+) patients	
Measurement for adherence	Pill count (patients brought leftover medicine to the hospital) and interview	pill count (at patient's home) and interview	
Drug regimen/ Supply of medicine	300 mg. dose of isoniazid and one tablet of vitamin B complex for 9 months; one time per day; one month supply of medicine.	6-12 months treatment; four anti-TB medicine for the first two months and two medicines for the remaining months; one time per day; one month supply of medicine.	
Characteristic of the service	A special clinic at a hospital; provided the service every workday from 8:00 a.m.- 4 p.m.; free medicine.	Two special clinics, one for TB (HIV-) and the other for TB (HIV+) patients; provided service once a week from 8:00 – 12:00; free medicine.	
Treatment completion rate	69.4% (n = 412)	TB (HIV+)	TB (HIV -)
		4 of 7 patients completed treatment	5 of 6 patients completed treatment
Reasons for non-adherence	<ul style="list-style-type: none"> <li>-work or family-related business (migration for work)</li> <li>-denial of HIV status</li> <li>-inability to cope with HIV status</li> <li>-perceived side effect of INH</li> <li>-misunderstanding of treatment duration</li> <li>-developed other illnesses</li> <li>-changed to herbal medicine</li> <li>-inconvenient travel</li> </ul>	<ul style="list-style-type: none"> <li>-died (2)</li> <li>-drug reaction (1)</li> </ul>	<ul style="list-style-type: none"> <li>-severe drug reaction and died (1)</li> <li>-perceived low efficacy of treatment of the public hospital and switched to a private hospital (1)</li> </ul>
Reasons for good adherence	<ul style="list-style-type: none"> <li>-accepted HIV status well</li> <li>-need to prolong life in order to take responsibility for children and family care</li> <li>-satisfied with the service (perceived psychological support from the providers)</li> </ul>	<ul style="list-style-type: none"> <li>-perceived TB treatment efficacy</li> <li>-love and concern about transmission of TB to young child</li> <li>-encouragement from the family to take medicine</li> <li>-need to prolong life in order to take responsibility for children and family care</li> </ul>	<ul style="list-style-type: none"> <li>-perceived TB treatment efficacy</li> <li>-love and concern about transmission of TB to their family</li> </ul>
Medicine reminder systems for good adherence	<ul style="list-style-type: none"> <li>-Storing medicine in a visible location linked to daily activities (e.g. putting medicine close to the rice cooker, drinking water, cosmetic desk, top of television, entrance of mosquito net)</li> <li>-marking a calendar after taking medicine</li> <li>-putting reminding message</li> </ul>	<ul style="list-style-type: none"> <li>-reminders from family members</li> <li>-administration of medicine by the caregivers</li> </ul>	<ul style="list-style-type: none"> <li>-marking a calendar after taking medicine</li> <li>-Storing medicine in the visible location which link to daily activities</li> </ul>

#### **4.4 HIV infection and lifestyle of tuberculosis patients (paper V)**

The consecutive home visits suggested that the lifestyle of TB patients who were co-infected with HIV was significantly different from the HIV-negative TB patients. The HIV infection considerably affected the patients and their family in many aspects. Change of lifestyle between male and female patients (regardless of HIV status) was also noted. Most female patients could not perform housework such as cooking or washing clothes when they were seriously sick in which case they were assisted by their mothers or husbands. Most male patients refrained from consuming alcohol and tobacco, especially at the beginning of the TB treatment.

##### **4.4.1 The impact of HIV infection on patients' lifestyle**

Table 17 compares the lifestyle of TB (HIV -) and TB (HIV +) patients which was different nearly in all aspects. Although all TB patients (both HIV status) were recruited for the study based on the same criteria (i.e. ability to walk to the toilet on their own at the time of TB diagnosis), the TB (HIV +) patients suffered more clinical symptoms. All except one TB (HIV +) patient suffered from oral and throat candidiasis and mouth ulcers. Some patients developed other HIV-associated symptoms at home after they were discharged from the hospital. The symptoms included convulsions, dermatitis, hemorrhoids as well as symptoms related to adverse drug reactions. As a result of suffering from more clinical symptoms two weeks after being discharged from the hospital, most TB (HIV +) patients appeared to be weaker than their TB (HIV-) counterparts. Of the seven TB (HIV+) cases, two patients were cured of their TB illness and five patients died between 3 weeks to 7 months after beginning their TB treatment. Accordingly, the TB (HIV+) patients heavily relied on the family caregivers. In contrast, most TB (HIV-) patients could maintain their daily activities (eating, bathing and going to toilet) by themselves. Moreover, the TB (HIV-) patients could quickly resume work.

Despite their TB being cured, the TB (HIV+) patients permanently changed their food habits and eating patterns, while the TB (HIV-) patients only temporarily changed their behaviors. The most common restricted foods among HIV-infected persons (paper II and paper V) were beef, catfish and fermented foods. The HIV-infected persons were not allowed to eat with other people at social gatherings. This was due to the perceived risk of HIV transmission through saliva. It was a typical community practice to serve food when people congregated. People would eat food together sharing their eating utensils such as cups and spoons. They ate food from the same bowl or plate. Consequently, the TB (HIV +) patients would isolate themselves from any social activities, as they could not enjoy sharing meals with other people.

##### **4.4.2 The impact of HIV infection on the family**

The TB (HIV-) patients had little impact on their family compared to the TB (HIV+) patients because TB (HIV-) patients could independently perform their daily activities and

normally resumed work within 2 months. The TB (HIV+) patients' illness had an important social, economic and health impact on the family.

Economic impact:

Not only were the TB (HIV+) patients unable to attend to their jobs, but also some of their family members. Several caregivers had to renounce to their jobs in order to take care of the patients. Families earned less income due to the AIDS stigma (see 4.7).

*“This year we will loose 20,000 baht (500 \$US) that we invested for planting corn. We don't have time to pick them. We just have to let the corn dry and die...no time to go to the field. I can not leave her alone. I am worried who will help her when she wants to go toilet, when she want to eat”.*

(a mother of a TB (HIV+) female patient)

Moreover, the family members usually gathered at the patients' homes and remained near the patients most of the time, especially during the week following their discharge from the hospital as well as when the illness was considered fatal. In one observation, seven sisters and brothers including a few relatives of a TB (HIV+) male patient did not go to work for almost a month. For days on end they sat around and watched the patient, who eventually passed away in the presence of all the family members.

Psychosocial impact:

Not only the TB (HIV +) patients, but also the family members became depressed by the HIV/AIDS stigma. All mothers expressed the same feelings of anxiousness, bereavement and shamefulness. Most mothers had no motivation to do anything, including any job, which may produce some income; some mothers refused to participate in the community gatherings; some mothers prohibited the patients to appear in public although the patients themselves did not mind being offended by other people. One mother did not want her daughter to sit and relax in front of her own house because of her appearance due to AIDS. One brother brought his sister to the hospital on his poor-functioning motorcycle instead of taking the public bus because people on the bus offended his sister.

Health impact:

The interviews and the observations show that the family members, especially the caregivers, were at risk of exposure to TB. This was due to the constant need of a caregiver on behalf of the TB (HIV+) patients suffering from serious symptoms. Therefore, the risk of TB exposure seemed to be high among the caregivers due to lengthy and the close care of the



patients. Repeated information from interviews found that most caregivers (mothers and wives) looked after the TB (HIV+) patients intensively both at home and at the hospital.

*“At the hospital, I was the only person who looked after my husband, day and night long for eleven nights. At night, I slept on a mat spread under my husband’s bed”*

(a TB (HIV+) female patient, whose husband had TB two years before her)

**Table 17.** Life style of TB(HIV-) and TB(HIV+) patients

Life style	TB(HIV-) (3 men, 3 women)	TB(HIV+) (4 men, 3 women)
Self helping in daily activities (eating, sleeping, bathing, toilet)	- Most patients could maintain daily activities by themselves.	-Almost all patients needed help from the caregivers
Food	Restricted Foods -Most patients restricted some food items for the first 1-2 months	-All patients restricted some food items for life.
	Special foods -Some patients ate special foods for the first 1-2 months	-Most patients did not eat special foods but they switched to drinking boiled water instead of tap water throughout their life.
Eating	-Most patients separated eating during the first two weeks or until coughing symptom disappeared	-Majority of the patients separated eating for life.
Tobacco and alcohol consumption	-The patients refrained from smoking or drinking while the coughing symptom existed, and resumed when the coughing symptom had gone.	-Most patients refrained from smoking and drinking throughout their life. Only one patient resumed smoking despite the coughing symptom.
Sex (married patients)	- Most couples avoided having sex during the first two weeks or until coughing symptom disappeared.	- same as TB(HIV-) patients
Social relationship Social activities	-Most patients withdrew from social activities while coughing symptoms existed and resumed normal relationship when they recovered from coughing	- Most patients withdrew from social activities throughout their life and modified activities by meeting with the least number of people
Working	- Majority of the patients stopped working for 1-2 months and then resumed.	-Majority of the patients could not work. Some patients could work for 1-2 months but subsequently became sick again.
Outcome of the 6-8 month follow up	-One patient died (heavy alcohol user ), the others were cured	-Five patients died and two patients were cured.

#### 4.5 TB and AIDS stigma (paper I,II,V)

Both TB and AIDS were stigmatized, however AIDS patients were far more stigmatized because AIDS was associated with immoral behavior, whereas TB was recognized to be contagious.

*“People usually feel that a person who is infected with AIDS had bad behavior, deviant from social norms. Out of my knowledge, although TB is a communicable disease, it is not due to sexual misconduct, right? Society is not disgusted by TB. People may feel that a TB patient is infected from other sources.”* (HIV-positive male)

The negative consequences of AIDS stigma on TB were stated earlier (4.4.2). Table 18 compares the various aspects of the TB and HIV/AIDS stigma, which clearly shows that the magnitude and negative consequences of the stigma related with HIV/AIDS are much more serious than that of TB. None of our TB (HIV-) patients concealed their TB to their family members. However, several HIV-infected patients, especially those who were in the non-symptomatic stage participating in TB preventive therapy program, concealed their HIV status to their spouses, parents and siblings. They felt HIV/AIDS was the most shameful disease and they did not want their family to suffer. None of our TB (HIV-) patients had thoughts, while two HIV-infected clients (both men) in the TB preventive therapy program are known to have committed suicide. One TB (HIV+) male patient attempted suicide but failed. Several TB (HIV+) patients admitted that they had suicidal thoughts because they wanted to escape from the community discrimination.

Furthermore, AIDS stigma seriously effected the economic situation of the patients and their families, especially those who earned their income from selling ready-cooked foods. The community people did not usually buy foods from the sellers who had AIDS, who were labeled as having AIDS, or the food sellers who were associated with AIDS patients (being the caregivers or living in the same house). People perceived that foods could be contaminated either by the caregivers or by the patients themselves. One man told us that he lost his body weight due to diabetic mellitus (HIV-) but the community perceived that he had AIDS and therefore refused to buy foods from him.

*“When my husband stayed in my mom’s house, my mom could not sell foods for months... as people saw him helping mom preparing foods. We moved out from mom’s house. A few months ago, I sold ice-snack, I sold well. One day my husband came to the selling place and he picked up a piece of ice to eat. Thereafter, nobody bought the snack from me. I had to stop and became jobless. My sister-in-law could not sell noodle after my husband helped washing dish for 2 times.”*

(Asymptomatic HIV-infected woman, wife of a TB (HIV+) patient)

In general, people did not want to share meals with TB or HIV/AIDS patients. They were disgusted by the thought of eating foods or drinking water that could be contaminated by patients' saliva. The eating style greatly generated felt-stigma and enacted stigma. In the Chiang Rai context, people worked separately in the field or in the office but they got together for lunch. Although each of them brought their own lunch, they sat in the circle and shared foods by placing them in the middle. The typical foods for lunch were sticky rice and various kinds of chili pastes with vegetables and meat. The use of a spoon and fork is uncommon. People eat with their hands and share drinking water from a common container and the same cup. This eating style is widely applied to all kinds of social gathering in the community (wedding parties, funeral ceremonies, making merit, etc.). Because of this way of eating, some patients could not work or did not want to go to work (although they were cured from TB and they were strong enough to work) because of the fear that they would be discriminated during mealtimes. Eating together seemed to make the foods tastier than eating alone. A common statement made by several patients, as well as general people in Chiang Rai was "*Gin kao kone diew bo rum...mun ngom*" (eating alone not delicious...so lonely).

The stigma surrounding AIDS also limited patients' benefit of public and private services. Most patients could not use public transportation and several patients did not dare to go to the market or other public places because they suffered from the way people looked at them.

*"My eye vision was terrible. It is like seeing through a thick fog. But it is better for me to take risk by driving my very old motorcycle to the hospital. I drove very slowly. It was very cold (winter--about 10-15 degrees Celsius). Well, it is better than going to hospital by a public bus. You know? Once I got inside the bus, every eyesight came to me. It seemed that I was a dangerous object. People on the bus tried to keep away from me".*

(A TB(HIV+) male patient with a skin rash due to drug reaction).

*"I go to market early to avoid meeting with people. I dare not touch or pick up the vegetable by myself. I ask the seller to choose for me because if I touch the vegetables or foods, no customers behind me will dare to buy the foods or vegetables"*

(A TB (HIV+) female patient, who was cured of TB)

With gender perspectives, male and female TB (HIV+) patients shared a similar magnitude of enacted and felt stigma, stigmatizing reaction and consequences of the AIDS stigma. However, felt stigma against TB between male and female TB (HIV-) patients differed. Several young HIV-negative TB males were relieved when doctors said they had TB and not AIDS. They openly disclosed their TB status to others, preferring this label to that of AIDS. In contrast with the majority of female patients who perceived a high TB stigma and would tend to

hide their TB status by telling others that they had pneumonia or a lung disease instead. As a result, these females strongly rejected home-based DOT due to the fear of the TB stigma.

**Table 18.** Aspects of TB and HIV/AIDS stigmatization (II, V)

		HIV/AIDS	TB
Type, Magnitude and degree of experiences with stigma	Felt Stigma	all patients – strong	some patients (female > male) -mild to moderate
	Enacted Stigma	most patients – strong	some patients – moderate
Cause of stigma		<ul style="list-style-type: none"> <li>-linked to bad behaviors (promiscuity, drug use)</li> <li>-contagious</li> <li>-awful appearance (underweight, skin lesions)</li> <li>-incurable and life threatening</li> </ul>	<ul style="list-style-type: none"> <li>-contagious</li> <li>-severe cough</li> </ul>
Stigmatizing Actions	By Patients themselves	<ul style="list-style-type: none"> <li>-concealing HIV status (even to the family members)</li> <li>-naming AIDS as “that disease”</li> <li>-engaging in marriage without notifying the spouse about HIV status</li> <li>-withdrawing from social activities</li> <li>-limiting exposure to other people (e.g. avoid using public bus)</li> <li>-committed suicide, having suicidal ideas</li> </ul>	<ul style="list-style-type: none"> <li>-concealing TB to neighbors</li> <li>-informing other people as having “other lung diseases” (e.g. pneumonia)</li> <li>-limiting social activities/relationship</li> <li>-maintaining distance from other people</li> </ul>
	By Other People	<ul style="list-style-type: none"> <li>-refusing foods prepared or sold by PLWHA</li> <li>-refusing to eat with PLWHA</li> <li>-keeping distance</li> <li>-avoiding direct contact</li> <li>-labeling all TB(HIV-) patients as having AIDS</li> </ul>	<ul style="list-style-type: none"> <li>-keeping distance</li> <li>-avoiding close contact</li> <li>-prohibiting patient to prepare or cook food</li> </ul>
Consequences of stigma	to patient and family	<ul style="list-style-type: none"> <li>-loosing/changing job</li> <li>-loosing/lowering incomes</li> <li>-depression, stress, discouraging feeling lonely, isolation</li> <li>-reducing accessibility and choices to other services</li> </ul>	-feeling lonely, isolation
	to public health	<ul style="list-style-type: none"> <li>-delay in seeking TB service</li> <li>-longer transmission of HIV and TB</li> </ul>	-no evidences
Duration of stigma		-lifelong	-temporary (usually ends when patient stops coughing and gains body weight)
Gender difference		-no gender differences	-female patients had stronger “felt stigma” than male patients

#### **4.6 Health care providers: knowledge, perspectives and practice regarding TB**

This section summarizes the findings from the FGD of groups of male and female health center staff reflecting their knowledge and attitudes towards TB-associated HIV (paper II, III). It also provides the analysis of the provider delay and a group discussion with the internal medicine doctors (paper IV).

##### **4.6.1 Knowledge about TB (etiology, transmission, prevention and treatment) (paper II)**

Most of the female staff members described the cause of TB as involving the TB germ and the individual's low immunity, while about half of the male staff members perceived the causes of TB to include "dirtiness". Although every health staff member knew that TB was transmitted through the respiratory tract, most staff strongly believed that TB was transmittable through eating and drinking. The staff believed that people could get TB by sharing eating and drinking utensils with TB-infected patients. In the focus groups, several staff members shared their experiences in the community about methods to avoid drinking or eating foods offered by TB patients and the family when they visited the patient's home.

*"We may get TB if we drink water from a cup that has been used by a patient. I think if we can avoid it, we had better not share the same cup even if the patient only quickly drinks water from it once". (Male staff)*

*"At the health center, if I see a TB patient drink water which is provided by the health center, I must immediately wash that cup in order to prevent other patients from using a cup, that has been used." (Female staff)*

Most female and male health staff members perceived that they ran the risk of becoming infected with TB as a result of their job. Among the 23 participants of the focus groups, one female staff had TB in the past. The majority of male and female staff believed that they could prevent TB by maintaining their health and a strong immunity by eating nutritious foods, performing regular exercise and resting adequately. However, these healthy behaviors may not be practical for every staff member. Most staff members believed that BCG was the most important intervention to prevent the spread of TB. Health center staff members were afraid of getting TB from the patients and they wanted maintain a distance from them. However, several staff, especially female staff, reported they would not explicitly show their fear in front of TB patients because of compassion for the patients. Although the health staff wanted to use masks to prevent the spread of TB when they were near patients, they felt that using masks while performing their duty in the community was culturally inappropriate.

*"I think prevention of TB depends on the type of health facility.*

*For example, we are staff at health center level. If we put on a mask while examining the patients, they will feel psychologically distanced from us or they may feel that we are disgusted by them. Health center staff have to work closely with people in the community, unlike a nurse working in hospital. That is why I feel that the best way to prevent ourselves from getting TB is keeping fit by exercising.” (Male staff)*

Based on their field experiences, most staff members witnessed that TB (HIV+) patients normally died very soon or died a few months after TB diagnosis and treatment. They perceived that TB attacked the AIDS patients when their immunity was very weak and that it was impossible to cure TB. Consequently, the staff had less motivation to care for the TB (HIV +) patients as they assumed they would eventually die of AIDS.

*“We have many works that we have to do in the health center. TB patients with HIV infection usually died soon after a few weeks of TB treatment. Finally, they would die due to AIDS. We can not help them. This makes us feel less priority”. (Male staff – FGD)*

#### **4.6.2 Financing incentives versus the intensive TB education for health staff (paper III)**

A common statement from several staff when discussing the feasibility of implementing DOT was that they were already overwhelmed by the existing amount of work. They felt that DOT was an extra job which was unnecessary and increased their workload. However, if the government would consider providing some financial incentives such as petrol supplies and allowance for implementing home-based DOT, the staff might become more motivated.

*“... Suppose we received 10,000 baht (250 US\$) per cured case. We would do DOT regardless of our tremendous workload. We would not complain even if we had to visit a patient’s home at 7:00 o’clock. Even if it means 4:00 o’clock in the morning, I will do DOT...” (Male staff)*

However, the above incentive demanded could be reduced if the staff were properly educated about the critical issues regarding TB. At the end of the focus group discussions with the health staff a brief TB education was delivered. The important educational message which changed the staff’s demand for incentives included the current situation of TB in Chiang Rai which showed a dramatic increase, the situation of multi drugs resistant-TB (MDR-TB) in Chiang Rai emphasized by the term “resistant **strain**” (in Thai – **saiy pan** due ya), the risk of exposure to MDR-TB for the health staff and for the general public and the contribution of DOT in controlling MDR-TB. It is noteworthy that one male and two female staff members (from different sessions) approached the moderator and confessed that they had never known about

MDR-TB and its impact on public health. They were concerned about this problem and they felt that if the staff were more aware of how critical this issue was, they would not ask for incentives. Noticeably, one of these was the same person who loudly proposed “allowance for home visit” during the focus group discussion.

#### **4.6.3 Provider delay in TB diagnosis (paper IV)**

The median provider delays of the total 557 TB patients were 8 days. Median provider delays for HIV-positive, -negative and -unknown were 7, 7.5, and 10 days, respectively. Median provider delays for men and women were 7 and 14 days, respectively. Provider delays were significantly longer in female patients than male patients, OR=1.43 (95% CI 1.01 – 2.04). A group of internal medicine doctors expressed their opinions in a meeting regarding longer provider delays in female patients that men presented with obvious and more severe symptoms, which prompted a suspicion of, and an investigation for TB. Females expressed high health awareness and sought treatment when the symptoms were not serious and therefore, doctors normally did not diagnose TB but other respiratory infection. Moreover, doctors felt that female patients did not clearly explain their symptoms, although they often spoke of multiple complaints. These doctors suggested that the quality of sputum might also be a problem in for the females, as they were considered physically weak as well as impolite, preventing them from coughing loudly to produce sputum.

The increase of TB cases in the hospital has increased the awareness among doctors to suspect TB and, to some extent, has influenced the TB-diagnosis behavior. The number of patients submitting sputum for microscopic examination between 1995 and 1999 increased significantly from 2,948 to 4,058 persons. The doctors considered the diagnosis of TB when they examined known cases of HIV-infected patients. However, all doctors who collaborated in the group discussion reported that they did not ask the suspected TB patients regarding “TB household contact” in order to facilitate the TB diagnosis.

#### **4.7 Feasibility of home-based and health center-based directly observed therapy (DOT) in the HIV epidemic setting (paper III, V)**

Both providers (health center staff) and clients (TB patient; PWH; community people; drug users) did not perceive the need for DOT. The clients felt that the current self-medication was the best. However, doctors should provide the adequate knowledge regarding the importance of taking the medicine and the problems regarding drug resistance. Table 19 summarizes the perception of DOT feasibility and preference for health center-based DOT and home-based DOT. Although the providers felt health center-based DOT was highly feasible for the staff, it was not feasible for the patients. Most clients preferred home-based DOT to health center-based DOT. Only TB (HIV-) female groups were strongly against home based-DOT due to the stigma.



Health center-based DOT was seen as impractical both by staff and clients because of the patient's inability to visit health centers daily as they were too sick (especially TB (HIV+) patients) or too old, being busy with daily work or child care responsibilities and the inconvenience of travel and the unaffordable daily travel costs. Home-based DOT was not feasible from the health staff's perspectives because it included inadequate staff visiting the patients' home everyday, the traveling inconvenience, especially during the rainy season in the mountainous area, and the high TB caseload in some settings. The health staff also expressed that implementing DOT in a high HIV-epidemic setting and mountainous area like Chiang Rai made DOT more complicated than in other areas of Thailand. In order to increase the feasibility of home-based DOT, additional financing incentives and additional staff should be provided. Moreover, special training to implement DOT in difficult HIV cases should be offered.

**Opportunities for implementing Home-based DOT** (related to paper V – unpublished data)

As reported in table 17, the TB (HIV+) patients not only suffered from TB but also from other HIV related clinical symptoms, including psychosocial and economic burdens. The consecutive home visits (paper V) suggested that home-based DOT conducted by the health staff was highly needed among TB (HIV+) patients and DOT may serve broader benefits for the individual patient and for the public health. In order to maximize the benefits, the home-based DOT does not only mean that the health staff visits the patient's house, watches them taking the medicine and finishes the role, but it can also achieve the following:

- (1) Home-based DOT serving as an active TB case finding among the household contacts, especially the HIV-positive partner.
- (2) Home-based DOT is a chance to conduct family counseling for HIV blood testing (active HIV case finding) among household contacts, especially of the partners of TB (HIV+) patients.
- (3) When the TB (HIV+) patients died, a reasonable amount of several expensive HIV-related medicines (e.g. anti-fungus, medicine for herpes zoster) were discarded. In these cases, the health staff can bring back the medicine to be used with other AIDS patients.
- (4) Home visits conducted by the health staff offers a chance to observe the housing environment and patient lifestyle that may affect the risk of TB transmission among the household contacts.
- (5) Home-based DOT is a means to provide a comprehensive and holistic care for the patients who usually encounter several health and social problems.

**Table 19.** Feasibility and preference for home-based and health center-based directly observed therapy (DOT).

DOT	Health staff		Clients	
	Perceived feasibility	Preference	Perceived Feasibility	Preference
Health center-Based DOT	High	Low	Very low	Very low
Home based DOT	Very low (female staff) Low (male staff)	Very low	Low	Moderate to high  Very low (HIV-negative TB, females)

Note: Health center-based DOT = A TB patient visits the nearest health center every day to take the medicine; Home based-DOT = A health staff visits the TB patient's house everyday to supervise the patient in taking the medicine; Clients = nine different groups of people (four female groups and five male groups), including community people, TB (HIV+) patients, TB (HIV -) patients, HIV-infected persons and drug users; Level of perceived feasibility and preference: Of a scale of 100; High = 75 up; Moderate = 50-75; Low = 25-50; very low = lower than 25.

## CHAPTER 5

### DISCUSSION

This thesis addresses some aspects of society and culture providing information on how the HIV epidemic influences the beliefs, perceptions and behaviors associated with TB transmission, prevention and care. Two perspectives could be considered to explain the burden and control of communicable diseases such as TB and HIV/AIDS. One perspective emphasizes the importance of understanding the cultural knowledge, attitude, belief, perceptions and behavior of the individual that may affect the disease pattern. The intervention scale is at the individual level. According to this perspective, TB control can be improved through interventions which must be sensitive to the cultural beliefs as well as to the people's existing behavior. Most social science research of TB has applied the outlook from this perspective (Mata, 1985; Nichter, 1994; Rubel & Garro, 1992; Sumartojo, 1993). The second perspective emphasizes that diseases like TB and HIV are the diseases of social and economic deterioration and structural violence. Therefore, the intervention scale should be at a macro level or societal structure. According to this perspective, overemphasis of the role of cultural belief and knowledge could reinforce the current patient-blaming attitude. The barriers in access to care include poverty, social and economic inequity and gender inequalities. Effective TB control cannot be achieved as long as the disease is considered isolated from the social process that maintains it, creating conditions to facilitate its expansion and act as a barrier to care. According to this perspective, a paradigm shift is needed in disease control (Chemtob, Weiser & Yitzhak, Weiler-Ravell, 2001; Farmer, 1997; Ogden, 1999). For the first perspective there is a wealth of information on how to address the research, however, it is unclear how to conduct research with the new paradigm that could lead to a change in the social structure (Barnhoorn & Van der Geest, 1997).

The key question from these two perspectives is: does one begin with trying to change the inequitable structure of the society or does one start at the individual level, with the person who is unfairly treated by the social, political, and health care systems? (Barnhoorn & Van der Geest, 1997). It is important to recognize the role of social-structural factors affecting disease control, but at the same time it is necessary for practical interventions to require a good understanding of the local perception of the illness and how it is changing as a result of public health campaigns. In the following, the above two perspectives are discussed in relation to the studies reported in this thesis. In particular, the discussion presents the role of socio-cultural factors in identifying the opportunities for change and for the improvement of service, care and the health education messages.

### **5.1 The role of knowledge, perception and behavior in tuberculosis and HIV control**

Belief and perceptions about health and illness usually guide behaviors. Studies from several countries (India, Pakistan, Kenya, Malawi and the Philippines) reported that belief about the etiology of TB was associated with the health-seeking behavior, for example, people who believed that TB is caused by supernatural forces would seek care from folk and traditional healers (Barnhoorn & Adriaanse, 1992; Brouwer, Boeree, Kager & Varkevisser, Harries, 1998; Liefoghe, Michiels, Habib & Moran, Muynck, 1995; Liefoghe, Baliddawa, Kipruto & Vermeire, De Munynck, 1997; Nichter, 1994; Steen & Mazonde, 1999). Results from our studies (II, IV, V) revealed that the beliefs regarding the causes of TB being associated to supernatural causes was uncommon and therefore, seeking care in the folk sector for TB treatment was rare. In the health-seeking behavior model (Chrisman, 1977; Kleinman, 1980), the process of care-seeking begins with "symptom recognition" or how people define the symptom, cause and severity of the symptom. The studies reported that people (including TB patients) in Chiang Rai defined symptoms of fever, weight loss and cough in productive age patients as AIDS symptoms. AIDS is defined as a disease caused by sexual promiscuity, which is highly stigmatized by the society. People also defined AIDS as a fatal disease and for which there is no available treatment. This perception may not exist at present in most resource-rich countries where antiretroviral therapy is available for PLWH. Antiretroviral therapy essentially prolongs life and improves the quality of life for PLWH (International AIDS Society-USA, 2000). Following the health-seeking behavior model, the next step was consulting the symptoms with laypersons and making a decision about treatment. However, due to serious AIDS stigma, some patients would not proceed to further steps (i.e. delay in seeking care), as they could not psychologically cope with the AIDS diagnosis. As a result, these patients would continue transmitting TB to others. According to the natural history of TB, prior to the HIV/AIDS era, without proper TB treatment about 50% of the patients would die (Harrie et al., 1997). This study (paper II) reported that both health center staff and several people would not consider TB unless the patients had been coughing for several months. This may lead to a delay in its diagnosis and the seeking of care (Mata, 1985).

Other examples showing the association between belief and behaviors are the beliefs surrounding TB and HIV transmission. Although the transmission of TB and HIV through meal sharing is very unlikely (Institute of Food Science & Technology, 2001; Moulding, 1983), studies from different cultural settings have consistently reported this popular belief (Bakhshi & Ali, 1995; Carey & Oxtoby, Nguyen 1997; Liefoghe et al., 1997; Marinac, Willsie & McBride, Hamburger 1998; Westaway, 1989). This study (paper II and V) also revealed that most people, including health staff, strongly believed in this route of TB transmission. Many of them strictly separated eating and drinking utensils for TB and HIV-infected patients. Although this deliberate behavior contributes to general hygiene practice, it may not reduce TB and HIV transmission. Before anti-TB drugs were invented, isolation of TB patients in sanatoriums was the mainstay of TB control (Dubos and Dubos, 1952). Isolation during mealtimes may have its root in this isolation. While health staff, patients and the community in general overestimated the role of TB

transmission through eating and drinking, they had little recognition that adhering with TB treatment was one of the most effective methods in preventing TB transmission. Most patients and participants said that TB was a communicable disease. However, several TB female patients reported that their husbands (paper II, V) refused to eat and sleep in isolation from their wives. These men did not believe that TB was truly transmittable because they did not get TB from their wives although they had been exposed to them for a lengthy period of time. In response to this misperception, patients, their family and the community should be educated that TB is not an acute communicable diseases like the common cold, measles or diarrhea in which the transmission takes place within 1-2 weeks after exposure to the patients. A simple message about the steps of TB infection and clinical TB disease may be helpful to explain why some people develop TB while others do not despite their exposure to it.

Human sputum is the most significant source of TB infection. Coughing and spitting produce very small droplets containing TB which float in the air and may be inhaled transmitting the disease (Crofton & Horne, Miller, 1992). Undiagnosed infectious TB patients are the sources of TB transmission. The risk of spreading TB among these patients may be reduced if they cough and spit sputum properly. During the aggressive TB control in New York at the beginning of 1900, nurses had to monitor TB patients to ensure that they covered their mouths when they coughed and disposed of their sputum as instructed (Frieden & Lerner, Rutherford, 2000). In Malawi, a cough officer taught hygienic coughing to every hospitalized patient (Harries, Kamenya, Namarika, Msolomba, & Salaniponi, Nyangulu et al., 1997). Although most participants (paper II) knew that they should cover their mouth whenever they coughed, they did not perform it properly. However, another study (paper V) reported that most patients performed the hygienic coughing procedure after being diagnosed with TB and being taught by the health staff. This can be important not only for TB patients but also the community who should consider hygienic coughing and proper sputum disposal as a social etiquette for the general public (Crofton et al., 1992).

## **5.2 The role of stigma in TB and HIV transmission**

Stigma is an important issue which affects health care-seeking behavior and its outcome and thus should be taken into consideration when planning for health policies and the provisions of health care. Stigma may shape the course and outcome of the stigmatized disease through the delay, evasion of care seeking or termination of treatment for treatable health problems (Link & Phelan, 2001; Songwathana & Manderson, 2001; Weiss & Ramakrishna, 2001). HIV/AIDS and TB are the well-known stigmatized diseases as reported by many studies. Findings from this study (paper I, II, V) confirm the results from other studies conducted in Thailand, reporting the enormous psychosocial and economic impacts of AIDS stigma (Busza, 2001; Songwathana & Manderson, 2001). However, some of our findings differed from previous studies. The qualitative studies conducted in the provinces in three different regions in Thailand (except the northern region), consistently reported that HIV patients were stigmatized and treated differently to other patients by doctors, nurses and non-medical staff in the hospitals (Songwattana &

Manderson, 2001). None of our patients (paper I, II, V) reported being poorly treated or discriminated by health care professionals, however, they complained about the AIDS stigma caused by other community members. Why does this result differ from others? The AIDS stigma varies by knowledge level. Health workers who are well educated about AIDS have less fear and are more willing to associate themselves with persons infected by AIDS (Songwattana & Manderson, 2001). The HIV/AIDS epidemic in Thailand began in the upper northern provinces, including Chiang Rai. The serious AIDS situation in Chiang Rai prompted the health authorities to provide extensive AIDS training for health staff in the province. The objective was that every staff nurse in public hospitals and staff at health centers were to be trained and should be able to provide HIV/AIDS counseling for the patients. This training strategy may have influenced the patients' attitude toward AIDS. Moreover, high AIDS prevalence in Chiang Rai may be contributed to low stigma towards AIDS patients among health care workers. It was not uncommon that death caused by AIDS usually occurred among friends, relatives or health staff, which may influence the staff members' attitude and empathy towards HIV/AIDS patients.

As highlighted by Goffman (1963), stigma occurs when human differences become associated with undesirable attributes involving a label and stereotype. The label links a person to a set of undesirable characteristics that form a stereotype (Link & Phelan, 2001). In our studies (paper II, V), the community labeled persons (in productive ages) who lost weight and had a chronic cough and fever as having AIDS. The "AIDS" label linked the patients to a stereotype of sexual promiscuity. The phrase in Thai for sexual promiscuity is "sum sorn tarnng pase", which is a strong condemnation that clearly conveys a bad image of persons with AIDS. This popular phrase extensively appeared in several mass media campaigns at the national and local levels for AIDS prevention from the beginning of the AIDS epidemic in Thailand. The media representation and public perceptions of AIDS led to fear, anxiety and stigmatization (Ngamvithayapong, Uthavivoravith & Sawanpanyalert, Yanai, 1994). The high AIDS stigma discouraged TB patients (both HIV positive and HIV negative) who had a history of sexual promiscuity or those who had sexual encounters with those who had died of AIDS, this delayed their seeking of care or, in some cases, they did not seek care at all. These persons believed that they were infected with AIDS and did not want to be diagnosed. Similar findings were reported elsewhere (Barnhoorn & Van Der Geest, 1997; Ngamvithayapong, Akarasewi, Rawangphan & Yanai, Wongkhomthong, 1995). A quantitative study from Zambia reported that although TB and HIV were understood as being closely linked and highly stigmatized, these attitudes were not associated with longer delays (Godfrey-Faussett, Kaunda, Kamanga, van Beers & van Cleeff, Kumwenda-Phiri, et.al, 2002). In contrast with a qualitative study from Vietnam, which reported that the main factor contributing to delay in seeking care among women was described as fear of social isolation from the family or the community (Johansson, Long & Diwan, Winkvist, 2000). The fact that the TB and AIDS symptoms are comparable, the AIDS stigma among TB (HIV-) patients are common in Chiang Rai as well as in sub-Saharan Africa (Ustianowski & Mwaba, Zumla, 1999). Although the availability to close health facilities is usually considered an indication of patients' accessibility and responsiveness to needs, the preference for more distant services for leprosy and TB has been observed (Weiss & Ramakrishna, 2001). Our study (unpublished data-paper I) found that some PLWH sought TB

preventive therapy services from the provincial hospital instead of the nearby community hospitals, as they wanted to avoid meeting with health staff and other patients who may know them. These patients believed their HIV status and information might not be kept confidential.

The “enacted stigma” (actual discrimination, or unacceptability) in our study (paper V) was closely associated with the fear of contagion. The awful appearance of their skin lesions, severe weight loss and cough induced fear of contagion. “Felt stigma” (fear of discrimination) was closely associated with the fear of being blamed for bad or deviant behaviors, as well as being blamed for contagion (paper II, V). Studies from India and sub-Saharan Africa reported that TB stigma was associated with supernatural causes or linked with the patient’s bad behaviors (e.g. bad people were punished by god) (Rangan & Uplekar, 1999; Ustianowski et al., 1999). TB stigma in our study was only related to the contagion issue and not related to social behaviors. Stigma and contagion, therefore, are interrelated. The social course of the disease may extend beyond its biological course so that each notion reinforces the other. Stigma is seen as contagious, and conversely, a disease that is contagious may be seen as making a person feel stigmatized (Das, 2002). Interestingly, while the study (paper V) reported how a patient encountered felt stigmatized at the vegetable shop as a customer, the following quotation from another study conducted in southern Thailand, reflects exactly what our patient experienced with the AIDS stigma. Songwathana and Manderson (2001) reported the perspective of an owner of vegetable shop as stating the following:

*“...His wife (wife of an AIDS patient) used to come and buy vegetables from my shop. I never talked with her, just non-verbal language. When she gave me money, I asked her to leave it there, not in my hand. I also left change on the table, not direct contact. I don’t want her to come back because I fear I’ll loose my business, it’ll be rejected by others”.* (Songwathana & Manderson, 2001)

Sharing food and beverages does not contribute to TB and AIDS transmission (Moulding, 1983; Institute of Food Science and Technology, 2001). However, many studies from developing countries similarly reported peoples’ strong belief in TB and AIDS contagion via meal sharing. This study encountered similar beliefs (paper II, V). The reason for the strong conviction about eating-associated contagion is unclear. This belief contrasts strongly with the Chiang Rai way of life, increasing the stigma and patient discrimination from social activities. The community’s eating style (e.g. one spoon for 4-5 persons, one cup for 10 persons) is less likely to transmit TB or AIDS, however, other viruses (e.g. hepatitis, herpes zoster) may be capable of being transmitted through saliva or through sharing eating utensils. In the context of Chiang Rai, eating together is a part of social life. Stigma exists, as long as TB and AIDS patients cannot eat together whenever there is social gathering. Public health campaigns for community hygienic eating (e.g. one set of utensils for one person) may indirectly reduce stigma-associated contagion and reduce social isolation by increasing the opportunity for patients to be a part of social gatherings.

The entire discourse of anxiety, feelings of guilt and shame surrounding stigma reduce the stigmatized persons sociality, excludes them from the moral community and reduces their capability to seek help although it may be easily accessible (Das, 2001). “Stigma” is blamed for the increasing risk of TB transmission because stigmatized patients are reluctant to seek care. Consequently, the undiagnosed and untreated TB patients continue spreading TB in the community. Nevertheless, another way to look at stigma and TB transmission is that the AIDS stigma may reduce the chance of the community being exposed to TB as the stigma isolates patients from social gatherings, and makes them avoid the use of public transportation, they tend to limit themselves to staying quietly inside the house (paper V).

### **5.3 Poverty, equity and gender**

Historically, TB is a disease closely related to poverty. The current TB situation clearly suggests that TB is a disease of lower income and low-resource base countries (Foster, 1999). According to the World Bank classification, 78% of the 22 countries with the highest TB burden in the world are low-income countries. None of the high TB-burden countries are high-income countries (Farmer, 1997; Hanson, 2002). Despite Thailand adopting an official policy of free care for TB (Payanandana et al., 1999), the current low-case detection and treatment completion rate for TB in Thailand may be due partly to the inability of poor patients to cope with the economic consequences of diagnosis and treatment (Kamolratanakul, Sawert, Kongsin, Lertmaharit & Sriwongsa, Na-Songkhla et al., 1999). Our study (paper IV) however revealed that 73% of the patients had health insurance. Nevertheless, in order to attend the hospital service, 16% of the insured patients had to borrow money from relatives. The patients who had to borrow money revealed a longer patient delay. Lower coverage of health insurance and longer patient delay among the hilltribe patients compared to the ethnic Thai patients, raised the issue of equity in health care. The study (paper V) showed that TB, especially TB with HIV infection, negatively affected the family’s economic situation. Most patients lost their income either before or after starting the treatment, this was similarly shown in different study conducted in Thailand (Kamolratanakul et al., 1999). Some patients could not follow the health care workers’ advice for TB prevention due to economic limitations such as not being able to sleep separately from their spouses because of their inability to afford an additional blanket and bed net (paper V).

Gender differentials are a potentially important source of inequity in TB control (Hudelson, 1999). What is gender? The word sex only refers to the genetic and physical appearance of boys and girls or men and women, while gender has a broader meaning including biological, psychological and social characteristics (Helman, 1990). In general, especially in low-income countries, women have a lower status than men and less access to economic resources, information and education (Valassof, 1994). The lower social status of women raises the question of inequality in health and the use of health care services. Research on gender and TB has been neglected and little attention is given to gender in the TB-control program (Thorson & Diwan, 2001). Uplekar and his co-workers (2001) proposed a number of research questions



for studying gender inequality in TB which includes whether women were vulnerable to the exposure to TB, whether women were suppressed to not recognize their TB symptoms, whether women with TB suspected symptoms could access the health care service, whether women were diagnosed, treated and taken care of as well as male patients, whether women could adhere to treatment and whether women experienced more negative consequences from TB.

This thesis provides perspectives on some of these components.

In countries affected by the HIV/AIDS epidemic, it is believed that women have a particularly high risk for both HIV and TB. Women are usually responsible for caring for ill household members and for replacing them in labor. Male patients expected and received care from their wives, while female patients seldom received care from their husbands (Hudelson, 1999). This study (paper V) found that HIV-infected men remarried without informing the women about the HIV status. AIDS husbands became sick before their wives did and were taken care of by their wives or mothers. The wives or caregivers who are loyal to TB (HIV+) males became highly exposed to TB. However, some wives discontinued the wives' role and did not take care of their TB (HIV+) husbands. A study conducted in Chiang Rai (Suggaravestsiri, 2002) reported that 66% of TB (HIV+) patients were divorced or separated due to HIV-related reasons. A study of Songwattana (2001) in southern Thailand revealed that HIV-positive women were responsible for caring for family members although they were sick. Female roles as family caregivers seem to be both psychologically and socially constructed. Buddhist beliefs of karma and metta inspired the spirit of women's work as the AIDS caregivers. The researcher concluded that tradition, persistent gender imbalance and inequality influence a women's sexuality, vulnerability, responsibility and care-giving, and hence there is a need for greater support among Thai women who are afflicted and affected with AIDS.

This study (paper IV) showed similar results as other studies that women with TB symptoms sought health care service quicker than men yet female patients were diagnosed with TB later than male patients (Auer, Sarol & Tanner, Weiss, 2000; Lawn & Afful, Acheampong, 1998; Long, Johansson, Lonroth, Eriksson & Winkvist, Diwan, 1999). The reasons for longer provider delay in female patients is not exactly known, although doctors in our study hypothesized that doctors did not suspect TB in women as much as men because women sought care when the symptoms were not as serious. Women with respiratory symptoms were less likely to undergo a sputum examination than men. If examined, women are less likely than men to be sputum-smear positive (Vikarunnessa, de Colombani, Das, Gupta & Salim, Hussain et al., 2001). A study from Zambia suggested that gender equity seemed to be promoted by the decentralization of TB services (Godfrey-Faussett et al., 2002). Regarding adherence and gender, a review on adherence studies conducted in industrialized countries and resource poor countries showed that women had better adherence to TB treatment and TB preventive therapy than men (Ngamvitayapong & Puangrassami, Yanai, 1998). Most reviewed literatures did not report a reason for better adherence in women. This study (paper I) reported similar findings in that the HIV-infected women (except female commercial sex workers) had better adherence to TB

preventive therapy. In Thailand, it is common that males with HIV/AIDS become ill and die before their wives (Manopaiboon, Shaffer, Clark, Bhadrakom & Siriwasin, Chearskul et al., 1998). The surviving women felt a high commitment to their children and parents, which motivated them to prolong their life (also reported by paper I, II). Several studies repeatedly reported that socially, psychologically and economically, female patients suffered from TB more than male patients. Female patients received less support from the family than men (Johansson & Winkvist, 2002). Married women with TB were likely to be divorced or mistreated by the husband's family. Unmarried women with TB were less likely to find marriage partners (Liefoghe, Michiels, Habib & Moran, Muynck, 1995; Rangan & Uplekar, 1999). These negative impacts were not reported in our studies (paper II and V) and some of our findings even rebutted the studies' results from different countries, for example; the decision to divorce or to separate was mainly made by women after being informed of their husband's HIV status; our female patients proposed to separate sleeping rooms and eating utensils, notions which were commonly refused by their husbands. An anthropological study by Potter (1979) reported on the structural dominance of women in a northern Thai village. Potter's study expressed that the linearity, the affinity and the inheritance of authority in a family is through the women, rather than through men. This structural significance may explain the negative impacts of TB in women in our study, which are not obvious in other studies.

#### **5.4 The role of fatalism and the lack of virtue in TB and HIV transmission (paper V)**

Although the "Health Belief Model" (HBM) has been considered a popular predictor model of health-related behaviors, Schwab and his co-workers (1994) criticized that the model is not culturally sensitive enough to design the health interventions. "Fatalism" was a component which these investigators added to the HBM. A number of studies in psychology and chronic diseases, including HIV/AIDS, mostly conducted in the United States, referred to "fatalism" as an important variable determining peoples' behaviors in disease prevention and early disease detection (i.e. screening program). "Fatalism" in most studies was associated with poor health. Depression was associated with greater fatalism (Robert & Robert, Chen, 2000); men who engaged in unprotected anal intercourse outside of exclusive relationships reported a greater fatalism (Kalichman, Kelly, & Morgan, Rompa, 1997); women with high fatalism had a higher risk of HIV (Somlai, Kelly, Heckman, Hackl & Runge, Wright, 2000); low acceptance of cancer screenings (Mayo & Ureda, Parker, 2001; Lee, 2000; Powe & Weinrich, 1999) and low adherence to diabetic treatment (Schwab et al., 1994). Factors determining fatalism included older age and lower social class (Mayo et al., 2001; Ross & Mirowsky, Cockerham, 1983). We discovered the notion of fatalism in the latest study (paper V). Therefore, we did not include "fatalism" as a study variable in the earlier studies (paper I-IV). Whether fatalism plays a role in patient delay or patient non-adherence to preventive therapy remains unknown. In paper V, fatalism was reported by two different age groups (productive age-patients and elderly caregivers) with different causes of fatalism, i.e. fatalism caused by HIV/AIDS and fatalism caused by aging and value of life. Both types of fatalism could increase the risk of the individuals to become exposed to or to transmit TB and HIV. The AIDS stigma created fear, shame and distress in the patients and their family (Helman, 1990; Ngamvithayapong et al.,

1994). The suicidal rate among persons with AIDS is 21-36 times higher than that of the general population (Weitz, 1991). The massive and clear evidences of AIDS mortality in Chiang Rai, (e.g. one of our informants took care of 7 son, sons-in-laws and a nephews) seems to be the reason why the community is left without hope for a cure of AIDS, and therefore accept to die. This fatalism discourages patients to access care and therefore increases the risk of TB transmission. The fatalism among the elderly care givers may be common among Asian people whose cultural value and norm were influenced by Buddhism, Hinduism and Confucianism, which define the life cycle as birth, aging, sickness and death (Bowman & Singer, 2001; Lee, 2000). The caregivers demonstrated having knowledge about TB and HIV transmission, they also knew how to minimize the risk of the disease exposure, however, they took the risks believing it was up to fate do determine if they would become infected and die at their age. This belief misconstrues the essence of Buddhism regarding the life cycle, as the individual is being heedless to death (Payutto, 1997).

Another complicated social issue, which goes beyond knowledge and educational interventions, is the HIV transmission rate among persons who were aware of their HIV-positive status. Although some studies suggested that a substantial proportion of HIV-seropositive adults reduce their HIV transmission behavior after learning their sero-status (Wight et al., 2000), our study (paper V) showed that some HIV-infected men remarried without informing their spouse and subsequently passed on the HIV. Some women became prostitutes after their AIDS-infected husband died. Our informants blamed the lack of virtue as the cause of the further HIV transmissions among these people. Persons inspired by Buddhism were less likely to transmit the disease to other people as it is considered a serious sin in Buddhism, equivalent to murder. Virtue-associated sexual behavior interpretations varied in different cultures and religions. In some Western religions, the virtue of abstinence from sex is recognized but Western psychologists and sexologists generally consider prolonged sexual abstinence as the source of mental and physical illnesses. In the Hindu culture, abstinence from sex is considered a virtue (Nag, 1995). From the Islamic perspectives, the deliberate transmission of the AIDS virus to a healthy person by any means is a violation of Islamic rules and is a sin as well as a legal offence necessitating punishment (The Islamic Organization for Medical Science, 1993). In the Buddhism's basic five precepts for virtuous-living, two precepts seem to be associated with the risk of HIV transmission, i.e. precept 1, abstaining from killing, taking life or doing bodily harm and precept 3, abstaining from sexual misconduct, not violating the loved or cherished ones of others, thereby destroying their honor and dignity and confusing their family line (Payutto, 1997). The promotion of virtue of each religion is recommended as the mean to prevent HIV transmission (Assavanonda, 2001; The Islamic Organization for Medical Science, 1993; Kanwanich, 2000). Law enforcement for controlling HIV transmission was applied in several countries. It is considered a crime if those who are aware of their HIV status spread their infection to others (Giesecke, 1993; Scheper-Hughes, 1993).

Our study also revealed that virtue was directly associated with TB transmission. Some patients disclosed their TB status to other people and asked them to keep their distance. These patients also strictly adhered to medical advice in preventing TB transmission to others (i.e. taking medicine, coughing properly). They felt responsible if other people became sick; it was considered a sin if they caused others to become ill.

## **5.5 Tuberculosis prevention in an HIV epidemic setting**

Two aspects of TB prevention will be discussed. Firstly, TB preventive therapy for PLWH who have the highest risk of their latent TB infection (sub-clinical TB infection) developing into a clinical TB disease. Secondly, preventing TB by curing active TB patients. The infectious TB cases should be diagnosed and treated at the earliest possible stage. This issue involves health-seeking behavior, delay in diagnosis and adherence to TB treatment.

### **5.5.1 Tuberculosis preventive therapy for people with HIV infection**

Several randomized control trials in the area with a high prevalence of HIV infection revealed that preventive therapy is an effective method in reducing the incidences of TB and deaths as a result of TB in the adult PLWH with a positive tuberculin skin test. However, preventive therapy does not have an effect on HIV progression or survival (Bucher, Griffith, Guyatt, Sudre & Naef, Sendi et al, 1999; Quigley, Mwinga, Hosp, Lisse & Fuchs, Porter et al., 2001; Lugada, Watera, Nakiyingi, Elliott & Brink, Nanyunja et al., 2002; Wilkinson, 2002). The major concern in the provision of preventive therapy is patient adherence to the therapy. Poor adherence is a cause of drug resistance and treatment failure. In our study adherence to the 9-month preventive therapy was at 67.5% (paper I) , which is slightly higher than a feasibility study from Uganda (62%) (Aisu, Raviglione, van Praag, Eriki & Narain, Barugahare et al., 1995) but lower than another study also conducted in Uganda (80%) in which TB preventive therapy services were delivered by community-based HIV clinics (Lugada et al., 2002). Improving the service system may increase the adherence to TB preventive therapy. A study from a community hospital in Chiang Rai reported that 57% of the defaults in the TB preventive therapy (served at out-patient service) was reduced to 17% when the hospital integrated an isoniazid preventive therapy into the PLWH day care center as part of the care package. Service and care including follow-up systems in this day care center were utilized by the PLWH and their network, and as a result, seemed to contribute to better adherence (Piyaworawong, Yanai, Nedsuwan, Akarasewi & Moolphate, Sawanpanyalert, 2001). As Wobeser and Hoepfner (1989) argued, there is little value in increasing the number of persons beginning preventive therapy if they will not complete it. Therefore, several issues should be considered to minimize non-adherence. PLWH should be carefully enrolled through good counseling. Before enrolling participants in the preventive therapy program, the counselor or the provider should identify the potential risks for non-adherence by discussing with the participants whether and how the risk of non-adherence could be avoided. Prior to starting the preventive therapy, the counselor should ascertain if the participants are able to cope with their HIV status, if they are able to visit the program on a monthly basis, their feasibility of migration for work during the 9-month therapy; the potential alcohol and substance use and abuse, as well as the potential use of other alternative medicines for the HIV care. Several medicine-reminder systems developed by PLWH in our study (paper I) may be applicable to participants in other settings.

After completing the 9-month preventive therapy, what needs to be done? Prior to the HIV epidemic, the efficacy of preventive therapy was shown to be of long duration, possibly even for life (Comestock & Baum, Snider, 1979). A study in Zambia reported that the effect of preventive therapy diminished over time. The protection against TB by a 6-month isoniazid regimen and a 3-month isoniazid in conjunction with pyrazinamide, was a minimum of 2.5 years (Quigley et al, 2001). The duration of the effect of the therapy and its re-infection raises the question of lifelong preventive therapy, which requires research to determine the appropriate dose and duration.

### **5.5.2 Preventing TB by detecting and curing TB patients**

Infectious TB patients are the source of TB transmission. The tuberculosis epidemiology using molecular methods shows that a single untreated patient can contribute to a mini-epidemic of tuberculosis (Genewein, Telenti, Bernasconi, Mordasini, & Weiss, Maurer, 1993; Small, Hopewell, Singh, Paz & Parsonnet, Ruston et al., 1994). The best way to prevent TB transmission is to detect TB patients as early as possible and cure and ensure treatment completion. Adherence to the TB treatment is critical as the number of TB bacilli is significantly reduced within two weeks of beginning the treatment (Hopewell, 1986).

The time of TB detection in our study, determined by patient delay and provider delay, was favorably short (paper IV). The increase in TB cases has improved doctor's awareness in the study hospital about the need to suspect TB. Improving the laboratory service by informing patients of the 30-minute duration time for sputum results may facilitate the diagnosis speed (unpublished data: an observation at the laboratory section of the study hospital). Short patient delay may be attributed to high health insurance coverage, easy access to the hospital (good roads with availability of public transportation), the acquaintance with the hospital's services and the fact of being a current or previous visitor. However, the inability to interview 124 patients (see chapter 3, topic 3.6.1) may be attributed to short patient delays, as these patients might have actually delayed seeking care. Furthermore, the study was a hospital-based study. This study utilized only those patients who sought hospital services. For this reason, the proportion of TB patients in the community is unknown. Many of these unknown cases could involve seeking care at private health care sectors, or not seeking care at all. Since the PLWH with dual infection are the highest risk group in developing active TB disease, the TB screening program should be available in a care package (WHO, 2002e).

Prior to the HIV epidemic period, patient's non-adherence to TB treatment was a common and complicated issue for TB control (Ngamvithayapong et.al, 1998). HIV has further complicated this issue. Our study (paper II) and evidence from sub-Saharan Africa (Ustianowski et. al., 1999) showed that TB patients with HIV co-infection might not adhere to the TB treatment as they feel they will ultimately die due to HIV. However, our study (paper V) shows that the motivation to adhere to the TB treatment could be enhanced by informing the patients of

its ability to prevent TB transmission to their family. Uplekar and Rangan (1996) reported similar findings in India where patients were convinced into take anti-TB drugs as a means of preventing rather than curing. Experience from Chiang Rai showed that TB (HIV+) patients and family members who felt defeated by HIV could be encouraged to adhere to the TB treatment with photos and stories of TB (HIV+) cases which were successfully cured despite their HIV co-infection and various health issues (unpublished data-personal communication with the nurses at Chiang Rai Hospital).

DOT has been claimed to be the best method to ensure patient adherence. WHO declared that DOT is possible in almost any cultural and social situation, including some of the world's poorest areas (WHO, 1997). However, in an HIV epidemic setting like Chiang Rai, where approximately half of TB patients are HIV co-infected, implementing DOT challenges both clinical and socio-economic aspects. Complications due to other opportunistic infections challenge the clinical management skill of the DOT supervisor. Health center-based DOT may cause financial burdens for the patients, as they are obliged to pay for daily transportation and the loss of income. Home-based DOT may cause stigma towards the patients. One challenging controversy of supervised therapy is universal versus selective DOT. Many health care workers have unrealistic hopes that an educational strategy directed at patients can greatly increase their compliance to treatment. The evidence does not support that intensive patient education alone can help high-burden countries achieve an 85% cure rate (Klaudt, 2001). However, Ogden (1999) reported that through various community-based strategies, Non-governmental organization (NGO) projects in India and in Nepal, which have achieved a high cure rate of over 80%, did not implement DOT. What marks the differences between NGO care from the government care service is that the first seems to stress the care and support of the patients, while the later relies on control and observation.

Based on experiences registered in the United States, there are several reasons for the support of universal DOT. In order to avoid invidious discrimination, all patients should participate in DOT, irrespective of their social or economic circumstances (Bayer & Wilkinson, 1995; Frankel, 1992). Citywide DOT (covered 54-87% of all cases) as it may be more effective than selective DOT targeting only high-risk patients (Chaulk, Moore-Rice, Rizzo, 1995). A recent study from Pakistan reported that there is a real danger that patients reached by selective DOT may become more stigmatized than those reached by universal DOT. These investigators suggested that universal DOT should be used (Mortelmans, Liefoghe, Mertens & Zaidi, Solangi, 2002). In a setting like Chiang Rai, where people tend to associate all TB cases to HIV/AIDS, there is a need for interventions to improve the misperception and to reduce stigma before expanding DOT. The thesis author believes that DOT can contribute a great deal to the patients' well being, especially home-based DOT. Importantly, DOT must not be delivered in an authoritarian style as it is likely to yield unsatisfactory treatment results (Zwarenstein, Schoeman, Vundule & Lombard, Tatley, 1998) and create negative attitudes towards the program. DOT should be viewed and delivered as a standard care (Meulemans et al, 2002) in the sense that the health service commits to curing the patients and to reducing the risk of TB transmission in the family. The challenge is preparing the health staff's attitude and willingness to provide care from this perspective.

## 5.6 The role of health care workers

The health care providers' behavior is an important issue, which has received little attention in the study (Rangan & Uplekar, 1999). In the AIDS epidemic context, it is important to ensure that there are sufficient motivated and skilled health care workers to care for PLWA (Horsman & Sheeran, 1995). In many sub-Saharan African countries, the HIV epidemic has heavily affected the health care workers where it has been impossible to find a replacement for the staff who become sick or die from AIDS (Foster, 1999). Fortunately, despite high HIV prevalence in Chiang Rai, the impact of HIV on the health worker is not the same as in sub-Saharan Africa. However, some health care workers' attitudes and beliefs regarding TB and its association with HIV in Chiang Rai are similar to those of the sub-Saharan Africa studies.

Some studies reported health care workers' fear of TB and HIV transmission, which negatively influenced the service behavior and their interaction with the patients (Horsman & Sheeran, 1995; Watson & Rosen, 1994). Experience from New York City in the beginning of the 1900's showed public's irrational fear of TB due to propaganda about TB resulting in the stigmatizing of TB patients (Frieden & Lerner, Rutherford, 2000). Our health workers (paper II) admitted a fear of becoming infected with TB as a result of their interaction with the patients, however they did not explicitly show their fear in front of TB patients because of the compassion they felt for them. They perceived that TB was easily transmitted but believed that they did not develop TB because of their body's strong immune system. Similar to community (lay) people, the staff members had strong misperceptions regarding TB transmissions through sharing eating and drinking utensils, while they had less recognition about the role of hygienic coughing in TB transmissions. Similar to a report from sub-Saharan Africa (Ustianowski, 1999), our studies (paper II, III) revealed that the health staff had little motivation to care for TB (HIV+). Staff members perceived the high mortality of AIDS victims despite being on the TB treatment. Most staff members expressed that DOT was impractical as well as feeling unmotivated to implement it unless financial incentives were provided (paper III). In the USA, substantial evidence (El-Sadr & Medard, Bathaud, 1996; Fujiwara, Larkin, Frieden, 1997; Iseman, Cohn, Sbarbaro, 1993; Klein & Naizby, 1995; Sbarbaro, 1980) indicated that improving the staff's attitude and forming positive relationships between the TB patient and the DOT provider significantly enhanced treatment adherence and the program's overall success. Staff members' demand for incentives may be avoided if they are well informed about MRD-TB (paper III). The education of health workers is an important priority of the DOT strategy. Where education resources are limited, the first priority should be to improve knowledge about DOTS among health care workers and volunteers (Klaudt, 2001). Educating health staff members about TB should include clinical knowledge of TB associated with HIV and incorporate subjects related to attitude development and human relationships. The training should motivate the staff to recognize the importance of preventing TB transmissions to the public and their willingness to care for TB patients. Importantly, training should not create an unnecessary fear of TB transmission, which will negatively affect the disease control. Experience from Zambia suggests that health system research is an effective and affordable tool to improve staff's knowledge, attitude and behaviors in the delivery of health service. The research process involves aiding the health staff in identifying the problem related to the TB services, designing the study, collecting and analyzing the data and participating in planning and taking actions to solve these problems (Godfrey-Faussett et al., 2002).

The health care providers' behavior significantly influences the patient's behavior. Providers' attitudes and their behavior in communicating health information can directly influence patients' retention of that information, which subsequently improves their health behavior (Boelm, Coleman-Burns & Chritensen, Schlenk, 1994; Rangan & Uplekar, 1999). Mechanic (1999) reported that the clinician-patient relationship remains a source of significant influence and opportunity to promote improved health. Our Studies (paper I, V) showed that reasons for good adherence to TB preventive therapy is partly contributed to by a positive relationship with the health staff. Several behaviors (e.g. adherence to TB treatment, coughing, spitting and food behaviors) improved due to the effective health education offered by doctors and the health staff members (paper V).



## CHAPTER 6

### CONCLUSION

Publishing research results in scientific journals is crucial in enabling other researchers to compare their study results. The ultimate aim, however, is that the research findings actually contribute to change and ultimately improve peoples' health. From the author's perspective and her capacity as a researcher involved in teaching and training for Thai and international medical and health staff, a goal for conducting social science research is translating research into action and getting policies improved. As referred to at the beginning of the previous chapter, the author has recognized the need for a social structural change for disease control but still believes that research at a socio-cultural aspect at the individual level has an important role in improving public health in both short and long-term perspectives.

This final chapter summarizes the major challenges, opportunities and recommendations for TB prevention and care in a high HIV prevalence setting. The summaries were drawn using results from paper I – V along with non-published data from the same project.

#### 6.1 Challenges for tuberculosis control in HIV epidemic areas

- The social stigma attached to HIV/AIDS is enormous. The HIV/AIDS stigma negatively affects the social, economic and physical health of the patients and their family.
- Increased awareness and stigmatization of AIDS and an inadequate knowledge about TB results in delays in seeking TB care. Most TB (HIV-) patients were stigmatized as having AIDS.
- The high mortality among TB (HIV+) patients during TB treatment discredited the TB treatment efficacy. Health staff members had a low motivation to care for the patients because the treatment results are discouraging.
- Fatalism attached to HIV/AIDS hindered the patients access to health care; patients felt hopeless and lacked the motivation to adhere to their TB treatment.

- The ways of social gathering in the community, eating styles and misperceptions about TB and HIV transmission through eating together were associated with TB and HIV stigma, causing lifelong social isolation among PLWH and a loss of income among patients and family.
- Some HIV infected persons continued to spread HIV to other people.
- Most caregivers in this study were women (wives and mothers). Despite having knowledge about TB being contagious, the caregivers could not avoid close contact with the TB patients, as they wanted to provide the best care for the terminally ill patients. The HIV-infected women caregivers were at a highest risk for TB.
- The health staff had low motivation to implement DOT unless extra financing incentives were provided.
- How can adherence to TB preventive therapy be best maintained among PLWH who can not avoid migrating in search of a job? Will TB preventive therapy work after completing the 9-month therapy if PWLH could not avoid being a caregiver for patients having TB?

This thesis not only investigates and reports problems but also proposes some opportunities to improve the TB situation in an HIV high prevalent area.

## 6.2 Opportunities for TB prevention and care in HIV epidemic area

- A key message which seemed to increase adherence to TB treatment among TB (HIV+) patients, who felt hopeless with the HIV and had no motivation to cure TB, but were concerned about TB transmission to their family is:

*“Taking TB medicine is the best way to prevent TB transmission to your love ones. The TB germs will be killed to level that the patients will not spread TB to the others”*

- Providing TB education to a community may influence community attitudes toward TB treatment, reduce patient delay caused by AIDS stigma, and reduce the stigma of TB (HIV-) patients. The community should be informed about the following:

-“Weight loss” is a common symptom of several diseases, not only of HIV/AIDS, e.g. TB, diabetes mellitus, hyperthyroidism and cancer. Case studies from research should

be shown to demonstrate how the fear of being labeled with AIDS could delay a patients search for care for TB.

- Despite having an HIV positive status, TB is curable. Showing case studies from our research with some photos (with permission from the patients), both before and after TB treatment of TB (HIV+) patients who were successfully cured and could resume work for the family. This educational strategy can also be applied with the patient and their families.
- TB patients who take TB medicine are less likely to transmit TB. Community people should not be disgusted with patients who are being treated for TB
- The following contents of TB training may influence the health care workers' attitude towards TB (HIV+) patients' care and may reduce the staff's demand for incentives:
  - The epidemiological situation of TB and MDR-TB (using the term "saiy pan due ya" for MDR-TB).
  - Showing case studies from research on how TB and MDR-TB are widely transmitted in public places and may affect the staff and their family as anyone may be exposed to persons with MDR-TB in a public setting.
  - Good care and DOT prevent MDR-TB. Taking TB medicine is the best way to prevent TB transmission. Providing TB treatment is not only beneficial to the individual but also to public health in general.
- Adherence to TB preventive therapy may be best maintained by careful enrollment of PLWH (preventive therapy should be provided only to persons who virtually accept the HIV status), systematic follow-up and running TB preventive therapy service as a part of package of care for PLWH. The medicine reminding system developed by good adherent clients can be shared with other clients.
- Home visits are beneficial to HIV and TB care, especially for TB (HIV+) patients. An effective home visit is a means for the health staff to holistically understand the problems that patients are encountering and allowing them to provide care in a more comprehensive manner. Active case finding for TB and HIV among other family members is possible through home visits.

### **6.3 Recommendations for social and behavioral research**

Based on the conceptual framework presented in chapter 2 and the research findings presented in this thesis, the following topics are recommended for further research:

**(1) Research to reduce the risk of exposure to HIV and TB**

- Strategies to prevent further HIV transmission among PLWH should be studied. The role of virtue in Buddhism for HIV prevention should be investigated.
- A participatory action research with caregivers (HIV-positive) should be promoted. Practical interventions to reduce risk of exposure to TB among caregivers who take care of TB patients at home and at hospital require investigation.

**(2) Research of TB preventive therapy among PLWH**

- Various care models to improve adherence to TB preventive therapy should be studied, for example, health facility-based versus HIV-community-based care.
- Applicability and effectiveness of the medicine reminder methods, which were developed by the participants (paper I, V), should be studied with other patients.

**(3) Research to promote intensified TB case findings and to reduce TB diagnosis and treatment delay.**

- The magnitude of persons having TB suspected symptoms but did not seek care; the role of private clinics in TB diagnosis and treatment and the role of private laboratory in HIV testing need to be investigated. Factors determining choices of public versus private care require examination.
- The reasons for longer provider delay in female TB patients require investigation and interventions to reduce longer delay.
- Association between the magnitude of the AIDS stigma, magnitude of fatalism and patient delay in seeking care need investigation.
- The role of communication and health education in reducing AIDS and TB stigma and in reducing patient delay.
- The role of home-based DOT in active case finding for TB and HIV among household members should be studied.

**(4) Research to promote adherence to TB treatment and DOT**

- The role of communication and health education in improving patient adherence should be investigated. Future research should examine effectiveness of the key messages and communication methods proposed by this thesis (see 6.2).
- The role of research-based TB training (see 6.2 for some training contents) versus incentive on health staff attitude and performance on DOT, should be studied.

**(5) Research on TB treatment outcome**

- The role of socio-cultural and economic factors associated with TB mortality among TB (HIV+) and TB (HIV-) should be investigated.

## REFERENCES

- Addington, W.W. (1979). Patient compliance: the most serious remaining problem in the control of tuberculosis in the United States. *Chest* 76, 741-743.
- Aisu, T., Raviglione, M.C., van Praag, E., Eriki, P., Narain, J.P, Barugahare, L., Tembo, G., McFarland, D., Engwau, F.A.(1995). Preventive Chemotherapy for HIV-Associated Tuberculosis in Uganda: An Operational Assessment at a Voluntary Counselling and Testing Center. *AIDS* 9, 267-273.
- Akarasewi, P., Pokaew, P., Sriyabhai, S. (1991). HIV-1 infection and associated risk factors among tuberculosis patients, Chaing Mai. *9<sup>th</sup> National Seminar on Epidemiology*, Bangkok, (abstract p116-117).
- Akarasewi, P. (2001). *National Recommendation Guideline: The Integrated TB/HIV strategies for the Control and Prevention of Tuberculosis in Thailand*. Department of Communicable Disease Control, Ministry of Public Health.
- Alonzo, A.A., & Reynold, N.R. (1995). Stigma, HIV, and AIDS: An Exploratory of Stigma Trajectory. *Social Science & Medicine* 41, 303-315.
- Ankrah, E.M. (1989). AIDS: methodological problems in studying its prevention and spread. *Social Science & Medicine* 29, 265-276.
- Assavanonda, A.(2001). Monks' role in helping patients discussed: Right conduct can help fight infection (AIDS Forum). *Bangkok Post* 25 April.
- Auer, C., Sarol, J., Tanner, M., Weiss, M. (2000). Health seeking and perceived causes of tuberculosis among patients in Manila, Philippines. *Tropical Medicine and International Health* 5, 648-656.
- Bakhshi, S.S., Ali, S. (1995). Knowledge, attitude and behavior of TB patients. *Journal of Public Health Medicine* 17, 343-348.
- Bayer, R., & Wilkinson, D. (1995). Directly Observed Therapy for tuberculosis: history of an idea. *Lancet* 345, 1545-8.
- Barnhoorn, F., & Adriaanse, H. (1992). In search of factors responsible for concompliance among tuberculosis patients in Wardha District, India. *Soc Sci Med* 34(3), 291-306.

- Barnhoorn, F., & Van Der Geest, S. (1997). "Culturalizing" the upsurge of tuberculosis. *Social Science & Medicine* 45, 1597-1599.
- Bender, D.E., & Ewbank D. (1994). The focus group as a tool for health research: issues in design and analysis. *Health Transition Review* 4, 63-80.
- Bleed, D., Dye, C., Raviglione, M. (2000). Dynamic and control of the global tuberculosis epidemic. *Current Opinion in Respiratory Medicine* 6, 174-179.
- Boehm, S., Coleman-Burns, P., Chritensen, M., Schlenk, E. (1995). Behavioral skill training for the patient and health care provider. In Center for Disease Control and Prevention. *Improving tuberculosis treatment and control: an agenda for behavioral, social, and health services research. Proceedings of tuberculosis and behavior*. National Workshop on Research for the 21<sup>st</sup> Century; 1994 Aug 28-30; Bethesda (MD). Atlanta: CDC.
- Bogg, L. (2002). Health care financing in China: Equity in transition. Stockholm: Karolinska University Press.
- Bowman, K.W., & Singer, P.A. (2001). Chinese seniors' perspectives on end-of-life decision. *Soc.Sc.Med.* 53 (4), 455-464.
- Britten, N. (1995). Qualitative interviews in medical research. *BMJ* 311, 251-253.
- Brown, P.J., & Inhorn, MC. (1990). Disease, ecology and human behavior. In T.M.Johnson and C.F. Sargent (Ed.), *Medical anthropology: contemporary theory and method* (pp.187-214). New York: Praeger.
- Brown, T., Sittitrai, W., Vanichseni, S., Thisyakorn, U. (1994). The recent epidemiology of HIV and AIDS in Thailand. *AIDS* 8 (suppl 2), S131-S141.
- Brouwer, J.A, Boeree, M.J., Kager, P., Varkevisser, C..M., Harries, A.D. (1998). Traditional Healers and Pulmonary Tuberculosis in Malawi. *Int J Tuberc Lung Dis* 2, 231-234.
- Bucher, H.C., Griffith, L.E., Guyatt, G.H., Sudre, P., Naef, M., Sendi, P., Battegay, M. (1999). Isoniazid prophylaxis for tuberculosis in HIV infection: a meta-analysis of randomized controlled trials. *AIDS* 13, 501-507.
- Burman, W.J., Gallicano, K., Peloquin, C. (1999). Therapeutic implications of drug interactions in the treatment of drug interactions in the treatment of human immunodeficiency virus-related tuberculosis. *Clin Infect Dis* 28, 419-429.

- Busza, J.R. (2001). Promoting the positive: responses to stigma and discrimination in Southeast Asia. *AIDS Care* 13(4), 441-456.
- Campbell, C., & Mzaidume, Y. (2002). How can HIV be prevented in South Africa? A social perspective. *BMJ* 324, 229-232.
- Carey, J.W., Oxtoby, M.J., Nguyen, L.P. (1997). Tuberculosis beliefs among recent Vietnamese refugees in New York State. *Public Health Report* 112, 66-72.
- Center for Disease Control and Prevention. Improving tuberculosis treatment and control: an agenda for behavioral, social, and health service research. Proceedings of tuberculosis and behavior: National Workshop on Research for the 21st Century; 1994 Aug 28-30; Bethesda (MD). Atlanta: CDC, 1995.
- Center for Development and Support for Chiang Rai's Hilltribe People. (1999). The 1998 Basic minimum need survey. *Chiang Rai*. (Mimeograph).
- Chaisson, R.E. (2000). New developments in the treatment of latent tuberculosis. *Int J Tuberc Lung Dis* 4, s176-s181.
- Chaulk, P.C., Chaisson, R.E., Lewis, J.N., Rizzo, R.T., (1994). Treating multi-resistant tuberculosis: compliance and side effects. *JAMA* 271, 103-4.
- Chaulk, P.C., Moore-Rice, K., Rizzo, R., Chaisson, R.E. Eleven years of community-based directly observed therapy for tuberculosis. *JAMA* 274:945-51.
- Chemtob, D., Weiser, S., Yitzhak, I., Weiler-Ravell, D. (2001) Medical anthropology: an important adjunct to international TB control. In L.Riechman & E.S.Hershfield (Ed.), *Tuberculosis: A Comprehensive International Approach* (pp.745-770). New York: Marcel Dekker.
- Chiang Rai Provincial Health Office. (2000). The 2000 annual health report.
- Chrisman, N. (1977). The health seeking process: An approach to the natural history of illness. *Culture, Medicine and Psychiatry* 1, 351-377.
- Comstock, G.W., Baum, C., Snider, D.E. Jr. (1979). Isoniazid prophylaxis among Alaskan Eskimos: a final report of the bethel isoniazid studies. *Am Rev Respir Dis* 119(5), 827-30.
- Corbett, E.L, De Cock K.M. (2001). The clinical significance of interactions between HIV and TB: more questions than answers. *Int J Tuberc Lung Dis* 5, 205-207. (editorial)

- Creswell, J.W. (1998). *Qualitative inquiry and research design: choosing among five traditions*. Thousand Oaks: SAGE.
- Crofton, J., Horne, N., Miller, F. (1992). *Clinical tuberculosis*. London: Macmillan Press.
- Cuneo W.D, Snider D.E. (1989). Enhancing patient compliance with tuberculosis therapy. *Clinics in Chest Medicine* 10, 375-380.
- Daramas, S., Konjanart, S., Sunakorn, B. (1981). The second national tuberculosis survey in Thailand. *Thai J Tuberc Chest Dis* 1, 179-91.
- Das, V. (2001 August). Stigma, contagion, defect: issues in the anthropology of public health. Retrieved [10/11/2002], from <http://www.stigmaconference.nih.gov>
- Denzin N.K., Lincoln Y.S. (Ed.). (1994). *Handbook of Qualitative Research*. Thousand Oaks: SAGE.
- Diferdinando, G.T, Klein, S.J., Novick, L.F. (1993). Directly Observed Treatment of tuberculosis. *N Engl J Med* 329, 136. (letter).
- Diwan, V., Thorson, A., Winkvist, A. (Ed.) (1998). *Gender and Tuberculosis*. Report from the workshop at the Nordic School of Public Health, Gothenburg, Sweden, May 24-26.
- Dye, C., Scheele, S., Dolin, P., Pathania, V., Raviglione, M.C. (1999). Consensus statement. Global burden of tuberculosis: estimated incidence, prevalence, and mortality by country. WHO Global Surveillance and Monitoring Project. *JAMA* 282(7), 677-686.
- Dye, C., Williams, B.G., Espinal, M.A., Raviglione, M.C.(2002). Erasing the World's Slow Stain: Strategies to Beat Multidrug-Resistant Tuberculosis. *Science* 295, 2042-2046.
- Dubos, J., Dubos, R. (1992). *The white plague: tuberculosis, man and society*. New Jersey: Rutgers University Press.
- Edgerton, R.B. (1984). The participant-observer approach to research in mental retardation. *Am J Ment Defic* 88, 498-505.
- Edlin,, B.R., Tokars, J.I., Gireco, M.H., Crawford, J.T., Williams, J., Sordillo, EM., Ong, KR., Kilburn, JO., Dooley, SW., Castro, KG., et al. (1992). An outbreak of multidrug-resistant tuberculosis among hospitalized patients with the acquired immunodeficiency syndrome. *N Engl J Med* 326, 1514-1521.



- Eisner, E.W. (1991). *The enlightened eye: Qualitative inquiry and the enhancement of educational practice*. New York: Macmillan.
- El-Sadr, W., Medard, F., Barthaud, V. (1996). Directly observed therapy for tuberculosis: the Harlem hospital experience, 1993. *Am J Public Health* 86, 1146-9.
- Farmer, P. (1997). Social Scientists and the new tuberculosis. *Social Science & Medicine* 44, 347-358.
- Fitzgerald, D.W., Desvarieux, M., Severe, P, Joseph, P., Johnson, W.D Jr., Pape, J.W. (2000). Effect of post-treatment isoniazid on prevention of recurrent tuberculosis in HIV-1 infected individuals: a randomised trial. *Lancet* 356, 1470-1474.
- Ford-Gilboe, M., Campbell, J.C., Berman, H. (1995). Stories and numbers: coexistence without compromise. *Adv Nurs Sci* 18, 14-26.
- Ford, M., Koetsawang, S. (1991). The socio-cultural context of the transmission of HIV in Thailand. *Soc Sc Med* 33, 405-414.
- Foster, S. (1999). The economics of tuberculosis diagnosis and treatment. In J.D.H. Porter & J.M. Grange (Ed.), *Tuberculosis: An Interdisciplinary Perspective* (pp.237-264). London: Imperial College Press.
- Fox, W. (1962). Self-administration of medicaments: a review of published work and a study of the problem. *Bull Int Union Tuberc* 32, 307-331.
- Frankel, D.H. (1992). USA: Civil liberty and control of tuberculosis. *Lancet* 340, 1459.
- Frieden, T.R., Lerner, B.H., Rutherford B.R.(2000). Lessons from the 1800s: tuberculosis control in the new millennium. *Lancet* 355, 1085-1092.
- Fujiwara, P.I., Larkin, C., Frieden, T.R. (1997). Directly observed therapy in New York City. *Clin Chest Med* 18, 135-48.
- Genewein, A., Telenti, A., Bernasconi, C., Mordasini, C., Weiss, S., Maurer, AM, Rieder, HL, Schopfer, K., Bodmer, T. (1993). Molecular approach to identifying route of transmission of tuberculosis in the community. *Lancet*, 342, 841-844.
- Giesecke, J. (1993). AIDS and the public health. *Lancet* 342, 942. (letter)
- Glaser, B.G. (1998). The future of grounded theory. *Qualitative Health Research* 9(6): 836-845.

Godfrey-Faussett, P., Kaunda, H., Kamanga, J., van Beers, S., van Cleeff, M., Kumwenda-Phiri, R., Tihont, V. (2002). Why do patients with a cough delay seeking care at Lusaka urban health centres? A health systems research approach. *Int J Tuberc Lung Dis* 6(9), 796-805.

Goffman, E. (1963). *Stigma: Notes on the Management of Spoiled Identity*. Englewood Cliffs, NJ: Prentice Hall.

Grange, J.M. (1997). DOTS and beyond: towards a holistic approach to the conquest of tuberculosis. *Int J Tuberc Lung Dis* 1, 293-296.

Greenhalgh, T., Taylor, R. (1997). Papers that go beyond numbers (qualitative research). *BMJ* 315, 740-743.

Guba, E.G., Lincoln, Y.S. (1994). Competing Paradigms in Qualitative Research. In Denzin N.K, Lincoln Y.S. (editors). *Handbook of Qualitative Research*. Thousand Oak: SAGE.

Hahn, R..A. (1995). *Sickness and healing: an anthropological perspective*. New Haven: Yale University Press.

Hanson, C.L. Tuberculosis, poverty and inequity. Retrieved November 20, 2002 from <http://www.healthinitiative.org>

Harries, A., Maher, D., Uplekar, M. (1997). *TB: A clinical manual for south east Asia*. Geneva: WHO.

Harries, A.D., Kamenya, A., Namarika, D., Msolomba, I.W., Salaniponi, F.M., Nyangulu, D.S., Nunn, P. (1997). Delays in diagnosis and treatment of smear-positive tuberculosis and the incidence of tuberculosis in hospital nurses in Blantyre, Malawi. *Transactions of the Royal Society of Tropical Medicine and Hygiene* 91, 15-17.

Helman, C. (1990). *Culture Health and Illness*. Butterworth: Heinemann.

Homedes, N., & Ugalde. (1993). A. Patients' compliance with medical treatment in the third world. What do we know? *Health Policy and Planning* 8, 291-314.

Holmes, C.B. (1998) A Review of Sex Differences in the Epidemiology of Tuberculosis. *Int J Tuberc Lung Dis* 2, 96-104.

Hopewell, P.C. (1993). Tuberculosis and infection with the Human Immunodeficiency Virus. In L.B.Reichman & E.S.Hershfield (Ed.), *Tuberculosis: a comprehensive international approach* (pp.369-393). New York: Marcel Dekker.

- Hopewell, P.C. (2000). Translating discoveries into control of tuberculosis in HIV-infected persons. *Int J Tuberc Lung Dis* 4, S82-S87.
- Horsman, J., Sheeran, P.(1995). Health care workers and HIV/AIDS: A critical review of the literature. *Soc. Sc. Med.* 41, 1535-1567.
- Hudelson, P. (1996). Gender differentials in tuberculosis: the role of socio economic and cultural factors. *Int J Tuberc Lung Dis* 77, 391-400.
- Hudelson, P. (1999). Gender issues in the detection and treatment of tuberculosis. In J.D.H. Porter & J.M. Grange (Ed.), *Tuberculosis: An Interdisciplinary Perspective* (pp.339-355). London: Imperial College Press.
- Institute of Food Science & Technology. (2001, September). *AIDS and the food handler*. Retrieved November 6, 2002, from <http://www.ifst.org/aids.htm>
- International AIDS Society–USA Panel. (2000). Antiretroviral Therapy in Adults: Updated Recommendations of the International AIDS Society–USA Panel. *JAMA* 283, 381-390.
- Iseman, M.D, Cohn, D.L. Sbarbaro, J.A. (1993). Directly Observed Treatment of tuberculosis: We can't afford not to try it. *N Engl J Med* 328, 576-8.
- Janesick, V.J. (1994). The Dance of Qualitative Research Design: Metaphor, Methodolatry and Meaning. In N.K.Denzin & Y.S.Lincoln (Ed.). *Handbook of Qualitative Research* (pp.209-219). Thousand Oak: SAGE.
- Johansson, E., Long, N.H., Diwan, V., Winkvist, A. (2000). Gender and tuberculosis control perspectives on health seeking behavior among men and women in Vietnam. *Health Policy* 52, 33-51.
- Johansson, E. & Winkvist, A.(2002). Trust and transparency in human encounters in tuberculosis control: lessons learned from Vietnam. *Qual Health Res* 12(4), 473-491.
- Kamolratanakul, P., Sawert, H., Kongsin, S., Lertmaharit, S., Sriwongsa, J., Na-Songkhla, S., Wangmane, S., Jittimane, S., Payanandana, V. (1999). Economic impact of tuberculosis at the household level. *Int J Tuberc Lung Dis* 3(7), 596-602.
- Kalichman, S.C., Kelly, J.A., Morgan, M., Rompa, D. (1997). Fatalism, current life satisfaction, and risk for HIV infection among gay and bisexual men. *J Consult Clin Psychol* 65(4), 542-546.
- Kanwanich, S. (2000). Suffer the innocent victims. *Bangkok Post*. August 20. (Perspectives)

Katon, W., Kleinman, A. (1981). Doctor-patient negotiation and other social science strategies in patient care. In L.Eisenberg & A.Kleinman (Ed.). *The relevancy of social science for medicine* (pp. 252-279). Dordrecht: D.Reidel publishing company.

Kenyon, T.A., Mwasekaga, M.J, Huebner, R., Rumisha, D., Binkin, N., Maganu, E. (1999). Low levels of drug resistance amidst rapidly increasing tuberculosis and human immunodeficiency virus co-epidemics in Botswana. *Int J Tuberc Lung Dis* 3, 4-11.

Kitayaporn, D., Tansuphaswadikul, S., Lohsomboon, P., Pannachet K, Kaewkungwal J, Limpakarnjanarat K, Mastro TD. (1996). Survival of AIDS patients in the emerging epidemic in Bangkok, Thailand. *J Acquir Immune Defic Syndr Hum Retrovirol* 11, 77-82.

Kitzinger J. (1995). Introducing focus groups. *BMJ* 311, 299-302.

Klaudt, K. (2001). Mobilizing society against tuberculosis. Creating and sustaining demand for DOTS in high-burden countries. In L. Riechman, and E.S.Hershfield (Ed.), *Tuberculosis: A Comprehensive International Approach* (pp.843-864). New York: Marcel Dekker.

Klein, S.J, Naizby, B.E. (1995). New linkages for tuberculosis prevention and control in New York City: innovative use of non-traditional providers to enhance completion of therapy. *J Com Health* 20, 5-13.

Kleinman, A. (1980). *Patients and Healers in the Context of Culture*. Berkley: University of California Press.

Krueger, R.A. (1994). *Focus Groups: A Practical Guide for Applied Research*. Thousand Oaks: SAGE.

Kvale, S. (1996). *Interviews: An Introduction to Qualitative Research Interviewing*. Thousand Oaks: SAGE.

Last, J.M. (Ed.)(1995). *A dictionary of epidemiology*. (3rd edition). New York:Oxford University Press.

Lawn, S.D., Afful, B., Acheampong, J.W. (1998). Pulmonary tuberculosis: diagnostic delay in Ghanaian adults. *Int J Tuberc Lung Dis* 2, 635-640.

Lee, M.C. (2000). Knowledge, barriers, and motivators related to cervical cancer screening among Korean-American women. A focus group approach. *Cancer Nurs* 23(3), 168-175.

- Liefoghe, R., Michiels, N., Habib, S., Moran, M.B., Muynck, A.D. (1995). Perception and Social Consequences of Tuberculosis: A Focus Group Study of Tuberculosis Patients in Sialkot, Pakistan. *Soc Sc Med* 41, 1685-1692.
- Liefoghe, R., Baliddawa, J.B., Kipruto, E.M, Vermeire C, De Munynck A.O. (1997). From their own perspective. A Kenyan community's perception of tuberculosis. *Tropical Medicine and International Health* 2, 809-821.
- Lincoln, Y., & Guba, E. (1985). *Naturalistic Inquiry*. London: SAGE.
- Link, B.G. & Phelan, J.C. (2002, August). On stigma and its public health implications. Retrieved [10/11/2002], from <http://www.stigmaconference.nih.gov>
- Long, N.H., Johansson, E., Lonroth, K., Eriksson, B., Winkvist, A., Diwan, VK. (1999). Longer delays in tuberculosis diagnosis among women in Vietnam. *Int J Tuberc Lung Dis* 3, 388-393.
- Lugada, E.S, Watara, C., Nakiyingi, J., Elliott, A., Brink, A., Nanyunja, M., French, N., Antivelink, L., Gilks, C., Whitworth, J. (2002). Operational assessment of isoniazid prophylaxis in a community AIDS service organisation in Uganda. *Int J Tuberc Lung Dis* 6, 326-331.
- Manopaiboon, C., Shaffer, N., Clark, L., Bhadrakom, C., Siriwasin, W., Chearskul, S., Suteewan, W., Kaewkungwal, J., Bennetts, A., Mastro, TD. (1998). Impact of HIV on families of HIV-infected women who have recently given birth, Bangkok, Thailand. *J Acquir Immune Defic Syndr Hum Retrovirol* 18(1), 54-63.
- Marinac, J.S., Willsie, S.K., McBride, D., Hamburger, S.C. (1998). Knowledge of tuberculosis in high-risk populations:survey of inner city minorities. *Int J Tuberc Lung Dis* 2, 804-810.
- Mata, J.I. (1985). Integrating the client's perspective in planning a tuberculosis education and treatment program in Honduras. *Medical Anthropology (winter)*, 57-64.
- Mayo, R.M., Ureda, J.R., Parker, V.G. (2000). Importance of fatalism in understanding mammography screening in rural elderly women. *J Women Aging* 13(1), 57-72.
- Mays, N., & Pope, C. (1995a). Rigour and qualitative research. *BMJ* 311, 109-112.
- Mays, N., & Pope, C. (1995b). Observational methods in health care settings. *BMJ* 311, 182-184.
- Mechanic, D. (1999). Issues in promoting health. *Social Science & Medicine* 48, 711-718.
- Mehra, B. (2002, March). Bias in qualitative research: Voices from an online classroom. *TheQualitativeReport*,7(1). Retrieved(5/12/2002) from [www.nova.edu/ssss/QR/QR7](http://www.nova.edu/ssss/QR/QR7)

Meulemans, H., Mortelmans, D., Liefoghe, R., Mertens, P., Zaidi, SA., Solangi, MF., De Muynck, A. (2002). The limits to patient compliance with directly observed therapy for tuberculosis: a socio-medical study in Pakistan. *Int J Health Plann Manage* 17(3), 249-267.

Ministry of Public Health. (1998). *National Policy Guidelines for the Newly Revised TB Control Strategy in Thailand. Agency Roles and Personnel Responsibilities at Regional and District Levels*. Nonthaburi: Ministry of Public Health.

Ministry of Public Health. (2000). National guidelines for the clinical management of HIV infection in children and adults. (sixth ed.). Nonthaburi: MOPH.

Morse, J. (1999). Qualitative generalizability (editorial). *Qualitative Health Research* 9(1), 1-2.

Mukadi, Y.D, Maher, D, Harries, A.D. (2001). Tuberculosis case fatality rates in high HIV prevalence populations in sub-Saharan Africa. *AIDS* 15, 143-152.

Murray, C.J.L., Styblo, K., Rouillon, A. (1990). Tuberculosis in developing countries: burden, intervention and cost. *Bull Int Union Tuberc Lung Dis* 65, 6-23.

Nag, M. (1995). Sexual behavior in India with risk of HIV/AIDS transmission. *Health Transition Review (suppl)* 5, 293-305.

Narayan T, Narayan R. (1999). Educational Approaches in Tuberculosis Control: Building on the "Social" Paradigm. In J.D.H., Porter & J.M.Gränge, (Ed.). *Tuberculosis: An Interdisciplinary Perspective* (pp.489-509). London: Imperial College Press.

National Statistical Office Thailand. The national household census 2000. Retrieved October 6, 2002 from <http://www.nso.go.th/pop2000>

Ngamvithayapong, J., Sarapirom, S., Yanai, H. (1993). A Focused Ethnographic Study of Tuberculosis in Ubonratchathani Province. *Com Dis J* 6, 32-37.

Ngamvithayapong J, Uthaiworavith W, Sawanpanyalert P, Yanai H. (1994). Participatory Development of Counselling Media for Asymptomatic HIV-Infected Persons. *Thai AIDS Journal* 6(1), 32-37.

Ngamvithayapong, J., Akarasewi, P., Rawangphan, N., Yanai, H., Wongkhomthong, S. (1995). Confronting tuberculosis problem in the AIDS era: The perspectives from various stakeholders. Third International Conference on AIDS in Asia and the Pacific. Chiang Mai [abstract].

Ngamvithayapong-Yanai, J., Puangrassami, P., Yanai, H. (1998). Compliance to tuberculosis treatment: A gender perspective. In V.Diwan, A.Thorson, A. Winkvist. (Ed.) *Gender and*

*Tuberculosis* (pp.127-148. Report from the workshop at the Nordic School of Public Health, Gothenburg, Sweden, May 24-26.

Nitcher, M. (1994). Illness semantics and international health: the weak lungs/TB complex in the Philipines. *Social Science & Medicine* 38, 649-663.

Ogden, J., Rangan, S., Uplekar, M., Porter, J., Brugha, R., Zwi, A., Nyheim, D. (1999). Shifting the paradigm in tuberculosis control: illustrations from India. *Int J Tuberc Lung Dis* 3, 855-861.

Payanandana V, Bamrungrakul T, Sareebutra W, Na Songkla S. (1992). Present situation of tuberculosis. *Thai Journal of tuberculosis and lung disease* 13(1), 49-57.

Payanandana, V., Kladphuang, B., Somsong, W., Jittimanee, S. (1999). *Battle against TB: National Tuberculosis Programme Thailand*. Tuberculosis Division, Department of Communicable Disease Control, Ministry of Public Health. Bangkok.

Payutto, P.A. (1997). *A constitution for living*. Bangkok: Department of Religion Affair, Ministry of Education.

Pelto, P. J, Pelto, G. H. (1990). Field methods in medical anthropology. In T.M. Johnson & C.F. Sargent (Ed.). *Medical Anthropology* (pp.269-297). New York: Praeger.

Piyaworawong, S., Yanai, H., Nedsuwan, S., Akarasewi, P., Moolphate, S., Sawanpanyalert, P. (2001). Tuberculosis preventative therapy as part of a care package for people living with HIV in a district of Thailand. *AIDS* 15, 1739-1741.

Pope, C., & Mays, N. (1995). Reaching the parts other methods can not reach: an introduction to qualitative methods in health and health services research. *BMJ* 311, 42-45.

Potter, S.H. (1979). *Family Life in a Northern Thai Village: A study in the Structural Significance of Women*. Berkeley: University of California Press.

Powe, B.D., & Weinrich, S. (1999). An intervention to decrease cancer fatalism among rural elders. *Oncol Nurs Forum* 26(3), 583-588.

Quigley MA, Mwinga A, Hosp M, Lisse I, Fuchs D, Porter JDH, Godfrey-Faussett P. (2001). Long-term effect of preventive therapy for tuberculosis in a cohort of HIV-infected Zambian adults. *AIDS* 15, 215-222.

Rangan, S., & Uplekar, M. (1999). Socio-cultural dimensions in tuberculosis control. In J.D.H. Porter & J.M. Grange (Ed.), *Tuberculosis: an interdisciplinary perspectives* (pp.265-281). London: Imperial collage press.

- Rangsin, R., Chiu, J., Sirisopa, N., (2001). Natural history of HIV subtype E infections in Thai men 5-7 years after infection. The 8<sup>th</sup> Conference on retroviruses and opportunistic infections. Chicago, February 4-8. Abstract no. 207.
- Raviglione, M.C., Harries, A.D., Msiska, R., Wilkinson, D., Nunn, P. (1997). Tuberculosis and HIV: current status in Africa. *AIDS 11 (Suppl B)*, S115-23.
- Rieder, H.L. (1998). Tuberculosis and HIV infection in industrialized countries. In P.D.O. Davies (Ed.), *Clinical Tuberculosis* (pp.347-363). London: Chapman & Hall.
- Roberts, R.E, Roberts, C.R., Chen, I.G. (2000). Fatalism and risk of adolescent depression. *Psychiatry 63(3)*, 239-252.
- Ross, C.E., Mirowsky, J., Cockerham, W.C. (1983). Social class, Mexican culture, and fatalism: their effects on psychological distress. *Am J Community Psychol 11(4)*, 383-399.
- Rubel, A.J., & Garro, L.C. (1992). Social and Cultural Factors in the Successful Control of Tuberculosis. *Public Health Report 107*, 626-636.
- Ruxrungtham, K., Phanuphak, P. (2001). Update on HIV/AIDS in Thailand. *J Med Assoc Thai 84 (Suppl1)*, S1-S17.
- Sbarbaro, J.A. (1980). Public health aspect of tuberculosis: supervision of therapy. *Clin Chest Med 1*, 253-263.
- Scambler, G. (1998). Stigma and disease: changing paradigms. *Lancet 352*, 1054-1055.
- Scheper-Hughes, N. (1993). AIDS, public health, and human rights in Cuba. *Lancet 342*, 965-967.
- Schwab, T., Meyer, J., Merrell, R. (1994). Measuring attitudes and health beliefs among Mexican Americans with diabetes. *Diabetes Educ 20(3)*, 221-227.
- Silvestre, A.J, Gehl, M.B, Encandela, J, Schelzel, G. (2000). A participant observation study using actors at 30 publicly funded HIV counseling and testing sites in Pennsylvania. *Am J Public Health 90*, 1096-1099.
- Small, P.M., Schechter, G.F., Goodman, P.C., Sande, M.A., Chaisson, R.E., Hopewell, P.C. (1991). Treatment of tuberculosis in patients with advanced human immunodeficiency virus infection. *NEJM 324*, 289-294.



Small, P.M, Shafer, R.W., Hopewell, P.C., Singh, S.P., Murphy, M.J., Desmond, E., Sierra, M.F., Schoolnik, G.K. (1993). Exogenous reinfection with multidrug-resistant *Mycobacterium tuberculosis* in patients with advanced HIV-infection. *N Engl J Med* 328, 1137-1144.

Small, P.M, Hopewell P.C., Singh, S.P., Paz, A., Parsonnet, J., Ruston, D.C., Schecter, G.F., Daley, C.L., Schoolnik, G.K. (1994). The epidemiology of tuberculosis in San Francisco: a population-based study using conventional and molecular methods. *N Engl J Med.* 330, 1703-9.

Smith, I. (1994). *Women and Tuberculosis: Gender Issues and Tuberculosis Control in Nepal*. Unpublished Master Thesis, Nuffield Institute for Health.

Songwattana P. (2001). Women and AIDS caregiving: women's work? *Health Care Women Int* 22(3), 263-279.

Songwattana, P., & Manderson, L. (2001). Stigma and rejection: living with AIDS in villages in southern Thailand. *Med Antropol* 20(1), 1-23.

Somlai, A.M., Kelly, J.A., Heckman, T.G, Hackl, K., Runge, L., Wright, C. (2000). Life optimism, substance use, and AIDS-specific attitudes associated with HIV risk behavior among disadvantaged innercity women. *J Womens Health Gend Based Med* 9(10), 1101-1011.

Spradley, J.P. (1979). *The Ethnographic Interview*. Orlando: Harcourt Brace Jovanovich College Publishers.

Spradley, J.P. (1980). *Participant observation*. Orlando: Holt, Rinehart and Winston, Inc.

Sriyabhaya, N., Payanandana, V., Bamrungrakul, T., Konjanart, S. (1993). Status of tuberculosis control in Thailand. *South Asian J Trop Med Public Health* 24, 410-419.

Starrin, B., Dahlgren, L., Larsson, G., Styrborn, S. (1997). *Along the Path of Discovery: Qualitative Methods and Grounded Theory*. Lund: Studentlitteratur.

Steen, T.W, Mazonde, G.N. (1999). Ngaka ya setswana, ngaka ya sekgoa or both? Health seeking behavior in Batsawana with pulmonary tuberculosis. *Soc.Sc.Med.* 48, 163-172.

Stewart, D.W, Shamdasani, P.N. (1990). *Focus groups: Theory and practice*. Newbury Park: SAGE.

Strauss, A., & Corbin, J. (1998). *Basic of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*. Thousand Oaks: SAGE.

Suggaravetsiri, P. (2002). Transmission of tuberculosis among household contacts in an area with a high prevalence of HIV infection, Chiang Rai, Thailand. Unpublished doctoral thesis in Epidemiology, Prince of Songkla University, Songkhla, Thailand.

Sumartojo, E. (1993). When Tuberculosis Treatment Fails: A Social Behavioral Account of Patient Adherence. *Am Rev Respir Dis* 47, 1311-1320.

Sumartojo, E. (1995). Adherence to the tuberculosis treatment plan. In F.L. Cohen & J>D. Durham (Ed.), *Tuberculosis: a sourcebook for nursing practice*. New York: Springer Publishing Company.

Sunakorn, B. (1969). The epidemiology of tuberculosis in Thailand. *J Med Assoc Thai* 52, 127-162.

Tanner, M., & Vlassoff, C. (1998). Treatment Seeking Behavior for Malaria: A Typology Based on Endermicity and Gender. *Soc Sc Med* 46, 523-532.

Talor, S.J, Steven, J., Bogdan, R. (1984). *Introduction to qualitative research methods*. (2<sup>nd</sup> edition). New York: John Wiley and Sons.

The Islamic Organization for Medical Sciences. (1993 December). Recommendations of the Seventh Islamic-Medical Seminar on: AIDS-related social problems-an Islamic perspective. Retrieved 22/11/2002 from [www.islamset.com/bioethics/aids1/recomm.html](http://www.islamset.com/bioethics/aids1/recomm.html)

Thorson, A., & Diwan, V.K. (2001). Gender inequalities in tuberculosis: aspects of infection,notification rates, and compliance. *Curr Opin Pulm Med* 7, 165-169.

Tipping, G., Segall, M. (1995). *Health Care Seeking Behavior in Developing countries: An Annotated Bibliography and Literature Review: Development Bibliography 12*. Institute of Development Studies, University of Sussex.

UNAIDS. (1997). *Tuberculosis and AIDS*. (UNAIDS Best Practice Collection: Point of View). Geneva: UNAIDS.

UNAIDS. (2002). Report on the global HIV/AIDS epidemic. Geneva: UNAIDS.

UNIFEM. Retrieved October 10, 2002 from <http://www.unifem.undp.org>

United Nation Development Programme (UNDP) (2001). *Human Development Report 2001*. New York: Oxford University Press.

Uplekar, M.K., Rangan, S. (1996) Tacking Tuberculosis: The search for solutions. Bombay: The Foundation for Research in Community Health.

Ustianowski, A., Mwaba, P., Zumla, A. (1999). Tuberculosis and HIV - Perspectives from Sub-Saharan Africa. In J.D.H. Porter & J.M. Grange (Ed.), *Tuberculosis: An Interdisciplinary Perspective* (pp.283-311). London: Imperial College Press. .

U.S. Department of Health and Human Services. (1992). *Principles of Epidemiology* (2<sup>nd</sup> edition). Atlanta: CDC.

U.S. Department of Health and Human Services. (1994). Improving patient adherence to tuberculosis treatment. Atlanta: CDC.

Valassof, C. (1994). Gender Inequalities in Health in the Third World: Uncharted Ground. *Soc Sc Med* 39, 1249-1259.

Vikarunnessa, B., de Colombani, P., Das, Gupta, S., Salim, A.H., Hussain, H., Pietroni, M., Rahman, S., Pahan, D., Borgdorff, M.W. (2001). Tuberculosis and patient gender in Bangladesh: sex differences in diagnosis and treatment outcome. *Int J Tuberc Lung Dis* 5, 604-610.

Voelker, R. (1996). "Shoe leather therapy" is gaining on TB. *JAMA* 275, 743-774.

Watson, L.H., Rosen, J.D. (1994). Educationg workers about tuberculosis. *Occupational Medicine* 9, 681-694.

Weiss, M.G. & Ramakrishna, J. (2002, August). Interventions: research on reducing stigma. Retrieved [10/11/2002], from <http://www.stigmaconference.nih.gov>

Weitz, R. (1991). *Life with AIDS*. London: Rutgers University Press.

Weniger, B.G., Limpakarnjanarat, K, Ungchusak, K, Thanprasertsuk, S., Choopanya, K, Vanichseni, S., Uneklabh, T., Thongcharoen, P., Wasi, C. (1991). The epidemiology of HIV infection and AIDS in Thailand. *AIDS* 5(suppl 2), S71-S85.

Westaway, M.S. (1989). Knowledge, beliefs and feelings about tuberculosis. *Health Education Research* 4, 205-211.

Wight, R.G., Rotheram-Borus, M.J., Klosinski, L., Ramos, B., Calabro, M., Smith, R. (2000). Screening for transmission behavior among HIV-infected adults. *AIDS Educ Prev.* 12, 431-441.

Wilkinson, D. (2002). Drugs for preventing tuberculosis in HIV infected persons (Cochrane Review). In: The Cochrane Library, Issue 3 2002. Oxford: Update Software.

- Wobeser, W., To, T., Hoepfner, V.H. (1989). The Outcome of Chemoprophylaxis on Tuberculosis Prevention in the Canadian Plains Indians. *Clinical Investigative Medicine* 12 (3), 149-153.
- World Health Organization. (1994). *WHO Tuberculosis Framework for Effective Tuberculosis Control*. Geneva: WHO. (WHO/TB/94.179)
- World Health Organization. (1995). *Stops TB at the Source WHO Report on the Tuberculosis Epidemic*. Geneva: WHO. (WHO/TB/95.183)
- World Health organization. (1997). *WHO report on the tuberculosis epidemic 1997*. Geneva: WHO. (WHO/TB/97.224)
- World Health Organization. (2001). *First Meeting of Global Working Group on TB/HIV, 9-11 April 2001, Geneva, Switzerland*. Geneva: WHO. (WHO/CDS/TB/2001.293)
- World Health Organization. (2002a). *An Expanded DOTS Framework for Effective TB Control*. . Geneva: WHO. (WHO/CDS/TB/2002.297)
- World Health Organization. (2002b). *Towards a TB-Free Future*. Geneva: WHO. (WHO/CDS/STB /2001.13)
- World Health Organization. (2002c) *The Global Plan to Stop Tuberculosis*. Geneva: WHO.. (WHO/CDS/TB/ 2001.16)
- World Health Organization. (2002d). *WHO Report. Global Tuberculosis Control: Surveillance, Planning, Financing*. Geneva: WHO. (WHO/CDS/TB/2002.295)
- World Health Organization. (2002e). *Strategic Framework to Decrease the Burden of TB/HIV*. Geneva: WHO. (WHO/CDS/TB/2002.296 WHO/HIV\_AIDS/2002.2)
- Young, J.C. (1981). *Medical choice in a Mexican village*. New Brunswick: Rutgers University Press.
- Zwarenstein, M., Schoeman, J.H., Vundule, C., Lombard, CJ, Tatley, M. (1998). Randomized controlled trial of self-supervised and directly observed treatment of tuberculosis. *Lancet* 352, 1340-1343.

**APPENDIX**

**TOOLS FOR DATA COLLECTION**

**Paper I**

**I.1 A medical record for participants enrolled in TB preventive therapy for people living with HIV**

Recruitment from:

blood donors  OPD  CDC-sex worker project  HIV anonymous testing unit

Date.....Interviewer.....  
H.N..... Q.N.....INH.no.....  
Name.....Sex .....  
Age.....Address.....  
Marital status.....Occupation.....  
Education.....

**Part I: Assessment before initiating preventiver therapy**

1. History of drug allergy  
 no  yes (specify).....
2. History of being diagnosed as TB  
 no  yes (when? what was the treatment outcome?)
3. History of being diagnosed as AIDS  
 no  yes (when? what were the opportunistic infections?)
4. Height .....cm.
5. Body weight .....kgs.
6. Temperature.....Pulse rate.....Blood pressure.....
7. Chest x-ray (date/month/year) .....  
 normal  
 abnormal (specify).....  
 suspecting TB submitting sputum for smear examination.  
Result of sputum examination.....

8. Tuberculin skin test (date/month/year) .....
- less than 10 mm.
  - bigger than 10 mm.
  - no skin test done
9. CD-4 testing (date/month/year) .....
- result.....  no testing
10. During last 3 months up to now, did/do you have the following symptoms?
- Oral thrush, candidiasis       no       yes
  - Herpes zoster       no       yes
  - chronic diarrhea       no       yes
  - chronic fever       no       yes
  - chronic cough       no       yes
  - skin lesion       no       yes
  - weakness       no       yes
  - weight loss       no       yes (how many kg. loss?.....)
  - enlarged lymph nodes       no       yes (specify location/size.....)
11. Enroll in TB preventive therapy program?  yes       no (specify.....)
12. Method of follow up when the client miss the appointment schedule (can tick more than one)
- telephone       letter       home visit       do not allow any method of follow up

Part II: Record for dispensing isoniazid tablets and measuring adherence to the therapy

visit	date/mo./yr	next appointment	no. of missed appointment days	no. of remaining pills	no. of pills dispensed today	reported side effects	note
1							
2							
3							
4							
5							
6							
7							
8							
9							
10							

**I.2 Interview guidelines for clients who missed scheduled appointment for more than 2 weeks (non-adherence)**

- What is the most important reason to visit the clinic today?
- Could you please let me know how do you feel about your health and your life? What did you do during missing the appointment?
- Could you please let me know what was the reason that you missed the appointment for .....days? (require in-depth probing for the reason of non-adherence)
- Do you know for how long you are supposed to take the pills (isoniazid)? how do you feel about the medicine?

**I.3 Focus group discussion guidelines for the good adherent clients**

- Introduction of FGD (building rapport, clarifying roles of FGD member and objectives)
- All of you completed the 9 months of medicine. Would you please discuss what kind of medicine that all of you took during last 9 months? Do you know what is the purpose of taking those pills?
- During the last 9 months, how often did you forget taking medicine? please share experiences among your group that what kind of situation make you forget taking medicine?
- We have had several clients who missed the appointment for several weeks and months. Members of your group quite strictly take the pills. Please share your experiences that what are the reasons motivating each of you to take the pills?
- Many clients said they forgot taking medicine. Could your group discuss about the medicine reminding methods you used during the last 9 months? Who suggested those methods?
- Could your group make suggestion that how can we motivate other clients to adhere to the medicine like you did?
- Could you please share your experiences when you first time knew about your HIV positive result? How did you feel? How each of you cope with HIV until today?
- End of FGD. Open for questions from the participants
- Thank you for active participation and contributions.



**Paper II-III            Focus group discussion guidelines**

- Introduction of FGD (building rapport, clarifying roles of FGD member and objectives)
- What are the most common diseases and most serious health problem in the community? Please indicate 3 diseases.
- What is the disease that your group are most afraid of? why?
- A 23 years old man has severe weight loss, chronic fever and chronic cough. What disease do your group think that the man may have?
- Do you know "tuberculosis"? Are you aware of other terminology used by the community?
- What is the cause of TB? Why some people get TB while some do not? What is the local belief about TB? (for the TB patient groups: what are the causes of TB in your cases?)
- What are the symptoms of pulmonary TB? Were the symptoms different from "asthma" and "pneumonia"? How to distinguish these three diseases?
- Do you think TB is communicable disease? What is route of transmission? How to prevent yourselves from TB?
- Is TB common in some population? e.g. Is TB common in male or female? children, youth, adult or elderly?
- Do you think TB is curable?
- Do you believe that TB is curable despite HIV-infection?
- Do you know for how long a TB patient should be treated?
- Is TB associated with HIV/AIDS?
- Do community stigmatize TB and AIDS patients? Why? What are the causes of stigma? What are the reactions to TB and AIDS stigma? What are the consequences of TB and AIDS stigma? Is there any difference between men and women regarding TB and AIDS stigma?
- Is there any traditional treatment for TB?
- What are the local belief and practice about TB? (e.g. special food and taboo food, work, rest and exercise)
- Have you ever heard about "DOTS"? (Write down on the white board, in case of health center groups) From where did you know? How do you understand?

- Suppose that, due to the problem of TB drug resistance caused by non-adherence to treatment, the government announces a policy requesting TB patients to go to the nearest health center every day, for six months. What do your group think?
- On the other hand, suppose that the government announces another strategy that instead of patients visiting the health center on a daily basis, the government requires health center staff to visit patient homes and provide medicine. What do your group think?
- What kinds of support do you need in order to make DOT possible either at health center or at home?
- Please suggest what is the best way to ensure that every tablet of TB medicine is swallowed every day until the disease is cured.
- Do you have any questions about TB or AIDS? Please feel free to discuss.

For the groups of TB patients (HIV and non-HIV), the following questions will be added:

- Besides you yourselves, who else know about your TB? (e.g. family member, neighbor, friend, and community) How did these people become to know?
- Do the persons who know of your TB interact with you differently from the previous time?
- What is your current practice about TB medication? Who takes care of you? Where do you keep the medicine?

**Paper IV: Structured questionnaire**

**Health Seeking Behavior and Drug Susceptibility to Anti-tuberculosis Drugs**

DST. Number \_\_\_ ## \_\_\_

Questionnaire No.....

Hospital No. (HN.).....

TB No. ....

Interviewer.....Date.....

Data Coder 1 .....Date.....

Coding verifier .....Date.....

Data enterer 1 .....

Data enterer 2 .....

**Note** (Other remarks during the interview)

.....  
.....

Note for research assistant: When to follow up the result?

Culture .....

HIV-testing.....

Cohort analysis .....

Other.....

**Part I: General Information**

1. Type of Patient 1. OPD 2. Ward..... 3. Refer from..... 4. follow up letter
2. H.N. ....
3. Do you bring your citizen ID. Card? 1. No 2. Yes (number).....
4. Name (Mr./Mrs./Ms.) .....Last name .....
5. Sex 1. Male 2. Female 3. Pregnancy.....months  
4. Post-partum.....months 5. Homosexual/Lesbian
6. Age .....(Years)
7. Permanent address  
House number.....Village.....Tumbol.....District.....  
Province..... Postal code.....
8. Nationality.....  
Ethnicity.....
9. Highest education..... (years)
10. Occupation .....
11. Marital status  
1. Single 2. Married, stay together 3. Married, separated stay  
4. Divorce 5. Widow (for.....years) 6. Other.....

**Part II: Illness, contact history to TB and some risk factors**

12. Have you ever been told having "Lung Disease"?  
 No  Yes, when.....  Don't know/not sure
13. Have you ever been told having "Pulmonary Tuberculosis"?  
 No  Yes, when.....  Don't know/not sure
14. Have you ever taken or injected for tuberculosis treatment?  
 No  Yes, when..... Don't know/not sure
15. Have you ever taken isoniazid for prevention of TB?  
 No  Yes, when.....  Don't know/not sure
16. Have you ever closely contacted with TB patient?  
 No  Yes, when..... Don't know/not sure
17. Have you ever been incarcerated or worked in the prison?  
 No  Yes, when.....for how long.....
18. Do you heavily drink alcohol daily?  
 No  Yes how heavy drinking?.....

19. Do you smoke cigarettes daily? or stay close to the smokers?  
 No  Yes how heavy smoking?.....
20. Did you use or are you using some drugs?  
 No  Yes, what kind of drug/route?.....
21. Have you ever been told as Diabetes Mellitus?  
 No  Yes  Don't know/not sure
22. Have you ever been tested blood for AIDS?  
 No  Yes (result)..... Don't know/not sure
23. How often do you expose to Chiang Rai Hospital or have you ever been hospitalized?  
 1. Used to be hospitalized or overnight taking care of the other 2. Occasionally visit  
 3. This is the first visit 4. Other.....

**Part III: History of current illness**

24. What is/are the symptom(s) leading you to visit the hospital today? .....
25. When these symptoms started? for how many days?/months?.....

Do you have the following symptoms?

- |   |   |                             |                                      |
|---|---|-----------------------------|--------------------------------------|
| 26. Cough?                                | <input type="checkbox"/> Yes, for .....days | <input type="checkbox"/> No | <input type="checkbox"/> Other.....  |
| 27. Hemoptysis?                           | <input type="checkbox"/> Yes, for.....days  | <input type="checkbox"/> No | <input type="checkbox"/> Other.....  |
| 28. Fever?                                | <input type="checkbox"/> Yes                | <input type="checkbox"/> No | <input type="checkbox"/> Other.....  |
| 29. Night sweating?                       | <input type="checkbox"/> Yes                | <input type="checkbox"/> No | <input type="checkbox"/> Other.....  |
| 30. Chest pain?                           | <input type="checkbox"/> Yes                | <input type="checkbox"/> No | <input type="checkbox"/> Other.....  |
| 31. Fatigue?                              | <input type="checkbox"/> Yes                | <input type="checkbox"/> No | <input type="checkbox"/> Other.....  |
| 32. Anorexia?                             | <input type="checkbox"/> Yes                | <input type="checkbox"/> No | <input type="checkbox"/> Other.....  |
| 33. Weight lost?                          | <input type="checkbox"/> Yes .....Kg.       | <input type="checkbox"/> No | <input type="checkbox"/> Other.....  |
| 34. Oral thrush?                          | <input type="checkbox"/> Yes                | <input type="checkbox"/> No | <input type="checkbox"/> Other ..... |
| 35. Chronic diarrhea? (more than 2 weeks) | <input type="checkbox"/> Yes                | <input type="checkbox"/> No | <input type="checkbox"/> Other.....  |
| 36. Other symptoms?.....                  | <input type="checkbox"/> Yes                | <input type="checkbox"/> No | <input type="checkbox"/> Other.....  |

**Part IV: Health seeking behavior**

37. Do you have right or insured-card for receiving medical service? (How do you pay the hospital charge?)
1. No, I pay from my own pocket 2. Low income card 3. Health card 4. Elderly card  
 5. Monk/Nun 6. Social security card 7. Veteran/Health Volunteer cards  
 8. Government officer 9. Private health insurance 10. Other.....

38. How much time did you spend for traveling to the hospital?.....hour/minute
39. How did you travel to the hospital?
1. Walking only
  2. Own vehicle
  3. Public/hired vehicle.....Baht
  4. Other.....
40. Did you have to borrow money from other persons in order to visit the hospital?
1. No
  2. Yes, I borrowed from.....
41. Did you sell any of your belongs or assets in order to obtain medical care?
1. No
  2. Yes (specify amount of cash you got).....
42. How do you feel about your illness? (perceived level of severity)
1. Mild
  2. Common
  3. Severe
  4. Very severe
  5. Other.....
43. Before coming to the hospital, what disease you think that you may have?
- .....
44. Based on your perception; what is the cause of the illness?
- .....
45. Did you seek treatment from the following healers or facilities prior to visit this hospital?  
(ask all items and fill-in the sequence in the provided front space)
- ...Came to this hospital? ( ) No ( ) Yes when?.....Diagnosis.....cost?.....
- ...Drug store? ( ) No ( ) Yes when?.....what drugs?.....cost?.....
- ...Health center? ( ) No ( ) Yes when?.....Diagnosis.....cost.....
- ...Community hospital? ( ) No ( ) Yes when?..... Diagnosis.....cost.....
- ...Private clinic? ( ) No ( ) Yes when?.....Diagnosis.....cost.....
- ...Private hospital? ( ) No ( ) Yes when?.....Diagnosis.....cost.....
- ...Traditional healer? ( ) No ( ) Yes when?.....Diagnosis.....cost.....
- ...Injectionist? ( ) No ( ) Yes when?.....Diagnosis.....cost.....
- ...Other? ( ) No ( ) Yes (specify).....

<p>Summary</p> <p>Number of steps of treatment .....steps</p> <p>Patient Delay.....days</p> <p>Provider Delay.....days</p> <p>Total Cost.....</p>
---

**Part V: Laboratory Results**

46. Sputum Examination

- 1 st Date.....Result 1. + 2. ++ 3. +++ 4. Non-seen 5. no examination
- 2 nd Date.....Result 1. + 2. ++ 3. +++ 4. Non-seen 5. no examination
- 3 rd Date.....Result 1. + 2. ++ 3. +++ 4. Non-seen 5. no examination

47. Sending of the isolate for culture and drug sensitivity test?

- 1. No
- 2. Yes Date.....  
Result Isoniazid = .....  
Rifampicin = .....  
Streptomycin = .....  
Ethambutol = .....  
Kanamycin = .....

48. Blood testing result for HIV

- 1. Negative 2. Positive 3. No result

49. Chest x-ray done?

- 1. Yes-cavity exist 2. Yes-no cavity 3. no result

50. CD4 Testing ?

- 1. No
- 2. Yes Date.....Result T-4 \_ \_ \_ \_  
T-8 \_ \_ \_ \_

51. Other investigation?

- 1. No 2. Yes (specify).....

**Previous registration in TB registry**

52. Was the patient registered in TB registry before?

- 1. No
- 2. Yes when?.....  
Regimen.....Treated for.....months  
Outcome:
  - 1. Cure
  - 2. Complete
  - 3. Treatment failure

4. Lost follow up > 2 months
5. Transferred to other health facility (specify).....
6. Other.....

**Part VI: Adherence to treatment and the Treatment Outcome**

53. Diagnosis

1. Pulmonary TB
2. Pulmonary TB with HIV/AIDS
3. Pulmonary TB with complication .....
4. Pulmonary TB with HIV with complication.....
5. Other.....

54. Treatment regimen.....

Treatment duration.....months Date treatment started.....

55. Method of drug administration

1. Self medication
2. DOTS by hospital staff
3. DOTS by health center staff
4. DOTS by family member
5. DOTS by volunteer.....
6. Other.....

56. Adherence pattern

Appointment date.....Date of visit.....No. of miss-appointment days.....

Appointment date.....Date of visit.....No. of miss-appointment days.....

Appointment date.....Date of visit.....No. of miss-appointment days.....

Appointment date.....Date of visit.....No. of miss-appointment days.....

Appointment date.....Date of visit.....No. of miss-appointment days.....

Appointment date.....Date of visit.....No. of miss-appointment days.....

Total miss-appointment days .....days Adherence rate \_\_ %

57. When the first miss-appointment occurred?

1. During intensive phase (the first two months)
2. Continuous phase
3. Other.....

58. Sputum conversion after two months of treatment

1. Converse from + to - (skip to item 60)
2. No conversion
3. No results (skip to item 60)
4. Other.....

59. Sputum conversion after three months of treatment

1. Yes
2. No
3. No result



60. Treatment outcome

1. Cured
2. Complete
3. Treatment failure
4. Died (cause of death).....
5. Defaulted
6. Transferred
7. On treatment
8. Other.....

**Paper V**

**V.1 Record for the home visit**

DST.no.....Nick name of the patient.....

visit	date/ time	interviewee(s)*	complements or compensation**	tape recording print-out	note
1					
2					
3					
4					
5					
6					
7					
8					
9					
10					
11					
12					
13					

**Note:** \* Interviewee(s) include patient, spouse, caregiver and their associates

\*\* Complements - some fruits or refreshment brought to the patients by researchers

Compensation - in the scheduled interview which cause the interviewees' income loss,  
the project compensates for the same amount as he or she receive from the job

## **V.2 Observation guidelines during the home visit**

### 1. During the first home visit:

- Housing and the surroundings (durability of the house, sanitation, crowding, number of persons living in the same house/same room, number of children < 5 years, ventilation)
- Availability of entities and facilities inside the house (indicators for economic status: TV, stereophonic, VDO, refrigerator, washing machine, cooking gas, motorcycle, car)

### 2. For every home visit:

- what is the patient doing, with whom?
- general appearance of the patient, coughing frequency, coughing manner, sputum spitting and sputum disposal
- sleeping place (size of the room, number of persons, ventilation--number of windows and position of the windows)
- eating (sharing eating? what kind of foods?, how to wash eating utensils)
- drinking (sharing drinking? what kind of drink and drinking utensils)
- medication (place for keeping drugs, list of drug being used, pill-count for TB drugs)
- relationship with the family members, neighbor, friend (observing distance between the patient and the others)
- observing use of tobacco, alcohol
- observing about job, entertainment
- observing the places, persons, activities that the patient refers to

## **V.3 Grand tour question for every home visit**

- Would you please describe about your health, your life and your feeling since we met last time?