

“I can’t believe that I have *robeng*”

**Understanding health-seeking behaviour related
to tuberculosis in Cambodia**

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DECLARATION

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ABSTRACT

Tuberculosis (TB) is a leading cause of morbidity and mortality worldwide, killing nearly two million adults annually, the majority of whom live in developing countries. Research has shown that multiple factors— individuals, misunderstandings of TB, economic hardship of patients, the fragmentation of health services, gender, and stigma all influence transmission, detection and treatment of TB.

After a decade of implementation of the international TB control strategy centred on the Directly Observed Treatment Short-course (DOTS), TB incidence and prevalence in Cambodia remains among the highest in the world, with a considerable number of cases remaining undetected. However, little is known about the factors hindering the success of the TB control programs efforts.

This thesis is based on ethnographic research conducted in Kampong Speu province, Cambodia, aiming to describe TB patients' pathways to the DOTS programs, and factors determining the pathways and treatment adherence. Methods used included in-depth interviews with TB patients, family members, health providers, community health volunteers and *Kru Khmer* (traditional healers); focus group discussions with community members; a community survey; participation in meetings and workshops aimed at health workers; and observation of daily activities at participating health facilities.

The two most important challenges for TB control in rural Cambodia were delayed presentation for TB diagnosis and non-adherence to TB treatment programs. Both contributed to persistent TB infection within the community, and were influenced by the interaction and combination of individual, institutional (related to the health system), and socio-economic factors. TB patients and community members had limited understanding of TB symptoms, causation, and treatment; therefore they did not respond appropriately, and present with early symptoms for timely diagnosis and treatment. Lay explanations of these early symptoms were mostly influenced by folk information shared within community networks. Despite this, community members chose providers of western medicine as their first choice, and only used *Kru Khmer* when western medicine did not resolve their symptoms.

Access to public health service presented significant barriers for obtaining early TB diagnosis, and was critically undermined by the interaction between the five dimensions: *accommodation*, *availability*, *accessibility*, *affordability* and *acceptability*. Low government salaries and shortages of

health staff, limited supplies, and dual job practices of health staff all significantly impacted on public service delivery. This under-performance increased people's reliance on the private health sector which, due to the lack of collaboration between the two health sectors, contributed to delayed TB diagnosis and increased health care costs. Ineffective monitoring of the private health providers further exacerbated diagnostic delays.

TB patients experienced prolonged pathways, consulted multiple providers, and spent substantial time and money before reaching DOTS. Large differences in delay were influenced by patients' ability to afford private treatment, TB diagnostics errors, and denial of the possibility of TB. Presentation to DOTS was resultant from social disruption, intervention by significant others and/or self-suspicion about TB. Patients usually enrolled in a directly observed treatment (DOT) promptly after TB diagnosis, however, although this required TB treatment to be taken under DOT by health worker or a community member, all patients self-administered TB medicines without observation. Thus treatment non-adherence was commonly reported, and discontinuation of treatment occurred mainly among vulnerable groups (elderly and poor) for two reasons: feeling better and side-effects. This study raised concerns related to the treatment of re-infection TB cases, as many such people return to treatment but are not correctly registered and treated.

Socio-economic factors played an important role in TB treatment-seeking and shaped available family support, ability to pay and stigma associated with TB. Stigma played a considerable role in delaying TB diagnosis, and affected the psychological well-being of patients. It was derived from fears of contagion and the dangers presented by TB, the perceived association between HIV and TB, misunderstanding about TB causation, and attitudes of health staff. Rejection of TB patients was associated with perceptions that TB patients lacked a sense of moral responsibility to protect others from contracting TB; their extremely low social status was also significant.

Although TB diagnosis and treatment was within reach of most of the population, obtaining timely diagnosis and compliance with TB treatment remained difficult, particularly for those who were most in need. Although challenges were caused by individual and socio-cultural factors, institutional factors related to the public health facilities created significant barriers for people in accessing the services. Improving TB patient outcomes requires effort and commitment to not only address individual and socio-cultural factors, but to redress shortcomings in health supply and staffing through effective public health system strengthening.

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ACRONYMS

AFB	Acid Fast Bacilli
AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
BCG	Bacillus Calmette Guerin
BK	Bacille de Koch
CDHS	Cambodia Demographic and Health Survey
C-DOTS	Community based Direct Observed Treatment Short Course
CENAT	National Centre for Tuberculosis and Leprosy Control
CMDG	Cambodia Millennium Development Goals
CPA	Complementary Package of Activities
DOT	Direct Observed Therapy
DOTS	Directly Observed Treatment Short Course
EPI	Expanded Program on Immunization
HC	Health Centre
IEC	Information Education Communication
IUATLD	International Union against TB and Lung Diseases
JICA	Japanese International Cooperation Agency
MOH	Ministry of Health
MPA	Minimum Package of Activities
NCHADS	National Centre for Control of HIV/AIDS, Dermatology and Sexually Transmitted infection
NGO	Non Government Organization
NTP	National Tuberculosis Program
OD	Operational Health District
PHD	Provincial Health Department
PLWHA	People Living with HIV/AIDS
PPMDOTS	Public Private Mixt DOTS
PTB	Pulmonary tuberculosis
RH	Referral Hospital
SPSS	Statistic Package for Social Science
UNDP	United Nations Development Program
UNFPA	United Nations Population Fund
UNICEF	United Nations International Children's Emergency Fund
VHV	Village Health Volunteer
WHO	World Health Organization

GLOSSARY

<i>Akum psam ayu</i>	Magic saves life
<i>Amas</i>	Ashamed
<i>Bab</i>	Sin
<i>Bon</i>	Faith
<i>Chaul Chnan Khmer</i>	Khmer lunar new year in mid of April (14-16)
<i>Chean areak</i>	Praying to remove spell from witchcraft
<i>Chheu</i>	Sick
<i>Chumgneu ring rey</i>	Chronic disease
<i>Chumgneu sout</i>	Lungs diseases
<i>Dann ta</i>	Ancestors
<i>Heut</i>	Asthma
<i>Kam</i>	Karma or sin
<i>Kambet muk pi</i>	Two sharp-edge knife (sharp on both sides)
<i>Kaok</i>	Cough
<i>kathen</i>	Religious yearly ceremony where people donate necessary materials and money to the pagoda for merit. The money is usually used to renovate pagoda, build school or shelter for the monks.
<i>Khos me ba</i>	Ancestors are unsatisfied with what family members do in the current time, for example if a family member has pre-marital sexual relationship or family members forgot to pay tribute to ancestor during in a particular ceremony, therefore ancestor curses someone in the family to become sick.
<i>Kour oy khpeum</i>	Disgusting
<i>Kour oy khlach</i>	Scary
<i>Kru Khmer</i>	Traditional healer
<i>Kru teay</i>	Fortune teller
<i>Kse keata</i>	A waist collar (fine belt) or bracelet with incantation of <i>pali</i>

	words
<i>Mean rub mean rok</i>	If you have life, you have disease
<i>Merok</i>	Germ
<i>Neak ta</i>	Spirit
<i>Pali</i>	Pali language
<i>Pchum Ben</i>	Religious yearly ceremony where people pay tribute to ancestors or family members who already passed away by donating food or money to the Buddhist monks for merit and convey the merit to all the death persons
<i>Peet</i>	Individual who provide health services, treatment or advice (doctor, nurse, midwife, laboratory technician)
<i>Peet ek chun</i>	Private health provider
<i>Peet phum</i>	Village health provider
<i>Puch ro beng</i>	TB family
<i>Chun pika</i>	People living with a disability
<i>Reus eung</i>	Discrimination
<i>Robeng</i>	Tuberculosis
<i>Robeng sout</i>	Pulmonary tuberculosis
<i>Robeng kon kandol</i>	Tuberculosis of the lymph nodes
<i>Saen</i>	Praying ceremony to spirit of ancestors or place
<i>Sabav</i>	Dangerous, cruel
<i>Sroch tek</i>	Sprinkling water while chanting <i>pali</i> words or Buddhist chanting
<i>Thmub</i>	Witchcraft
<i>Yean</i>	A piece of cotton on which were written with incantation of <i>pali</i> words

CHAPTER 1

INTRODUCTION

Nearing 10 am on a sunny, hot and humid day in Kampong Speu Province (Cambodia), approximately 15 people sat waiting for health staff outside a Tuberculosis Ward. They quietly sat on chairs, the floor, on their motorbikes or bicycles. Every now and then, they would look towards walkway, take a deep breath and look at each other, before continuing to wait patiently. The laboratory and staff rooms were open, and a motorcycle was parked in front of the laboratory, indicating that staff were present but perhaps busy with other work. There was no notice about when they would be available. Neary (aged 27 years) was one of those waiting. She had arrived at the hospital with her husband and their three young children (aged 6 years, 4 years, and 9 months) early that morning to seek TB diagnosis, as she had suffered with repetitive cough and fever for about a year. She had usually treated herself with assorted medicines provided by multiple private health providers. However, recently, her cough had intensified, and the medicines she took were no longer effective. One of her relatives suggested she determine whether she had TB from the hospital. When she arrived at the hospital, she talked to a staff member at the reception, about where and how she could be diagnosed, and was told to seek a sputum test from the laboratory. While she waited, Neary coughed several times, as she breastfed her baby and cuddled her to sleep. Her other two children played around her and her husband sat beside her quietly.

When the laboratory staff finally came, the clients all rushed to see them. A Staff member explained that they were late because they had staff meeting and were then asked by the hospital manager to join the hospital smoke-free declaration day, which delegations from Phnom Penh were attending. She invited clients who came to submit sputum to give them their sputum samples. Those who sought a sputum test were each given three containers: one for 'spot' sputum where they had to cough sputum in the container and return it to the laboratory the same day, and the other two to take home to collect early morning sputum, to be returned to the laboratory the following day. After attending to patients who wanted a sputum test, staff members invited people who came to collect the test result to see them. Those

whose test was negative went home without further consultation with a clinician or a request for a follow-up test. Those clients who had a positive result were referred to a clinician to obtain medication. The clinician has not yet arrived.

Although only a small number of clients sought sputum examinations each day, the laboratory staff were very busy. As soon as they were at the office they started their work: registering patients, preparing sputum, and reading sputum samples. In addition to those of the clients, laboratory staff also read many sputum samples brought from health centres.

Neary could not produce sputum, although she was coughing. The staff told her that her sputum had too much saliva, and this would make it difficult to test. The laboratory suggested that she cough at home in the early morning and bring the other two samples in on the following day. They also suggested that Neary talk to a clinician about having an x-ray to confirm her diagnosis, given that she could not produce a spot sputum sample. Neary waited for the clinician with the other patients; he finally arrived at nearly 12 pm, after a meeting at the operational health district. He quickly registered the clients into his patient record book, took their weight, and provided them with medication. Neary was sent to the x-ray unit, but all staff had gone for lunch, and they were unlikely to come back to work in the afternoon, so she was told to come for an x-ray the next day. She went home — about 20 kilometres away around 30 minutes by motorbike. The next day, Neary returned to the hospital in the early morning. To avoid delay, she negotiated with a health worker to get her x-ray and sputum test done on the same day; usually patients who seek sputum tests from the hospital have to wait from two days to one week to obtain the test result. Neary could not come to the hospital for multiple visits as her husband had to work, and she wanted to get treatment as soon as she could because she felt very sick. So Neary paid ‘informally’ for the x-ray and the sputum test, even though she was entitled to get them free of charge. In addition, she had to pay for transport, and her husband’s loss of work to come to hospital many times was also a high cost. She was subsequently diagnosed with TB and was referred to a health centre near her home to receive medication and to be monitored while being treated.



Figure 1: People wait in front of the laboratory and staff room of the TB ward

TB diagnosis can be confirmed through a very simple sputum test. However, as Neary's story shows, and as I will illustrate in this thesis, patients were driven to seek a sputum test only after they had suffered with persistent TB-related symptoms for months or years, and had treated their symptoms with therapies provided by several providers with limited success. Engagement with public health facilities varied in their accounts, due to the complex intersection of social, structural and personal factors. This thesis is based on ethnographic work that explores the pathways of patients to TB diagnosis and treatment. It examines what factors shaped these pathways. In doing so, it provides insights into barriers that possibly prevent the National TB Control Program from reaching the relevant Millennium Development Goal.

Tuberculosis (TB) is an infectious disease caused by the airborne bacteria *Mycobacterium tuberculosis*. It can affect any organ in the human body, although predominantly it occurs in

the lungs: 75% of active TB cases are pulmonary (lung) TB, and the term is usually used to refer to this (Enarson, et al., 2000; Dutt, 2006). TB is transmitted from one person to another through inhaling ‘droplet nuclei’¹ containing tubercle bacillus (*Mycobacterium tuberculosis*) (Manabe & Dannenberg, 2006). Transmission is facilitated by close and prolonged contact with an infected person in a closed, dark place with low ventilation, hence people living in shared, small and crowded dwellings are especially vulnerable (Enarson, et al., 2000). The disease is mostly characterized by respiratory-related symptoms such as cough, sputum, haemoptysis (blood in sputum) and breathlessness, and is often associated with weight loss, anorexia, fever and malaise (Hopewell, 1994; Campbell & Oumou, 2006; Manabe & Dannenberg, 2006). However, there is no singular symptom that is indicative of TB and, when all of the above symptoms are present, the disease may already have progressed to an advanced stage.

Global burden of tuberculosis

In the contemporary time, more than two billion people worldwide—one third of the world’s population—are infected with TB bacilli. Of these, 10% develop clinical TB while the other 90% have a latent infection which could develop into TB at a later time should their immune system become deficit (Hopewell, 1994). In 2008, TB killed 1.8 million people, or about 4,500 deaths a day (WHO, 2009a); 98% of these deaths occurred in developing countries (Maher & Raviglione, 2005).

The global estimate of the prevalence and incidence of TB was 9.6-13.6 million and 8.9-9.9 million respectively for 2008 (WHO, 2009b, 2009c). Actual case notification in 2008 was

¹ Droplet nucleuses are the residue formed by the evaporation of droplets which enter the air by coughing, talking or sneezing. They dry rapidly, become droplet nuclei carrying the *M. tuberculosis*, and may remain suspended in the air for several hours (Enarson, et al., 2000).

5.7 million, representing 61% of estimated TB cases in the world, and was about 10% below the target of global case detection rate of all incident cases (WHO, 2009c). In addition, the 2009 WHO report showed that the target of an 85% cure rate was achieved for the first time in 2007 meaning that over 85% (in fact, 87%) of TB patients who were registered in 2007 completed treatment (WHO, 2009a).

TB has spread disproportionately all over the world. Most cases occur in developing countries, mainly in adult populations in Asia and Africa (Khan, et al., 2000; Dye, 2006). Asia had the highest estimated number of TB cases in 2008 (55%), followed by Africa (30%), with a smaller proportion of cases in the Eastern Mediterranean (7%), Europe (5%) and America (3%) regions. The WHO ranked 22 countries, in terms of absolute numbers of TB cases, as high burden countries in relation to TB;² these countries account for 80% of all estimated TB cases worldwide. The top five countries—India, China, Nigeria, Indonesia and South Africa—accounted for about half of all new cases each year (Dye, 2006; WHO, 2007a, 2009b). Cambodia is the 21st highest burden country with TB, a concerning statistic in light of the relatively small population.

Tuberculosis and HIV

The HIV/AIDS epidemic is a major factor contributing to the persistence of TB in the present day. The virus results in the gradual deterioration of the human immune system, making individuals more susceptible to infectious diseases. HIV infection promotes the progression from latent to active clinical TB in those already infected with *Mycobacterium tuberculosis*, and increases the chance of primary transmission of *M. tuberculosis* to community members, whether or not they are HIV-infected (Smith & Moss, 1994; Maher, et al., 2005).

² The high burden countries are: India, China, Indonesia, Nigeria, South Africa, Bangladesh, Ethiopia, Pakistan, Philippines, DR Congo, Russia Federation, Vietnam, Kenya, UR Tanzania, Uganda, Brazil, Zimbabwe, Thailand, Mozambique, Myanmar, Cambodia, and Afghanistan.

Globally, approximately 13% of people diagnosed with TB are estimated to be HIV positive (WHO, 2006a). The impact of HIV on TB is significant, contributing to the re-emergence and increase of cases of TB and hampering TB control in developing countries. A review of TB and HIV interaction in sub-Saharan Africa indicated that HIV infection had enormous impact on both TB patients and national TB control programs (NTPs) (Maher, et al., 2005). Impacts on individual patients include the effects of HIV on the diagnosis of TB, which are related to the fact that the presence of HIV makes diagnosis of TB more complicated, especially during later stages of HIV infection. In particular, it reduces the effectiveness of anti-TB chemotherapy outcomes, due to the malabsorption of TB drugs (rifampicin and isoniazid), and so it increases the recurrence of TB. HIV infection affects TB control programs by increasing the case load related to people who are HIV positive, increasing the workload for the NTP beyond the capacity of its regular human and financial resources, and overloading and straining the public health system. Ultimately, this impairs NTP performance (Maher, et al., 2005).

Generally, the combination of TB and HIV/AIDS makes both conditions difficult to control. In high TB burden settings, 30-40% of people living with HIV/AIDS will develop TB in their lifetime if they cannot access chemoprophylaxis with isoniazid (Bock, et al., 1999). Such figures reflect the magnitude of global TB, and the resurgence of TB in recent decades has driven the need for a global strategy for TB control.

Global TB Control Strategy

Without treatment, TB kills most (50%-80%) of its victims within 2 years of infection (Newell, 2002). Responses to epidemic TB have been developed, and are either curative (action taken after diagnosis) or preventive (steps taken to prevent infection): medication, immunization and prophylaxis. TB medication first became available following the discovery of *Streptomycin* by an American scientist, Selman Waksman, in 1943. In 1944, the

first case of TB was treated with Streptomycin; however it was soon discovered that TB bacteria became resistant to this medicine, thus significantly reducing its effectiveness. At around this time, another drug, para-aminosalicylic acid (PSA, also discovered in 1943) was identified as preventing TB bacteria from becoming resistant to Streptomycin, and the two drugs began to be used in combination for an extended time to effectively treat TB. The effectiveness of pharmacotherapy in treating TB was subsequently improved after the finding of Isoniazid (the first oral anti-mycobacterium) in 1952, followed by the introduction of Rifampicin (an anti-mycobacterium with high efficacy over a broad spectrum of the mycobacterium population) in the 1970s (Harding & Bailey, 1994; Daniel, 2006). The use of these drugs in combination significantly improves the effectiveness of TB treatment, and treatment duration was shortened from 18 to 9 months (Chaisson, 2003; Khan & Kimerling, 2006). In 1980, Pirazinamid (PZA) was introduced into the anti-TB regimen, reducing treatment times further, to only six months (da Silva & Ainsa, 2007).

These effective drugs have not been sufficient alone to stop the TB epidemic, as other factors also play a role in TB transmission and control. In many parts of the world, TB has yet to be controlled (Frieden, et al., 2003) as a result of growing prison populations, homelessness, injecting drug-use, over-crowded housing, immigration from high-prevalence TB countries, decline in TB control efforts, deficiency of health care systems and the HIV/AIDS epidemic (WHO, 1998). In 1993, WHO declared TB a global health emergency and, in response, the International Stop TB Strategy launched the Direct Observed Treatment-Short course (DOTS) in 1994 (WHO, 2006b), DOTS was aimed at resource-poor countries, and, as a strategy, it consists of five key elements: (1) political commitment, (2) case detection by sputum microscopy analysis, (3) secure anti-tuberculosis drug supply, (4) standard reporting and recording system of TB cases, and (5) direct patient observation while taking each dose of medication (Espinal, et al., 2000; WHO, 2004).

DOTS therapy uses five combined first-line³ anti-tuberculosis treatments including Isoniazid, Rifampicine, Pyrazinamide, Ethambutol, and Streptomycin to treat TB patients for six (at least) to eight months (Espinal, et al., 2000). More than 95% of TB patients can be cured if the DOTS strategy is applied adequately (Frieden, et al., 2003). However, TB control programs encounter challenges in bringing TB patients to DOTS, distributing drugs to patients, and ensuring patients' compliance with the full course of treatment (WHO, 2006c; Frieden, 2009). Further affecting the efficacy of TB control programs, many TB patients are not treated with DOTS. In 2001, only one-third of all estimated TB patients worldwide were treated the under DOTS approach, and not all people who commenced DOTS completed the course (Frieden, 2002). Incomplete TB treatment remains one of the major challenges for eradicating the disease. Poor compliance with anti-TB treatment also prolongs the time that the patient is infectious and leads to drug resistance, so reducing the effectiveness of the current medication regimens for anyone infected, meaning higher likelihood of relapse of TB or even death. Non-adherence to anti-tuberculosis treatment therefore poses a serious risk for individuals and the community (Walley, et al., 2001; Volmink & Garner, 2006). As those who are infected with TB are most likely to be the poorest and the most marginalized populations in the world, they face significant barriers to access DOTS programs and to comply with treatment. They may delay seeking DOTS or are treated by unqualified providers, and thus become both chronically ill and transmitters of TB in their communities. As a result, having the DOTS strategy available at public health services without addressing other factors that may

³ Drugs for treating TB are classified as first- and second-line drugs. The second-line is to treat TB drug resistant cases. It includes the aminoglycosides kanamycin and amikacin, the polypeptide, capreomycin, PAS, cycloserine, the thioamides ethionamide and prothionamide, and several fluoroquinolones such as moxifloxacin, levofloxacin and gatifloxacin (da Silva & Ainsa, 2007).

influence TB patients' health-seeking behaviour, particularly among poor and marginalised groups, may make the DOTS strategy ineffective.

Immunization: BCG

Vaccine development against TB begun in the early 1890s when *Mycobacterium-bovis*, *Bacille Calmette-Guérin* (BCG) was developed by French scientists Leon Calmette, a physician, and Camille Guérin, a veterinarian. The vaccine was developed from living bacteria, which were weakened until they were too weak to cause the disease, but were strong enough to stimulate the body's immune system against TB (Larkin & Fordham, 2006). By 1921, the BCG vaccine had been developed and was administered to humans (Basel, 1998; Routh, 2004; Brennan, 2005); it was formally certified as safe for human use in 1928 by the League of Nations. However, BCG was only introduced into the TB control program initiated by the WHO in 1947.

Currently, the BCG vaccine is used in the global immunization program as a major component to reduce the risk of TB transmission and death. The vaccine is administered in 170 countries to children at birth (Cohn, 2001). However, the vaccine does not provide complete coverage, protecting around 80% of those who receive it (Routh, 2004); the duration of protection is limited to 15 years or less (Brennan, 2005). While the vaccine has shown consistently high efficacy against childhood TB meningitis and miliary TB, its efficacy against adult pulmonary TB and other mycobacterial diseases is marginal (Long, et al., 1999b; Trunz, et al., 2006).

Prophylaxis

Prophylaxis measures aim to reduce the transmission of TB. Prophylaxes are used in health care settings by (a) teaching TB patients to cough into their cupped hands; (b) ensuring that health staff wear tight-fitting effective masks when attending TB patients, (c) providing BCG vaccination to newborns in TB endemic areas, and (d) increasing air

ventilation in places where TB patients are resident (Manabe & Dannenberg, 2006). Where resources are available, chemoprophylaxis is used to treat latent TB in individuals who present a positive tuberculin skin test. In these cases, a single therapy with Isoniazid is given daily for 6 to 12 months (Berg, et al., 2004). This Isoniazid chemoprophylaxis is also necessary to prevent TB in people living with HIV/AIDS (Bock, et al., 1999). All three components of the global TB strategy are included in the Cambodian NTP.

In the following section, I elaborate the burden of TB in Cambodia. Firstly, however, I provide an overview of Cambodia, including geography, demography, socio-economic conditions, and the health system of the country. These factors have all impacted on the existence and control of TB.

Cambodia: geography, demography, and socio-economic features

Geography

The Kingdom of Cambodia is located in South East Asia, covering an area of 181,035 square kilometres. It borders to Thailand to the west and northwest, Laos to the northeast, Vietnam to the east and southeast, and the Gulf of Thailand in the south, with a 443 kilometre coastline (Figure 2).

Roughly square in shape, the country is a lacustrine plain— the bed of a lake, from which the water has disappeared either by natural drainage, evaporation or other geophysical processes—and is enclosed by mountain ranges: Dangrek Mountains to the North, Cardamom Mountains and Elephant range to the Southwest. The land is dominated by the Tonle Sap (great lake) River and the Mekong River traversing the country from North to South. Forests cover two-thirds of the land.



Figure 2: Map of Cambodia

(<http://asianstudies.wikispaces.com/file/view/cambodia-map.jpg/30186315/cambodia-map.jpg>)

The diversity of geography in Cambodia results in the isolation of some communities; in addition, the impoverished transportation infrastructure creates barriers to the distribution of and access to health services. Road and transport have been significantly improved recently, but, rural roads are still poorly maintained and they are usually cut off during the rainy season.

Cambodia's climate is highly seasonal, dominated by the monsoon cycle, with two seasons: wet and dry. During the dry season from November to April, high air pressure over central Asia results in rainless and dry weather to Cambodia. From November to February the temperature is cool and dry (around mid 20⁰ C), while the weather in March and April is hot and dry. The wet season lasts from May to October, and is characterized by regular rainfall, peaking in July and August. During this season, many parts of the country along the Mekong and Tonle Sap are in flood, making access to health facilities even more difficult than at other times.

Demography

The Cambodian population in 2008 was 13,338,910 (National Institute of Statistics, 2009) (see Table 1). The population is relatively homogenous, and 90% are of Khmer origin and speak Khmer, the country's official language. The remainder are from Chinese, Vietnamese, Cham (Muslim community) and Khmer Loeu (hill tribe) ethnicities. Approximately half of the population is younger than 22 — they were born during the population boom after the collapse of the Khmer Rouge regime. In older age groups, there is a biased sex ratio: the number of females aged 54 and over well exceeds the number of males, due to the high mortality among men and the exodus of adult males from Cambodia during the Khmer Rouge period (1975-1979) (National Institute of Statistics, 2009). Most Khmer people live in extended and supportive families, with an average household size of 5 in 2008. Ill health is typically managed wherever possible on a household level, and the

family takes responsibility to provide economic support and care if a family member is sick. Population density is 75 people per square kilometre, but this varies greatly from place to place, with high density (5,358 inhabitants per square kilometre in Phnom Penh) (Ministry of Health, 2003b) and extremely low density (22 per square kilometre) in some plateau and mountainous areas (National Institute of Statistics, 2009)). High population density tends to favour the transmission of infectious diseases including TB and a greater prevalence of these diseases in urbanised areas. However, this does not mean that TB infection is less likely in dispersed communities—people living in low density areas tend to live close to each other in extended families. They lack access to health care, and live in poverty; therefore there is a high possibility of TB transmission within the household once someone in the family is infected with TB.

Table 1: Socio-demographic characteristics

Population	13,338,910 ⁴
Urban	19.5%
Rural	80.5%
Sex ratio (male per 100 females)	94.2
Annual population by age group	
0-4 years	11.0% ⁵
0-14 years	39.0%
5-14 years	27.0%
15-49 years (women in reproductive age only)	26.0%
Crude Birth Rate (CBR) per 1000 population	25.6/1 000 or 2.6%
Life expectancy at birth	
Male	63.11 years
Female	67.48 years
Average of household size	4.7
Density per Km ²	74
Education	
Adult Literacy age 15 and over (total)	74%
Male	85%
Female	64%
Urban (both sexes)	84%
Rural (both sexes)	72%

Source: National Health Statistics Report 2008 (Ministry of Health, 2008)

⁴ Cambodia Population Census 2008

⁵ The Cambodia Inter Census Population Survey 2004

Religion and beliefs

Predominantly, Cambodians practice Theravada Buddhism (95%), with small minorities of Muslims (3%) and Christians (2%) (National Institute of Statistics, 2009). As Buddhists, Cambodian people hold a profound belief in *bab* and *bun*. The former, *bab*, refers to sin or bad consequences as the result of bad actions in the past or present life; the latter refers to good consequences— for example, good luck, good fortune or being wealthy— as a result of their good behaviour in a past or current life. Buddhism encourages believers to accept *kam* (Karma), the consequences of their actions, so that they can be freed from *kam* in their future life (discussed further in Chapter 4). At the same time, Khmer people believe in animism: that the world is inhabited by various spirits such as ancestral spirits (or souls) and spirits associated with places (house, road, mountain, river, forest, sea). Respect for spirits is believed to result in good consequences (happiness, good health, good fortune); on the other hand, if they do not receive appropriate respect spirits can cause bad luck (sickness, accidents) to people. Figure 3 shows travellers stopping to pray to the spirit of the mountain for travel safety and happiness. People mostly believe that spirits and *Kam* are associated with illness or bad luck in their life. Reliance on these beliefs tends to mean that community members lack interest in identifying the cause(s) of their health problems and prevents or limits them in taking actions to prevent the problem. Instead, it encourages community people to rely on folk providers to treat their illness.



Figure 3: *Pich Nil*, a famous sacred place

(National road 4 in Kampong Speu province, field photo, 18-Sept-2008)

Economy

Civil war and internal conflict from 1970 to 1999 (including the years of the Khmer Rouge Regime from 1975-1979) left Cambodia economically devastated. According to the UN Human Poverty Index, Cambodia ranks 73rd out of 78 developing countries, is one of the lowest ranked countries in the Human Development Index (129 out of 177) (ADB, 2001; WHO, 2001). More than 35% of the Cambodian population live below the poverty line, with an income of less than US\$0.45 per day— considerably less than the World Bank’s ‘dollar-a-day’ adjusted measurement for extreme poverty (World Bank, 2008). Furthermore, 2.6 million people, mainly in rural areas, live in extreme poverty and face chronic food shortages (World Food Programme, 2007 #3064). Agriculture is the most important sector of the Cambodian economy, with approximately 60% of the population relying on agriculture (farming, animal production, and fishing) for subsistence. Agriculture in

Cambodia uses few instruments, and people rely on natural conditions (*iven sre pravas mek*—‘rice farming occurs according to the rainfall’), using traditional farming tools. In addition, the lack of a sustained market for agricultural products, poor road infrastructure and lack of transportation causes difficulties for farmers when selling their products and therefore they could not maintain a fair income for living. Householders spend 30% of their income on rice alone; many rural households face seasonal food shortages each year. Poor incomes from agriculture cause many rural people to look for wage labour or other income-generating activities, which are mainly casual and poorly paid (FAO, 2010).

Cambodia Health System

The prolonged civil war and associated collapse of the economy devastated the Cambodian health system. Fewer than 50 out of 600 doctors who practiced medicine before 1975 survived the Khmer Rouge regime—the period from 1975 to 1979, when Cambodia was under communist rule and widespread genocide occurred. The Khmer Rouge regime aimed to change Cambodia to an agriculture-based communist society, and millions of people were forced to move from cities or larger towns to the countryside. Approximately 2 million Cambodians are estimated to have died during this time from murder, torture, and starvation; most of them were educated and of middle and high class. In addition, all social infrastructure including health services and facilities were completely dismantled (Mam & Key, 1995). The post-*Khmer Rouge* government, the People's Republic of Kampuchea (then the State of Cambodia), prioritized the health care system by reconstructing and renovating health facilities, and trained health professionals within Cambodia and in other allied communist countries (Mam & Key, 1995). Remodelling of the health system was based on a socialist model, which aimed for a provincial hospital (PH) in each province, a district hospital (DH) in each district, a commune clinic in every commune, and national hospitals in the capital city, Phnom Penh. From 1979 to 1993, the

public health system was intended to be totally free of charge (Romeo & Spyckerelle, 2004; Mam & Key, 1995). However, the economic conditions resulting from imposed economic sanctions, geographic isolation, and unstable political conditions as a result of continued devastating internal conflict, contributed to an impoverished national health system and poor health status of the population.

Health sector reform

In 1993, the first UN-supported democratic election was held in Cambodia. The new government, the Kingdom of Cambodia, was opened up to the international community, receiving bilateral and multilateral aid to develop the country, sustain peace and create unity. The public health system was a priority sector that received assistance from several United Nations organizations —UNICEF, UNFPA, WHO, UNDP and International Organizations (IOs). Many non-government Organizations (NGOs) were established to address health system strengthening and improve health service delivery. With this support, Cambodia began to reform the public health system in 1994 to improve health coverage to the Cambodian public. In 1995, a new policy, the ‘Health Coverage Plan,’ was launched to address health reform. This involved building new facilities in areas where none existed, and transformed 121 existing hospitals and almost 800 commune clinics into health centres. Concurrently, capacity in managing local health services was developed at provincial and operational district (OD) levels through several training programs and support from NGOs at the local level. The new public health facilities (hospitals and health centres) were built on the basis of two criteria: population size covered by the facility and accessibility to the facility (Ministry of Health, 1997) (Hill & Eang, 2007; Ministry of Health, 2007).

The Cambodian public health system is managed at three levels: central, provincial and operational district (OD) levels (Ministry of Health, 2009a). At the central level, the

Ministry of Health (MoH) administers all health programs, national hospitals, and training institutions. The MoH develops national policies, guidelines, planning of health programs to be implemented throughout the country, and provides training and support to the lower levels. The central level also coordinates and monitors the implementation of the private health sector through providing licenses and quality checks. However, a large part of the private sector remains unlicensed and, in general, quality of private health service is not monitored regularly.

At the provincial level, each of the 24 provinces has a Provincial Health Department (PHD) that is responsible for overseeing the public health sector and coordinating the private health sector. The PHD liaises between the central level and the OD level. The PHD develops strategic plans for the public health system in the province based on national policies and guidelines, and provides technical support to the OD. Each province has between one and several OD(s) according to its population size. The third level is the OD. The OD is responsible for ensuring service delivery to community members. Each OD consists of one referral hospital (RH) and several health centres (HC).

Despite these health reforms, the management of health system in Cambodia remains centralized. PHD and OD usually follow the strategies set by the central level without adapting these to their local priorities. As I demonstrate in this thesis, the health service delivery through health centres is usually determined by inputs from the central level. This practice leads to the demotivation of health staff and the passive contribution of low level health staff to health service delivery at local levels.

Following health reform, Cambodian health facilities were built or renovated. In 2007, there were 960 health centres, 99 health posts, 69 referral hospitals and 9 national hospitals throughout Cambodia (Table 2).

Table 2: Health facilities in Cambodia

Health facilities	Number	Health services delivered
Health Centre	960	Minimum package of activities (MPA)
Health Post	99	MPA
Referral Hospital	69	Complementary package of activities (CPA 1, CPA2, CPA3)
-CPA 1	25	
-CPA 2	28	
-CPA 3	16	
National Hospital	9	Specialized treatments Internships for medical students and health staff

Source: Ministry of health (2007)

Health centre

The health centre is the closest public health facility to the population, with each serving 8,000-12,000 people. It provides basic preventive and curative services through the Minimum Package of Activities (MPA), including the treatment of common diseases (malaria, dengue, diarrhoea, sexually transmitted diseases); diagnosis and treatment of TB, leprosy and HIV; treatment of minor injuries; child (aged 0-4) immunization; ante-natal care and family planning; and referral of cases to the referral hospital (RH) if necessary (Ministry of Health, 2007). Each health centre employs 8-11 staff (discussed in Chapter 5). In remote communities with low population density (much lower than the criteria for having a health centre), and located at a distance of more than 15 kilometres from a health centre, health posts have been established. Each health post employs two staff, one midwife and one nurse, serving a population 2,000-3,000. Like the health centre, each health post provides MPA to the population in their coverage areas. To date, there are 99 health posts around the country. Health centres and health posts receive drug supplies and medical equipment from the Ministry of Health through the provincial health department and OD.

Referral Hospital

In addition to the MPA, the referral hospitals (RH) provide a Complementary Package of Activities (CPA), including treatment of referred cases from health centres; treatment of medical, surgical and obstetrical emergency cases; maternal and child health; provision of x-ray, ultrasound and laboratory services; treatment of complicated TB cases; and rehabilitation services (Ministry of Health, 2006). Each RH serves approximately 100,000-200,000 population. There are three levels of RH in Cambodia, providing CPA1, CPA2 or CPA3. Only 16 out of 69 RH provide CPA 3 (see Table 2 and 3) (Ministry of Health, 2006)

Table 3: CPA provided at RH

Medical services	CPA 1 40-60 beds	CPA 2 60-90 beds	CPA 3 90-150 beds
Intensive care and emergency services	X	X	X
General medicine	X	X	X
Surgery		X	X
Gynecology and obstetrics care	X	X	X
Pediatric	X	X	X
TB	X	X	X
Other specialize services (Ophthalmology, OtoRhino Laryngology)			X
Para-medical services			
Laboratory	X	X	X
Blood donation			X
X-ray	X	X	X
Ultrasound		X	X
Ambulance	X	X	X

Source: (Ministry of Health, 2006)

National Hospital

National hospitals are located in Phnom Penh. Each provides specialized care to patients around the country. The national hospitals are also places for internships and research for medical students and health professionals throughout the country. There are nine national hospitals, including three paediatric, one maternal and child health, one national TB hospital, one Ophthalmology and OtoRhino Laryngology (ORL), and three general

hospitals. Access to each national hospital is out of reach for many poor rural community members due to the high cost of health services, indirect costs for patients and family (transport, food and living costs in the city), and distance.

Health funding

Total health expenditure per capita was estimated to be US\$37 in 2005 with US\$8 contributed from external funding and US\$ 4 from the government budget. The rest (approximately two-thirds of the expenditure) was funded out-of-pocket that is, individual patients met the costs at the time the health service was provided (WHO, 2007b). However, the excessive burden of these out-of-pocket payments for health care created financial barriers for people to access appropriate health care (Annear, 2007). This out-of-pocket amount for health expenditure is considered to be a major cause of bringing rural poor families into debt and destitution; therefore, many desperately poor people cannot access appropriate health care (Bigdeli & Annear, 2009). Khun (2008) showed that health care costs— costs of health services, medicines, and other indirect costs— to treat children with dengue profoundly affected household economies. Frequently, families had to rely on loans, or selling their property, goods or labour to finance health care costs. These costs usually deterred absolutely poor mothers from obtaining health care for their sick child (Khun & Manderson, 2008).

Health workforce

The Cambodia health system faces shortages and the mal-distribution of the health workforce. Two-thirds of all health centres in the country were unable to deliver full MPA because of shortages of midwives and nurses, while shortages of qualified physicians delayed the upgrade of some Referral Hospitals to fully implement the Complementary Package of Activities (CPA3), including surgery and some specialist care (Ministry of Health, 2005a, 2006). The shortage of health staff is due to the unequal distribution of

doctors and increasing shortages of midwives (Oum, et al., 2005b). Health staff distribution is heavily skewed toward urban areas, with approximately 54% of physicians employed in the capital city, Phnom Penh, where only 9.3% of the total population lives (Oum, et al., 2005b), as shown in Table 4.

Table 4: Health personnel-to-population ratio disparities in Cambodia

	Province with the best ratio	Province with moderate ratio	Province with the worst ratio
Physician	1:2,385	1:11,450	1:15,460
Secondary nurse	1:1,010	1:3,730	1:8,740
Secondary midwife	1:1,040	1:3,870	1:12,700

Source (Ministry of Health, 2001b)

The ratio indicates a severe shortage of human resources in the health sector in Cambodia compared to the WHO's recommendation of a minimum threshold of 2.5 health workers (doctors, nurses, and midwives) per 1,000 people for health system strengthening and to achieve the Millennium Development Goals (MDGs) (Chen, et al., 2004; WHO, 2006d). Estimates suggest approximately 10,000 untrained providers—such as traditional birth attendants, traditional healers, and untrained individuals—work alongside the formal health system in Cambodia; the majority are unlicensed (Ministry of Health, 2001b).

Health status of Cambodians

The poor health system, combined with low socio-economic status, has resulted in the poor health status of the Cambodian population. Infectious diseases, HIV/AIDS, TB, and diarrheal diseases remain the leading causes of morbidity and mortality (WHO, 2007b). The Cambodian Demographic and Health Survey (CDHS) (2005) showed improvements in population health status since 2000 (Table 5). Infant and under-five mortality rates have both declined significantly over the past 25 years, with declines of 39% and 35%, respectively, to 66 and 83 deaths per 1000 live births since the late 1990s. This could result

from improved socioeconomic status, improved living conditions, and better education of mothers but these figures still remain among the highest in the region (CDHS, 2005; Grundy, et al., 2009).

Table 5: Health indicators

	1990	1995	2000	2005
Life expectancy at birth (years)	54	55	56	61
Infant Mortality Rate (per 1,000 live birth)	78	93	109	61
Under 5 Mortality Rate (per 1,000 live birth)	115	124	127	83
Maternal Mortality Ratio (per 100,000 live birth)			437	472
Total Fertility Rate (births per woman)	5.5	4.8	4.3	3.4
Birth attended by skilled health staff (% of total)			32	43

Source: (Ministry of Health, 2008) (CDHS, 2005)

Between 1998-2008, life expectancy increased from 52 to 63.1 years for men and from 56 to 67.5 for women. In addition, the total fertility rate dropped from 4.0 births per woman in 2000 to 3.4 in 2005, thus achieving the Cambodian Millennium target for 2010: this predominantly occurred as a result of declines in fertility among rural women. As a result, the annual population growth rate declined from 2.5% to 1.5% over this time (CDHS, 2005). Nonetheless, maternal health status remains problematic, with a maternal mortality rate of 472 per 100, 000 live births, the second highest in the region after Laos (WHO, 2007b).

TB burden in Cambodia

Epidemiology of the disease

Cambodia is one of the 22 highest burden countries globally in relation to TB (WHO, 2007a), and has the fourth highest incidence globally. In 1997, the WHO estimated that 64% of the Cambodian population was infected with *Mycobacterium TB* (CENAT, 2009); this estimate is considered to be relevant to date. The latest WHO estimates on TB in Cambodia from 2009 indicate a high incidence rate of all TB cases (495/100,000 population per year), and new smear positive cases (219/100,000 population per year). The

prevalence of all cases was estimated at 664/100,000 and the estimated number of deaths due to TB was 89/100,000 annually (NTP, 2008; WHO, 2009b).

The Cambodian national prevalence survey on TB (2002) showed that the smear positive prevalence of TB among the population aged 10 or more was 362/100,000 (CI: 284-461). TB prevalence was gendered with prevalence rates of 551 in men and 208 in women, giving a male/female ratio at 2.6:1. However, the reasons for these gender differences in TB prevalence have not been discussed, and remain unsolved. In general, men and women seem to have a similar chance of getting infected with TB; however, the higher prevalence of TB among men may result from their engagement in risky behaviour and hard work, which could worsen their immune system. On the other hand, a Bangladeshi study suggests that women are less likely to be diagnosed with TB because they give poorer quality sputum samples than men, as a result of a lack of understanding about how to produce good sputum, and the fear of stigma associated with TB (Begum, et al., 2001). These findings may also be relevant to the Cambodian context, as women may fear being diagnosed with TB and therefore may not produce good sputum for pathology testing during prevalence surveys. Further investigation is needed.

The prevalence of all TB cases was 1,208/100,000 (CI: 997-1463), 1506 in men and 983 in women (giving male/female ratio of 1.5:1). TB greatly affected older age groups in the country, with prevalence rates of smear positive TB of 1,512/100,000 among people aged 65 or more (NTP, 2005a). The prevalence of TB among men aged 65 and over was more than four times higher than that in women of the same age (Figure 4). This may be resultant from the preference of older men to gather among their peers in their communities—they often meet each other in the afternoon at a pagoda or at someone's house to have tea and talk—which may provide opportunities for infection.

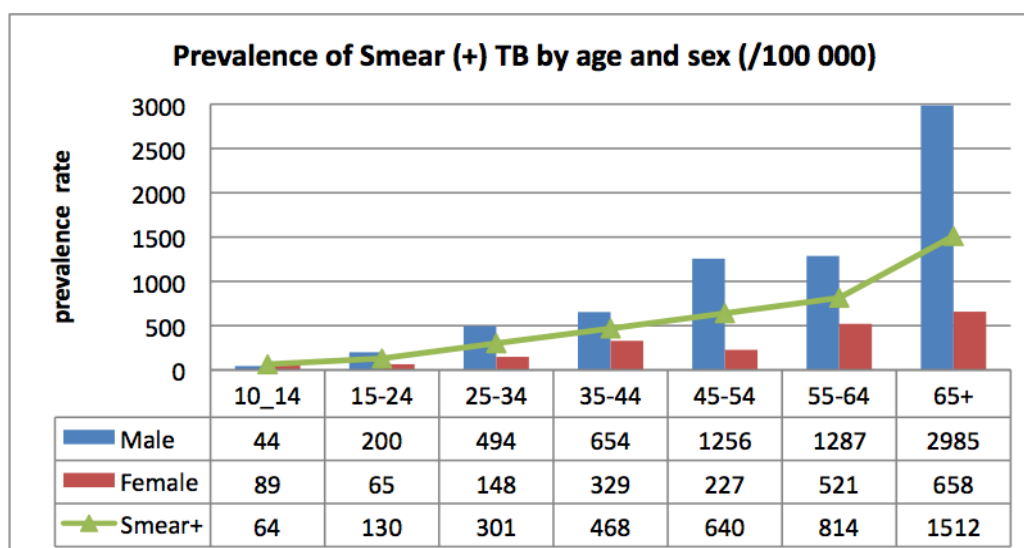


Figure 4: Prevalence in smear positive TB by age and sex

Source: National TB Prevalence Survey 2002, Cambodia

The National Health Statistics Report of the Ministry of Health (2005) showed a gradual increase of case detection of smear-positive TB from 112/100,000 population in 2001 to 158/100,000 in 2005 (Ministry of Health, 2005c). Increased case detection may have resulted from the expansion of DOTS coverage; improved diagnostic facilities (laboratories and radiology services); or the enormous impact of HIV/AIDS on TB in Cambodia (CENAT, 2005b). While the national target of TB smear positive case detection rate was attained in 2005 as a result of active case finding (NTP, 2006), the case detection rate declined to 65% in 2006, before rising again to 66% and 69% in 2007 and 2008 respectively (Ministry of Health, 2009b)(Figure 5). These fluctuations may result from a range of inputs, for example, health funding, commitment of health staff at all levels, and additional commitment to active case finding. However, case detection of smear negative TB and extra-pulmonary TB remains problematic due to the lack of diagnostic facilities and shortages of highly qualified health staff (doctor) for diagnosis (CENAT, 2006a).

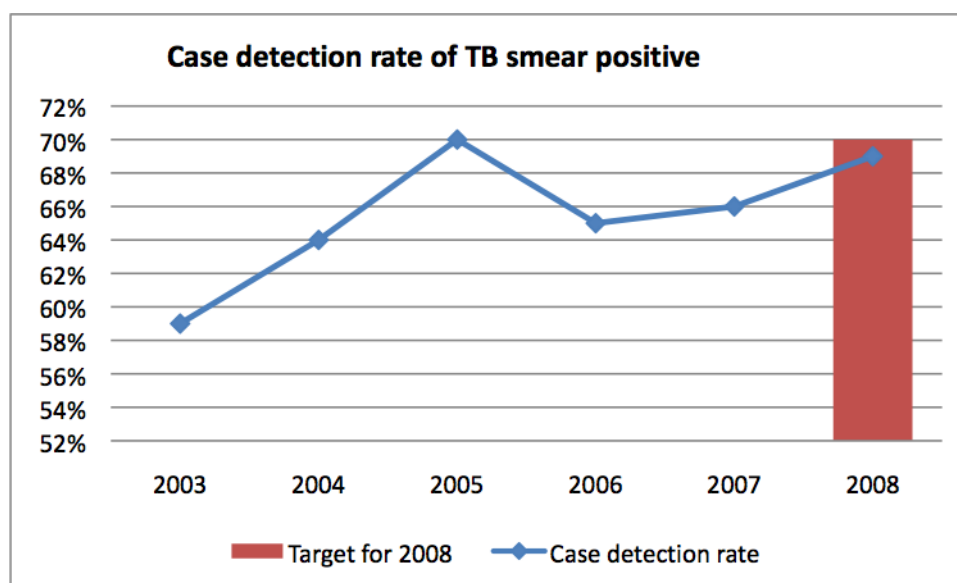


Figure 5: Case detection rate of TB smear positive

Source: MHO, 2008

Adding to the TB burden is HIV/AIDS, which is estimated to affect 1.9% of the Cambodian population aged 15-49, and major public health challenge in Cambodia (Ministry of Health, 2003a). The 2003 Cambodian National HIV Prevalence Survey among TB patients revealed that 12% of TB patients were HIV positive, although this dropped to 10% in 2005 (WHO, 2004; CENAT, 2005a; Eang, et al., 2007; Tamura, et al., 2008) and 7.8% in 2007, possibly explained by the declining HIV prevalence in the general population (NTP, 2008). No data exist on TB incidence or mortality among people living with HIV/AIDS (PLWHA) in Cambodia (WHO, 2005). A follow-up study of 381 AIDS patients admitted to a public hospital in Phnom Penh, showed that approximately 50% of patients had two or more opportunistic infections: predominantly chronic diarrhoea (41.2% of cases), TB (26%), cryptococcal meningitis (12.6%), *Pneumocystis carinii* pneumonia (8.4%), or encephalitis (4.7%) (Senya, et al., 2003).

TB Control in Cambodia

DOTS in Cambodia

The National TB Control Program (NTP) was set up in 1980, at the same time that Cambodia restored the whole health system after the collapse of the Khmer Rouge. The NTP then suffered a severe shortage of funding for TB drugs, diagnostic equipment, training, and supervision. The implementation of the NTP was based on a vertical model, aiming to construct a TB unit that consisted of a laboratory, TB specialist and in-patient facilities, and a TB statistics system, separate from the general hospital.

At the central level, the NTP was managed by National Centre for TB and Leprosy Control (CENAT) jointly with the national TB hospital. At the provincial level, TB units functioned separately from the general hospital. At the district level, TB units are located inside the district hospital, and the TB staff are also involved with other programs. There was no TB diagnosis and treatment offered at commune clinics, therefore suspected patients were required to travel to the district or provincial TB Unit, generally located at a great distance from their home, for TB diagnosis and treatment. Before the introduction of DOTS, NTP followed the 12-month TB treatment regimen, with a cure rate of TB estimated at around 40%; in addition, many TB patients could not access anti-tuberculosis treatment (Norval, et al., 1998).

In 1994, when the DOTS strategy was introduced in Cambodia, TB control began to be integrated into general hospitals (Hill & Eang, 2007). DOTS implementation followed the five key elements of WHO-DOTS. *Political commitment* for TB control was strengthened, including with the establishment of a high-level National Committee against TB, chaired by the Prime Minister. The NTP was considered to be a priority health program, receiving specific attention from the government and donors. The *anti-tuberculosis drug supply* was maintained with a national budget allocation, supplemented by grants and loans from

various donors and organizations; and a *standard reporting and recording system* on TB was improved with technical assistance from the WHO, the Japanese International Cooperation Agency (JICA), and other donors. This means that all TB patients registered in DOTS programs at government health facilities are reported within the national TB report and national health statistics reports, which are then reported to the WHO Regional Office. Efforts have been directed to *improve quality microscopy* to establish TB diagnosis; and patients are treated under *direct observation of DOTS providers* (health workers or community DOTS observers) (CENAT, 2006b; Uchiyama, et al., 2006; Hill & Eang, 2007). DOTS has been progressively expanded in public health facilities in Cambodia at all levels, and since 2005, DOTS has been available at all public health centres (CENAT, 2006b). The success of DOTS implementation has greatly improved treatment outcomes, by increasing the cure rate (the percentage of TB patients enrolled in TB treatment at public health facilities who are confirmed cured via a pathology test after completing TB treatment) of infectious cases from 85% in 1995 to 91% in 2000. The TB cure rate in Cambodia has for many years exceeded WHO's cure rate target of 85% (WHO, 2007a).

DOTS treatment provided at public health facilities in Cambodia is free of charge. In addition, each TB patient is entitled to receive a food supplement during treatment, which includes rice, salt, and oil. The food incentive has been provided by the World Food Program since 1994 to all TB patients treated at a public health facility (regardless of their economic status). Such food supplements are provided on a quarterly basis during treatment (each patient receives food supply twice during treatment—each time consist of 60 kilograms of rice, 1.5 kilograms of oil, and 1 kilogram of salt) based on treatment compliance (CENAT, 2006b). This supply aims to attract TB patients to seek treatment and to comply with the full course of treatment. As many TB patients are poor or extremely poor, providing them with food incentives may improve their food security and

enable better recovery during treatment (World Food Programme, 2007; Martins, et al., 2009). However, the impact of food incentives on TB diagnosis and treatment compliance in Cambodia is unclear, as it was reported that patients have to wait several months before they can have the food (Martins, et al., 2009).

Community DOTS

To improve the case detection rate and ensure TB treatment adherence, the NTP launched community DOTS (C-DOTS) in 2002. This initiative involves nominated community members (usually health volunteers), trained and supervised by the health centre, to observe TB patients taking medicine during the intensive and continuation phases of TB treatment. The nominated community members are assigned to support TB patients who live far from health centres and cannot come to the health centre every morning for treatment; neither can health staff come to their place to observe treatment. In 2008, 506 out of 960 health centres implemented C-DOTS. However, multiple challenges were associated with its implementation. These include the lack of support (technical and financial) from the health sector to C-DOTS activities, such as no supervisory visits to communities, limited or no provision of health education to patients and C-DOTS observers, and an unfulfilled need to implement adequate recording and reporting systems for C-DOTS. Population mobility is another issue. Frequently, appointed C-DOTS observers and TB patients may move according to the season for work.

Public-Private Mix DOTS

In 2005, the NTP initiated the Public-Private Mix DOTS (PPM-DOTS) to improve TB case detection, to reduce delays to TB diagnosis, and to prevent the waste of health care funds on inappropriate treatment. To date, PPM-DOTS have been implemented in some selected ODs (as small scale projects; however, these projects encounter multiple barriers. For example, a large number of referred suspected cases do not show up at public health

facilities, there is a lack of motivation of providers on both sides, and a lack of resources for supervision of the activities. In addition, the lack of confidentiality and privacy at public health facilities possibly contribute to the high drop-out of suspected TB cases referred from the private sector to seek diagnosis at public health facilities (NTP, 2008).

TB prevention

The BCG vaccination program is coordinated by the National Immunization Program in Cambodia. It is included in the National Immunization Calendar for newborn babies, so it is given at birth at all public health facilities. Where a baby is born in a location outside of public health facilities, he or she can be brought for vaccination at the public health centre or during outreach⁶ activities of health centre staff (CENAT, 2006b). Health education activities and campaigns related to TB prevention are scarce. Little information on TB causes and prevention is integrated into the curriculum of junior high schools in Cambodia, despite education about other respiratory infections being delivered.

Factors associated with health-seeking behaviour of TB patients

TB control programs, globally and in Cambodia, aim to cut TB transmission through early case detection and effective treatment (Lonnoroth & Raviglione, 2008); however, although methods of prevention and treatment of TB have been available for many years, control programs face challenges to attain benchmarks to reduce the incidence of disease. This is at least in part associated with the health-seeking-behaviours of TB patients, many of who delay presentation for TB diagnosis, do not enter DOTS, and/or do not comply with the therapeutic regimen, thus causing persistent TB infection in the community (Dye, et al., 2002; WHO, 2006c). In the following section, I explore the literature related to the health-

⁶ Health centre staff conducts monthly visits to villages under the health centre coverage area to provide immunization, ante-natal care check-ups, and health education to members of the community.

seeking behaviour of individuals, and social-cultural, institutional and structural factors that shape their behaviour. This literature is used to develop a conceptual framework underpinning my research. I finally elaborate on research on health-seeking behaviour among Cambodians.

Medical anthropological research exploring health-seeking behaviour has focused on how illnesses are constructed at a local level, in contrast with those of biomedicine, and how this influences diagnosis and treatment-seeking. The extent to which traditional beliefs and practices contradict biomedical approaches to illness determine treatment-seeking behaviour (Inhorn & Brown, 1990). Foster (1977) demonstrated that western medicines were often rejected due to their incompatibility with local cultural beliefs on illness and understandings of the quality, cost and convenience of medicines. He suggests that individuals' decisions concerning the use of western medicines to cure illness occur as a result of interactions between local understanding and the distribution of western medicines. Young (1981) argued that people make decisions about the treatment of specific illnesses based on their knowledge about health, the meanings they give to their symptoms, and the potential consequences of an illness (Young, 1981). This is consistent with health promotion approaches worldwide that have long been argued on the idea that providing knowledge about the cause(s) of ill health and the (treatment) choices available will promote individual behavioural change towards more beneficial health-seeking behaviour (MacKian, et al., 2004). These models, however, had led to patients being blamed for neglecting to take proper care of their own health (Lambert & Stuyft, 2005).

Health-seeking behaviours have been elucidated through complex anthropological models of underlying factors including the (perceived) severity of illness, knowledge of home therapy, faith in treatment, and costs and resources available to afford treatment (Mathews & Hill, 1990; Weller, et al., 1997). These models are premised on the understanding that

much medical care was in the hands of lay people: when given a variety of treatment options, they choose what to do first and next. A Cameroon study, for example, showed that local people followed common patterns regarding their medical decision-making (Ryan, 1998). Firstly, ill people and their families wait after the emergence of symptoms for at least 24 hours before doing anything; this delay allowed patients and/or caregivers to identify potential illness explanations and to determine the appropriate health actions. The second step involved people trying to solve the health problem with cheaper and more readily available treatments, for instance, by using home remedies or over-the-counter medicines. If the symptoms were still not resolved, patients then tried several therapies within and outside their community with the hope of finding an appropriate treatment (Ryan, 1998). The micro-level socioeconomic context was profoundly important: for example, participants initiated their treatment with no or low-cost remedies before consulting professional health providers at a later stage. Common themes influencing the decision-making process towards a particular treatment were patients' interpretation of illness severity, treatment knowledge, and family analysis of treatment and associated costs.

Research on health-seeking behaviours has often focussed on patient-level determinants. However, this approach has been criticised for privileging individual and cultural illness beliefs and neglecting the influence of other factors (Farmer, 1997). The spread or persistence of a disease within specific population groups is associated with many factors, which are not all cultural, and which are generated on global and local levels. For example, economic and political factors shape the country and living conditions for the population, and may create risks for people to be exposed to infectious disease. Through his work in Haiti, Farmer (1997) demonstrated that social inequality is the root of poverty—in this way: he showed poverty is not just a result of local conditions but is also influenced by global and historical contexts including being a former colony, having undeveloped infrastructure,

and inability to produce goods for global market competition. As a result of being a poor person in a poor community, Haitians lack access to the basic preconditions to protect their health, and are therefore more prone to any infectious diseases (Inhorn & Brown, 1990; Farmer, 1997, 2004).

Medical anthropological interest in the control of infectious diseases has emphasized on two aspects: a) the identification of local beliefs about the cause(s), symptoms, treatment and prevention of infectious diseases, and, b) the translation of these local perceptions into culturally and economically acceptable and accessible disease control measures in a way that is sustainable and affordable for local government (Manderson, 1998). In response, many researchers are exploring how the cultural, political-economic and institutional structures of health care interact together (Ho, 2004; Chard, 2009). Tanzanian research showed that mothers delayed taking their febrile child to a local dispensary when they perceived that the child's health problem was just an "ordinary" fever, as opposed to suspecting malaria. More importantly, however, poor patient-provider interactions led to further delays to appropriate diagnosis and treatment (Kamat, 2006). Similarly, Thai research on health-seeking behaviour in the context of *khai mak mai* "fruit fever" found that although locally constructed models of the illness were opposite to biomedical understandings, ineffective patient-provider relationships were the main reason leading patients to refuse professional health care and instead prefer to use traditional healers (Pylypa, 2007). On the other hand, Ugandan research has illustrated that participants' health-seeking behaviour was influenced by a combination of structural, social and economic factors (Chard, 2009).

Individuals' health-seeking-behaviour also differs according to type of disease: acute or chronic health conditions stigmatized or not. For example, Kenyan mothers classified their child's illness into four main categories: not serious, which included coughs, colds and diarrhoea; serious but not life-threatening (e.g. malaria); sudden and serious (e.g.

pneumonia); and chronic (including malnutrition, tuberculosis and chronic cough) (Nyamongo, 2002). These lay distinctions of illness were based on mothers' knowledge of the 'danger signs' of illness, which influenced their responses and the time of delay. Mothers tended to treat 'not serious' conditions with pain killers and observed the symptoms because they considered these diseases as not life-threatening. In the case of malaria, mothers treated their children with over-the-counter medications and waited for three days before moving to private health providers when the symptoms did not improve; the waiting time was much longer for chronic health conditions and did not involve focused actions. In contrast, where mothers perceived that their child had pneumonia, they immediately presented at a health facility (Nyamongo, 2002). In general, studies on health-seeking behaviour have demonstrated that the decision to engage with a particular medical channel is influenced by a variety of socio-economic variables, gender, age, access to health services, and type of illnesses (Tipping and Segall, 1995).

Research from other developing countries has showed that several factors determine people's health-seeking-behaviour in response to emergence of TB symptoms, they fit into three categories identified by Barnhoorn and Adriaanse (1992) including predisposing or individual factors, enabling factors which include institutional health system, and reinforcing factors including stigma, social support and socio-economic status. These factors influence one another and affect health-seeking behaviour of TB patients.

Predisposing factors

Individuals' knowledge about TB symptoms, cause(s) and treatment, and their knowledge about and attitudes toward health care options, play an important role in their decision-making of whether or not to seek health care. Anthropological studies conducted in a variety of settings showed that people interpret TB-related symptoms differently across cultures, although they experience similar clinical episodes. Cultural understandings of

disease are often juxtaposed with biomedical knowledge about disease, so that 'lay beliefs' about illness incorporate some of these biomedical aspects. Such juxtaposition significantly affects their treatment-seeking behaviours (Barnhoorn & Adriaanse, 1992; Nichter, 1994; Menegoni, 1996; Carey, et al., 1997; Vecchiato, 1997). Barnhoorn and Adriaanse (1992) explained that individuals' knowledge about TB and the healing process contributed to their compliance with TB treatment. Furthermore, Menegoni (1996) showed that most TB patients understood that cough was an important TB symptom, and that it may be associated with sputum, difficulty in breathing, weight loss, persistence fever, or bleeding cough; however, at the onset of their illness, these patients often overlooked cough or confused these symptoms with other respiratory infections. This perception increased delays to diagnosis (Menegoni, 1996).

Although cough is the most frequently recognized signs of TB, there is limited information explaining the lay categories of cough, why people hold such categories, and how these categories link cough to TB by patients. Nichter's (1994) study on local understanding of TB in the Philippines identified that several types of coughs, productive cough (cough with a lot of sputum), dry cough (cough with little or no sputum), cough with noisy breathing, and bleeding cough were believed to be associated with 'weak lung' or TB. Coughing with blood was considered to be severe, and led patients to seek medical advice from a hospital, where TB might be diagnosed or eliminated as a cause of (Nichter, 1994). However, lay perceptions of bleeding cough differ across cultures, and do not always prompt people to seek treatment. For example, Ethiopian participants considered bleeding to be the result of drainage bad blood from the body, and it was therefore considered to be an embodied treatment of some underlying pathology (Vecchiato, 1997). A study of Filipino caregivers in response to acute respiratory infections (ARI) in children showed that lay categories of cough influenced their selection of health care and management of childhood ARI (acute

respiratory infection) (McNee, et al., 1995). Participants interpreted cough in several ways: cough due to wind; cough or cold due to change in temperature; hard cough; whooping cough; and asthma cough. Two important salient factors influencing caregivers' decision to seek a particular type of health care were perception of cause(s) and interpretation of symptoms. For example, caregivers would bring the child to a traditional healer when they perceived that cough and fever were caused by *piang* (McNee, et al., 1995). *Piang*—dislocation of tissue or bone in the chest or back— was regarded as the main cause of serious cough and fever.

These studies have highlighted the importance of cultural beliefs about cough in influencing patients' and caregivers' decisions with regard to health care. However, they do not explain why people in those contexts held particular beliefs, and do not discuss the influence of other factors, such as the health system and socio-economic status, in influencing health-seeking behaviour. Similarly, ethnographical research conducted in three different geographic locations in Aceh Province (Indonesia) showed a range of explanations for cause of cough including poison, exhaustion and wind. Their explanations were influenced by Islamic culture, the western medical system in the local areas, level of formal education and peoples' familiarity with TB. But again, health services and systems factors are ignored.

Local constructions of cough remain important in understanding health-seeking behaviour related to TB in different settings. Xeuatvongsa (2005) illustrated that people in Laos defined cough into several categories according to perceived cause, severity and prognosis. 'Ordinary cough' referred to cough associated with a cold or sore throat; 'lung-localized cough' was defined as cough associated with lung diseases including lung oedema, lung infections, and TB; 'productive cough' referred to cough with or without phlegm (also included dry cough and cough with blood); 'weather cough' referred to cough associated

with changes of weather; ‘chicken cough’ usually occurred among children under 5 years of age; and a range of other coughs are defined according to length of cough, for example, of sudden onset or chronic cough. These categories were based on people’s understandings and experiences related to cough. There was no single type of cough indicating TB, although patients may suspect TB infection when their cough persisted or became severe (Xeuatvongsa, 2005). Similarly, participants in other settings (Liam, et al., 1999; Khan, et al., 2000; OBoyle, et al., 2002) were not initially concerned about TB, and typically attributed their symptoms to other diseases such as the common cold, ordinary cough, respiratory infections, asthma, lung cancer, diabetes, having a weak body, excessive work, or due to smoking. Consequently, they sought health care according to their initial lay (self) diagnosis and delayed presentation for diagnosis.

Lay understandings of cause(s) of TB also varied. Participants in some research explained TB causation in relation to physical factors (e.g. working hard, lack of self-care, poor health status, and smoking), environmental factors (e.g. exposure to extreme weather, working or living in a dusty environment), psychological problems (e.g. worry or stress), and traditional or folk factors (e.g. magic, sorcery, hereditary); these perceptions influenced treatment-seeking behaviour and adherence to treatment (Gibson, et al., 2005; Sagbakken, et al., 2008). In Ethiopia, participants perceived that *bird* (cold or any cold element such as wind, water, or air) was a cause or a predisposing factor for TB (Sagbakken, et al., 2008). Exposure to blowing or cold wind, or sudden changes between cold and warm weather, were seen as damaging bodily strengths and causing TB. They often explained the cause of their TB by saying that “they were attacked or hit by *bird*”, and therefore managed their early symptoms with home remedies (oil-seed tea or herb porridge) for some weeks prior to seeking help from private or public providers; this practice contributed to delays in TB diagnosis (Sagbakken, et al., 2008).

Similarly, Timor-Leste research has demonstrated that participants' treatment options were associated with the perceived cause(s) of their symptoms; for example, those who associated TB with *meas or muta ran* (haemoptysis or bleeding cough), a very serious condition, sought medical interventions urgently, while those who believed that TB occurred as an inherited disease felt ashamed of being diagnosed with TB and therefore avoided seeking treatment. Some participants believed that western medicine could effectively treat TB if the patient had already performed a ritual ceremony, *sakit ain iba mota*, officiated by a traditional priest to remove any spiritual or magical factors that were associated with illness. Lack of understanding about TB treatment led many Timor-Leste patients to interpret that they were "cured" as their TB symptoms diminished, and therefore they stopped taking TB medications (Martins, et al., 2008). Similarly, Balinese participants perceived that TB was caused by physical factors, hereditary, or Balinese magic or spirit (Watkins & Plant, 2004). Lack of awareness about TB contributed to the delayed presentation for diagnosis and treatment, as patients initially overlooked the possibility of having TB and managed their symptoms using low-cost treatments from local health providers. Watkins argued that improving awareness of TB in the community would help to remove misunderstandings associated with TB, which also perpetuated TB-associated stigma, and that therefore would contribute to improved TB case detection (Watkins, et al., 2004). Another Indonesian researcher has confirmed that patients' lack of awareness about TB treatment duration contributed to interruptions in treatment, particularly when patients felt better; this research also highlighted other factors that influence treatment adherence, including lack of money to pay for treatment fees or for transport, and the negative attitudes of health staff to people with TB (Widjanarko, et al., 2009). A study with 234 new smear-positive TB patients in Nepal found that participants' perceptions of benefits of TB treatment was significantly associated with adherence to the treatment (Bam, et al., 2006).

Traditional beliefs related to the cause and treatment of TB can create significant barriers to compliance to treatment (Johansson & Winkvist, 2002). Poor understanding of treatments required to cure TB and lack of associated information and education provided by health workers has led to non-adherence to TB treatment in many contexts (Barnhoorn & Adriaanse, 1992; Tekle, et al., 2002; Watkins, et al., 2004). An Ethiopian-case control study with 80 cases of TB defaulters and 160 controls (non-defaulters) found that defaulted treatment often occurred during the continuation phase (the last four months) of TB treatment; 14% of these defaulters stated that the main reason for defaulting was their lack of understanding about the duration of treatment (Tekle, et al., 2002).

Lay understandings of TB transmission also influence health-seeking behaviour particularly in relation to prevention practices. Research across cultures has shown that these lay explanations draw on two contradicting concepts: contagion and non-contagion. Those who believed that TB was contagious explained several pathways of transmission: sharing food or eating utensils with patients, being in close contact with a TB patient, talking with a TB patient or being in close proximity when TB patients cough, or through sexual transmission. Participants who believed that TB is not contagious explained disease transmission in term of: hereditary, sorcery e.g. evil eyes, sins, breaking social taboos, exposure to extreme weather changes, physical hard work, and smoking (Liefvooghe, et al., 1997; Poss, 1998; Caprara, et al., 2000; Xeuatvongsa, 2005). These perceptions of TB transmission led to choices about prevention practices: people who perceived TB as non-contagious usually did not take precautions to prevent transmission; in contrast, those who regarded TB as a food-borne disease avoided sharing food, utensils or being in close contact with TB patients (Long, et al., 1999b). Perceptions of TB transmission also created stigma associated with the disease, creating high levels of fear of TB patients, leading people to avoid contact with them to avoid transmission (Dodor, et al., 2008).

An individual's knowledge of TB remains an important factor to predict health-seeking behaviour, and can lead to delayed presentation of TB patients to the DOTS program. However, the process of selecting a treatment option was often influenced by factors beyond culture and/or the individual. I now turn to these enabling factors.

Institutional factor associated with TB

Enabling factors facilitate or hinder people's health-related behaviour, and in this context the term refers to factors that allow people to access TB services and comply with treatment (Becker, 1974b; Barnhoorn & Adriaanse, 1992). The public health system itself also influences health-seeking behaviour and access to services. Both the health system structure and models of service delivery are important factors enabling or constraining patients' access to TB treatment; they also affect treatment adherence (Munro, et al., 2007b; Storla, et al., 2008; Gele, et al., 2010). A systematic review found that the health care system significantly caused delays to TB diagnosis in low and middle income countries (LMICs), which ranged from 2 days in China to 87 days in Pakistan (average 28.4 days) (Sreeramareddy, et al., 2009). Delays related to the health system were predominantly caused by health provider's lack of knowledge about TB, poor patient-provider interactions, and fragmentation of TB diagnostic facilities (Yimer, et al., 2005; Gaglotti, et al., 2006).

Delays to diagnosis present a great challenge to TB control programs (Needham, et al., 2004). Like other transmissible diseases, delayed diagnosis and treatment of TB has two consequences: short-term consequences affect the individual, where severity of disease is escalated and transmission to others may increase, while the long-term consequences are continued transmission of TB and the development of drug resistance (Manderson, 1998). Delays to TB diagnosis are harmful as they extend the period of disease infectivity for health workers and community members who have a contact with patients. US research on

delays to TB diagnosis and its implications for TB transmission found that people who had contact with patients who experienced 90 days delay from symptoms onset to diagnosis were almost twice as likely to be Tuberculin Skin Test (TST) positive, compared to those with a delay of less than 60 days (40% and 24%, respectively) (Golub, et al., 2006).

In addition to socio-demographic factors, socioeconomic status, knowledge about TB, and stigma (Godfrey-Faussett, et al., 2002; Gaglotti, et al., 2006), access to TB diagnosis and treatment was often prevented by multiple factors. These include poor access to the public health sectors, caused by administrative procedures, long waiting times, costs, lack of diagnostic equipment and supplies, and geographic distance, and individuals' preferences for using traditional healers and/or private providers (Combanis, et al., 2005; Moro, et al., 2005).

These main barriers to access to health facilities in resource poor countries indicate long distances from public health facilities, poor road conditions, and high transportation costs—led to delays in presenting to health services by TB patients (Needham, et al., 2001; Demissie, et al., 2002; Gele, et al., 2009). For example, one study exploring access to health services among Somali pastoralists in Ethiopia found that delays to diagnosis were due primarily to the limited accessibility of TB control programs. As participants migrated from place to place according to season, they delayed seeking medical care until they moved to a place close to health services; they typically waited until the wet season when they had more free time to attend the health service (Gele, et al., 2010). Similarly, distances have been found to prevent access among the poorest population groups (Lonnroth, et al., 2007; Sagbakken, et al., 2008). In Myanmar, delays in TB diagnosis and treatment were mostly attributed to ineffective performance of the public health service. For example, health providers did not inform patients about free treatment available in the public sector; this was compounded by inconvenient opening hours, unavailability of a sputum microscopy

service, long waiting times, and excess documentation required in the public health services (Saw Saw, 2006). In addition, poor physical characteristics, lack of privacy, rigid administrative procedures, poor patient-provider interaction, and lack of information about health services are major barriers contributing to delays in accessing public health facilities for the diagnosis and treatment of TB and, indeed, for other health and medical care (Lonnroth, et al., 2001; Van Damme, et al., 2004).

In consequence, these health system factors shaped patients' preference for private health services. In Vietnam despite trust in the quality of TB treatment provided free of charge by the TB Control Program, TB patients (particularly women) preferred to seek treatment from private practitioners, because they perceived the private services as convenient (close to their homes), offering more privacy, having fewer administrative requirements, and requiring no formal registration of TB cases; they thus posed less of a threat of stigma (Lonnroth, et al., 2001). In Pakistan, non-adherence to TB treatment was closely linked to health system deficits rather than the unwillingness of TB patients to comply with the treatment regimen (Khan, et al., 2007). The authors of this study showed that medical and paramedical staff described limited provider-patient interactions due to high workloads and limited numbers of staff. In addition, patients who sought health care in public services experienced unsatisfactory service quality, long waiting times, and little or no TB education (Khan, et al., 2007).

Access to TB diagnosis has also been shown to be affected by the multiplicity of health care options offered by medial private providers and traditional healers. Depending on country setting, private providers, particularly local drug stores, pharmacies and local injectors, were usually the first providers consulted by TB patients, particularly those who lived in rural or remote areas where physical accessibility to health services was difficult (Saw Saw, 2006; ten Asbroek, et al., 2008; Rintiswati, et al., 2009). However, significant

problems have been identified in relation to such trends. Inappropriate treatment and follow-up by private providers have been found to delay access to TB health care in many countries: Vietnam, Thailand, India, Zambia, Nepal, Indonesia, Laos and Myanmar (Kamolratanakul, et al., 1999; Long, et al., 1999b; Rajeswari, et al., 2002; Needham, et al., 2004; Xeuatvongsa, 2005; Saw Saw, 2006; ten Asbroek, et al., 2008). This has led to a greater likelihood of developing severe illness, ineffective use of the limited health resources of individuals, and increased mortality. Furthermore, inappropriately prescribed medicines potentially can lead to the development of TB drug resistance, making the disease more difficult to treat, so requiring longer treatment duration and greater resources (Nichter, 1994; Farmer, 1997). Some studies also revealed that the alternative TB treatment provided in the private sector created confusion for TB patients; for example, some patients dropped out of the treatment provided by the public TB program and turned to private services because of its perceived convenience, confidentiality and flexibility regarding payment (Nair, et al., 1997; Uplekar, et al., 2001a; Buu, et al., 2003).

Economic factors associated with TB

The relationship between poverty and TB has been well documented: poverty leads to poor living conditions, housing, sanitation, and nutrition in addition to overcrowding. People who live in these conditions are more prone to infectious diseases, including TB. Furthermore, the financial constraints experienced by poor people in their daily lives lead to delayed presentation for TB diagnosis and/or inability to comply with treatment (Kamolratanakul, et al., 1999; Xeuatvongsa, 2005). In Laos, poverty caused patients with TB symptoms to seek low-cost treatment with traditional healers or low-qualified providers, and therefore delayed presentation to DOTS; desperately poor patients could not afford transportation costs to attend DOTS treatment which was often located in more populous areas. Poverty further contributed to non-adherence to TB treatment, as some

patients refused to be hospitalized during the intensive phase of their treatment (Xeuatvongsa, 2005). Lack of money to seek diagnosis and comply with treatment was repeatedly reported as leading to delayed diagnosis and non-adherence to TB treatment in Indonesia (Caprara, et al., 2000; Watkins, et al., 2004; Widjanarko, et al., 2009). Poor patients in this country could not afford to comply with treatment, as they needed to hold down a job, particularly when their health became better. Although TB treatment was provided free, Thai patients too encountered high costs associated with transport, thus some desperately poor patients did not present to the hospital for diagnosis (Kamolratanakul, et al., 1999). Low-income families in the Philippines were more likely to engage in self-treatment for TB-related symptoms using local remedies or herbal products, and therefore delay presentation to health services for appropriate TB diagnosis (Navio, et al., 2002). These findings reinforce long recognized knowledge that the economic status of families and societies is the key reason for non-adherence. Even if patients held traditional beliefs about TB causation (e.g. 'evil eyes'), in Haiti, they still complied with TB treatment if resources were available for them to afford the treatment (Farmer, 1997).

Although TB treatment is provided free of charge in many settings, costs associated with this illness impacted significantly on family economics, leading to debts and deepened poverty (Needham, et al., 2004; Kemp, et al., 2007). Costs associated with TB treatment include direct (expenses incurred related to medical consultations, medicine, medical tests, food and travel costs during treatment) and indirect costs (e.g. loss of income during sickness) (Long, et al., 2001; Needham, et al., 2004; Russell, 2004; Xeuatvongsa, 2005; Kemp, et al., 2007). In Laos, costs associated with TB treatment prior to and during treatment under DOTS significantly impacted on household economics. TB patients spent significant amounts of money before presenting to the DOTS program, because they used multiple traditional and/or unqualified providers. These costs were not always cash: for

example, in Laos although traditional healers did not ask patients to pay cash for their services, their ritual ceremonies required patients to sacrifice buffaloes (each costing US\$300-400) or other animals (chickens, pigs, goats) to ancestor spirits— an often expensive undertaking. Similarly, some patients spent significant amounts of money attending multiple private health providers, and therefore often had few remaining resources when they presented to a DOTS program: the longer they delayed, the greater the costs. To meet these costs, patients took loans with high interest rates from the informal sector; very often, young adult family members had to migrate to the city or Thailand to earn enough money to repay the loan (Xeuatvongsa, 2005).

Considerable costs were encountered during hospitalization through unofficial costs for special food, and lost work days (Khan, et al., 2000; Kik, et al., 2009). More than 60% of Indian patients who treated their TB through government clinics, private providers, or NGO clinics had borrowed money in order to comply with treatment (Rajeswari, et al., 1999). Tanzanian patients encountered significant costs during period of illness: examinations and laboratory tests cost US\$2, consultations and drugs cost US\$17-50, and transport cost US\$13-20; further the indirect costs patients encountered due to their inability to work were reported as between US\$154-1384. These costs led family members to fall into debt and deepen family economic problems (Wyss, et al., 2001). These costs were catastrophic for the household, and indicate that, although TB drugs may be provided for free, desperately poor TB patients may not be able to afford to enrol in DOTS (Aye, et al., 2010; Zhang, et al., 2007). In Malawi, direct and opportunity costs in TB treatment faced by the poor were around three times less than those faced by the non-poor (US\$15 compared to US\$48), because the poor spent less on fees, food, and transport. Nonetheless, compared to total income, the poor were strongly impacted by TB-associated costs, and spent 244% of their total monthly income (compared with 129% for the non-

poor). In seeking diagnosis, recovery of the associated costs meant that the poor had to work for 2.5 months (Kemp, et al., 2007). These studies suggest that although DOTS is provided without cost, people from poor households were deterred from seeking health care due to household costs, which prevented health services from reaching those most in need.

Social stigma associated with TB

According to Goffman, stigma ascribes negative social meanings to certain behaviour or to individuals (Goffman, 1963). His analysis of people living with physical disabilities, deformities, blindness or deafness, or engaged in prostitution, or homosexuality, and those who were illiterate, showed that society categorized people according to series of normative expectations about behaviour. As a result, where these expectations are transgressed, a boundary is created between the 'normals' (non-deviant) and the 'deviants'. In consequence the 'deviants' are ascribed as having a 'spoiled identity' and become socially excluded.

However, Goffman's definition has been critiqued: as vaguely defined, individualistic and focused on micro-level phenomena, without providing adequate attention to the social processes that exclude and discriminate against them (Das, 2001; Link & Phelan, 2001; Parker & Aggleton, 2003; Scambler, 2009). Stigma and discrimination are closely related, but they are not the same. The former refers to a severely discrediting attribute; the latter refers to circumstances by which the stigmatized person's life opportunities are minimized (Parker & Aggleton, 2003; Reidpath, et al., 2005). There are two forms of discrimination: direct discrimination happens when a person is treated less favourably than other members of their community because of their health problems; while indirect discrimination occurs when a set of requirement or condition is imposed on health grounds, so that people with a disease are treated less favourably because they cannot comply with it (UK Acts of Parliament outlawing discrimination cited in Baral, et al, 2007). Examples from the

HIV/AIDS literature shows that people living with HIV/AIDS tended to be discriminated against not only on the basis of their stigmatized attribute but also by class, gender, and race. In identifying the shortcoming of Goffman's stigma in relation to health conditions, Weiss and colleagues (2004) suggested a modified concept of stigma that could be better applied to research on health-related stigma, including TB:

Stigma is typically a social process, experienced, or anticipated, characterized by exclusion, rejection, blame or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgment about a person or group. This judgment is based on an enduring feature of identity conferred by a health problem or a health related condition, and the judgment is in some essential way medically unwarranted. In addition to its application to persons or a group, the discriminatory social judgment may also be applied to the disease or designated health problem itself with repercussions in social and health policy. Other forms of stigma, which result from adverse social judgments about enduring features of identity apart from health-related conditions (e.g. race, ethnicity, sexual preferences), may also affect health; these are also matters of interest that concern questions of health-related stigma (Weiss et al, 2006:280)

Weiss's definition of stigma takes into consideration the broader social context as contributing to stigma associated with a health problem. This can be applied better to my research on stigma associated with TB, as I aim to explore the causes of stigma and discrimination by taking into consideration the broader significance of socio-economic status (e.g. poverty, poor living conditions and lack of hygiene) in contributing to stigma, rather than just focusing on the features of disease itself (Johansson, et al., 1999; Leao & Portael, 2007).

Earlier studies showed that stigma associated with TB may result in delayed treatment seeking and non-adherence (Tupasi, et al., 2000; Godfrey-Faussett, et al., 2002; Watkins, et al., 2004; Cambanis, et al., 2005; Rajeswari, et al., 2005). TB-related stigma includes both felt stigma and enacted stigma (social exclusion or discrimination concentrated on the TB

patients) (Hovell, et al., 2003; Balasubramanian, et al., 2004; Karim, et al., 2007). Kelly (1999) demonstrated that TB patients and community members' fears regarding the dangers caused by TB create stigma toward TB patients (Kelly, 1999), making them feel embarrassed, distressed, or scared to be so diagnosed; therefore they delayed presentation for TB diagnosis until their symptoms became very severe (Watkins, et al., 2004). As described in a multi-country study on gender and TB in Bangladesh, India, Malawi, and Columbia, the exaggerated fear of TB transmission very often placed limits on the relationships between TB patients, their family members, and members of their community (WHO/TDR, 2006). The majority of participants in the four sites sought to cover up their illness because of concerns about social stigma created by members of their community, as a result of their worries about TB transmission (WHO/TDR, 2006; Karim, et al., 2007).

Research on social responses to many infectious diseases highlights the moral basis of stigma, particularly in relation to origin of disease transmission. A study comparing TB-related stigma with that of HIV/AIDS and SARS (Severe Acute Respiratory Syndrome) showed that stigma is greatest for individuals with HIV/AIDS, followed by those with TB, and least for people with SARS (Mark, et al., 2006). Stigma was highly linked with the attribution of infection to internal and external factors. Infection with HIV/AIDS has often been associated with voluntary and immoral behaviour, which thus leads to the greatest level of stigmatization; HIV/AIDS infection is often associated with drug use, sexual promiscuity (regardless of sexual orientation), and homosexuality or bisexuality, which are considered to be inappropriate, unacceptable, and immoral behaviours in many societies. Central to the stigma associated with HIV/AIDS is the notion that individuals voluntarily engaged in these high-risk behaviours. In contrast, these perspectives of sexual taboo are not attributed to individuals infected with TB (Mark, et al., 2006). However, the presumed direct association between HIV and TB is often present, and creates a huge

stigma towards TB patients; as was reported in Malawi where members of the community presumed that those who had TB also had HIV/AIDS, and thus they avoided contact with them (Ngamvithayapong, et al., 2000; Godfrey-Faussett, et al., 2002; WHO/TDR, 2006). In Zambia, 49.3% of TB patients believed that presenting at a clinic for TB diagnosis could make community members suspect that they also carried HIV/AIDS (Godfrey-Faussett, et al., 2002). Furthermore, TB-related stigma was also caused by its association with disadvantaged social status: desperately poor, homeless, or incarcerated (Brewin, et al., 2006).

The experience of stigma is also gendered. In some cultures, stigma is more pronounced when a condition is experienced by women than men. For example, women in Vietnam were often extremely scared of social stigma and isolation when diagnosed with TB, reporting fears of being rejected by their husband, harassed by their in-laws or, for single women, worrying about considerably reduced chances of marriage (Long, et al., 1999a). In Malawi, single women reported problems getting married despite being cured of TB, as men perceived that a woman who had had TB was dangerous as she may be infected also with HIV/AIDS (WHO/TDR, 2006; Somma, et al., 2008). Women in Bangladesh described feeling shame and embarrassment, worthlessness, and faced being secluded from the rest of their family or forced by their in-laws and husband to commit suicide following TB diagnosis (Karim, et al., 2008). Men in Vietnam and Bangladesh, on the other hand, were mainly concerned about the economic burdens of TB diagnosis, such as loss of income, poor job performance, reduced capacity for work, and being refused sex by their wives (Long, et al., 2001; Karim, et al., 2008). However, in some cultures, stigma was not always significant for TB control. Studies from Laos and Myanmar showed that stigma and discrimination attached to TB is not a problem, as community members often maintain a normal relationship with TB patients. Stigma may exist among educated people who

understood the pathway of TB transmission; therefore they tried to avoid physical contact or avoided sharing eating utensils and other facilities with TB patients (Xeuatvongsa, 2005). This indicated a lack of appropriate knowledge of TB transmission and prevention for Laotian people. In Myanmar, only a few participants felt ashamed to be known as TB patients because this disease was associated with extreme poverty, and usually occurs among people who cannot afford enough food for adequate nutrition. However, here stigma is not recognized as a barrier for people to access to TB diagnosis and treatment (Saw Saw, 2006).

Gender issues associated with TB

Both sex—the biological characteristics that identify someone as female or male—and gender—the associated social constructions and practices—appear to be implicated in TB diagnosis and treatment (Mackenzie, 2007). Epidemiological research indicates that more men suffer from TB than women. Dye (2006) reported that in 2004, 1.4 million smear-positive cases were reported globally for men, but only 775,000 women (Dye, 2006), with a ratio of less than 1 (Borgdorff, et al., 2000; Dye, 2006). TB is the leading cause of death among women of reproductive age. It kills one million women worldwide each year (Thorson & Diwan, 2001), and is more likely to affect women at younger ages (25 years or under) than men (Martinez, et al., 2000). TB tends to progress more rapidly in female patients of childbearing age (15-40 years) (Austin, et al., 2004). However, the reasons behind these gender differences remain blurred and suspicions of under-diagnosis and under-reporting among women remain (Hudelson, 1996; WHO/TDR, 2006). Imbalances in TB incidence encompasses gender issues, stigma, and issues around access to health services among women, rather than biological phenomena (Uplekar, et al., 2001b; Austin, et al., 2004).

Social and cultural factors shape the different roles and responsibilities of men and women, which create different opportunities and exposure to risk of infection and diseases (Manderson, et al., 1996). In addition, unequal social values placed on women and men put women in a position of disadvantage and poorer status than men in households and in society (Allotey & Gaypong, 2004). This results in their poorer access to adequate health services for TB diagnosis and treatment (Hudelson, 1996). Research has highlighted the way in which socio-political, economic and cultural factors contribute to delay or under-diagnosis of TB among women. Khan (2007) demonstrated that low TB diagnosis among women in Pakistan may be caused by women's poor knowledge regarding the need for sputum collection and the techniques to do it properly, affecting collection of their sputum specimens; this results in the submission of poor quality of sputum by women (Khan, et al., 2007). Their randomized control trial in 2007 found that TB smear-positive rates were significantly higher among women who were given clear instructions about how to collect their sputum specimen, due to better quality sputum submission, compared with women in the control group; no differences were found between instructed and control groups for men (Khan, et al., 2007). Research in the Bavi district of northern Vietnam indicated similar prevalence rates of TB for men and women (90/100,000 and 100/100,000 respectively); however TB case-detection rate for women was significantly lower (39% and 12%) (Thorson, et al., 2004). In Bangladesh, women with respiratory symptoms had less access than men to outpatient public clinics, and those who entered the clinics were less likely to undergo sputum smear examination due to lack of understanding about TB and fear of stigma associated with it (Begum, et al., 2001).

Women delayed seeking care because of household responsibilities and unwillingness to use their limited resources; this led them to self-medicate, and seek care from traditional healers or under-qualified providers (Long, et al., 1999b; Begum, et al., 2001; Yamasaki-

Nakagawa, et al., 2001; WHO/TDR, 2006; Khan, et al., 2007). In Vietnam, women delayed longer than men in accessing health services, chose cheaper health care, and did not submit sputum for TB diagnosis (Thorson, et al., 2000; Huong, et al., 2007). In addition, they often hid their illness. As a result, the average delay to TB diagnosis was longer for women than men (13.3 weeks cf. 11.5 weeks). In Laos, significantly more men than women were treated under DOTS (Xeuvatvongsa, 2005), and women delayed longer than men in accessing the TB program, mainly because of multiple household roles particularly their care giving roles.

Where household resources were limited, men's health care was privileged over women's because men play more important roles in the family as the head of a household, they also tended to be the main source of household income. Furthermore, women often relied on their husband's decision-making about their health care needs, yet their husband were reluctant to spend household resources on (women's) health needs (Hardeman, et al., 2004; Xeuvatvongsa, 2005). Impaired access to household finance, poor social networks and lack of independence when travelling on their own, placed women with TB in Pakistan in a desperate positions regarding decision-making about their own health care (Khan, et al., 2007). Social pressure related to TB is also more pronounced among women. In India and Bangladesh, for example, TB created extreme psychological distress in women who feared divorce, a spoiled chance of marriage, rejection by in-laws, worthlessness, and loss of their abilities to care for children—thus women may avoid seeking TB diagnosis (Lonnroth, et al., 2001; WHO/TDR, 2006). At the same time, women who were the caregivers for sick family members, including TB patients, increased their vulnerability to infection with the disease (Xeuvatvongsa, 2005; Khan, et al., 2007).

Research associated with health-seeking behaviour in Cambodia

Research on health-seeking behaviour in Cambodia is limited. What people do to seek diagnosis and to cope with TB treatment, as well as the adverse impacts of the disease and

treatment adherence on patients and their families, has not been carefully studied, and much knowledge tends to be anecdotal or recorded via feedback during TB project assessments. In the following section, I outline the current literature on the social and institutional factors associated with TB and health-seeking behaviours in Cambodia.

Although not directly concerned with TB, two studies have addressed the health-seeking behaviour of mothers (Yanagisawa, et al., 2004; Khun & Manderson, 2007). Yanagisawa's (2004) cross-sectional study of 257 married women in rural Kandal province (southeast Cambodia) sought to understand what women do when their children or a family member is sick. The first action taken, regardless of disease or symptoms, was the use of home remedies, mainly *kob Khchol* (coining), a traditional practice involving scratching the skin with a coin edge, using liquid balm or another topical ointment, until the area becomes red. Women believed that using *Kob Khchol* could help the body to release 'bad wind', therefore helping a person recover from the symptoms. The second action involved self-medication, using medicine purchased at a small grocery store in the village or with medication left over from a previous illness. Many illness episodes (42%) were treated with a combination of home remedies and self-medication. If the illness did not improve, women would then turn to a private provider (Yanagisawa, et al., 2004). In contrast, Khun's (2007) ethnographic research conducted in Kampong Cham province (eastern Cambodia) with mothers whose children had been sick with suspected dengue fever showed that when their child was sick, most women first purchased over-the-counter (western) medicine for the child; some concurrently used western and traditional medicines to treat their sick child and a few managed the illness with home remedies alone. If this first attempt failed to help their children, mothers then consulted private providers; only a few visited the local health centre. The treatment options used by mothers varied according to their interpretations of the severity of their child's condition, confidence in quality of the service, and their ability

to pay. Although all of the mothers in the study knew what health care was required for their sick child, poverty combined with the limited availability of services and poor perceived quality of care provided by the public health centre and the referral hospital discouraged them from presenting (Khun & Manderson, 2007).

Other studies have also shown that health-seeking behaviour is associated with health care costs, which often brought debt to families and deepened poverty (Van Damme, et al., 2004; Bigdeli & Annear, 2009). Generally, individuals and their families took the primary responsibility for caring for sick family members, including finding and paying for appropriate health services (Van Damme, et al., 2004). Khun (2005) showed that, because of poverty, mothers delayed accessing health centres for their children's treatment; when the disease became severe, some borrowed money or sold household assets (e.g. rice fields, cattle) to take their sick children to a health centre or hospital (Khun, 2005). Van Damme's study (2004) with 72 households in which a child had dengue in Banteay Meanchey Province showed that households paid different amounts according to the type of health care they sought: exclusive use of private providers required, on average, US\$103; combined private and public providers costs about US\$32; and public hospitals required US\$8. To finance this expenditure, families used a combination of savings, sale of assets or borrowing money. One year later, most families had not yet cleared themselves from debt and continued to pay high interest rates (2.5 -15% per month), pushing households to sell their most productive assets, including land (Van Damme, et al., 2004), and thus deepening poverty.

These studies all highlight the profound influence of poverty and health system factors on health-seeking behaviour, but did not identify factors underpinning difficult access to and under-performance of public health services. Further, socio-cultural norms and gender also affect people's willingness to choose a particular place providing health care. For instance,

female-headed households, particularly those with small children, can least afford to go to the hospital because no resources are generated, and sick and young children cannot be left behind. Thus, decisions to help-seek from hospitals would be the last option (Hardeman, et al., 2004). Due to their household responsibilities women may have more difficulty accessing health facilities outside their village.

Research on health-seeking behaviour and TB is very limited. The report from the National Prevalence Survey of TB (2002) conducted by the National TB Control Program showed that 6.8% of 22,160 participants experienced cough for 3 weeks duration or longer. Of suspected pulmonary TB cases, only 3% used public health facilities when they had symptoms, 60% used private services including pharmacies and private clinics, and the rest used self-treatment, ignored the symptoms, or visited a traditional healer (CENAT, 2005b; NTP, 2005a). Reluctance to use public health facilities may contribute to a delay in TB diagnosis. However, the survey failed to explain explicitly how different health care options were used and people's reasons for doing so. Saly (2006) found that significant delays to TB diagnosis occurred in Cambodia, with patients who lived in the areas where DOTS program was available at health centres reporting delays of 58 days, and for those in areas where DOTS was only available at the referral hospital of 258 days. TB patients in this study firstly sought health care from private clinics, pharmacies and/or drug stores, because of the proximity of these point of care to home, and belief in the quality of service provided (Saly, et al., 2006). However, this study did not fully elucidate the health-care seeking practices among TB patients before presentation to DOTS, or the individual, institutional and socio-economic factor associated with delay.

TB-related stigma and its gender-specific features has received little attention in Cambodia. Yi (2009) found that fear of stigma associated with TB led patients to refuse HIV testing at a volunteer counselling and testing centre (VCTC). Participants had negative attitudes

towards HIV/AIDS: for example, they believed that patients are dirty, cannot be trusted, or must have done something wrong (Yi, et al., 2009). Similarly, a 2004 study conducted by the University Research Company found that over 85% (of 60) TB patients expressed that they were embarrassed when seeking TB diagnosis. In addition, approximately 48% of doctors (n=162) acknowledged that TB patients felt ashamed to be diagnosed with TB (University Research Company, 2004). However, the causes of stigma and its influence on access to diagnosis and treatment remain unaddressed, and the study did not explore reasons behind their embarrassment despite considerable research in other settings (discussed earlier) suggesting the impact of stigma on patients' health-seeking behaviour.

In addition, the influence of gender remains insufficiently addressed. Cambodia health data related to health topics, including TB, are generally presented as if gender neutral. While some data, such as TB prevalence rates, are stratified by gender, gender-specified health data has not yet received attention in relation to, for instance, health service utilization, diagnosis, or treatment outcomes. This may be derived from an ideology of 'health for all' of the Cambodian population, regardless of age, gender, ethnicity, and religion, as well as a lack of appreciation that there might be gender differences in health outcomes. Although it has been shown that TB prevalence and incidence is higher among men, blurred explanations of the differences between the sexes in relation to TB case notification remain. In the hierarchical order of Cambodian society, women are considered to be of lower status relative to men. A gender assessment report conducted by the Ministry of Women Affairs in 2002, based on a review of existing information from government, donors and non-governmental organizations, and consultations with various stakeholders, confirmed that women do face greater difficulties in accessing health care (Ministry of Women Affairs, 2004). The report found that 95% of Cambodia women reported difficulties in accessing public health services, and 88% complained about the high costs of

health services, informal user-fees and inequitable user-fee exemptions at public health facilities (Ministry of Women Affaires, 2004). The Cambodia Demographic and Health Survey (CDHS 2000) indicated that 40% of female participants reported distance and cost of transport as barriers in accessing public health services. Very frequently, women bear the burden of responsibilities and roles in the family, which leads to neglect of self-needs including the need for health care (Ministry of Women Affaires, 2004). Women shoulder the burden of infectious diseases, as they are the care-givers of affected partners or family members; women living with an infectious disease are thus often in a unsafe and difficult situation as they continue to carry out household work and care of children, which consequently results in delays in accessing diagnostic facilities or their decision to discontinue treatment (Ministry of Women Affaires, 2004). Moreover, women often have poor nutritional status, making them more prone to infectious diseases, including TB (CDHS, 2000, 2005).

The NTP identified the need for extensive research on health-seeking behaviour related to TB, factors influencing full compliance with treatment, and the roles of gender in TB case notification and the use of health services. This was highlighted in the Ministry of Health Cambodia National Health Strategic Plan for TB 2006-2010 (NTP, 2005a; CENAT, 2006b). In addition, research into the social, cultural and behavioral factors contributing to case detection and barriers of care are highlighted as research priorities (Onyebujoh, et al., 2006).

Justification of the study

NTP increased TB case findings and treatment cure rate significantly with the implementation of DOTS strategy. However, a joint review in 2006 identified that the NTP faced several challenges including funding, program management, case finding, treatment, and monitoring and supervision. TB control in Cambodia is largely dependent on

external funding, mainly on Global Fund to Fight HIV/AIDS, TB, and Malaria. The government budget allocated to the NTP remains minimal and has not increased since 2005. This raises concern related to financial sustainability for the NTP, as donor support is projected to reduce. The management and supervision of TB control remains centralized, following a top-down management approach. The NTP sets the national targets and all provinces, districts, and health centres follow these guidelines and targets without significant adjustment or assessment to take into account the local context. Lack of human resources at lower levels and low staff motivation, due to low government salaries may also be a barrier to TB control in Cambodia (Chhea, et al., 2010).

Further, although TB case detection had increased, the incidence of TB has not decreased as expected. Although Cambodia has reached the target of TB cure rate, variations in this rate persist and the quality of monitoring and supervision of TB activities is problematic. While there are large numbers of supervisory visits, the documentation of findings from such supervisions is limited and related feedback is not sufficient to motivate improvements in TB control activities at the local level.

There has been no clear explanation about the magnitude of delay presentation for TB diagnosis among patients, and on factors influencing the delay. Often patients are blamed for their poor health-seeking behaviour, and thus waste their valuable resources on inappropriate care with private practitioners and the informal health sector. The influence of socio-cultural factors such as gender and social stigma, on health-seeking behaviour has rarely been discussed, and confusion about whether TB patients and their families experience stigma persist. Some NTP and NGOs reports recognise that stigma associated with TB could affect access to DOTS, but these have not clearly explained how it happens and to what extent it affects patients' presentation to DOTS.

Due to these challenges, Cambodia is unlikely to reach its Millennium Development Goals to reduce the prevalence of smear-positive TB from 428/100 000 in 1997 to 135 in 2015, and TB-related deaths from 90/100 000 in 1997 to 32 in 2015 (Cambodia, 2003; WHO, 2007b). The transmission of TB persists, particularly among poor and vulnerable community members as a result of their poor health status; delays in seeking appropriate diagnosis, and non-compliance with TB treatment.

Research questions

To understand the health-seeking behaviour of TB patients in Cambodia, this study sought to address the following questions:

1. How do TB patients, family members, and other members of the community understand TB, including its transmission and treatment, and the period of the infectivity while receiving drug therapy?
2. What do people do between symptom onset and diagnosis? What factors contribute to early case detection of TB? To what extent does health-seeking behaviour within households vary by gender and gender roles?
3. How are health services delivered in rural Cambodia? To what extent does this impact on the health-seeking behaviour of rural Cambodians?
4. How is DOTS implemented in Cambodia? What systems barriers affect implementation?
5. How do patients manage to comply with TB treatment? What factors contribute to treatment outcome (cure, completed, relapsed, and defaulted)?

6. What social-cultural factors are associated with health-seeking behaviour and TB treatment outcomes? To what extent do these factors support compliance with anti-TB treatment and actions to minimize infection of TB?
7. Does stigma associated with TB exist in rural Cambodia, and if so, for what reasons? How do TB patients react toward stigma and discrimination against them? And how does stigma affect TB case finding, family relationships, and treatment outcomes?
8. How does TB impact on family economic circumstances? Are economic roles within the household modified in any way when a member is sick with TB?

In order to answer these questions, the following aims and objectives were examined.

Aim and objectives of the study

Study Aim

This study aimed to investigate the understandings of rural people in Cambodia about TB, and to explain the impact of the nature of the health care system, the social and cultural context (including stigma and gender roles), and the effect of household economics on the health-seeking behaviour of TB patients, and members of their families. It is particularly concerned with how these factors influence the transmission and prevention of TB, and the treatment outcomes of TB patients.

Research Objectives

- 1- Describe how TB patients, their family members, and other members of the community understand transmission, severity, susceptibility, prevention and treatment of TB.
- 2- Explore how health care is delivered in rural areas of Cambodia and identify the impact of the health care system on health-seeking behaviour of community members with or without TB.

- 3- Describe the practices of individuals with TB and their families from disease onset and recognition of problematic symptoms until entering DOTS.
- 4- Understand how TB patients cope with treatment, particularly the extent to which TB affects the physical and mental well-being of TB patients, and identify factors associated with poor TB treatment outcomes.
- 5- Explore economic and socio-cultural factors, including stigma and gender roles, which support or discourage early TB case detection, prevention, and compliance with the treatment regimen.

Structure of thesis

The thesis has been divided into eight chapters. In chapter one, I provide an overview of TB including its natural history related to cause and transmission, the epidemiology and control of TB, the global burden of TB, and TB control in the contemporary world. In addition, I describe the TB situation in Cambodia, before I reviewed the scholarly literature on health-seeking behaviour and social health determinants related to TB success and failure. This literature review provides the background to this research project; it discusses social and cultural meanings of illness, issues of delay to TB diagnosis and treatment. In Chapter 2, I describe the research design and field site, and provide an overview of data collection. I discuss my position in relation to my research participants, and discuss how I selected my participants. This chapter describes how I collected the data. I used qualitative methods, including in-depth interviews, focus group discussions, observations, document reviews, and participation in various trainings, meetings and workshops related to TB. These data were supplemented by a survey with community members. In Chapter 3, I present my findings on participants' explanatory models of illness, in relation to the symptoms, cause, and transmission of TB. In this chapter, I discuss how ethnomedical

knowledge influences people's interpretation and self-diagnosis of illness, as well as how they respond to health complaints. Access to peripheral health services, including public health centres, private services and traditional healers available at the local area, and how these services interact with each other are described in Chapter 4. In doing so, I elaborate the health-seeking practices of rural community members with and without TB. Chapter 5 elaborates the pathways taken by TB patients to reach diagnosis and treatment. I also highlight delays to TB diagnosis and factors influencing delay, particularly institutional factors such as poor access to general health services, misdiagnosis of TB, the use of private or unqualified providers, use of traditional healers, and the impact of poverty.

The focus of Chapter 6 is the implementation of TB diagnosis and treatment at the local level. Other issues such as local explanations of treatment compliance and cure, factors associated with treatment compliance and treatment outcomes (relapse and default), and the physical and mental well-being of TB patients after completing TB treatment are illustrated in this chapter. In chapter 7, I describe the determinants of stigma related to TB in Cambodia, and discuss how stigma interacts with other factors to contribute to diagnosis-seeking and treatment outcomes of TB patients. Finally, in Chapter 8, I draw conclusions and make some strategic recommendations for the future implementation of TB control in Cambodia.

CHAPTER 2

RESEARCH METHODS

Conducting research in rural Cambodia was not my first fieldwork experience. But what made this project special and exciting for me was that it was my first fieldwork that not only allowed me to collect rich data, but also to understand the broader context of Cambodian rural life and to reflect on my own ethical research practice. My fieldwork occurred over an eleven month period in 2008. At the start, I was absolutely out of my comfort zone: the research location was new, my research participants (TB patients) were socially distant from me and also carried an infectious disease. Over time, however, I became deeply attached to my fieldwork, field site and, most importantly, my participants. In this chapter, I outline the characteristics of my research site and describe my field experiences. In doing so, I detail the process of fieldwork including the preparation phase, data collection, reflecting on ethics in practice, and finally, data analysis and study limitations. First of all, I discuss the conceptual framework underpinning this research.

The research conceptual framework

In much research conducted in public health and health promotion, the conceptual frameworks used to answer questions on health-seeking behaviour have focused on two models: 1) the *pathways model* addresses the different steps that patients follow when seeking health care; and 2) a *determinants model* focusing on a set of factors influencing patients' choices of different forms of care. This includes: *predisposing factors*, which influence health care including, patients' beliefs and knowledge about TB and its treatment; *enabling* (i.e. structural and institutional) *factors* within the health service system; and *reinforcing factors*, such as socio-economic factors and support from family members and health providers (Kroeger, 1983; Barnhoorn & Adriaanse, 1992).

Public health research on health-seeking behaviour and disease control has proposed a set of behavioural models to understand factors associated with patients' behaviour and to encourage behaviour change. A commonly-used approach to understanding health-seeking behaviour is the Health Belief Model (HBM). This model predicts that individuals will take action to seek health care or to choose a particular health-related behaviour depending on their beliefs about their perceived susceptibility to a disease, the perceived severity and consequences of that disease, any perceived benefits which will arise as a result of a particular action/behaviour, the costs of service or actions required, and whether the cost(s) will outweigh the benefits obtained. The HBM focuses on the individual taking responsibility for their health care. However, as already noted, individual health behaviour is also influenced by local, national and global economic, political, institutional and structural factors, including factors related to the health system and social and economic conditions (Farmer, 2004).

Studies on health-seeking behaviour in relation to TB have constantly demonstrated twin problems: 1) patients experience delays to diagnosis and 2) patients do not complete the lengthy course of TB treatment. These problems have been reported as resulting from complex social and cultural factors: patients' misunderstandings of symptoms and cause(s), costs associated with transportation to health services, medication costs, organizational problems in providing adequate follow-up services, and the social stigma attached to TB (Rubel & Garro, 1992).

One Indian study (Barnhoorn & Adriaanse, 1992) employed the HBM to explore factors contributing to non-compliance among TB patients, and demonstrated that treatment non-compliance is influenced by multiple factors, including demographic variables (age, sex, marital status, family size, relationship with head of the family) and socio-economic

variables (household income, religion, housing and education of individuals) in addition to individual factors.

This present study draws on both the pathway and determinant models of health-seeking behaviour. It explores the health actions taken by patients in response to their symptoms and examines the predisposing, enabling and reinforcing factors underpinning these health-seeking behaviours. This is based on the hypothesis that an individual's ability to seek appropriate TB-related health care in Cambodia is influenced by multiple intersecting factors beyond the individual. The conceptual framework I adopt for this study is based on the HBM, but I expand it to include other factors that are strongly connected to the individual factors influencing health-seeking behaviour. Although the HBM is not a new model, it remains valuable as a means of distinguishing attitudinal and structural factors that influence health-seeking behaviour and adherence to medical advice. While in this study, I did not attempt to test any paradigm or aim to develop a theory or paradigm, I sought to explore factors that facilitated or prevented early access to diagnosis and treatment that are important to consider when developing a more responsive and relevant strategic health component of the TB control program. As elaborated in Chapter 1, three types of factors interact with one another: individual or predisposing factors, enabling or institutional factors, and reinforcing factors which determine people's health-seeking behaviour in response to symptom episodes of TB (see Figure 6).

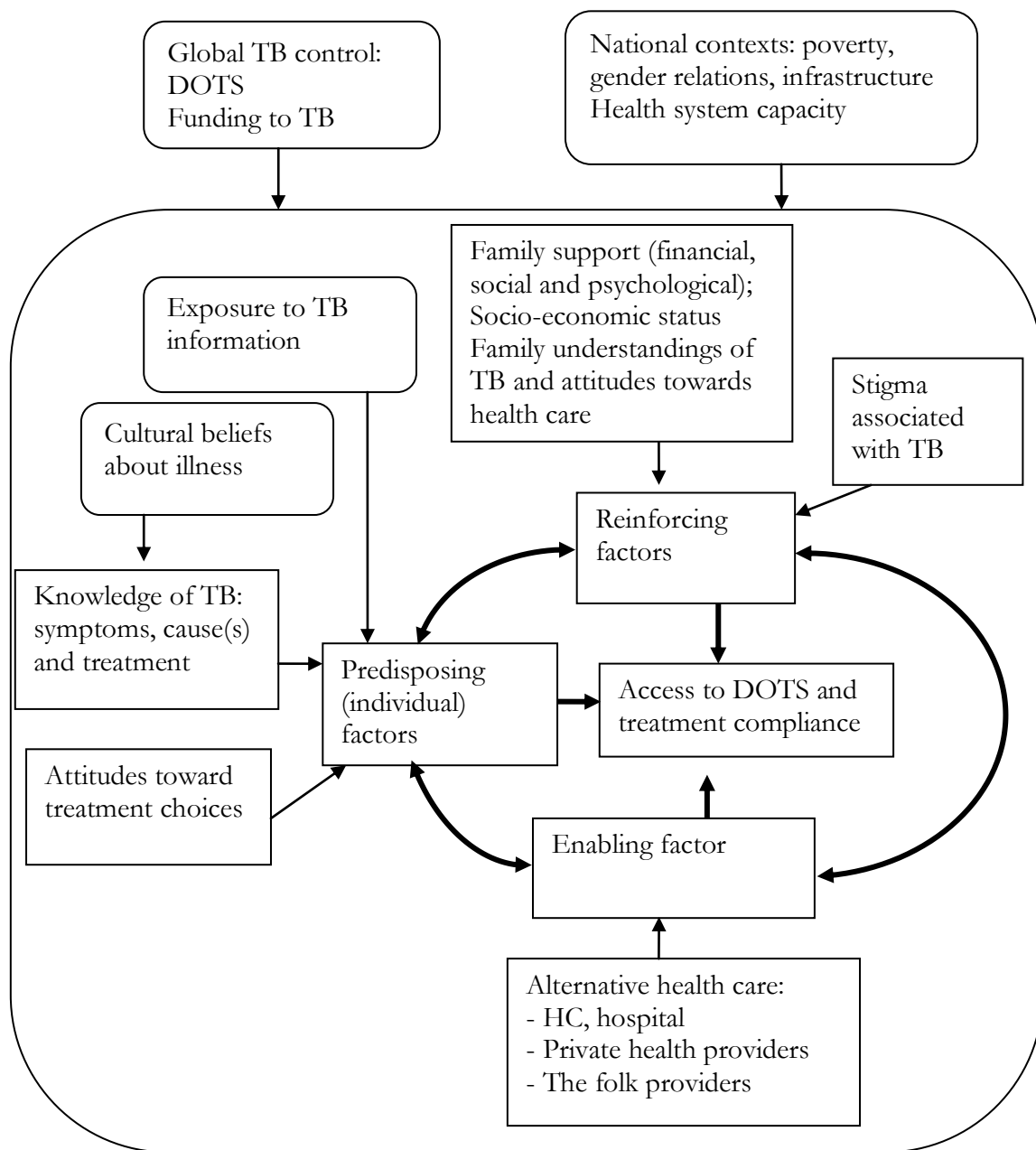


Figure 6: Conceptual framework of the study

The health-seeking behaviour of TB patients in searching for a diagnosis and complying with treatment under DOTS is a complex process and involves multiple stakeholders. In

the following section, I discuss the study site and research techniques I used to collect rich data related to my conceptual framework.

Characteristics of the study site

Kampong Speu is located in southwest of Cambodia, 50 kilometres from Phnom Penh, the capital city. It is home to 716,944 people (5.3% of the total Cambodian population), of whom around half (368,432) are women (National Institute of Statistics, 2009). The geographical features of the province shape the population distribution, with villages in the provincial capital and lowland areas having higher populations than villages located in the plateau and mountainous areas. Kampong Speu covers an area of 7,017 square kilometres and is subdivided administratively into eight districts, 87 communes and 1,351 villages (Cambodia Census, 1999) (Figure 7). The geographical characteristics of the province, of which two-thirds is the forest, plateau or mountainous, made some villages in three districts (Oral, Basedth and Phnom Srouch) extremely isolated from the provincial capital, despite only being 20-60 kilometres away. This caused by poor road infrastructure, particularly during the rainy season.

The majority of the population in Kampong Speu are farmers; young people usually out-migrate to Phnom Penh or other provinces for work, particularly after rice planting and harvesting times. Young women predominantly work as garment factory workers or maids, while men work as construction workers, labourers for construction, and in business. Because I began my fieldwork in January (dry season), when farmers had finished their rice harvesting, I did not meet many young people at home during the day time, with the exception of mothers of young children. I was told that most young people went to find jobs outside home: some returned home in the late evening and some only came home during special ceremonies (Chinese or Khmer Lunar New Year, or religious ceremonies).

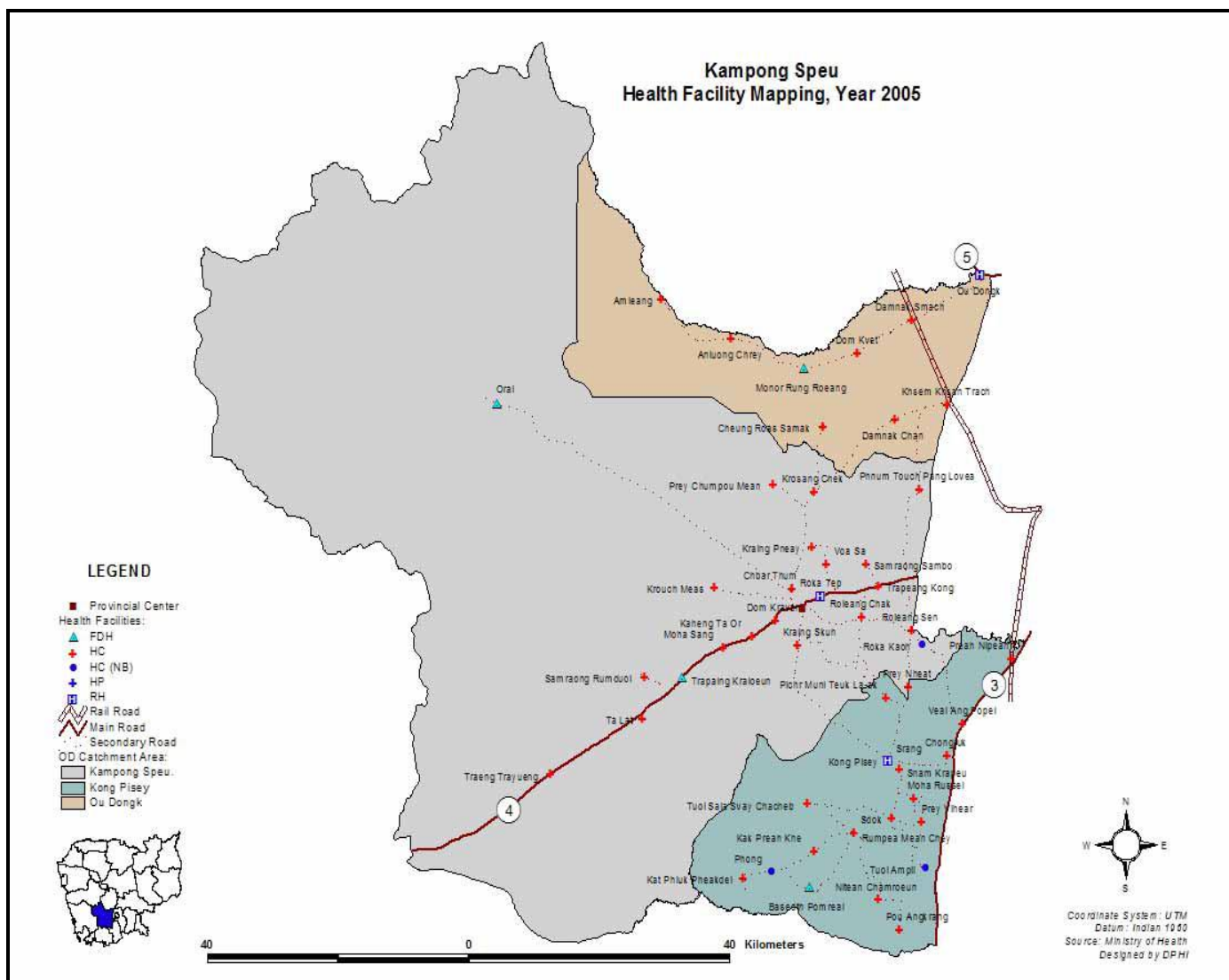


Figure 7: Map of Kampong Speu province
Source: Ministry of Health, National Health Coverage Plan, 2006

Kampong Speu is one of the poorest provinces in Cambodia, experiencing flood and drought almost every year (USAIDS, 2008). Economic development in the province varies according to geographic location. Highland populations are poorer because they often experience droughts and floods, and do not have access to other casual job opportunities besides rice-farming. During my fieldwork in early 2008, when the economy and land market in Cambodia peaked, land in the lowland areas of Kampong Speu had good market prices. Many local people sold their land (rice fields or farms) and became wealthier. At this time, it was quite common to see small restaurants and karaoke shops in the rural lowland areas, the constructions of new wooden or concrete houses, and new motorbikes in villages, indicating better living conditions for people who had land to sell. However, there was also concern about the long-term economic impacts on families who had sold their rice fields, and possibly did not manage their resources well, who could end up in deeper poverty and landless.

Although living conditions improved for families who had land to sell, the general living conditions of the provincial residents remained poor. Only the provincial centre and some district towns had electricity and tap water, although that was often in short supply. Most parts of the province did not have access to electricity, safe water and latrines; however, some wealthier families had their own generators or batteries for electricity use (to provide TV and light in the house from 7-9 pm). Access to clean water was problematic, especially during the dry season when water in ponds or lakes dried up. Although there were pump-wells in every village, residents preferred to use water from ponds or lakes for drinking (boiled or unboiled) and cooking; they complained that water from the pump-well had a strange taste, and therefore they only used it for cleaning, bathing and watering plants. Figure 8 shows a house typical of my participants in highland areas.



Figure 8: House of a participant in highland areas of Kampong Speu Province

Field photo, 15 November 2008

The Health System in Kampong Speu

Like other provinces of Cambodia, the Provincial Health Department (PHD) directed the health system in Kampong Speu. Under direct supervision of the Ministry of Health Cambodia, the PHD was responsible for overseeing the public health system and monitoring the implementation of the private health sector, as well as health-related NGO initiatives in the province (Ministry of Health, 2005b). The headquarters of the Kampong Speu PHD consists of four offices: Administration and Personnel, Finance, Pharmacy and Food Safety, and Technical. The Technical Office supervised the technical implementation of five units, including the Maternal and Child Health Unit, Health Promotion Unit, Communicable Diseases Unit, Planning and Statistic Unit, and Continued Education and Research Unit.

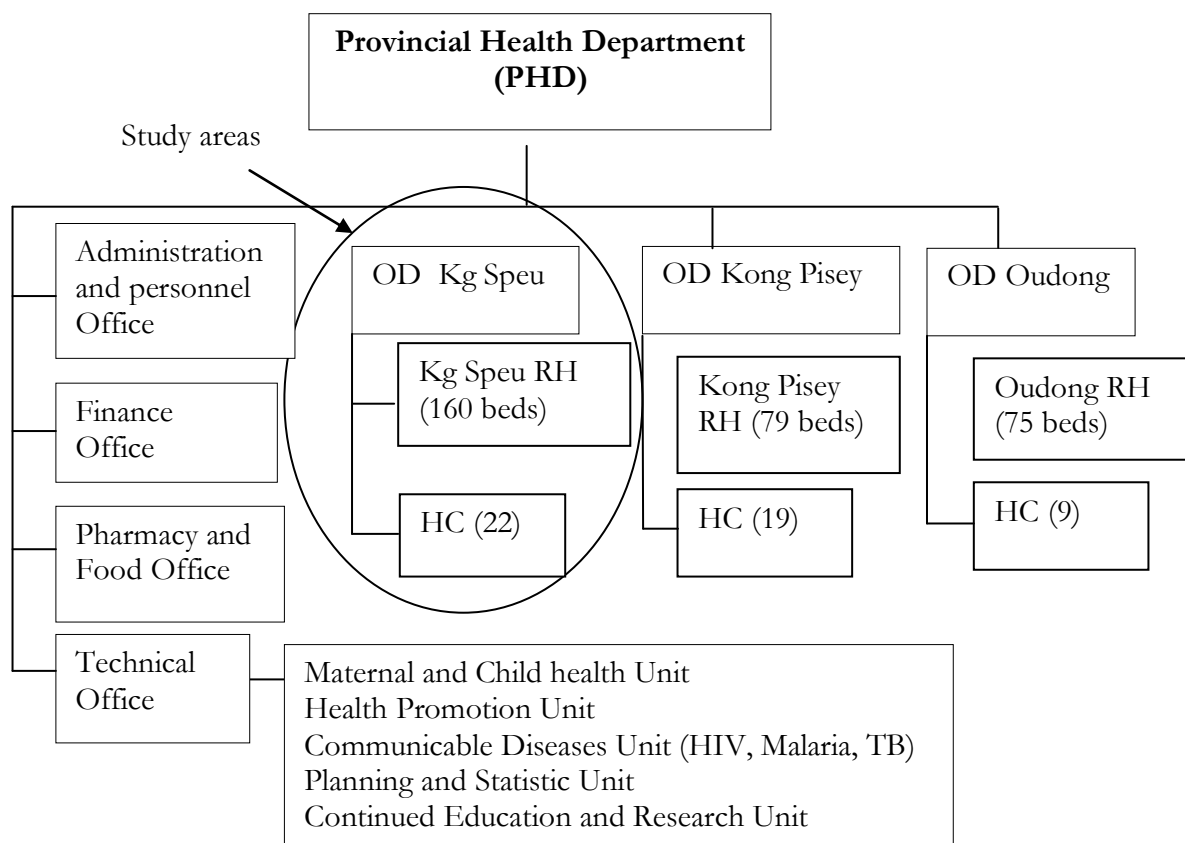


Figure 9: Structure of Kampong Speu PHD

Source: Achievements in 2008 and annual work plan of 2009, Kampong Speu PHD

The public health system in Kampong Speu is divided into three operational health districts (OD): Kampong Speu, Kong Pisey, and Oudong. Each OD comprises of one Referral Hospital (RH) and a number of Health Centres (HC), and serves the population from a number of administrative districts (see Figure 9 and Table 6).

Table 6 Coverage of each OD

Name of OD	Number of administrative districts covered	Population covered	Percentage of population covered
OD Kampong Speu	4	768,335	49%
OD Oudong	2	137,298	18%
OD Kong Pisey	2	252,069	33%
Total	8	757,702	100%

Source: Report of achievement in 2008, Kampong Speu

The Kampong Speu OD is the largest OD, consisting of one RH (the provincial hospital or *peet khet*), the biggest hospital in the province, providing multiple services including the treatment of referred cases, specialized treatment, emergencies and complicated health problems, and having capacity for hospitalization and continued care. It also supported HCs through providing clinical training and supervision, laboratory services (blood and sputum test), radiological and ultrasound diagnosis.

Kampong Speu had 314 hospital beds in total: Kampong Speu OD had 160 beds, of which exactly half were allocated for TB, Oudong OD had 75 beds (35 for TB), and Kong Pisey had 79 beds (46 for TB). The bed occupancy rate (BOR) of the public hospitals in the province had decreased in the three years to 2008, and was 63.95% at the time of fieldwork, compared with 70.17% in 2007 and 79% in 2006 (Kampong Speu Provincial Health Department, 2009). According to health staff, the decreased hospitalization rates at the public hospital were related to an increased number of private facilities that had the capacity to absorb a high number of clients from the hospitals.

The main public health problems reported in Kampong Speu were respiratory infections, traffic accidents, diarrhoea, TB, malaria and dengue fever. In 2008, 7,761 patients were hospitalized in the three RHs in the province for reasons related to respiratory infections, diarrhoea, typhoid, dengue fever, TB, hypertension and other heart diseases, traffic accidents, dysentery, and other diseases (see Figure 10 for details). The hospital reported low mortality rates: death due to diarrhoea accounted for one case, respiratory infection 26 cases, TB 3 cases, heart diseases 7 cases, traffic accidents 30 cases, and other diseases 35 cases (Kampong Speu Provincial Health Department, 2009). However, the explanation for these low mortality rates became clear during observations in the TB and other wards in the hospital: patients with severe health conditions and without hope of cure, recovery, or access to treatment, were discharged so they could die at home.

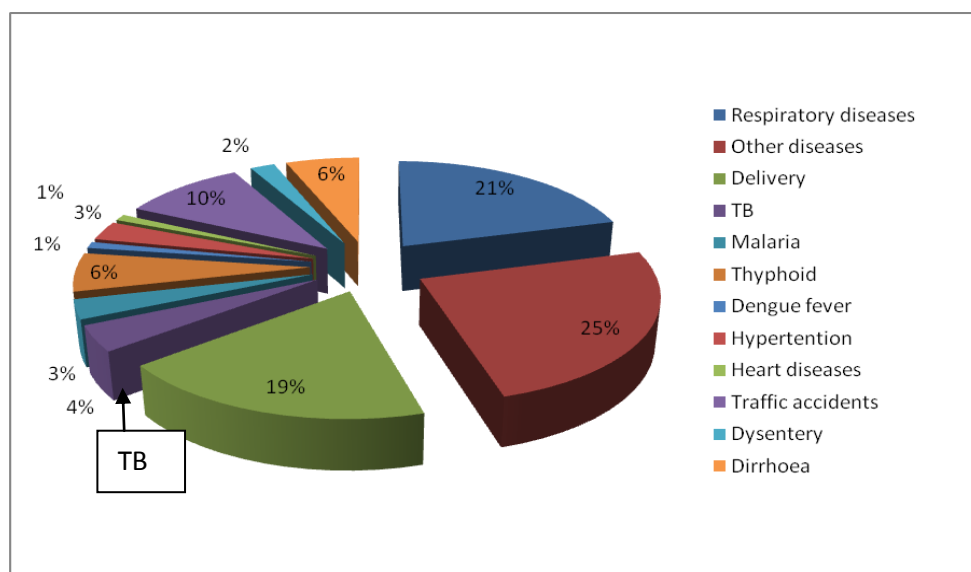


Figure 10: Main health problems among in-patients (n=7,761)

Source: Achievement reports, Kampong Speu Province 2009

The Kampong Speu PHD employed 711 health workers, accounting for 3.82% of the total Cambodian health workforce, with 116 health workers working to some extent for the TB control program in the PHD, ODs, and HCs (Ministry of Health, 2008). The province still faced challenges with staffing issues, especially in terms of lack of specialized doctors, midwives, and secondary nurses (three years training in nursing). Another critical staffing issue related to the misdistribution of health staff. Although there were high numbers of health staff assigned to work in the province, only a small number of health providers, usually those with low qualifications, worked in rural areas. In response to the health care shortages in rural areas, the private health sector in Kampong Speu has grown rapidly. In 2008 in the province, there were 140 chemist stores, 47 private clinics, 16 dental clinics, two private maternity clinics, two private nursing clinics, and a number of unregistered clinics run by health workers who also worked in the province's public services. In addition, there were a great number of *Kru Khmer* (traditional healers), traditional birth attendants, and informal health providers without medical or other qualifications who provided health care to the population (Hourt, 2006).

Tuberculosis in Kampong Speu

As outlined in Chapter 1, after the collapse of the *Khmer Rouge*, TB control activities did not exist in Kampong Speu province until the provincial TB control program was established in 1981. TB diagnosis and treatment, following the national 12-month treatment regimen (Norval, et al., 1998), then became available at a few hospitals in the province. However, because of a lack of funding, shortages of anti-tuberculosis drugs, and poor health infrastructure, the cure rate of TB in the province was low. In response, DOTS was introduced to the province in 1994, which provided hospital-based TB diagnosis and treatment—this was decentralized to health centres in 2002 who provided out-patient ambulatory DOTS, where patients were required to attend a health centre every morning to take TB drugs in front of a health worker. Since then, DOTS has become available through every public health services in Kampong Speu (Kampong Speu Provincial Health Department, 2009), extending to community-DOTS in 2005. TB activities in the province have progressively improved, reaching the national targets of smear positive pulmonary TB case detection and cure rates in 2004.

The NTP report (2008) showed that the total number of TB cases in Kampong Speu was 1,947; this included 1,316 new smear positive TB (NTP, 2008). The province reported achieving the national targets of 81% and 90% respectively related to TB case detection and cure (Kampong Speu Provincial Health Department, 2009). However, the provincial TB control program faced several challenges in terms of difficult access for TB patients to obtain diagnosis, relating to the implementation of community-DOTS, following up TB (and suspected TB) cases, and in providing TB health education to community members.

Based on my experience working at the Ministry of Health, I was aware that many health projects and research projects had overlooked Kampong Speu for two reasons: priority attention is given to remote provinces (along the borders) and a low per-diem is paid to

government health staff when doing field visits in provinces around Phnom Penh. This drew my interest to work in the province. Furthermore, its specific geographic features, including remote-mountainous, rural and semi-urban areas, raised questions about access to health services, directly relevant to the study objectives.

Preparation of fieldwork

Before I could commence my data collection, my research required human research ethics approval from three institutions: Monash University, the National Ethics Committee for Health Research (NECHR) Cambodia, and the UNICEF/UNDP/World Bank WHO/Special Program on Research and Training in Tropical Diseases (WHO/TDR) (Appendix 1).

Furthermore, it was also necessary to obtain permission to access the research site from gatekeepers in this study sites (Campbell, et al., 2006; Clark, 2010). Gatekeepers can be individuals, groups or organizations who can facilitate or prevent access to participants, but who do not provide technical or financial support to the researchers and are largely independent from the research participants (Miller & Bell, 2002). Clark (2010) identified the support, challenges and mechanisms for engaging gatekeepers in research. Gatekeepers support research for several reasons: political representation, showing moral responsibility to research, and that expectation that identifying good practices may be useful to the gatekeepers. However they can also create challenges, for example, through their political influence on research methodology, their control over access to participants, intrusion and disruption (Reeves; Clark, 2010). I obtained support from multiple gatekeepers because there was an identified lack of research on TB and health-seeking behaviour in Cambodia, and these gatekeepers expected that the study findings would provide insights to improve current practices related to TB control at provincial and country level. The primary gatekeepers who influenced my research were officials from the Ministry of Health

Cambodia and the National Centre for Tuberculosis and Leprosy Control (CENAT). Prior to commencing data collection, I met with the Secretary of State, Ministry of Health, who was responsible for health-related research activities and took charge of the NECHR. During the meeting, when I informed him about my research project, I received his support related to conducting TB-related research and health-seeking behaviour in Cambodia, and obtained his formal support (and that of the Ministry of Health) to carry out the project.

Once I obtained ethical approval from the NECHR, I sought assistance from other gatekeepers: at CENAT and the provincial health department to access the field sites and to learn more about Cambodian TB control activities. I described my research to the CENAT director and requested permission to attend various organizational activities such as workshops, seminars, trainings, and conferences on TB control. I also obtained permission to access the TB hospital in Phnom Penh, where I spent time meeting with the health workers who were responsible for diagnosing and treating patients, and with the TB patients who were hospitalized in these wards. Meeting these gatekeepers allowed me to gain a better understanding of TB diagnosis and treatment at the hospital; it also gave me the opportunity to pre-test my research tools (in-depth interview guides and explanatory statements) with hospitalized patients who came from different provinces.

I then visited Kampong Speu province, introducing my research to the director of the provincial health department (PHD), after which I submitted my research proposal and ethical approval to the PHD. I introduced my project to all TB supervisors in the province (from ODs and HCs) by giving a presentation about the research project during a one-day meeting on monitoring related to TB at the PHD. I briefed supervisors about the research background, objectives, and plans for data collection. From this, I received valuable insights related to recruitment and about accessing to different locations in the province; I

also had the opportunity to introduce myself informally to health workers from different health centres of the OD Kampong Speu, which facilitated my data collection.

Field site, selection and research

It was impossible for me to conduct this extended fieldwork without help from others. After being introduced to the PHD, I selected my study sites. The provincial hospital (PH—the only hospital) and another four health centres were purposively selected from the total 22 health centres in the OD Kampong Speu in order to include those that served populations from the lowland (populous) areas, as well as those serving populations from rural and remote mountainous areas. My first visit to the five (PH and 4 HCs) study sites was facilitated by the chief of the provincial TB office, which allowed me to visit the hospital and each health centre to introduce myself and the research project to the head of the TB ward (at PH) or health centre. I then asked each health facility to assign one staff member familiar with the local area to be my research facilitator, to assist me to recruit participants, to accompany me to participants' homes (if necessary), and to facilitate other necessary administrative procedures related to access to local areas. I paid a daily per-diem (based on the government per-diem rate at US\$5 per day) to my research facilitators when they went on the field with me.

Once I recruited these research facilitators, I spent one day with each of them to introduce the research project and explain the process of recruitment and associated ethical issues; we also developed work-plans for recruitment. I worked in close collaboration with my research facilitators throughout data collection.

To assist with my fieldwork, I recruited one research assistant to work with me for the entire data collection phase. She (Viriya – pseudonym) had a bachelor degree in sociology and experience in conducting both qualitative and quantitative data collection. I provided

her with additional training about research methodology, note-taking skills, field note transcription and the administrative procedures required for this extended research project. The main tasks performed by Viraya included note-taking during in-depth interviews and the focus group discussion, assisting with quantitative data collection, and data entry.

Data collection

Both qualitative and quantitative methods were used to yield comprehensive data to address the research questions, an approach that allowed the weakness of one method to be covered by the strengths of the others (Steckler, et al., 1992; Marshall & Rossman, 2006; Creswell & Plano Clark, 2007). For example, quantitative methods do not encourage participants to respond in-depth but allow larger data sets; on the other hand, a qualitative approach allows participants to elaborate, but limits the opportunity for generalizing data (Marshall & Rossman, 2006). The use of mixed methods in this study occurred for two purposes: 1) for data triangulation and validation and 2) for clarification, explanation, and fuller elaboration of the results of analyses (Sandelowski, 2000). The qualitative approach employed in this study was designed based on grounded theory, a methodology suitable for the study of social processes and patterns for understanding provided by participants in their own worlds (Strauss & Corbin, 1998). The unique characteristic of this approach is that the researcher is employed as a research tool, and thus the research process, including recruitment of participants, data collection and data analysis, occurred concurrently (Strauss & Corbin, 1998). I employed qualitative methods—specifically, in-depth interviews, focus group discussions and observations—to explore the experiences and understandings of TB patients, their families, and of members of their communities about the transmission and treatment of TB, speaking in their own words, and providing meanings based on personal histories or experiences. In addition, using various qualitative methods can help to ensure reliability and validity of the data (Mitchell, 1986; Sandelowski, 1986; Pyett, 2003; Tobin &

Begley, 2004), by triangulating interviews, observation data, data from focus group discussion, and document reviews (Angen, 2000; Whittemore, et al., 2001). I collected data from multiple groups (e.g. TB patients, family members, health providers, C-DOTS observers, policy makers, and community members), and have compared and contrasted their views throughout this thesis.

I employed quantitative methods to conduct a survey of community members without TB. The survey built on the themes emerging from the qualitative data analysis, and sought to assess the distribution of characteristics, understandings, perceptions, attitudes, and social norms of community people with regards to TB. The data reported in this thesis derived from both methods, and allowed me to identify commonalities and differences between TB patients and the general population regarding TB knowledge, attitudes towards TB and TB patients, and practices relevant to health-seeking behaviours.

Data collection occurred in two phases. Phase one (January to May 2008) was the preparation phase and early qualitative data collection: in-depth interviews, focus group discussions, and observation occurred. After one month (June 2008) based at my host University (Melbourne, April) undertaking a preliminary analysis of qualitative data and presenting my preliminary findings to my supervisors and colleagues to help inform and guide the next phase of data collection, I commenced phase two (July-November 2008), where qualitative data collection continued and quantitative data collection occurred. Each data collection technique is discussed in the following section.

In-depth interviews

In-depth interviews were conducted with TB patients, their family members, health workers, TB managers and officers at the national program and provincial TB program, community DOTS observers, traditional healers, and private pharmacy owners. In-depth interviews are more like conversations than structured questionnaires; they allow the

exploration of participants' meanings and interpretation of events in their own language and settings (Olszewski, et al., 2006). They are particularly suitable for exploring “how” and “why” questions in the context that the investigator has little understanding about existing events (Yin, 2003).

I conducted the interviews in Khmer and my research assistant took notes throughout. Interviews were guided by the list of themes, which ensured that I did not miss any important topics. Separate interview guides were developed for each group of participants (see Appendix 2 for the interview guides) according to the research questions and a review of relevant literature. The interview guides, questionnaire and Explanatory Statement (ES) were developed in English, then translated into Khmer and pre-tested before data collection commenced. I obtained ethics approval from the NECHR Cambodia based on these translated documents. I also used probing and prompting techniques during the interviews to encourage participants to further elaborate some details. The probing technique was important in order to seek clarification when participants' statements were brief or unclear, while prompting was necessary when I was introducing a particular topic, when the topic did not arise spontaneously during discussion (Liamputtong & Ezzy, 2005).

In-depth interview with TB patients and their care-givers/family members

Residents living in the coverage areas of the Kampong Speu OD aged 18 or over and who had been diagnosed and treated TB with DOTS were invited to participate in the study. My only inclusion criterion was that potential participants must have been under treatment for TB for at least four consecutive weeks at the time of recruitment. This criterion ensured that I recruited TB patients who had experience in: encountering the illness; treatment, including anti-tuberculosis medication side effects; taking family precautions to prevent disease transmission; family support or conflict in relation to disease prevention; and who had a history of managing the illness from its onset to the current time. In addition, the

criterion also helped to minimize the risk of TB infection for the research team, as TB (without drug resistance) is no longer infectious if a TB patient has been under treatment for more than two weeks. The recruitment of this group occurred through non-random sampling—participants were selected on the basis of a set criterion (e.g. as shown above) (Berg, 2006).

TB patients and family members were recruited from the provincial hospital and the four selected health centres. Recruitment through the hospital occurred as follows: the research facilitator introduced me to prospective (hospitalized) participants who met my selection criterion. I explained to them verbally about the nature of the research project, including the aims, objectives, methods, expected outcomes, and what was expected from participants. If they expressed interest, I then invited them to participate in the study. At this point, I provided potential participants with a written Explanatory Statement (ES) outlining the research project containing all of the information from my verbal introduction, although most participants were not interested in taking a copy (see Appendix 3); this allowed potential participants to think about the study before deciding whether to participate. Potential participants who were interested in the project usually responded to the invitation in person to me or to the nurse, and I then made an appointment for an interview. Participants recruited from the hospital suffered severe TB symptoms (e.g. very thin, pale, and having difficulty breathing), although they had been under treatment for four or more weeks.

The recruitment of patients from the health centres occurred in a similar way to the hospital. The research facilitators at each HC informed me of the number of patients who had been under treatment for at least four weeks and who came to collect medicines on a particular day, so I came on that day to meet them. To collect medicines, patients or their family members came to the health centre early in the morning and waited for the stock

keepers to give them the medicines. While people were waiting, my research facilitator introduced me to them. I started by telling them my background (name, education, occupation and children) and also asked them about themselves. I then introduced my research and invited them to participate. I provided them with the ES, and encouraged them to take some time to decide about whether they wanted to participate in the study or not. I gave them my telephone number in case they wanted to contact me for further clarification. I also sought permission to contact them by phone if they had one, after a couple of days, to determine whether they would participate or not. For those who did not have a telephone contact, I encouraged them to inform the research facilitator about their decision.

The recruitment of TB patients from the hospital and health centres occurred continuously over time, with a couple of patients recruited each month. Ten participants were recruited from the hospital, twenty were recruited from the four health centres (five from each health centre), and two were recruited through community members because they were treated outside public health facilities: one was treated with community DOTS and another was treated by private providers. Based on theoretical sampling, which meant that I continued sampling and data collection until no new themes had emerged, a total of 32 TB patients (14 women and 18 men) were recruited for this study.

Most patients were farmers (Table 7). Generally, women in rural areas participated, to some extent, in economic activities, and this was true of the female TB patients: they were full-time factory workers, farmers on their own or rented land, or worked as labourers for other farmers. These women were also housewives who looked after their families, as their jobs were casual and were often located in their own or neighbourhood villages (see Appendix 4 for demographic characteristics of participants).

Table 7: Characteristics of TB patient participants in the study

	Male (n=18)	Female (n=14)	Total (n=32)
Literate (based on self report)	15 (83.3%)	9 (64.3%)	24 (75%)
Illiterate	3 (16.7%)	5 (35.7%)	8 (25%)
Age			
18-20	1	2	3
21-30	2	3	5
31-40	3	4	7
41-50	2	3	5
51-60	4	3	6
>60	6	0	6
Occupation			
Farmers	7	9	16
Factory workers	1	5	6
Construction workers	5	0	5
Student	1	0	1
Retired	3	0	3
Government officer	1	0	1

The caregivers who participated in the study included spouses, parents, children, siblings, and other relatives of TB patients aged 18 or over who had been providing care to TB patients during their sickness; tasks included taking care of patients at the hospital or at home, collecting medicines from the health centre, and/or observing patients taking medicine.

The recruitment of caregivers occurred through TB patients. After interviews with patients, I asked some participants to invite their caregivers to participate in the study. If they agreed, I made an appointment to conduct an interview with the caregiver later. Twelve family members (3 men and 9 women)—the mothers, daughters, wives, sisters, nieces, husband or father of TB patients—participated in the study. Two family members were recruited through research facilitators. Both had family members (one son and one father) who had died with TB.

Interviews with TB patients took place in the hospital, health centre or in participant's homes, according to participants' choices and availability. I attempted to conduct

interviews at a time that was convenient for each participant and when interruptions from others could be avoided. All participants requested that their interviews took place after lunch or in the afternoon, when most of their family members were away at work or at school; if they stayed at home, as was the case for women caring for children or elderly family members, interviews were scheduled during afternoon nap times. For interviews that occurred in the hospital or health centre, this time was quiet because health workers were having their lunch breaks and thus there were no outpatients in attendance.

Before going to participants' home, I informed them that a number of people would be travelling with me (including research assistant or research facilitator), of my transportation means (car or motorbike), and highlighted that my presence in the village may reveal their illness status to fellow villagers. All participants agreed that I could come to their homes, and were not concerned that my visit would disclose their illness status because most of their neighbours already knew about their illness. I asked them to give their address to the research facilitator, who accompanied me to each participant's house, but who did not remain during the interview. I did not require the company of research facilitators when I visited participants on the second or third occasion unless I visited participants who lived in very remote and isolated areas.

On the day of the interview, TB patients and their family members were usually ready and waiting for me. They dressed up with clean or new clothes, tidied their beds (for those who were hospitalized) or their houses, and put some chairs or a nice mat on a bed under or in front of their house to welcome me. During hospital/health centre interviews, I usually suggested that participants sat with me in an open space (for example, under a tree beside the TB ward or the health centre), or in the corridor of an empty ward near the TB ward. For interviews in people's homes, I invited participants to sit under the veranda or under a tree beside the house so the interviews could be conducted away from other family

members. Before starting the interview, I reiterated the purpose of the research, interview procedure, and ethical issues related to participation in the research, including confidentiality, privacy and anonymity. After this, I obtained signed informed consent before I started the interview (see Appendix 5 for consent forms); I accepted verbal consent from participants who hesitated to sign. I also asked permission from participants to audio-record the interviews. During interviews, I gently reminded TB patients to cover their mouths when they talked and suggested that they take breaks if they felt the need to cough or sneeze. Two patients had difficulty breathing when they talked for long, so I encouraged them to take several breaks during interviews.

I interviewed TB patients and family members separately and on different days. Each interview lasted around 90 minutes. The interviews with TB patients were often conducted over several occasions (usually 2-3 times). After the first interview, I made an appointment for a follow-up interview with participants two or three months later. The aim of the second interview was to follow-up their treatment status (compliance with treatment) and to seek clarification of or explanations related to themes that emerged from the initial interviews. Before conducting each follow-up interview, I asked the research facilitator to follow up the participants and make an appointment for the interview. For those who had a telephone, I telephoned them to confirm the interview date.

I found that the follow-up interviews with TB patients allowed me to get more in-depth information, as participants had established trust in and were more familiar with me. Caregivers were only interviewed on one occasion.

Some TB patients and family members were emotional during interviews as they had experienced the death of family members from TB, had personally relapsed from TB, or suffered with the side effects of TB medications. One mother was very emotional when she talked about the death of her son from TB. She cried a lot during the interview, and

was very upset that the health workers at the hospital did not do enough to help her son because they were extremely poor. I kept silent as participants told me their stories, and let them express their frustration and sadness; I then asked them whether they would feel comfortable continuing their conversation with me. All of them did and I moved on to a less sensitive topic.

Interrupted interviews

The interviews that occurred in the hospital or health centre were usually smoother because there was less disruption from others. As the interviews at the health centre required participants to travel from their homes to the health centre, I reimbursed them the cost of transportation or fuel. It was impossible to avoid interruptions during the interviews at home and during focus groups. Noise, children playing and screaming, babies crying, and household chores always occurred simultaneously with the interviews. For example, mothers with young children or babies very often had to interrupt interviews when their baby cried or a child needed something. In most cases, curious neighbours interrupted interviews or family members came in the middle of interview to listen to the talk or to join in the discussion. They usually stayed for around 10-15 minutes, and then the participant would ask them to leave us alone. In one case, my participant had her relatives arrive from another province during the interview, so I decided to defer the interview to another date. In some cases, if the participants wanted, I allowed other family members to participate in the interviews; for example, some participants invited their parent, husband or children to participate in the interview for a short time when they need clarification from that family member regarding a particular question. Usually the family members left the interview after they had provided their information. The focus group discussion was very noisy because all participants brought along their young children and babies; they played not far from the discussion, and very often I had to gently ask them to minimize their voices.

In-depth interviews with providers

Health workers, TB program officers and private providers were invited to participate in in-depth interviews in order to obtain data on the diagnosis and treatment of TB, the delivery of public and private health care in local areas, factors affecting the motivation of health staff, stigma associated with TB, and enablers as well as barriers to TB control activities. This group consisted of four policy makers involved in planning the National TB Control Program (NTP) and Provincial TB Unit (all men), ten health workers (nine men and one woman, see Appendix 4) who were also involved in the diagnosis and treatment of TB at the five research sites, and three private pharmacy owners (two women and one man). Purposive sampling was employed to recruit this group. The four policy makers were recruited through my informal contacts, while the recruitment of other provider participants occurred via the research facilitators at the five field sites.

Once I obtained agreement from these participants, I introduced myself and described the research project to them, provided them with the ES and made an appointment for their interview. All were happy to voluntarily participate in the research. I used the same process for each provider interview. Prior to each interview, I provided assurances of confidentiality and anonymity of the information shared in the interview. I asked the participants to consent to the in-depth interview and also asked their permission to audio-record it. Each interview lasted for approximately one hour, with all interviews conducted at their offices in the hospital ward, health centre or pharmacies. A single interview was conducted with each of these participants, except for seven of the health workers who participated more than one interview (between 2-4 interviews each) and also had several informal meetings with me to clarify the themes that emerged during the interviews.

Most participants in this group were comfortable with providing written consent and having their interviews audio-recorded. Some refused the audio-recording and, although

others agreed that I could record, I noticed that they did not feel comfortable talking when the recorder was on: the conversation was formal, careful, and they often referred to written policy or guidelines and suggested that I also read those documents. The unrecorded interviews were more interactive and informal; therefore, I conducted some interviews without a tape recorder and expanded my notes immediately after the interview.

In-depth interviews with traditional healers, village health volunteers and DOTS observers

Two local *Kru Khmer* (traditional healers) who had experience in treating illness, including TB-related symptoms, and seven community volunteers who had been trained by the health centre to observe TB patients taking medicine at home (C-DOTS observers) were also invited to participate in in-depth interviews. The recruitment of traditional healers was based on snowball or network sampling. This respondent-driven recruitment allowed me to select prospective participants through an initial respondent who suggested other people who might wish to participate in the study (Liamputtong & Ezzy, 2005; Berg, 2006). Snowball sampling is appropriate in the selection of participants from a particular setting or on a particular target population that is difficult to approach directly. I asked TB patients, family members and other members of the community whether they knew a traditional healer who was able to treat many diseases, which they did. Then I asked my research facilitator to meet the *Kru Khmer*, explain the study, and invite them to take part. My research participants obtained consent from two traditional healers to pass their contact details to me and I contacted them directly.

Interviews with the two *Kru Khmer* took place at their houses. My research facilitator accompanied me and my research assistant to the *Kru Khmers'* houses, then waited in the village while we conducted the interview. I followed the same process described for other in-depth interviews. Before commencing the interview, I provided assurances of confidentiality, privacy and anonymity of the interview before obtaining informed consent.

Each interview took around one hour, after which the *Kru Khmer* showed me the herbal medicines and other materials he used for treating diseases, such as *yeau* and *kse keata*. They did not show me how they treated patients. One traditional healer had a client arrive while I was there for an appointment to be sprinkled with holy water after our interview; however he did not allow me to observe the treatment session as he explained that my presence might make his clients feel uncomfortable.

The research facilitator provided me with information on the number of community DOTS observers in their health centre. They then contacted the C-DOTS observers, explained the research, and invited them to participate in the study. I recruited seven community DOTS observers from the four health centres. Interviews with community DOTS observers followed the same process as for all other interviews. Three interviews were conducted at a health centre and four were conducted in participants' houses; each interview took around one hour.

Focus Group Discussions

Focus group discussions (FGD) are typically used to provide a rich and detailed set of data about perceptions, thoughts, feeling and impressions of participants through group interaction (Morgan, 1997; Liamputtong & Ezzy, 2005; Dawson, et al., 1993; Hollander, 2004). In this study I conducted three focus group discussions with community members who did not have TB in order to explore their understandings about TB infectivity, perceptions of disease threats, prevention measures, beliefs about TB stigma, and health-seeking behaviours. Participants were recruited from villages where a person diagnosed as having TB was recorded by the health centre as residing.

Participants of each FGD should be of similar age, social position and socio-economic status in order to ensure group interaction and to allow free-flowing dialogue among

participants (Morgan, 1997; Manderson, et al., 2006). Each group in my study consisted of men and women who were of similar age and social status: because the FGD research questions were not related to sexual issues, putting men and women together in a group did not affect group interactions. In addition, the mixed gender group discussions allowed men and women to interact with each other in relation to their perceptions. Group 1 consisted of eight participants (five women and three men) aged less than 30 years, Group 2 comprised eight participants (six women and two men) aged 30-40, and Group 3 was conducted with participants (six women and two men) aged 40 or more (Appendix 4). The unequal numbers of men and women resulted from my difficulties in recruiting male participants, most of whom were busy with work and could not make the appointment date. Each FGD took place at a mutually convenient setting for participants. The first group took place in the village in a public rest hall for travellers; the second group took place in a pagoda; and the third was held in the house of a participant. Prior to commencing each FGD, participants were informed about the ethical issues related to participation the focus group discussions, confidentiality and privacy; I also asked their consent to participate by presenting them with the consent form and asking them to sign or to consent verbally. I read the ES to those who could not read it. All participants gave verbal consent. I also informed them that they could withdraw from the discussion at any time or refuse to answer any question. I asked permission from participants to audio-record the FGD before commencing. I began each discussion by introducing my research assistant and myself, then asked participants to introduce themselves.

For the focus group discussion, I suggested participants sit in a circle and I placed the tape recorder in the middle. My research assistant sat in the circle opposite me; I facilitated the group discussion and she took notes of the discussion. Each FGD lasted for around 90 minutes. I explained the ground rules of the FGD to participants to encourage them to talk

freely and also to ensure that all members were respected: for example, only one participant should talk at a time and participants should not interrupt when someone else was speaking.

It was hard to facilitate active interaction within the group discussions as a couple of participants were silent and a few women were very talkative, leading other members in the group to remain very quiet. To prevent the “contamination” of ideas (Wilkinson, 1998), I politely invited the dominant participants to slow down and encouraged others to talk first. I provided snacks and drink after the FGD, and presented each participant with a small gift (a Khmer scarf and a pair of flip-flops) to express my gratitude. I paid for transportation for all participants to travel to the focus group discussions.

Observations

Observations are an important data collection method that allows a researcher to understand certain behaviours in context (de Much, 1998). It can include simple observations, carried out by systematically watching people’s behaviour, and participant observation, which involves the interaction of observers with participants (Patton., 2002; Liamputtong & Ezzy, 2005). In this study, I conducted observations of the health service settings (noting the reception procedure, equipment available, activities, statements of staff attitudes, and signs outlining the procedures to get services), of interactions between patients and providers at health facilities, and of the interactions between patients and family members at the health facilities and at home. Health workers were aware of the purpose of my observations and allowed me to observe multiple provider-patient interactions, including when providers attended TB patients on the TB wards or in the health centres (when patients submitted sputum or those who had come to take medicines

in front of a health worker). I also conducted unobtrusive observations while I was at the homes of TB patients, in the village, or at the village health facilities.

Quantitative data collection

Face-to-face interviews using a structured questionnaire (consisted of closed and opened-ended questions) were employed to collect data on people's knowledge, perceptions and stigma associated with TB, and the health care seeking behaviour of healthy people: this is referred to throughout this thesis as the community survey. The face-to-face paper and pencil interviewing technique used here requires the interviewer to talk to participants and record their answers on paper questionnaires (De Vaus, 2002). The strengths of this method are building rapport, allowing clarification of misunderstandings or questions between interviewer and respondent, and boosting the response rate (McLennan, 1999). In the present study, the questionnaire was developed based on themes which emerged from preliminary analysis of the qualitative data and was also based on a review of the relevant literature (see Appendix 6 for the questionnaire).

Four experienced interviewers (2 males and 2 female) worked under my supervision to administer the questionnaires. They were trained for the research project on interviewing techniques and relevant ethical issues. Following training, the four interviewers pre-tested the questionnaire with 30 participants in Kampong Speu province (outside the study area) and contributed to the revision of the questionnaire. This process took one week in September 2008, with survey data collection conducted in September and October 2008.

Participants of the survey were adults aged 18 and over who lived in 73 villages under the coverage areas of the four selected health centres and where a confirmed TB case, who had been treated at the health centre, was resident. The reasons I chose participants who met this criterion was because it allowed me to understand how well community members were

aware of other community members who had TB and their attitudes toward TB patients; I then compared this information with what TB patients had reported. In addition, as TB patient participants were also members of the communities where I selected the survey participants, I could compare the patterns of health-seeking behaviour among general community members and TB patients.

Sample size

Questions of sample size are critical for any quantitative research and relate to ethical matters, as a too small sample would not be able to answer the research questions and would be considered a waste of time and resources; a larger sample than necessary is also a waste of time and resources (Kirkwood & Sterne, 2003). The estimation of sample size also depends on how much error is reasonable, the power for generalization, and the resources available (De Vaus, 2002). Sample size calculation draws on two statistical concepts that help specify the degree of accuracy of the survey: sampling error and confidence level (De Vaus, 2002). The size of population from which a sample is drawn is not relevant to the accuracy of the sample, but is very related to known heterogeneity in the whole population, meaning that the greater heterogeneity of the population, the larger the sample needed to be selected in order to represent that heterogeneity (Schensul, et al., 1999).

In this study, the survey sample was drawn from a population (across 73 villages) of approximately 20,000 people aged 18 and over. According to the availability of resources, including researchers' time, I calculated sample size based on critical assumptions that the study would provide 95% level of confidence within an acceptable sampling error of 5%, and with an assumption that 80% of the population would have similar understandings of TB. Because there was no previous data on people's understandings of TB in Cambodia, this assumption of homogeneity was based on the results of the preliminary analysis of my

qualitative data, which showed that most participants (around 80%) explained TB in the same way. This yielded a sample size of around 230 people (De Vaus, 2002).

Multi-stage sampling was applied when recruiting participants of this group. This approach allowed me to overcome the constraints of cost and time associated with a dispersed population (McLennan, 1999; De Vaus, 2002). I aimed to recruit participants from different villages to maximize community member participation. First, I randomly selected 20 villages from 73 villages (which is more than 25% of the total villages where a confirmed TB patient lived). Secondly, because each selected village had similar numbers of adults aged 18 and over (approximately 200-300), I decided to recruit an equal number of participants in each selected village; I therefore selected 12 prospective participants (6 male and 6 female) per village using a lottery draw. Because lists of people aged 18 and over in the village were not available for research purposes, I firstly conducted a lucky draw of households, then I did another lucky draw to select one participant from each household. Before conducting the lucky draw, the research team sought assistance from a village representative to draw a village sketch map (if the map already existed, we obtained it from village head and updated it), and numbered all houses. Based on the number of houses in the sketch map, 12 houses were randomly selected. Finally, in each selected household, one respondent was selected (see Figure 11 for the recruitment map). The selected participants were contacted to explain the nature of the research project, including its aims, objectives, methods, expected outcomes, and what was expected from participants. They were provided with the ES and invited to participate in the project.



Figure 11: Village sketch map

(Drawn by research team with assistance from village chief, field photo 24 September 2008)

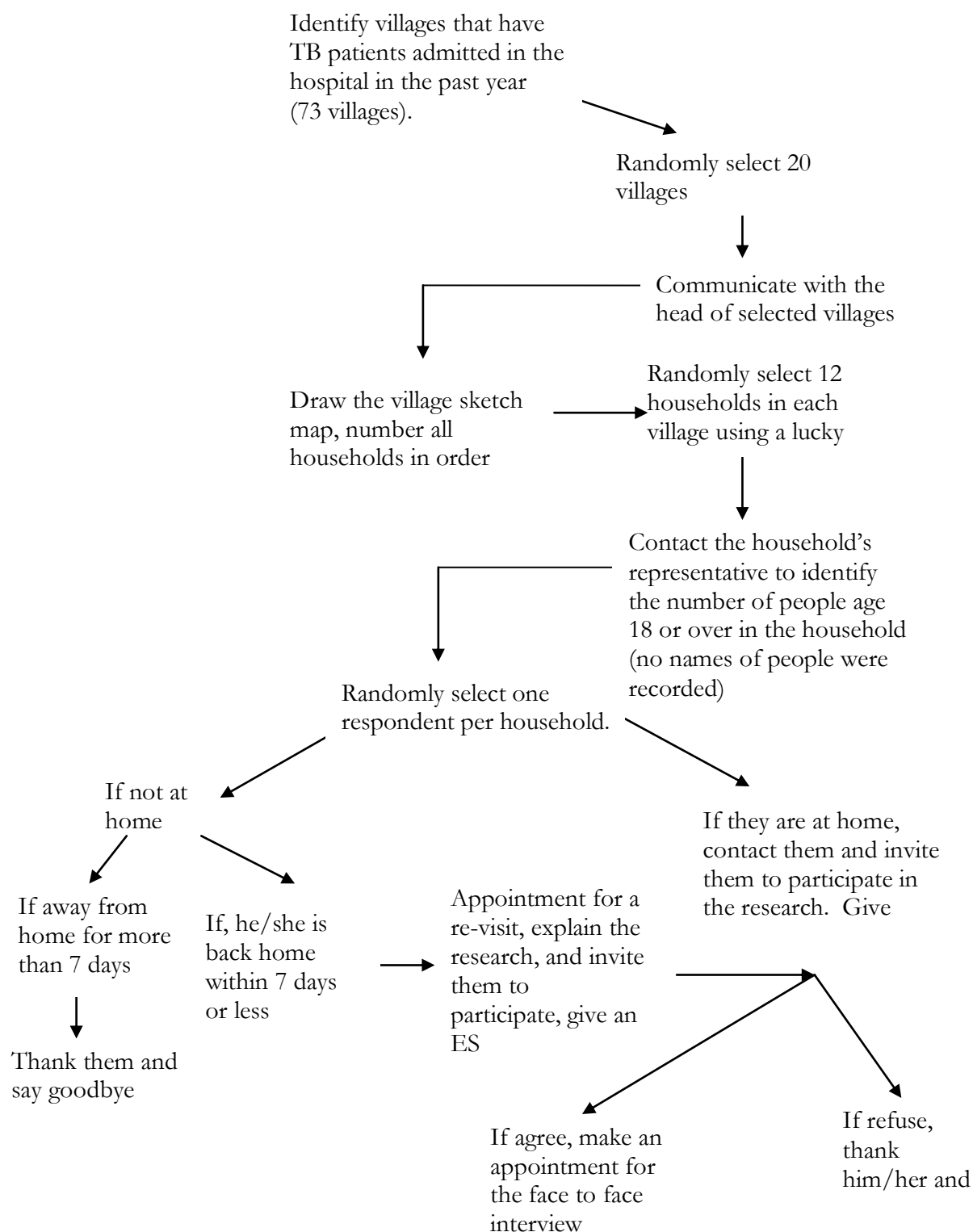


Figure 12: Recruitment map of community members for the survey

Collecting community survey data

On the allocated survey day, interviewers presented at participants' houses. Interviewers were matched with participants based on gender, where men interviewed men and women interviewed women. Interviews took place in an open space near the house or under a tree behind the house. Interviewers explained the purpose of the research to participants, then provided the participant with the consent form to read, or read it to participants, and invited them to sign a consent form. In general, it took about 45 minutes to complete the questionnaire, but sometimes participants were willing to talk at length, particularly when responding to the open-ended questions; those interviews continued longer, for around one hour. Once each interview was completed, the interviewers handed the completed questionnaire to me and I checked it for accuracy and completeness in case there were any points missing or unclear; in such cases, the interviewer would go back to the participant. Before leaving the village, the research team met, reviewed the questionnaires again, and debriefed with each other on issues they experienced during the interviews.

Ethics in practice

Throughout fieldwork, my own ethical practice was constantly checked. I am a medical doctor and a public health worker, employed as a government officer in the Ministry of Health (MoH) Cambodia for more than ten years. My position affected the way that my participants (local health providers, and community members, and TB patients) interacted with me. Health workers in Kampong Speu PHD usually regarded me as a high-ranked officer from the Ministry rather than a student researcher. They were therefore cautious when they made comments about health service delivery in rural areas and tried to tighten their practice (by cleaning and tidying up the health facilities) when I visited the health facilities. At first, every

time I asked their permission to observe patient-provider interaction or to take some photos of the health facilities, they did not refuse but were embarrassed. Because I was present at the health facilities for an extended period of time and never caused any trouble for them, they gradually gained trust in me, and our interactions became more informal and open. In consequence, they regarded me as a resource for expressing their frustration regarding to their difficulties at work and suggested that I take their requests related to the supply of medical equipment, drugs and stationery to higher level at the OD, PHD or to the Ministry. For example, at one RH, the microscope lamp was broken for several months and the health workers did not receive a replacement although they had made a formal request, and so asked me to assist. Although I did not promise them that I could make any changes for them, I always listened to their complaints carefully and brought up questions related to those issues when I participated in meetings or workshops at the PHD or the NTP.

For TB patients, members of the community, traditional healers, private providers who were not employed as government staff and health volunteers, I was an outsider who they were meeting for the first time. The social distance between “me” and “them” was significant, but varied by the “type” of participants. For example, the traditional healers tended to consider me as a scientific person who might oppose their concepts. Although my research facilitator informed them that I was a researcher who wanted to learn about their service delivery, I was not totally confident that they trusted me, and they often did not openly talk about their practices when we met. For example, the two *Kru Khmer* participants refused to let me observe their therapeutic processes as were they applied to patients.

On the other hand, for TB patients, I was a highly educated woman who may have been able to help with their illness. To clarify my role to my research participants and to reduce the social

distance between “me” and “them,” I always showed them respect, listened to them without judgment, and treated them as equals. I told them frankly about what I could do and could not do to help them. Furthermore, having a research facilitator to back up my position in the field was very helpful in building a mutual relationship with participants. Yet I cannot say that I became a friend to them. My social status (highly educated, urban-resident woman) presented strong barriers, but I built a friendship-like intimacy with them. Such intimacy formed naturally over time (e.g. at the beginning potential participants call me *neak kru*—teacher, but later they called me *bong/oun*—sister, *kmoy*—niece, or *kon*—daughter) and led participants to feel comfortable when sharing their rich stories with me (Tillmann-Healy, 2003).

Although I introduced myself to my participants as a research student, conducting research on TB through government health facilities made participants automatically assume that I was a *peet* (health worker) from the city. Accordingly, participants or their family members often sought medical advice or therapies from me for some health problems—such as joint pain, pain, skin diseases, eye problems, diarrhoea, or high blood pressure—or to confirm a prescription and test result from a provider. Despite telling them that I could not provide any therapies to them, some participants persisted in seeking medical advice from me, asking questions including: what had happened to them (i.e. seeking a diagnosis), based on an array of symptoms they suffered; where should they go to get appropriate treatment; or was there any medication to reduce the side effects of TB medication? Very commonly, participants asked me to confirm that their understandings and practices related to TB treatment were adequate.

Their questions alerted me to their reality that participation in my research prompted them to seek more information on TB, and they therefore felt a need to consult with someone with a wealth of medical knowledge who could help them to manage their illness adequately and to

find the right treatment. Despite this, I was very careful to maintain boundaries as a researcher and not to provide therapy (Dickson-Swift, et al., 2006). In doing so, I kept referring patients to seek advice from the health centre, as I believed that this was the only ethical way to proceed. But I was aware that if I only referred them without support or follow-up, they would never be able to access to any useful advice. I therefore became more involved in my referral; for example, on the day that my participants went to collect TB medicines, I encouraged them to ask questions of the health workers. I also encouraged them to collect health education materials from the health centre if they were available to read (or have a family members read). I also collected information on health facilities provided by non-profit organizations in the province, and shared this information with my research participants if it was relevant to their needs. However, I never provided medical advice or therapy to my participants.

The success of the recruitment of participants for this study was based on my face-to-face communication with potential participants, aided by the facilitation of research facilitators (who were the local people). The ES was not helpful in convincing participants to talk openly in the interviews; however, it often made participants believe that the interviews were formal sessions, which sometimes made them reluctant to decide to participate in the study. I was also cautious during recruitment, as I was concerned that some participants might agree to participate without understanding the implications of participation in the study. To minimize this, I gave participants some time to think about participation in the research, before contacting them later to confirm their willingness. I was also concerned that people participated in the research because they expected immediate benefits from their participation, such as receiving medicines or medical advice or referral for free TB treatment. This was not an unfounded concern: Kravan (52), for example, heard about the research project through one of her in-laws, who was a health volunteer. She contacted the research facilitator and

confirmed her intention to participate in the study. As Kravan had relapsed two times from TB treatment and was under her third course of treatment, she was very concerned about her health, and expected that participating could help her to find a special treatment to cure her TB. To avoid any participant misunderstandings related to the benefits of participating in this research (like Kravan), I was very diligent about explaining the benefits of participating in this research, and emphasised that I did not provide any treatment for any disease. Ultimately, Kravan agreed to participate in the study although she did not receive any treatment for her illness.

These challenges reflect the culture of lack of confidence felt by community members to provide public criticism or express individual opinions on a particular issue. It is very unlikely in Cambodian culture that someone will express their opinions or talk openly about their life experiences to a researcher or stranger when they meet for the first time. Participation in research was also a new (unfamiliar) experience for community members and it was therefore not straightforward to encourage people to trust the related ethical procedures (such as confidentiality and privacy in relation to participation in research). However, I discovered that participants talked more openly when they developed trust in my assistants and me over time.

Data analysis

Qualitative analysis

Data were analysed using a grounded theory approach (Strauss & Corbin, 1998; Charmaz, 2006). After the first few interviews, I spent time expanding and transcribing the interviews verbatim, reading through them carefully to gain familiarity with the data and to identify themes and sub-themes (Ryan & Bernard, 2003; Markovic, 2006; Olszewski, et al., 2006). This

also allowed me to identify themes arising in one interview, which I then used to inform subsequent interviews. This process also allowed me to ensure data saturation and, therefore, to determine sample size (Guest, et al., 2006).

I organised my data using Nvivo7, although I also conducted manual coding, as I found this process both helped my eyes to relax from constant use of the computer and that working with coloured pencils was more enjoyable. I identified themes through line-by-line coding techniques. I read each transcript line by line to identify themes or sub-themes; I constantly compared one theme to another to see which belonged together, and then I grouped them into conceptual categories that reflected commonalities among themes (Ryan & Bernard, 2003). Themes were identified inductively (Markovic, 2006). I continued searching for themes and sub-themes in other transcripts; themes were used in developing my theory when approximately half of the participants spoke about them (Sandelowski & Barroso, 2002). Selected sections of interview transcripts were translated into English for presenting in the thesis, however specific terms that were commonly used and which explained the meaning of the analysis in these transcripts were kept in Khmer in order to reflect the true meaning of participants' voices. Pseudonyms were used through data analysis and presentation; participant characteristics (position, qualification, address) were disguised to avoid identification.

Quantitative data analysis

At the completion of the survey, the research assistants entered the data twice using Epi-data software; data were then merged to identify inconsistencies or errors in data entry. The dataset was rechecked for accuracy using case summary and frequency tables. The clean dataset was exported to SPSS (version 17) for analysis. I conducted descriptive analyses (using frequency and cross-tabulations) and also applied useful statistic tests, including Chi-square, Mann-

Whitney, or Wilcoxon tests wherever necessary to determine associations or differences between groups of participants. I employed these non-parametric tests because my data did not meet the assumptions for parametric tests; for example, my selection of participants was not based on simple randomised methods and my data were not normally distributed (Gravetter & Wallnau, 2007; Pallant, 2007).

Study limitations

The data from this study provide important insights into participants' understanding of TB, access to peripheral health services, and social stigma associated with TB. It also highlights how these factors influence patients to find their way to the DOTS program, and how they complied with TB treatment in rural areas of Kampong Speu Province, Cambodia. This study has some limitations related to sampling and time constraints. Sampling and sample size may limit the generalizability of the study findings; for example, most of the TB patients participating in this study were recruited from public health facilities and were diagnosed and treated through the same. In consequence, the findings may not reflect patients who could not find TB treatment or were treated for TB with other providers. Furthermore, the small sample size of TB patients may limit the generalizability of the findings. The use of theoretical saturation in determining sample size and the variety of different participant backgrounds in terms of socio-economic status and location of residence suggest that the findings were internally valid, and that the findings may be relevant for other TB patients in this province. Similarly, the survey recruited participants from villages in which a TB patient had been treated through a health centre, and recruitment was thus not based on simple random sampling. This may limit the possibility for generalization of the findings to other parts of the country. However, the sample size calculation and recruitment procedures followed established

protocols as much as possible to ensure that findings represented other rural community members in the province.

Decisions were made during my data collection about what issues were to be included in this study. In particular, the high drop-out rates of suspected TB patients referred by private pharmacies to health centres, the motivations of health workers, information about insecure flows of drug and medical supplies from central to peripheral public health services, the TB treatments accessed through informal providers, and the dual job practices of government health staff were not examined in greater detail here due to time constraints despite their potential relevance.

This research is the first mixed methods study of health-seeking behaviour, stigma and gender in relation to tuberculosis in Cambodia. It provides in-depth information about the lay experience of living with TB in familial, social and cultural contexts. In addition to its contribution to academic knowledge, the findings of this study are expected to be used, following the completion of my PhD, to advocate an appropriate behavioural intervention to improve TB early case detection, improve compliance with anti-tuberculosis treatment, prevent TB multi-drug resistance, mobilize support for patients and their families, and reduce stigma against TB patients. I return to these points later in my thesis.

CHAPTER 3

WHAT IS TUBERCULOSIS?

EXPLANATORY MODELS OF ILLNESS AMONG RURAL CAMBODIANS

I think I got TB because I worked hard all my life; I worked in the rice fields, farmed, dug the ground, and carried soil, water, and heavy things on my shoulders. I worked under the sun, in the rain, in cold and hot weather (Pin).

I don't think I contracted TB from someone. It happened because I was working hard, especially during the *Pol Pot* (Khmer Rouge) regime. The head of my village, my friend, also had this disease; many men my age had TB. At that time, we were working hard, sleeping on the ground, in the rain, and never had enough food. Our health was already ruined during that time; that is why I now have TB (Samreth).

I heard about TB a long time ago, but I don't have [any] knowledge about the disease. In the past, I heard old people say that TB could be passed down through generations, from parents to children. I don't know if that was right or wrong. But from my own experience, I have observed that there has always been one TB patient in a TB family, generation after generation. In my family, my father had TB in the 1980s, now my daughter has TB. I also heard that TB can pass from one to another through breathing and talking to each other, but I don't totally believe it because my mother stayed with my sick father and took care of him, and she had never got TB. My daughter never ever met her granddad but she has TB (Chan).

We know someone has TB if she or he suffers from a strong cough and is very thin. The cough sounds like it's coming deep from the lungs; sometimes it is accompanied by difficulty breathing or blood. A TB patient looks pale. There are several types of coughs: dry cough caused by eating the wrong food or cold food, cough and cold, asthmatic cough, and bleeding cough (Heng).

TB is a dangerous disease. It is treatable at the hospital, but the patients became weak after the treatment; they cannot work hard or they will relapse. TB medicines are very strong and they cause strong side effects (Soma).

These extracts from in-depth interviews and focus group discussions with TB patients, family members and other members of the community illustrate the various explanatory models that people have about the nature of TB, including its symptoms, causes, transmission and treatment. An Explanatory Model of Illness (EM) is an individual's representation of opinions and beliefs about a disease or illness, including its causation, the experience of symptoms, treatment alternatives, and therapeutic outcomes. These EMs lead to choices about diagnosis, prevention, and the management of the illness (Kleinman, et al., 1978). A person's EM usually originates from the three overlapping sectors of the health system: the professional sector (doctor and TB program), the popular sector (family, friends and community members) and the folk sector (traditional or spiritual healer)(Kleinman, 1980). A person may hold several EMs, which draw on all three sectors. For example, a person's EM may include instances where they have obtained ideas about TB from the professional sector, including text books, health education materials (including booklets, leaflets, posters), and health messages delivered by health workers, as well as TB information shared through his/her social networks (family, friends, and community), and the knowledge provided by folk providers (Kleinman, 1986).

Earlier research related to TB illustrates the elasticity of such models, including when local models are influenced by biomedical information and by other models of disease (Ailinger & Dear, 1997; Poss, 1998; Caprara, et al., 2000). For example, people in the West Coast region of Aceh, Indonesia, explained TB as being caused by a poison or resulting from supernatural factors, such as the evil eye or breaking a social taboo; therefore they used traditional healer as their first choice for treatment, and only moved to biomedical providers when their first choice

could not help them (Caprara, et al., 2000). Mexican farm workers in western New York state (United States) held explanations of the cause, severity, prevention and treatment of TB that were consistent in many aspects with medical models of TB: they believed that TB was caused by a germ, microbes, a virus or bacteria, and could be transmitted from one person to another through breathing in close proximity to a TB patient (Poss, 1998). In Laos, TB patients explained the cause of their illness as associated with germs, smoking, excessive working and weak health, resulting from spirits and/or spells and hereditary; and therefore they sought diagnosis and treatment from multiple *moorh* (therapeutic practitioners) from both the professional and the traditional health sector (Xeuatvongsa, 2005). As both patients and health care providers use EMs to guide decisions regarding diagnosis, treatment and prevention measures (Kleinman, 1986), it is important to investigate lay EMs of TB for rural community members.

Lay understandings of TB symptoms

The *Khmer* term for tuberculosis is '*robeng*'. Participants in this study (TB patients, family members, and other members of the community) were familiar with *robeng*, although they did not always understand the biomedical meaning of the disease. They usually heard about TB through other community members:

Since I was *deung kadey* (grown up and could understand things—became adult), I heard of *robeng*. I heard older people called it *robeng si sourt* (TB eats the lungs). In the past if a person had TB, he/she would be thinner and thinner and died (Soma).

Historically *robeng* was considered to be a 'fatal disease.' Although TB treatment is available, participants perceived that *robeng* was a 'dangerous disease' because it eats the lungs, and

without healthy lungs, patients will have difficulty breathing and will die. Nevertheless they could not explain how TB started in the lungs and attacks the organ.

I heard that TB eats the lungs. When my daughter had her x-ray, *peet* [doctor] also said that my daughter had TB and that eats a part of her lungs. He showed us on the [x-ray] film that one part of her right lung was gone, we can see from the x-ray that part of the lung is white and the remaining part is black (Pheakdey).

“Eating the lungs” was the term that health providers used to simply explain the manifestation of TB on the lungs to patients and family members. Thus, TB patients and their family members adopted this term without clearly understanding the cause of the infection, and they shared this concept among other lay people in their communities. Participants explained that *robeng* stays in the lungs and eats the lungs (tissue and vessels), creating wounds in the lungs, little by little making the lung tissue rotten. As a part of the lungs is eaten, a patient would suffer from several symptoms associated with the respiratory system, such as cough and/or bleeding cough or difficulty breathing, chest pain and/or several other symptoms that contributed to the patient’s poor health status—being skeletally thin, having a recurrent fever, feeling weak, and experiencing a loss of appetite—as Sophon explained:

TB goes into the lungs through the air we breathe in, and then it eats the lungs little by little. That’s why patients have cough and chest pain. Like me, I had bleeding cough. I think it’s because TB caused a big wound in my lungs (Sophon).

The community survey sought to examine how lay people understood TB. All participants (240) had heard about the disease. The two most commonly reported TB symptoms were cough and weight loss, reflecting that most participants had an understanding of TB symptoms consistent with biomedical descriptions of symptoms of TB. However, most participants did not see bleeding cough as a TB symptom; they often attributed bleeding cough to other causes.

There was a significant association between gender and the perceptions of cough and weight loss as TB symptoms (Table 8), suggesting that women may see or hear about these symptoms more often than men through their roles as caregivers or in daily activities.

Table 8: TB symptoms reported by community people (n=240)

Symptoms	Male (n=119)		Female (n=121)		Total	
	N	%	N	%	N	%
Cough	100	84%	114	94.2%	214	89.2%*
Weight loss	44	37%	80	66.1%	124	51.7%**
Bleeding cough	20	16.8%	21	17.4%	41	17.1%
Difficulty breathing	20	16.8%	14	11.6%	34	14.2%
Fever	12	10.1%	11	9.1%	23	9.6%
Weakness	5	4.2%	6	5%	11	4.6%
Chest pain	4	3.4%	1	0.8%	5	2.1%
Loss appetite	4	3.4%	0		4	1.7%
Don't know	9	7.6%	3	2.5%	12	5%

Multiple answers provided

Chi-Square test * $p < 0.05$; ** $p < 0.01$

Cough was the most common sign of TB reported by both TB patients and community members. Patients and their family members usually observed the progression of cough. Patients presented at the hospital or health centre when the cough progressed and became more disruptive: when they noticed blood, or when they produced plenty of sputum with the cough, or when the cough was accompanied by other symptoms such as fever, weight loss or difficulty breathing. Given the importance of cough in people's recognition of symptoms of TB, in the following section, I elaborate on types of cough, perceptions of cough among community members and their actions toward cough.

Community perceptions of cough

In Cambodia, cough was a central feature in TB health education messages to draw people's attention to TB screening: 'If you cough for three weeks, please come to your nearest health centre for TB screening. Diagnosis and treatment of TB is free'. This possibly explains why

most participants recalled cough as a leading TB symptom. But, when I explored understandings of cough in in-depth interviews and focus group discussions, the duration of the cough tended not to drive participants to seek TB diagnosis; instead, their treatment-seeking behaviour was determined by the perceived lay category of cough associated with perceived severity of cough. There were six lay categories of cough, as follows.

Ordinary cough

With ordinary cough, participants thought that nothing was wrong within their body, and therefore believed no action was required. Ordinary cough was described as having a sudden onset (acute cough) following exposure to bad weather, rain, wind, or polluted air (dust or the smell of chemicals or petroleum). Ordinary cough could be isolated or could occur in association with a runny nose, sore throat, fever, or body pain; it may be a dry cough or accompanied by a little sputum. Ordinary cough was generally related to the common cold, seasonal cough, especially in dry season (December to April), or another occasional respiratory infections. No participants suspected any serious illness or harm related to, or thought of tuberculosis as the underlying cause of, ordinary cough, even if they had had a family member who had previously been diagnosed and treated for TB. Ordinary coughs lasted from a couple of days to weeks, and disappeared with or without simple treatments such as home remedies or over-the-counter anti-pertussives.

Ordinary cough was common in rural environments where people lived in dusty environments and were exposed to the weather (sun, rain, wind) during their daily work in rice fields. TB patients described this kind of cough as coming and going repeatedly, and they did not worry about it; they assumed that each new cough was a separate example of an ordinary cough, with each cough unrelated to the other. Such perceptions had important implications for people's

health-care seeking: these misunderstandings of the duration of cough meant that symptoms of TB were neglected at the early stage of the illness, which led to delays in diagnosis and appropriate treatment. These practices were common among community members, as reflected in the survey data: 15.8% (n=38) of participants had experienced a cough lasting more than three weeks in the last six months (Table 9). Generally, they did nothing about the cough as they considered it to be normal, although three men bought medicines from a pharmacy to alleviate it (Table 10).

Table 9: Cough in the past six month and actions toward cough

Cough more than 3 weeks	Male (n=119)		Female (n=121)		Total (n=240)	
	N	%	N	%	N	%
Yes	18	15.1%	20	(16.5%)	38	(15.8%)
No	101	(84.9%)	101	(83.5%)	202	(84.2%)

Table 10: What did you do when you coughed for more than 3 weeks?

Actions taken	Male (n=18)		Female (n=20)		Total	
	N	%	N	%	N	%
Do nothing	15	(83.3%)	20	0(100%)	35	
Buy medicine	3				3	

Wet cough

In contrast, “wet cough” or “productive cough” was described as occurring when phlegm (sputum) or pus was coughed up. People were generally unclear about the origin of the sputum or pus; they perceived that wet cough resulted from a wound or infection in the respiratory tract. This kind of cough therefore made people concerned about their health. A wet cough was associated with difficulty breathing, leading people to think about problems associated with the lungs, as they were known as the breathing organ. Wet cough was not considered ordinary or to be ignored: people classified its severity according to the quantity, colour,

texture, smell of sputum or pus, and the presentation of other associated symptoms. Wet cough with abundant thick, yellow sputum or blood accompanied by difficulties breathing indicated the need for immediate presentation to professional providers, mainly at the hospital. This cough was commonly associated with severe lung infections, lung oedema, or TB.

Dry cough

Dry cough was considered similar to ordinary cough; as already noted, it was generally thought to be caused by bad weather, dusty environments, the common cold or smoking. However, it differed from ordinary cough because it lasted longer than ordinary cough and could be disruptive to patients. Treatment was not always required for this cough. The daughter of one participant suffered repetitive dry cough, causing difficulty breathing and leading to loss of sleep. These characteristics led him to seek help from the health centre:

My daughter started coughing as if an ordinary cough. She did not have any phlegm. Then the cough progressed to be more frequent with little sound, but causing her difficulty breathing. I bought medicines from the pharmacy and also boiled traditional medicines for her, but it did not help. I brought her to the health centre, and then she was diagnosed with TB (Chan).

Bleeding cough

Bleeding cough was a sign that alerted health providers to investigate for TB, especially when it presented in a person with a history of cough, who was thin, or who had a family history of TB. In contrast, although cough with blood was the most frightening sign of illness for all participants, it did not always indicate TB to lay people: the survey findings indicated that only 17% of participants described bleeding cough as a sign of TB. The severity of bleeding cough was assessed according its quantity and colour. For example, a cough with abundant ‘fresh-red’

blood and air bubbles was seen as very severe and having the potential to claim a patient's life. It indicated the possibility of lung trauma, injury or rupture of the lungs or throat. Cough with a little old blood mixed with sputum or pus was regarded as less severe than cough with plenty of fresh blood, and was perceived to indicate a chronic wound in the lungs. The greater the volume of blood, the greater the anxiety and fear experienced by patients and family members, leading them to immediately seek help from professional health providers, particularly those at a public hospital or health centre.

There are several types of bleeding cough. The most severe one is the cough with fresh blood with bubbles of air. This could be caused by internal trauma e.g. a fall from a high tree, or a traffic accident or working hard. Bleeding cough with old blood (dark and coagulated) could come from the stomach or the lungs. And cough with sputum with strips of blood could originate from lung infections or TB. Patients with bleeding cough should see *peet* quickly (FGD).

I had coughed for a prolonged time, but it would come and go, until one day I coughed very hard with a strip of blood, then I coughed more with more blood mixed with sputum. My father said that I could have TB. Because he had had bleeding cough before, he took me to the hospital (Navy).

Bleeding cough is dangerous. When I saw fresh red blood with the sputum, I was so frightened, and I coughed more with a lot of blood, like vomiting. My son and grandson took me immediately to the hospital, and *peet* referred me quickly to the TB ward (Soma).

Bleeding was recognised as an urgent sign of illness that drove patients and their family to seek treatment from professional health providers. As demonstrated above, bleeding cough was an important reason for some patients to present immediately to public hospitals or health centres: seven out of 32 TB patients in this study rushed to hospital or a health centre immediately after they began to cough with blood.

Chronic cough

Participants referred to chronic cough as one that continued over an extended period of time, from months to years. Chronic cough could be either a dry cough or wet cough; for some, it started with a dry cough then later developed into a wet cough. In some instances, chronic cough was considered by some people as similar to an ordinary cough provided it did not disrupt their daily activities, but for others, it turned into a severe cough when it progressed to be more intense (more frequent or stronger cough), began to be accompanied by sputum, pus or blood, and was accompanied by other worrying symptoms:

I had chronic cough because I had asthma from when I was young. I coughed very often and I got used to having cough. If I am exposed to rain or wind, then I have more cough and difficulty breathing. It's not a problem; I never worry about it, but if the cough becomes severe and obstructs my airway, then I go to hospital (Meng).

Some people have a very prolonged cough, but it is not disruptive or causing any trouble, like my father coughs almost every day. We took him to the health centre, and gave a sputum sample, but *peet* said he doesn't have TB. Usually he has no serious health problem except cough. He is nearly 70 now, he eats like anyone else but he smokes a lot. We cannot stop him (Rath).

TB cough

TB patients, and people who had been around TB sufferers for a period of time, described a "TB cough" as a cough that could not be alleviated with any treatment other than with TB treatment. TB cough was distinguished from other cough in various ways: it was accompanied by a strong feeling of itchiness in the throat, the sound originated deep in the lungs, it was repetitive, it was accompanied by abundant yellow-green sputum or bleeding, and was associated with difficulty breathing, remittent fever, loss of appetite, and tiredness:

I coughed for a long time. I always bought medicines to treat the cough, but later my cough became stronger and stronger, especially at night. Once I just lay down and I had itchiness in my throat. Then I started coughing very strongly, the phlegm came up and stuck in my throat. I could not breathe until I coughed it out. I coughed very strongly and repetitively. I felt very tired. I suspected that I could have TB because the cough was making things very difficult. I could not sleep and I could not eat, [so] I decided to come to this hospital (Sophal).

Last year, I started coughing and feeling weak in my body, but I didn't think it was a big problem. The cough became very strong at night and I had night sweats, I could not eat. I took cough medicine that I bought from the market, but it did not help me. It was the most difficult cough I ever had in my life, it is hard to describe it to other people (Phally).

TB cough was regarded as the most disturbing cough, leading sufferers to seek treatment from hospital or health centre promptly. However, this cough usually presented after a prolonged delay in obtaining appropriate care for their symptoms.

In Table 11, I summarize a hierarchical schema of cough types described by research participants, their interpretations about the reason or cause of the cough, and the actions they took in response.

Table 11: Summary of cough categories

Cough type	Description	Individual's interpretation of reason for cough	Treatment (s) indicated by this cough type
Ordinary Cough	Isolated cough during day or night. Either a dry cough or wet cough, with little/light phlegm. Accompanied by runny nose or sore throat.	- Common cold. - Acute respiratory infections. - Resultant from smoking	No formal treatment (s) required Food restrictions: avoid eating salty and fermented fish, cold drinks and hot fruits. Reduce smoking. Coining/home remedies Anti-cough medicines from local drug stores.
Dry cough	Without sputum, pus or blood.	- Common cold, - Exposure to dust - Smoking and drinking.	No treatment required unless symptoms become more persistent. Food restriction. Behaviour change: stop smoking and drinking.
Wet cough	Cough with phlegm, pus Associated with other symptoms: difficulty breathing, fever, chest pain, feeling weak, and loss appetite.	- Associated with wound in lungs. - Lung infections (lung oedema, lesion, inflammation in the lungs) - HIV/AIDS.	Treatment is required: Treatment from pharmacy or a health provider Treatment from <i>Kru Khmer</i> Immediate referral to hospital when cough co-occurred with abundant sputum and difficulty breathing.
Chronic cough	Cough presented for long time Dry cough or wet cough. Can be accompanied by other symptoms	- Common cold or seasonal flu. - Asthma - Smoking	Treatment is not always required, unless it is disruptive. Traditional/herbal medicines. Reduce smoking, drinking Food restrictions.
Bleeding cough	Cough with fresh blood or blood, air bubbles and blood, or with sputum or pus mixed with blood	- Lung injury, rupture of lung or throat vessels. - TB	Treatment from hospital required immediately to stop bleeding.
TB cough	Very strong cough with lots of phlegm (smelly) followed by itchiness in throat which makes it difficult for people to sleep. Difficulty breathing With remittent (not necessarily high) fever. Loss of appetite	- TB	Treatment is required from western medicine. Tractional medicines or spiritual healers are used if western medicine treatments don't help to cure the cough.

The data presented in Table 11 suggests that, although cough was the most observable sign of TB, there was no single type of cough which exactly indicated TB. Participant's explanations about the cause of cough or other symptoms related to TB varied from time to time as the

illness progressed. The extensive use of western medicine, including antibiotics, in this community allowed participants to attain relief from cough and other symptoms, either completely or partly, for a period of time (weeks or months). This practice may have led to misinterpretations about the severity and duration of cough, as participants perceived that they suffered multiple discrete ordinary episodes of cough that were not connected to each other. This may explain why no participant immediately thought that they could have TB when they first had cough. Participants described trying different medications to alleviate their cough: for these people, if the cough disappeared, they considered it to be an ordinary cough and therefore did not worry about it. This perception and associated actions regarding their cough posed a challenge, as health education messages aimed at improving early TB case detection encouraged people with a cough of three or more weeks duration to access TB screening. Similar findings from research in rural Rwanda on perceptions and beliefs about cough and TB showed that cough worried people only when it was accompanied by other symptoms such as breathing difficulties, weight loss and the appearance of blood in sputum (Ngang et al, 2007). People subsequently diagnosed with TB did not rely only on the duration of cough when deciding to seek health care, but did so after conducting their own “illness appraisal”. The illness appraisal involved consideration of several factors: the severity and cause of cough, alternative courses of treatment, availability of money, and having faith that a health provider could resolve their cough (Godfrey-Faussett, et al., 2002).

Lay perceptions about the cause (s) of TB

A central component of people’s explanatory models of illness lay in their understandings about the aetiology of the illness (Kleinman, 1980). Following this, a central issue that I explored with participants was: what did they think caused their illness? Community survey

findings showed that, while every participant was familiar with TB, when they were asked what caused the disease, 37% responded ‘don't know’ (Table 12). Around six percent of participants identified that TB infection was caused by *meh rok* (germ, described below), although none specified *mycobacterium TB*. Nearly ten percent believed that people developed TB because they inherited the disease from their ancestors. The rest of the participants related TB to smoking, dust, hard work, and poor hygiene.

Table 12: Cause of TB stated by community people (N=240)

What causes TB?	Male (n=119)		Female (n=121)		Total (n=240)	
	N	%	N	%	N	%
Smoking	34	28.6%	25	20.7%	59	24.6%
Cough	14	11.8%	28	23.1%	42	17.5%*
Hereditary	13	10.9%	10	8.3%	23	9.6%
Cold	5	4.2%	14	11.6%	19	7.9%*
Lung infections	9	7.6%	10	8.3%	19	7.9%
<i>Meh rok</i> (germ)	7	5.9%	8	6.6%	15	6.3%
Hard work	4	3.4%	11	9.1%	15	6.3%
Dust	11	9.2%	3	2.5%	14	5.8%
Hygiene	5	4.2%	8	6.6%	13	5.4%
Don't know	42	35.3%	47	38.8%	89	37.1%

Multiple answers provided, Chi-Square test * $p < 0.05$

Some respondents held misunderstandings about TB causation, believing that TB could be caused by lung infections (7.9%), cold (7.9%), and cough (17.5%), which indicated that participants believed that some respiratory health problems could develop into TB.

People’s understanding of the aetiology of TB was not influenced by literacy. Table 13 shows that literate participants explained the cause of TB in similar way to those with low or no literacy. This may reflect limited health information relating to the aetiology of TB available for rural Cambodians.

Table 13: What causes TB, analysed by literacy levels?

What causes TB?	Literate		Limited or no literacy		Total (n=240)	
	N	%	N	%	N	%
Smoking	25	36.8%	34	19.8%	59	24.6% **
Cough	12	17.6%	30	17.4%	42	17.5%
Hereditary	6	8.8%	17	9.9%	23	9.6%
Cold	5	7.4%	14	8.1%	19	7.9%
Lung infection	9	13.2%	10	5.8%	19	7.9%*
<i>Meh rok</i> (germ)	7	10.3%	8	4.7%	15	6.3%
Hard work	5	7.4%	10	5.8%	15	6.3%
Dust	3	4.4%	11	6.4%	14	5.8%
Hygiene	5	7.4%	8	4.7%	13	5.4%
Don't know	21	30.9%	68	39.5%	89	37.1%

Multiple answers provided

Chi-square test, *p<0.05, ** p< 0.01

TB patients and family members held similar beliefs to participants in the community survey, describing the causes of TB in term of *meh rok* (germ), environment and work, individual susceptibility, personal behaviour, and hereditary.

Meh rok

As highlighted in Table 13, a small percentage (6%) of survey participants identified that TB is caused by *meh rok*. Participants in in-depth interviews and focus group discussions also maintained that TB was caused by some sort of *meh rok*. *Meh* translates as 'germ': it combines the word '*meh*' (mother or boss) and '*rok*' (disease), so the term *meh rok* merges the meanings of the two words to refer to any species from which disease originates. For example, people spoke of *meh rok* of flu, *meh rok* of typhoid, *meh rok* of diarrhea, *meh rok* of liver diseases, *meh rok* of malaria, *meh rok* of AIDS, and *meh rok* of TB to refer to various pathogens, without specifying a particular germ. Those who related *meh rok* to TB did not know which germ caused TB, and furthermore did not understand how it contributed to the development of the disease in the human body.

There are severe *meh rok* in the air, water, food that can cause illness, e.g *meh rok reak* (diarrhea germ), *meh rok* flu, *meh rok* liver, *meh rok robeng* (TB germ), a lot more. We cannot see *meh rok*, so we can get any *meh rok* anytime. I heard that TB is caused by a *meh rok* that lives in the air and food, so people can get the TB *meh rok* if they talk closely or eat with a TB patient (FGD).

TB is caused by *meh rok*. When we work hard or do not have good hygiene, the *meh rok* can enter our body and make us sick. I don't know what *meh rok* caused TB, but *peet* told us to take medicine regularly to kill TB *meh rok* because it is very strong (Sophon).

Although some participants identified *meh rok* as the cause of TB, they generally explained this according to their generic understanding rather than indicating their understanding of the cause of TB by a *mycobacterium*, as explained biomedically.

Environment factors and work

Participants indicated that the environments in which people lived and worked could be associated with the onset of illness. These factors were perceived to be beyond the control of individuals, who had limited opportunities to exercise choices to avoid or control such factors unless they were to quit their jobs, change their living places (home or residence), or abandon their sick relatives. Key environmental factors included climate and work location (including exposure to rain, sun and wind; hot and cold weather at work and poorly ventilated living places), dust in factories, chalk dust (from white chalk used to write in classrooms), street dust, as well as petroleum fume, fertilizer, pesticide, and cigarette or tobacco smoke. People regarded these factors as contributing to the development of TB, because pathogenic particles in the air were perceived to accumulate in the lungs, causing frequent cough and lung infections that could later develop into TB. This was particularly the case where people had extended exposure:

I see teachers who got TB when they become old, I think because they breathed in a lot of chalk dust when they wrote on the [chalk]board. Teachers talk and shout a lot, so they had TB later because the dust may accumulate in their lungs (FGD).

All bad environments can cause TB. If people use a lot of fertilizers or pesticides, those chemicals can come into the lungs and cause TB. If see my uncle, he worked on the farm very hard. He sprayed pesticides for many years, and he later had TB (FGD).

I work in the road maintenance section. I drive a road cleaning truck. Every day I am exposed to dust, and the smell of boiling rubber for road surfacing is very strong. I had been thinking for a long time that one day I would have a problem with my lungs because of too much dust and the smell of chemicals going into my lungs. I had cough and cold very often; that is why I have TB (Sopha).

Participants understood that exposure to polluted air may cause TB, although they could not explain how this condition could cause TB. However, their concerns about the connection of bad air to TB were logical. Historical studies show that the widespread distribution of TB is associated with poor quality air as a result of overcrowding and poor circulation of air (Bates and Stead, 1993; Manderson, 1996; Daniel, 2006). Study participants elaborated on these points:

I worked as a construction worker for years. I always worked hard under the sun and carried heavy stuff like cement, metal, bricks on my shoulders. At the construction sites, it was always dusty. Dust from sand, dust from cement went up my nose every day. I think that is why I became weak and have TB (Bona).

I made charcoal from wood for years, from the collapse of *Pol Pot* (Khmer Rouge) to recent times; then I stopped because it was hard to find wood. It was not very hard work for me, but every day, I breathed in heaps of ash and dust from the charcoal, and when I spitted or sneezed or coughed it come out as black sputum full of charcoal. I think this could have caused my health to be weak (Kiri).

Work was another factor that TB patients and family members commonly blamed as causing TB. These participants relied on their physical strength to farm rice fields or to earn a daily wage through casual jobs. They were often used to physical hard work that may result in extreme exhaustion, digging the ground, cutting trees, carrying rice and other heavy materials all day long, over an extended period of time. In addition to extreme fatigue as result of hard work, these rural people often had a poor nutritional status as a result of poverty. Rural farmers and workers generally ate whatever they could afford or find from the rice-fields, local ponds and elsewhere in the local environment. However, few participants did linked poor nutritional status and TB. Only one participant thought that lack of food combined with hard work could make people weak and more vulnerable to developing the disease:

I think my husband has developed TB because he works very hard in his whole life, and we do not have enough food to eat. You know, sometime we only have rice with salt (Mony).

Again participants' explanations of TB as associated with hard work and air pollution was not unreasonable, given their own observations and lay medical knowledge. Hard work combined with a poor work environment and poor nutrition can impair health, ultimately facilitating TB contagion and the progression from latent (silent) to active TB.

Individual susceptibility to illness:

An important category of TB causation was individual susceptibility, the internal response of each human body to a particular illness; it refers to bodily strengths and weaknesses, including the ability of an individual to resist the illness.

Mbean roub mbean rok: “you live, you get sick”

People believed that individual ability to resist illness was inherent, and that this differed from one person to another. They observed that some children were born weaker than others, especially those who were born to sick mothers, who had insufficient breastfeeding, or who had accidents or were severely sick during early childhood. People regarded these children as *kmeng toon* (soft children): they were characterized by frequent illness and being underweight, although they may have had normal intellectual development. Growing-up, these children were perceived as becoming weak adults who had relatively poor health and were more susceptible than others to illness. These explanations did not contradict medical explanations of illness causation, and may have reflected these biomedical understandings related to the immune system, where it was perceived that individuals with immune deficiency were usually more susceptible to illness, and so were more vulnerable to disease transmission. Once infected, they were seen as more likely to develop active TB disease. These perceptions were consistent with the medical model. Among people infected with TB, only about 10% develop active TB disease (Manabe & Dannenberg, 2006). In addition, it has been demonstrated that people with compromised immune systems, such as in the case of HIV/AIDS, are more likely to develop active TB (Maher, et al., 2005). In addition, people understood individual susceptibility to illness to be associated with age, with ageing reducing the body’s strength to fight disease, so reducing the chance of being cured from the disease:

I think I got TB because of AIDS disease. I heard *peet* say that, when people have HIV, it makes the body’s protection system weaker and weaker, so the patient may suffer from opportunistic diseases and TB is one of these diseases (Rotana).

When my daughter was sick, I took her to different places to treat her. I did not think that she could have TB, because she was young, until she coughed with blood. Then I

decided to take her to the TB ward in the hospital. I used to have TB years ago, because I was old and I worked hard. But I could not believe that she had it, she is young and she has never worked hard at all (Pheakdey).

None of my family had TB. I had a relative who had TB but I did not see him often. I could not say I got this disease from him; maybe I already had TB in my body even before him, but it just waited until the day that I became sick (Pisey).

Like Pisey, many TB patients suspected that their TB originated in their own bodies, and that it was just latent, waiting for the time to “come out”: they did not blame anyone for transmitting TB to them. Furthermore, some participants attributed TB to the concepts of *mean roub mean rok*, a local idiom with which everyone was familiar, translated as ‘having life, having disease’ or ‘you live, you get sick,’ which suggested the inevitability of sickness and disease. This did not relate to hereditary factors; rather, people explained that disease is a part of human life and no one can avoid being sick sometimes. A sense of fatalism therefore pervaded people’s understandings of cause of illness including TB, making participants accept “being weak” or “having severe or chronic disease” as resultant from bad luck or *kam* (*Karma*), the result of actions from the past or present life of an individual. Khmer people believed in *kam* (*Karma*, the Sanskrit term, literally means action or doing), and that people deserved their *kam* (“do good get good, do bad get bad”). They often referred to *kam* as *baab* (sin), and they interpreted the cause of some problems (such as having accidents, chronic illness, or loss in business or works) as their *kam* when they lacked the ability to manage or control it. This perception meant community members felt passive in identifying and controlling the cause of illness, and thus in finding out how to prevent it. Community members tended to accept their misfortune.

Understanding of susceptibility to TB

Nearly 43% of community survey participants perceived themselves as having no risk of developing TB: no contact with TB patients, being healthy, and having no family members who had had TB. In contrast, many others perceived that they had some chance of contracting TB. About 18% of survey respondents perceived that they had a high chance of getting TB (Table 14). In general, family members of TB patients, including their children, spouses or parents, were generally not concerned about developing TB; they believed that they were strong and healthy so the disease could not attack them.

Table 14: Participants' perceived likelihood of getting TB

Do you have any chance of getting TB?	Male (n=119)		Female (n=121)		Total (n=240)	
Yes	66	55.5%	64	52.9%	130	54.2%
No	51	42.9%	52	43%	103	42.9%
Don't know	2	1.7%	5	4.1%	7	2.9%
How much chance of getting TB?	Male (n=66)		Female (n=64)		Total (n=130)	
High chance	8	12.1%	16	25%	24	18.5%
Medium chance	13	19.7%	16	25%	29	22.3%
Low chance	43	65.2%	31	48.4%	74	56.9%
Don't know	2	3%	1	1.6%	3	2.3%

People's explanations of the relationship between individual susceptibility and illness were influenced by biomedical models of illness causation; however, they also described individual susceptibility to illness in terms of what people were born with or as a result of misfortune or *karma*. Participants may have neglected illness prevention methods because of their beliefs that people either "deserved" or inevitably would develop the disease. For either explanation, there was not much that could be done to avoid infection. Furthermore, people's perceptions that they had no or low chance of developing TB led to their neglect or dismissal of symptoms, and

a subsequent reluctance to access TB screening at the time of onset of TB symptoms. These beliefs may also have been associated with delayed self-referral to TB services.

Heredity as a cause of TB

Understandings of heredity in the aetiology of TB were pervasive, and supported the findings of other studies in Laos, Vietnam, Ethiopia and Pakistan, in which many people believed that TB was a disease that could be passed from ancestors to later generations (Liefoghe, et al., 1995; Vecchiato, 1997; Long, et al., 1999b; Xeuatvongsa, 2005). This study confirmed that many people in rural Cambodia attributed causality to hereditary, and one in ten community members believed that TB could be passed down through generations. Participants understood that TB is a *son pouch* (hereditary) disease that could be handed down within the same kinship group, for example, from grandparents to grandchildren or from parents to children, regardless of age or sex. They believed that a family member of a TB patient would have higher chance of developing TB at some time in their life compared to people without a family history of TB. However, they were not able to explain *how* the disease could be hereditary. These understandings, as indicated above, contrasted with medical explanations of causation: they observed that some TB cases were not transmitted to people who had lived with a patient, but could be transmitted to a later generation, even when the person had no contact with the older patient. People also described how TB seemed to occur in some families in particular; they noted that some families always had members with TB, generation after generation, while members of other families in the same village had no history of the disease. In contrast, some TB patients who had no kin with TB disagreed that TB could be handed down through generations, and instead related their infection to work, pollution, or personal behaviour.

Personal behaviour

Personal risk behaviour, most commonly cigarette smoking, was blamed as a cause of TB. Community survey data showed that smoking was the most commonly reported cause of TB, and was identified by about one in every five participants (24.6%). Cigarette smoking is prevalent in Cambodia, particularly among the rural population, and people were aware that lung disease could be often attributed to smoking, so they referred to smoking as a cause of TB. The impact of tobacco on lung health was caused by the toxicity of chemicals in the cigarettes. Participants believed that the fumes of cigarette containing tobacco chemicals would reach the lungs of smokers, and then caused damage to their lungs day by day; this meant that smokers would often suffer from chronic cough that may then develop into TB. The fumes of mass-produced cigarettes were regarded to be more harmful than home-made cigarettes, which were made from pure dried leaves of tobacco grown either on a person's farm or in their backyard. Despite recognizing the adverse health impacts of smoking, its addictive properties and social norms meant that it was often difficult for people to change their behaviours until after the onset of TB:

I think I have TB because I smoke and I drink. It's normal for men. We always engage in some of this behaviour, either a little or a lot. I coughed for a long time because of my smoking, and I also had stomach problems. I've smoked for a very long time, but now I have reduced my smoking and I don't drink because I am sick (Kiri).

Men in rural Cambodia were often heavy smokers, and they reported that it made them feel good, reduced their hunger, helped them to endure long hours of work, and protected them from insects while they were working in the forest or a farm. As Kiri explained, however, when they became addicted to smoking or drinking, their health deteriorated as they lost their appetite and did not eat regularly. The gendered nature of personal risk behaviours was

reflected in people's observations that TB occurred in men more than women because of their higher levels of risky behaviour such as drinking, smoking and working hard.

Gaining an understanding of causation: "after diagnosis"

Encounters with public health services did not help TB patients and family members build a medical understanding of what caused their illness. Health providers tended not to explain the cause of TB to their patients, although they spent time explaining the medication and treatment plan, which they regarded as essential to help cure people. TB patients and family members had little interest in finding out what caused their disease and how it had happened to them once they were diagnosed. Like health workers, patients often concentrated on the medication and improvement of their physical health when they were under course of treatment, and this practice may prevent them from seeking correct health messages related to the cause of their TB:

I do not know why TB happened to me and I don't know what causes TB. I haven't asked *peet*. I think it's more important to get diagnosed and to get the right treatment for my disease; I don't care about why it happened to me because it's already happened. *Peet* explained me that I have to take treatment regularly, then I will be cured, they did not talk about why this disease happened to me (Navy).

Peet told me that I had TB because they found *meh rok* in my sputum. He did not explain anything about how the *meh rok* happened in my body, and I did not ask him. At that time, I felt confused. What I want to know is how to be cured from this disease (Lim).

Lack of understanding about TB among diagnosed TB patients may relate to the short consultation times with health providers, lack of patient's confidence in questioning the cause of their health problems, and provider's confusion and poor knowledge about TB.

Despite this, as discussed above, people's explanations of TB causation were influenced by the biomedical model. However, this explanation was limited and reflected a gap in adequate information about TB aetiology. People's understandings about causes were loosely consistent with medical explanations. However, the persistence of knowledge gaps often led to ignorance of prevention methods and delayed access to TB services. This meant that community members remained at risk of TB infection because they lacked understanding of the cause(s) and ways to prevent the disease.

Traditional beliefs associated with illness

In contrast to previous studies (Steen & Mazonde, 1999; Caprara, et al., 2000; Pronyk, et al., 2001; Xeuatvongsa, 2005; Sagbakken, et al., 2008), none of the participants in this study explicitly mentioned supernatural powers as a cause of TB. This is not to say that they did not believe in supernatural causes for ill health: they believed that supernatural powers could cause some health conditions, including sudden or chronic stomach pain, vomiting with blood, and becoming weaker and weaker, as well as multiple symptoms that were associated with TB including bodily pain, prolonged cough, bleeding cough, and repetitive fever. They also believed that supernatural powers could exacerbate existing illness conditions and prevent diagnosis by western medicine providers.

The powers that were commonly involved in sickness included ancestral spirits, spirits of places, magic spells, evil powers, witchcraft, and sorcery. These beliefs reflected broader understandings about supernatural powers. Most houses, big or small, had a small, dedicated place for worshipping ancestral spirit and the spirit of the house. Participants claimed that beliefs in supernatural powers were not as strong now as they were in the past, when people overwhelmingly relied on traditional healers and did not use western medicine as they do now.

Despite the influence of biomedicine in people's explanatory models of illness, as discussed earlier, people also relied on supernatural healers to confirm diagnosis and to seek therapies, especially when early symptomatic treatment from western medicine failed to help them (discussed in chapter 4).

In the following section, I outline people's beliefs about the source of supernatural powers and spirits worshiped by Khmer people: spirits of ancestors and place, and supernatural powers that influenced the illness of participants.

Ancestral spirits

People believed that the spirits of ancestors were involved in the happiness of current generations. Ancestors were perceived to care for and protect their living descendants from evil, bad luck and illness. People perceived that failure to worship ancestors made them upset or angry, and this may result in misfortune in the family, such as the sickness of family members, accidents, property loss, or business failure.

Even now [when] we have good western medicines, high technology, we cannot give up our traditional beliefs. We have to respect the spirits of our ancestors, it is very crucial to do that. It costs nothing, [you] just pray to them. When a family member does something wrong, e.g. there is a dispute in family, they have love affairs, it could make ancestors angry. In consequence the ancestors could make someone in the family became sick. [So] we have to apologize to the ancestors (Punleu).

If someone in my family is sick, my mother always prays to ancestors to apologize for any mistake we may have made unintentionally. We usually do both—go to *peet* and *bann srann* (pray) (Keo).

Spirits of ancestors were believed to affect every aspect of family life, including illness; people believed that the mistakes that family members did to ancestors could be removed through

prayers. Traditional healers could help a family that had met with misfortune by arranging a ceremony to pray to or apologise to the ancestors with the aim of establishing peace between the two parties (family and ancestors). People believed that if a patient was sick because of an attack from ancestral spirits or spirit of places, he or she would not find appropriate treatment until the spirits were treated respectfully.

Spirits of places

Most participants believed that a spirit looked after each place—house, rice field, road, forest, or mountains. Like the spirits of the ancestors, spirits of the places also protect the place and residents who lived or worked there, and people respect these spirits. If the residents showed a lack of respect to the spirits—i.e. did not pray regularly, or destroyed or modified the place without praying to the spirits—they may have bad luck, including sickness and accidents that sometimes could be fatal. One participant explained:

I saw with [it] my own eyes, a group of musicians came from Phnom Penh to perform music in my districts, but at the start they forgot to pray to the *mjas teuk dey* (spirit of the place). Then the next day, one of the team was severely sick, he had stomach pain and vomited with blood. The musicians invited a *Kru Khmer* to arrange ceremony, and then the patient became better. We can't deny spirits, you see when people travel to Kampong Som they always stop to pray at *yeay Mao* because they believe in spirits. Old people said *akum psam ayu* (Seila).

Beliefs in spirit of places were widespread, and were influenced by community experiences relating to accidents caused by spirits and beliefs in concepts of *akum psam ayu*, (that magic or spirits could save life); they believed that life is surrounded by invisible, untouchable and unheard powers (spirit or magic). These powers were believed to be involved in people's lives to some degree, so to respect and worship these powers could protect them from misfortune.

Ampen (magic powers)

Attack by *ampen* (magic spell, evil eyes, or witchcraft) was another kind of supernatural power that people believed could result in sickness. This was stronger than an attack from a spirit of ancestor or place, could cause severe health problems, and was sometimes fatal. Magic spells made by people with great supernatural powers were used to attack others frequently through witchcraft. Participants believed that witchcraft sent spells into others' bodies, whereby the spell could turn into a harmful object such as glass, cowhide, a pin or a nail, making the 'target' person very sick with symptoms such as stomach pain, bodily pain, vomiting with blood, or a cough with blood. These symptoms occurred suddenly or silently, gradually progressed to be severe, and did not respond to western medicine. Because the symptoms were caused by a spell, the cause of poor health could not be identified, and treatment from western medicine was neither appropriate nor effective. The only way to cure a person attacked by *ampen* was to find a traditional healer with sufficient power to remove the *ampen*; otherwise their health condition would not improve. Some patients changed from one healer to another in search of a healer with sufficient powers.

Regardless, the presence of beliefs in supernatural powers and participants' reliance on those beliefs seemed to be influenced by a lack of trust in western medicine treatment outcomes. TB patients and their families described lacking medical information to refer to when their symptoms re-emerged, or when western medical therapies failed, and so they interpreted their condition as an attack from spirits or magic spells. They then sought confirmation from a traditional healer. Although these beliefs were not as strong as they may have been in the past, the existence of such contributed to delays in accessing appropriate treatment, which resulted in poor treatment outcomes and high health care costs.

Understanding TB transmission

Most participants (97.5%) understood that TB was contagious. Research in other countries found that community members understood that TB was caused by contagion or proximity, with transmission from one person to another through several means: air, food, blood, sex, social contacts, sharing utensils, or hereditary (Ailinger & Dear, 1997; Liefoghe, et al., 1997; Long, et al., 1999a; Caprara, et al., 2000; Xeuatvongsa, 2005; Kasse, et al., 2006). Research from Laos showed that 71% of TB patients enrolled in DOTS services believed that TB was contagious, while 20% did not know whether the disease was contagious or not, and 9% considered TB to be non-contagious (Xeuatvongsa, 2005). Similarly, a survey of 1,115 participants in rural China found that the majority of participants (92%) regarded TB as contagious (Wang, et al., 2007a). Ecuadorian research of (212) adults undergoing diagnostic TB testing also found that most participants (87%) regarded TB as transmissible (Armijos, et al., 2008). Explanations of TB transmission among members of rural community in Cambodia were therefore in line with those found elsewhere. Only five participants in this community survey believed that TB was not contagious and instead originated in the body of the patient (see Table 15 and 16). Six participants did not know of any routes of TB transmission.

Table 15: Can TB go from one person to another (N=240)?

	Male		Female		Total	
Yes	117	(98.3%)	117	(96.7%)	234	(97.5%)
No	1	(0.8%)	4	(3.3%)	5	(2.1%)
Don't know	1	(0.8%)	0		1	(.4%)

Table 16: How does TB pass from one to another (N=240)?

	Male		Female		Total	
Airborne (respiratory tract)	95		102		197 ⁷	
Droplets	38	32.5%	23	19.7%	61	26.1%
Cough	55	47%	55	47%	110	47%
Talk face to face	32	27.4%	71	60.7%	103	44%*
Breath face to face	8	6.8%	11	9.4%	19	8.1%
Food-borne (ingestion)	73		80		153 ⁸	
Sharing food	51	43.6%	56	47.9%	107	45.7%
Sharing drink	3	2.6%	19	16.2%	22	9.4%
Sharing utensils	49	41.9%	29	24.8%	78	33.3%*
Sexual	0		4	3.4%	4	1.7%
Don't know	4	3.4%	2	1.7%	6	2.6%

p<0.05;

Multiple responses provided

Generally, participants' understandings of TB transmission were based on scarce health information provided by the professional health sector, through casual gossip about TB in the community among lay people, or through conversations with a former TB patient. Some TB patients had heard from their health providers that TB was contagious, and they were asked to cover their mouth with a mask or *krama* (scarf) when they talked to health providers in case they coughed or sneezed. Some patients were advised about safe eating practices: to use separate eating utensils (such as plates, bowls, spoons, cups, and glasses) from their family members, and not to share their food or leftover food with others. In practice, TB patients followed the providers' advice whenever possible; however they often breached this because it was inconvenient or they did not totally believe the advice:

⁷ Total participants who provided at least one of the multiples responses related to airborne transmission

⁸ Total participants who provided at least one of the multiples responses related to food-borne transmission

I think I may have got this disease from my husband, but I don't know how my husband got this disease. In the past, no one in our family ever had TB. I heard that TB is contagious; it transmits through coughing or speaking. I know about this because *peet* (health provider) asked us to cover our mouths when we talked to them or to other people, but they did not need to cover their mouth when they talked to us because they were not sick. But you know, sometimes I cannot do this at home, it's difficult for us, we are not used to covering our mouths or using separate eating utensils. We lived in a small cottage, we didn't have many utensils, so I just lived as normal with my husband. I didn't pay attention to what could happen to me later. How could I avoid him? He was my husband. Now I have TB, I am afraid that I will transmit the disease to my kids. When I cough or sneeze, I run away from my kids or cover my mouth with a *kerama*. But I'm not sure whether or not I can protect them from contracting TB. As a mother, I don't want my kids to have any disease from me, but if it happens, I would just accept that it is *karma*. If we have *karma* we can't avoid it (Lili).

Lack of appropriate explanations provided by health providers about TB transmission and prevention meant that appropriate prevention of TB infection within household was not encouraged. Participants classified TB transmission pathways into four categories: airborne transmission, food-borne transmission, hereditary (includes blood-borne infection), and sexual contact. Participants' understandings about routes of transmission often referred to more than one category, as discussed below.

Airborne transmission

Over 80% of survey participants identified at least one type of airborne transmission (see Table 16), including droplets, cough, and talking or breathing face-to-face with a TB patient. These categories were overlapping. Participants explained that when a TB patient coughed, sneezed, or talked, he or she expelled droplets of saliva or sputum that may contain *meb rok* (germ), so if someone was close to or in a confined space with a TB patient, they may breathe in those infected droplets, which later may develop into TB:

When a person talks, they spread saliva into the air. If you put a scarf in front of a person's mouth while he/she talks, you will see that the scarf will become wet. If the person has TB, there will be a lot of *meh rok* spread in the air, so if people talk face to face with a TB patient in a short distance, they can get TB infection (Kiri).

Although this explanation was offered by the overwhelming majority of participants, different people identified different components: over a quarter (26%) of participants referred to droplets as a potential source of TB transmission; 47% believed that TB is transmitted through cough; and 44% of participants identified transmission through talking face-to-face. Knowledge was gendered: women identified talking face-to-face as the routes of TB transmission much more than men ($p < 0.05$). Literacy also influenced participant's knowledge and perceptions that TB could be transmitted through droplets and cough (Table 17).

Table 17: Understandings of TB as an air-borne disease by literacy levels

	Literate		Limited or no literacy		Total	
Airborne (respiratory tract)						
Droplets	26	38.8%	35	21%	61	26.1%**
Cough	42	62.7%	68	40.7%	110	47%**
Talk face to face	24	35.8%	79	47.3%	103	44%
Breath face to face	7	10.4%	12	7.2%	19	8.1%

** $p < 0.05$

Those who believed that TB could be transmitted through air usually feared being in close contact with a TB patient and stated that they would avoid talking to or visiting someone if they knew they were infected with TB. In contrast, family members of TB patients were not especially concerned about the possibility of getting the disease, despite knowing the pathways of transmission. This may be due to multiple factors: they had not immediately developed TB after they had been talking to or had been in contact with a TB patient; in addition, they perceived that they were strong and healthy enough to resist the disease. This lack of

understanding about TB, and over-confidence in physical strength as a way of preventing transmission, led to their neglect of TB preventive activities within the family and the community. In Cambodia, people usually lived in extended families. When one person is sick, family members (such as parents, spouse, children, or siblings) are responsible for their care, either in home or hospital, including feeding the patient, cleaning their body, washing their clothes and linen, and keeping them company, especially when they were severely sick. This practice put family members at risk of transmission. Caregivers and family members generally had limited knowledge on TB transmission, leading them to neglect prevention practices. Ui explained:

At the start of my mother's treatment, I heard *peet* tell her that she had to cover her mouth with *kruma* (scarf) when she talked, coughed or sneezed, and not to spit in public places to avoid transmission to people around her. She always covered her mouth with *kruma* when she talked to *peet*, but she did not cover it when she talked to me or to other people. I don't know why a TB patient has to cover [their mouth], I guess maybe to prevent the spread of *meh rok* from their mouth. My mum doesn't know about this either, but as she was told to cover, she just covers her mouth when she talks to *peet*. She was afraid that *peet* would blame her if she did not do it. But the rest of the time, she never covered her mouth. She coughed, talked, sneezed, and spit freely because, you know, she forgot. She forgot that she had to cover, and one more reason, she thought she was with other TB patients so they were not afraid of each other. For me, I am not afraid of my mum. I just live normally with her. But I've never had any disease. I'm scared of TB, because it affects the lungs, it eats the lungs, and a patient can die, but now we are lucky. If I have TB, I can have treatment (Ui).

Throughout my fieldwork, I observed that TB patients and family members were always in close contact with each other, especially young children. At home or in hospital, TB patients engaged in family life as usual once their health improved. They helped their families to care

for young children or elderly family members, as well as with cooking food and doing housework while others worked outside the home.



Figure 13: Health provider giving health education to a TB patient in Kampong Speu TB ward

(Photo of Radio Free Asia, accessed on 08/April/2009)

TB as a food-borne disease

The perception that TB could be transmitted through sharing food and drink was common. Table 16 showed that the majority (153/240) of participants mentioned at least one variable related to food-borne pathways: that TB could be transmitted through the ingestion pathogens mixed with food or drink, or from contaminated eating utensils. This perception led to an understanding that TB patients should not share food or eat with family members at the same time. Approximately 89% of participants stated that a TB patient should not eat with family members or others (same time and same mat/table). This perception was significantly associated with literacy level and age: participants who were illiterate or had low literacy were

more likely to agree with this than those who were literate (90.8% vs 87.6%, $p<0.05$), as were those aged 35 years or older (Table 18).

Table 18: A TB patient should not eat with family members and others

	True		False		Don't know	
Sex						
Male (119)	108	90.8%	10	8.4%	1	0.8%
Female (121)	106	87.6%	15	12.4%	0	
Literacy						
Limited and no literacy (172)	159	92.4%*	12	7%	1	0.6%
Literate (68)	55	80.9%*	13	19.1%	0	
Age						
18-35 (n=121)	99	81.8%**	21	17.4%	1	0.8%
>35 (n=119)	115	96.6%**	4	3.4%	0	
Total (240)	214	89.2%	25	10.4%	1	0.4%

* $p<0.05$, ** $P<0.01$

Qualitative data also indicated that patients, their family members and community members believed that TB could be transmitted through food, drink and sharing utensils. For some TB patients, the concept of food-borne disease derived from health providers, who had advised them to eat, drink and sleep separately from their family members during the course of treatment to avoid transmission to others. Based on this advice, participants reconstructed their understandings that TB could be transmitted through food, especially when family members ate from the same plates or bowl as TB patients or when they ate food left over from patients. Participants believed that when TB patients eat, their spoon transported TB pathogens, which were carried through the patients' saliva into food. Therefore, if someone had shared food or soup with the TB patients, they may have accidentally ingested TB pathogens. Participants believed that once inside the human body, pathogens would penetrate into the blood, until they finally reached the lungs, where the pathogens later became TB. Participants also understood that eating together with family members at the same time

involved talking to each other, which would enable the air-borne spread of TB pathogens from patients.

Some participants believed that pathogens could stay on the body, clothes, or linen of TB patients. They therefore believed that using the patients' materials or touching the patient's body could place others at risk of infection. Like participants' understandings of TB as food-borne, these understandings had their origins in formal health advice: health providers often recommended that patients should eat and sleep separately from other family members, to limit proximity and risk of transmission. One TB patient, Samreth, who was from a remote mountainous area of the province, highlighted some of the difficulties participants faced when trying to make sense of advice from health providers:

At the start of the treatment, *peet* told me to take the medicines regularly. He said that I should not eat with other people to avoid transmission. *Peet* said that I had to maintain my body hygiene, moving my body (exercise), and not spit... that's what I can remember. In fact, they said a lot, but I'm not clever. I didn't understand everything. I didn't remember everything. I continued my life as usual, I hung around with members of my family, but I did not eat with them, I ate alone.

Since I learned that I have TB, I eat separately from my family members. I use separate plates, cup, glass, and bowl. I don't talk to them as much as before. I don't stay close to my relatives and young kids. I love my baby niece so much, but since I got sick, I've never touched her or kissed her. I'm afraid that I could transmit this disease to my family members, so I avoid gathering with them. I always stay in this small cottage behind our house (Samnang).

These multiple models of TB transmission through air, food and contact demonstrate how the ambiguous explanations provided by health providers led to misunderstandings about disease transmission, and also lead to inconsistent prevention practices in the family and community,

as patients tried different ways to prevent transmission in their family. Some family members ignored the health provider's advice, and continued their habits as usual in order to show sympathy, compassion, love, and support to the patient during their sickness:

I ate with my mum as usual, although she was sick; we used the same plates, bowls, cup, or glasses. We had never eaten separately. Whatever my mum cooked, we all always ate together. I wasn't scared of her. I used to live with her, she is my mother, it is not fair to be separate from her when she is sick. We never have any health problems. My dad, my siblings and I were healthy, we had never coughed nor were sick, no problem (Ui).

This was sometimes the result of pragmatic reasoning: some families did not have enough utensils to separate between sick and non-sick family members. Pisey's comments highlighted the challenges experienced by TB patients who were looking after their own health, while being responsible for the health and wellbeing of other family members:

In my family, there are four people: my husband, my two sons and I. We did not change anything although I was sick with TB. I lived as normal with my family; we slept in one bed together. I continued breastfeeding my baby as usual. I worried that I may transmit disease to my kids, but I didn't know what else to do, I had to look after them. My husband was busy with his work. He could not help me with housework or take care of the children, except when I felt very sick or tired, and then he stopped his work and helped me.

Patients chose to abide with prevention practices according to their perceptions and beliefs about the prevention practices advised by health providers. Patients who were hospitalized tried to adopt TB health education messages through measures such as following hospital hygiene rules (avoiding spitting in public spaces, cleaning the ward, and covering their mouths with a mask or *kruma* when they coughed or sneezed). Once discharged from the hospital, they resumed their ordinary lives. On the other hand, those who were not hospitalized, but who

were treated at the health centre or through the community DOTS program had less exposure to formal health education messages and hygiene rules. Some, especially women and the elderly, presented to the health centre only once, at the start of the treatment; their relatives or spouses would then come to collect TB medicines on their behalf for the remainder of the treatment program. A few patients had never presented to health centres during their treatment because of work commitments or difficulty travelling. Compared with other TB patients, these patients usually did not receive health information messages about transmission and prevention of TB; they were not concerned about these factors, nor had they implemented any preventive measures within their families or their household. Kolab, a factory worker, never visited a health centre; instead, her father went to the health centre to consult with the health provider about her health problem. The health provider gave the containers to her father and requested that she submit sputum; her father brought the sputum to the health centre, and she was then diagnosed with TB. Her father brought her medicines from the health centre every one or two weeks because Kolab was busy with her work. Kolab never received any advice related to preventive practices; she continued her life as usual with her family and friends:

I live as normal. I sleep with my other two sisters, and I eat with my family. No one is concerned about the transmission. At my workplace, I eat with my friends as usual, no one knows that I have TB.

Patients could not always present at health facilities due to work or being old and frail, therefore they were not exposed to health education messages on preventive practices. However, implementing preventive activities in households was also potentially influenced by concern by family members regarding TB transmission. Vath had never visited a health centre. His son took his sputum to the health centre for diagnosis and arranged to bring TB medicines

from the health centre for him. Vath did not understand how to prevent TB transmission in his family, but his family members tried to abide by prevention practices during his TB treatment:

I never go to the health centre. My son brings medicine for me, and sometimes he calls *peet* to give injections to me. I live in this small house alone and I eat alone. My son and his family live in the big house (the big house and the small house are in the same compound). My daughter-in law cooks food and she brings it to me every day. She cleans my plates, bowl, spoon and folk and keeps them separately to avoid transmission to others. I don't feel disappointed with them. I don't want to transmit to them.

The implementation of prevention practices in families therefore varied. Families that did not understand TB transmission pathways were not concerned about prevention practices, while patients or family members who understood TB transmission or were advised by health providers about prevention practices seemed to implement this advice, although they may not have been able to strictly implement all preventive activities.

TB as a hereditary disease

While most participants recognised that TB was infectious, five survey participants and a few from the qualitative phase maintained that TB was not contagious. Although they had heard public health messages about TB contagion and transmission, they were not convinced. Instead, they considered it to be a hereditary disease transmitted through kinship from generation to generation, such as from parents or grandparents to their children or grandchildren through blood; this was based on their observations of families with histories of infections (that is, other members in the past two generations who also had TB):

My father had TB more than five years ago. Now I have TB. I heard that this disease is contagious, but I don't really believe that, because none of my family members got this

disease from him. Now only I have received this disease from my father. I am not upset because it's my *karma*. I accept it. But I always pray to spirits that my siblings and the next generation of my family will escape from this disease (Phally).

Phally did not believe in TB contagion, largely because of the time that had elapsed between her father's treatment and recovery, and when she became ill with TB. She could not explain why other members of her family had not contracted TB from her father. Patients perceived that TB was transmitted through blood; however, they were not upset with their ancestor(s), they accepted it as their *karma* and neglected TB prevention within household.

Previous studies in Vietnam, the Philippines, Indonesia and Laos have all shown that participants believed that TB was hereditary (Long, et al., 1999a; Caprara, et al., 2000; Xeuatvongsa, 2005). Participants in the Philippines believed that TB could be transmitted from mother to baby while the baby was in the uterus of the mother. This was not the only form of TB inheritance, as participants also believed that disease could be transmitted from father to mother through sexual intercourse, and then spread into the mother's blood, and ultimately be passed to the baby (Nichter, 1994). Kinship understandings varied, however: research from Laos highlighted that parents passed TB to children according to sex, for example, from father to a specific son, or from mother to a specific daughter; it was then believed that these children would develop TB when the parents passed away (Xeuatvongsa, 2005). Participants in my study offered a different use of the term 'hereditary' to refer to the transmission of the disease through blood-ties, which may pass down from parents to children regardless of sex. They believed that children could have the same blood as their parents, and therefore they may have inherited certain personal attributes from their parents, or grandparents, including illnesses. TB inheritance was therefore seen in a similar way to height or eye colour. Participants

who perceived that TB was hereditary were not concerned about other transmission pathways, and therefore did not take any precautions to avoid transmission in their families.

TB as a sexually transmitted disease

Perceptions of TB transmission through sexual contact were not common. Only four women in the survey believed that TB could be transmitted through sex. In addition, a couple of participants believed that TB was similar to HIV/AIDS and could be transmitted through multiple ways including sex; they also understood that sexual contact could be source of transmission for many illnesses as the couple were in close contact, talking, and touching. However, participants could not provide a clear explanation how TB could pass through sexual contact; their beliefs in the sexual transmission of TB therefore seemed to be influenced by their knowledge of HIV transmission:

Sex could transmit diseases such as HIV, TB, *Svay* (syphilis), *Promes* (Gonorrhoea). I think TB is also transmitted through sex because a husband and a wife sleep together so they could transmit [it] to each other. Since I have this disease [TB], I've never slept [had sex] with my husband, so I think that my husband won't get this disease from me (Mali).

Understanding TB treatment

Knowledge, attitudes and beliefs about TB treatment, including about its duration and benefits, influenced treatment-seeking behaviour (Munro, et al., 2007b). In this study, most participants knew that TB treatment was available at public health facilities including the health centre and referral hospitals (see Table 19). More than two-thirds of participants knew that TB treatment was available from public health centres, indicating that information about treatment

availability was well publicised in rural Cambodia. This could be useful for participants as they could encourage suspected TB patients to seek appropriate treatment.

Table 19: Where should people seek TB treatment?

Places for TB treatment	Female		Male		Total	
Health centre	96	79.3%	95	79.8%	191	79.6%
Referral hospital	40	33.1%	54	45.4%	94	39.2%
National hospital	11	9.1%	7	5.9%	18	7.5%
C-DOTS observer	3	2.5%	5	4.2%	8	3.3%
Private	10	8.3%	19	16%	29	12.1%
NGO's clinic	2	1.7%	6	5%	8	3.3%
Don't know	3	2.5%			3	1.2%

Curable

Data from the survey and qualitative interviews showed that most participants regarded TB as curable, although some participants believed that TB was incurable. The concept of curable and incurable is discussed below. Three-quarters of participants (75.4%) believed that TB could be cured with appropriate treatment from health centre or hospital. Participants used the concept 'curable' to indicate a full recovery from TB, meaning that they were able to perform their daily life and work as normal after their treatment.

Table 20: TB could be cured with appropriate treatment?

	Yes		No		Don't know	
Sex						
Male (119)	99	83.2%	16	13.4% **	4	3.4%
Female (121)	82	67.8%	34	28.1**	5	4.1%
Literacy						
Little literacy and no literacy (172)	119	69.2%	45	26.2% ***	8	4.7%
Literate (68)	62	91.2%	5	7.4% ***	1	1.5%
Age						
18-35 (n=121)	98	81.0%	21	17.4%*	2	1.7%
>35 (n=119)	83	69.7%	29	24.4%*	7	3.8%
Total	181	75.4%	50	20.8%	13	3.8%

* p<0.1, ** p<0.05, *** p<0.01

Despite knowing that TB was curable, only one-third of participants knew that TB would require six months of treatment (see Table 21). Most participants (64.2%) perceived that a TB patient was cured from TB when his or her symptoms had disappeared.

Table 21: Length of TB treatment

Duration of TB treatment	6 months		Don't know	
Sex				
Male (119)	37	31.1%	82	68.9%
Female (121)	34	35.5%	78	64.5%
Literacy				
Literate (68)	35	51.5%	45	26.2%*
Little literacy and no literacy (172)	33	48.5%	127	73.8%*
Age				
18-35 (n=121)	33	27.3%	47	39.5%
>35 (n=119)	88	72.7%	72	60.5%
Total	80	33.3%	160	66.7%

*P=.000

These beliefs persisted despite most TB patients and family members having received information from their health providers confirming that they could be cured if they followed the treatment rules and completed the treatment course, which took six months. They did not understand why the treatment required for TB was considerably longer than many other diseases they knew (e.g. malaria, typhoid, respiratory infections). A few participants explained that TB required a long time to treat because the TB *meh rok* was stronger than any other *meh rok*:

I think TB *meh rok* (germ) is very strong, that is why the drug to kill it is also strong. You know, I've never taken any drug that makes me very sick like the TB drugs. At the start of my treatment, it was very difficult. Once I took the drug in the morning, I felt that all my muscles turned weak. I could not move my body, I felt dizzy so I had to lie down all day. I was thinking that I could not stand the medication, but I do my best because I want to be cured (Bona).

TB patients believed that the purpose of prolonged treatment was to kill the TB germs in their lungs, and they expected that their health would be improved by the treatment. Many patients and family members perceived that the effectiveness of medication also depended on age, nutritional status, and personal behaviour (e.g. smoking, drinking, and hard work). They believed that younger patients (aged under 40) who took care of themselves (with good food) and avoided risky behaviour could be completely cured:

I think I can be cured from TB if I take medicines for six months, because I am young and I keep myself well. [I have good] hygiene, I drink boiled water and I eat as normal. I could see that about 3-4 weeks after I began treatment, I felt better and able to work, although I do not have the same strength as when I was not sick (Kolab).

Participants' understandings about the duration of TB treatment and their confidence in efficacy of treatment may have encouraged TB treatment adherence.

Incurable

Incurable referred to the idea that patients could not recover from TB despite adherence to treatment. This included the possibility of re-infection with TB after the treatment, suffering strong side effects of TB medication, and death. About 20.8% of survey participants believed that TB could not be cured even with appropriate treatment. There was a significant association between gender and perceptions that TB could not be cured ($p < 0.05$), which suggested that women may be less exposed to information about TB treatment. Similarly, participants who had little literacy or were illiterate were more likely to report that TB could not be cured (26.2% vs 7.4%, $p < 0.01$). Age was also important: elder participants (aged over 35 years) were more likely than younger participants to report that TB could not be cured (24.4% vs 17.4%, $p < 0.1$) (see Table 21 above).

Some TB patients who undertook TB treatment doubted the efficacy of TB medications. For example, four TB patients were re-infected after they had been undergoing treatment for some time. They were concerned that they would not be cured from the disease:

I've heard that older people aged 40 and over can't be cured from TB. I had TB in the past, and now I have this disease again. I'm very worried that I cannot be cured (Chantha).

Re-infection with TB and lack of explanation about the causes of re-infection led to concern and misunderstandings that TB could not be treated. TB patients and community members also believed that, although TB treatment was available, some patients could not be cured because they could not tolerate the side effects of the medicines, as Sokun explained:

I had TB before and was treated at the hospital. I had completed treatment for about one year. Now I have this disease again. But this time I could not tolerate the treatment that *peet* gave me, it made my health problem worse. I think that this disease [TB] could not be treated, because I am already old. For young people, they may be cured.

The strong side effects of TB medications and lack of support from health providers for patients who suffered side effects caused a lack of confidence in the efficacy of TB treatment, and led to perceptions that TB could not be treated. Therefore patients modified doses or interrupted treatment (discussed later in Chapter 6). In addition, information about side effects or death caused by TB shared among community members contributed to perceptions of incurability.

In summary, participants held multiple explanatory models regarding TB. The different groups of participants in this research had many similarities in their explanatory models of TB, mainly influenced by the knowledge they drew from the popular sector (information shared by lay

people), but with added information learnt from the professional (health) and the folk sector (traditional healers or non-professional healers) (Kleinman, 1988). To some extent, participants' explanations about the aetiology, transmission and treatment of TB contradicted the medical model, including perceptions that TB is a hereditary disease, TB is not transmissible or that TB is not treatable. This was possibly due to very limited information provided by professional health providers regarding the aetiology of the disease to community members, particularly to patients and family members during their course of treatment.

Folk beliefs about supernatural powers causing illness remained prevalent in rural Cambodia, although participants did not believe in the association of supernatural power and TB. This belief tended not to be a critical barrier in accessing TB diagnosis, as participants usually did not rely on traditional healers as their first choice (see also Chapter 5). In addition, nearly half of the survey participants and many family members of TB patients believed that they had no chance of getting TB; this perception reflected misconceptions about transmission and cause of the disease, led to neglect of TB preventive activities in the community and households, and possibly contributed to delayed access to TB services. As many participants believed that they had no chance of contracting TB, they were not likely to think about TB when they self-diagnosed the presentation of early symptoms, or they did not describe their symptoms clearly to health providers, therefore possibly delaying their diagnosis. For example, TB patients participating in this study did not think about TB when they had early symptoms; their self-suspicion about TB came later when their symptoms became critical (discussed further in Chapter 5). As in other developing countries, there was a mixture of transmission factors and vulnerability factors in patients' understandings about the cause of TB (WHO/TDR, 2006). In addition, there were misunderstandings about pathways of TB transmission and a lack of understanding about TB treatment among patients and members of the community, especially

women. Earlier research found that poor understandings of TB and lack of information provided by health providers regarding the reasons behind the long course of treatment could lead to defaults from treatment (Khan, et al., 2000; Tekle, et al., 2002; Watkins, et al., 2004). The explanatory models of participants in this study reflected inconsistent understandings of TB among community members, which contributed to delayed access to appropriate diagnosis and treatment. In the following chapter, I will illustrate patient's perceptions and experiences regarding access to public health services, which were the enabling and inhibiting factors contributing to health-seeking behaviour of TB patients and family members.

CHAPTER 4

ACCESS TO PERIPHERAL HEALTH SERVICES: FROM USERS AND PROVIDERS PERSPECTIVES

In the preceding chapter, I described pluralistic explanatory models of illness held by TB patients, their family members and other members of the community with regard to symptoms, causes and transmission of TB. These understandings influenced people's management of illness and determined the ways in which they accessed health care (Rojpibulstit, et al., 2006; Mahendradhata, et al., 2008b; Storla, et al., 2008). The health care system—both structure and delivery—is also important in shaping patients' access to health care (Becker & Maiman, 1975). In Cambodia, primary health care is delivered by multiple health providers. Kleinman (1986) categorised three sectors of the health care system: the professional sector, the popular sector and the folk sector. The former sector comprises western medicine providers in public and private services; the folk sector refers to non-professional healers who provide herbal and or spiritual therapies. The popular sector comprises individual, family, and community beliefs and activities regarding sickness and care (Kleinman, 1986).

While the boundaries between these sectors are sometimes fluid, Kleinman's categorization remains a useful heuristic to analyse the health system. In this chapter, I illustrate the complexity of access to peripheral health services—public health centres, local private health providers and the folk providers in rural Cambodia. Using this to provide a context for health-

seeking, I then explore the utilization of peripheral health services by rural community members.

Terminology of access

Access is a primary focus of health care policy and, although its definition varies, it is widely used to refer to the health care system in policy documents (Campbell, et al., 2000; Wyszewianski, 2002). Access, used here, refers to both physical (geographical) access and the availability of health care (Haynes, 1991), and to the appropriate use of services according to the needs of the users (Campbell, et al., 2000). For the purposes of this chapter, I follow Penchansky and Thomas (1981), who conceived of access based on the ‘fit’ between health services delivery and the expectations of patients. The five dimensions of access, ‘the 5 As’—Accommodation, Availability, Accessibility, Affordability, and Acceptability (Penchansky & Thomas, 1981)—are outlined in Table 22 below:

Table 22: Dimensions of access

Dimension of access	Definition
Accommodation	The extent to which the health system is organized (the buildings, waiting room(s), wards, telephone communication, and administrative procedures, working hours), and the extent to which these respond to the needs of the patient (s).
Availability	The extent to which health facilities have the services and requisite resources (such as health workers, medicines, laboratory and medical equipment and referral systems) to meet patients’ expectations.
Accessibility	The distance to the health facility from patients’ homes. Other concerns related to accessibility include transportation-related factors: means, costs and times.
Affordability	The fees of the health services compared to patients’ ability and willingness to pay for services and their methods of payment.
Acceptability	The relationship between patients and providers, taking into account the responsiveness of health provider to the social and cultural expectations of the patients and their communities.

Source: Penchansky and Thomas (1981)

These dimensions of access are inter-connected, and all influence patients' utilization of health services to varying degrees. Thus, improving the *affordability* of health care by providing health insurance or user-fee exemptions may not significantly improve utilization of health services if the other four dimensions have not also been addressed (Peters, et al., 2008), for example, if it is too far from patients' homes or they have no means of travel to the health service.

Access to public health facilities in developing countries remains problematic. The most commonly reported barriers relate to the three dimensions of *accessibility*, *affordability*, and *availability* (Wyszewianski, 2002). Physical accessibility significantly influences utilization of health services (Hjortsberg & Mwikisa, 2002; Hjortsberg, 2003; Noor, et al., 2003; Basnet, et al., 2009), as poor road conditions and lack of transportation are common problems preventing patients' access to health facilities. They also create barriers for the distribution of health staff, medical supplies and medicines to rural and remote facilities, and cause difficulties when referring patients to higher-level facilities in cases of emergencies. Difficult terrain (mountainous and isolated areas) combined with poor road infrastructure leads to difficulties in the supervision of rural health services (Perry & Gesler, 2000; Martinez, et al., 2005). Research in rural Kenya highlighted that the distance from the place of residence to the health clinic significantly impacted on utilization of health facilities for a sick child; for example, every increase of 1 km in the distance between residence and a health clinic meant that the rate of clinic visits decreased by 34% (Daniel, et al., 2009). This was further exacerbated by barriers posed by geophysical features of the environment where participants lived in remote mountainous terrain, where *accessibility* could be cut in difficult weather (David, et al., 2008).

Other reported barriers to health service utilization have been associated with *availability* of health services, particularly lack of supplies and medicines at public health clinics and lack of qualified health workers (Chaudhury & Hammer, 2003; Hanson, et al., 2003; Ranson, et al., 2003; Mendis, et al., 2007). These barriers resulted in low levels of confidence in public health clinics, leading many patients to skip local clinics and to present to more distant clinics or instead to consult private providers where they trusted in the quality of their services (Akin & Hutchinson, 1999; ten Asbroek, et al., 2008). Financial factors also affect the dimensions of *accessibility* and *affordability*.

Financial barriers to accessibility included transportation costs, food and lodging expenses (where relevant), as well as the opportunity costs associated with the time of patients and family members who accompanied patients to the health service (David, et al., 2008). These *accessibility* factors contributed to *affordability*, which was also shaped by the direct costs (user-fees and informal payments) incurred by people seeking health care. Direct and indirect costs were usually high and could cause household financial crisis, leading patients to incur debts or sell family assets in order to pay for health care (Hock-Long, et al., 2003; Russell, 2004; McIntyre, et al., 2006; Xu, et al., 2006; Xu, et al., 2007b). Consequently, concerns about the *affordability* of health care were significant barriers in accessing health services. Barriers associated with acceptability were mainly associated with patients' dissatisfaction with quality of care and the lack of information provided about their health problems. In most cases, poor patient-provider interactions at public clinics drove patients to consult private providers who understood their problems and expressed more helpful attitudes toward them (Brugha & Zwi, 1998; Andaleeb, 2001; Zwi, et al., 2001; Baltussen, et al., 2002).

In Cambodia, research on factors shaping access to public health services (both health centres and hospitals) is limited. Access to public health has been determined by affordability of health services and physical accessibility (distance and transportation time) (Hardeman, et al., 2004; Yanagisawa, 2004; Saly, et al., 2006; Khun & Manderson, 2007). Costs of health services (user fees and under-the-table payments) deterred poor people from presenting for appropriate health care (Akashi, et al., 2004; Bigdeli & Annear, 2009). For example, parents often delayed seeking appropriate treatment for their sick child with dengue because of their inability to afford direct and indirect costs, combined with lack of confidence in the quality of care provided at the local health centre or public referral hospitals (Khun & Manderson, 2007). Parents who eventually sought care for their sick child spent on average US\$34.50 and up to US\$150 for a single episode of dengue, which was much higher than their estimated monthly income at US\$13.50 per month; therefore, families had to take out loans and sell property, livestock, goods or labour to finance health care costs (Khun & Manderson, 2008). Yanagisawa (2004) illustrated that economic status affected the dimensions of *accessibility* and *affordability*, and determined people's health-seeking behaviour (Yanagisawa, et al., 2004).

Over the past decade, the Cambodian Ministry of Health and donors have implemented several initiatives to redress access to public health facilities, particularly for the poor, such as contract management and the introduction of health equity funds (HEF). The former strategy addresses the management of public hospitals by providing contracts to NGOs to assist with hospital management and supplement salaries for health staff. The latter strategy of HEF is a mechanism that provides health subsidies for the poor. It is implemented by NGOs, using funding provided by donors, government and community. HEF provide partial or full subsidies (including cost for health services, medicines, transport and food during hospitalization) according to the socio-economic status of patients (Grundy, 2001; Soeters &

Griffiths, 2003; Barber, et al., 2004; Hardeman, et al., 2004; Van Damme, et al., 2004; Jacobs, et al., 2010). These strategies have been effective in improving the utilization of health services among the poor (Akashi, et al., 2004; Meessen, et al., 2006; Noirhomme, et al., 2007; Bigdeli & Annear, 2009; Jacobs, et al., 2010). However, their long-term feasibility remains in question, particularly in terms of cost-effectiveness and sustainability, as these strategies are largely dependent on donors' funding and management.

Access to public health centre in rural Cambodia

In the following section, I begin by elucidating the concept of access (as defined by Penchansky, 1981) as it applied to the four public health centres in rural Cambodia, where I recruited TB patients to participate in my study. These were the closest health facilities to the participants in term of geography but, as I will demonstrate below, patients' presentation at these centres was profoundly shaped by the five dimension of access.

Accommodation

Since public health reform was initiated in 1995, Cambodia's health infrastructure has been improved through the renovation of old facilities or by the construction of new health facilities to be close to the public. The four health centres where I worked were in good physical condition: Moy, Pi, Bei, and Boun (pseudonym) were each housed in good buildings, built on large blocks of land, and were enclosed within wire fences. Moy was a renovated former commune clinic; similarly, Boun was renovated from the facilities of a former district hospital. It had the largest number of rooms, including rooms to hospitalize people with TB, and was equipped with a TB laboratory. Pi and Bei health centres were newly built.

There were many similarities between the four health centres. On the gate, the name of the health centre was clearly written. Each also had a billboard clearly stating that the health centre provided diagnosis and treatment of TB free of charge. Each health centre was conveniently located along a main thoroughfare close to markets, schools, pagodas and the commune council office. Each health centre had one pump-well located at the front and one water-flush toilet available to the public, and an incinerator for medical waste disposal located at the back of the building. The health centres were relatively clean; Bei was the exception. It was located next to the market waste disposal area and was therefore quite smelly. Each health centre had a reception hall where there was a desk for one staff member to take patient records, and benches, chairs or beds where clients could sit and wait to be called. Along the walls of the hall, there were whiteboards describing the services available and the fees for services; a list of services provided free of charge, including the diagnosis and treatment of TB and HIV and child immunization; and list of people who were entitled to user-fee exemptions (the elderly, people with disabilities, students, monks, and those who might criteria as poor). The organizational chart for the health centre, including the names of staff members, their job titles and responsibilities, working hours and contact numbers, and the opening hours of the health centre were printed on paper and displayed on the wall. Health centres were generally divided into five small rooms: one consultation room, a delivery (birthing) room, a minor surgery room, a drugstore (pharmacy), and a staff room. There was no electricity on any of the premises, so staff used batteries or a generator as needed. Health providers considered that the infrastructural improvements made to the health centres tended to improve service delivery to the community:

Our maternity unit has improved since we received support from UNICEF. We have a new consultation room, the delivery room has been renovated, and we have equipment

for delivery. Now that we have a generator, our services will be better than before (Kosal).

The laboratory unit was renovated. Now that I have comfortable place to work, shelves to store laboratory equipment, a place to store reports and other documents, and a place to prepare sputum, I feel more comfortable to work (Seth).

These quotes suggest that the incremental improvements in public health accommodations enhanced the optimism of health workers in their work. At the same time, community members also acknowledged these improvements:

The health centres now are better than before: they're clean and there is place to sit while waiting. Health staff are also kind. But the problems are short opening hours, staff that are not present at work, and the low quality of drugs, which cannot cure the disease (Sopheap).

As Sopheap highlighted, the improved accommodation for public health services was not enough to increase the access of community members to quality health services. Convenient access to public health centres was also determined by other challenges related to accommodation and availability, for example, short opening hours and long waiting times, as Pov described:

The bad thing about the health centre is that I have to wait a long time to see staff, and sometimes the staff member who I want to see does not turn up. In the afternoon or evening, there are no staff at the health centre, so if people want to go there, they should go in the morning from around 8 to 10 am.

Although health centres were mandated to open for 8 hours each day, from 7 to 11:30 am and from 1:30 to 5pm, the centres were usually open from 7 to 10 am, with some variance according to the number of patients seeking services. Outside of working hours, it was the responsibility of rostered staff to provide services. However, staff who were rostered were not

present regularly at the health centre and there was no rostered night shift; as a result, health staff left their personal phone numbers so patients could contact them in case of emergencies such as child delivery. As the health centres did not have telephones, staff used their personal mobile phones for work purposes. People could use either their personal mobile phone or a public phone to communicate with health staff.



Figure 14: Clients wait in the reception hall of the health centre

Field photo 4 September 2008

However, access was not always possible despite this: clients were reluctant to telephone if they did not have money to pay for the health service or did not have transport, particularly at night:

There are no staff at the health centre in the afternoon, and there is no night shift. If we have a problem at night, we can call health staff to help us at home or we can go to the health centre. But we can only do so when we have money to pay. It's difficult to call health staff to help at night unless the health worker knows the patient well, and a family member will have to pick up the health staff (FGD).

Obtaining health services outside the shortened opening hours of the health centre was even more difficult because health staff regularly engaged in other activities such as meetings, workshops, outreach activities and their private practices, as a health worker explained:

We try to open the health centre long enough for our patients to use it, but it is difficult. In the afternoon, staff have to go to villages, providing child immunization to villagers; other staff are busy with their other work in the afternoon. Sometimes most staff have to participate in training activities provided by different national programs at the same time, so we don't have staff at the health centre [even from 7-10am] (Oudam).

In practice, there were no strict regulations related to the punctuality of public health workers; they advised each other informally (verbally) when they could not attend the health centre or would be late, and there was no punishment related to this practice. The health centre management appeared to make compromises with staff regarding punctuality, as they understood that this was due to low government health salaries. They also believed that fixing the problem was impractical and could lead to worse rather than better services, as staff may have to leave their government posts because they could not work full-time at the health centre due to low salaries. Furthermore, fixing the problem was perceived to be beyond the capacity of local health centre management:

We cannot be so strict about staff punctuality or absence, but we encourage them to take care of their responsibilities as much as they can. For example, those who do the immunizations have to be responsible for their tasks (e.g. achieve their work plan) and

midwives should be available at the facility at a particular time to attend to their patients. I cannot do anything more than this because staff need time to do other work to earn their living (Dara).

Blaming low government salaries as the key reason for lack of punctuality meant that health centre management did not attempt to resolve staff-related barriers affecting *accommodation* (staff presence and punctuality) of the health services. However, they acknowledged that the long waiting times undermined access to the health centre, rendering the services less available. It is this dimension to which I now turn.

Availability

The dimension of *Availability* is concerned with the existence of qualified health professionals, adequate health services, and treatment regimens for patients (Penchansky & Thomas, 1981); some aspects of the accommodation dimension, discussed above, are relevant here. As elaborated earlier (in chapter 1), each health centre was assigned to deliver a Minimum Package of Activities (MPA) to community members. However, the provision of services such as outpatient consultation, child delivery and antenatal care, and treatment of communicable diseases was variable due to barriers related to availability. Each of these barriers— staffing, shortage of medicines, lack of medical equipment, and lack of referral systems in place—will be discussed below.

Staffing issues

The Ministry of Health has assigned approximately 8-10 health workers per health centre, including one or more doctor or medical assistant, one or two secondary (with three-year training) midwives, one or two primary (with one-year training) midwives, two secondary (with three-year training) nurses, one or two primary (with one-year training) nurses, and other staff as necessary. Table 23 shows distribution of health staff in the four health centres.

Table 23: Distribution of health staff at each health centre

Health Centre and population covered	Doctor or Medical Assistant (MA)	Secondary Nurse	Primary Nurse	Secondary Midwife	Primary Midwife	Other
Moy (14,076)	1 MA	1	5	1	0	1
Pi (13, 897)	0	3	5	1	1	0
Bei (19,256)	0	2	4	1	1	0
Boun (14,618)	2 doctors, 1 MA	3	9	3	1	0

Source (Ministry of Health, 2005b)

However, the low government salaries contributed to staffing issues—staff absenteeism, lateness, and shortage of qualified staff — which profoundly affected the dimension of *availability*. The absences and lateness of health staff was common, resulting in other staff being regularly overloaded with work as they performed a wide range of duties: patient consultations, recording and reporting health centre activities, conducting outreach activities, and participating in training or meetings. The work load did not necessary reflect high patient numbers, but was caused by the working hours devoted by each staff member, often resultant from other (dual) jobs. Staff who were frequently absent or who did not fully undertake their health centre responsibilities did so for two reasons: firstly, as noted already, low government salaries meant they were unable to attain a reasonable standard of living on that income alone, and secondly they perceived that there were few interesting assignments leading to professional development, hence a mismatch between their roles and qualifications:

I come to the health centre one or two times a week. I don't have important things to do because we don't have many clients daily. There are only simple cases at the health centre; we just give some tablets to the patients, no hospitalization. For severe cases we cannot help patients, we just tell them to go to the hospital (Sambo).

Low government salaries were the root cause demotivating health staff. The net monthly salary of health staff participating in this study ranged from approximately US\$40 to US\$110 (average US\$60) per month, depending on qualification and position. To attain a salary to support their families, most health staff held more than one job, where the second typically involving the provision of private health services to community members. The dual job practices of health staff have been acknowledged in Cambodia (Sin, et al., 2005; Henderson & Tulloch, 2008), creating potential conflicts of interest and undermining the capacity of public health services to deliver quality care, directing clients away from the public health centre. But, on the other hand, this practice assisted in retaining health staff in rural public health services because the additional income supplemented low government salaries (Oum, et al., 2005a; Chhea, et al., 2010). Although dual job practices contributed to the retention of government health staff at their posts, the competition generated by this practice was critical in undermining access of public health services. Health staff usually regarded their private practices as the *chhnang bay* (rice pot— primary source of income) and were more likely to devote time and efforts to improve their private work:

It is common that health staff have private practices to earn additional income. In the past, patients could not reach the health centre because of distance, poor roads and no transport. But now patients cannot reach health centres because the private providers drag them away. Private providers are mostly government health staff too, but their services are far more convenient than those provided at the health centre (e.g. quick and friendly service, and using good medicine). More importantly, private providers are located not far from the health centre, so for people who have money to pay, they will go to private providers (Nareth).

Health staff are more accountable in their private practices, they are always punctual and available for their clients because the jobs are their *chhnang bay* (main source of income). Some staff have big clinics or pharmacies at home; they rarely turn up at the health

centre—especially doctors and medical assistants. They have many clients at their private practices, so they have no time to care about their work at the health centre (Dara).

Staffing issues also meant that there was a shortage of qualified health staff at health centres:

Our health centre has a human resource problem. We have one medical assistant but she can't come to work every day. We do not have enough midwives, so our maternal health services cannot provide delivery on the premises. But we provide many services such as antenatal care, immunization, and treatment of common diseases, although we cannot diagnose or treat difficult cases because we do not have a doctor. This is also the reason that we cannot attract patients because they want to see highly qualified health staff, so they go to a private practice (Kosal).

Lack of qualified health workers in attendance at the health centre meant that service delivery was mainly provided by lower qualified health staff. These staffing issues undermined the roles of the health centre, so it was rendered no more than a dispensary, which further demotivated highly qualified health workers to commit to their work responsibilities.

Lack of medical equipment and facilities

The relegation of the health centre's role to that of a dispensary resulted from more than staffing issues alone. Basic medical equipment, including thermometers, blood pressure cuffs, scales and height measures, were available at most of the health centres. However, health staff did not always use this equipment during consultations, and diagnosis was consequently based on information provided by clients. Clients described their symptoms, or the symptoms of a family member (when the patient did/could not come to the health centre), and a diagnosis was made accordingly. Medicine to treat the ailment was then prescribed according to what was available at the health centre. If the diagnosis required other medications, the patient was advised to purchase it from the private pharmacy. Similarly, if patients needed further medical examinations or investigations, such as a blood test, they were referred (mainly verbally) for

pathology services at a private laboratory or at referral hospital. Sambath described some of the challenges faced by the health centre related to service provision:

People come to the health centre to ask for medicines for headache, cough, cold, fever, and stomach disease. Some clients come to the health centre to buy birth control pills or to request child immunization. Some people come to request medicines for a family member who is sick. We do not have the facilities for blood tests or sputum tests. For example, for suspected typhoid or dengue (fever), we send patients for blood tests at the hospital or a private clinic; most patients disappear and never come back. For sputum, we take it from patients at the health centre then take it to the hospital, but patients are not happy because they have to wait for at least a week to get the result (Sambath).

At the health centre, *peet* gives medicines but does not do patient examinations. But at a private clinic, *peet* do examinations, they give the medicines. I think *peet ek chun* is better because they check the patients before giving medicines and they have good tools to do tests for patients (Som).

Reluctance by public health workers to perform medical examinations may reflect the limited capacity of health staff to perform diagnosis (if they were not medical doctors or medical assistants) and the lack of time of health staff to perform examinations. The latter was likely to result from the conflict of interest posed by dual job practices, so that health workers were reluctant to provide their best services to their patients at the health centre. Lack of medical examination and lack of equipment to undertake diagnosis (including laboratory equipment and facilities) made patients lose confidence in the health service, and led to the perception that the health centre was only able to handle simple diseases that did not require physical examinations or laboratory tests.

Shortage of medicines

Each health centre received essential drugs (including antipyretic, antibiotic, anti-malarial, anti-parasite and anti-pertussive medications, birth control methods, vaccines, and medication for tuberculosis, diabetes and blood pressure) and related medical supplies from the OD each month, which the OD received from the central medical store (administered by the Ministry of Health) on a quarterly basis. However, each health centre regularly experienced shortages of some drugs and medical supplies, as a consequence of a lack of supplies from the Ministry of Health and national budget shortages. In addition, some drugs leaked into the private sector. Health staff understood that the availability of drugs and other medical supplies had significant impact on access to the health centre, as Oudam explained:

We see 10 to 20 clients daily when we have drugs. But when the drugs run out, we only see two or three patients per day. We face a shortage of drug supplies almost every month. It is very difficult when we lack drugs; our clients are not happy when they come to the health centre and they can't get any medicine. Those who live close to the health centre do not have much of a problem [with it], but those who live far from the health centre get upset and may not come to the health centre again. When we have drug shortages, what I do is follow up with the OD. It is difficult for the health centre to solve this problem alone. If the shortage of supplies is minimal, for example, if there is a lack of cotton wool or alcohol, we buy it. For medicines, it is expensive to buy from the market and our budget is minimal, so we cannot afford to buy medicines [this way].

The shortages of drugs had a huge impact on the utilization of peripheral health services and affected the confidence of users. In such situations, those who lived far from the health centre felt that they wasted their time and resources attending the health centre for nothing, leading them to choose not to use that health centre again.

Adding further complexity to this, people who used medicines provided by the health centre had different perceptions of the drugs they were given. While some people considered that the medicines provided by the health centre were not fake and were given at low cost, others perceived that these medicines were not as high in quality compared with medicines available in the market. Khun and Manderson (2007) found that health workers and villagers had contradictory perceptions regarding the quality of drugs at the health centre. While health workers argued for the superior quality and lower costs of drugs provided by the health centre, villagers believed that the drugs provided by the health centre were of lower quality than those purchased commercially. In addition, usually only antipyretics were available (Khun & Manderson, 2007). These perceptions also impacted on the utilization of public health services:

When my child is sick, I take him to *peet's* house near the market. He works at the health centre too, but going to his private practice is better, he gives good medicine and my child can recover quickly. Medicine at the health centre was not effective for my child's disease (Sokha, FGD).

In contrast, health workers regarded patient's perceptions toward drug quality as reflecting their misunderstandings about particular drugs, influenced by perceptions about medicine quality and availability in the private sector, as Rotha explained:

The drugs used at the health centre are provided by the Ministry of Health, so the quality is assured and there are no fakes. Patients don't understand that. If they are sick, they want strong medicines that can help cure them quickly, so private providers may give them many drugs, for example, several antibiotics at one time and also multiple antipyretics, so patients are happy because they get relief from the symptoms fast. At the health centre, we cannot do that. We start by giving them simple medicines and then we follow-up. But you know, some patients do not come for follow-up. They say that our medicine is poor, [that it] did not help them, and then they go to a private provider.

Besides concerns about the quality of medicines used at the health centre, clients also questioned the capacity of health staff to provide appropriate prescriptions to treat their illness. This added to patients' concerns about medicine quality and undermined their trust in the public health services, as one community member noted:

The health centre does not have medicines. I went there many times in the past, I saw that whatever disease I had, I got *para* (Panadol). I know that *para* is for fever, it is not for cough, so why do they give *para* to me when I have cough too. The quality of *para* is not good (Dina).

In some cases, inappropriate treatment provided to patients was possibly due to a shortage of medicines at the health centre, but this contributed to patients' lack of confidence and undermined the performance of the health centre.

Accessibility to health centre

The Cambodian health coverage plan sought to address accessibility to public health centre by ensuring that each health centre is located within a radius of approximately 10 kilometres, or two hours walking distance, from the population served (Ministry of Health, 1997). This planning is supported by previous research on accessibility in Cambodia, which showed that people who live in villages located further than ten kilometres from the health centre did not have access to public health services (Yanagisawa, et al., 2004). Other research in resource-poor countries shows that long distances from public health facilities, poor road conditions, and transportation costs leads to significant delays in presenting to health services by TB patients (Needham, et al., 2001; Lonnroth, et al., 2001; Saly, et al., 2006).

Each of the four health centres where I recruited my research participants served a population within a 10 to 15 kilometre radius. In recent years, road conditions in rural Cambodia have improved and transportation means have become more convenient; motorcycles and trucks are used for public transport in every corner of the country. Transportation costs were high for extremely poor people, but they could still access health care by walking or riding bicycles to the health centre. However, barriers still existed for elderly people and women with small children, who often experienced difficulties getting to the health centre because they needed someone to accompany them or because they did not have someone to look after their children at home.



Figure 15 (above): Patients sought health care at local health centre

Figure 16 (below): Queue of parents (from many provinces) with sick children at Kunthabopha Pediatric Hospital in Phnom Penh (non-government hospital) to obtain free treatment



During fieldwork, I regularly talked with people who were waiting for services at the health centre. Most were women, who attended for multiple reasons. They brought their babies for immunization, requested birth control (contraceptive pill or injections), had antenatal check-ups, or came for the treatment of acute health problems (for example, cough, diarrhoea or fever) for themselves, their children, or other family members. Men also attended to the health centres for their own health problems or to collect medicines for family members. I never met anyone from villages that were far from the health centre; all were from the village where the health centre was located or from neighbouring villages. Accordingly, during data collection, it was apparent that physical distance to the local health centre was relevant to access. Those who lived closer to health centres used the services more than those who lived further away; this was largely explained in terms of convenience, as they could attend the health centre on their way to work, farm, or market. People who lived nearby were also often well informed about when health workers were in attendance and when drugs were available. In contrast, those who lived further from the health centre lacked this information and were therefore afraid of wasting time and money to travel to the health centre for uncertain services. This could, at least in part, explain the low utilization of the health centre amongst those who lived further from the health centre, as two participants explained:

My family and I have never used the health centre. From my home to the health centre, it is about 7 kilometres. I think it is the same distance to the pharmacy or the private clinics at the *Thnal Totenung* market. But I don't go to the health centre because I have heard people say that at the health centre, they had to wait for a long time and they give only *thnam ann ann* (weak tablets) to patients (Pisey).

I live about 4 kilometres from the health centre. I'm very poor, so when I, or a family member, is sick, I like to go to the health centre because it's cheap. I go to the health centre by bicycle. Last time, I went there in the afternoon, because my daughter had to

take the bike to school in the morning, but when I arrived at the health centre, it had already closed. I came back home with nothing. Next time, I managed to go to the health centre in the early morning, and then I could get medicines (Chantha).

These quotes indicate that patients managed to access the health centre if they were confident that they could get appropriate help from the staff. But most participants reported that they sought health services located further away than the health centre, such as from a private provider (clinic, pharmacy) or hospital, because of their limited confidence in the availability of health services. Distance alone was not a major barrier, but was exacerbated by other factors related to access. A motorcycle-taxi driver, Rin, who lived in about one kilometre from the health centre, gave the following account of his family's health care seeking:

When a member of my family is mildly sick, I buy medicines from the market. I always drive past the health centre, but I've never gone in because it looks so quiet. It may already be closed. If we have a moderate illness, for example, when my dad and my mum have joint or stomach pain, they go to a health clinic near Phnom Penh, around 20 kilometres from my place. It is a Korean-funded clinic, it is free, and they accept [people with] all types of illness. To go there, we have to wake up early in the morning; once we arrive, we take a number and line up, there is always a long queue. It opens from 7am to 5 pm. The clinic is crowded with many people from other provinces (Rin).

Studies from Pakistan and India have similarly demonstrated that distance from government facilities was not itself a barrier for mothers when accessing health services; rather, confidence in the services was a major factor in their preference for private practices located further away than public facilities (Noorali et al. 1999, Bhatia et al. 2001). In the present study, as noted, access to health centres was not significantly hindered by physical distance, as all health centres were (relatively) well located, and both road infrastructure and transport modes were not

barriers. However, *accessibility* was affected by people's lack of confidence in the *availability* of services.

Affordability of public health services

Affordability refers to the costs of services, providers, and other related costs relative to the patient's income; it also refers to whether a user-fee system is in place, as well as patient's perceptions about costs related to treatment. In Kampong Speu, health services at public health facilities were provided at a minimum cost ('user-fee') approved by the Ministry of Health, provincial health department, operational health district, and the local community. The user-fee was introduced during health system reform in order to achieve five aims: 1) ensure quality of services provided to patients, 2) prevent informal (illegal) payments, 3) improve the sustainability of the health centre, 4) increase utilization of public health services, and 5) enhance staff motivation. Vulnerable populations (elderly, veterans, and people with a disability), monks, students, and the poor were entitled to user-fee exemptions. Through the user-fee policy, health centres were motivated to generate their own revenue: 50% of the user-fee revenue was used to supplement government salaries, 49% funded the running costs of the centre, and 1% was returned to the government through the Ministry of Finance (Ministry of Health, 2007). User-fee rates were set through consultations between health centre staff and community representatives, and varied according to the living standards of community members (with approval from the operational health district). Therefore, the fee varied between health centres according to the economic status of the population covered. In each of the four health centres where this study was conducted, however, the user-fee was set at similar rates, as illustrated in Table 24 (below). Two health centres, Moy and Bei, had slightly lower fees in some services compared to the other two health centres.

Table 24: User-fee rates (in *Riels*) of health centres in 2008

Items	Boun	Bei	Moy	Pi
Medical record book	500	500	500	500
Consultation	1,000	500	500	1,000
Antenatal check up	1,000	1,000	1,000	1,000
Contraceptive pills	1,500	1,500	1,500	1,500
Condom	100	200	100	100
Contraceptive injection	1,500	1,500	1,500	1,500
Gynaecology treatment	1,000	2,000	1,000	1,000
Delivery	30,000	40,000	30,000	40,000
Minor surgery	5,000	4,500	4,500	4,500
Blood test (Malaria)	1,000	2,000	1,000	1,000
Emergency	20,000	15,000	15,000	20,000

US\$1=4,000 Riels

User-fees at health services were generally affordable for community people. This was consistent with Yanagisawa (2004), who found that the costs of treatment at health centres were lower than those at private services, and it therefore did not affect utilization of the health centre (Yanagisawa, et al., 2004). Khun and Manderson (2008), however, found that user-fees still acted as a financial barrier for extremely poor people, because they had no cash for upfront payments for health services. Further, user-fees exemptions were often given on the basis of sympathy from health staff, or because of a personal connection between health staff and clients (Khun & Manderson, 2008). In the present study, most participants perceived that the costs of public health services were lower than those at the private clinic, and perceived that this benefited community members:

The consultation used to be 500 Riels and each patient could get medicine for five days. That's cheap. If the health centre has medicines, people in my village call each other to go to the health centre and ask for medicines, regardless of whether they are poor or rich. We live close to the health centre, [it's] around 300 metres away. However, the health centre has shortages of medicines sometimes, so it raised the consultation fee to 1,000 Riels. This fee is still cheaper than private fees. For me, I get a fee exemption from the health centre, but I like to buy my medicines from the pharmacy [owned by a health

centre staff member] when I am sick. 'The fee is 1,000-2,000 Riels for two days' medicines—a bit more expensive than the health centre, but it works very fast (Prak).

As described above, community members were concerned about the quality of drugs and health advice at the public health centres. They were concerned that if people required better services with better medicines through the public health service, they may be expected to pay additional or under-the-table payments, which would mean that out-of-pocket costs might exceed those encountered at the private clinic.

The health centre service and medicine is cheap, but it does not have good medicine. If we want to use good medicines, we have to buy them from outside. If we want other services, such as injections or perfusion, we have to pay the health worker. So when we add up the cost, it is not so different from private clinics, plus it is sometimes inconvenient as we have to wait for a long time, or have to go out to buy medicine. [Therefore] although I live close to health centre, I like to go to the clinic. It belongs to the head of the health centre, and the cost is quite reasonable. He has a pharmacy and laboratory at his place, so everything is very quick (Sareun).

This suggests that the user-fees at the health centre were not major obstacles to using the public health centre, but it did not improve utilization of the health centre either. Health staff believed that revenue from user-fees was not effective in motivating health staff to commit to their assignments, and further believed that budget allocation to purchase medicines or equipment for the health centre from user-fees was not practical:

The monthly user-fee revenue is around 300,000-400,000 *Riels* (around US\$100 or less). We use it to buy some necessary materials, such as cotton wool, alcohol, for printing and to buy some medicines. We cannot use user-fees to support everything, because the user fee revenue is low. Each month, user-fees are divided between staff; it is around US\$5, it cannot motivate health staff because the amount is very small (Dara).

Our service is very cheap, 500-1,000 *Riels*. We cannot charge more than this because our patients are poor. Sometimes we don't have many clients because we have a shortage of drugs, so our user-fee revenue is small. Some months, we cannot divide the user-fee revenue between health staff, so we have to wait until after two or three months then we divide it (Seth).

As discussed above the user-fees varied according to the living costs of the population. However, the low costs and under-utilization of services mean that the health centre could not generate sufficiently high revenue to support the running costs of the health centre and to provide a reasonable income supplement for staff. This impacted *availability*. Possibly the dual job practices of health staff also affected availability: many did not rely on the health centre for their primary source of income, so they had little incentive to improve the quality of their services and to generate better revenue.

Acceptability of health care

Acceptability in this context refers to patient-provider interactions, attitudes of patients towards providers, and those of providers toward patients (Penchansky & Thomas, 1981). Health centre staff members were local people who had lived in the community for many years and community members knew them well. Generally, health staff held positive attitudes toward and were friendly with patients who sought help from the health centre. However, despite this, communication between providers and patients was not productive. Health workers had very short consultation times with patients (approximately 15 minutes), in which they recorded limited information from patients: demographic information, address, and information about their health problem. Explanations regarding the presenting health problem, including discussion about cause of the health problem, how to follow-up their illness, the importance of

medication, and preventive activities, were brief. Patients also played a role in this, as they were reluctant to ask questions regarding their health problems. As a consequence, patients often misunderstood the cause of their illness and the course of treatment they should follow.

Challenges encountered by the health centre

As outline above, each health centre faced several challenges, which limited access by community members to public health services and subsequently increased reliance on private providers and the folk sector. These challenges interacted with each other in multiple ways, as summarised in Figure 17 (below) in terms of the five dimensions of access. Low government salaries for health staff and low funding were important factors underpinning the challenges associated with *availability* and *accommodation* dimensions of access to health centres.

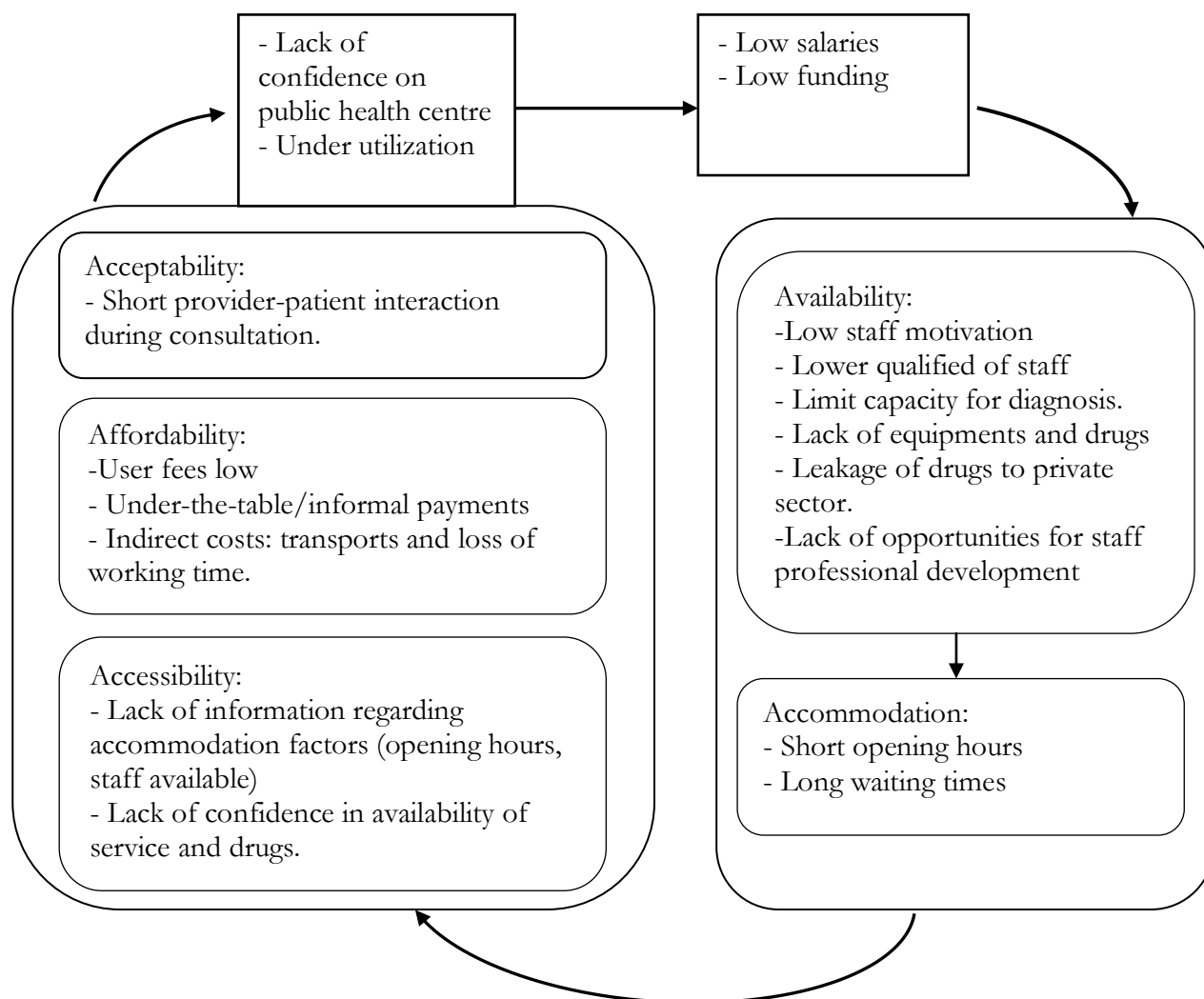


Figure 17: Challenges of peripheral health services

These factors caused low motivation of health staff, leading to absences and shortened opening hours because staff was engaged in dual job practices (discussed above) to earn enough or additional income for living. This created a paradox: dual job practices played a central role in keeping health workers in public facilities as their private work enabled them to earn a better income, but at the same time, this practice undermined service delivery at the public health service because of conflicts of interest (Gruen, et al., 2002; Ferrinho, et al., 2004;

Jan, et al., 2005; Oum, et al., 2005b; Henderson & Tulloch, 2008; Chhea, et al., 2010). *Availability* and *accommodation* dimensions of access interacted with each other and affected the other three dimensions, resulting in the poor performance of each health centre. Barriers to qualified services presented by these two dimensions affected accessibility by causing patients to perceive the public health services as unreliable. In order to deal with this perceived unreliability, patients were encouraged to initiate under-the-table payments (affecting affordability) in order to obtain a better quality of care from health workers (acceptability). This practice ultimately impacted on people's confidence in the public health services, leading to under-utilization of health services and low user-fee revenues. These factors lead to lower salaries and fewer opportunities for professional development of health staff, which in turn affected the dimension of availability and accommodation. Access to the health centre influenced the treatment-seeking behaviours of community members, as echoed in my quantitative data. The ethnographic survey with 240 community members showed that, when an illness occurred, community members would predominantly choose private providers (49.6%; included private pharmacies, private providers or *peet phum*), followed by the health centre (32.9%) as their first-line provider. The uses of pharmacy and health centre as the first provider were associated with gender (Table 25 and 26). A Chi-square test for independence (with Yates Continuity Correction) showed an association between use of pharmacy and gender (X^2 (1, n=240) = 7.35, p=0.007, phi=.18), and an association between the use of health centre and gender (X^2 (1, n=240) =11.47, p=0.001, phi=-.23) in order. Women were more likely to use private providers or a private clinic when they had illness, possibly due to the convenience of these services.

Table 25: First providers used by community members (n=240)

	Male (119)	Female (121)	Total (240)
Private provider*	48 (40.3%)	71 (58.7%)	119 (49.6%)
Health centre**	52 (43.7%)	27 (22.3%)	79 (32.9%)
Hospital	9 (7.5%)	8 (6.6%)	17 (7.1%)
Private clinic	4 (3.4%)	12 (9.9%)	16 (6.7%)
Home care	4 (3.4%)	3 (2.5%)	7 (2.9%)
Kru Khmer	1 (0.8%)	0	1 (0.4%)
Don't know	1 (0.8%)	0	1 (0.4%)

Multiple answers provided

Chi-square test * p=0.007, ** p=0.001

However, community members' choice of health providers was not influenced by literacy level.

Table 26: First providers used by community members stratified by literacy level

	Literate (n=68)	Limited or no literacy (n=172)	Total (n=240)
Private provider	35 (51.5%)	84 (48.8%)	119 (49.6%)
Health centre	23 (33.8%)	56 (32.6%)	79 (32.9%)
Hospital	2 (2.9%)	15 (8.7%)	17 (7.1%)
Private clinic	5 (7.4%)	11 (6.4%)	16 (6.7%)
Home care	2 (2.9%)	5 (2.9%)	7 (2.9%)
Kru Khmer	0 (0.0%)	1 (0.6%)	1 (0.4%)
Don't know	1 (1.5%)	0 (0.0%)	1 (0.4%)

Multiple answers provided

The use of the health centre as the first provider was not influenced by physical distance from participants to a health centre. In this study, participants were asked to estimate the distance from their home to their closest health centre (in metres). A *Mann-Whitney U* test showed that there was no significant difference in distance between those who used health centre as the first provider ($Md=3,000$ metres, $n=79$) and in those who did not use the health centre ($Md=4,000$ metres, $n=161$), $U=5520$, $z=-1.66$, $r=.1$. However, using the health centre as the first provider was influenced by monthly income of the participant's family. Each participant was asked to estimate the average household monthly income – that made by all the

breadwinners in the family (e.g. parents, husband and wife, and children); the estimations were made by participant alone or with assistance with their family members. A Mann-Whitney *U* test indicated that there was a significant different in monthly family income between participants who used the health centre ($Md= 200,000$ Riels or approximately US\$50, $n=79$) and participants who did not use the health centre ($Md=270,000$ Riels or approximately US\$70, $n=161$), $U=4951$, $z=-2.79$, $p=.005$, $r=.19$. This suggested that poor people do use health centre more than better-off participants.

The health centre was overwhelmingly characterised by its long waiting times and no medicines for patients. This may explain why many community members did not use the health centre to cure their symptoms. Less than 20% of participants believed that the health workers at the health centre had a good attitude toward patients.

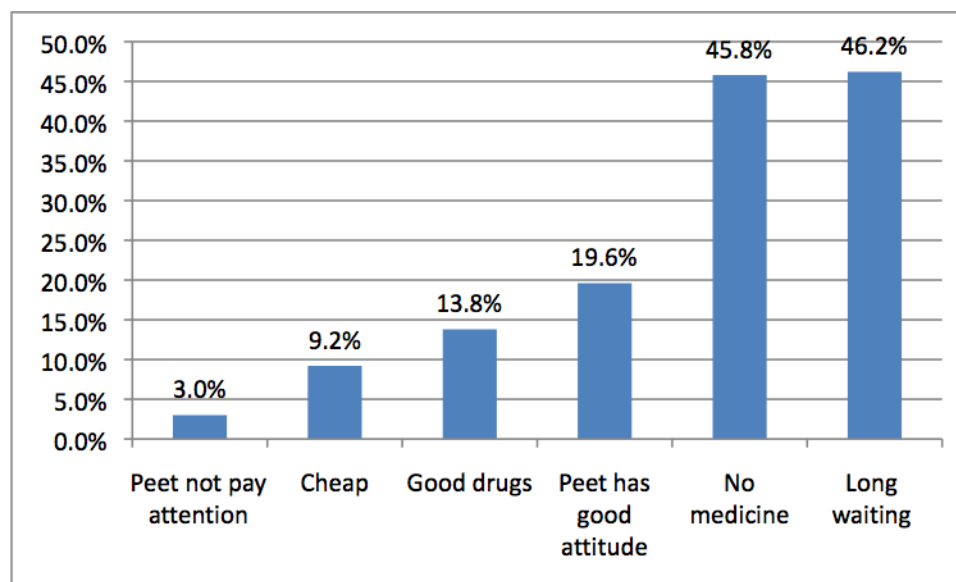


Figure 18: What do you describe the health centre (n=240)

If an illness episode persisted or worsened, participants would move to a higher qualified health provider. Most participants (45%) used the referral hospital (RH) which was located in

the province; about 31.2% used the national hospital (NH); 21.2% used private provider; 14% went to the health centre; and 2.5% used *Kru Khmer*. A Chi-square test for independence (with Yates Continuity Correction) showed a significant association between gender and the use of private provider, and the use of RH when an illness episode was severe (X^2 (1, n=240) =9.54, $p=0.001$, $\phi=.21$, and X^2 (1, n=240) =4.25, $p=0.04$, $\phi=-.14$ respectively). While men tended to seek care from higher qualified health facilities (e.g. RH), women appeared to use lower qualified services (e.g. private providers or health centre). Furthermore, the use of *Kru Khmer* was not common and was only reported by female participants who had limited or not literacy (Table 27 and 28).

Table 27: Providers used by participants when their illness became severe by gender

	Male (119)	Female (121)	Total (240)
RH*	62 (52.1%)	46 (38.0%)	108 (45%)
NH	36 (30.3%)	39 (32.2%)	75 (31.2%)
Private providers**	15 (12.6%)	36 (29.8%)	51 (21.2%)
Health centre	14 (41.2%)	20 (58.8%)	34 (14.2%)
Kru Khmer	0	6 (5%)	6 (2.5%)

Multiple answers provided

** $p=0.001$, * $p=0.04$

However, there was no significant association between the choice of provider and the literacy level of participants.

Table 28: Providers used by participants when their illness became severe by literacy levels

	Literate(68)	Limited or no literacy (172)	Total (240)
Referral hospital	33 (48.5%)	75 (43.6%)	108 (45%)
National hospital	22 (32.4%)	53 (30.8%)	75 (31.2%)
Private providers	11 (16.2%)	40 (23.3%)	51 (21.2%)
Health centre	9 (13.2%)	25 (14.5%)	34 (14.2%)
Kru Khmer	1 (1.5%)	5 (2.9%)	6 (2.5%)

Multiple answers provided

The data did not indicate a significant association between income and a choice of provider when illness was severe. This may reflect that, when people's illness progressed to be more severe, participants and family members were more likely to seek the best care for their health, regardless of family income.

Table 29: Providers used by participants when their illness became severe by literacy levels

	Very low income	Low income	Moderate income	High income
Referral hospital	27 (44.3%)	26 (44.1%)	34 (50%)	21 (40.4%)
National hospital	19 (31.1%)	12 (20.3%)	28 (41.2%)	16 (30.8%)
Private providers	11 (18%)	13 (22%)	16 (23.5%)	11 (21.2%)
Health centre	8 (13.1%)	12 (20.3%)	9 (13.2%)	5 (9.6%)
Kru Khmer	0	2 (3.4%)	2 (3.4%)	2 (3.8%)

Multiple answers provided

Access to private health providers: *Peet ek chun*

The term 'private health providers' refers to individual practitioners or a group of practitioners, who operate private-ownership health services for profit or not-for-profit (Hanson & Berman, 1998). In low and middle income countries, the growth of the private health sector has been influenced by the low quality and inadequacy of public health services (Ogunbekun, et al., 1999; Huff-Rousselle & Pickering, 2001), as well as economic (increased income of the population) and political (support and/or lack of regulation from the government) factors (Bennett & Tangcharoensathien, 1994). Services offered by private providers were often perceived by users to be more attractive, providing alternatives for community members to access modern medicines (Ogunbekun, et al., 1999). However, there were concerns about the poor quality and unethical practices of private services, contributing to high costs of health care among poor people, leading to their delays in presenting to appropriate health services, as this group tended to use less qualified or untrained private providers (Brugha & Zwi, 1998;

Ogunbekun, et al., 1999; Zwi, et al., 2001). Similarly, challenges accessing public health services in Cambodia (describe above) led to significant increases in the number and type of private providers. They operated outside of the control of government. In theory, this sector was regulated by the Ministry of Health and the Provincial Health Department. In practice, a large number of existing private health facilities operated without appropriate licenses, and health services were not monitored. The actual market size of the private health care sector in Cambodia and in Kampong Speu province is relatively unknown (Ministry of Health, 2001a). As already described, most private health providers in Kampong Speu were public health workers who ran a private practice outside of their (shortened) working hours in the public health centres or hospital, although there were also providers who worked exclusively in the private sector. The different types of private providers in rural Cambodia included the pharmacy, *peet phum* (village provider), qualified private provider, and private clinics (Table 30). In the following section, I first describe unique characteristics related to staffing and key services of each provider, then discuss their commonalities in terms of the five dimensions of access.

Table 30: Different types of *peet ek chun* in Kampong Speu

Peet ek chun	Key services	Staffed by
Pharmacy	Located at crowded areas (provincial, district or commune town) in market place - Advice and sell medicines - Prescribe medicines - Provide injections of medicines, or fluid perfusion - Provide laboratory services: blood test, sputum test	- Lay people, - pharmacist, - health workers
Peet phum	- Located in rural or remote areas - Sell medicines (only a few items) - Prescribe medicines - Provide injections of medicine and fluid perfusion. - Provide home-based care	- Lay people, - health volunteers
Qualified private provider	- Located in rural or town areas - Provide prescriptions - Provide injection or serum perfusion - Provided home-based care (in rural areas) - Sell medicines - Sometime combined with pharmacy store	Nurses, midwives or medical assistants (MA), most who are staff of the health centres or the RHs
Private clinic	- Located in provincial centre or district town - Provide prescriptions - Provide hospitalization - Provide other diagnostic services: laboratory or ultrasound - Provide services on the premises	-Doctors or medical assistants (mostly staff of public hospital)

Private pharmacies

In Kampong Speu province, there were three types of pharmacies determined by the licensing arrangements. First level pharmacies were licensed to registered, university-trained pharmacists to run large pharmacy stores. Level two pharmacies were licensed to pharmacist assistants, who ran smaller pharmacy stores; and third level pharmacies were temporarily licensed to retired nurses to run chemist stores stocking a small range of essential pharmaceutical items (approximately 50 drug items) such as antibiotics, antipyretics, antipertussives and antidiarrheal

medication (Yang, et al., 2004). Pharmacy licenses were required to be renewed annually by the PHD. Some pharmacists and health providers who obtained licenses did not own the pharmacies; instead, they hired their license to the pharmacy owners, who then ran the business. In such cases, the licensed person was not on the premises; instead they visited the shop occasionally and let the pharmacy owner—who often had little or no pharmacological training—manage and sell the drugs. Purchasing medicines from the pharmacy did not require a prescription from a health professional, which meant that people could buy medicines whenever and wherever they needed. To obtain these drugs, the clients either told the person at the pharmacy the name of the medicines they wanted, or alternatively described their symptoms to the person at the pharmacy and asked him/her to combine medicines to treat their health problems. Pharmacy staff usually learnt about prescriptions through family members. Some had knowledge of French or English, which enabled them to read the medicine labels, which were usually written in one or the other language:

My mother had a pharmacy in my home-town for a very long time and I always helped her selling medicines. I can understand how medicines are used because I can read some French and English. Since marrying, I moved to this community, and started my own pharmacy. My husband is a health worker at the health centre; he has his clinic and laboratory in my pharmacy. I also learn from him about medicines and how to treat patients (Nita).

The key function of the pharmacy was to sell a variety of medicines to clients. Each pharmacy carried a variety of pharmaceutical products to fit with clients' budgets, including products made in Cambodia, as well as those that were imported. However, to attract clients, pharmacies also provided other services such as taking blood pressure (using a digital blood pressure cuff), testing glycaemia, and providing injections of the purchased medicines, despite the owner not having a formal training in medicine. These additional services made pharmacies

particularly popular. Most study participants chose a pharmacy as their preferred first provider because they could get services promptly and the cost of services was reasonable:

I like to go to the pharmacy if I am sick because it is friendly, it is not very expensive, and the medicines are good quality. We can ask them to combine drugs for us according to the money we have. For example, they will combine medicines for 1,000 or 2,000 *Riels* (US\$0.25-0.5), or we ask them to combine medicine for 2 or 3 days (Chum).

Beside the multiple services and flexible costs, pharmacies were popular because of advertisements of pharmaceutical products through the mass-media (radio and television) and printed materials (billboards, T-shirts, caps). Such advertisements were common, increasing community familiarity with certain products and leading them to choose those products for their own treatment based on advertising information, rather than the appropriateness for their health condition. This was particularly the case for TB treatment. Anti-tuberculosis medicines (including such drugs as Rifampicine, Isoniazid, Ethambutol, and Pyrazinamide) were available in many pharmacies in my research sites. People purchased the drugs as they required them, and many TB patients reported that they purchased these medicines from the markets after they had missed an appointment to take the medicines at the health centre.

Peet Phum

Peet phum, or local injectors, were lay people who did not have formal medical or health training, although they may have learnt or gained practical experience from working with a health professional, or received this training during the *Khmer Rouge* regime. *Peet phum* continued to operate particularly in remote areas, providing home-based services such as injections or serum perfusions to villagers and treating several illnesses including TB. For example, Sokha was a village health volunteer, and had been a *peet phum* for more than 10 years. She did not have any formal qualifications in medicine, but had acquired her skills and

knowledge in health care through working in a Phnom Penh hospital for several years during the 1980s. This was enhanced through her role as a village health volunteer, which provided her with knowledge and skills related to birth spacing, HIV/AIDS, and DOTS:

I have been a volunteer of the health centre since 2006. I'm happy with this work because I can help people in the community. I have also been a *peet phum* for quite a long time; I treat common illnesses such as fever, cough, cold, and diarrhoea. People in my village often call me to help when they are sick. If I see that the health condition is critical, I tell them to go to the health centre or to the hospital, I don't keep patients. I'm very available for people who have health problems to consult with me, because I'm also a health volunteer. Sometimes, I accompany pregnant women to the health centre for delivery (Sokha).

We have one *peet phum* in our village. Before, he was a teacher but later he became *peet phum*. He gives injections and serum perfusion. I don't know how he learned to treat people, but his services are helpful; I've never heard him causing any harm to people. If people are sick at night, they call him (Chrep).

In the study area, *Peet phum* worked independently without support, monitoring or collaboration with any organization. Their services were perceived to be useful by community members, particularly when access to other professional health services was difficult (e.g. if elderly or very far from the centre). Participants used *peet phum* to treat their illness because of their convenient services, reasonable cost, and also because of the longstanding relationships which developed between provider and their clients.

I usually use *peet phum* in my village when I am sick. I call him to give serum perfusion, or injections of *thnam kamlang* (vitamins). The cost is reasonable, and if we can not pay him upfront, he lets us to pay by instalment. The *peet phum* is useful because we live far away and the road is very difficult. If we call *peet* from the health centre or a private provider at night no one would come to our place (Meas).

Qualified private providers

Many villages in Kampong Speu had private health providers. Most were nurses or midwives who engaged in dual jobs in the public health services (as documented earlier). Their independent practice provided key services such as treating childhood and adult illness (typhoid, diarrhoea, respiratory infections and malaria), providing injections or serum perfusions, maternity services (antenatal care, delivery and postnatal care) and home-based care. Generally, health services provided by health providers at their private practice were highly preferred by community members when they had moderate health problems. One public health staff member who also had a private clinic located in the market area explained his work:

I have my pharmacy in the market. My wife sells medicines and looks after the shop when I work [at the health centre]. After work, I stay at the shop to sell medicine and provide injections. We don't make good profits; it just helps us to survive. Most patients are from my neighbourhood, and have known me for a very long time (Sambath).

Private clinics

Private clinics were staffed by health workers, mainly doctors or medical assistants from the provincial hospital or the PHD. These provided multiple services such as treating general health problems, maternity services, minor surgery, and hospitalization. Most private clinics had multiple facilities: a drug store, laboratory, and ultrasound (at the time, the most popular medical equipment). Clinics varied in size; some operated from the ground floor of a 4m square 16m flat, with the pharmacy located at the entrance and beds located behind, separated from one another by cloth screens. A few clinics were located in two-storey flats. Private clinics were used by the wealthier members of the community and by people who were critically ill:

I was hospitalized at a private clinic in the Kampong Speu provincial town three times, each time was 3 to 4 days. *Peet* told me that I had a weak heart and lung infection. They gave me injections, ultrasound and perfusion; each time cost me around US\$50. But finally, because my health did not improve, *peet* at the clinic told me to go to the hospital; he suspected that I could have TB (Meas).

The quality of services provided by private clinics was perceived to be higher than that of other providers, as they were usually delivered by a well-known health worker in the province. However, the cost was also high, causing economic catastrophe for some participants (discussed later).

Five dimensions of access to *peet ek chun*

All types of *peet ek chun* had commonalities. Each attempted to absorb more clients and to sustain their practices in the community. Their services reflected the five dimension of access as discussed below:

Availability and accommodation

Private practices (big or small) provided a major income source for the practice owners, who were often government health staff. Health workers had a great sense of ownership of their private practices, and were committed to provide services to patients, regardless of the time of day or night. This was reinforced by the location of the private practice, often at the practice owner's home. The sense of ownership encouraged private providers to tailor their services to the patient's needs and ability to pay. For example, a patient could ask the provider to give them fluid perfusion or injection of vitamins if they prefer, a choice not available at the public health centre.

Competition among private providers was significant, leading each provider to put effort into delivering more convenient, friendly, quick, effective and affordable treatments to patients. As a result, all necessary complementary examinations were on the premises or could be expedited by the private providers without complex referral:

I have my own private clinic at home. I provide services according to the demand of patients such as: selling medicines, giving injections or serum perfusion, and treating many diseases. Sometimes, I provide home-based care to my regular clients, especially the elderly. If my clients need a blood test, I take the blood samples and send them to the laboratory at the market. It is very important for private providers to be available for clients whenever they need us and provide convenient services for them; otherwise they will not use our service again (Vannak).

Providers clearly understood that the availability and variety of services were essential to attract and maintain clients. This motivated them to improve their services, and to acquire multiple skills to serve clients, so to compete with other private providers. A pharmacy owner explained:

I started selling medicines in the 1980s after the collapse of the *Khmer Rouge*. At that time, there were not as many pharmacies as now, so I could make good business. Now there are many pharmacies, and high competition between pharmacies. Some pharmacies are combined with clinics, they have beds for patients to stay overnight, and they have other services such as blood tests or ultrasounds. I don't have those facilities, but I also give injections or perfusion to clients if they need it. I combine medicines for patients; if they need a blood test, I take the blood samples and send the sample to another pharmacy with a laboratory. I don't send patients to the lab because I'm afraid to lose my clients. I keep my costs reasonable and my service is friendly and convenient. That is why I still have many clients (Chey).

Peet ek chun faced high competition to maintain their services. Patients perceived that such competition provided them better options for their health care, as Dany explained:

There are many *peet ek chun* near the market. They provide multiple health services such as combining medicines for many diseases, doing blood tests, ultrasound, measuring blood pressure, and treating diseases. The private services are convenient, they open every day, even at night. Some providers have beds for patients to stay at their places. Now it is much easier than before, because we have many *peet* in our area. We don't have to travel to the provincial hospital or to Phnom Penh, as *peet* in our area can treat many diseases too.

Accessibility

Pharmacies, *peet phum* and qualified private providers were often located close to community residences, and as noted, some also provided home-based services. This ensured the accessibility of community members to private providers.

Peet ek chun is not far. In the village, we have a drug store (combined with a grocery). If we want good medicines made in France and other services, we go to the big pharmacy at the market, about 5-10 minutes by motorbike. Or we can call *peet* to give injection or serum perfusion, or call a midwife to attend childbirth at home. Transport and the road are much better now, so travelling to *peet* is not difficult (Rath).

Accessibility was reinforced by the availability and accommodation of *peet ek chun* and facilitated by improved road infrastructure and transportation; most families had a motorbike. However, private clinics or high qualified providers were generally located at the provincial centre or a larger district town; therefore accessibility to these providers tended to affect the overall affordability of the services due to high the cost of transport (discussed later)

Acceptability

The three dimensions of access to *peet ek chun*—availability, accommodation and accessibility—determined the dimension of acceptability of this services, leading *peet ek chun*, mainly pharmacy and *peet phum* and qualified private providers to offer primary health care options for rural community members:

I used to bring my son to the health centre when he had fever and cough because I wanted cheaper treatment, but the medicines there did not help him. At last I had to bring him to *peet* Loun (pseudonym) at the market. He is a well-known *peet* in the area, he also works at the provincial hospital. I didn't bring my son back to the health centre because it was difficult, I would have to wait and I didn't think that they would have any better treatment for him (Lili).

Generally, patients' decision to choose a *peet ek chun* was determined by the perceived quality of the providers. Patients did not choose a private provider based on their legal (licensed) status, although providers who were also full-time government health staff were highly preferred, as their status confirmed that they were officially trained and recognised by the government. The most important indicator of quality of the provider was his/her ability to provide the patient with a speedy recovery from his/her illness. Thus, lack of speedy recovery led to questions about the professional skills of the health staff in handling disease, and led to shifting from one provider to another.

Normally villagers told each other about the good *peet* and we all go to that *peet*. *Peet ek chun* usually paid attention to treat illness, however, some *peet* may be less talented than others, so if we see that a health condition does not improve, we change *peet ek chun* because we want the more talented one (Navy).

Ensuring speedy recovery was important, but there was concern related to this. Anecdotal sources revealed that many *peet ek chun* attempted to provide speedy recovery by over-

prescribing to ameliorate the symptoms rather than focus on the *cause* of the symptoms. They therefore regularly used several drugs at once to treat symptoms, for example, treatment for acute diarrhoea illness may include anti-diarrhoeal medication, antibiotics, and antispasmodic drugs, so making the symptoms resolve quickly. However, qualified health providers believed that they provided a range of professional services and health care options. Although there was little regulation, individual health providers were very careful, as accidents in professional practice would potentially harm their business:

I provide treatment to patients the best I can, and I am very careful to give prescriptions, injection or serum perfusion to my clients. For us, providing health services for living is not easy. If my client died at my place, it would be big trouble for my job, people will not have confidence in me, and I may have to face court and pay compensation. [So] every *peet* is very careful when providing treatment to patients (Nareth).

Beside quality, private health practices were also popular for their confidentiality services and sensitivity to the needs of their clients; thus patients with stigmatized health conditions were more likely to use private services:

Although TB treatment is free at the public health centre, some TB patients who are wealthy choose to treat their diseases with private providers because they do not want many people to know about their disease. In addition, private providers did not require them to come every day to take TB drugs on their premise; instead the patient can take home enough TB drugs for at least one month (Rotha).

From patients' perspectives, the services of *peet ek chun* met all important dimensions of access: availability, accessibility, accommodation, and acceptability. However affordability was often a barrier to obtaining private health care, especially from higher qualified providers, as I discuss now.

Affordability

Patients directly paid for private health care through out-of-pocket costs. In Cambodia, there was no private health insurance system for most of the population. Private health service fees were set by individual providers based on their qualifications, and again there was no official regulation regarding the fee charged. Fees varied by the type of provider: pharmacy and *peet phum* charged lower fees than qualified providers and private clinics. In general, *peet ek chun* were aware of financial barriers of their clients. Part of the provision of services meant that they had to take the financial circumstances of the clients into consideration; as a result they had to ask patients about their ability to pay before providing services to them. In some cases, providers had to modify the treatment plan according to their patient's ability to pay. For example, pharmacy staff often provided incomplete prescriptions (i.e. selling medicine per intake, not for a full course of therapy).

I sell medicines according to patients' money. Some patients can only afford a couple doses of treatment, so I sell that amount to them (Neng).

Some people blame us that we are only concerned about money, not the health of people because we ask patients whether or not they can pay our services before helping them. I told them that I'm not a humanitarian organization who can treat everyone for free. I have to tell patients frankly about the cost of service and ask them how they can pay it. If they cannot pay, I cannot provide treatment for them or I can only give them what they can pay, or tell them to go to public hospital (Rotha).

The fees of private providers were (much) more expensive than the user-fees at the public health facilities. Despite this, patients paid them because they believed that good service was worth a set price, with no need to make informal payments, and better drugs. In some instances, patients negotiated with the providers to make their payments by instalment:

When my child was sick, I took him to *peet* at the market. He's a doctor in one health centre. He is very skilful in treating child's illness. If I go to the health centre, it is very difficult to see him, as he may be busy with other things, so I prefer to go to his place. He's always there during his opening hours. He has a laboratory and good medicine too. Each visit, I pay 15,000 Riels (US\$3.5), and he gives me enough medicines for 2-3 days, then my child is cured. It is expensive, but worth it (Lin).

Peet in my village works at the health centre. When my family members are sick, I call him to give injections. If someone is sick at night, they usually call him too. In case, we don't have enough money to pay him upfront, we can pay him later. Some families owe him money forever because when one family member is cured, another member is sick, so they always need *peet* (Punleu).

The cost of private health services was considerable, and for some rural and remote residents cost of transport added to the burden of health care. However, this did not stop most community members from using private health providers, as they were confident about the quality of the service. They financed health care costs through savings, loans or selling livestock or assets, as three participants explained:

I feel weak. My feet and hand are cold. I go to a private clinic for treatment. He gives me medicine to take for a week, and asks me to go to his place once a week for injections. The cost is about 250,000 Riels (US\$60). It is very expensive, but it is necessary for me. I tried to find treatment from the health centre and public hospital but it was not effective; that's why I use the private clinic. I have no savings to pay for this cost [so] I borrow money with 10% interest from a money lender in my village. When we are sick, the most important thing is to treat it, so we do what we can (Bopha).

We have *peet phum* in my village, but he cannot treat serious disease, so we have to go to private clinic at Trapeang Kraleung. Each round trip costs 16,000 Riels (US\$4). It is expensive, nearly the same as the cost of health services and medicines, but I have to go there because *peet* at the clinic can help us (Lili).

Every time I had cough or fever, I ask *peet phum* to combine medicine for me for 1,000-2,000 Riels (US\$0.25-0.5). I never called *peet* to give injections and I never go to the private clinic because I don't have the money to pay them (Sok).

Affordability was the main concern raised by community members who used *peet ek chun*. Although it did not stop them from using such services, poor community members usually relied on lower qualified providers for an incomplete treatment course; they would go on and off with private providers as necessary, and when they could afford the services.

Access to the folk sector

The folk providers also played an important role in providing health care to the community members, even though western medicines were widely available. The most common folk healers involved in providing health care in Cambodia are *Kru Khmer* (traditional healers) and *Kru teay* (fortune tellers). The unique characteristics and commonalities related to access to folk providers are discussed below.

Kru Khmer

The term *Kru Khmer* refers to individuals who practiced as healers or helpers using traditional natural medicines or sacred beliefs as the basis of their treatment of sickness, injuries or grief. Yanagisawa (2004) and Khun (2005) have shown that the category of *Kru Khmer* includes three main types of healing, herbalist, blower and sender:

A *herbalist* used herbs and parts of plants and other natural substances to treat illness. Herbalists usually chanted incantations during the preparation of herbal medicines and as they administered treatment to patients, in order to enhance the effectiveness of the medicines and/or treatment.

Blowers specialized in treating fractures (mainly closed fractures), especially those of the arm and/or leg. To treat fracture, blowers immobilize the broken bone with a splint made from bamboo, and then apply (topical) rice wine, natural drugs and incantations.

Senders or spiritual or supernatural therapists have supernatural powers which they use to communicate with the spirits of ancestors or the spirits of the guardian(s) of the house, the forest, or rice field. They help people who suffered spirit attack by arranging prayers for them.

It was very common for one *Kru Khmer* to practice all three modalities, but each *Kru* typically possesses a special talent in one particular field. Both *Kru Khmer* who participated in this study practiced as full-time healers and had expertise as herbalists, blowers, and spiritualists, but each had a particular expertise. Chamreun's (aged 81) unique specialty was as a herbalist and blower; he also made *kase katha* (protection wire) in different forms, such as necklaces, belts and bracelets. Pich (50) was skilled in using herbs and spiritual practices, such as *saen* (praying) and sprinkling water. Both men were well-known in their villages and in neighbouring areas. *Kru Khmer* generally gained their knowledge and skills from their ancestors, which were passed on to the next generation or from master to their pupils. They acquired years of practice with a senior *Kru Khmer*, before they were able to prescribe herbs or apply blowing practices to patients:

I learnt the knowledge and skills about herbs and blowing for many years. When I was a little boy, I lived in the pagoda and I learn *thour* (Buddhist incantations). Later I got married and lived with my parents-in-law. My father-in-law was a *Kru Khmer*, he observed that I had a special talents and knowledge of *thour*, and then he taught me everything he knew. At first, I helped him to collect herbs and prepare the medicines. I assisted him when he treated fractures and diseases. It was a very long time of practice, until my father-in-law passed away; I continued to do his work alone. I treat many diseases,

especially severe diseases that were refused treatment by the hospital. I also write *yeann* (a piece of cotton written with incantation words), make waist belts (made from cotton with incantations), necklace, and bracelet inserted with incantations (Chamreun).

Kru Khmer diagnosed patient's health problems in multiple ways: for example, asking for a story related to the patients' complaints, touching the client's hand while reciting magic (*pali* words), or organizing a ceremony (*chean arak*) to call the spirits into his or her mind to tell him the cause of the patient's health problem. They used incantations, holy water, *yeann*, *kase katha*, and natural herbs to treat health problems. The treatment procedure involved blowing, sprinkling holy water, *saen* (praying), and rubbing patients' bodies with medicines (herbs mixed with ointment and incantation).

Kru teay (the fortune teller)

Kru teay was commonly used by rural community members. There were different types of *Kru teay* who could foresee what had happened in the past and/or foretell what might happen in the future. Variously, they read palms or facial traits, used cards to make predictions, or calculated a person's horoscope. Like *Kru Khmer*, *Kru teay* usually acquired their knowledge and skills by learning from their ancestors or masters, or, in some cases, they were given these powers (Khun, 2005). Khun (2005) found that common problems identified by *Kru teay* related to illness causation were: causing offence to the ancestors' spirits, often related to the misbehaviour of a family member (for example, a family member forgetting to pray to ancestors, especially during an important ceremony); or breaking cultural convention and affecting a family's good name, in the case of premarital sex. In the present study, participants sought *Kru teay* for various reasons, usually related to health, business, or family problems. *Kru teay* usually identified the causes of their clients' problems and identified what people should do to avoid misfortune, but did not perform ceremonies or pray for clients. Participants who

sought *Kru Teay* for health reasons did so when they had no idea what was causing their illness, usually after their illness did not improve with biomedical treatment.

The difference between *Kru Khmer* and *Kru teay* is that *Kru Khmer* were more involved in health care than *Kru teay*. For example, they provided specific health advice and treatment for various illnesses. *Kru teay*, on the other hand, could foresee what happened in general, in relating to health, or another business of the clients. However, there were commonalities in terms of access.

Availability and accommodation

Kru Khmer and *Kru teay* were commonly available to community members. *Kru teay* were usually found in market areas or at recreation sites, such as parks or riversides. Rural *Kru Khmer* provide services from their homes. Their daily work included the preparation of traditional medicines (collecting, buying or growing herbs or plants, and preparing them as medicine by cutting into small pieces, drying under the sun, combining the medicines by proportion, mixing and packaging), and the treatment of their patients. *Kru Khmer* treated various health conditions ranging from mild to severe, in children, adults and the elderly. For some illness conditions, such as chronic pain (body, joints, stomach and chest), numbness, chronic headache or mental illness (psychotic, anxiety) patients were required to be under treatment for weeks or months. In such cases, patients who travelled from other villages were allowed to stay in the compound of the *Kru Khmer's* house during treatment period. They were not required to pay for accommodation or living expenses, and were also allowed to bring food to cook during their stay. There were no traditional medicine shops in the local markets and, although some retailers bought herbal medicines to sell in the village, people did not like to purchase traditional medicine this way because they feared fake herbs. To buy traditional medicines,

people would go to *Kru Khmer*'s place or order them through their social networks (friends or relatives).

Accessibility

Community members usually travelled to *Kru Khmer* or *Kru teay* when they needed their services, or in some cases, *Kru Khmer* or *Kru teay* provided home-based services to their clients. Accessibility was a problem as, although they were located in the local vicinity, it was not uncommon for community members to seek *Kru Khmer* in other places located far from them because they believed in their greater skills:

My parents always sought help from a *Kru Khmer* in Takeo province where my brother lives, they believe in him. So every time if someone in my family has serious health problem and could not be treated by *peet*, they will go to that *Kru Khmer* for help. But we also go to *peet* at the same time (Chealy).

Affordability

The costs associated with the use of *Kru Khmer* were mainly incurred for the preparation of the ritual ceremonies performed in order to identify the health problem, to remove the curse or spell, and to treat symptoms. For example, fees of services covered the purchase of fruit, boiled chicken, or materials such as candles or incense sticks to use in the ceremony. Typically costs varied from 70,000-150,000 *Riels* (US\$15-35), and the cost of purchasing traditional medicine was usually around 5,000 *Riels* (US\$1.2) per package, which equalled three to four days' medicine. There was no fixed price for *Kru Khmer's* service as payment varied according to the client's generosity and ability to pay.

I stayed at a *Kru Khmer's* place for about two months; I spent around US\$100 during that time, but mainly for my food. The first prayer when I arrived was expensive, because I had to buy a lot of stuff for praying. It was around US\$20, but later I paid only 2,000

riles (US\$ 0.5) to the *Kru Khmer* every time he performed a ceremony for me. My mum sold one cow; she gave me this money to seek *Kru Khmer* because she suspected that I was under a spell (Kanika).

Although *Kru Khmer* did not impose fixed costs, the costs associated with ceremony and other costs were significant. The costs of *Kru teay* services were usually smaller than *Kru Khmer*, as *Kru teay* only identified the cause of a problem. Usually *Kru teay* did not have a fixed fee, and were instead paid according to the generosity and wealth of their clients. Many community members used this service often:

Kru teay is available at *Prey Pdav* market. When I have any problem in my family, including illness, I always consult *Kru teay*, he reads my face and date of birth to foresee what will happen. Sometime, he suggests *saen* to raise *reay* (faith). *Kru teay* is cheap; usually I paid 1,000-2,000 riel (US\$0.25-0.5), and it is useful (Dany).

Acceptability

Traditional healers in rural areas practiced independently from one to another, and from any formal registry bodies. Both *Kru Khmer* in this study claimed that they practiced responsibly, offering the highest quality of care they could, in order to help their clients and maintain their practice for the next generation. Both *Kru Khmer* were aware of the TB program implemented at the health centre and the hospital; they stated that they never treated TB patients and believed that TB treatment was the domain of western medicine. However, they had both treated patients suffering with chronic cough, remittent fever, or bleeding, which they believed could be caused by a spell. Neither *Kru Khmer* had much knowledge of TB symptoms, and therefore could not promptly refer patients with TB-related symptoms to the health centre, although they said they could do so, as Pich explained:

Most of my clients get great results from my treatment. I have many patients who were sick for a very long time and could not find treatment anywhere, but I can help them. I know that *peet* are skilful, they have had years of training and experiences, but some illness have many things associated with it, and I have the power to understand that cause. Then I can treat the patient, or can help patient to be diagnosed by *peet*. For diseases that are not associated with black power, I send patients to hospital. I never treat TB because I know that the treatment is available at the health centre. I accept many diseases including mental diseases, chronic pain, cough or vomit with blood and others. Patients who were cured distribute information about my services to others, so I always have clients from all provinces.

Kru Khmer measured their popularity through the number of clients consulting them. Their reputation was usually spread through community networks. Patients perceived that *Kru Khmer* were important in their health care, although they did not choose them as the first provider. They generally used folk services at some point during the course of their illness for one of several reasons: 1) due to a lack of improvement following western medicine treatments, 2) because they suspected that their problems could be caused by a spirit or a spell, 3) as they preferred natural medicines, and 4) from a belief that *akum psam ayu* (magic saves lives). These people usually did not object to the use of western medicines: they opted for western medicine as the principal treatment for their illness, while also using *Kru Khmer* as a complementary therapy to achieve a better treatment outcome:

We cannot refuse *aepey chum neur* (beliefs in spirits). In our daily life, we have to respect spirits. Some diseases are caused by a magic spell from a witch; these cannot be cured by western medicines alone. Those people usually have chronic pain because the witch sent blades, needles inside the stomach. Some patients who were under a spell had psychotic behaviour (kept screaming and running around), so they need to *saen* (pray) or use *Kru Khmer*, who have the power to remove the spell first. Then the western

medicines from *peet* can be effective, so we have to use both western medicine and *Kru Khmer*. Like old people say, *akum psam ayu* (Phavy).

I have one child who always has *korm* (a skin disease characterised by blisters and itchy) on his head. I took him to several *peet* in this area, then I took him to Kunthabopha Paediatric Hospital in Phnom Penh, but *peet* could not cure him, only could help to heal *korm* for a short time. Then I finally took him to *Kru Khmer*, who used the *och* (burning using incense stick and chanting incantations) on the back of his neck. Since then he was cured, he never had *korm* again (Chan).

The persistence of beliefs about spirits associated with illness and the benefits of *Kru Khmer* in modern day rural Cambodia may result from several factors, such as: low educational status among the rural population, lack of accurate health information, limited access to that information, and limited access to professional health services. However, health staff believed that beliefs about *Kru Khmer* were less than in previous times, and the use of western medicines increased as community members were increasingly exposed to health information through the mass media (radio, television), due to several health education activities implemented by the local health centres and NGOs:

Beliefs about spirits and magic associated with illness remain in the community, but I can see that it is much less than before. People now understand more about western medicine and use it more. But some people still have those beliefs; they go to traditional healers to seek services such as sprinkling water, or buying waist belts for protection. I think we cannot stop them from their beliefs; as long as they also use the health centre or hospital, it is a good sign (Phanna).

Community members at the time of the study tended to be less reliant on the folk providers than previous generations, and sought *Kru Khmer* or *Kru teay* to complement western medical treatment. No participant relied on folk providers alone to treat their illness. However, folk providers sometimes contradicted western medical treatment. For example, Kanika was told by

a *Kru Khmer* to stop using her TB medication while undergoing treatment for bodily pain and numbness with a traditional healer, because the healer believed that medication would decrease the effectiveness of his magic. She was initially willing to comply with her TB medication regime, but based on the advice of *Kru Khmer*, she stopped her treatment:

When I was treated with TB medicines for about two months, my health did not improve much. My cough stopped, yet I felt weak and I felt heat at the extremities of my hands and feet. My whole body was in pain, but in some parts I felt numb. It was really difficult for me; my skin became darker and dry. I reported to *peet* about these problems, but he could not help anything. He just told me to continue my treatment. I suspected that I may be under a spell of someone because I had a dispute with a lady in my village, so I asked my aunt to find me a *Kru Khmer* in a district far from my home. When I first arrived, the *Kru Khmer* did a ceremony to find out what was wrong with me. He told me that I was under a spell. My condition was severe. I could have died. I needed to stay at his place to remove the spell. I actually brought my TB medicines with me, and I asked my mum to send more to me, but once the *Kru Khmer* knew that I took western medicine, he asked me to stop during his treatment. So I stopped. I was thinking that I can resume my TB treatment again if my health becomes better (Kanika).

Kanika may have suffered from side effects of TB medications, but because of a lack of support and explanation from health staff about her concerns, she interpreted this as a magic spell attack. She therefore needed to seek help from *Kru Khmer*. This lack of knowledge about TB and its treatment meant that Kanika had to interrupt her TB treatment in order to obtain treatment from him. Such practices were not uncommon, and could be harmful to Kanika as well as her community, as non-adherence to TB treatment could lead to continued transmission of TB in the community.

The principal treatment provided by *Kru Khmer* was providing reassurance and psychological support, but the effectiveness of their therapies was questionable. Anecdotal evidence revealed that some *Kru Khmer* used significant doses of western medicines mixed with the herbal medicines. These practices potentially could be harmful to clients, where medicines were not used correctly in terms of dose and period of use. In addition, some practices used by *Kru Khmer*, such as blowing, spitting, sprinkling water, or burning (burning an incense stick on the stomach of a patient, while delivering an incantation) may relieve symptoms for a short time but may possibly worsen symptoms, and delayed patients from seeking appropriate treatment. This trend was evident in my data: participants who used *Kru Khmer* acknowledged that their health improved for a while following the therapies, but this was not sustained. A participant (Meas) acknowledged that consulting *Kru Khmer* delayed his TB diagnosis, causing his health to deteriorate, and led to higher health care costs:

I used *Kru Khmer* because I believed in traditional medicine and spirits of our ancestors. It helps me for a while after the treatment and the praying, but then my symptoms became worse. My children took me to a *Kru Khmer* near the mountain and bought medicine from him to boil to drink. I used traditional medicine and *peet phum* for quite long until my symptoms persisted and worsened, then my children decided to take me to private clinic. I don't know how much we spent for *Kru Khmer*, my children paid it, but I know it's quite a lot.

It can be seen above that the folk sector played an important role in providing health care for community members; however, this sector is generally ignored by the formal health system in Cambodia. There has been no initiation of formal interactions between *Kru Khmer*, *Kru teay* and the professional practitioners, although attention has been paid to traditional medicines, which have been incorporated in the curriculum of the School of Pharmacy. The Department of Traditional Medicines of the Ministry of Health is responsible to sustain and promote

traditional medicines; however, there has been very limited research, training, or documentation on traditional medicines. The continued lack of recognition afforded to the folk sector providers was problematic giving their continuing popularity. *Kru Khmer*, particularly in rural areas, work without cooperation, support or follow-up from any particular body. Patients were frequently blamed for their ‘insanity’ in using *Kru Khmer*, which was seen by health professional and health policy makers as leading to a waste of resources and delaying access to professional health services.

I have illustrated that multiple providers deliver health care in rural Cambodia, but access to those health providers remains challenging. Access to the public health centre was hindered by the availability and accommodation resultant from low government salaries for health staff, low health funding, lack of an effective system to motivate health staff, and poor technical supervision. These two dimensions ultimately impacted the other three dimensions of access, and therefore undermined the role of the local health centre in delivering primary health care (MPA) services. In consequence, patients generally lacked confidence on the availability of health services, quality of services and medicines, therefore skipped or delayed seeking health care from the health centre.

As elsewhere in developing countries, since public health providers are not always available and often perceived to be ineffective, private health providers became an important alternative health care resources (Saw Saw, 2006; Bhattacharya, 2007). Private providers were more attractive to users because of quality, shorter waiting, greater confidentiality, and sensitivity to users’ needs (Zwi, et al., 2001). Generally, access to *peet ek chun* in rural Cambodia met users’ expectations in terms of the five dimensions, although in some cases, it was impacted by affordability when poor rural and remote residents sought help from a higher qualified

providers. Given economic constraints among community members, the pharmacy— often providing low cost prescriptions— appeared to be the preferred primary provider for most community members seeking treatment or health advice. But this did not mean that users turned to private health providers without concern. Lack of speedy recovery, sometimes combined with inability to afford private providers, led to patients' self-referral to other private providers, to the public health centre and/or to the folk providers.

There has been concern from health policy makers about the quality and lack of regulation of private providers and the possibility that private providers exploited patients by demanding unnecessary diagnostic test and over prescription (Mills, et al., 2002; Bhattacharya, 2007). This concern is relevant to this study. The widespread availability of *peet ek chun* in rural Cambodia tended to complement health care delivery provided by the public health sector. However, the effective contribution of this sector in providing equitable quality health service to rural community members remains unclear. Quality of private providers remains questionable, especially among lower qualified providers who lack formal education in medicine. In addition, competition among private providers (often staff of the public health sector) posed significant challenges to public health services, as they drained wealthy patients from the public health centre, leading the public health centre to be seen as a place for poor people to seek health care. This could possibly created stigmatization toward health centre users.

Lack of confidence in western medicine providers (both public and private) led to the persistent use of folk providers, especially when people could not find appropriate treatment for their illness from a western medicine provider and/or did not have the resources to pursue higher quality of health care (doctor or specialist).

The structure of health services in rural Cambodia was complex. Government failure to ensure community access to public health centres, and to regulate the private and the folk sectors, significantly impacted on people's health-seeking behaviour. Although most community members relied on *peet ek chun* (mainly pharmacy and *peet phum*) for their health care, there was no particular provider on whom community members could rely. Consequently, it was not surprising that community members usually engaged in provider-shopping in search of appropriate and affordable treatment. In the next chapter, I elaborate on the journeys undertaken by TB patients to seek diagnosis and treatment for their illness, and highlight the factors shaping their routes to DOTS.

CHAPTER 5

PATHWAYS TO TB DIAGNOSIS

Pisey was 28 years old, married with two children aged 6 years and 6 months. She left school when she was in Grade 8 to seek a job; she became a factory worker when she was 19 years old. Her husband was a farmer and casual construction worker.

Following the birth of her first child, Pisey believed that her health changed. She felt unwell: tired, weak, and often coughing. She thought that this was probably caused by a lack of sleep and rest, as she breastfed her baby at night and worked in the factory by day. On a typical day, Pisey woke up at 5.00am, breastfed her baby, and prepared the daily meals for her husband and herself. She left home at 6:00am and travelled on a crowded local truck that routinely transported workers from the village to the factory. The trip took about 45 minutes and, on her way, Pisey ate her breakfast. She worked from 7am to 5pm, with a lunch break from 11am-12noon. Her monthly wage was around US\$60-70 (240,000-280,000 *Riel*), including overtime. Her husband was self-employed, and her mother looked after the baby at home while Pisey worked.

Pisey initially ignored the changes in her health because she assumed that she had a common cold or some other mild illness. She believed that she needed to be active to overcome her illness. She sometimes felt ill during work and needed to rest, interrupting productivity; her boss was not pleased. Pisey did not know what was happening and thought that her health had deteriorated due to weakness from hard work and having a baby. Over time, her upper-back pain became more intense. She coughed more; her skin was hot and dry. When the symptoms bothered her, Pisey bought medicine from the pharmacy and stopped eating food like fermented salty fish (*prahok* or *pha ak*) because she believed that those foods might aggravate her cough. The medicine helped her to continue working, but her cough, back pain, and fever continued to come and go. Pisey did not know what medicines she took because whenever she bought them she just told the seller that she had a cough and back pain, and the seller would combine assorted medicines for her. Her cough intensified, so that she was coughing at work, home, and through the night. She also had chest pain, fever and could not eat. Eventually, she could

not work. Her husband and parents suggested that she go to a private clinic, where she was diagnosed with a lung infection. *Peet* gave her four types of medicines to take for one month. Pisey still had no idea what the medicines were, but believed they were better and stronger than those from the pharmacies. The total cost of consultations, ultrasound and medicines was nearly US\$100, more than her monthly wage. After the treatment, Pisey seemed to recover; her cough disappeared, and her back and chest pains were relieved.

Seven or eight months later, however, she started having the same symptoms again. One day a relative from another village who had had TB and completed treatment suggested that Pisey go to the provincial hospital for a chest x-ray. He suspected that she had TB. Pisey and her family did not follow his suggestion, because none of her immediate family had ever had TB before.

Weeks later, Pisey coughed very strongly with sputum. She was very sick and could not go to work. At this point, her family suggested that she go to the provincial hospital for an x-ray; the trip from her home, with her husband, took about one hour. At the hospital, she was referred to the outpatient consultation ward where she was asked to have a chest x-ray. She had to wait until midday to get the x-ray; by 2pm she learned that her lungs were normal. Pisey was very happy to hear that there was no problem with her lungs, but she was still concerned about what was wrong and why she was so ill. Getting the chest x-ray took one day and cost 15,000 *Riels* (approximately US\$4); she was given neither the x-ray film nor medicines to alleviate her symptoms. Pisey continued to buy medicine from the pharmacy to relieve her symptoms: cough, fever and upper back pain.

She became pregnant with her second child in early 2007 and decided to quit her job before she gave birth because she was often sick. Following the birth of her baby, Pisey was often terribly sick, especially with her cough, which was very strong. She could not sleep at night, she lost her appetite, and became very thin. She went to a private clinic but the treatment did not help her. This worried her family. They went to *Kru Khmer* to find out what was wrong with her; and were told that the ancestors were angry with the family. In response, they arranged several prayers to be said to their ancestors at her parents' house. Pisey also bought traditional medicines. Regardless of what she did,

Pisey' health did not improved: one day she was sick, the next day better. She was disappointed with the fact that the medicines she had taken were not effective, and so decided to consult a village health volunteer who she had heard delivered TB medicines to TB patients. The volunteer suggested Pisey take her sputum to the local health centre. Three weeks later, Pisey was diagnosed with TB. She began her treatment on 21 January 2008.

This story details Pisey's illness pathway, a process which begins with a person observing bodily changes, then identifying and interpreting the symptoms, and then taking actions to alleviate such symptoms through self-management at home (initial response), before drawing on informal and formal health care systems and the folk provider. Pisey used a range of health providers according to her bodily observations, perceptions of severity, and perceived cause of her illness. These providers included the popular sector (through home care, and consultation with relatives and the village health volunteer), the professional health sector (pharmacies, private providers, hospital and health centre), and the traditional sector (*Kru Khmer*). This practice is commonly referred to as doctor or provider shopping—the changing of doctors without professional referral in the same illness episode (Lo, et al., 1994). Doctor-shopping has elsewhere been associated with dissatisfaction with regards of the quality of the present service, in the context of a chronic health condition, and/or derived from issues with doctor-patients relationship (Lo, et al., 1994; Sato, et al., 1995). This practice could contribute to provider failure to investigate appropriate diagnosis due to lack of continuity of health care (Meintjes, et al., 2008; Rintiswati, et al., 2009). Pisey's treatment seeking behaviour was also influenced by lay consultations with family members, relatives and friends. As echoed in the community data, family members did health triage and chose a health provider according to the perceived severity of their illness.

These findings echo Balinese research which illustrated that TB patients usually consulted a number of providers prior to DOTS, including traditional healers, nurses, midwives, doctors, medical specialists, and folk providers (Watkins, et al., 2004). Several factors influencing the pathways of TB patients to the DOTS program have been identified. These include: lay (mis)interpretations of TB symptoms, work and family responsibilities, financial barriers, stigma, and a lack of confidence in health services (Demissie, et al., 2002; Watkins, et al., 2004; Mahendradhata, et al., 2008b). In Laos, most participants interpreted their early TB symptoms, such as cough, fever or appetite loss, as normal or as a mild illness (Xeuatvongsa, 2005). They therefore managed their illness with self-treatment through home remedies and consultation with traditional healers. TB patients presented at a DOTS program only when their symptoms were so severe that their daily life was completely interrupted. Pathways to TB treatment in Indonesia were influenced by income status, the affordability of health services, and advice from family members and friends (based on their previous illness experiences) (Rintiswati, et al., 2009). Thai TB patients regularly spent prolonged periods searching for an appropriate diagnosis, with delay associated with the age of the patient, having mild symptoms, and using unqualified providers (Rojpibulstit, et al., 2006). Nepalese research indicated that TB patients generally used a pharmacy before consulting multiple providers, until they reached more competent health providers who diagnosed TB (ten Asbroek, et al., 2008). This research highlights that delays to TB diagnosis remain problematic in many settings, resulting in a higher rate of mortality among patients and increased transmission of the disease within the community (Bustamante-Montes, et al., 2000). Understanding pathways and associated factors of TB patients is therefore useful for evaluating and implementing TB control programs.

Pathways to DOTS

Patients typically experienced protracted pathways from the onset of symptoms to TB diagnosis. My analysis of these pathways employs Knafl and colleagues' (1995) typology, which identified five pathways to chronic illness diagnosis: direct, delay, detour, quest, and ordeal. Each pathway type varied from the next in terms of time, effort, symptom complexity, and disruption between onset of symptoms and diagnosis. *Direct* pathways occurred when patients were diagnosed within a short period of onset of their uncomplicated symptoms. *Delay* pathways occurred when symptoms were initially normalized by a patient (or caregiver) and explained in terms of non-medical conditions; medical help was sought only when the symptoms disrupted daily life. These pathway types derived from issues in the patient's initial response. *Detour* pathways occurred when health provider(s) normalized or misdiagnosed the symptoms. *Quest* pathways were characterised by a long period of persistence on the patient's behalf when searching for a diagnosis despite barriers, such as health providers' normalization of symptoms and/or misdiagnosis. *Ordeal* pathways were described as long and complex pathways resulting from multiple ineffective patient-provider communications, which persisted over an extended duration of time (Knafl, et al., 1995). The later three pathways commonly evoked provider shopping, and were driven by issues related to a given health provider's knowledge about TB and the health system.

In the following section, I will clearly elucidate these five pathways, by defining into six steps the actions that participants undertook in searching for an illness diagnosis (Table 31). Each step varied from the next according to the types of providers used. Participants determined whether to employ the actions described in each step according to the perceived severity, cause of illness, and the influences from their family members, relatives or friends. While the notion

of steps suggests an ordinal flow from one to the next, this was not always the case—some patients consulted multiple providers within a single step, where other patients bypassed some steps altogether. There was also some forward and backward movement. Three participants were excluded from this analysis: Kravan and Sokun were relapse cases and did not clearly remember their first treatment-seeking behaviours. Rotana lived with HIV/AIDS and was diagnosed with TB when she had a check-up for opportunistic infections. Each step is clearly defined and described below:

Table 31: Defining characteristics of each step in pathways to TB diagnosis

	Step 1: Self-management (n=11)	Step 2: Management with unqualified providers (n=22)	Step 3: Engaging with <i>Kru Khmer</i> (n=7)	Step 4: Qualified private providers (n=14)	Step 5: Health centre (n=21)	Step 6: Hospital (n=15)
What's happening	Appearance of non-specific symptoms	Appearance of new symptoms; Early symptoms worsened	Symptoms persisted/ worsened; Appearance of new symptoms	Symptoms persisted/ worsened; Appearance of new symptoms	Appearance of TB specific symptoms (e.g. prolonged cough with sputum, fever, and weight loss)	Appearance of severe symptoms or severe TB-specific symptoms (e.g bleeding cough, cough with difficulty breathing)
Perceived severity	Mild/moderate	Moderate	Moderate/severe	Moderate/severe	Moderate and indicative of TB	Severe
Self-care/ actions	Home remedies; Medicines bought over the counter; Making herb or plant extracts	Injections; Serum perfusion; Assorted medicines and antibiotics	Traditional medicines; Prayers	Injections; Serum perfusion; Assorted medicines and antibiotics; Blood test	Anti-cough; Antipyretic; Antibiotic; Sputum test; TB medication	Oxygen; Blood test; Sputum test; X-ray; Serum perfusion; Injections; TB medication
Provider consulted	None	Pharmacy=18 Peet phum=4	<i>Kru Khmer</i> =5 <i>Kru teay</i> =1	Private clinics=7 Private provider=9	Health centre=21	Provincial hospital=11 National hospital=2 TB hospital=2
Lay perceptions of cause	Weather; Excessive work; Common cold	Weakness; Fever; Chronic cough; Flu/common cold	Attack by magic spell; Spirit of ancestors	Lung infection; Stomach disease; Typhoid	Suspected TB=21	Lung infection; Injury; Chronic pain; Typhoid; Suspected TB=7

Preliminary diagnosis by a provider		Weak; Fever; Chronic cough; Flu/cold	Magic spell/ spirit of ancestors	Lung infection=5; Stomach disease=4; Typhoid=4	TB=21	Lung infection=1; Chronic pain=1; Typhoid=1; Suspected TB=12
Diagnosed with TB	No	No	No	No	N=18	N=11
Role(s) of others	Suggested medicine or herbs	Recommendations to consult local providers	Suspected health condition had metaphysical cause	Suggested consultation with more qualified providers	Suspected TB; Compared symptoms with the TB symptoms of other family members.	Acknowledged severity of health problem; Suspected TB

Step 1 was the initial response of participants when they recognized the occurrence of a non-specific health complaint. This interpretation was based mainly on a single symptom, such as chest or stomach pain, cough, fever, or loss of appetite. Although these problems were usually mild, they generally required treatment; this usually involved the participant using simple home remedies, including coining and cupping, restriction of food, and minimizing health risk behaviours. Home remedies included self-medication using a variety of over-the-counter medicines and antibiotics and/or herbal medicines, which were either self-made using herb or plant extracts or purchased from traditional healers. Men often reported minimizing health-risk behaviours, including such actions as reducing or stopping smoking and/or drinking, and/or reducing hard physical labour:

When I had a strong cough, I bought anti-cough tablets and *thnam psass* (antibiotics) from a pharmacy, but it helped just for a short time. Then I reduced my smoking, avoided working hard, and stopped eating fermented foods. The cough would often come and go; if the cough disappeared, I would stop the medicines (Bona).

These behavioural changes usually occurred in response to patients' perceptions that their poor health condition was due largely to their behaviour. Many changed their behaviour during the period when they felt sick and resumed these behaviours when they recovered.

Step 2 occurred when participants realised that new symptoms had emerged or previous symptoms had worsened after initial treatment. Participants reported that step 2 involved the first actions undertaken in response to symptoms. Symptoms were usually regarded as moderate, leading participants to consult with unqualified providers located locally, generally either a pharmacy or *peet phum*. Within this step, participants sometimes consulted multiple pharmacies or *peet phum*, or consulted a pharmacy then *peet phum* (or vice versa). They observed treatment outcomes based on this, and looked for other alternatives depending on their symptoms. In step 2, patients also sought treatment with western

medicines (tablets, or injections), including antibiotics, antipyretic, antipertussives, painkillers, and/or vitamins. This treatment often provided some relief. Patients therefore continued to comply with taking it as long as they needed. Patient behaviour in this instance was consistent with earlier studies (Yanagisawa, et al., 2004; Saly, et al., 2006; Khun & Manderson, 2007), where the reasons for choosing the pharmacy or *peet phum* were associated with perceived seriousness of illness (as mild or moderate), in addition to the dimension of access: proximity of service to home, perceived quality of the provider(s), flexibility of therapy options, and cost of services. For all 22 cases who described step 2 actions, neither participant nor providers suspected TB from the presentation of patients' symptoms.

Step 3 was characterised by participants engaging with the folk sector to identify the cause, and/or subsequently obtaining treatment for their health problems. Most patients omitted this step, but seven participants who failed to regain their health through the measures employed in Step 1 or Step 2 suspected that their health problems were associated with a spell, or an evil or angry spirit. They therefore followed the advice of family members to seek help from the folk healers, *Kru Khmer* (n=6) and *Kru Teay* (n=1). Meas lived in a very remote area, and initially treated his poor health through *peet phum*. However, his health became worse and he suspected that it could be caused by a spirit or magic spell, so he sought help from *Kru Khmer*. He believed that some illnesses should be treated with traditional medicines:

In the past, we did not have western medicines like nowadays, so our ancestors used traditional medicines to treat diseases. It was good, effective. When my treatment with *peet phum* did not help me much, I told my children to take me to *Kru Khmer*. He arranged to pray for me and treated me with herbal medicines. I felt better for about one or two months. Then I was sick again, so my children took me to a private clinic.

Consulting *Kru Khmer* was associated with individual beliefs about the influence of supernatural causes of illness as well as their own and their family's beliefs about the effectiveness of herbal medicine (discussed later in the chapter).

Some participants swapped between different *Kru Khmer* in search for the one with the most power to deal with magic spells or spirits. In this step, participants sometimes experienced relief from their symptoms for a period of time, but then sought other alternatives when their symptoms re-emerged.

The use of highly qualified private providers (private clinics, or nurses or doctors in private practice) was characteristic of **Step 4**. Participants usually had new symptoms, or their previous symptoms had worsened and could not be helped by home remedies, unqualified providers, or folk providers. Fourteen participants went through this step, as they perceived that their symptoms were severe. Here, providers interpreted a participant's condition as critical, indicating medical conditions such as lung infections, typhoid, or as resulting from complications of stomach diseases. However, only three participants were told by their private provider to seek a TB diagnosis; these patients presented with more definitive TB symptoms: bleeding cough, a cough with difficulty breathing, and/or significant weight loss:

I coughed for about one month. I took medicines from the pharmacy, but the cough remained. I lost my appetite, had night sweats. One day, I coughed with blood, so my father took me to a private doctor, and he treated me with serum perfusion and injections to stop the bleeding. The treatment took around one week and I felt better (Chamrong).

The use of a qualified private provider was influenced by family economic status. Wealthier families preferred to use these services because of their perceived high quality. Private providers usually treated patients with several western medicines that generally provided

some relief from symptoms; however, as described in chapter 4, it was this practice that contributed to long delays to TB diagnosis. In addition, qualified providers sometimes overlooked TB symptoms, particularly when participants did not fit their stereotypical understandings of TB patients: being skeletally thin, having poor clothing, or looking unhygienic. This was also associated with the common perceptions that only extremely poor and unhygienic people have TB.

Step 5 occurred when participants developed more specific TB symptoms after being sick for a prolonged period of time. They had treated their symptoms with either home remedies or treatment from a range of providers. However, their symptoms had been relieved by their treatments only for a limited time before returning with greater severity. The symptoms usually made family members, relatives or friends, or the patients themselves, suspect TB and decide to seek TB diagnosis:

I was coughing a lot for couple of months. I bought medicines from the pharmacy but it did not help me. My husband suspected that I could have TB as he had had this disease in the past. I heard that the health centre had recommended that individuals who had had a cough for more than three weeks should have a chest x-ray. I attended for the x-ray and *peet* found an abnormality in my lungs and referred me to do a sputum test (Romdol).

Step 6 involved participants presenting at a public health hospital or the TB hospital to seek a specialist care for their symptoms. Usually participants reached this step because they suffered severe acute or chronic symptoms, such as a bleeding cough, cough with difficulty breathing, repetitive fever and weight loss, or chronic back or chest pain. Fifteen participants reached Step 6; however, four were not diagnosed with TB. There were no clear reasons as why this occurred, but it is possible that health workers overlooked TB diagnosis because they expected a greater number of indicative TB symptoms in those patients. These four participants then returned to the health centre (reverted to Step 5)

when their symptoms progressed to be more indicative of TB, leading them to suspect the disease. For example, Sovann presented at a hospital suffering with a cough and breathing difficulties. He was diagnosed with pleurisy and was treated accordingly, but his health provider did not request further examination such as a sputum test or x-ray:

My chest pain became more intense and it spread to the back. I decided to have a check-up at the hospital; *peet* told me that I had water in the lungs. *Peet* pumped the water out, I was hospitalized for a week, and then I felt better.

Pathways of TB patients

By examining individual patient's progression through these six steps, it is clear that the five pathways to diagnosis (see Figure 19) described by Knafl's and colleagues (1995) are relevant here. Each was impacted by some of the five dimensions of access. Each pathway had implications for individual patients, their family and community members, as well as the health service and providers; these are discussed below:

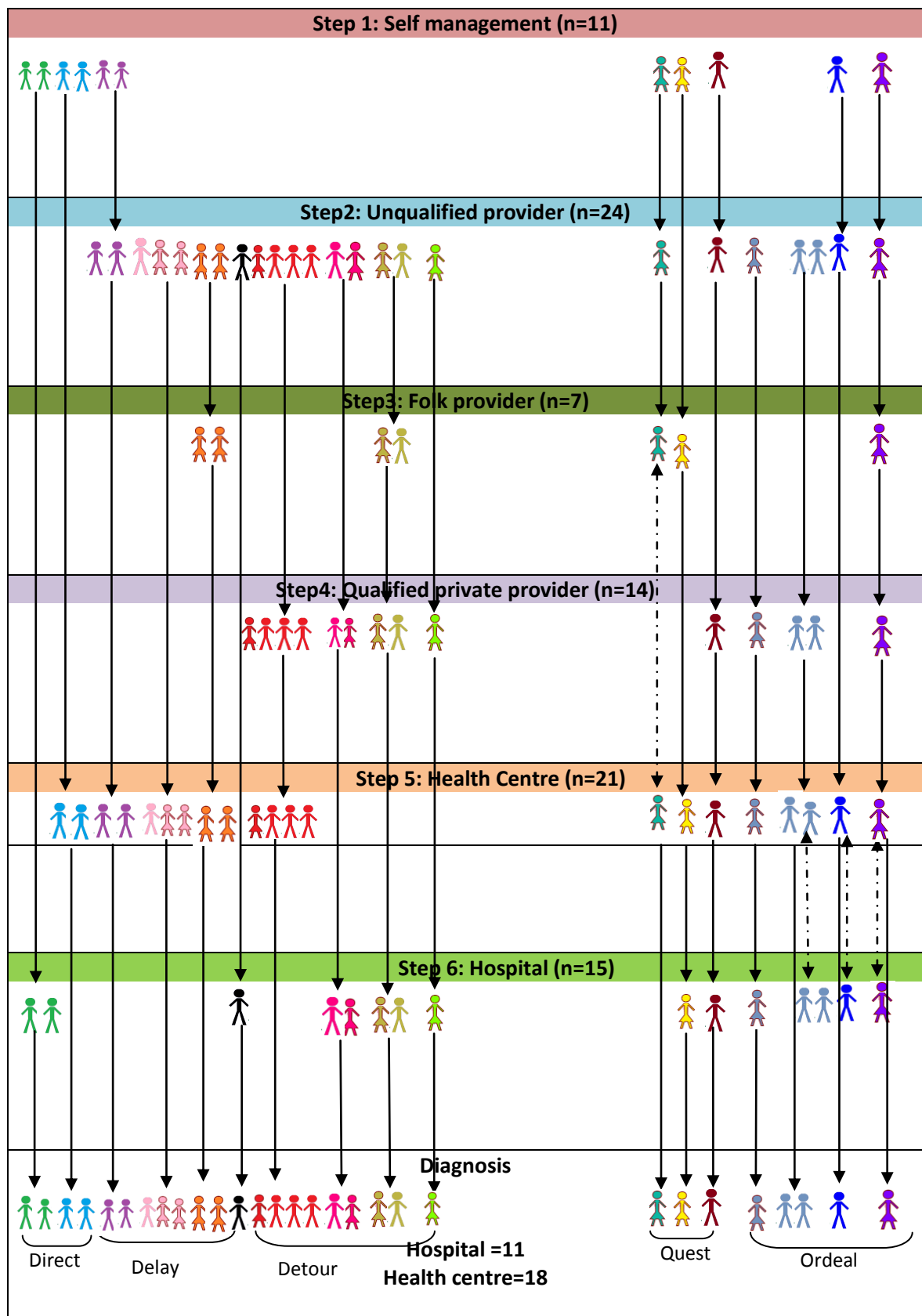


Figure 19: Pathways of TB patients from symptoms onset to diagnosis (n=29)

Direct pathways

Only four men in this study described a direct pathway to TB diagnosis, in which they moved from Step 1 (self-management) to Step 5 or Step 6, where they were given a TB diagnosis immediately. However, direct pathways still took one to two months before a diagnosis was reached and, by the time of diagnosis, their symptoms were usually quite advanced. For example, Sophon and Samreth both presented to the hospital following the emergence of a bleeding cough after they had previously managed their (prolonged) cough with home remedies:

I've never had any serious illness in my life. I started having a dry cough, so my sister bought medicines for me from the pharmacy and made some herbs for me to drink. But the cough became stronger and stronger and I lost my appetite and felt weak. One day, I coughed sputum with a little blood, and then again with more blood. My nephew and my sister took me to the hospital (Samreth).

Since I had a traffic accident last year, I had chest pain and cough. I bought medicines from the pharmacy to treat the cough and the pain. But after the rice harvesting time this year, I coughed with blood. I was very scared and I went to hospital immediately. The hospital referred me to the TB ward. *Peet* gave me serum perfusion and other medicines, and then took my sputum for the test (Sophon).

The bleeding cough precipitated patients' decision to seek TB diagnosis, even if they believed that their bleeding cough was caused by internal trauma or physical hard work. Kiri and Sok each presented to the health centre when home remedies could not alleviate their cough, and when the development of symptoms (such as weight loss and difficulty with breathing) led them to seek help from the health centre:

My health problem was a cough. I had it for a long time but I didn't do anything much to cure it. If it was strong, I took anti-cough medicines or drank *chi cheung keras* juice (a

kind of herb). Before *Pchum Ben* (a religious ceremony in September 2008), my cough was very strong with a lot of sputum so I went to a health centre to ask for some medicines. *Peet* suggested that I do a sputum test and told me that I had TB. So I was given TB medicines (Sok).

These four participants were all extremely poor, and could not afford to go to a private provider or to purchase good medicines from the pharmacy. They also lived in hygienically poor living conditions and did hard physical work. Given their daily lack of food, which may have weakened their immune systems, the progression of TB was likely to be quickened. Their impoverished clothing and frail appearance, where they looked skeletally thin and pale, tended to lead health providers to suspect TB, leading to a direct pathway. However, these pathways differed from those described by Knafl et al (1995), where a direct pathway was associated with early diagnosis and, therefore, prompt resolution of the symptoms. Direct pathways in the present study occurred as result of the quick progression of symptoms resultant from lack of appropriate care. In addition, patients' ability to present promptly to public health facilities following severe symptoms was particularly influenced by their inability to pay for private health services. Although these patients were not confident in the availability and acceptability of the public health services, their financial constraints forced them to choose a health centre as the only possible point of care, which may have meant they were diagnosed more promptly.

Delay pathways

Eight patients experienced delay pathways, which were characterized by patients normalizing their symptoms by explaining them as a common cold, an "ordinary" or "weather" cough, or a respiratory infection, and then using an unqualified (Step 2) or folk provider (Step 3). It was only when their symptoms worsened that they resorted to Step 5 or Step 6, where they were diagnosed with TB. Participants who had a delay pathway spent two to four months treating

their illness with unqualified providers, who did not suspect TB from their symptoms and managed the illness according to the patient's lay explanation. This lack of providers' knowledge about TB, its symptoms, and diagnosis contributed to patients delaying their recognition of their symptoms as serious, and this subsequently delayed their presentation to a public health centre or hospital for diagnosis:

I started coughing during the harvesting season so I thought that it was just a normal cough caused by debris from the rice, which I was packaging every day. I thought that I just had a normal cough and cold, so I asked the pharmacy to give me a combination of medicines. Then I had persistent fever and weight loss and could not work. Then I decided to go to health centre (Chantha).

Participants' perceptions about the severity of their symptoms influenced their decision to seek health care. Generally participants did not perceive that their early symptoms were indicative of TB and so they consulted low-qualified (more affordable and accessible) providers until their symptoms worsened. Their delays in presenting to a health centre promptly at the onset of their illness also resulted from barriers related to the five dimensions of access to the health centres (mainly accommodation and availability), such as short opening hours, long waiting time, and lack of confidence in the staff and medicines. However, most of these participants eventually presented to the health centre when they perceived that the symptoms were related to a critical medical condition. More importantly, patients, family members or relative suspected that their health conditions were possibly related to TB, for which diagnosis and treatment were available at the health centre.

Detour pathways

Nine of the 29 participants described detour pathways, which were characterised by participants using three or four steps, and involved a period of four to six months in searching

for an illness diagnosis. These participants all began with **Step 2**, with two consulting *Kru Khmer* in **Step 3** before all of them moved to qualified private providers because their symptoms had progressed to be more persistent. They perceived that their health condition was becoming critical and could no longer be managed with unqualified or folk providers. However their *providers* normalized or misinterpreted their presenting symptoms, which delayed their progression toward diagnosis (either Step 5 or Step 6); diagnosis only occurred when their symptoms further worsened and became more indicative of TB. For example, Kim had managed her symptoms with unqualified providers for some time, but as her illness progressed to be more disruptive, she suspected that she had a disease that required more serious therapy, and then consulted a private provider, who was also a staff member of a public hospital. After several therapeutic programs provided by the private provider did not improve her condition, her family suspected that she could have TB and she presented at the TB hospital for diagnosis:

I started coughing last year and often asked the pharmacy to combine medicines for me, but this only helped to relieve the symptoms for a couple of days. Then my problem became worse: I had more coughing and felt hot on my chest, and lost my appetite. My children brought me to *peet ek chun* in the district town, and he gave me injections and medicines to take for about two weeks. But my health did not improve much. I felt weak as I could not eat, so my children called *peet phum* to give me injections at home. But all the medicines and treatment that I tried did not help. My children, who worked in a factory in Phnom Penh, brought me to the TB hospital in Phnom Penh because they suspected that I might have TB, because I was very thin and coughed a lot. After I was diagnosed there, I asked *peet* if I could come back to my village, and they referred me to this health centre (Kim).

The five dimensions of access again had important implications for diagnosis and subsequent treatment. Like other participants, Kim's home was not far from the local health centre where

she eventually obtained DOTS treatment. Prior to their TB diagnosis, however, all participants sought services from both unqualified and qualified providers because they were not confident about the quality of services provided by the health centre. They therefore bypassed the health centre that was closest to them in order to consult private health providers even though the fees were often far more expensive than at the health centre.

Quest pathways

Three participants (two women and one man) described quest pathways to TB diagnosis, which were characterised by prolonged delays of approximately 12 months. They used three to four steps, including the government facilities where TB diagnosis was provided. In these examples, quest pathways emerged because of TB diagnostic errors occurring in the health facilities, which were exacerbated by the lack of follow-up systems to trace suspected TB patients (discussed later). Lili, Soma and Sophal all experienced diagnostic errors and so continued to treat their symptoms using folk providers. It was only when their symptoms progressed to be a severe bleeding cough, cough with abundant sputum, and difficulty breathing that they sought diagnosis:

As my cough and chest pain became more severe, I went to a health centre near my village. I told them that I suspected that I had TB because I remembered how my husband was sick with TB before. I submitted sputum. About a week later, I went to collect the result but *peet* told me that I did not have TB. I felt very relieved to hear the result that I did not have TB. My relatives suggested that I go to *Kru Khmer* [for my cough and chest pain]. Later I had a bleeding cough and I thought again that I could have TB. I decided to move to my mother-in-law's place because she is close to the health centre (*Boun*) where my husband was treated for his TB. I think that health centre is better than the one that I went to before, because after I submitted my sputum, a week later the result was that I had TB and I started treatment (Lili).

In addition to incorrect TB diagnosis, quest pathways were also caused by a lack of attention and follow-up to patients who presented with TB-related symptoms by public health staff, as Soma explained:

I was sick with cough, repetitive fever and a lost appetite. I was treated by *peet phum* and the pharmacy, but I did not get better. My neighbour also had the same problem and she asked me to go to the health centre with her. There we were asked to submit sputum, and *peet* told us that when they had the result they would inform us. I just waited and waited, but I never got my result (Soma).

Both incorrect TB diagnosis and lack of follow-up were serious problems in the public health system and led to extended pathways for diagnosis, meaning that participants did not get appropriate treatment until their conditions were very severe. This access to public health services had significant impacts on patients' pathways, as echoed in this analysis. Although patients may suspect TB and present for diagnosis, lack of equipment for laboratory tests, as well as the low motivation and lack of a sense of responsibility of public health staff in investigating TB contributed to drive these patients away and thus, delayed diagnosis.

Ordeal pathways

Five participants (three men and two women), including Pisey, described experiencing ordeal pathways before they entered the DOTS program. An ordeal pathway was a prolonged and complex path, whereby participants used five or six steps, and spent approximately 15 to 24 months in search of a cure for their illness. These prolonged pathways had multiple contributing factors: patients' denial that they had TB, their lack of understanding about TB, utilization of multiple private providers, lack of support from health providers, diagnostic errors, and under-the-table payments for TB diagnosis and treatment. Chanthy described the interactions and impacts of these factors on his pathway to diagnosis:

I was sick for very long time with back and chest pain. I also had cough but it was really problematic. My children took me to clinics in the provinces and in Phnom Penh to find a diagnosis for my illness, but no treatment cured me. It only improved for a short time. I also tried to treat the pain with several therapies from the pharmacy. I bought several types of balm that were advertised on TV, but the pain would often come and go, until late last year when I became very sick with loss of appetite and had more cough, [when] the lady who worked as health volunteer suggested that I should check for TB at the local health centre.

The lack of indicative TB symptoms, as well as lack of knowledge about and recognition of these symptoms, and lack of attention by health providers in investigating TB, led to these extensive 'ordeal' pathways. Participants could not find a cure for their illnesses and therefore continued to use different providers across all sectors of the health system, often moving back and forward between steps. The therapeutic programs provided by different providers often helped them to gain relief from their symptoms for a short period of time; however, the search for diagnosis continued when their symptoms re-emerged. They continued this frustrating search for appropriate health care until their symptoms were more clearly indicative of TB and no longer responded to the different treatments tried. This led both patients and their family members to suspect TB, and therefore they presented to a health centre or hospital for TB diagnosis.

Circumstances leading to TB diagnosis

Although participants had different pathways to diagnosis, they generally experienced a cycle of symptoms such as a cough, fever or loss of appetite that came and went with their use of different treatments. They usually sought health care when their symptoms were critical, and then stopped treatment as their symptoms were relieved. Ultimately, their decision to seek TB diagnosis occurred in response to three circumstances: when symptoms began to disrupt their

life (either through the appearance of new or worsening of existing symptoms), when their family members suspected TB, or when patients themselves suspected TB. These reflect the ‘circuit breakers’ described by Manderson and colleagues (2008); participants in that study referred to a “catalyst” – a critical event or dramatic change that led to a prompt transition from their perception of their health as normal to recognising it as a pathological condition – as an alert to seek diagnosis. Four main types of circuit breakers were identified: intercession, social disruption, biographic disruption, and self-recognition (Manderson, et al., 2008). Each had its own implication for patients’ health-seeking and the delivery of health care in the case of TB, as they provide insights into how health education can be better directed to encourage less prolonged pathways to diagnosis, and thus earlier access to treatment. In the following section, I discuss the importance of the three aforementioned circumstances that led participants to seek TB diagnosis.

Social disruption

The main circumstance that led to TB diagnosis was the presentation of severe symptoms that could not be treated by therapeutic programs provided by the pharmacy or folk providers. Whilst these symptoms could be life threatening, they most often stopped people from undertaking their work or daily activities, and thus prompted patients to seek diagnosis, as Meng explained:

I often coughed because I had asthma. If the weather changed or I accidentally ate something wrong I [got] cough and then my daughter bought some medicines for me from the pharmacy. But after I came from the beach [following playing in the water and eating seafood], I had serious cough and fever. My children bought medicines from pharmacy for me, but I coughed more and had difficulty breathing, and could not eat or sleep. My daughter took me to the health centre where *peet* diagnosed me with TB and gave me TB medicines.

The quicker those symptoms progressed, the earlier patients presented to DOTS facilities. Delays in the progression of TB symptoms caused by the use of multiple non-TB treatments by patients also directly contributed to delays in TB diagnosis, regularly leading to prolonged pathways. In addition, the rate of the critical progression of symptoms to becoming more disruptive to patients' lives contributed to the suspicion of TB, and their suspicions were influenced by others: former TB patients, relatives, and friends as well as their own recognition of TB, particularly when they compared their symptoms to information they obtained from health promotion materials or through the mass-media.

Significant others, particularly former TB patients, were important in influencing patients to seek TB diagnosis. Four participants— Romdol, Lili, Bonna, and Kolab— had had a spouse or relative who had been treated in a DOTS program in the past. As these participants' symptoms became more disruptive, their significant others suspected TB and suggested that they present for diagnosis. However, the influence of others was not always a 'circuit breaker', because their intercession was based on experiential knowledge rather than medical expertise (Manderson, et al., 2008); in consequence, health care may not be sought promptly. In the present study, some patients received advice from family members or former TB patients to seek a TB diagnosis, but they continued to seek non-TB treatment because they were not confident about that advice. For example, although their relatives suggested TB, Pisey and Phally did not seek TB diagnosis promptly because they assumed they did not have TB (based on their explanatory models, see chapter 4) and only sought a TB diagnosis after they became very sick.

Self-suspicion of TB

Some participants sought TB diagnosis after due consideration of whether their symptoms were related to TB, and presented directly to a provincial TB ward or health centre for

diagnosis. Their self-recognition of TB may have been influenced by social knowledge of the disease and experience of other family members. Samnang was a community DOTS (C-DOTS) observer and suspected she had TB when she began to have a repetitive cough accompanied by fever and weight loss:

I had cough and fever, but I never thought that I could have TB. I asked for medicine from the health centre, but it didn't help. I bought medicine from the pharmacy, but it didn't help either. I asked *peet* to give me injection, but my health became worse. I lost a lot of weight and had stronger cough especially at night. I suspected that I might have TB. I remembered what I had learned about TB symptoms and I requested *peet* at health centre to test for TB. I submitted sputum and the result showed that I had TB.

Samnang drew on her knowledge and skill as a C-DOTS observer to evaluate the change in her symptoms and sought TB diagnosis. However, despite having this specific knowledge, she did not immediately suspect TB: her self-recognition of TB still occurred at a relatively late stage of illness, when she already had indicative TB symptoms.

Sometimes, self-suspicion about TB did not encourage patients to seek diagnosis promptly. This was particularly the case for extremely poor people who worked for their bare survival. As a TB diagnosis would force them to have even greater difficulty to earn a living, they often delayed diagnosis until their symptoms stopped them from working at all:

I was sick with cough and feeling weak, but I continued my construction work as usual. I suspected TB, because I had heard radio advertisements that if [said that] people coughed for more than one or two weeks, they should go to a health centre. But I didn't have time to go to health centre. I have to work every day from morning to night, seven days a week. I stayed at the construction site, because the owner wanted us to finish the work very soon. I bought medicines from the pharmacy to treat my cough. Later, I was

very sick. My cough became more repetitive with strips of blood and I couldn't work. [So] I went to a health centre where I was diagnosed with TB (Phirum).

Although participants may have suspected TB based on their own or others' knowledge, most participants presented for TB diagnosis only after severe symptoms began to disrupt their work or everyday life.

Time (duration) of delay

Previous research has defined 'time of delay' as the interval of time that elapsed from the onset of TB symptoms to the initiation of a TB therapy (Needham, et al., 2001). In this study, the 'time of delay' from the onset of illness to diagnosis was estimated in months, as TB patients had often been sick for a long time before diagnosis and could not estimate their delay more specifically. The total elapsed time before diagnosis varied between one to 24 months (mean=7.17 months, median=6 months). The median delay of 6 months (approximately 180 days) was even higher than that found in other TB high-burden countries such as Tanzania (136 days), Burkina Faso (120 days), Ethiopia (120), and Thailand (120 days) (Madebo & Lindtjorn, 1999; Wandwalo & Morkve, 2000; Ouedraogo, et al., 2006; Storla, et al., 2008). However, this median delay was not consistent with the finding of an earlier study on delays to TB treatment in Cambodia, which found that, in the areas where DOTS was available at the hospital and health centres, the median delay was 58 days (Saly, et al., 2006). In my study areas, DOTS was available at hospitals and every local health centre; however, duration of delay to DOTS remained high. Duration of delay varied by gender, male participants in this study spent a mean of 6.24 months (range 1-20 months, median=4 months) prior to seeking diagnosis, while women spent a mean=8.5 months (range 2-24 months, median=6 months) before seeking diagnosis.

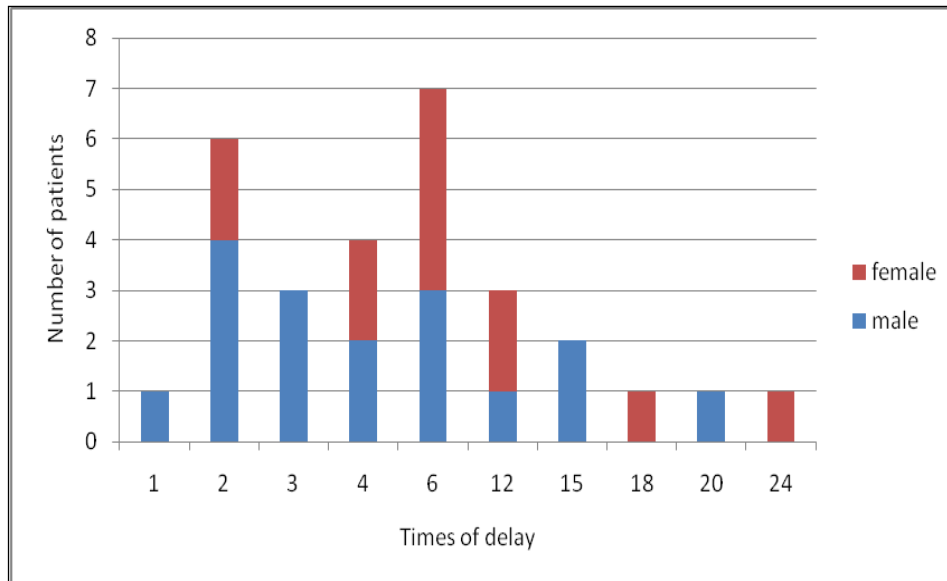


Figure 20: Elapsed time from symptom onset to TB diagnosis (n=29)

Men seemed to have shorter delays than women because they were often the primary income earners, who engaged in hard physical work, and so the social disruption of TB symptoms was noticed earlier. Men often ignored their early symptoms or managed these with home remedies or through pharmacies; they also often engaged in risky behaviours, such as smoking and drinking, which tended to aggravate their TB symptoms, promoting early diagnosis. Women delayed longer because they tended to care for their health better than men, for example, by not smoking, drinking, or undertaking hard physical work. Women also often treated their early symptoms by seeking advice from lower qualified providers (pharmacy and *peet phum*), and this helped them to obtain relief from their symptoms and so delay the progression of symptoms. In addition, women tended to believe in and seek care from traditional healers more than men. Although men and women had different durations of delay, all participants here entered DOTS only when they suffered severe symptoms and their health condition had deteriorated.

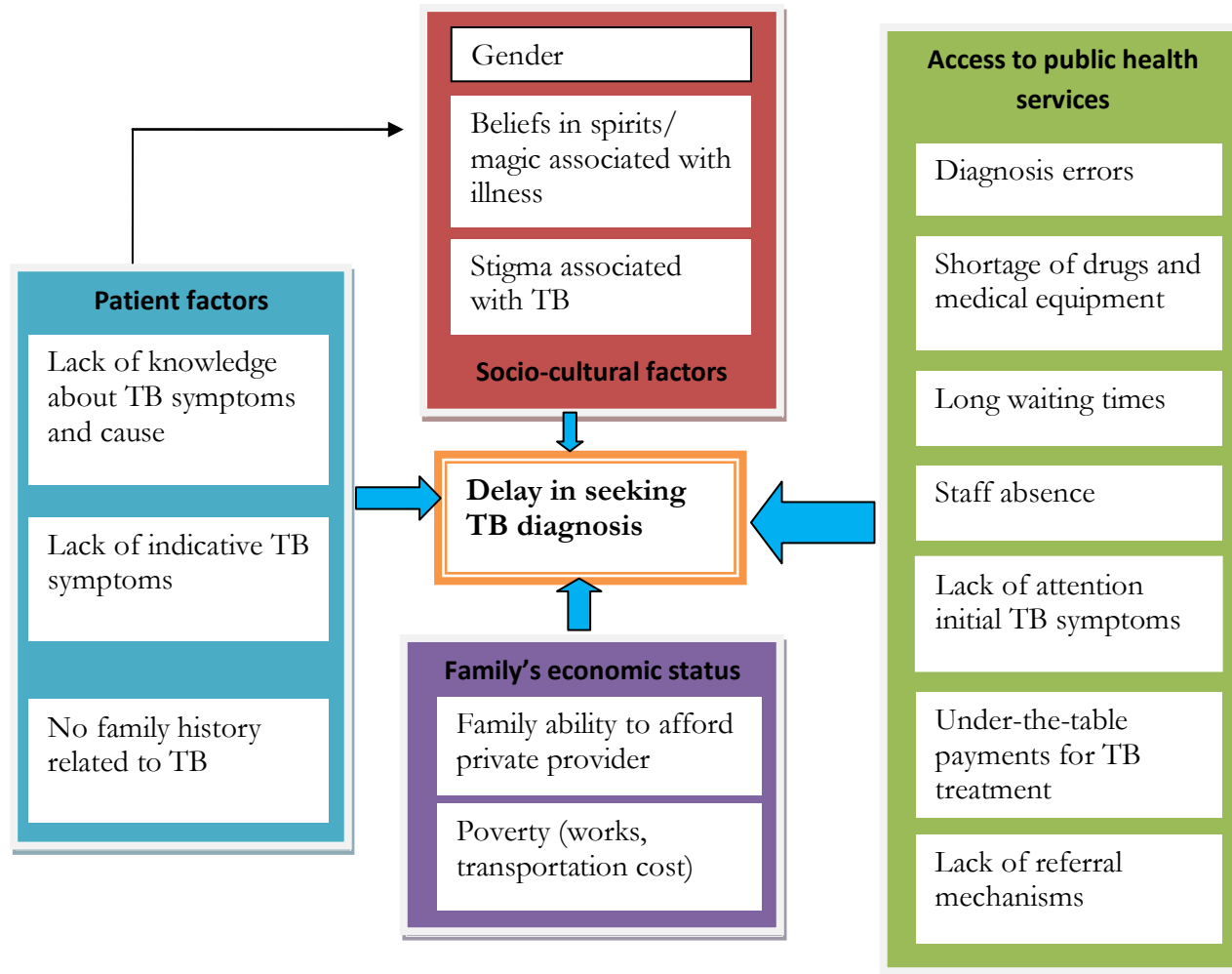


Figure 21: Factors associated with delay

Reasons for delay

Delays to TB treatment resulted from the complex health-seeking behaviour of TB patients, ineffectiveness of health providers, and problems related to the general health system (Gaglotti, et al., 2006; Storla, et al., 2008). The pathways undertaken by patients in this study were shaped by several factors (see Figure 21), including patient factors, socio-cultural and economic factors and, most importantly, barriers related to access to the public health system. Each is discussed below.

Patient factors

As shown in previous studies, patients' knowledge regarding TB influenced the time elapsed from symptom onset to TB diagnosis (Kiwuwa, et al., 2005; Mesfin, et al., 2009). In particular, a lack of understanding about TB, especially the early indicative symptoms, had significant impacts on delay. Participants often attributed early symptoms to common illnesses such as cold, typhoid, and/or stomach diseases, and sought diagnosis accordingly. The persistence and severity of symptoms led to self-suspicion of TB, and thus forced them to present to a DOTS program. For example, patients who presented with a persistent cough that later progressed to a cough more indicative of TB, with difficulties breathing or bleeding, were more likely to present to a DOTS program for TB diagnosis. For some, this progression was slow: lack of recognition of the possibility of TB meant that patients treated symptoms with multiple antibiotics. This led them *not* to suspect TB, as the cough was often intermittent. Others with symptoms such as back or chest pain, fever and/or weight loss often experienced longer delays because they assumed that their symptoms were related to other health problems such as typhoid, respiratory infections, and stomach disease. For instance, Pisey was sick for a prolonged period but she lacked knowledge of TB and its indicative symptoms, and also perceived that she had no chance of having TB. Pisey spent a significant amount of time and resources searching for a

diagnosis, and her presentation to a DOTS program only happened when her health condition had deteriorated and was not improved by other therapeutic programs.

Other studies have also shown that patient's perceptions of the severity of early symptoms were associated with delay to diagnosis (Auer, et al., 2000; Yimer, et al., 2009). An Ethiopian study of 1,006 TB-suspected cases, where individuals had one or more of cough longer than two weeks, chest pain, and difficulty breathing, showed that individual patients with prolonged cough were more likely to visit a medical health provider than those presenting with a shorter duration of cough (Yimer, et al., 2009). Research among 222 newly diagnosed TB-patients in China also showed that bleeding cough reduced delay to diagnosis (Wang, et al., 2007b).

Socio-cultural factors

Two main socio-cultural factors have been reported as associated with delays in seeking a TB diagnosis: stigma and traditional beliefs associated with illness (Pronyk, et al., 2001; Storla, et al., 2008). In this study, both of these factors contributed to delays in seeking diagnosis.

Stigma associated with TB

Early research showed that fear of rejection from family and community members was a reason for long delays to TB diagnosis for many patients (Kelly, 1999; Long, et al., 1999a, 2001; Kiwuwa, et al., 2005; Pungrassami, et al., 2010). My findings indicated that patients denied that their symptoms were due to TB and instead often referred to non-stigmatized health conditions, such as seasonal cough, common cold, stomach diseases or typhoid, because of fear of the disease and the associated risk of social rejection. For example, Phally (28) refused to seek a TB diagnosis, despite her mother's suggestion, because she feared that having TB would make her different from her peers:

My mum said that I may have TB, but I didn't want to think about it. I felt ashamed to have TB. I'm still young, and none of my friends have the disease. That's why I don't want anyone to know about this. At first, I tried several other therapies but because my health did not improve, I decided to seek TB diagnosis. At the beginning of the treatment, I was very disappointed about myself and I felt down. I wanted to die. I felt that my life has always had bad luck: my first husband died, then my only child died, and I was very sick with TB. I encouraged myself so much to go through the treatment and I had support from my family and my (current) husband. Now I don't feel so ashamed. Since I started the treatment, my health has improved; I've put on some weight and look normal. *Peet* said that I can be cured from the disease because I am still young.

Fear of TB also led to distress among patients when they were diagnosed. However, the availability of treatment and support of family were important factors in enabling patients to overcome their distress and undertake TB treatment. Health workers and community DOTS observers acknowledged that the stigma associated with TB was not obvious, but it could create challenges for them when encouraging patients with early TB symptoms to present at DOTS for diagnosis (discussed further in chapter 7).

Beliefs in traditional and spiritual healer

Beliefs in traditional and spiritual healers were particularly significant in rural and remote areas of Cambodia and potentially contributed to delaying access to TB diagnosis. As discussed earlier in this chapter, although patients did not choose traditional or spiritual healers as their first choice of health care, their beliefs in traditional healers contributed to a delay in diagnosis and subsequent deterioration in their health. At the same time, using traditional healers also contributed to the economic burden to the patient. In this study, the particular beliefs associated with traditional medicines and spiritual healers varied by geographic locations: the remote mountainous population seemed to hold stronger beliefs related to magic spells or witchcraft as being associated with illness. This may be at least partly related to the barriers in accessing to health centres due to distance, lack of

transportation, and cost; as a result, this population generally received scarce information related to health and health care services. In contrast, participants in the lowland areas believed in the association of spirits (mainly ancestors and place) with illness, and they were more likely to use traditional healers or traditional medicines as complementary treatment with their western medicine therapy.

Traditional beliefs associated with illness are not unique to Cambodia. Studies in Mexico, Indonesia, Pakistan, Vietnam, Ethiopia, Bolivia, South Africa and Laos show that people hold varied beliefs associated with the cause of TB and sought health care from traditional healers prior to their presentation to a DOTS program. Although local ethno-medical beliefs did not create conflicts with TB control activities in Cambodia and elsewhere, such beliefs contribute to longer delays due to the time spent treating the illness through traditional means (Liefoghe, et al., 1995; Long, et al., 1999b; Caprara, et al., 2000; Greene, 2004; Cambanis, et al., 2005; Xeuatvongsa, 2005; Barker, et al., 2006; Ouedraogo, et al., 2006). Brouwer et al. (1998) found that 37% of 89 TB patients in Malawi consulted a traditional healer prior to presentation to a medical care professional, spending an average of four weeks; most reported that their health either had not improved or had worsened during that time. Barker et al (2006) found that TB patients in rural South Africa who had used traditional healers experienced a longer delay to DOTS than those who had not. Similar findings were reported by Mesfin et al. (2009) in Ethiopia.

Socio economic status of patient

While all patients delayed presentation to DOTS, social-economic status shaped patients' health-seeking behaviour: wealthier patients delayed because they were able to afford treatment from private providers or traditional healers and could therefore manage their TB symptoms for a period of time outside DOTS. Poorer patients delayed because of their inability to take time off work, as they relied on their income for day-to-day living; at the

same time, these patients lacked the resources to meet overall health care costs: under the-table payments, transport costs, and for medicines. This study showed that extremely poor patients had shorter delays than the better off patients due to their limited health care options. These findings support research from Sarawak (Malaysia) which found that the income status of 316 new smear-positive TB patients was associated with the delay for the first medical consultation to TB diagnosis because wealthier patients used several private doctors initially before seeking diagnosis and treatment from a government clinic, which occurred only when their symptoms became severe (Chang & Esterman, 2007).

Provider's factors

Although most patients had presented with TB symptoms to unqualified or qualified health providers, the majority were not immediately suspected as having or diagnosed with TB. There are several possible explanations: 1) health providers lacked knowledge about TB and its symptoms, or were not concerned about investigating TB; 2) related to this, health providers often managed the presenting illness according to the lay explanatory model(s) of symptoms explained by their patients and usually used a variety of antibiotics in their treatment. These symptomatic treatments often masked or concealed the progression of TB by giving patients short-term relief from their symptoms. Patient and provider thus understood the symptoms as being cured and any subsequent presentation of symptoms was seen as a new illness, not a recurrence. Health staff acknowledged that health providers' lack of TB knowledge could be caused by a lack of formal and on-going training about TB:

We do not provide TB training to all health providers. Generally speaking, professional health providers may have some knowledge and experience related to TB gained from their official training curriculum but the knowledge may not be enough or may not be updated according to the standard of diagnosis and treatment of the NTP. We need training and support to private providers and pharmacy, so

that they can identify TB patients and refer them for diagnosis and treatment at a public health centre or hospital (Health centre manager).

Medical providers should all have received some training regarding TB when obtaining their formal medical qualifications. However, mid-level health staff (such as nurses and midwives) had limited training on TB; therefore they were not able to effectively suspect TB in patients. Interviews with DOTS providers showed that diagnoses of TB were only recommended for patients with symptoms of a prolonged cough:

Diagnosis of TB at present is based on a sputum test. We request a sputum test for patients who present at the health centre with cough for more than three weeks accompanied by night sweats, fever, chest pain, or difficulty breathing, loss of appetite and weight loss. Some patients come to the health centre and request the test. They understand about TB and suspect they have TB themselves. But there are also some patients who don't want to do the test (Navuth).

This excerpt highlights the challenges related to TB diagnosis at public health services. Health workers may successfully diagnose TB in a patient if he/she presents with typical TB symptoms; however, patients with atypical TB symptoms may not be suspected, and therefore may have a longer delay to diagnosis. For example, Navy consulted several private health providers (one who also worked at the provincial hospital), but none suspected TB because she presented with back pain, mild cough and fever. Instead, Navy was diagnosed with typhoid and stomach problems, and was treated accordingly. Similar errors in diagnosis occurred for other patients in this study.

Difficulties related to the continuity of patient care also contributed to provider-related delays. Patients often changed providers when their symptoms did not improve, and so health providers could not follow-up patients. The change of providers resulted from a lack of confidence in the quality of care delivered by a provider, and in unproductive patients-provider communication. For example, Sophal presented to the DOTS program for

diagnosis, but was not diagnosed with TB. He received no support from health providers to undergo TB testing, and was not encouraged to return to the health centre for follow-up:

A week after I submitted sputum I went to check for my result. *Peet* said that I'm alright, no TB, that's it. He did not say anything else and I did not ask him anything. I never came back to the health centre again (*Sopha*).

Although Cambodia is a high-burden country in relation to TB, health providers did not pay sufficient attention to investigating TB when consulting with patients, particularly those with symptoms less indicative of TB. Similar findings have been reported elsewhere, where the lack of knowledge of TB among health providers led to their failing to investigate TB promptly, particularly among patients presenting with atypical symptoms (*Chang & Esterman, 2007; Metcalf, et al., 2007; Rintiswati, et al., 2009*). In Myanmar, general practitioners and basic health staff had inadequate knowledge on and so misdiagnosed TB (*Saw Saw, 2006*).

Fragmentation of TB diagnostic facilities

Health centres did not have laboratory facilities for blood or sputum testing, and health staff had to take sputum samples to the referral hospital (RH) or a TB unit (health centre with a TB laboratory) for this purpose. Therefore, patients had to wait for a period of time (at least one week) to obtain a result from the laboratory. During these waiting periods, patients with less disruptive symptoms were not provided with any medication, while those with more obvious illness were treated symptomatically, mainly with antipyretic and antipertussives:

It took one month for me to hear the test result. I gave my sputum to a health volunteer; she took it to the health centre. One month later, I got the result and started treatment. While I waited for the result, I asked the pharmacy to give me a mix of medicines, the health centre did not give me any medicines (*Chanthay*).

I submitted sputum to the health centre. *Peet* told me to collect the result the following week. I came, but I did not get the results because *peet* hadn't got them yet from the lab. My health became worse, so *peet* gave me medicines for the cough, and I also bought medicines from the pharmacy. A week later, I got the results and I started treatment promptly (Bona).

The fragmentation of TB diagnostic services meant patients could experience delays from one week to one month. Health staff expressed concerns about the implications of the shortage of laboratory facilities: the long waiting times to obtain a sputum test result contributed to patients seeking treatment from private providers and not returning to collect their results:

Patients were not happy when they could not get a result quickly because they were in need of treatment immediately. But we were unable to provide them with any until we received the sputum test result. If patients were very sick, I sent them to the hospital, and if a patient wanted to get a quick result, I told them to go to the laboratory directly. In this case, patients have to pay for their own transport, but the test is free if they have a referral letter from the health centre (Phanna).

It takes 20 days to one month to get a sputum test result for TB patients. Some patients complain about the long time it takes to get the test result but we can't do better than this; the lab is also busy. We need patients to submit three sputum samples but some patients submit only one, and do not return to submit the second and third samples. Some patients do not produce a good sputum sample because they don't understand how to do it. I need to ask for a second sample, but they don't return for this (Rotha).

Delays in obtaining diagnosis caused frustration for some patients, leading them to offer providers informal payments to get early test results:

My dad brought me to a health centre to seek TB diagnosis. *Peet* told us that it would take around one to two weeks to get the result. He said if I wanted to have a diagnosis quickly, I'd have to go directly to the TB ward at the hospital. My parents took me to the hospital and requested TB diagnostic test. *Peet* sent me to have an x-

ray and I got the results the same day, showing that I had a problem in my lungs. *Peet* asked that I submit sputum that day and gave me another container for another sample the following day. To get this quick result, my mum paid 13,000 *Riels* (US\$4) for the x-ray, and 6,000 *Riels* (US\$1.7) to the lab, for the sputum test. I got the result on the same day as I provided my second sample (Navy).

Consequently, the fragmentation of diagnosis was a particularly significant contributor to delays among those people who could not travel directly to the laboratory, or who were not able to afford informal payments and thus could not negotiate for a quick result. Diagnostic test results were considerably quicker among participants who sought a TB diagnosis at the hospital (9/29), although this may have also been because they presented with very severe symptoms.

Diagnostic error

This study showed that diagnostic errors also contributed to delays, by leading patients on a quest or ordeal pathway for a correct diagnosis. Sophal was one participant who described a quest pathway due to incorrect diagnosis, and he continued treating his illness outside DOTS until he became very sick:

I coughed with sputum for months; I went to a health centre to submit sputum. But you know, I think *peet* at the health centre was not paying attention to his work. When I brought my sputum, he asked me to put it on a shelf and he did not check it. The next day, I came for the result and he said that I didn't have TB. I was happy to hear the result and did not suspect an error. I did not think about TB again until I was very sick with cough, difficulty breathing and fever. Finally, I submitted my sputum to the laboratory at the hospital, where my name and a number was put on the sample and it was stored safely. This led me to believe that *peet* at the health centre did not do my test correctly. Because of this error, I continued to seek treatment from private providers, which delayed my diagnosis until I was very sick (Sophal).

Errors in the diagnosis test themselves, and false negative results, also led patients to seek treatment outside DOTS. The report of the NTP showed that the quality of laboratory testing remained a concern, with over 15% of negative smear samples later found to be falsely negative. The quality of a sputum test was influenced by the performance of the health worker in preparing the smear, the quality of equipment such as microscope and laboratory supplies (containers, boxes to store sputum samples) and, more importantly, health providers' motivation. Low motivation of health staff caused by low government salaries, and lack of health equipment and supportive supervision, was the root cause contributing to low performance of health staff in TB screening activities. The high number of false negatives was thus an important modifiable factor contributing to diagnostic delay.

Under-the-table payments

Although DOTS is provided free of charge by the Cambodian Ministry of Health, under-the-table payments were still expected by government health staff in order to supplement their low salary. For example, Kanika and Sovann delayed treatment and instead spent time searching for free treatment from other government or NGO health facilities, because they were unable to pay under-the-table payments.

Following a chest x-ray at a health centre, it was suspected that Kanika had TB. She was asked to submit sputum for further testing, but could not produce sputum. In consequence, the health provider refused to provide TB medicines because she did not meet the diagnostic requirement unless she paid 120,000 *Riels* (US\$30) for them. As Kanika could not afford this, she went to another health centre for TB diagnosis and treatment. Because she again did not have sputum, the health centre recommended that she obtain a letter from the hospital confirming her diagnosis so that she could be given TB medication. When Kanika went to the hospital, she was diagnosed with TB but was not given a

confirmation letter and instead was recommended for hospitalization. She resisted hospitalization because she was the caregiver for her elderly mother and was unable to find someone to help her with other household chores. She eventually had TB treatment at a private clinic, as her illness progressed to be more critical, after she borrowed money from a local moneylender to pay for the treatment.

Kanika's story demonstrates how financial and other social factors contributed to delay. Although she ultimately sought treatment through the least preferable option, she was unable to be treated in the public system because of her family and household responsibilities. Similarly, social/economic responsibilities played an important role in delaying Sovann's access to TB treatment. Sovann, a factory worker, had a chest x-ray in a hospital in Phnom Penh which showed that he had TB, but he was not given medication at that time because the hospital did not have a TB unit. Instead, without being given a formal referral, he was told to get TB medicine from a health centre. He went to health centre near his workplace for treatment, but was request to pay under-table for the medicines. Thus he decided to delay the treatment. Subsequently, Sovann became very sick and could not work. As a result, he had to move to his hometown in Kampong Speu, where he sought treatment at a nearby health centre. There, he was asked to submit sputum. He was then diagnosed with TB and received treatment free of charge.

In both of these cases, patients delayed treatment because of failings in public health referral systems. They were either not referred or were referred inappropriately and without adequate follow-up or support. Inability to meet the under-the-table payments required for speedy TB diagnosis and treatment also meant that patients moved from one provider to another, delaying their treatment until they were very sick. In addition, the inconvenience derived from the institutionally rigid structure of the public health system caused Kanika's

delay in accessing TB treatment and pushed her to use a private provider, at considerable personal debt.

Patients' routes to DOTS were intricate and prolonged, even though DOTS was generally located within their reach. Patients typically began their health-seeking journey with home remedies, over-the-counter medications, or unqualified private providers (pharmacy or *peet phum*) because of convenience in relation to proximity to their home, reasonable costs, and patient familiarity with the providers. Participants moved from one provider to another according to how serious they perceived their illness to be, and their expectations about the quality of care and costs of the health service. This finding is consistent with other studies related to health-seeking behaviour in Cambodia (CDHS, 2000; Yanagisawa, et al., 2004; CDHS, 2005; NTP, 2005a; Saly, et al., 2006; Khun & Manderson, 2007), and to studies in other countries such as Indonesia, Nepal, Malaysia, Myanmar, Laos, and Ethiopia, where patients usually sought health care from a pharmacy shop, a private provider (nurse, midwives, doctors) or traditional healer prior to presentation to DOTS (Yamasaki-Nakagawa, et al., 2001; Watkins, et al., 2004; Xeuatvongsa, 2005; Chang & Esterman, 2007; ten Asbroek, et al., 2008; Mesfin, et al., 2009; Saw, et al., 2009; Yimer, et al., 2009). However, unlike elsewhere (Watkins, et al., 2004; Xeuatvongsa, 2005), these Cambodian participants did not choose traditional healers as their first provider. Instead, they generally used the folk sector after their therapeutic program(s) with western medicine had failed to significantly improve their health condition, leading them to consider that magic, spell or spirits might cause their health problems. More women than men (6/12 cf. 1/17) used traditional healers, possibly because of their accessibility and due to stronger beliefs in supernatural powers as a cause of illness.

Patterns of health-seeking behaviour showed that patients' pathways were delayed mainly due to their misinterpretation of early TB symptoms and/or misdiagnosis of TB by health

providers. Three circumstances influenced TB diagnosis: social disruption caused by the symptoms, the influence of significant others, and self-suspicion of TB. Social disruption from severe symptoms was the most influential factor leading to diagnosis.

TB patients in this study reported considerable delays between the onset of symptoms and the start of treatment, and patients used two to six steps to reach diagnosis. Women appeared to delay longer than men. Research elsewhere showed that their longer delays were associated with difficulties in travelling to public health clinics, as women depended on their husband or a male relative to accompany them (Long, et al., 1999b; Ahsan, et al., 2004; Cheng, et al., 2005; Chang & Esterman, 2007; Huong, et al., 2007; Karim, et al., 2007; Karim, et al., 2008). Women's delays also derived from their decision not to use family resources for their own health care (WHO/TDR, 2006; Weiss, et al., 2008). In contrast, this study shows that women delayed longer because they used more providers, particularly unqualified providers or private providers, prior to presentation to DOTS; this tended to slow down the progression of TB symptoms.

Delays associated with diagnostic pathways were therefore influenced by patient and health system factors. Patients' perceptions of the severity of symptoms and their interpretation of cause were associated with the delay. Stigma associated with TB was also an important factor, as were the use of traditional healers and the socio-economic status of patients. Institutional (health system) factors impacted immensely on patients' routes to TB diagnosis at the same time. Health providers' lack of knowledge of TB, particularly among unqualified or private providers outside DOTS programs, and low staff motivation contributed to failure to diagnose or follow-up suspected TB patients. This was relevant to findings elsewhere showing that delay to TB diagnosis was more significantly caused by provider failure to identify TB (Meintjes, et al., 2008; Skordis-Worrall, et al., 2010) than any other factor.

As discussed in chapter 4, the challenges faced by public health care facilities contributed to ineffective health care delivery in the public sector and led to delays in presentation for diagnosis, as indicated. Other research has illustrated that poor access to public health services and pluralistic use of private providers increases the delay to diagnosis (Lawn, et al., 1998; Yamasaki-Nakagawa, et al., 2001; Odusanya & Babafemi, 2004; Rojpibulstit, et al., 2006; Saw Saw, 2006; Yan, et al., 2007; Yang, et al., 2008; Chard, 2009; Mesfin, et al., 2009).

Other barriers related to the institutional factors in Cambodia were the shortage of TB diagnostic facilities, low staff motivation, and under-the-table payments. TB patients in rural areas faced significant delays due to multiple factors, which interacted to substantially exacerbate delays, and led to deteriorations in patients' health status, higher costs of health care, and continued transmission of infection in the community. Strategies to smoothen the routes and shorten periods of delay to DOTS should be addressed through community health education around the interpretation of early TB symptoms, improving early referral of TB patients by private providers and informal sector to the DOTS programs, and improving medical knowledge of TB to all health providers. In the next chapter, I discuss how TB patients were treated under DOTS and factors associated with treatment adherence and non-adherence.

CHAPTER 6

COPING WITH TB TREATMENT

As explored in Chapter 5, patients travelled long pathways to find appropriate diagnosis and treatment for their symptoms. Their routes to DOTS were shaped by multiple factors: knowledge and experience of TB, perceptions of individual susceptibility of TB, family history, economic factors (socio-economic status); social and cultural factors (stigma associated with TB); and institutional factors (access to health care). For most patients, being diagnosed with TB brought hope and relief that treatment was available. But for some, diagnosis led to considerable upheaval in their families' lives, particularly when the resources needed for treatment were not available, and diagnosis was accompanied by fears about failure of treatment and death. Treatment under DOTS, patient attitudes towards treatment, and factors influencing treatment adherence and non-adherence are the focus of this chapter.

TB diagnosis and treatment in Cambodia: policy and protocol

The implementation of DOTS in Cambodia followed the specialized managerial and integration approach supported by the WHO (Raviglione & Pio, 2002), TB control at the national level was directed by a specialized TB centre: the National TB Control Program (NTP) of the National Centre for Tuberculosis and Leprosy Control (CENAT), in the Ministry of Health, Cambodia. The NTP oversaw DOTS implementation through providing guidance for implementation and technical support (training and provision of diagnostic facilities), monitoring the implementation of DOTS, maintaining a reporting system of patients treated under DOTS, and mobilizing funding and support to DOTS. It also had a specialized TB hospital, a national TB laboratory, and TB para-clinic facilities (x-

ray unit). As described in Chapters 4 and 5, TB diagnosis and treatment was implemented throughout the general health system at every referral hospital and health centre in Cambodia. At the provincial level, TB control was under the management of each Provincial Health Department (PHD). Each provincial TB unit was responsible for developing a provincial action plan for TB control, in line with the policies and priorities of the NTP and managing TB control in the province. This meant that every provincial TB unit in every province worked towards the same priority and followed the same strategies set by the NTP. Their duties included training and supervision of DOTS implementers at hospitals and health centres throughout the province. However, the implementation of these activities varied according to the inputs and supervisory visits from the NTP. At the operational health district (OD) level, TB activities were integrated with communicable disease control. The OD's TB supervisors had similar roles to their provincial counterpart, overseeing the implementation of TB at the referral hospital and health centres in his or her coverage area. The NTP drew on the WHO guidelines for diagnosis and treatment of TB in Cambodia to inform their policies (WHO, 2008b). These guidelines suggested that individuals suffering with cough for 3 or more weeks and who sought health care at a public hospital or health centre (Figure 22) were potentially suffering from TB.

As indicated in earlier chapters, suspected patients were required to submit three samples of sputum⁹ spot sputum (produced by patient at the health facility), early morning sputum, and second spot sputum. A patient who submitted sputum smear positive (two positive samples) was registered as a pulmonary TB case with BK+ (Bacilli de Koch, positive). Patients with only one positive sample were required to undergo a subsequent sputum

⁹ The WHO handbook for national TB control program 2008 suggested two sputum samples; one must be the early morning sputum. However, Cambodia still required three sputum samples during my fieldwork.

smear examination. Those who had a negative (BK negative) sputum test were treated like others with other respiratory infections, using antibiotics. If there was no improvement under the treatment, the suspected patient was required to undergo another sputum test or chest x-ray.

Chest x-rays were important when investigating TB, especially when suspicious TB symptoms existed but the sputum test was negative. They were also recommended for people who may have TB but were unable to produce sputum. X-rays helped to confirm the possibility of pulmonary TB disease in these people, and in those who have a positive reaction to the tuberculin skin test (Campbell & Oumou, 2006; Richeldi, 2006). The NTP relied on the diagnostic diagram (Figure 22) when making a diagnosis of pulmonary TB. Three factors influenced diagnosis: quality of sputum smear examination and/or radiology, patient's medical history, and the decision of a physician. Therefore, the lack of clear medical information provided by patients (e.g. length and characteristic of cough, presentation of other related TB symptoms) may have contributed to health providers' negligence in investigating TB; similarly, the lack of a quality sputum test or radiology may have led to TB diagnosis errors.

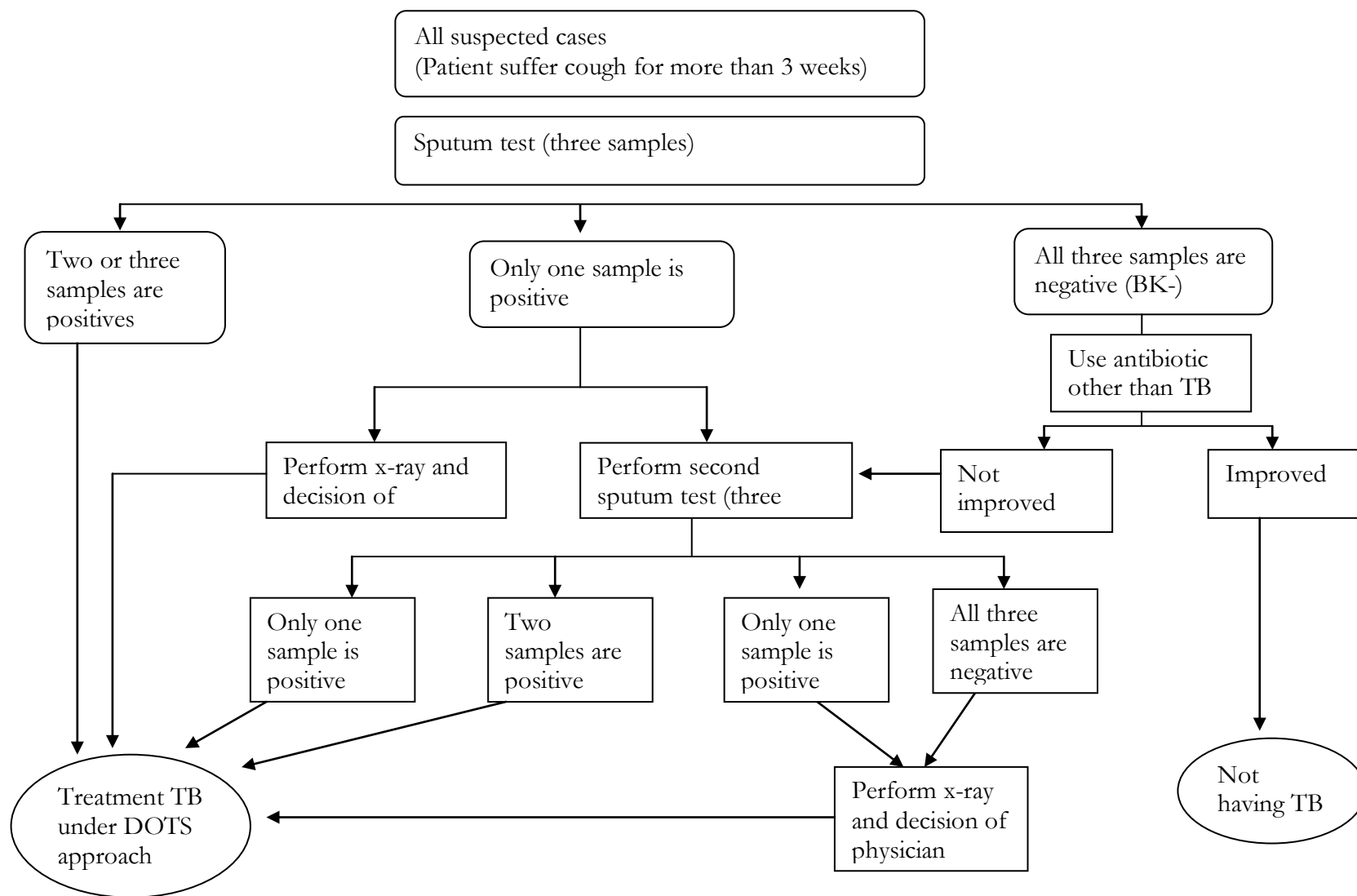


Figure 22: Diagram of Pulmonary Tuberculosis (PTB) Diagnosis 2005

Source: Training document on diagnosis and treatment of TB at health centre NTB 2005

Following the diagnostic test, patients were registered with the central register of pulmonary TB in one of five different categories: a) a *new case*—TB patient who had never had TB treatment or who had received treatment for less than one month; b) a *relapse case*—a patient who was previously declared cure or had completed TB treatment, but was later diagnosed with a new episode of bacteriological-positive TB; c) a *failed case*—a smear-positive patient who needed to be re-treated because he/she remained smear positive at the fifth month or later; d) a *returned after defaulted case*—a patient who had been treated for TB for at least one month, who remained biologically positive after interrupting their treatment (defaulting) for at least two consecutive months; and e) an *other case*—someone who did not meet any of the above four criteria (NTP, 2005b). However, as I will discuss throughout this chapter, the registration was not always correct, and some defaulted or returned or failed cases were registered as new cases. The misclassification of patients could affect their treatment outcome (discussed later).

TB medication was given to patients according to these categories (e.g. new case, relapse case). Five essential TB medicines were used in chemotherapy in Cambodia (Table 32), and TB treatment for adults in Cambodia was divided into three categories.

Table 32: First line drugs and dosage (s) for treatment of TB in adults

	Drugs	Daily dose (mg/kg)	Maximum dose
1	Isoniazid (H)	5	300mg
2	Rifampicine (R)	10	300mg
3	Pyrazinamid (Z)	15-30	2g
4	Ethambutol (E)	15-25	
5	Streptomycin (S)	15	1g

Table 33: The DOTS treatment categories in Cambodia

Category	Applied to	Intensive phase	Continuation phase
Category I 2RHZE/4RH	New case of pulmonary TB with BK+ or BK-, extra pulmonary TB, and TB/HIV.	RH (150/75) ¹⁰ /ZE For two month, take daily.	RH 150/75 for four months, taking daily.
Category II 2SRHZE/1RHZE/ 5RHE	Relapsed patient with BK+, failure case, or patients who return to program after defaulting.	RH (FDC) Z,E and S For three months (S only for two months) Take daily.	RH (FDC), and E For 5 months Take daily.
Category III 2RHZ/4RH	For TB BK- and extra pulmonary TB in less severe form.	RH (2FDC), and Z For two month, take daily.	RH (2FDC) For 4 months Take daily.

Category I was for new cases of pulmonary TB with BK+ or BK-; forms of extra-pulmonary TB such as meningitis, millary TB (TB characterized by a wide dissemination into the human body by tiny lesions, which may infect any organ in the body, mainly lungs, liver, spleen), and TB in the context of and HIV infection. The category required two months of intensive phase treatment during which time patients' treatment was directly observed by a health worker or other nominated person. Anti-tuberculosis drugs administered in this phase were Rifampicin and Isoniazide fixed doses combined (FDC), Pyrazinamid, and Etambutol. The second phase of treatment required four months of FDC drugs RH.

Category II was designed for people who had relapsed, failed, or returned to treatment after defaulting. This category required 3-4 months intensive phase and 5 months of continuation treatment. Anti-tuberculosis drugs used for the intensive phase here were the same as in category I, plus Streptomycin injections (one dose every day) for the first two months of treatment. At the end of the third month of treatment, if sputum control was negative, the patient moved to the continuation phase; however, if sputum remained

¹⁰ Fixed doses combined of 150mg Rifampicin and 75mg Isoniazide

positive, the patient had to continue RHZE for one more month, before moving to the continuation phase. The continuation phase used RH (FDC) and E.

Category III was for less severe TB cases, including TB BK- and extra-pulmonary TB. It required six months treatment. The intensive phase used RH and Z for two months, and RH for the four months of the continuation phase. During treatment, TB patients were requested to submit sputum for testing at the end of the second or third month of treatment, then at the fifth, sixth, seventh and eighth month (NTP, 2005b). The sputum test at the second or third month was intended to obtain biological test results before moving to the continuation phase of TB treatment. The sputum test at the fifth or seventh month of treatment checked the effectiveness of treatment: if the patient was positive at this stage, he or she was considered a 'failure' and a new treatment ought to have been given to the patient. Sputum tests at the sixth or the eighth month were used to confirm that the patient was cured from TB; if the test was positive the patient will be re-treated. However, sputum tests during TB treatment were not done regularly with all TB patients. Many patients moved from the intensive phase to continuation phase without a sputum test, and most completed treatment without a sputum test to confirm cure.

Enrolment of TB patients into DOTS

Once TB diagnosis was confirmed, it is expected that patients would begin on the DOTS program promptly. There were three types of DOTS implemented at public health facilities: *hospital DOTS* required patients to be hospitalized during the intensive phase of the treatment; *ambulatory DOTS* required TB patients to come to a hospital or health centre every morning to take TB medicines in front of a health worker during the intensive phase of the treatment; and *home DOTS* required patients to take medicine at home under the supervision of a health worker or nominated and trained community member, during both intensive and continuation phases of treatment. Home DOTS was divided into two

categories: Home DOTS by health workers, who travelled to their patients' houses to observe them taking their TB medicines; and Community DOTS (C-DOTS), where treatment was supervised by a trained nominated community worker. Categories of DOTS differed according to the location where the TB patients took their drugs and who directly observed the therapy (DOT). Each category of DOTS is described in detail below:

Hospital DOTS

Severely ill TB patients often enrolled in hospital DOTS. The TB ward of the Kampong Speu provincial hospital was the biggest TB ward in the province. It was located at the back of the hospital, isolated from other wards. It looked older than the other wards and consisted of a laboratory unit, one staff room, and four patient rooms with 9-10 beds each. Hospitalized patients here were from every part of the province, not only from rural and remote areas. In-patient characteristics varied but most were elderly, suffered from severe health conditions such as haemoptysis, difficulties in breathing and were skeletally thin. Patients were required to be hospitalized at least for the intensive phase of the treatment; after this time, depending on their health condition, they discharged but were requested to come in each day to take tablets in front of health staff. Some patients were transferred to a health centre close to their home during the continuation phase. An average of 10-15 in-patients were hospitalized at the provincial TB ward each month throughout the year, and so the TB ward was not especially busy.

Patients who sought care from the TB ward were either self-referred or had been admitted after they presented with indicative symptoms, such as bleeding cough or shortness of breath, accompanied by other symptoms. Some patients chose to seek diagnosis and treatment from the hospital ward because they expected quicker and better service quality during diagnosis; they recognised that the hospital had higher qualified health staff and better equipment for diagnosis (e.g. laboratory and x-ray facilities) and better or more TB

medicines than the local health centre. The hospital TB ward also received referred cases from all over the province. It was also able to diagnosis pulmonary TB (BK+ and BK-), extra-pulmonary TB, and other severe forms of TB that were not available at health centres. The hospital TB laboratory performed sputum tests for hospital patients and 17 other health centres (covering a population of more than 100,000). In consequence, the laboratory was overloaded with sputum samples, and there were often delays in giving test results to the patients. The x-ray unit also faced limitations, such as lack of equipment and lack of qualified staff to perform and analyse x-rays.

In-patients often had a family member (caregiver) accompanying them at the hospital. Caregivers and patients usually stayed together in the TB ward without appropriate prevention practices. Those in better health tended to stay by themselves at the hospital where their family members sometimes visited; they could also request short periods of leave from the ward to visit their families. The hospital provided food to all patients, which was subsidised by the government with a budget of around 1,000 riels (US\$0.25) per patient per day. This amount did not cover the actual food costs at the market, so food provided to patients was always of poor quality, and patients routinely complained that it was inedible. Patients often brought food from home (rice and other foods) to cook at the hospital, or bought food from the market, which contributed to the additional costs associated with TB treatment. Medicines were provided free of charge.

Of the 32 participants in this study, ten were treated with hospital DOTS because of the severity of their condition. Nine were treated as category I, one (relapse case) was treated under category II. They were all hospitalized because they required intensive care from health providers (e.g. serum perfusion, injections of streptomycin, oxygen, or other additional treatment). Hospitalization also ensured that they swallowed their TB drugs under direct supervision from a health worker, as Nareth explained:

Every morning the staff member who is on roster brings the TB medicines to patients and watches each of them take the medicines. We need to do it early in the morning so that patients can have their breakfast afterward.

However, it emerged through observation and interviews with in-patients that health providers did not always observe patients taking their TB medicines. Patients were often provided with enough medicines to last for several days or a week (especially during public holidays) and they were advised to take their medicines by themselves, as Sophal explained:

Sometimes *peet* gives medicines in the evening. Sometime they give medicines for 2-3 days, or if sometimes I ask to go home for 2-3 days, they give me the medicines. Every morning at 5:30 or 6am, I take the medicine. One hour later, I have my breakfast; other patients also take medicine around this time. *Peet* do not watch us taking medicine every time.

In reality, health workers did not observe all patients taking their TB medication; they attended to TB patients in a severe condition, and let patients with less severe symptoms take the medicines by themselves.

Ambulatory DOTS

Ambulatory DOTS was available at all health centres throughout the province. To implement DOTS, each health centre assigned one staff member (often the head or deputy-head of the health centre) to be in charge of DOTS and one assistant in charge of the drug store. These staff members were responsible for: (1) TB case detection, (2) collecting sputum from suspected cases and sending such samples to the TB laboratory, (3) providing advice to suspected cases on sputum collection, (4) providing health education regarding TB prevention, (5) providing treatment to TB patients and following them up, (6) requesting supplies for the health centre from the provincial TB unit, (7) recording and reporting TB cases, including producing regular monthly reports on TB cases to the NTP,

(8) maintaining infection control, and (9) participating in training sessions and workshops held by the provincial health department and the NTP.

The extension of TB control into health centres significantly contributed to increased TB case detection. However, these control programs had not yet reached their full potential. As discussed earlier, health centres did not have diagnostic facilities, and so health workers had to collect sputum samples from patients and send them to the TB unit for diagnosis and collect the results within varying timeframes. This contributed to delayed diagnosis and inconsistent sputum testing procedures (discussed later). In addition, follow-up systems to trace patients who missed collecting their TB drugs from the health centre were not effective, especially for patients who lived in rural and remote areas; this was mainly due to lack of financial support for these activities. Health centre TB activities received a budget of US\$32-US\$40 per month to send sputum to laboratories for diagnosis, to travel to villages to follow up patients, and to provide health education to the community. This budget was too low to meet all transportation costs, particularly for health centres in dispersed locations. Consequently, health workers did not regularly follow-up patients (as described by participants), although they reported otherwise:

We allow patients to take medicines for one or two weeks at home, but we follow them up. We also remind family members to support patients to take medicines regularly. If patients do not come to collect medicine on time, we warn them that we will request them to take medicine from the health centre every morning. We use multiple ways to push patients to comply with treatment, such as supporting them, advising them, or sometimes scolding them if they missed medicines. But it is difficult to follow up patients who live in the remote areas because we do not have enough support for transport (Kosal).

Each month a health centre receives US\$32 from the NTP. This amount is divided into 8 trips, so it is US\$4 per trip (for transportation) to trace patients, to bring sputum to the TB unit. The actual fuel cost has increased, so we cannot go to very

remote villages to trace patients who do not turn up to collect medicines, or trace suspected cases. Instead we send messages through people from the same village or through the village chief to patients. This may not be an effective way to follow-up patients, but we have no choice. There are difficulties at the lower level, we have lot of work but the payment is very low (Dara).

This lack of an effective follow-up system contributed to the non-adherence of TB patients.

In this study, seventeen TB patients were enrolled in ambulatory DOTS, which meant that they *should* travel to health centre every morning to swallow TB medicines in front of a health worker. However, only two came to the health centre daily during the intensive phase of treatment to take medicines in front of a health worker; other patients collected TB medicines weekly, fortnightly or monthly from the health centre and took the medicine at home by themselves. In most of these cases, treatment observed by a health worker was not feasible (discussed below).

Home DOTS

Home DOTS was delivered by a health staff member or a nominated community member (usually a village health support group members, C-DOTS). In the first type of Home DOTS, health staff travelled to a TB patient's home to watch them taking their medicine. This strategy did not work effectively in my study area, as it was not feasible for health staff to travel to patients' home each day. C-DOTS was introduced to improve case detection and to ensure direct observation to TB patients who live far from health centres. Each village that implements C-DOTS had two volunteers (recruited through election or nominated by the village chief) who received a one-day training session from the health centre staff on TB symptoms, prevention and treatment. They were expected to observe TB patients taking medicines and to facilitate TB diagnosis. C-DOTS observers were taught that they should collect TB drugs for patients every week or two weeks from a

health centre, and keep the medicines at their home. The TB patient should then have gone to the C-DOTS observer's house to take their TB medicine, or the C-DOTS observer should go to the patient's house to provide and observe the patient. C-DOTS observers worked on voluntary basis, but received incentives (e.g. bicycle, training opportunities, or per diem) from non-government organizations (NGO) in some places. C-DOTS observers in this study worked without any incentives from any organization; thus their involvement in TB control depended on their personal commitment, collaboration with health staff members, and contributions of patients (e.g. paying transportation to the C-DOTS observer).

Three patient participants were enrolled for treatment under C-DOTS. Each had a C-DOTS observer collect medicine for them each month, and usually paid for the volunteers' transportation costs. In each case, however, the C-DOTS observer did not observe the patient taking their medicines. Pisey described:

I take medicine by myself, no one observes me. I receive TB drugs from a volunteer every month: she brings the medicines to my home. The volunteer doesn't have time to come to my home every day, and I don't have time to go to her place either. I give her some money for transport, because she travels to get the drugs for me from the health centre.

Like home DOT by health workers, DOT by community members appeared not feasible for three main reasons: lack of support from the health centre (training, follow-up and rewards), lack of financial support to C-DOTS observers to collect medicines for patients, and their engagement in other work. Health workers acknowledged that lack of appropriate support to C-DOTS observers was the main factor de-motivating C-DOTS:

The contributions of volunteers to the TB program remain problematic. Some C-DOTS cannot travel at their own expense to collect medicines for patients. Some give up the job because they do not get any incentives. At the beginning, after

training, C-DOTS observers seemed to follow C-DOT policy and were keen to do their work, but later they may be careless. They can't go to patient's house every day. Some C-DOTS still help patients because patients pay the transport for them. I think this is fair because C-DOTS spend time to collect medicines for them (Phanna).

Although C-DOTS has been established, the lack of appropriate support to the volunteers meant that they could not perform their tasks as expected, and in general the program was not feasible. Sokha, a C-DOTS observer, outlined:

I volunteered to be a C-DOTS observer to help people in my village, and I also expect experience and training from the health centre. But I can't contribute my money to my volunteering work. For example, I can't go to the health centre to collect TB drugs for patients because petrol is expensive. So I remind patients to take medicine from the health centre by themselves, and I follow them up with their treatment sometimes. But I can't go to their place every day. I also need to work and some patients don't want me to observe them taking the medicine.

Regardless of the DOTS program (hospital DOTS, ambulatory DOTS, or home DOTS), TB patients usually took the medicine by themselves without observation. Direct observed therapy appeared to be modified according to patients' situation and needs, as I discuss below. I consider whether direct observed therapy is necessary from the perspective of patients and health providers, and the impact of this strategy on TB treatment adherence.

Directly observed therapy (DOT): Is it necessary?

DOT was an important recommendation to improve treatment outcomes, and has been a dominant message associated with TB diagnosis and treatment (Figure 23).

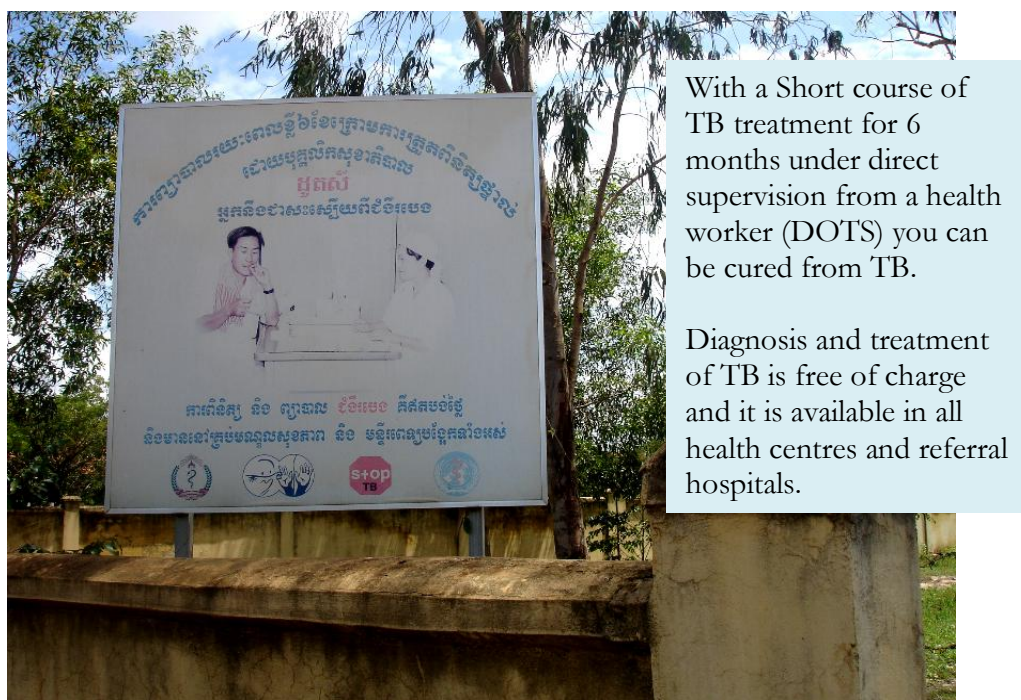


Figure 23: Billboard on TB treatment on the fence of a health centre

Field photo 28-March-2008

As discussed, however, there were challenges regarding DOT reported by health staff and by C-DOTS observers. Health staff acknowledged that DOT was important to ensure treatment compliance among patients; however it added to their workloads and caused more burden for patients. In this way, DOT prevented patients from obtaining treatment, as Kosal explained:

The policy requires patients to take medicines in front of a health worker for at least the first two months of treatment. But for those who live far away, it is impossible to force them to come every morning to take medicine. For patients who live close to the health centre, I don't let them take medicine home. I keep them coming every day, otherwise the health centre will be very quiet. They complain a lot about this.

Health staff understood that DOT posed difficulties for patients and in some cases was impossible, especially for those who were very poor and could not be away from work, who were elderly, or who were women with young children. Therefore, health staff

provided flexible treatment to patients by allowing them to take medicines at home by themselves:

We have difficulty encouraging people to come to take medicine at the health centre every day. Some patients live far from the health centre, some women have little children, some patients have to work, they can't come to the health centre every day. I have to be flexible to allow them to take TB medicine home for one or two weeks. If the patients do not turn up to collect medicine on time, we follow them up. The DOTS policy doesn't allow me to do this, but if I don't allow patients to take medicine, they can't have treatment for their disease. I believe that if a patient wants to be cured, they will take responsibility to complete their treatment (Sambath).

Health providers were flexible when providing DOT to patients according to their situation. However, there were no standard guidelines related to the flexibility of DOT and it varied according to negotiations between patients and providers, and the sympathy of the health providers. In addition, as Sambath explained, provider's flexibility regarding to DOT was also influenced by their perception that TB patients would make commitment to their TB treatment if they wanted to be cured. This commonly held perception tended to overlook the important role of health staff in supporting patients to comply with treatment, and also reflected misunderstandings of health workers about the importance of DOT. Originally, DOT was designed to improve treatment compliance by improving patient-provider interactions through observed therapy, and to encourage the active involvement of health workers in TB treatment (Chaulk & Kazandjian, 1998; Frieden & Driver, 2002; Kaona, et al., 2004; Mishra, et al., 2006). Like health workers, the present study showed that patients mainly viewed DOT as just a mechanism of watching a person dropping TB drugs into his or her mouth. As a consequence, the practice was perceived as unnecessary:

I have to go to the health centre every morning to take medicine. I asked *peet* if I could collect the medicine and take it at home, but he refused because I live close to the health centre. He said that it is a requirement from the higher level, and he has to

follow. He gives me medicine for the weekend or for 2-3 days if he is busy. I don't think it is necessary to go to the health centre just to take medicine in front of *peet* and come back home. Although I live close to the health centre, I need my father to drive me [by motorcycle] every morning, and I have to quit my job to go to health centre every day at 7-8 am, just for taking medicine. About a month later, I felt better and I wanted to go back to work. I could not follow this requirement so I requested *peet* to give medicine to me for one or two weeks (Navy).

DOT was designed to improve treatment compliance. However, due to burdens associated with obtaining DOT from a health worker (such as time and transportation costs), this strategy was not practical for most patients and they could not comply with treatment if strictly required to take medicines from the health centre every day:

I collect medicines from the health centre every two weeks, and I take it by myself at home. My house is not very far from the health centre but I can't go to the health centre every day because I have to work to earn my living. Every morning I wake up early to collect *slek ampil*, *maam*, *lngeng*, *slek bas* (types of vegetables and herbs), and go to market to sell them. The days I collect TB medicine from the health centre, I can't go to collect vegetables and can't go to market. Because I have to go to the health centre around 7am come back home around 10 am, it is already late to go to the market¹¹. At first *peet* asked me to come every day to take medicines in front of him, but I explained my problems, and he felt sorry for me and allowed me to take medicine at home (Romdol).

Although many TB patients were not able to attend DOT as a result of time, transport and their need to work, this was not always the case. Some patients refused DOT by a health worker or a C-DOTS observer because they were uncomfortable with having someone to watch them take medicine. They perceived that DOT undermined their control and responsibilities over their treatment:

¹¹ Markets in rural areas usually open in the very early morning, so rural people can take food to sell to those who buy it to sell in big market in the provincial city.

The C-DOT observer helps me get medicines from health centre, but I don't bother her to come and check me taking medicine every day. I'm not a kid, I know what I do, and I want to be cured from TB. I know that the C-DOTS observer is also busy and she also has many things to do (Chanthy).

TB patients perceived that it was unnecessary for them to have DOT in order to comply with treatment. They negotiated with health providers to avoid daily DOT at the health centre. In doing so, some patients necessarily made under-the-table payments. As a consequence, while some may have received sympathy from the health provider and thus obtained free treatment, others had to turn to a private provider for treatment.

Under-the-table payments caused by DOT

Because many TB patients could not comply with the requirement of DOT at a health facility, they negotiated with health staff to obtain TB medicines for periods of time. This provided an opportunity for some health workers to use DOT as a rigid policy with which patients had to comply to get treatment, pressuring patients to make under-the-table payments for medication. For instance, those who were not able to come to health centre for DOT had to negotiate with health providers for a flexible treatment plan. They often accepted the need to pay health workers to avoid having to present to the health centre everyday:

My husband paid US\$20 to the health centre to take TB medicines for my father in-law, because we asked to get medicine for one month. If we came to the health centre every day for him to take his medicine, there would be no cost. We live not far from the health centre but, you know, to bring him to the health centre every day to take medicine is difficult; he's old and frail, and the fuel is also costly. [So] we decided to pay (FGD).

I paid US\$20 to a staff member at the health centre, so that my husband can collect medicine for one week or two weeks. It's always like this. We can't get anything free. Everywhere and everything, we have to pay, at school or at *peet*. At a private clinic, it

costs even more. You know, peet has a low salary, so they need more to survive (laughs) (Phally).

Patients and their families were generally not happy with informal payments, but they felt compromised and thus kept the informal payments secret. None had ever complained to any authority about these informal payments, which they perceived to be normal practice for government health workers because of low salaries; they were familiar with this practice as it commonly occurred in other government institutions. There was also no formal complaint-reporting system for the Ministry of Health. If they complained, no one would have paid attention to them, and they were concerned that it might lead to disputes with their local health worker. However, they complained to their close relatives and friends. Some TB patients kept informal payments secret, and some requested that the information shared with me related to informal payments of TB treatment be kept confidential, as they did not want to cause any trouble with health providers.

According to patients, the amount of money paid was based on negotiations with providers. Patients' reluctance to talk about the under-the-table payments also derived from the benefits they received:

My husband doesn't need to wait long when he collects TB medicines for me. And when food distribution comes to the health centre the health worker sends information to us quickly. We're good to them, they're good to us too (Phally).

Informal payments created inequalities between patients who paid them and those who could not pay them in terms of the quality and convenience of health care provided by health staff. This encouraged people to pay informal fees to obtain better services. Rumours about informal payments were widespread in the community, leaving extremely poor people reluctant to seek help from public health facilities.

The under-the-table payments relating to TB treatment were not uncommon elsewhere in Cambodia, and have been reported through non-government media in some provinces. Health workers in Preveaeng, Siem Reap and Kampong Cham were accused of charging TB patients for medicines, and the media expressed concerns that informal payments prevented the poor from accessing to TB treatment. As health workers rejected these accusations, no further investigation was undertaken by either the Ministry of Health or the NTP in this matter. This lack of response to community complaints discouraged community members from giving feedback about any problems related to the public health service delivery.

TB treatment by private providers

TB diagnosis and treatment was also provided by private providers, including qualified and unqualified providers. In this study, two patients were treated for TB by private providers: one patient (Kanika) sought treatment from a qualified private provider, while another (Saran) was treated by a *peet phum*. Both patients were aware of the availability of TB treatment at the public health centre and hospital, but chose private providers because they could not comply with the DOT requirements. Kanika was diagnosed at the TB hospital but, because she did not want to be hospitalized, the attending health provider refused to provide her with TB medication. She was then transferred to a private clinic, which was run by a health provider from the provincial hospital, and there she could obtain TB drugs for one month of treatment to take at home. Her example was not atypical. Health workers sometimes diverted patients who could not comply with the DOT requirements of the public health facility, or who required special treatment, to their private practices (Oum, et al., 2005b; Meessen, et al., 2006). Although some patients preferred private providers because of their quality and convenience, in many circumstances, poor patients felt forced

into using private health services, despite the high cost. Kanika described her devastation when she was very sick, poor, and was pushed to use a private clinic:

I went to the hospital because I needed a paper from [there] to confirm that I had TB, so that I could get TB medicine from the health centre for free. But after the x-ray, *peet* explained me that I had to be hospitalized. I didn't want to be hospitalized because I did not have anyone to stay with my mother. I was [also] scared of the TB ward. I saw the ward with many severely sick patients. I'm not that sick like them. *Peet* told me that I had no choice, [and asked] if I wanted to be treated at a health centre, why I came to the hospital? [He said] if I didn't want to be hospitalized, they could not treat me, instead I should go to a private clinic. At last, I decided to go to a clinic that belongs to a staff member from the hospital. I have no other options (Kanika).

The main reasons why Kanika refused hospitalization were: her perception that being hospitalized was unnecessary as she thought that hospital was only for severely ill patients, the lengthy period of hospitalization (at least two months), and her reluctance to stay on the TB ward and share a room with other TB patients. However, she was not given any alternatives, and so sought health care that suited her needs from a private provider. Her example suggests that health providers may have intentionally created difficulties in accessing treatment at public health facilities in order to divert clients to their private clinics.

In contrast, Saran treated his TB with a *peet phum*, his regular health provider, because he could not travel to the health centre by himself. This was reflected in Saran's recruitment in this study, which was quite complex. During data collection, I frequently talked to patients or family members who brought sputum to the provincial hospital's Laboratory. One day, I talked to a man who had brought Saran's sputum to the laboratory, and it was confirmed that Saran had pulmonary TB. I then learned that Saran lived in a village covered by one of the health centres where I worked. As couple of weeks later, I did not see Saran come to

collect his medicines from the health centre, and thus I did not know where he received treatment, so I asked my research facilitator to follow him up. She learned that Saran had passed away after taking TB medication for a couple weeks; his daughter Vany, who had been his caregiver, agreed to participate in the study and shared his story:

My father had been sick with cough and fever for several months, and he was treated by a *peet phum*, but his condition did not improve. His cough persisted, especially at night. The *peet phum* suggested a sputum smear test to check for TB. His sputum confirmed that he had TB, then *peet phum* suggested that we should start treatment. He charged us 300,000 Riels (approximately US\$75) for six months of TB medicine. *Peet phum* told us that he paid this money to a health worker in the provincial town to get the medicine. At the start of the treatment, *peet phum* gave him 6 tablets per day. He lost his appetite and vomited a lot. His condition worsened day after day. After 18 days, *peet phum* decided to stop the treatment, then gave him injections of *thnam kamlang* (vitamins) and serum perfusion. But we could not help him; approximately 20 days later, he passed away because he hadn't eaten.

Saran's case indicated TB treatment in rural Cambodia was available, even through low qualified providers. His story also illustrated patients' attitude towards TB treatment, that this disease can be diagnosed and treated by any health provider. Vany's account suggested that while low qualified private providers could administer TB medication to patients, their lack of knowledge and training about TB may contribute to premature morbidity and mortality.

Health staff acknowledged the availability of TB treatment through private providers, and believed that those services provided options to community people who did not want to treat their TB in public facilities.

I don't deny that some staff who work for TB control at the hospital or health centre treat TB patients at their private practice, and some *peet phum* also provide may provide TB treatment to their fellow villagers. Actually, it depends on the patient's preference about where they want to be treated (Navuth).

This ignores people like Kanika, who were basically told it is either a private provider or no treatment. In reality, people's options to be treated for TB with a private provider meant that they spent money paying for treatment to which they are entitled at no cost, but the rigid implementation of DOT and lack of confidentiality of TB diagnosis and treatment at public health facilities influenced their choices:

Some patients don't want to take the medicine at the hospital or health centre, because it is difficult for them to come everyday. They may come to the hospital to seek diagnosis, [but] when they know that they have TB, they buy TB drugs from the pharmacy or they go to private providers for treatment, so we don't have a medical record for them. TB drugs sold at a pharmacy are not very expensive compared to what patients have to spend on transportation and time to come to a health centre. More importantly, services there are very confidential and quick. If we, the government are strict and can control TB drugs sold at the pharmacy, I think the number of TB patients treated at public facilities would increase (Dara).

Coping with TB treatment: adherence and non-adherence

The availability of treatment did not always bring happy results to TB patients, as they were required to bear prolonged treatment and adverse effects of the medication (Amuha, 2009)(Volmink & Garner, 2006). Not all patients completed or fully complied with the medication course, leading to prolonged infection and the increased possibility of drug resistance, relapse, or death (Volmink & Garner, 2006; Munro, et al., 2007b). Generally, adherence was determined by multiple factors: institutional context (specifically, accessible and appropriate health care), social support, and individual factors including knowledge and attitudes towards TB treatment (Volmink & Garner, 2006; Munro, et al., 2007b; Widjanarko, et al., 2009).

The main strategies used by the NTP Cambodia to encourage treatment adherence included: ensuring supplies of TB medicine, implementation of DOT by a health worker or a nominated C-DOTS observer, and follow-up visit to TB patients by health workers.

However, despite the availability of TB medicines at every health centre, challenges persisted in the implementation of this strategy. As discussed earlier, implementation was variable and follow-up systems were often fragmented. These factors affected adherence.

The term ‘adherence’ refers to an individual personal commitment to collaborate with health workers to follow and complete a treatment program (Naidoo, et al., 2009). However, there is no clear definition of non-adherence in terms of TB treatment: some researchers have defined non-adherent TB cases as those who have interrupted TB medicines for two weeks (Widjanarko, et al., 2009), or missed 10% or more of their prescribed medicines (Gelmanova, et al., 2007). Onyebujoh et al. (2007) indicates that even missing a small percentage of prescribed doses can influence treatment outcomes. The Cambodia NTP often uses the term ‘non-adherence’ to refer to defaulter cases, which means that only patients who interrupted treatment for two or more consecutive months (WHO, 2009) were classified as non-adherent:

We classify a patient to be non-adherent based on the national definition that they missed treatment for at least two consecutive months. Generally, we don’t have many patients who interrupt treatment for two consecutive months. Normally if patients do not turn up for their appointment to take TB medicines, after 2-3 days, we send word to remind them through other villagers or we follow them up. We don’t wait until two months [have passed] (Seth).

There are few TB defaulter cases in Cambodia; the 2008 national TB report showed only 1.4% of TB patients defaulted treatment (CENAT, 2009). This was similar to the percentage in Kampong Speu of 1.55% (Kampong Speu Provincial Health Department, 2009). These rates were based on patients’ medical records from health centres and hospitals; however, the actual rate of non-adherence may have been higher than reported, as discussed, because some patients who interrupted treatment were not recorded as ‘non-adherent’.

I followed 32 TB patients who underwent TB treatment (category I or II) at the health facilities from time of first interview until they completed treatment. At the start of the treatment, most participants received some information from health providers about their treatment, including the period of treatment, how they should take TB drugs (regularly, at around the same time every morning, before having breakfast) and the possible side effects they might encounter. However, patients commonly reported missing doses of their medications because they missed or were late collecting their TB drugs from the health facilities, forgot to take their drugs, and due to side effects. Patients believed that missing some doses of medication would not affect the effectiveness of the treatment, as long as they managed to complete the course:

I took TB medicines every morning, but sometimes I forgot and sometimes I ran out of the medicines. I did not intend to do that, I wanted to be cured, and my daughter always reminded me to take medicine. One time, I didn't have medicines for a week, because my daughter forgot to get medicines for me, then the health centre was closed on holiday. In total I think I missed around 10-15 days, but I don't think it is a problem because I'm cured now (Chanthy).

I took medicine for six months. I don't know why I had to take the medicine for such long time; I think it is a kind of medical requirement, [as] I also see other people take medicines for six months too. Frankly speaking, I missed some doses of medicines. Because the medicines made me so sick, I skipped some days because I couldn't bear it. But I didn't tell my mum. Sometimes I also forgot; I went to my parents' home town and forgot to take the medicines, and sometimes I finished medicines on Saturday or Sunday so I did not have medicines to take [until Monday]. *Peet* said that it was no problem and I should continue to take the medicine as usual until six months. In total, I probably missed around 10-20 days. I'm not sure (Chamrong).

Despite missing some doses, participants tended not to worry about the effectiveness of treatment as long as they observed an improvement in their health condition. However,

those who did not observe a full recovery worried that their non-adherence had affected their treatment outcomes:

Now, although I completed treatment, I still have cough and feel tired. I asked *peet* at the health centre for more medicine, but he said that I had completed the treatment. I missed some doses of medicines, especially during the last two months of the treatment since I started working. I'm worried that I might not be cured (Pin).

Adherence to treatment was complex. Based on self-reports, most patients missed noticeable doses of TB medicines (between 10 to 30 days) at some point in their treatment. However, the lack of a clear definition of 'non-adherence' meant patients and health staff did not consider this practice to be significant, and patients did not usually discuss their non-adherence practices with a health provider. Even though some of them did, health staff could not or believed they could not do anything further to help. To remind patients to take medicine regularly, each was given a pink card (Figure 24) to check off when they took their medicine at home. If the treatment was observed by a health provider or a C-DOTS observer, the observers checked the card; because patients mostly self-administered the medicines, they checked the card themselves. They frequently forgot to check the card, especially those who were elderly and illiterate, and thus the card useless for following up treatment adherence. Health workers thus played an important role in 'non-adherence'. Patients who missed or were late collecting TB medicines reflected on how irregular short opening hours at clinic inadvertently led to their non-adherence.



Figure 24: Pink card for patients to indicate when they took TB medication

This was further exacerbated during treatment, when patients were required (by the health centre/hospital) to submit sputum to monitor treatment effectiveness. Although health workers reported that they did sputum control for all patients and confirmed that they were cured, many participants reported that this was not the case (Table 34)

Table 34: Patients self-report on sputum submission

Place to treat TB	Sputum for diagnosis	2 nd /3 rd month sputum control	5 th /7 th month sputum control	6 th /8 th month sputum control
Hospital	10	9	1	1
Boun	4	3	1	1
Moy	5	0	0	0
Pi	4	2	2	0
Bei	4	0	0	0
C-DOTS	2	0	0	0
Private	1	0	0	0
Total	30*	14	4	2

* Total patient participants were 32, but two patients are excluded from the table because they were not diagnosed through sputum test.

Table 34 shows that, of 30 patients were diagnosed through sputum smear examination, less than half of participants (14) had a sputum control test after the second month of their medication (one positive); four patients had a sputum test for the third time at around the fifth month of treatment, and only two had a sputum test at the completion of their treatment.

The performance of sputum control was significantly influenced by health worker's motivation as well as access to a laboratory, which varied across the province. For example, the provincial hospital and Boun health centre both had TB laboratories located in the same compound, while Bei, Pi and Moy did not have any laboratory facilities. This may have explained why the sputum control test at the second month at these first two facilities was higher than the other three health centres. The sputum test control at Pi was better than the other two health centres, possibly due to the high motivation of health staff. However, health staff considered that sputum control test was influenced by patients, as Rotha explained:

Some patients don't submit sputum for control. They say they don't have sputum, and some patients don't send the sputum sample to us. We have difficulties regarding sputum control because some patients do not come to health centre; they have a family member get their medicines for them. Some patients, particularly the elderly, do not understand about sputum control, so they don't care when we tell them to submit sputum for control.

However, some patients did know that they should submit sputum during their course of treatment to follow-up the effectiveness of treatment. Some were requested to submit sputum after two months of treatment, but were not informed about the purpose of the sputum test:

Before I started treatment, *peet* did a sputum test to find *meh rok*, then after two months of treatment, I did another sputum test three times, and then a couple of

months later, *peet* asked me to do sputum test again. I don't know why they need to do the sputum test, but I always follow *peet's* advice. Now *peet* told me that I'm cured and I feel normal like before (Chamrong).

Lack of sputum control among participants in this study raises concern about reporting cure rates of TB patients in rural health centres. Only six had pathology by way of sputum tests to confirm that they were cured at fifth or sixth month of treatment. Although patients missed some doses of their treatment, most (28/32) completed the six or eight-month treatment course. According to the WHO's definition, a completed therapeutic course did not automatically result in a cure if sputum control was not performed in the second, fifth and sixth months of treatment. This meant that while there was likely to be a high completion rate among TB patients, the reported cure rate was possibly incorrect.

Factors associated with treatment completion

TB treatment completion was driven by several reasons: confidence in TB treatment, health provider's support and family support. Each of them is discussed below.

Confidence in TB treatment

Patients' commitment to TB treatment was influenced by their attitudes on treatment and their confidence that the treatments were effective:

I think this [TB] disease is severe and can kill patients if we do not get treatment on time. If we do not take treatment correctly, we may not be cured, or may relapse later. I do my best to take the medicines. Although I have side effects, I do not give up because I know that this is the only way I can be cured (Soma).

I have one patient, when we gave her TB medicines, she threw them away because she could not stand the side effects, and she did not listen to our advice. She did not believe that the treatment could help her. She bought other treatments from pharmacy. But later she was very sick and came back to the TB ward. Finally she knew that there is no other treatment that could cure her TB. So she committed to

the treatment, because she was so scared that she would get worse and worse and die if she skipped treatment again (Oudam).

Beliefs that TB treatment could cure the disease encouraged patients to continue with treatment despite unpleasant side effects. Completion was also influenced by patients' understanding of the practical aspects of treatment, including the length of treatment and the importance of regular treatment:

At the beginning of treatment, I almost gave up. The side effects were very strong that could almost kill me, but I still love my life.... I have to struggle with it. I thought that the *meh rok* must be so strong to need a very strong medicine to kill them, unlike other diseases: malaria, typhoid or diarrheal that needs treatment only for one or two weeks. *Peet* told me to take medicines in the early morning before eating anything. I think this is because he doesn't want food to mix up with medicine, so slowing the action of the medicine, so that the medicine is not strong enough to kill the *meh rok*. I follow his advice. I know 2-3 former TB patients who were cured after taking the medicines for six months. I think I'm can be cured too, because now already I feel better (Sophal).

Patients' motivations to complete the full treatment course and beliefs about the effectiveness of treatment were influenced by their experiences of seeing former TB patients recover, and their confidence in the efficacy of treatment was assured as they noticed their physical health improve:

I take medicine in the early morning but I can't take it at exactly the same time. Sometimes [I take it] at 5:30am, sometimes at 6:30 or 7am. Although the TB drugs made me very sick, I continue taking medicines because day after day, I cough less. I heard that because I'm young, if I finish treatment for six months, I can be cured and become like other people without TB (Chamrong).

Patients' age shaped their perceptions and understanding of the TB treatment, as well as their confidence in its efficacy. Younger patients believed that if they followed treatment

correctly, they would fully recover from TB. This message was reinforced by health workers:

I don't need someone to watch me taking medicine. I always take medicine. I'm scared that if I forget to take medicine, I can't be cured. I think that if a patient wants to be cured, we have to be careful and follow *peet* to collect medicine and take it regularly. I believe if we don't help ourselves, no one can help us. *Peet* said that if I take the medicine regularly, I can be fully cured because I am still young. So I do my best to complete the treatment (Romdul).

Patients' positive commitment to and perceptions of the treatment important role in encouraged them to continue with treatment. Despite this, completion treatment was largely dependent on support from the health worker.

Support from health provider

Provider-patient interactions were important in treatment compliance (Leventhal & Cameron, 1987), and the attitudes of health providers toward TB patients have been reported as an important factor for adherence to treatment (Johansson, et al., 1999). Providers' communication of TB-related information, including information/details of treatment and recovery, may help patients to understand the need and do their best to follow treatment (Jaiswal, et al., 2003). The TB program delivered at the local health centres and referral hospitals in Cambodia did more than simply supplies of TB medicine—TB patients in this study received information on treatment from their health providers, which encouraged them to persist with treatment. Samnang described the information she received, and its value:

Peet told me to take medicine regularly for six months, so I can be 100% cured from TB. He said that I have to take medicine in the early morning when the stomach is empty, around half to one hour before taking food. I take medicine every day at 4 or 5am, I wait until 7 before I take food because I'm afraid that if I take food so soon after taking the medicine, the medicine may not be effective. *Peet* said I could eat any

kind of food, but should limit fermented food and ice because it makes the cough worsen. I don't know why the treatment is so long, maybe because TB is a very dangerous disease (Samnang).

Despite the importance of health worker-provided information in encouraging patients to stay with treatment, health providers usually gave limited information to patients, caused at least partly by brief provider-patient interactions in public health settings. Health workers were usually busy with multiple tasks in and outside public health clinics.

Health workers supported treatment adherence also by offering a flexible alternative to DOT, in order accommodate the multiple demands facing many patients and thus to enable them to complete the course. Lili described that, without this flexibility, she would have been unable to be treated:

I cannot come to the health centres very often to collect TB medicines. [So] I asked *peet* to give enough medicines to me for at least 2-3 weeks, because I have two small children and do not have a motorbike to travel to the health centre. At first, *peet* hesitated to give the medicine to me. I begged him, he understood that I'm very poor and have difficulties to travel often, so he agreed. I'm so grateful to him. If he did not agree, I could not have TB treatment.

Adherence to treatment was challenging as the treatment takes so long. This made health staff question whether, by strictly following DOT policy, patients may be non-adherent and so jeopardise their chance of cure. However, the decision by health workers to forego DOT policy removed some of the formal structures supporting patients through TB treatment and suggest that health workers relied on a belief that patients would do their best to comply with treatment, because they wanted to be cured.

Family support

Socio-cultural support, encompassing family, community and social support, influenced treatment adherence. In Cambodia, family members usually provided support to sick family

members. This support included both practical and emotional aspects: financial and psychological support, taking care of the patient at home or at hospital, collecting TB medicines, and reminding patients to take medicines regularly. Without this support, patients would be unable to complete treatment:

At first, when *peet* asked my daughter to take medicine from the health centre, I took her [there] every morning before I went to work. Now we take enough medicine from the health centre for one week. I always remind her to take her medicine regularly. Sometimes, if she runs out of TB drugs on a weekend or public holiday, I buy the medicines from the pharmacy for her (Pheakdey).

My husband collects TB medicines for me from the health centre every week. He counts my medicines every day to make sure that I don't miss any medicine. He is very serious about my medicines because he wants me to be cured (Phally).

Support of family members also reflected strong family bonds, and the values of respect and good care that family members should show to a sick person, particularly to an elderly family member (parent or grandparent):

I give medicine to my father every day in the early morning and watch him taking it. My father is old. We collect the TB medicine from health centre, and I'm the one who keeps the medicine and give it to him. I look after him and give him good food (Pov).

Family support also often allowed patients to live as usual and to continue to work or undertake other activities during treatment. However, outside of their immediate family, patients usually hid their TB status because of fear of stigma and rejection from colleagues or employers. However, no TB patient in this study interrupted treatment because of the fear or experience of stigma associated with TB.

Factors associated with treatment failure

TB treatment ‘failure’ refers to cases that resulted in default, relapse, or death. In this study, four patients defaulted during treatment, four patients experienced a relapse following completion of the course, and two patients died. These are described in turn below.

Sok was diagnosed with TB at a health centre. Following his diagnosis, he enrolled in ambulatory DOTS, and was treated with TB treatment category one. At the start, he was given enough TB medicines for one month to take at home, because the health workers understood that he could not come to the health centre to take medicines every day in front of a health worker. Sok and his wife were extremely poor, and lived about 3 kilometres from this health centre. Their daughter who worked in a factory in Phnom Penh; the couple looked after three young grandchildren at home. To go to the health centre, Sok walked one hour each way, as he could not afford a motor taxi. His daughter and son-in-law could not collect his medicine, and did not monitor his treatment because they were busy with their work. After about two months of medication, Sok felt better and believed that he was cured, so he decided not to ask for more medicines from the health centre. He had no idea about the length of TB treatment he should follow. Although the health worker asked him to collect more medicines, he did not turn up because he thought that he was cured.

Sok’s case illustrates how vulnerable (old, poor and illiterate) patients may not complete treatment for several reasons. He decided to stop taking his TB medications because he believed that the disease was cured, his poverty prevented his access to the health centre, and he lacked family support:

I do not have a fever, no difficulties in breathing, though I still cough sometimes. I sleep and eat as well as normal people. Even if I have only rice with salt and raw tamarind, it’s already very tasty for me. I think I’m cured, that’s why I didn’t go to collect more medicine from the health centre. *Peet* sent word with my neighbour, one or two times, that I have to collect more medicines from him, but I didn’t go; since then he’s never asked me to collect medicines again. My daughter did not follow up my treatment because she is always very busy with work from the morning until

night to support the family. She wants me to be cured. I told her that I'm cured now, she is happy for me.

Sok interrupted treatment because he perceived that he was cured. However, this interruption may not have happened if Sok were aware of the length of treatment and had obtained support from family members (to collect and monitor his medication) and the health worker (regular follow-up and encouragement to persist with treatment).

Samreth, divorced and childless, lived with his married sister and her family. He decided to cease TB treatment after fifth month. He lived around 7km from the health centre, and when required to attend, he took a motor taxi (cost around 15,000 *Riels* or US\$4 for a round trip). He stopped TB medicine because he believed that he was cured from the disease and his symptoms had diminished; also his poverty meant he could not afford the transport to collect medicines.

Both Sok's and Samreth's stories show how the interaction of factors contributed to defaulting of TB treatment, as reported elsewhere (Xeuatvongsa, 2005; Shargie & Lindtjorn, 2007; Widjanarko, et al., 2009). A cohort study of 404 smear-positive TB patients in Southern Ethiopia showed that physical access to public health services (distance from home, travel costs, and being too tired to walk), misunderstandings of cure, loss of hope in medication, and inadequate knowledge of TB were all reasons for interrupting medication (Shargie & Lindtjorn, 2007).

Elderly and poor patients often neglected their health care and, as a result of their difficulties in accessing health care, willingly accepted whatever happened to them. Health workers also acknowledged the difficulties in encouraging old and poor patients to complete TB treatment, although they did not initiate any support to assist them:

Old patients refuse to continue TB treatment if they feel better. They do not understand about the treatment, and they believe that they are cured. We can't force them if they don't want to continue treatment. It may be easier to encourage old people who have good support from family members (Sambo).

The elderly were more vulnerable to interruption of TB treatment; and had difficulty travelling to health facilities due to their physical frailty and financial dependence on other family members. In addition, they were more likely to suffer unpleasant side effects of TB medicines, leading to interruption of TB medication. Sokun (64) skipped treatment because of side effects; he was treated with TB treatment category II at the hospital (with injections of Streptomycin):

The TB medication almost killed me. It made me feel very uncomfortable: hot in my body and unable to eat. It tasted sweet and bitter in my mouth. I kept losing weight. I asked *peet* to stop the treatment. If I died, I would accept it. I skipped for about two months. I called a private provider to give me injection of *thnan kamlang*, and I use traditional medicines and Chinese medicines. I feel better, I can eat more. I will never take TB medicine again.

Side effects and lack of health provider's support caused Sokun to give up treatment. Health providers were also concerned that the most common cause of non-adherence was the side effects, leading patients losing hope in the treatment, which then led to the interruption of treatment (Wares, et al., 2003; Watkins, et al., 2004; Xeuvatvongsa, 2005; Munro, et al., 2007b).

Four participants in this study were TB relapse cases and had previously undergone a treatment course at a different health centre. According to their medical records, three—Chantha, Kravan, Kiri—were actually classified as new cases and treated with TB treatment category I. It emerged during interviews, however, they had completed treatment before, and had been well for some time before they were re-infected with TB. All completed their current treatment and felt better, although they were not confident that

they were cured. None had a sputum test to confirm cure. Kravan was sick for the third time— she had been treated in 1988, 2005, and again early 2008. Kravan was concerned that hard work was the cause of her relapse:

My treatment is good, I put on some weight, and I feel that I'm normal. But sometimes I cough, and I get tired when I do hard work. I don't know whether I can be cured or not. I have already relapsed two times, because I was working hard. I hope that I can be cured this time. *Peet* told me that I have to avoid working hard. He told me to be hospitalized to rest, and *peet* can give me injections. He said that if I continue working hard, I can't be cured. But I urged *peet* to let me take medicines at home, [as] I can't stay at the hospital. I have many things to take care of at home: housework, the chicken farm, and grandchildren. My daughter is a widow; she works full-time in a factory, so I have to help her looking after my grandchildren. My other two children study in Phnom Penh, and I need to support them. I think if I just take the medicines, eat, and rest, I may be cured. But I can't, I am not a free person. I don't know what will happen after this treatment.

Although TB patients perceived hard work was the main cause of relapse, they could not avoid it because of family responsibilities. For example, Kravan believed that if she completed treatment, when combined with good nutrition and time to recover, she might be cured, but she felt she could not do more than take the medicine, as her need to provide for her family was more important than her own health. Other perceived causes of relapse were related to non-adherence to TB medications and poor lifestyle behaviours (smoking and drinking).

Health workers were concerned that the relapse was caused by lack of treatment adherence. They suspected that allowing patients to self-administer TB drugs contributed to non-adherence, and relapse. Health workers believed that although DOT by a health worker was difficult to implement, it was important to ensure adherence:

DOT is important to help a patient taking TB drugs regularly. I am concerned that if we do not follow DOT properly, especially at health centres, and allow patients to take medicine at home for one week or two weeks, this could lead to infective treatment or relapse. I see now there are more relapse cases. I suspect that this may be caused by patients not taking the drugs regularly by themselves; they may not take the medicines every day, or may forget the medicine (Saray).

From providers' point of view, there was no clear strategy to improve adherence and, in many cases, medicines at home was seen as a better alternative to not taking medicine at all. Furthermore, it was not clear about the impact of DOT on treatment adherence and treatment completion. Very often patients were blamed for lack of commitment and lack of support from their family members, although I have demonstrated that health providers had a clear role in treatment adherence. They did not reflect on their—or the health system's—responsibility for non-adherence and relapse.

TB is still a major cause of death in Cambodia. In this study, I recruited two people who had a family member (one son and one father) who had died of TB. Their accounts indicate the importance of adherence. Nara lived in a slum area next to the hospital. He became sick with TB in 2005, then undertook TB treatment at the hospital TB ward, but skipped treatment after three months because he believed that he was cured. In mid-2008, Nara became sick again, and sought TB treatment from the same hospital. But, according to his mother, health workers in the TB ward refused to admit him, and instead referred him to seek treatment from the TB hospital in Phnom Penh, because he had skipped treatment in the past without informing them. Because his family could not afford transport to Phnom Penh and did not know how to access the TB hospital there, Nara returned home. He died six days later:

[Nara] was sick with cough and had difficulty breathing. He was admitted to the general [medicine] ward, and was hospitalized there for about one month. *Peet* took his sputum and test. They knew that he had TB and they prepared to send him to the

TB ward. But *peet* at the TB ward did not accept him because they were angry that he had skipped treatment the previous time. *Peet* told me to take him to Phnom Penh. I begged *peet* to accept my son, but he refused to admit him.....[crying].....I took him back home because I did not have the money to go to Phnom Penh, I did not know the TB hospital in Phnom Penh, I didn't have anyone to help (Thavy).

Nara's death was caused by his extreme poverty and inadequacies in the health care structure, including lack of support from health workers and the fragmentation of the referral system. Nara's mother could not afford transport to the city and did not have access to a loan, because she was too poor to afford to pay back the debt. Instead she treated him with herbal medicines until he died:

I told *peet* that I did not have money to go to Phnom Penh and did not know Phnom Penh... I begged *peet* to let my son stay longer in the hospital, but they refused. So I decided to take him home and I used the roots of plants and some herb to make medicines for him, but I could not help him. If he died in the hospital in the hands of *peet*, I would not so be upset, but he died because I could not help him (Thavy).

As Thavy outlines, extreme poverty prevented patients from obtaining TB services although it was theoretically free and available to everyone.

In contrast, Saran died after being treated with TB medicines by a *peet phum* for a month. Several explanations for his death can be summarised as follows: inappropriate treatment (possibly incorrect doses) as he was treated by an unqualified provider, and he may have had other health problems that were aggravated by the side effects of the TB medicines. Saran's death made his family frightened about TB medicines, as they believed that he died because of the medicines. These fears transformed into (mis)information which spread throughout the community, creating misconceptions and fear related to TB medication, therefore potentially affecting other community members' decisions to undertake TB treatment.

Although most participants completed the full course of TB treatment, non-adherence was inevitable. Based on patients' self-reports, non-adherence was significant, however neither patients nor health providers had a strategy to ensure full treatment compliance. This reflects earlier research findings (Xeuatvongsa, 2005; Naidoo, et al., 2009), indicating that TB patients tended to adhere to treatment during the early stages of treatment, when they were suffering with acute symptoms, but experienced non-adherence at some point later, particularly during the continuation phase.

As noted, non-adherence was influenced by lack of involvement of health workers. Low staff motivation had several implications for the DOTS program. For example, short opening hours of the health centre prevented health staff from being able to provide DOT to all patients, contributing to late or missed collections of medicines; there were delays and errors in sputum testing; and ineffective follow-up. Health staff believed that treatment adherence should rely on patients' motivation and willingness to comply with treatment. Like studies elsewhere, participants in this study could not follow DOT because of high transportation costs, difficulty travelling because of ill health, and the need to work (Moore, 2001; Pungrassami, et al., 2002; Greene, 2004; Sanou, et al., 2004; Khan, et al., 2005). Chinese data showed that although DOT by a health worker is the national policy for TB control, less than 5% of patients were treated in line with this policy, and both providers and patients regarded the policy as unnecessary and impractical (Hu, et al., 2008). Another study illustrated that DOT tended not to result in significant differences in completion rates between patients treated under DOT and those who undertook self-administered therapy (Wang & Shen, 2009). However, Thaim and colleague (2007) showed that a DOT approach which supported improved patient-provider interactions, offered decentralization of treatment, allowed patient choices of an observer, and provided supervision activities, could result in better adherence than traditional DOT (Thiam, et al., 2007).

Completion of TB treatment was also influenced by individual factors, as described, was consistent with other studies (Barnhoorn & Adriaanse, 1992; Menegoni, 1996; Martins, et al., 2008; Naidoo, et al., 2009), which confirmed that patients' adherence to TB treatment was associated with their beliefs about the effectiveness of treatment, experience of relief from the symptoms of disease, and knowing someone who had been cured from TB by taking the treatment. A study with 234 new smear-positive TB patients in urban Nepal, for example, showed that knowledge of TB and its treatment were associated with treatment adherence. In contrast, lack of knowledge about the length of TB treatment led to interruption of TB medication as symptoms improved (Newell, et al., 2006). Findings of the present study indicated that the perceived severity and threat of the disease, combined with belief in effectiveness of treatment, encourage adherence, and supports the Health Belief Model (HBM) (Becker, 1974a; Munro, et al., 2007a), although other factors played important role in treatment completion (Figure 25).

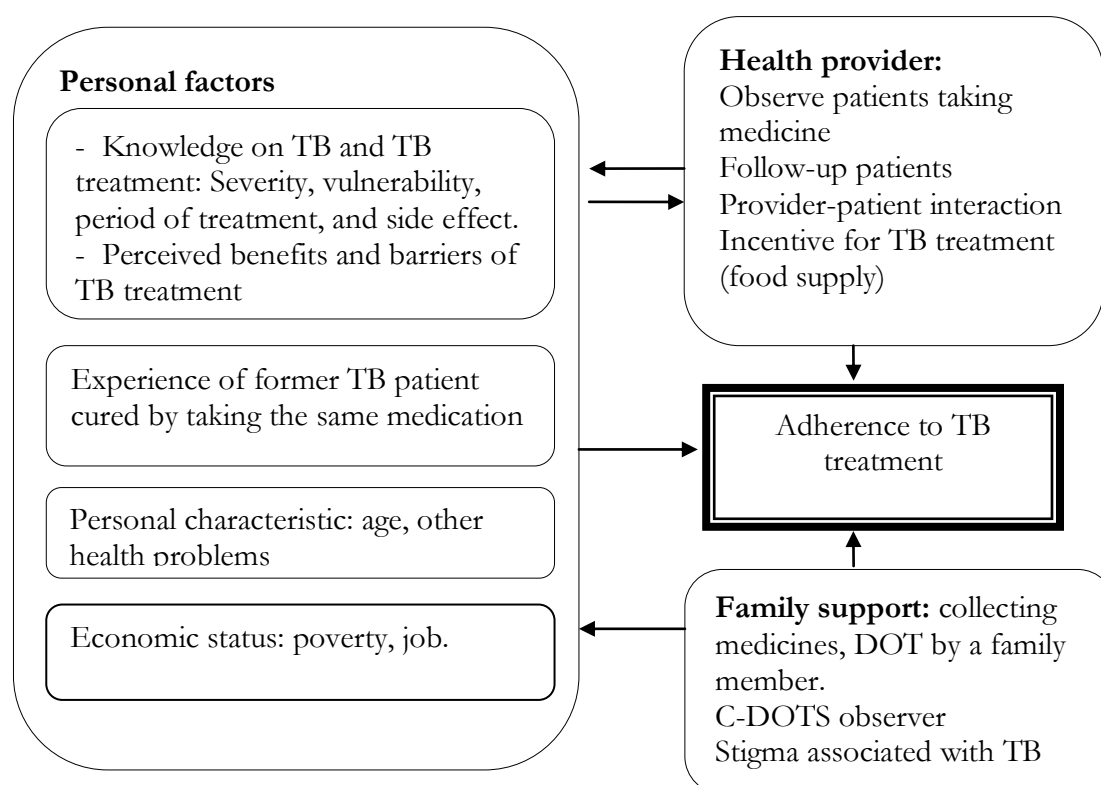


Figure 25: Factors associated with TB treatment adherence

At the same time, family support (financial and psychological) was important for treatment completion; this is similar to other findings that family support and care were crucial to patient's adherence to treatment (Macq, et al., 2003; Newell, et al., 2006).

Factors associated with failures (default, death and relapse) were: side effects, relief from symptoms, misconceptions about cure, an ineffective health system, and lack of family support, ageing, and poverty. It was very common that adverse effects related to TB medications or relief of TB symptoms contributed to interrupted TB treatment (Tekle, et al., 2002; Chang, et al., 2004; Xu, et al., 2009). More importantly, the current structure for TB diagnosis and treatment in Cambodia remains a challenge for the success of TB treatment. For example, there were no standards related to the flexibility of DOT, leading some health workers use DOT to generate under-the-table payments. Provider-patient interactions appeared to be ineffective; many patients did not understand TB treatment and this might have led to interruption to their treatment. Follow-up provided to TB patients was uneven and depended on individual health provider and geographical variation: patients who lived in remote areas were not followed-up due to time constraints of health staff and high transportation costs.

CHAPTER 7

STIGMA AND ITS IMPLICATIONS: EXPLANATIONS FROM THE FIELD

In most societies, stigma associated with TB remains significant (WHO, 2003; Balasubramanian, et al., 2004; Weiss, et al., 2006), contributing to set backs in the success of TB control programs and particularly affecting TB case detection and adherence to TB treatment (WHO, 2003; Weiss, et al., 2006). The burden of TB-associated stigma in societies varies, according to the ways in which society understands TB (Bennstam, et al., 2004; Rajeswari, et al., 2005; Somma, et al., 2008). Generally, patients experience some level of being stigmatised: usually either self perceived stigma and/or enacted stigma. Self-perceived stigma refers to the fear of rejection by family members, friends, and acquaintances anticipated by TB patients, so that they exclude themselves from their society. In contrast enacted stigma refers to the way society judges TB patients and act towards them; for instance, patients have reported feeling hatred or rejection by family members, friends, acquaintances, and members of community (Kelly, 1999; WHO/TDR, 2006; Baral, et al., 2007). The stigma associated with TB in many societies mainly resulted from fear of infection, perceived association(s) between TB and other sources of discriminations including poverty, low social status, HIV/AIDS, and divine punishment (Macq, et al., 2006; Baral, et al., 2007; Dodor, et al., 2008), and attitudes of health workers toward patients (Auer, 2003; Dodor, et al., 2009).

From previous research, it remains unclear whether people living with TB and their families in Cambodia experienced stigma. Although the Cambodian NTP acknowledged that stigma could possibly be a barrier to the success of control program, there was no

explicit discussion on how stigma associated with TB operates in Cambodia and its impacts on patients, family members and control activities. In this chapter, I first elaborate determinants of stigma; I then discuss how TB patients cope with stigma, before demonstrating how stigma affects relationship within the family and community. I conclude with an explanation of the implications of stigma on case detection and treatment adherence.

Determinants of stigma

Stigma associated with TB existed in rural Cambodia in the form of self-stigma and self-discrimination, as well as stigma and discrimination by relatives, friends and community members. Stigma was caused by multiple factors: fear of contagion and danger of TB, perceived association between TB symptoms and HIV/AIDS, myths and misunderstandings about the cause of TB (including the persistence of beliefs that TB is an hereditary disease), and the attitudes of health providers toward TB patients. These themes interacted with and further influenced stigma associated with TB. Each is discussed below.

Fear of contagion and danger of TB

Most contemporary Cambodians believed that TB disease caused less shame to patients than that experienced in the past, because of the availability of treatment. People generally felt compassion towards TB patients and their families, although they were reluctant to stay in close contact with them:

CC: Why are you scared of TB patients?

Mom: Contagion, I am scared of that the most. I don't want to get sick with TB. TB patients are dangerous to other people [so] they should not be in close contact with other people. They should not eat or share food or cooking utensils with others.

CC: Wouldn't that upset the patient?

Mom: They may be upset, but what can we do? They carry a contagious and dangerous disease. We have to protect ourselves from the disease, though we don't hate them.

CC: Do you mean that they should stay alone somewhere, away from others?

Mom: Not necessarily. They can live with their family and other people as usual. But they should be careful when talking to people. For example, they should wear a mask, and not cough or spit anywhere. I hate TB patients who do not care about transmission of TB to other people. I know an old man, he is *acha* (assistant to the monk), he has TB, but he skipped treatment; he doesn't care about transmission to others. He likes to speak to the public with a microphone. He speaks and he coughs at the same time. I think this man is dangerous. Some people don't know that he has TB, so they don't protect themselves. I hate that kind of person; they don't worry about transmitting disease to others.

Mom's account echoed those of other Cambodians. Generally, community members avoided TB patients because they viewed them as a dangerous source of infection that would endanger others. Fear of contagion often led to stated hatred of TB patients, particularly if the patient, like the man described by Mom, lacked a sense of responsibility to protect others from getting the disease. Some participants suspected that some TB patients were dangerous, as they could infect other people, and therefore they excluded them from social gatherings, as these two focus group participants highlighted:

My neighbour has the disease. She is very thin, and always coughs with sputum. But she still goes to the market and talks to people. Sometimes, she passes by my house and spits on the ground. I am really mad at her. I think she should stay home and be isolated from other people until she is cured. Doing this, she may want to make everyone else have the disease like her.

TB patients look *kour oy khpeum* (disgusting) when they cough and spit because the *merok* can spread everywhere around them and if we stay with them we can be infected too (FGD).

In rural Cambodia, TB patients usually lived with family members and continued their lives as usual if their symptoms were not severe. However, patients were expected to minimize their contact with others (e.g. not visiting other people's home or talking to others) and to act responsibly, by abiding with basic prevention practices, such as covering their mouths when talking to people and using separate eating utensils to prevent contagion to others.

Fear of transmission was also echoed in the community member survey data. Community members feared contagion and death caused by TB. There were few gender differences regarding fears related to TB, with two significant exceptions: men were more likely to be concerned about the health consequences of TB ($p < 0.001$) and the prolonged duration of treatment ($p < 0.05$) compared to women. This suggested that men, as family breadwinners, were worried about the economic impacts of TB, because the threat of TB contributed to loss of work productivity and income. Although there was no statistical significance, more women than men appeared to be scared of TB transmission.

Table 35: What makes you scared about TB?

	Male	Female	Total
Transmission	50 (42.0%)	64 (52.9%)	114 (47.5%)
Death	49 (41.2%)	41 (33.9%)	90 (37.5%)
Consequence after cure	20 (16.8%)	3 (1.3%)	23 (9.6%)*
Stigma (shame)	8 (6.7%)	7 (5.8%)	15 (6.3%)
Job loss	8 (6.7%)	7 (5.8%)	15 (6.3%)
Prolonged treatment	12 (10.1%)	4 (3.3%)	16 (6.7%)*

Multiple answers provided

Chi-square test ** $p < 0.05$, *** $p < 0.01$

Fear of contagion was exacerbated when TB patients presented with visible symptoms and physical frailty, particularly cough with abundant sputum or blood. People perceived that TB patients at this stage had a high chance of infecting others and therefore should be either hospitalized or restrict communication with others. Patients, such as Chantha, were aware of these fears and their implications:

I know that people disliked me because I had TB. They were scared of me, they were scared of my cough, and they were scared that I could infect them because I coughed so much. During that time, my neighbours and friends didn't come to my place or, if they met me somewhere, they didn't want to talk to me. But now it's not that bad. People have started talking to me again because I don't cough as much as before (Chantha).

As this comment suggests, fear of TB infection was influenced by the severity of symptoms, and patients without obvious symptoms did not experience much shame. They usually lived as normal, without censure, because others were not aware of their health problem:

I felt very ashamed to have TB, and I did not tell people at my work place that I had this disease. Since I started treatment, I don't have cough and I've put on some weight so I look normal, like others. Nobody suspects that I have any disease, so I can go to different functions in my village (Phally).

This implied that the presentation of severe TB symptoms amplified the fear of TB infection among community members, intensifying fear of TB patients. TB patients, on the other hand, may cover up their TB or not follow prevention advice to avoid being identified as TB patients because they feared rejection. This led some patients with suspected TB symptoms to refuse to seek diagnosis because of the implications of confirmed diagnosis. From a health providers' point of view, transmission of TB in the community remained a primary concern because there were some TB patients who would not enter DOTS treatment because they were scared of being diagnosed with TB, so that they continued their life as normal in the community and were treated with medication from pharmacy. These patients risked infecting other community members. The fears of health staff were described by Kosal:

Transmission of TB in the community remains high because some patients have TB symptoms but refuse to seek diagnosis, because they feel ashamed about the disease.

The transmission is particularly high within families of TB patients. I had one patient aged around 20. His father had TB, then died. His step-father also had TB. Now he has cough. I told him to submit a sputum sample, but he refused. I think he feels ashamed if he has TB, as people may call him *pouch robeng* (TB family). I have difficulties with these kinds of patients; I can't do anything to help them. These patients can be dangerous because they continue to infect people around them.

People's fear of contracting TB resulted from fears about its danger. TB was viewed as a dangerous or deadly disease if appropriate treatment was not provided on time. As shown in Table 35, more than one-third of the population feared death caused by TB, and nearly one in ten feared the health consequences even after completing TB treatment. Further, people with past experience of seeing a patient die of TB had witnessed a horrible death: vomiting with blood or severe dyspnoea—and this terrified them:

In the past, if people knew someone who had TB, no one *rab an* (wanted to be friends) with the family because they were scared of the disease that was very dangerous, and there were no drugs to cure it. TB patients, in the end, die miserably in a puddle of blood. The family members who were left behind would be very ashamed. *Tuk dak keon chav* (arrange marriage for children) was also difficult because some families discriminate against *puch robeng* (family of TB) (Chamreun).

Community people usually shared their experience about the dangers associated with other community members, making people scared about contracting the disease. Although TB treatment was readily available, re-infection and deaths patients led to perceptions of TB as dangerous and possibly untreatable:

I heard that TB cannot be cured if the patient is old [40 or over], but for the young, if they take medicine correctly, they can be cured. I know one patient, he had TB then took treatment. He completed [it] but still looked thin and could not work. Later, I heard he had *robeng* again. This disease is scary (Heng).

In addition, many TB patients became weak after treatment and could not perform their work as usual, which contributed to making community members afraid of TB:

When my husband had TB, he coughed up a puddle of blood. That time, if I had not gotten help from relatives who lived in Phnom Penh, he would have died. My relatives took him to Phnom Penh, there he needed a blood transfusion, and then he was referred to the TB hospital in Phnom Penh. He was cured from TB, but he can't work hard like before (Romdol).

The impact of TB on patients' health after they were cured was a major concern. Many TB patients (men and women) lost work productivity after being sick with TB; however, community members perceived that the impacts of TB on women were more significant than men as the disease possibly affected women's general well-being including reproductive health:

Women who have TB are more ashamed than men, [as they] may have less chance to get married because TB destroys her beauty, so that no one wants to marry her. Plus, TB may affect to her *sbone* (womb) and her general health, so that she may not be able to have kids in the future. But men don't have that problem; they can get married and have a family as normal (FGD).

But not all believed that women would lose their chances of getting married or job opportunities if they fully recover from TB, as Navy explained:

I lost a lot of weight (around 10 kilograms). I was very worried as people started questioning about what had happened to me. But since I took the medicines, I have gained weight gradually. I think my health has been good during and after the treatment. But I heard that TB can affect *sbone* (womb). I don't know what will happen to me, I'm also worried about this (Navy).

Association with HIV/AIDS

Many studies have found that TB is particularly stigmatised because of its connection to HIV/AIDS—a very stigmatised disease (Macq, et al., 2005; Mark, et al., 2006; Dodor, et al.,

2008; Mahendradhata, et al., 2008a). In the present study, people also associated TB with HIV/AIDS, leading to increased stigma. The association between TB and HIV resulted from: common symptoms (weight loss, repetitive fever, and prolonged cough) shared by both conditions and the NTP's requirement for TB patients to undertake HIV testing.

It was common that community members regarded symptoms such as persistent fever, cough, and being skinny in term of HIV/AIDS. Many community members had experienced seeing people living with HIV/AIDS, or seeing patients co-infected with both HIV and TB:

A son of my relative worked at a factory in Phnom Penh and was sick with persistent fever, severe cough, and weight loss. We suspected that he had AIDS, but the family said that he had liver disease, then TB, and they sought treatment from many providers. At last we heard that he had AIDS. Shortly after he was diagnosed with HIV/AIDS, he died (Neang).

Although TB was often associated with HIV/AIDS, community members perceived that HIV/AIDS was more stigmatised than TB because the HIV is more dangerous, has no cure and, more importantly, it is caused by 'bad behaviour', for example having multiple sex partners at the same time, which is considered to be immoral. TB, on the other hand, was believed to be caused by factors that are beyond control of the patient:

AIDS making patients felt more *amas* (ashamed) because they have bad behaviour. They have sex with sex workers. AIDS is very dangerous. People with AIDS look terrible; their skin is full of blisters, much worse than TB. For TB patients, however, people are scared of them when they carry the disease, but they can recover if they take medicine and follow health staff advice, and they can have normal relationships with people when they are cured. For HIV, there is no cure. Having HIV means the end of life (FGD).

Some TB patients who suffered persistent symptoms of cough, fever, weight loss, and feeling weak, experienced suspicion about their HIV status from their family members. For

example, Rithy (40, M) was suspected as having AIDS after several TB treatment programs for him had failed and his health continued to worsen. Rithy denied that he could ever have AIDS and he did not want to have the HIV test. He viewed that his wife's suspicions about AIDS showed lack of trust and respect. However, his denial increased suspicions about AIDS from his wife and relatives, leading them to secretly seek an HIV test for him when he was hospitalized:

Since I was sick for a long time my wife got fed up with searching for a treatment for me. We spent a lot of money [by selling property] to treat my illness. My wife and my relatives suspected that I have AIDS. At that time, when I was hospitalized, my wife asked *peet* to do my blood test but they did not let me know about the test. On the day they got the result, my wife and *peet* were smiling and told me that I was *phot kros* (free from bad fortune), because I did not have HIV/AIDS. *Peet* said that I had severe typhoid and he advised that I should take medicines and rest, so I can be cured. Not long after I was discharged from the hospital, I was sick again and I coughed with blood, I suspected that I may have TB, and then I went to the health centre and requested TB diagnosis (Rithy).

The practice of seeking HIV diagnosis initiated by caregivers reflects that HIV tests were sometimes performed without consent of the patients. After receiving their test results, TB patients who did not have HIV usually received support from family members to seek an appropriate diagnosis and treatment.

Besides the presentation of similar symptoms for both TB and HIV/AIDS, the NTP requires that all TB patients enrolled under DOTS undergo HIV testing. This led to misunderstandings that TB and HIV are inevitably co-infections, whereby people believed that when someone had TB, they could develop HIV. Mali explained why she would need to have an HIV test:

I think *peet* asked me to do a HIV test because TB and HIV are related to each other. At first, patients have cough or lung infection, then [it becomes] TB and later it may

become HIV. When I was first admitted to hospital, *peet* asked me to do the [HIV] blood test before taking my sputum. I am scared the most about AIDS, but my test result showed that I don't have AIDS. I think possibly because I have treated my TB in time (Mali)

Mali's account also reflected misunderstandings that untreated, failed, or defaulted TB could result in HIV/AIDS, which could lead to further stigma for reinfected patients. Misunderstandings about the association between TB and HIV could result from lack of explanations about the benefits of HIV testing to TB patients (i.e. ensure effectiveness of TB treatment by providing correct indication; treat HIV/AIDS on time). This caused rejection of or doubts about the purposes of the test, and increased stigma associated with TB. Further, patients often felt distraught when they were requested to undergo an HIV test because they presumed that the request meant that they might also carry HIV, as Bona explained:

Last time, when I collected medicines, *peet* told me that I should go to a volunteer counselling and testing centre (VCTC) to have a blood test. I was quite shocked and upset about what was wrong with me. I asked *peet* why I needed to do a blood test. He said that it's up to me, but *peet* needed a blood test for his record. So far, I haven't had HIV test yet.

In addition to the perceived connection between TB and HIV, the diagnosis of HIV among TB patients led to perceptions that TB and HIV are associated:

I was sick very long time, and then I was admitted to the hospital. *Peet* asked me to submit sputum, then they knew that I had TB. I was hospitalised on the TB ward. One day *peet* sent all patients to do a blood test in another ward. I didn't know what the blood test was for until *peet* provided counselling before taking my blood. Then I knew that it was a blood test for HIV. Actually, I didn't want to do the test, but I felt it was too hard to refuse because I was already in the room, so I agreed to do the test. My result was positive. I was very upset, but *peet* support me and sent me to an NGO for further support. They registered me and consoled me. They provided food

support for my family. *Peet* told me to bring my wife and my children for blood testing. My wife also has HIV, but none of my eight children have AIDS. Many people in my village know that we have AIDS. Some of them felt compassion towards us, but some hate us (*Vuth*).

Although HIV testing is required for all TB patients enrolling in DOTS, not all participants were informed about the test or had undertaken the test. Of the 32 TB patients in this study (one of whom knew her HIV status before having TB), six had had a HIV blood test. Four did the test at a VCTC because they were sent there, one did the test at a private laboratory, and one had a blood sample taken at the health centre but never heard the result.

Many patients were not asked to have HIV test because they were not considered to be in a high-risk group. *Kolab* reported that she had a blood test to check for her health problem, but no provider had ever asked her to have a HIV/AIDS test as she was young and single:

I did a blood test before to find out what was happening with me, but not for AIDS.
Peet didn't ask me to do HIV test. I don't need the test. I'm single (laughs).

Kolab laughed when she talked about HIV testing, as she thought it was ridiculous and nonsense to propose HIV testing to single women like her. She, like others, believed that HIV tests should be proposed only to people who possibly were engaged in risky behaviour related to HIV, as *Kravan* explained:

Peet did not ask me to do HIV testing, possibly because I'm already old and my husband is also old, so we don't need HIV test. We never engaged in such disgusting behaviour. I think if old people have AIDS, it makes young people laugh at them "old age and bad behaviour!". I think he should hide the disease or commit suicide because it is very shameful to disgrace other old people. If it was me, I would do that.

These accounts confirmed HIV testing was usually proposed to particular patients who tended to be regarded as most vulnerable to HIV. Young single women or old people tended to be regarded as having low risk of HIV because they were considered unlikely to engage in risky sexual behaviour. It also seemed this group would face more stigma and social exclusion if they had HIV, as it was believed that they should be role models for society. This expectation also contributed to high refusals of HIV testing among this group.

Myths and misunderstandings of the cause of TB

As discussed in chapter 3, some community members perceived that TB was a hereditary disease that could be passed between generations. Although most people understood that TB is transmitted from one person to another, some community members misunderstood that TB belongs to *puch ro beng*, and that members of those families were more at risk of getting the disease. The perceptions of *puch ro beng* led to self-stigma among families that had TB patient across generations. Romdol felt ashamed to be a member of a 'TB family'. Romdol's husband had TB years ago. Her father-in-law had also had TB and passed away before she married her husband. Romdol believed that she got TB from her husband.

My husband had TB several years ago, his father had TB and passed away. I think TB always happens in a family. My father-in-law had TB; maybe his ancestors also had TB. I'm worried that my children could have TB too. If I had known that he [the husband] had *puch robeng*, I would not have married him. I'm serious, it is shameful. I don't deny that TB can go from one to another, but I believe it more likely that TB goes from parents to children. It was painful when I heard my neighbours call my kids *puch robeng*, I felt sorry for my kids (Romdol).

Romdol's and her neighbours' perceptions of TB as a hereditary disease focussed on inheritance, and this made them blind to the fact that it was likely to be the social environment that lead to TB transmission among family members. Furthermore, some

community members held misconceptions that TB was associated with poor lifestyle, such as heavy use of alcohol or tobacco and lack of hygiene in their living environment. This led to blaming of TB patients who were seen as deserving the disease as a result of their lifestyle:

Normally TB happens among those who smoke and drink (alcohol), especially women. I see a woman who drinks and smokes often end up having TB, and if she has TB, it is hard to get it cured (FGD)

TB happens in families with poor hygiene. They have the disease one after another. We educate them to be hygienic about not spitting, but they don't listen (Dara).

The perceptions of TB as a consequence of poor lifestyle led to a stereotype of TB as a disease of poor, unhygienic people, associated with heavy smoking and drinking. Again, these perceptions reinforced the fact that patients were not stigmatised only because they had TB, but because of their low-social status. Poor people tended to present with obvious severe TB symptoms due to their lack of appropriate care and nutrition before and during TB diagnosis and treatment, and this led to other members of the community easily identifying them as TB patients.

Stigmatized by health staff attitudes

From patients' and community members' points of views the attitudes of health staff towards TB patients made them believe that TB is highly contagious and they felt ashamed or embarrassed if they had the disease. Health staff usually advised patients to cover mouth with *kruma* (scarf) when coughing or talking to them (which may further impact on patient-provider communication); further, patients who failed to follow this advice (not covering when talking to health staff members, spitting in the hospital compound) would be blamed for not paying attention to medical advice and lacking morality to protect others from infections. Such blame made patients feel ashamed:

Peet move away when a TB patient approaches them. They scold patients who spit on the ground or cough without covering their mouths. I can see that they are scared of TB infection and they want patients to be hygienic, and this makes me scared of TB too (Ui).

I saw *peet* scold patients who spit on the ground or talk to him without covering his mouth, so I am very careful not to spit anywhere. I think *Peet* also scared of TB, they do not come into the TB ward, or they just come in for a short time. I don't talk to *peet* often, although I stay at the hospital because *peet* do not attend me every day (Sophal).

Health staff attitudes towards patients made them feel ashamed and reinforced the idea that TB is a very dangerous disease and they needed to be isolated from others. In addition, health staff attitudes towards patients led to increased fear among community members regarding infection and therefore avoidance of contact with TB patients.

Despite these community perceptions, health staff believed that they minimized stigma associated with TB when working with patients. For example, health staff were advised by the NTP not to wear masks or gloves when attending to TB patients who were already under treatment in order to reduce stigma against patients. However, this practice may not help to reduce stigma because it caused health staff to feel uncomfortable when interacting with patients without this protection. Health staff perceived that working without proper protection could put them at risk of contracting TB:

We don't worry much about transmission because we know that after 15 to 20 days of treatment, TB does not transmit anymore. But I once had a severe TB case admitted in the hospital. I had to save him urgently, [so] I did not take serious precaution. My work could put me at risk (Vannak).

Our work is risky. I try to explain patients to cover mouth when they talk or cough. But some patients are stubborn; they talk and cough loudly without caring that other people are around. I have one patient seeking TB diagnosis; the result showed [that in] just one sample of his sputum, he has 3(+) [so many bacterial in the sputum]. I

asked him to stand and wait outside, he came in the room, talking and coughing without covering his mouth, and I didn't wear mask either at that time. This was very dangerous for me. When I told him not to talk loudly and to cover his mouth, he was upset and thought that I was looking down on him (Kunthea).

Health staff were aware that the risk of TB infection was increased when someone had prolonged contact with a patient (smear positive) in a confined space with lack of ventilation. Although they knew that TB was no longer infectious after two weeks of their proper medication (WHO, 2003), they were concerned about their risk of infection, as they experienced that some TB patients still had sputum positive smears after completing the intensive phase of treatment. For TB prevention purposes, health workers usually asked patients to stand or sit at a distance (more than one metre) from them, and kept their interactions brief.

Patients who sought TB diagnosis at public health facilities felt ashamed due to the lack of confidentiality and privacy. During my observations, health facilities did not provide a private space for patients to provide sputum or to take their medicines. To collect sputum from patients, health staff gave sputum cups and advised patients to go far from others to cough. Phally explained how she gave her sputum samples:

Peet gave me one cup and told me to cough up sputum and put it in the cup, then give it back to him. I went to cough behind a tree, I felt ashamed to cough there, but I couldn't find a quiet place. I felt ashamed when *peet* talk loudly to me in front of everyone about my disease, but I wanted to get medicine so I had to do the best I could. The next day I brought sputum that I cough at home in other two containers to *peet*. It was more convenient to get sputum at home because I can do it privately.

Health workers also admitted that the lack of a private place for patients to cough made patients embarrassed to produce sputum when there were people around them, and this possibly affected the quality of sputum provided. Staff members understood that patients

should drink hot water and should walk around before coughing sputum; despite this, the health staff did not attempt to provide a private place and hot water to patients.



Figure 26: A TB patient waits to take medicine at health centre

In addition, the lack of confidentiality and privacy at the health centre made patients feel ashamed and embarrassed when taking TB medicines in front of other patients. Taking medicine at a health facility usually disclosed patients' status to other community members; therefore some patients would try to negotiate with health workers to take their medicines at home. Through observation, TB patients who took TB medicine at the health centre usually met the stock keeper—a staff member who was responsible for the health centre's pharmacy, and then they took their medicine in front of him/her. This usually occurred outside the pharmacy room where other patients could see them:

After I was diagnosed with TB, *peet* asked me to come to the health centre every morning to take medicines. My father took me... I took medicine outside the pharmacy where other patients at the health centre could see me. I felt very ashamed

that I have this disease, although no one said anything to me. Later my mum negotiated with *peet* for me to take medicine at home (Navy).

Health providers were not sensitive to stigma associated with TB; they usually handled TB patients in a similar way to other patients who sought care from public health facilities. Therefore, patients who were concerned about the stigma associated with TB may have sought treatment from more confidential facilities, such as pharmacy or private practices.

Coping with stigma: patients' strategies

TB patients were aware that, historically, TB was a stigmatised disease, and that the bearers of the disease continued to be perceived as risky to other members of the community. This made TB patients anticipate that community members would reject and avoid them if they discovered their disease, and they therefore felt reluctant to communicate with others outside their immediate family. Some patients faced enacted stigma by community members, where they were rejected or hated because of their TB status. To cope with stigma, TB patients usually self-isolated or hid their disease, as discussed in the following section.

Social Isolation

TB patients generally isolated themselves from family, friends and community members, particularly when experiencing severe symptoms. This 'self-isolation' was undertaken to prevent or minimise transmission:

Since I have been diagnosed with TB, I eat separately from my family. I don't sleep with my wife and do not stayed close to my grandchildren as before. I use separate eating stuff...I heard *peet* say that I should be isolated from others to avoid transmitting my disease to them, so I do my best to prevent my family members [from contracting TB]. I don't want them to be sick (Lim).

Isolation was common at the stage when symptoms are obvious (repetitive cough, with sputum or blood). Some patients who had had severe health conditions choose to stay in the hospital, because they did not want to bother family members to take care of them and to avoid transmission of the disease to family members. Samreth explained:

Being hospitalized here is good because I stay away from my family, I don't want to transmit the disease to them. When I don't have a cough and feel better, I will ask *peet* if I can to go back home and I can live as normal with my family.

Some patients isolated themselves from friends or relatives because they feared rejection. This was a very real fear: some patients reported experiencing rejection from relatives and community members. In order to minimize rejection, these patients tried to restrict communication with others and did not participate in gatherings or in any functions in their villages, quit their job, or ceased their business until they were cured or their symptoms disappeared.

Fear of gossip was a main reason why patients isolated themselves from neighbours and friends:

I don't want to meet people because I don't want them to ask about my disease. I think that people are scared of TB and if they know that I have this disease, and they will start to gossip about me (Kanika).

Patients who had both TB and HIV experienced particularly heightened levels of stigma, making them isolate themselves from community members or family members in order to avoid shame or gossip. Rotana explained:

When I go somewhere in my village, I never look at other people's faces. I'm scared of their eyes; I know that they are going to talk behind my back. I never visit friends or family members because I know that they are scared of me. One day, I went to the house of the village head to ask him to sign a letter. When I was about to leave, I heard his wife and other family members *dem dam* (insult me indirectly) about my

disease. It is painful to hear that, but I have gotten used to it, so I just let it go. If I am not very sick I go to the city or to other provinces to find a job. There, nobody knows me, and I come back when I have to collect medicines and rice from the hospital. I focus on finding a job when I can, because I have to support my two children who live with my parent-in-laws in a pagoda in Phnom Penh. I don't have them with me because I don't want them to be ashamed of me. They don't know that I have HIV and TB.

Hiding the disease

Some patients who did not have severe symptoms continued to work or live as normal, but took steps to hid their status from others. TB patients referred their illness a 'lung disease' instead of TB in order to cover their status; this was also reported in a study conducted in Java (Indonesia)(Widjanarko, et al., 2009). Other patients, particularly those who worked during treatment, did not tell anyone about their health condition. Phally, a factory worker, left her job during the intensive phase of her TB treatment, then resumed her work after completing the first month of treatment. She did not tell her boss or her friends that she had TB:

CC: Do your friends know that you were sick?

Phally: No, I didn't tell them and now I'm normal. I look normal and I try to work like a normal person, I don't tell people that I'm sick.

CC: Why don't you let them know that you're sick? They may give you special treatment?

Phally: No, if they knew that I had TB, they may not accept me, and if my colleagues knew that I had TB they would dump me, they are scared of infection. Now nobody at the factory knows that I had TB, everything is normal; I eat and go along with my friends as normal.

Covering (hiding) the disease was very common among TB patients, regardless of their age and gender or socio-economic status, and in a range of contexts. They covered their illness

to acquaintances, neighbours, or fellow villagers if they anticipated that those people might reject them. But, more importantly, patients covered up their TB when they looked for a job (mainly as a labourer or as a daily worker) because they feared being rejected, as TB patients were labelled as ‘weak person’, unable to work hard:

I don’t tell anybody at my work about my disease. Some saw me taking medicine everyday, and they asked me. I told them that it’s medicine for *kamlang* (to boost energy), so they don’t ask any more (Kiri).

However, TB patients disclosed their status to close relatives, friends, and to individuals or organizations that seemed not to make judgements about the cause of their TB, and that offered support:

The members of the church are very kind to me. When I told them that I have TB, they felt compassion. They offer me good food and encouraged me to take medicines properly. The head of the church supports me with 10kg of rice and some money every month, because they want me to avoid working hard when I am under treatment (Rithy).

Patients’ disclosure of their illness was influenced by their confidence that people around them would not reject them because of their TB. Usually TB patients disclosed their status to family members and close relatives and friends. Older people usually faced much less stigma by their peers as other old people were not much concerned about TB transmission:

At this old age I’m not concerned much about dying. I go to the Pagoda every *sel* (the Buddha’s day). Other old people are not scared of me; they do not hate me when they see that I come to the pagoda. They were happy [to see me], and everyone asked about my health. I asked about their health, too (Vath).

This lack of concern about transmission reduced stigma experienced by patients, but it may contribute to increasing transmission among the elderly. Furthermore, the lack of appropriate nutrition and weakened immune systems among older population could favour

the progression of latent TB to active TB in this group, and may, at least in part, explain the high prevalence of TB in older people in Cambodia.

Implication of stigma

Implication on self

As discussed above, TB patients were very aware about stigma and struggled to cope with it. Those who believed that TB could be transmitted from one to another through contact perceived themselves as ‘sources of transmission’ that could potentially endanger others, particularly their immediate family members. This perception made them felt upset about themselves, particularly when they did not have other options to prevent transmission, as Lili explained:

I breastfeed my baby and looked after my other son as usual. I’m very worried that I may transmit TB to them because they live with me all the time. Further, I am very concerned that the medicines I take may affect my baby’s health in the future. If anything happened to him, I would be very upset, because I am the one who infected them. I don’t know what to do. I can’t afford to stay away from them. I can’t afford infant formula. I knew that TB medicines come through my breast milk to him, I see the colour of the milk has changed; it looks like the colour of [TB] medicine.

I feel ashamed about myself having this [TB] disease; it’s dangerous and affects much of my life. I can’t hang out with my friends like before because I don’t want to infect them, beside they are also afraid of me. I am absent from school quite often because I have side effects from the TB medicines. My results at school this year are not good; I am not sure whether or not I can pass the grade, because I’ve missed many exams. I feel ashamed to fall behind other friends (Chamrong).

Lili and Chamrong were like other patients who regarded themselves as a ‘source of TB transmission’ and who could harm others. This perception tended to bring distress to patients and increased felt stigma, such as feelings of shame and embarrassment. Patients

also felt that the disease affected roles in the family and therefore they lacked self-esteem and pride.

Since I felt sick [before and during treatment with TB] until now, I could not work, [so] I moved here to live with my parents. Now if I tried to work in the rice fields or carry something heavy, I feel very tired. I'm very worried that if I can't work hard, how I can survive, I am a man, but I can't help my family. My parents cannot feed me forever; they are old. Beside I have my family... my wife stays with her mother, she is pregnant, and I don't want to take her here because I am afraid that I could infect her and the baby (Sovann).

TB patients thought that they were a 'source of transmission' although under treatment. This reflected their lack of understanding about the period of infectivity and proper prevention practices. Some TB patients perceived that TB was associated with their poor lifestyle, and they believed that they developed TB as a consequence of their unhealthy behaviour:

Because we coughed, *kak, sdas* (cough-up sputum and spit) make people around us felt horrible and are scared of TB. I am angry with myself of having this strange disease. I think that if I have to die, I should die. I should not carry this dangerous disease. I don't want it to transmit to others, this disease is difficult and I feel very uncomfortable in my body... It's my fault. I was smoking and drinking so much. I didn't look after myself well, that's why I have the disease (Meng).

Perceptions of TB as associated with poor lifestyle led to self-blame for their bad behaviour and lack of responsibility. However, TB patients viewed that, despite potentially endangering others, they did not deserve discrimination because of their illness:

Who wants to have the disease? People should take this point to think, put themselves in our position, who wants to have TB? It affects patients' lives; it costs a lot of money to cure the disease. I think TB patients should be treated the same way as other patients and should be supported (Samnang).

Within families

The impact of stigma associated with TB on family relationships was not significant. Although family members feared contagion, or some level of shame of having a family member contract TB, they did not reject the patients. In contrast, they provided full support to the patient to go through their treatment:

I felt compassion for my daughter; she is still young and has this disease. I am concerned about her health now and in the future. I always remind her to take her treatment properly. I don't tell people that she had TB because I think it's unnecessary, people can create rumours about her, and it may affect her work too (Chan).

Family support provided to patients included financial support as well as care at home or in hospital. Most patients received warm treatment from their family members during their sickness, especially as they struggled with the side effects of treatment:

My wife always prepared good food for me. Every day she spends a lot [of money] on me because she wanted me to be strong to beat the disease and [cope with] the treatment. My family is poor, but she borrowed money from our relatives to buy good food for me (Sophal).

Support from family members was paramount for patients to overcome distress related to TB and to comply with treatment, as Phally explained:

CC: Have there been any changes in the relationship with your husband?

Phally: No, my husband said he isn't afraid of transmission from me. I asked him to stay away from me, but he refused. He doesn't worry about the transmission.

CC: Do you sleep in the same bed?

Phally: Yes, but I always face the other side [of the bed]. If I cough, I cover my mouth with *kerama*. We haven't slept in separate beds since I became sick.

CC: What makes him not scared of getting the disease from you?

Phally: He said that if anything happens to him, it will happen. He doesn't believe that TB can be easily transmitted. He has always been with me, but he has never had a cough. But he loves me and he cares about me; he always reminds me to take my medicine regularly.

As Phally's account suggests, family relationships were modified or not depending on family members' perceptions of TB transmission. Families that were not concerned about transmission tended to continue their life as usual with the TB patients:

Since I became sick, nothing has changed in my family. I eat with my family and sleep with my wife and children as usual. So far nobody in my family has a cough like me, they only have ordinary diseases—colds or fever—for a short time (Phirum).

However, family members who perceived that TB is highly infectious disease modified their lifestyle to prevent infection within the family. For example, they required patients to follow preventive practices, such as eating separately, using separate eating utensils, and sleeping separately from their husband, wife, or children. However, this practice did not upset patients, because they wanted to prevent their family members contracting the disease:

My family asked me to eat separately from them, and they throw away any food leftovers from me. I also use separate plates, bowls, and spoons from others, and I have to wash and dry them under the sun. I sleep alone down [another part] the house (Rithy).

The prevention methods aim to minimize the risk of infection within the family. Some patients experienced anger from family members if they do not abide by family rules related to prevention.

My daughter would scream at me if I accidentally cuddled or kissed my grandson. She said that I could transmit disease to him. I didn't mean to do that to the little

baby, but sometimes I forgot. I love him so much. I don't want anything bad to happen to him (Kiri).

Other patients were worried about the possibility of infecting other family members, but they were unable to separate from their family members because they had to continue their roles in the family including cooking and feeding children. This was particularly the case for women, for example, they continued to take care of young children and family members although they had TB.

During my observations, family members and patients managed the same living arrangement before or after TB diagnosis was confirmed. However, some families made changes in the interpersonal contact with patients in order to prevent TB transmission. This practice may not be beneficial, however, as family members were exposed to a high risk of TB infection before treatment commenced, possibly accounting for the continuing TB infections in the community.

In the community

Most community members expressed that they did not hate TB patients, but were not comfortable communicating with TB patients because they feared TB infection:

The old couple in my village has TB; they were treated and have had it again many times. I told my children not to play with the children of that house. They may also have TB, and their children look very thin (Bopha).

Data from the survey with community members (Table 36) showed that most participants had positive attitudes toward TB patients. For example, nearly 90% of participants would agree to give money to support a relative who had TB, and about 85% would allow a relative who had TB to visit their home. On the other hand, nearly half of participants showed they would feel ashamed if they were themselves diagnosed with TB, and nearly

one fourth of participants would keep it secret if a family member had TB. This suggested that considerable stigma remains.

Table 36: Attitudes of community members toward TB patients (n=240)

	Strongly disagree	disagree	DK	agree	Strongly agree
TB is a curse for patients	42.5%	31.7%	1.2%	9.2%	15.4%
I would be ashamed if I had TB	25.8%	25%		25.8%	23.3%
I'll keep it secret if my family members has TB	47.9%	29.6%		9.6%	12.9%
I would allow relative with TB to visit my home	8.3%	6.7%		44.2%	40.8%
I would give money to relative with TB	4.2%	4.2%	0.4	37.5%	58.3%

Although most community members showed compassion and sympathy toward TB patients, it was not uncommon that TB patients experienced rejection by community members when they disclosed their status, as a result of fear of infection:

When I go to a wedding or to *Wat* (pagoda), people who know that I have TB don't want to sit at the same table and eat with me or talk to me. But now, when they see me put on weight and my skin looks bright, they talk to me as normal. They may think that I'm cured from TB, so they no longer discriminate (Kiri).

The discrimination against TB patients typically only occurred while patients presented with visible symptoms and thus, their relationships with community members became normal when they realized that the patients were cured or when TB symptoms disappeared (e.g. putting on weight). Generally, community members reported that they could not *identify* who had TB and who do not have TB if the patient covered their status; in contrast, however, they reported suspecting someone has TB based on whether he or she has physical weakness, cough and thinness.

Impact of stigma on case detection

Fear of stigma associated with TB led to delayed seeking of diagnosis and subsequent treatment, as patients sometimes denied that TB caused their early symptoms. 'Denial of TB' referred to people's tendency to reject suspicions regarding TB (Long, et al., 2001); thus patients often explained early TB symptoms as typhoid, colds or respiratory tract infections (ARI, bronchitis), then sought treatment accordingly.

In addition, health staff and community DOTS observers also faced challenges to encourage patients with early TB symptoms to seek diagnosis because patients denied thinking promptly about TB, and they regarded the suggestion by health staffs or C-DOTS for them to seek diagnosis as offensive:

I met one woman when I had outreach activities in the village, she [had] coughed for long time. When I told her to go the health centre to check for TB, she was mad at me for humiliating her. I suspected that she had TB, but she doesn't have any family members to care for her. She is a drinker, she gets drunk most of the time, so I cannot help her. I let her choose what she wants (Rotha).

Health staff faced difficulties in encouraging suspected patients to undertake a sputum test. Vulnerable patients seemed to be more likely to encounter stigmatization and discrimination due to their social status, and may have feared that being diagnosed with TB would bring more shame on them. In addition, the lack of special attention paid by health workers to disadvantaged groups led them live with TB infection, and to continue to spread the disease throughout their community. Community volunteers (C-DOTS observer) also faced difficulties in communicating with people with suspected TB in order to encourage them to seek an early diagnosis:

My role is to explain to people with health problems to go to a health centre or hospital. If I see people cough for a long time, with weight loss, I ask them about the symptoms and then I tell them to go to a health centre. I usually send patients to the

health centre if they have clear TB symptoms. I don't talk with them about TB if they just have a cough for some time but with no fever, no weight loss. I am afraid that they may be angry with me because they might think that I curse them or want them to be sick, so I have to be careful (Sunary).

I suspect one family in my village may have TB. They are very poor and look thin. The mother is very thin, she coughs very often, and one of her sons also has cough. I suggested that they go to the health centre to check for TB, but she was angry with me, saying that I looked down on her family. She said she is thin but does not have TB, so I keep quiet and have never talked to her again (Cheata).

These excerpts indicate that community health volunteers may only send patients who had already developed indicative TB symptoms to seek diagnosis at public health facility, and are therefore playing a limited role in early detection. Reluctance to refer people without full TB symptoms to seek diagnosis was caused by fear of angry reactions from other members of the community where the C-DOTS lived. This reluctance may have also reflected the lack of communication skills among health volunteers that could limit them from being effective in encouraging community members with early TB symptoms to present promptly at a public health facility.

Implications of stigma on treatment outcome

Stigma had little effect on the treatment outcomes of TB patients who had entered DOTS program. Although TB patients felt ashamed and disappointed when they were diagnosed with TB, these feelings did not affect the ways in which they went through with the treatment, including whether they defaulted or were non-adherent. To avoid rejection in of the workplace, patients who suffered severe side effects of TB treatment usually quit their job or changed jobs (e.g. went from working as a full-time factory worker to becoming a casual labourer) in order to comply with treatment. Those who continued working managed to take their medicine before or after work; these patients tended to receive full

family support when collecting TB medicines from the health centre. Their families also played an integral role in adherence to treatment, by reminding them to take the medicines:

I worked in the factory from early morning and arrived home late every day; my father took enough medicines for me from the health centre for two weeks. *Peet* told me to take medicines in the early morning, but I take it at night before going to sleep, because if I take it in the morning, I can't work. I feel sick the whole day and I don't want to be fired from work, so I take it in the evening instead, then I sleep. I'm worried that the medicines may not be as effective as when taking at the morning, but I can't do anything because I have to work. I didn't consult *peet* about the change of treatment (Kolab).

As Kolab described, out of necessity, TB patients changed the time they took medicines (e.g. from morning to evening) in order to continue their work. Kolab was not necessarily doing that to hide her TB status, but more to ensure that the side effects from the medication did not affect her work performance. This allowed her to keep her job and allowed her to not disclose her TB status. This suggests that, although stigma associated with TB did not affect individuals' compliance to treatment, it may instead affect their decision-making about where and how they sought treatment, which may also affect their treatment outcomes.

Stigma associated with TB in Cambodia has long existed. Improvements to TB treatment through the introduction of DOTS has improved outcomes, and therefore changed perceptions of community members towards TB. The disease is now viewed as a curable disease, and thus the stigma associated with TB has decreased compared with the past. Nonetheless, stigma associated with TB remains an important determinant of health-seeking in rural Cambodia and has implications for the lives of TB patients, case detection activities and treatment outcomes—none of which should be neglected by health providers and policy makers.

The fear of contagion and the perceived dangers of TB appeared to be the most potential determinants of stigma in this setting. These fears led to rejection of TB patients and poor staff attitudes toward patients, as described above. This is supported by international research confirming that the fear of contracting TB was the main cause of stigma and discrimination against patients (Bennstam, et al., 2004; Macq, et al., 2005; Weiss & Ramakrishna, 2006; WHO/TDR, 2006; Somma, et al., 2008). Kelly, 1999 #319;Dodor, 2009 #2690;Dodor, 2008 #2692;Karim, 2007 #465;Weiss, 2008 #517}. The fear of contagion played an important role in Nepal, where TB patients experienced discrimination from friends, family members, health workers, and community members (Baral, et al., 2007). Fear of infection was identified as underpinning other factors, such as the physical weakness of patient, the perceived association of TB and HIV, public health practices and discourse, self-stigmatization by patient, judgment, blaming and shaming of TB patients, and past experiences with TB (e.g. having seen someone died with TB) (Dodor, et al., 2008; Dodor & Kelly, 2009); all of which contributed to community stigma.

The attitude of health staff towards TB patients could also lead to stigma. In Ghana and Nepal, health staff were viewed as potential stigmatisers of TB because of their practices such as excluding and isolating TB patients from others, providing inaccurate health education messages to community members, and prohibiting full burial rites for TB patients who died; in this way, health providers brought shame to TB patients and family members (Baral, et al., 2007; Dodor, et al., 2009). This present study illustrated that, although health staff attempted to minimize shame associated with TB to patients, their interactions with the patients led community members to perceive that TB is frightening, and that people should avoid close contact with patients.

Stigma associated with TB was more pronounced when patients presented with visible, physical frailty and symptoms such as severe cough, bleeding cough, difficulty breathing

and significant weight loss. At the same time, the bodily condition (e.g. skeletally thin) of patients made community members promptly suspect that the patient may have been infected with HIV/AIDS. Other authors have also confirmed that the perceived link of TB and HIV has increased TB stigma (Godfrey-Faussett & Ayles, 2003; Bond & Nyblade, 2006). Moreover, as pointed out by the participants, the requirement of HIV testing among TB patients increased the stigma associated with TB, as both community members and patients were confused that about the relationship between TB and AIDS. Patients with 'double disease' (TB and HIV) were therefore perceived to be both dangerous, because they carried a contagious disease; as they were seen as having been engaged with sexual taboo behaviours, were thus perceived as deserving the disease. TB-related stigma was exacerbated further by the disadvantaged status of patients (e.g. being extremely poor and/or unemployed), which meant that they were further discriminated against when they had TB because of their low social status.

The implication of stigma for TB patients in this study varied. TB patients were the stigmatized individuals, who were either "discreditable" or "discredited" (Goffman, 1963). Those who were discreditable possessed stigmatising characteristic (e.g. symptoms which may indicate TB) but had not been discredited because the devalued quality was not fully revealed—through diagnosis or disclosure in this case (Goffman, 1963). Some TB patients did not present with visible symptoms, and could thus prevent themselves from being stigmatized. A discredited person has been socially excluded and marginalized because of their uncovered social devalued identity; in this study, thus included patients with severe symptoms or those who lived with both HIV and TB. The implication of stigma on TB patient life was considerable, and TB patients frequently self-reported perceived stigma, which led them to feelings of self-hate, self-isolation, low self-esteem, and depression. Moreover, some TB patients experienced being rejected or discriminated by community

members, health workers, and family members. Inside the family, for example, TB patients were asked to eat and sleep separately from family members and not to kiss young children. Within the community, TB patients were expected to abide with preventive practices or were rejected from joint gatherings. Within health settings, TB patients were isolated from other patients and were required to follow preventive practices when talking to health workers. TB patients therefore responded to perceived stigma by attempting to self-isolate or conceal their status. This study also found that self-isolation occurred as a way of reducing gossip and this way, echoes Nepalese research (Baral, et al., 2007), where stigma led patients to isolate or conceal their illness by seeking confidential health services (Johansson, et al., 2000; Long, et al., 2001; Lonnroth, et al., 2001). Self-perceived stigma appeared to be more pronounced among women, who perceived that their roles as caregivers of the family could bring harm to family members, particularly young children. Similarly, women in India, Bangladesh and Vietnam experienced more distress than men as a result of TB associated stigma, as reported, being abandoned by their husbands, isolated within their household, or being neglected by their family members (Long, et al., 2001; Gosoni, et al., 2008).

Stigma associated with TB also impacted on case detection. Most community members were aware of the stigma and discrimination towards TB patients; and it is possible that, if they had any early TB symptoms, they may have feared being diagnosed with and thus sought another diagnosis. Indeed, TB patients in this study commonly understood their early symptoms in term of non-stigmatized conditions such as typhoid, stomach disease, or cold, and thus sought treatment accordingly. This echoes other research from Vietnam, Ethiopia, India, Taiwan and Thailand (Long, et al., 1999a; Johansson, et al., 2000; Atre, et al., 2004; Hansel, et al., 2004; Cambanis, et al., 2005; Jittimanee, et al., 2009; Wu, et al., 2009) illustrating that fear of the social isolation caused by stigma associated with TB led

patients to deny suspecting TB, avoid seeking TB diagnosis or seek diagnosis from confidential services (private health providers or traditional healers), and prefer to keep their diagnosis secret.

Stigma has also been found to be associated with non-adherence to TB treatment (Watkins, et al., 2004; Naidoo, et al., 2009). However, this study found that, once patients were diagnosed and began treatment at public health facilities, they continued through treatment, even if they felt ashamed about the diagnosis. The study also showed that with appropriate support and without stigma and discrimination against them, TB patients tended to disclose their disease. Thus, interventions related to TB stigma in rural Cambodia have two main tasks: 1) removing the myths and misconceptions related to TB causation transmission and HIV testing for TB patients, and 2) improving access to public health services by ensuring confidentiality and privacy for TB patients.

CHAPTER 8

RESEARCH IMPLICATIONS

Since the introduction of DOTS in Cambodia in 1994, the NTP has made remarkable improvements in TB control. TB diagnosis and treatment is available in every health centre and referral hospital (RH) throughout the country (CENAT, 2006b), allowing the NTP to attain the WHO target of 70% for smear-positive pulmonary TB case detection and maintain the TB cure rate of 85% among patients enrolled in the DOTS program (WHO, 2001; CENAT, 2009). However, despite these achievements Cambodia has not reached expected reduction in the TB incidence rate. After more than a decade of DOTS implementation, the country remains one of the 22 highest burden countries in relation to TB (WHO, 2008a). The present study illustrated that the main challenges for DOTS implementation related to the significantly delayed presentation to DOTS amongst TB patients, and the inability of a number of patients to complete treatment, leading to continued TB infection in the community. These challenges are not Cambodia's alone, and are encountered in many developing countries. Although DOTS has been implemented for many years, TB incidence has not decreased as expected due to increases in continued TB infections in particular population groups due to delayed presentation to and failure to complete treatment (Lonnroth, et al., 2009).

Although, in theory, in Cambodia, TB diagnosis and treatment is universally accessible free of charge at the public health services, TB patients experienced significantly delayed access to diagnosis and treatment. Patients commonly used multiple providers and treatment including home remedies, over-the-counter medication from pharmacies, private providers and/or *Kru Khmer* before presentation to DOTS. This practice is similar to health-seeking behaviour in other settings (Lonnroth, et al., 2001; Nyamongo, 2002; Xeuatvongsa, 2005;

Saw Saw, 2006; Chuma, et al., 2007). This study has demonstrated key reasons why patients engaged with these other providers prior to their presentation to the government facilities where the DOTS program is provided. Their health-seeking behaviour is shaped by the interactions of multiple factors (see Figure 27): individual factors, including understanding on TB, institutional factors related to access to public health services, and reinforcing factors including family and economic status. These findings have significant implications for the delivery of the TB-related health care in Cambodia; these, with recommendations for policy change, are discussed below.

Addressing health education to improve early case detection and TB treatment adherence

Patients' health-seeking behaviour from symptom onset to the DOTS program was driven by people's cultural beliefs about TB. Their explanatory models shaped how patients interpret and respond to their symptoms. As they were often without exposure to effective TB program health campaigns, people in rural communities generally had limited knowledge of TB regarding symptoms, aetiology, contagion, prevention, and treatment. Their explanations of TB were overwhelmingly influenced by inappropriate and/or inaccurate information about TB, based on folk and traditional beliefs regarding health. For example, participants learnt about TB through folk ideas (e.g. TB was caused by hard work or extreme climate) shared among community members. TB information from the professional health sector was very limited due to the lack of health education provided at the public health facilities and/or in the community. Lack of understanding of TB symptoms led many participants to delay their presentation to a DOTS program at a public health facility because they did not suspect TB from their early symptoms. Furthermore, lack of understanding about TB treatment, including duration of treatment, possible side effects and how to overcome these side effects, was a contributing factor in patient failure to complete a course of treatment.

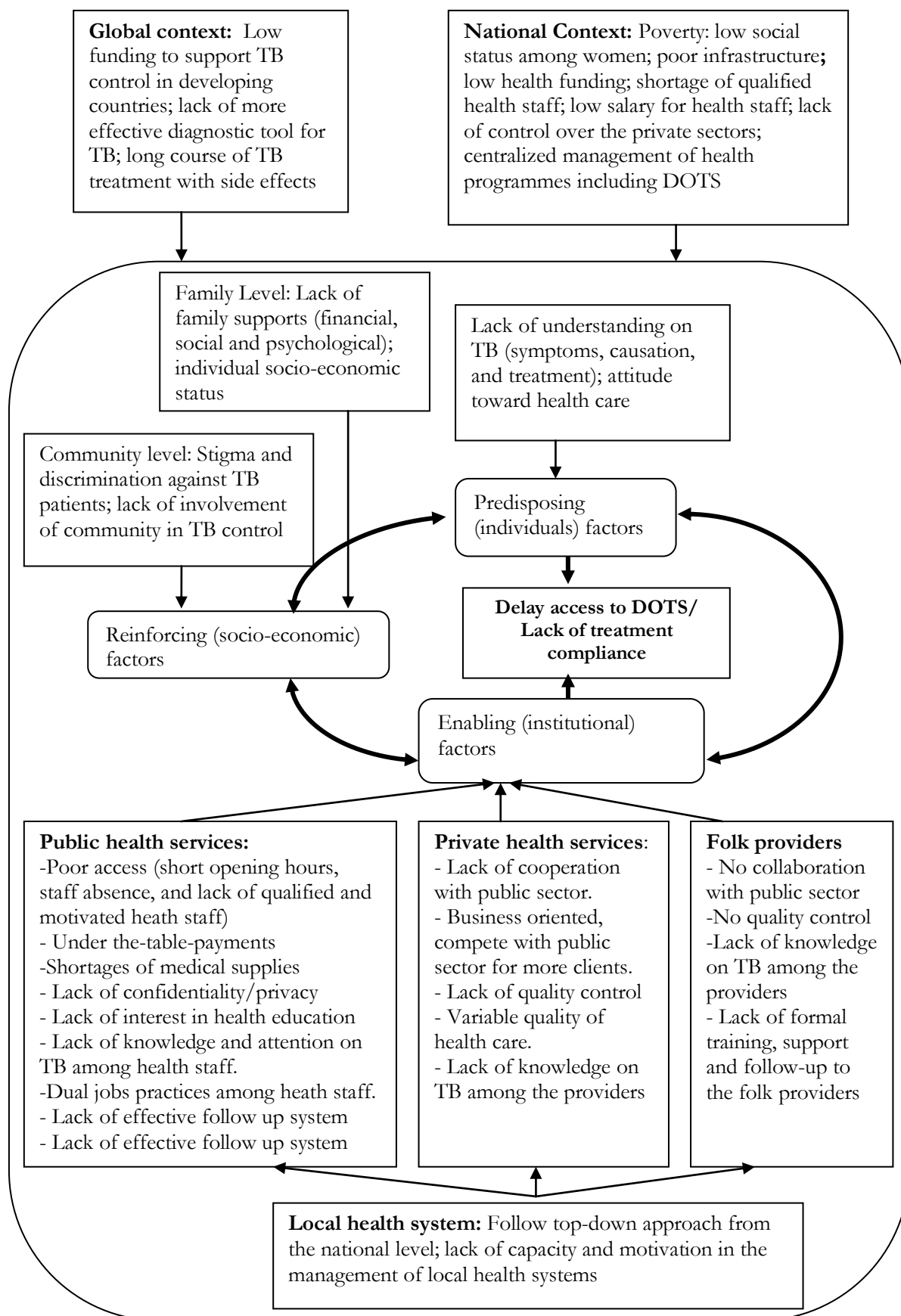


Figure27: Factors associated with treatment seeking behaviour and TB treatment

Participants knew that cough was an important sign of TB. This understanding was possibly gained from health education messages encouraging people who experienced cough for 2-3 weeks or longer to present at a public health centre or hospital for free TB diagnosis. However, this health message was not convincing. For example, no patients in this study sought TB diagnosis following cough that persisted for three weeks. This was because community members shared cultural understandings about cough which were influential on their treatment-seeking behaviour. Cough was classified into several folk categories, as follows: first, an 'ordinary cough' referred to a dry or wet cough that did not require formal treatment, because it was perceived as to be associated with common cold, change of weather, a sore throat or a simple respiratory tract infections. 'Dry cough' referred to cough without phlegm, pus or blood, and was seen as caused by dust, food, and smoking. 'Productive cough' contained sputum, pus or blood, and, if this persisted, was associated with a lung infection that required treatment. 'Chronic cough' was a cough that occurred for an extended period of time, and was either considered as a normal cough or as requiring treatment, should it worsen. 'Bleeding cough' was cough with fresh blood or with sputum mixed with blood, and was perceived to be caused by lung injury, rupture of the throat vessels, or TB. 'TB cough' was described by TB patients and their caregivers as the most *difficult* cough because it was usually accompanied by breathing difficulties, loss of appetite, abundance of sputum and/or the appearance of blood.

According to lay concepts of cough, no single type of cough indicated TB. TB cough described by patients and their caregivers occurred at an advanced stage of TB, after a prolonged delay to treatment. People's interpretation of early symptoms was often influenced by other common illnesses such as typhoid, respiratory infections, stomach diseases and common cold; they then

sought health care from different western medicine providers accordingly. This practice led to delays to diagnosis, as the treatments they used often provided temporary relief from symptoms and led them to misinterpret that they were cured.

Explanations about the cause(s) of TB were also influenced by folk concepts, and participants explained the causes of TB related to five categories: 1) environmental factors and work conditions, which referred to prolonged exposure to dusty and/or toxic (pesticide, fertilizer) environments, exposure to extreme weather conditions (hot, cold or rain), and individual engagement in prolonged hard work; 2) individual susceptibility, i.e. physical weakness or vulnerability that made specific people more prone to TB; 3) personal behaviour, i.e. living in poor sanitation or crowded places, or engaged in cigarette or tobacco smoking; 4) hereditary factors, which meant that the disease was passed down from one generation to another within a family; and 5) infection factors, for example, TB was caused by a germ that entered the human body through air or food. Misunderstandings about the cause(s) of TB influenced participants' explanations of transmission. Although most understood that TB could be transmitted from one person to another, they usually misunderstood the transmission pathways. For example, participants believed that TB was transmitted through sharing food and eating utensils with a TB patient, and they therefore avoided contact with TB patients. On the other hand, those who believed that TB was transmitted through hereditary or other factors did not pay attention to prevention practices. Lack of understanding about the cause(s) and transmission of TB influenced participants' perceptions of their risk of contracting TB. About 43% of the community members surveyed believed that they had no chance of contracting TB because they did not have a family member who had TB or because they had never been in contact with a TB patient. Such perceptions contributed to delayed diagnosis, as those people may have rejected the possibility of TB when they presented with early

symptoms. Although TB patients received treatment from public health facilities, they continued to have a limited understanding of the cause(s) and treatment of the disease. Their explanatory models were similar to those of other community members, and they were also influenced by folk ideas shared through their networks. This indicates that the lack of health education messages on TB provided by health providers extends to patients during treatment. This may indicate that health providers lacked interest in providing health education about TB to patients and their family members during consultations, possibly due to their short working hours and pressure of time at the public health facilities.

There was growing interest in raising public awareness of TB among community members. The NTP and local NGOs encouraged health staff to conduct health education to community members (TB patients and general population). However, community health education on TB rarely occurred, due to budgeting issues, lack of skills among health staff in communicating messages to community members, lack of education materials, and, more importantly, a lack of supportive supervision for health staff to implement health education activities within health facilities and in the community.

Facility-based health education was also very irregular. Health staff gave limited education about TB during consultations with patients, and did so mainly by ordering patients to do what they believed to be best, without understanding particular circumstances. Health education materials were not displayed appropriately for patients at health facilities, there was no dedicated space for such information, and old— torn out or faded— IEC (Information Education Communication) materials were frequently displayed on the wall inside the health centres. These were in areas not accessible to patients and also not visually attractive to

patients. In addition, IEC materials were not available for clients to take home. Audio visual materials were not available at public health facilities.



Figure 28: Old posters displayed on the wall of a health facility

Field photo 21 May 2008

Health education activities and materials need to respond to local context, and should take cultural understandings of TB symptoms, causes and transmission into consideration. Educational activities also need to be adapted to the local context. Although health education alone may not lead to a change in the health-seeking-behaviour of TB patients, improving the understanding of community members regarding TB would be a positive first step in changing the beliefs of community members, and would therefore encourage them to present to health centres for TB diagnosis in a more timely way.

Central to this call is the urgent need for accurate health information messages about TB. These messages should be disseminated through both professional health sector and community networks; and there are several ways (outlined below) how these recommendations could be translated into practice.

First, there is a need to implement regular one-to-one health facility-based counselling and education sessions for all TB patients. Through the provision of supportive monitoring, health staff could be motivated to deliver regular health education or counselling sessions to TB patients. In this way, TB patients and family members would be provided with an accurate and reliable understanding of their diagnosis, the cause(s) of TB, and the treatment regimen, and have correct information on how to prevent further transmission in the family and community. This information would encourage patients to commit themselves to the full course of treatment, as well as to share reliable information with community members. Furthermore, by involving family members in health education, patients could be encouraged and supported to complete TB treatment.

Secondly, health education and health promotion materials and activities through health centre or hospital, for all clients seeking health care services, needs to be provided. As a first step, health facilities could display up-to-date, visually appealing and accurate health education materials, such as posters or billboards located where clients could read them while waiting at the health facility. In addition, health education materials such as brochures or information leaflets should be made widely available and clients should be encouraged to take these home.

Third, however, given the limited literacy levels of the rural population, audio and/or visual materials (radio, TV, or DVD) may be more appropriate than written materials. Audio-visual materials could be screened or displayed at health facilities for clients to watch or listen to

while waiting for consultations with health workers. Mass-media campaigns may also be appropriate. Approximately 45% and 28% respectively of study participants owned a radio or TV. However, as many desperately poor community members did not have access to electronic devices including radio, there needs to be continued investment in community-based health education performed by a health volunteer or a former TB patient, particularly given the vulnerabilities of this group.

Fourth, former TB patients who are cured, and their family members, should be encouraged to become a community DOTS observers or community health educators to provide TB-related health education to community members. These people understand the diagnostic process, how to take their treatment, and are aware of how the health facility and providers might assist them (Macq, et al., 2007). Evidence elsewhere shows that cured TB patients play important roles in case finding and encouraging TB patients to comply with treatment (Banerjee, et al., 1997; Johansson & Winkvist, 2002). In addition, as shown in this study, some TB patients decided to seek TB diagnosis following the advice of former TB patients and their confidence in treatment was influenced by their experiences of seeing former patients cured from TB.

Promoting access to public health centres to increase TB case detection

Cambodia follows passive TB case detection, which means that a person with suspected symptoms is required to present at the health centre or RH for TB diagnosis—it is therefore passive in terms of the roles of health providers in encouraging people for testing. This strategy contributed to delayed TB diagnosis, as it relies on patients interpretation of their symptoms. Thus, TB patients usually sought health care from other providers prior to presenting to the DOTS treatment program (Xeuatvongsa, 2005; Rojpibulstit, et al., 2006; Saw Saw, 2006; Xu, et al., 2007a).

Findings from the present study shows that community members did not promptly present to government health facilities when they had early symptoms, at least in part due to their lack of confidence in the health services. Despite over a decade of health reform, access to public health services in rural Cambodia remains problematic, and present important challenges to the five dimensions of access as defined by Penchansky and Thomas (1980). In particular, issues related to the accommodation and availability of health services including short opening hours, staff absences and lack of motivation, and shortages of medicines and medical supplies, remain unresolved. The root causes affecting the performance of health centres centre around two factors: low government salaries for health staff and, to a lesser extent, low health care funding. Low salaries led health staff to engage in dual job practices, whereby a second, higher paying job was held outside of the public health service in order to earn sufficient income to maintain their standard living. Dual job practices undermined the performance of public health facilities as staff tended to devote more time to their private practice and often directed patients from public services to their private practice. Ineffective access to public health centres made community members bypass these facilities (despite that they were usually located close by). Furthermore, although they did not have many choices for their health care, community members opted for private health care if they had money to pay. People often paid for private health care despite potential financial hardship, and chose to obtain a loan or sell property in order to meet their needs. Desperately poor patients who were unable to afford private health care commonly managed illness with home remedies and turned to the public health services only when their symptoms worsened; others chose to (or had no choice but to) die at home.

The private health sector comprised unqualified providers (pharmacy workers, *peet phum*), qualified providers (private clinics, private doctors, nurses and midwives, many of whom were

also staff at public health clinics), as well as traditional healers. This sector is often unregulated and thus is not formally involved in TB control activities. Despite this, private health providers were preferred by most community members over public services because they were perceived as offering more convenient services (longer working hours, shorter waiting times, and good quality of drugs), privacy, and were more sensitive to patients' ability to pay. However the cost of these services was the main barrier to access, particularly among extremely poor community members. Usually participants' inability to afford costly health care led, through provider or self-referral, to government health facilities, where TB was then diagnosed.

Under-performance of public health centres significantly affected people's health-seeking behaviour and the implementation of DOTS, because many patients by-passed the health centre where DOTS was available for free of charge. While the Cambodian health care system is designed around the principle of geographic proximity, with health centres located close to the population served, this did influence patients used of health services. It was very common for participants to seek health care from sites located further away than the public health centres, because they were more confident in the quality and availability of private health services. These issues were not restricted to TB-related care.

The underutilization of rural health centres was not absolutely due to the lack of management skills and capacity of health staff to run the health centre, but was derived from the lack of responsibility and motivations of public health staff. This was reported by health staff as due to low salaries and ineffective monitoring and supervision, but it was also strongly influenced by the conflict of interest posed by dual job practices. As discussed in this thesis, health staff actively maintain their reputation to encourage clients to use their private practices, and in this way, they were able to sustain the services in the community.

Although private health services are popular in Cambodia, given the socio-economic context of the country at the current time, improving access to public health services would be of most benefit to community members who had difficulties in affording private health care, and would contribute to improve the access of people with TB-related symptoms. Strategies to improve access to these public health centres should address four related factors, which would lead to improvements in staff motivation: increasing financial remuneration to health staff, providing opportunities for professional development, ensuring greater security of medical supplies, and strengthening monitoring activities.

In the study area, some health programs attempted to improve staff motivation through the payment of performance-based salary incentives (PBSI). This approach was not entirely successful. While it increased the motivation of staff who received PBSI, it simultaneously created conflicts of interest with staff who were not on PBSI. As a result, those staff did not actively increase their responsibility in delivering health care, which meant that the overall performance of the health centre was unchanged. Improving the performance of public health centres need to address the *dimensions* of access and factors underpinning the challenges associated with these. Although increasing staff salaries and health funding tends to be the most effective strategy to improve public access, it alone is not the only way to move forward and therefore other health system strengthening must be implemented.

Improving public health service delivery to compete with or to be seen as a viable alternative to private health providers would rely on the commitment of health staff at the local level. Although it is not legal for health staff to engage in dual job practices (Henderson & Tulloch, 2008), it is not practical to ban health staff from engaging in such practices given that appropriate salaries have not been initiated—as staff need economically to sustain their

families: dual job practices are the only way they can maintain their posts in the government facilities in the current situation. Each health centre should be supported and encouraged by the Ministry of Health to develop their autonomy by delivering its own strategies to improve access, for example, by extending working hours and ensuring the availability of necessary medical supplies. An effective strategy should address personal (e.g. increased opportunities to earn financial rewards) institutional (e.g. capacity building of health staff, secure medical supplies and drugs), structural (e.g. the health care system factors) that would motivate health workers to be more effective in their posts.

Shortening delay by improving collaboration with private providers

Pathways of TB patients in this study were complex and protracted, as most participants began their path with private providers and remained treated by those providers for a prolonged period. Each participant began their pathways with the self-management of symptoms, by using home remedies or unqualified providers (at a pharmacy or from *peet phum*); they subsequently engaged in provider shopping according to the perceived severity of their illness and their abilities to pay for different health care services and other associated costs (including transport, food and absence from work). Participants followed different pathways before reaching the DOTS program. *Direct* pathways occurred among participants who presented to DOTS shortly after self-management of symptoms failed. *Delay* pathways happened among participants who used two to three unqualified providers, because they perceived their symptoms were mild. *Detour* pathways occurred when patients believed that they had a health problem and sought care from a qualified provider(s). However, health providers normalized their symptoms and failed to investigate their TB. *Quest* pathways occurred when patients continued to seek a satisfactory diagnosis from public and private health providers; however,

diagnosis error and lack of providers' attention to investigate TB led to prolonged pathways, and *ordeal* pathways occurred among participants who spent a significant amount of time in search of an appropriate diagnosis. They experienced diagnostic errors and lack of attention of health providers in investigating TB, and resisted the idea that they might have TB. Regardless of the type of pathways they followed, participants in this study sought TB diagnosis in three main circumstances: when symptoms caused social disruption; following concerns of significant others; and as a result of self-suspicion about TB. These three factors encourage participants to present promptly to a health centre or hospital for TB diagnosis.

Several factors shaped participants' pathway to DOTS, including socio-cultural factors and the socio-economic status of patients. But in addition, pathways were influenced by the lack of attention of health providers in investigating TB in patients. As illustrated in this study, private health providers generally interpreted and managed symptoms according to patients' lay explanatory models, and thus overlooked investigating TB in people who presented with early symptoms. Further, their treatment program always included multiple antibiotics that provided temporary relief to participants. In the case of TB symptoms, antibiotics could help patients obtain relief from cough and fever, and patients usually terminated the treatment program when their symptoms abated and used the medications again when their symptoms re-emerged. This practice delayed the progression of TB symptoms and therefore delayed diagnosis. In addition, the lack of knowledge of health providers, particularly among unqualified providers (pharmacy workers, *peet phum* or folk providers) meant that they may not have been able to identify TB.

To shorten delays, strategies should address the involvement of health providers (private and public) in DOTS implementation, and improve TB diagnosis facilities. The NTP has initiated

‘public and private mix DOTS’ (PPM-DOTS) which encourages private providers to refer patients presenting with early TB symptoms to the DOTS program. However, the effectiveness of this program is questionable. In 2008, under PPM-DOTS, 2,030 suspected TB cases were referred from private providers, yet only 1,066 of these people (approximately 52%) presented at DOTS program. Thus, a large number of suspected patients did not seek TB diagnosis from the government health facility, even when asked to do so by a provider. The main barriers to successful implementation of PPM-DOTS are low referral of suspected TB cases and a high drop out among referral cases. Again, there is likely to be an issue of competition between sectors of the health system. As this study has shown, private health providers compete with the public sector to absorb more clients; therefore they tended to keep clients as long as they could afford their health services rather than referring them on, or they referred them later. This exacerbated the lack of referral that resulted from a lack of knowledge about TB symptoms.

To ensure the effective involvement of private health providers in the implementation of DOTS and to improve the current PPM-DOTS strategy, the NTP needs to address capacity building of health providers (public and private) by giving them training and knowledge to pay more attention to TB symptoms and encourage referral to the DOTS program. Incentives may have a role here: private health providers who treat TB would be motivated to collaborate with the public health sector to follow DOTS and to report TB cases to the health centre, to ensure appropriate epidemiological surveillance of TB.

Ensure adherence to TB treatment by improving support to vulnerable groups

The NTP appeared unconcerned about treatment adherence, as they have claimed victory of achieving the WHO target of more than an 85% cure rate of TB. The NTP report of 2009 indicated that only a few TB patients interrupted TB treatment (CENAT, 2009). However, the present study highlights concerns related to treatment adherence and cure of TB patients enrolled in DOTS. While all participants enrolled in DOTS completed treatment, most did not undergo a pathology test to confirm cure. Further, non-adherence to TB treatment was a concern as many participants missed several doses of their medication. Unsuccessful treatment (incomplete treatment, relapse or death) was common among vulnerable population groups (desperately poor and elderly). Therefore, special interventions are needed to support those who are vulnerable to complete TB treatment.

According to DOTS policy, TB patients are required to take direct observed therapy (DOT) by a health staff member or a nominated community member for six to eight months in order to ensure that the full course of treatment is followed, to encourage patient-provider communication, and to provide support to patients to comply with treatment. However, as illustrated in this study, many participants could not afford, financially or practically, to stay at the hospital or to travel to the health centre every day for DOT by a health worker. Patients and health providers did not typically consider DOT to be necessary in TB treatment adherence. They perceived that DOT was just a mechanism of watching a TB patient dropping medicine into his/her mouth, and believed that treatment adherence solely depended on an individuals' understandings of and commitment to treatment. In consequence, participants often negotiated with health providers or community DOTS observers to self-administer at home, and this negotiation often led to under-the-table payments for TB treatment.

To promote DOT, the NTP has promoted the community-based DOTS (C-DOTS) program to improve treatment adherence for patients who live far from a health facility. This program requires a nominated community member to observe a patient taking TB drugs at home. However, the implementation of this activity was inconsistent, due to the lack of appropriate support and monitoring provided to the DOTS observer from health centre. C-DOTS was also challenging as participants treated with this mode could not travel every day to the volunteer's house to take medicines, and neither could the C-DOTS observer travel to the patients' houses to observe them taking medicines. Although some participants enrolled in C-DOTS, they self-administered TB medicines and usually collected medicines from the health centre themselves.

This study showed that although participants enrolled in different DOTS program (hospitalized DOTS, ambulatory DOTS or community DOTS), they usually self-administered medicines at home. Most participants (28/32, or 87.5%) completed treatment, yet only six (approximately 20%) had sputum control in the fifth or sixth month to confirm cure. Completion of TB treatment was influenced by patient's confidence in the treatment, family support, and health provider support. Although they completed treatment, some participants continued to suffer from symptoms such as cough and feeling weak from time to time, and could no longer perform their work as before. This may be resultant from deterioration in their health status caused by prolonged delays to appropriate diagnosis and treatment. In addition, participants who were re-infected with TB were concerned about the effectiveness of treatment.

Discontinuation of treatment mainly occurred due to its side effects, feeling better, lack of family support, and poverty. Participants' misunderstandings of treatment and ways of treating

other illnesses led them to interrupt treatment when they felt better. This happened among elderly participants who had difficulty travelling to health facilities to collect medicine, lacked family support, and had difficulties affording transport. On the other hand, a couple of participants interrupted treatment due to unexpected side effects. The lack of explanation about side effects and lack of support from the health providers in overcoming these made patients lose confidence in treatment and they therefore discontinued medication. To improve TB treatment adherence and remove barriers caused by requirement of DOT, the NTP should promote home-based DOTS by a family member and improve regular follow-up of health workers to patients. Patients should be encouraged to nominate their observer, and patient and observer should be provided with appropriate information about TB treatment and prevention. Furthermore, DOTS providers should be trained with appropriate counselling skills and comprehensive TB health education. In this way, patients with side effects could be provided with appropriate support, including counselling, other necessary treatment and/or biological tests (e.g. for liver function). In addition, as discontinuation of treatment was commonly happened among vulnerable groups, there is a need to establish a special support protocol for health providers and social support mechanisms in the community.

Addressing stigma and gender issues associated with TB

In Cambodia, stigma and discrimination attached to TB was associated with fear of transmission, the perceived dangerousness of TB, misconception of TB as a hereditary disease, the association between TB and HIV (and inaccurate knowledge about the link), and the attitude of health staff towards patients. Stigma associated with TB was more pronounced among participants who presented with clear TB symptoms, such as bleeding cough, severe cough with abundant sputum, and when the patient was skeletally thin. Stigma resulted in the

imposition of socio-physical distance, with many restrictions placed upon TB patients regarding participation in different activities. There were two forms of stigma: 'self-perceived stigma' was reported commonly by TB patients who felt ashamed to be diagnosed with TB and were concerned that community members would avoid them, and 'enacted stigma' where patients were shunned by community members because they feared contracting TB. In response, participants usually isolated themselves from other community members. Those without apparent symptoms hid their status or associated their symptoms with general non-stigmatized illnesses, such as a lung infection or lung disease.

Stigma associated with TB has contributed to extended delays to diagnosis as some participants denied the possibility of having TB at the early stages of illness. Stigma also affects health-seeking behaviour of patients, as some preferred to seek health care from services that offered privacy and confidential services, particularly private providers. Furthermore, although stigma did not affect compliance to TB treatment, it contributed to psychological distress among patients. To address stigma and to change attitudes of community members towards TB and TB patients, there is a need to develop and implement a community-based health education campaign related to TB causation, transmission and treatment. Additional health education should seek to address discriminatory attitudes of health staff towards TB patients by providing knowledge and skill for appropriate infection control and equipment for prevention of TB in these workplaces.

TB case detection was gendered. Earlier studies elsewhere found that more men than women are diagnosed with TB, although the exact factors leading to this have not been identified (Hudelson, 1996; Uplekar, et al., 2001b; Crampin, et al., 2004; Xeuatvongsa, 2005). In the present study, I observed that fewer women than men were diagnosed with TB under DOTS,

and this was consistent with the NTP annual TB report. Women's diagnosis with TB tended to occur at a younger age than men, and they often developed TB following child birth. This study also found that men may be more vulnerable than women to developing TB, because men were often engaged in hard work, engaged in poor life-style behaviour (e.g. smoking, heavy alcohol consumption and inadequate nutrition), and often had more social contact their peers. Although both sexes usually delayed presentation to DOTS, women tended to delay longer than men. This was because men seemed to experience a quicker progression of TB symptoms due to their lack of appropriate health care, and health risk behaviours. Women delayed longer because they preferred to treat their illness with low qualified private providers, and prioritised the health of family members over their own. These patterns have implications for future research and suggest a need for gendered health promotion messages, addressing these different factors.

Implications of this study

This research provides insights into how the institutional structure of health care interacted with individual and socio-economic factors to influence the health-seeking behaviour of participants in Kampong Speu province, Cambodia.

Specific challenges were encountered on many levels by TB patients, and health policies can seek to redress these. The issue of classification of TB cases has implications for treatment outcomes. As shown in this study, some participants were re-infected with TB, but were treated as TB new cases (treatment category I), because they either did not tell the provider of their TB history or were unable to be hospitalised or present to the health centre every morning for Streptomycin injections (as is prescribed for treatment category II, i.e. re-infected cases). Furthermore, although all many patients completed treatment, most did not have any

pathology testing to confirm cure, and some patients continued to suffer with TB symptoms after treatment. This has implications in term of re-infection, and more research on the follow up TB patients after treatment is required to identify the magnitude of this problem, discover the factors associated with TB re-infection, and identify the barriers associated with treatment of TB among re-infected TB patients. These findings will be useful to ensure better treatment outcomes and appropriate management for relapse TB cases, issues that were beyond the scope of this project.

The NTP currently focuses on maintaining the WHO targets of case detection and treatment completion rate. The implementation of DOTS strategy at all levels aims to achieve targets set by the NTP, PHD and the OD, without placing appropriate emphasis on the socio-cultural factors associated with individual patients' pathways to obtain diagnosis and to undergo TB treatment regimens. Reaching the proposed targets may therefore not be sufficient to reduce TB incidence, as TB continues to transmit in the community, due to delayed presentation among TB patients to DOTS and lack of treatment adherence. Vulnerable groups, already susceptible to TB due to poor living conditions and overall health status, are at particular risk of re-infection or adverse outcomes.

Health indicators of the achievement of TB control should address the quality of NTP performance, not only on quantitative performance measure. TB case detection has been evaluated only on the number of patients diagnosed with TB through each health centre annually, and treatment outcome has been based on the percentage of patients who complete treatment. But other factors are equally significant. How patients find their ways to DOTS, how they comply with the treatment regimen on a daily basis, and how individual factors and institutional aspects of health care may prevent a number of desperately poor patients from

reaching DOTS programs, all require consideration by the NTP. Although DOTS is available in all public health facilities, the implementation of DOTS has been set back by the under-performance of public health services. Therefore, the further success and sustainability of DOTS strategy is dependent upon public health system strengthening and addressing individual barriers related to access to health services. Only once these barriers have been successfully overcome, can NTP claim success in its response to the national health problem of TB.

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Appendix 1: Ethics Approval Letters



MONASH University

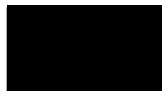
Standing Committee on Ethics in Research Involving Humans (SCERH)
Research Office

Human Ethics Certificate of Approval

Date	16 October 2007
Project Number	CF07/3676 - 2007001837
Project Title	Coping with tuberculosis: Understanding Health Seeking Behaviour in Cambodia
Chief Investigator	Prof Lenore Manderson
Approved	From 16 October 2007 To 16 October 2012

Terms of approval

1. Approval is only valid whilst you hold a position at Monash University.
2. It is the responsibility of the Chief Investigator to ensure that all pending information (such as permission letters from organisations) is forwarded to SCERH. Research cannot begin at an organisation until SCERH receives a permission letter from that organisation.
3. It is the responsibility of the Chief Investigator to ensure that all investigators are aware of the terms of approval and to ensure the project is conducted as approved by SCERH.
4. You should notify SCERH immediately of any serious or unexpected adverse effects on participants or unforeseen events affecting the ethical acceptability of the project.
5. The Explanatory Statement must be on Monash University letterhead and the Monash University complaints clause must contain your project number.
6. **Amendments to the approved project:** Requires the submission of a Request for Amendment form to SCERH and must not begin without written approval from SCERH. Substantial variations may require a new application.
7. **Future correspondence:** Please quote the project number and project title above in any further correspondence.
8. **Annual reports:** Continued approval of this project is dependent on the submission of an Annual Report. This is determined by the date of your letter of approval.
9. **Final report:** A Final Report should be provided at the conclusion of the project. SCERH should be notified if the project is discontinued before the expected date of completion.
10. **Monitoring:** Projects may be subject to an audit or any other form of monitoring by SCERH at any time.
11. **Retention and storage of data:** The Chief Investigator is responsible for the storage and retention of original data pertaining to a project for a minimum period of five years.



Dr Souheir Houssami
Executive Officer, Human Research Ethics (on behalf of SCERH)

Cc: Ms Narelle Warren; Ms Chhordaphea Chhea

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Building 3E, Room 111, Clayton Campus, Wellington Road, Clayton
Telephone +61 3 9905 5490 Facsimile +61 3 9905 1420
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ABN 12 377 614 012 CRICOS Provider #00008C

រាជធានីភ្នំពេញ, ថ្ងៃទី. ១៦...ខែ... ១២...ឆ្នាំ ២០០៧...

Dr. Chhea Chhordaphea

Project: Coping with Tuberculosis: Understanding Health Seeking Behaviour in Cambodia

Reference: December 21st, 2007 Expedited meeting minute

Dear Dr. Chhea Chhordaphea ,

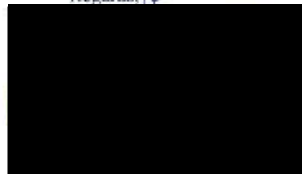
I am pleased to notify you that your project entitled " Coping with Tuberculosis: Understanding Health Seeking Behaviour in Cambodia " has been approved by National Ethics Committee for Health Research (NECHR) in the meeting of the expedited review dated on December 21st, 2007. This approval is valid for twelve months after the approval date.

The Principal Investigator of the project shall submit following document to the committee's secretariat at the National Institute of Public Health at #2 Kim Il Sung Blvd., Khan Tuol Kok, Phnom Penh. (Tel: 855-23-880345, Fax: 855-23-881949):

- Annual progress report
- Final scientific report
- Patient/participant feedback (if any)
- Analyzing serious adverse events report (if applicable)

The Principal Investigator should be aware that there might be site monitoring visits at any time from NECHR team during the project implementation and should provide full cooperation to the team.

Regards, ១៩



H.E. Prof. ENG HUOT

Appendix 2: Interview Guides

Interview Guides for the In-depth Interview with TB patients/ family members

Research objectives/themes	Sample questions
9. Understanding of TB	<ul style="list-style-type: none"> - What do you know about TB? - What are the symptoms and causes of TB infection? - Can TB be gone by one person to another? - Can it be prevented? How can it be prevented? - How can it be treated? - How do you learn about TB? - Why do you think it has infected you? - How has your understanding of TB changed after you've diagnosed with TB?
10. How health care is delivered	<ul style="list-style-type: none"> - What do you do when you or your family member is sick with a particular illness? - Who do you commonly consult with when you have a health problem? - What are the most important things you look for when you choose a health provider? - Have you ever used the health centre? If yes, what do you like or don't like about the services? If no, what make you not using the health centre? - How do you finance health care costs?
11. Practice from onset of symptoms until diagnosis and treatment at the hospital.	<ul style="list-style-type: none"> - What did you do between falling sick and your first visit to the hospital/health centre? - What factors influence decisions to seek a particular treatment for TB patient? - Why did you decide to come to the hospital/health centre? Who made the decision about your health care? - Where did you learn about the services for TB diagnosis? - Can you estimate times is it from the onset of your illness until you are diagnosed with TB? - How much did you spend before, and during TB treatment? How do you finance these costs?
12. Understand how TB patients cope with TB treatment?	<ul style="list-style-type: none"> - What type of DOT are you enrolling in? - Do you take TB treatment under DOT of someone? If yes how do you arrange it, and how do you feel about it? If no, why not? How do you take TB medicines? - How do you take TB medicines? Have you ever forgotten or missed taking TB medicines? - Why do you forget or miss taking TB medicines?

	<ul style="list-style-type: none"> - How do you feel about the progress of your health during and after treatment? - What factors do think that making you re-infect with TB? (for relapse case). - Why do you stop taking TB treatment? (for default cases).
13. Factors including stigma, which support or discourage early TB case detection and prevention.	<ul style="list-style-type: none"> - How do you think the public perceive about TB? - What are reactions of people in your village towards you and your family before and after you have been diagnosed with TB? Are there any changes in their attitudes to you or your family? - How did your doctor tell you about your TB diagnosis? - What are the attitudes of your employers toward you and your family? - What are the supports from work-place to you and your family? - What are the supports from the hospital or health workers to you and your family? - Have you ever experienced being rejected by your employer, neighbour or family member because you have TB? - How do you feel about yourself as a TB patient?

Interview Guides for focus group discussion with community members

Research objectives/themes	Sample questions
1. Understanding of TB	<ul style="list-style-type: none"> - What do you know about TB? - Why do you think it has infected someone? - What do you fear the most about the illness and its treatment? What are the symptoms and causes of TB infection? - Can TB be gone by one person to another? - Can it be prevented? How can it be prevented? - How can it be treated? - How do you learn about TB?
2. How health care is delivered	<ul style="list-style-type: none"> - What do you do when you or your family member is sick with a particular illness? - What do you think about access to public hospital/health centre? - Who do you commonly consult with when you have a health problem? - What are the most important factors influencing your decision to choose a particular health care - Have you ever used the health centre? If yes, what do you like/ or don't like about the services? If no, what make you not using the health centre? - How do you finance health care costs?

3. Practice from onset of symptoms until diagnosis and treatment at the hospital.	<ul style="list-style-type: none"> - Have you known any TB patient in your village? - Where can people obtain TB diagnosis? - What do they do before obtaining diagnosis as a TB patient?
4. Understand how TB patients cope with TB treatment?	<ul style="list-style-type: none"> - What do you hear about TB treatment - How long is TB treatment? What do patient need to follow during treatment? - What are facilitating /barriers for patients in relation to compliance with TB treatment?
5. Factors including stigma, which support or discourage early TB case detection and prevention?	<ul style="list-style-type: none"> - How do the public perceive about TB? - How do you feel about TB patients and their family members? - How does TB affect life of a TB patient you've seen/known? - How would you feel if you had TB?

Interview Guides for the In-depth Interview with Health Workers/TB officer

Research objectives/themes	Sample questions
1. Understanding of TB	<ul style="list-style-type: none"> - How much do community members understand about TB? - How do community members learn about TB? - What sort of activities do you do to provide information on TB to community members? What are the present shortcomings in relation to those strategies? - What are main causes of TB transmission in this province?
2. How health care is delivered?	<ul style="list-style-type: none"> - What do people do and where do they go when they have an illness? - How do people finance health care costs? - What are the difficulties for health service delivery at the hospital/health centre?
3. Practice from disease onset until diagnosis and treatment at the health facilities	<ul style="list-style-type: none"> - Where did people go for treatment when they first have TB indicating symptoms? Why? - What factors influence people's decision to use a particular provider? What makes patient present to you for a TB diagnosis? - What are the processes of TB diagnosis? - What factors make people delay presentation to TB diagnosis? - What sort of thing need to be done to improve early TB case detection?
4. Understand how TB patients cope with	<ul style="list-style-type: none"> - How do you treat a TB patient? - How do you observe patient taking medicine? What are barriers

TB treatment?	<p>for observing patient taking medicine?</p> <ul style="list-style-type: none"> - What factors make TB patient cannot fully comply with treatment? - What factors make TB patient become re-infected with TB? Or stops taking TB treatment?
5. Factors including stigma, which support or discourage early TB case detection and prevention.	<ul style="list-style-type: none"> - How do you think the public perceive about TB? - How do people react to TB patients and their families, and how do these affect TB patients you see? - What are the supports from the hospital or health workers to TB patient and family? What have you done to address stigma? - Have you ever seen/known patient or family member being rejected by employer, neighbour or family member because they have TB?

Interview Guides for the In-depth Interviews with private provider, *Kru Khmer*, C-DOTS-observers,

Research objectives/themes	Sample questions
1. Understanding of TB	<ul style="list-style-type: none"> - What are the causes of TB infection? - How is the disease transmitted? - Can it be prevented? How can it be prevented? - What are the symptoms of TB? How does it affect the body? What symptoms indicate TB? - How can it be treated? - How do you learn about TB?
2. How health care is delivered?	<ul style="list-style-type: none"> - How do you learn about treating an illness? What kind of health services do you have? - How do you maintain your service to community member? - How do clients know about your services? - How do people finance health care costs? - What are the difficulties for you to deliver health services to community members? - What kind of things need to be addressed to improve your services? - What do you think about access to public hospital/health centre?
3. Practice from disease onset until diagnosis and treatment at the health facilities	<ul style="list-style-type: none"> - How do you treat people with cough, fever or loss of appetite? - Have you ever refer patients with cough to seek TB diagnosis to health centre or hospital? If yes, what are barriers in relation to your referral? - (For C-DOTS observers): what do you if you see a person has

	<p>cough, fever and loss of appetite? What do you do to encourage patient with suspect TB symptom to seek TB diagnosis?</p> <ul style="list-style-type: none"> - What factors make TB patients delay presentation to TB diagnosis?
4. Understand how TB patients cope with TB treatment?	<ul style="list-style-type: none"> - What are facilitating factors/barriers in relation to compliance with TB treatment? - How do you observe patient taking medicine? What are barriers for observing patient taking medicine? - What factors make TB patient cannot fully comply with treatment? - What factors make TB patient become re-infected with TB? - Why do TB patient stops taking TB treatment?
5. Factors including stigma, which support or discourage early TB case detection and prevention.	<ul style="list-style-type: none"> - How do you think the public perceive about TB? - How do people react to TB patients and their families, and how do these affect TB patients you see? - What are the supports from the hospital or health workers to TB patient and family? - Have you ever seen/known patient or family member being rejected by employer, neighbour or family member because they have TB?

Appendix 3: Explanatory Statements

Date.....

Explanatory Statement – TB patients

Project Title: Coping with Tuberculosis Understanding Health Seeking Behaviour in Cambodia

This information sheet is for you to keep

Introduction

My name is Chhordaphea Chhea and I am conducting a research project towards my PhD degree at Monash University, Melbourne, Australia. This means that I will be writing a thesis – this is like a 300 page book which will be examined. My supervisors are Professor Lenore Manderson and Ms. Narelle Warren from the School of Psychology, Psychiatry, and Psychological Medicine. We have funding from the UNICEF/UNDP/World Bank/WHO Special Programme for Research and Training in Tropical Diseases (TDR) to support this work.

Who is invited to participate in this research project?

I obtained general information about you from the hospital nurse. I understand that you have, and are currently being treated for at least four weeks, and that you are aged 18 or over. If this is correct, I would like to invite you to participate in my research study which I have called “Coping with TB Understanding Health Seeking Behaviour in Cambodia”. As the project is about health seeking behaviour of patients and family, your views would be really valuable.

What is aim/purpose of this research?

In this study, I want to learn what people know about the symptoms, cause, transmission and treatment of TB, as well as how the disease affects the patient, including in relation to family and community. I hope that the results of this study will be used to develop a health promotion program to improve TB early case detection, reduce stigma against TB patient, improve compliance with anti-TB treatment, and mobilise support to TB patient and their families.

What does the research involve?

I will ask you some specific questions about your understanding of TB transmission and treatment, how you make decisions about your health care, and about the impact of TB on your health, job, and your family and community relationship. With your permission the interview will be tape-recorded so that I have an accurate record of what you say. Notes can be used if you prefer.

How much time will the research take?

Interviews will occur at a time and place that is convenient for you, and will take approximately 60-90 minutes. After the first in-depth interview, I would like to have follow-up interviews with you to improve my understanding of your experiences as you gone through the treatment. This will involve interviews with me on several sessions while you are being treated. We would meet around once a month for about 60 minutes each time, for a period of 4 to 6 months, depending on the time you have available to meet with me.

Inconvenience/discomfort

The questions that I will ask you are not very likely to cause distress, although minor stress or inconvenience could possibly occur when we recall your experiences of illness. Most people find it helpful to participate in this kind of research, because it gives them a chance to freely talk about their experiences in a safe and non-judgemental environment. If at any stage of interview, you feel distressed, you will be able to cease the interview. If you need extra help and support, I will help you to contact a local counsellor or social worker who would be able to talk with you.

Can I withdraw from the research?

Being in this study is completely voluntary. You are under no obligation to participate. If you want to withdraw from the study, you can do so at any time during the research process. All unprocessed information that you provide will be destroyed. There will be no consequences for you if you do withdraw, or if all or part of the information is not provided.

How will my confidentiality be protected?

Your participation in this research and the information you have provided will not be disclosed to anyone. If I refer to your story when I am writing, I will be changing your name and your background (such as your job and workplace, and the name of your village) so that you cannot be identified. According to university regulations the tape and transcripts will be kept on university premises in a locked filing cabinet for 5 years. Your information will not be used for other purpose than that mentioned above without your consent.

How will I receive results?

Once I have completed writing my thesis – a long report – using what I learn in conducting this research, a brief summary of the findings in Khmer will be available. If you would like a copy, please contact the student researcher or the nurse Ms.<insert name> at Kampong Speu Hospital.. The results will be presented at academic conferences and in scientific journals. I will also give a short talk on preliminary findings of the research in late November 2008 (place and date to be identified), and every community members can attend.

Complaints

If you have a complaint concerning the manner in which this research <insert project number > is being conducted, please contact:

National Centre for Health Promotion #162, Preah Sihanouk, Phnom Penh Tel: 855-23 213 608 e-mail: nchp@camnet.com.kh	Human Ethics Officer Standing Committee on Ethics in Research Involving Humans Building 3e Room 111 Research Office Monash University VIC 3800 Tel: +61 3 9905 2052 Fax: +61 3 9905 1420 Email: scerh@adm.monash.edu.au
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Thank you.

<insert signature>

Chhordaphea Chhea

PhD Candidate

School of Psychology, Psychiatry and Psychological Medicine

Faculty of Medicine, Nursing and Health Sciences, Monash University

Tel: <insert local mobile number>

Email: chhodaphea.chhea@med.monash.edu.au

Date...

Explanatory Statement – Community People

Project Title: Coping with Tuberculosis: Understanding Health Seeking Behaviour in Cambodia

This information sheet is for you to keep

Introduction

My name is Chhordaphea Chhea and I am conducting a research project towards my PhD degree at Monash University, Melbourne, Australia. This means that I will be writing a thesis- this is like a 300 page book which will be examined. My supervisors are Professor Lenore Manderson and Dr. Narelle Warren from the School of Psychology, Psychiatry, and Psychological Medicine. We have funding from the UNICEF/UNDP/World Bank/WHO Special Programme for Research and Training in Tropical Diseases (TDR) to support this work.

Who is invited to participate in this research project?

I have obtained your household information from the map provided by the village's head. According to our selection strategy your house has been randomly selected for my study which I have called "Coping with TB Understanding Health Seeking Behaviour in Cambodia". I would like to invite, one person man or woman age 18 or over in this house is invited to participate in this research project. As the project is about health seeking behaviour of patients and their families in rural Cambodia, your views would be extremely valued.

What is aim/purpose of this research?

In this study I want to learn what people know about the transmission and treatment of TB, that is what causes TB and how it can be cured. I also want to learn to what extent the disease affects people living with TB (TB patient) including in relation to family and community. I hope that the results of this study will be used to develop a health promotion program to improve TB early case detection, reduce stigma against TB patient, improve compliance with anti-TB treatment, and mobilise support to TB patient and their families.

What does the research involve?

You are invited to participate in a face to face interview with a researcher, using a questionnaire. The questions ask about your understanding of TB transmission and treatment, your attitudes toward TB, choices of health care and the impact of TB on family and community. The researcher will read a question for you, and your answer will be ticked on the questionnaire for further analysis.

How much time will the research take?

The face to face interview will take about 60 minutes.

Inconvenience/discomfort

The questions that I will ask you are not very likely to cause distress, although talking about illness is sometime difficult and upset. Most people find it helpful to participate in this kind of research, because it gives them a chance to freely talk about their experiences in a safe and non judgemental environment. If at any stage of the discussion, you feel distressed, you will be able to cease the

interview and if you need extra help and support, I will help you to contact a local counsellor or social worker who would be able to talk with you.

Can I withdraw from the research?

Being in this study is completely voluntary. You are under no obligation to participate. If you want to withdraw from the study, you can do at any time during the research process. All unprocessed information that you provide will be destroyed. There will be no consequences for you if you do withdraw, or if all or part of the information is not provided.

How will my confidentiality be protected?

Your participation in this research, and the information you have provided will not be disclosed to anyone. In this survey, we will not ask/ record your name, and address so there will be no way to identify your information. According to university regulations the questionnaires will be kept on university premises in a locked filing cabinet for 5 years. Your information will not be used for other purpose than that mentioned above without your consent.

How will I receive results?

Once I have completed writing my thesis – a long report- using what I learn in conducting this research, a brief summary of the findings in Khmer will be available. If you would like a copy please contact the student researcher or the nurse Ms. <insert name> at Kampong Speu Hospital. The results will be presented at academic conferences and in scientific journals. I will also give a short talk on preliminary findings of the research in late November 2008 (place and date to be identified), and every community members can attend.

Complaints

If you have a complaint concerning the manner in which this research <insert project number > is being conducted, please contact:

National Centre for Health Promotion #162, Preah Sihanouk, Phnom Penh Tel: 855-23 213 608 e-mail: nchp@camnet.com.kh	Human Ethics Officer Standing Committee on Ethics in Research Involving Humans Building 3e Room 111 Research Office Monash University VIC 3800 Tel: +61 3 9905 2052 Fax: +61 3 9905 1420 Email: scerh@adm.monash.edu.au
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Thank you.

<insert signature>

Chhordaphea Chhea
PhD Candidate
School of Psychology, Psychiatry and Psychological Medicine
Faculty of Medicine, Nursing and Health Sciences
Monash University
Tel: <insert local mobile number>
Email: chhordaphea.chhea@med.monash.edu.au



Date

Explanatory Statement – Caregivers of TB patients

Project Title: **Coping with Tuberculosis: Understanding Health Seeking Behaviour in Cambodia**

This information sheet is for you to keep

Introduction

My name is Chhordaphea Chhea and I am conducting a research project towards my PhD degree at Monash University, Melbourne, Australia. This means that I will be writing a thesis-this is like a 300 page book which will be examined. My supervisors are Professor Lenore Manderson and Ms. Narelle Warren from the School of Psychology, Psychiatry, and Psychological Medicine. We have funding from the UNICEF/UNDP/World Bank/WHO Special Programme for Research and Training in Tropical Diseases (TDR) to support this work.

Who is invited to participate in this research project?

I learnt through <insert name of TB patient> that you are his/her care-giver and that you are aged 18 or over. If this is correct, I would like to invite you to participate in my research which I have called “Coping with TB Understanding Health Seeking Behaviour in Cambodia. As the project is about health seeking behaviour of patients and family, your views would be really valuable.

What is aim/purpose of this research?

In this study, I want to learn about what people know about transmission and treatment of TB, that is, what cause TB and how it can be cured. I also want to learn about how the disease affects people living with TB (TB patient), including in relation to family and community. I hope that the results of this study will be used to develop a health promotion program to improve TB early case detection, reduce stigma against TB patient, improve compliance with anti-TB treatment, and mobilise support to TB patient and their families.

What does the research involve?

I will ask you some specific questions about your understanding of TB transmission and treatment, how you involve in making decisions about health care of your family member, and about the impact of TB on family. With your permission the interview will be tape-recorded so that I have an accurate record of what you say. Notes can be used if you prefer.

How much time will the research take?

The interview will occur at a time and place that is convenient for you and will last for about 60-90 minutes.

Inconvenience/discomfort

The questions that I will ask you are not very likely to cause distress, although talking about illness is sometime difficult and upset. Most people find it helpful to participate in this kind of research, because it gives them an opportunity to freely talk about their experiences in a safe and non judgemental environment. If at any stage of the discussion, you feel distressed, you will be able to cease the interview and if you need extra help and support, I will help you to contact a local counsellor or social worker who would be able to talk with you.

Can I withdraw from the research?

Being in this study is completely voluntary. You are under no obligation to participate. If you want to withdraw from the study, you can do so at any time during the research process. All unprocessed information that you provide will be destroyed. There will be no consequences for you if you do withdraw, or if all or part of the information is not provided.

How will my confidentiality be protected?

Your participation in this research and the information you have provided will not be disclosed to anyone. If I refer to your story when I am writing, I will be changing your name and your background (such as job, workplace, and the name of your village) so that you cannot be identified. According to university regulations the tape and transcripts will be kept on university premises in a locked filing cabinet for 5 years. Your information will not be used for other purpose than that mentioned above without your consent.

How will I receive results?

Once I have completed writing my thesis- along report – using what I learn in conducting this research, a brief summary of the findings in Khmer will be available. If you would like to have a copy please contact the student researcher or the nurse Ms. <insert name> at Kampong Speu Hospital. The results will be presented at academic conferences and in scientific journals. I will also give a short talk about preliminary findings of the research in late November 2008 (place and date to be identified), and every community members can attend.

Complaints

If you have a complaint concerning the manner in which this research <insert project number > is being conducted, please contact:

National Centre for Health Promotion #162, Preah Sihanouk, Phnom Penh Tel: 855-23 213 608 e-mail: nchp@camnet.com.kh	Human Ethics Officer Standing Committee on Ethics in Research Involving Humans Building 3e Room 111 Research Office Monash University VIC 3800 Tel: +61 3 9905 2052 Fax: +61 3 9905 1420 Email: scerh@adm.monash.edu.au
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Thank you.

<insert signature>

Chhordaphea Chhea

PhD Candidate

School of Psychology, Psychiatry and Psychological Medicine

Monash University

Tel: <insert local mobile number>

Email: chhodaphea.chhea@med.monash.edu.au

Date

Explanatory Statement – Village Health Volunteers/ DOTS observers/ Traditional healers

Project Title: **Coping with Tuberculosis: Understanding Health Seeking Behaviour in Cambodia**

This information sheet is for you to keep

Introduction

My name is Chhordaphea Chhea and I am conducting a research project towards my PhD degree at Monash University, Melbourne, Australia. This means that I will be writing a thesis-this is like a 300 page book which will be examined. My supervisors are Professor Lenore Manderson and Dr. Narelle Wareen from the School of Psychology, Psychiatry, and Psychological Medicine. We have funding from the UNICEF/UNDP/World Bank/WHO Special Programme for Research and Training in Tropical Diseases (TDR) to support this work.

Who is invited to participate in this research project?

I have learnt about your roles from members of your community. I understand that you are a village health volunteer, or a DOTS observer, or a traditional healer, and that you have ever had experience of working with people living with TB (TB patient), and that you are aged 18 or over. If this is correct, I would like to invite you to participate in my research study which I have called “Coping with TB Understanding Health Seeking Behaviour in Cambodia”. As the project is about the health seeking behaviour of patients and family, your views would be really valuable.

What is aim/purpose of this research?

In this study, I want to learn what people understand the transmission and treatment of TB, and what cause TB and how it can be cured. I also want to learn about how the disease affects TB patient, including in relation to family and community. I hope that the results of this study will be used to develop a health promotion program to improve TB early case detection, reduce stigma against TB patient, improve compliance with anti-TB treatment, and mobilise support to and their families.

What does the research involve?

I will talk with you about your understanding of TB transmission and treatment, and your experiences of helping or treating a TB patient. With your permission, the interview will be tape-recorded so that I have an accurate record of what you say. Notes can be used if you prefer.

How much time will the research take?

I will ask you to participate in an interview for about 60-90 minutes, so that I can get a more detailed picture of your understanding and your experiences of working with TB.

Inconvenience/discomfort

The questions that I will ask you are not very likely to cause distress, although talking about illness is sometime difficult and upset. Most people find it helpful to participate in this kind of research, because it gives them a chance to freely talk about their experiences in a safe and non judgemental environment. If at any stage of the discussion, you feel distressed, you will be able to cease the

interview and if you need extra help and support, I will help you to contact a local counsellor or social worker who would be able to talk with you.

Can I withdraw from the research?

Being in this study is completely voluntary. You are under no obligation to participate. If you want to withdraw from the study, you can do so at any time during the research process. All unprocessed information that you provide will be destroyed. There will be no consequences for you if you do withdraw, or if all or part of the information is not provided.

How will my confidentiality be protected?

Your participation in this research and the information you have provided will not be disclosed to anyone. If I refer to your story when I am writing, I will be changing your name and your background (such as job, workplace, and the name of your village) so that you cannot be identified. According to university regulations the tape and transcripts will be kept on university premises in a locked filing cabinet for 5 years. Your information will not be used for other purpose than that mentioned above without your consent.

How will I receive results?

Once I have completed writing my thesis-a long report-using what I learn in conducting this research, a brief summary of the findings will be available in Khmer. If you would like to have a copy, please contact the student researcher or the nurse Ms. <insert name> at Kampong Speu Hospital. The results will be presented at academic conferences and in scientific journals. I will also give a talk on preliminary findings of the research in late November 2008 (place and date to be identified), and every community members can attend.

Complaints

If you have a complaint concerning the manner in which this research <insert project number > is being conducted, please contact:

National Centre for Health Promotion #162, Preah Sihanouk, Phnom Penh Tel: 855-23 213 608 e-mail: nchp@camnet.com.kh	Human Ethics Officer Standing Committee on Ethics in Research Involving Humans (SCERH) Building 3e Room 111 Research Office Monash University VIC 3800 Tel: +61 3 9905 2052 Fax: +61 3 9905 1420 Email: scerh@adm.monash.edu.au
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Thank you.

<insert signature>

Chhordaphea Chhea

PhD Candidate

School of Psychology, Psychiatry and Psychological Medicine

Faculty of Medicine, Nursing and Health Sciences

Monash University

Tel: <insert local mobile number>

Email: chhordaphea.chhea@med.monash.edu.au

Date

Explanatory Statement – Health workers, and TB Control Program managers
Project Title: **Coping with Tuberculosis: Understanding Health Seeking Behaviour in Cambodia**

This information sheet is for you to keep

Introduction

My name is Chhordaphea Chhea and I am conducting a research project towards my PhD degree at Monash University, Melbourne, Australia. This means that I will be writing a thesis-this is like a 300 page book which will be examined. My supervisors are Professor Lenore Manderson and Ms. Narelle Warren from the School of Psychology, Psychiatry, and Psychological Medicine. We have funding from the UNICEF/UNDP/World Bank/WHO Special Programme for Research and Training in Tropical Diseases (TDR) to support this work.

Who is invited to participate in this research project?

I have learnt about your job from the provincial health department. I understand that you are a health worker in TB ward of the Kampong Speu hospital; or that you are an officer, or that you are a manager of the Provincial TB Control Program. If this is correct, I would like to invite you to participate in my research which I have called “Coping with TB Understanding Health Seeking Behaviour in Cambodia”. As the project is about health seeking behaviour of patients and their families, your views would be valuable.

What is aim/purpose of this research?

The aim of this study is to explore how people understand transmission and treatment of TB, and to learn to what extent the disease affects TB patients, including in relation to family and community. I hope that the results of this study will be used to develop a health promotion program to improve TB early case detection, reduce stigma against TB patient, improve compliance with anti-TB treatment, and mobilise support to TB patient and their families.

What does the research involve?

I will talk with discuss with you on your experiences of working with TB patient or working with the TB Control Program. With your permission the interview will be tape-recorded so that I have an accurate record of what you say. Notes can also be used if you prefer.

How much time will the research take?

Interview will occur at a time and place that is convenient for you, and will take approximately 60-90 minutes.

Inconvenience/discomfort

The questions that I will ask you are not very likely to cause distress, although talking about illness is sometime difficult and upset. Most people find it helpful to participate in this kind of research, because it gives them an opportunity to freely talk about their experiences in a safe and non judgemental environment. If at any stage of the discussion, you feel distressed, you will be able to

cease the interview and if you need extra help and support, I will help you to contact a local counsellor or social worker who would be able to talk with you.

Can I withdraw from the research?

Being in this study is completely voluntary. You are under no obligation to participate. If you want to withdraw from the study, you can do so at any time during the research process. All unprocessed information that you provide will be destroyed. There will be no consequences for you if you do withdraw, or if all or part of the information is not provided.

How will my confidentiality be protected?

Your participation in this research and the information you have provided will not be disclosed to anyone. In all publications I will be changing your name and your background (such as job, workplace, and the name of your village) so that you cannot be identified. According to university regulations the tape and transcripts will be kept on university premises in a locked filing cabinet for 5 years. Your information will not be used for other purpose than that mentioned above without your consent.

How will I receive results?

Once I have completed writing my thesis – long report - using what I learn in conducting this research, a brief summary of the findings in Khmer will be available. If you would like to have a copy, please contact the student researcher or the nurse Ms.<insert name> at Kampong Speu Hospital. The results will be presented at academic conferences and in scientific journals. I will also give a short talk to share preliminary findings of the research in late November 2008 (place and date to be identified), and every community members can attend.

What should I do if I want to get further information or I have a complaint?

If you have a complaint concerning the manner in which this research <insert project number > is being conducted, please contact:

National Centre for Health Promotion #162, Preah Sihanouk, Phnom Penh Tel: 855-23 213 608 e-mail: nchp@camnet.com.kh	Human Ethics Officer Standing Committee on Ethics in Research Involving Humans (SCERH) Building 3e Room 111 Research Office Monash University VIC 3800 Tel: +61 3 9905 2052 Fax: +61 3 9905 1420 Email: scerh@adm.monash.edu.au
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Thank you.

<insert signature>

Chhordaphea Chhea

PhD Candidate

School of Psychology, Psychiatry and Psychological Medicine

Faculty of Medicine, Nursing and Health Sciences

Monash University

Tel: <insert local mobile number>

Email: chhordaphea.chhea@med.monash.edu.au

Appendix4: Demographic data of participants

TB patients (pseudonyms have been used)

	Pseudonyms	Gender	Age	Occupation
1	Bona	M	32	Construction worker
2	Chamrong	M	18	Student
3	Chantha	F	41	Farmer
4	Chanthy	M	56	Farmer
5	Kanika	F	34	Factory worker
6	Kim	F	59	Farmer
7	Kiri	M	56	Farmer
8	Kolab	F	20	Factory worker
9	Kravan	F	52	Farmer
10	LiLi	F	27	Farmer
11	Lim	M	52	Farmer
12	Mali	F	48	Farmer
13	Meas	M	69	Farmer
14	Navy	F	20	Factory worker
15	Phally	F	27	Factory worker
16	Phirum	M	32	Construction worker
17	Pin	M	48	Construction worker/farmer
18	Pisey	F	28	Farmer
19	Rithy	M	40	Construction worker
20	Romdol	F	34	Farmer
21	Rotana	F	32	Factory worker
22	Samnang	F	40	Farmer
23	Samreth	M	68	Farmer
24	Sok	M	70	Retired Farmer
25	Sokun	M	64	Farmer
26	Soma	F	57	Farmer
27	Sophal	M	54	Government officer
28	Sophon	M	28	Construction worker
29	Sovann	M	28	Factory worker
30	Meng	M	73	Retired farmer
31	Vath	M	78	Retired farmer
32	Vuth	M	41	Farmer

Family members (pseudonyms have been used)

	Pseudonyms	Age	Relationship with TB patients	Patient's name
1	Chan	54	Father	Kolab
2	Pov	22	daughter	Chanthy
3	Seng	29	Husband	Pisey
4	Ui	20	Son	His mother did not participate in the study

5	Mony	38	Niece	Soma
6	Pheakdey	56	Father	Navy
7	Thavy	56	mother	Her son (Nara) died of TB
8	Sitha	61	wife	Meas
9	Sary	62	Wife	Sok
10	Mach	62	Mother	Rotana
11	Vanny	28	daughter	Her father (Saran) died of TB
12	Tevy	35	Wife	Vuth

Community DOTS observers (pseudonyms have been used)

	Pseudonyms	Age	Gender	Experience s as DOT observer
1	Mana	51	F	3 years
2	Kheun	54	M	6 months
3	Sunary	40	F	4 years
4	Cheata	39	F	1 year
5	Sona	43	F	3 years
6	Sokha	55	F	3 years
7	Prak	27	M	2 years

Health worker at Kampong Speu Province, TB officers, and Pharmacy's owners and *Kru Khmer* (pseudonyms have been used)

	Pseudonyms	Gender	Qualification	Position/place of work
1	Kosal	M	Secondary nurse	Deputy head of HC
2	Sambath	M	Pharmacy assistant	Pharmacy and gives medicine to TB patient
3	Dara	M	Secondary nurse	Head of health centre and responsible for TB
4	Sambo	M	Medical assistant	Health staff at health centre
5	Oudam	M	Secondary nurse	Head of health centre and responsible for TB
6	Nareth	M	Medical assistant	Health staff at hospital
7	Vannak	M	Medical assistant	Health staff at hospital
8	Kunthea	F	Labo-technician	Laboratory
9	Rotha	M	Secondary nurse	Health centre staff
10	Seth	M	Secondary nurse	Staff at HC and responsible for TB
11	Phanna	M	Not identified	Provincial TB Unit
12	Navuth	M	Doctor	Provincial Health Department
13	Saray	M	Doctor	NTP
14	Chey	M	High school	Pharmacy owner
15	Neng	F	Junior high school	Pharmacy owner
16	Nita	F	High school	Pharmacy owner
17	Pich, aged 50	M	High school	<i>Kru Khmer</i>
18	Chamreun, 81	M	Pagoda	<i>Kru Khmer</i>

Participants of the focus group discussion (pseudonyms have been used)

	Pseudonyms	Age	Gender	Occupation
1	Bopha	33	F	Farmer, married
2	Chealy	56	F	Farmer, widow
3	Chum	39	M	Farmer, married
4	Chim	64	F	Farmer, married
5	Chrep	46	F	Farmer, married
6	Dany	37	F	Farmer, married
7	Dina	56	F	Farmer, married
8	Heng	64	M	Farmer, widower
9	Keo	28	F	Factory worker, married
10	Lin	26	F	Farmer, married
11	Lina	36	F	Farmer, married
20	Mok	62	M	Farmer, married
12	Mom	25	F	Farmer, married
13	Neang	35	F	Farmer, married
14	Phavy	59	F	Farmer, married
15	Punleu	27	M	Casual labourer, farmer
16	Rany	28	F	Factory worker, single
17	Rath	32	F	Farmer, married
18	Rin	28	M	Motorcycle-taxi driver, farmer
19	Sareun	26	F	Farmer, married
22	Seila	27	M	Farmer, married
21	Sokha	52	F	Farmer, married
23	Som	37	M	Farmer, married
24	Sopheap	34	F	Farmer, married

Appendix 5: Consent Forms

Consent Form of Focus group- <Name of participant group>

Title “Coping with Tuberculosis: Understanding Health Seeking Behaviour in Cambodia”

NOTE: This consent form will remain with the Monash University researcher for their records

I agree to take part in the Monash University research project specified above. I have had the project explained to me, and I have read the Explanatory Statement, which I will keep for my records. I understand that agreeing to take part means that:

1. I agree to involved in a focus group ☐ Yes ☐ No
2. I agree to allowing the focus group to be audio-taped ☐ Yes ☐ No

I understand that my participation is voluntary, that I can choose not to participate in part or all of the project, and that I can withdraw from the project at any time during research process, without being penalised or disadvantaged in any way.

I understand that any data that the researcher extracts from the focus group for use in reports or published findings will not, under any circumstances, contain names or identifying characteristics.

Participant's name

Signature

Date

Consent Form for Interviews - <Name of participant group>

Title “Coping with Tuberculosis: Understanding Health Seeking Behaviour in Cambodia”

NOTE: This consent form will remain with the Monash University researcher for their records

I agree to take part in the Monash University research project specified above. I have had the project explained to me, and I have read the Explanatory Statement, which I will keep for my records. I understand that agreeing to take part means that:

- | | | |
|---|------------------------------|-----------------------------|
| 1. I agree to be interviewed by the researcher | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 2. I agree to allow the interview to be audio-taped | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 3. I agree to make myself available for a further interview if required | <input type="checkbox"/> Yes | <input type="checkbox"/> No |

I understand that my participation is voluntary, that I can choose not to participate in part or all of the project, and that I can withdraw at any time during the research process without being penalised or disadvantaged in any way.

I understand that any data that the researcher extracts from the interview for use in reports or published findings will not, under any circumstances, contain names or identifying characteristics.

Participant's name

Signature

Date

Consent Form for Survey Interviews

Title “Coping with Tuberculosis: Understanding Health Seeking Behaviour in Cambodia”

NOTE: This consent form will remain with the Monash University researcher for their records

I agree to take part in the Monash University research project specified above. I have had the project explained to me, and I have read the Explanatory Statement, which I will keep for my records. I understand that agreeing to take part means that:

I agree to be interviewed by the researcher

☐ Yes

☐ No

I understand that my participation is voluntary, that I can choose not to participate in part or all of the project, and that I can withdraw at any time during the research process without being penalised or disadvantaged in any way.

I understand that any data that the researcher extracts from the interview for use in reports or published findings will not, under any circumstances, contain names or identifying characteristics.

Signature:

Date

Appendix 6: Questionnaire

Coping with Tuberculosis: Understanding health seeking behaviour in Cambodia

Hello, my name is <insert interview name>, I work with the project “Coping with TB: understanding health seeking behaviour in Cambodia. As outlined in the explanatory statement, we are conducting this project to explore how people understand the transmission and treatment of TB, and to learn to what extent the disease affects TB patients, their family members and members of the community. This study will be used for the development of thesis to fulfil a requirement of my PhD degree. The interview will take about one hour to complete. All information you provided will be kept strictly confidential, and will not be shown to any other persons.

Participation in this interview is voluntary and you can choose not to answer any individual question or all of the questions. However, I hope that you will participate in this interview since your views are extremely important.

At this time, do you want to ask me anything about the interview?

[Obtain consent-indicated by consent form]

May I begin interview

Time start interview.....Time complete interview.....

Time of interview.....

Date of interview: Day..... Month..... Year.....


ID of village..... ID of Health centre.....

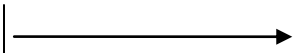
Result code: 1- Complete questionnaire 2- Incomplete 3- Interviewer refuse to continue 4- Other		
Data entry	First entry	Second entry

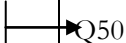
Section 1: Demographic information

No.	QUESTION AND FILTER	CODING CATEGORIES	SKIP			
1	Record Sex of respondent	1. Male 2. Female				
2	Age of respondent	In year..... <table border="1" style="display: inline-table; vertical-align: middle;"><tr><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td></tr></table>				
3	Areas of residence	1. Urban 2. Rural				
4	Can you read and write	1. Yes 2. Little literate 3. Can't read and write	→ Q6			
5	What is the highest level of school you attend?	1. Primary 2. Lower secondary 3. Upper secondary 4. Higher 5. Other.....				
6	What is your religion?	1. Buddhism 2. Muslim 3. Christian 4. Others (please specify).....				
7	Marital status	1. Single 2. Married 3. Divorced/separated 4. Living with a partner 5. Widowed/widower 6. Others (please specify).....				
8	How many people live in your house?	Members of household				
9	What is your current occupation?	1. Unemployed 2. Farmer 3. Professional 4. Business + sale 5. Craftsman 6. Housewife 7. Students 8. Unskilled employee 9. Others (please specify).....				
10	What is the monthly income of your family?				
11	What possession does your family have?	1. Buffalos 2. Cows 3. Rice fields 4. Cars 5. Motorbikes 6. Bicycle				

		7. TV 8. Radio	
	Section 2: Knowledge on TB Now I would like to ask you questions related to TB (TB)		
12	Have you ever heard of TB (TB)?	1. Yes 2. No →	Q50
13	What are the causes of TB infection? Record all answers provided	1. Germ 2. Hard work 3. Smoking 4. Heredity 5. Magic spells 6. Karma 7. Others (please specify).....	
14	What symptoms indicate TB? Record all answer provided	1. Fever 2. Difficult breathing 3. Cough more than 3 weeks 4. Loss of appetite 5. Weakness 6. Blood in sputum 7. Don't know 8. Others (please specify).....	
15	Can TB be gone by one person to another?	1. Yes 2. No 3. Don't Know	
16	How is TB transmitted?	1. Infectious droplet spread 2. Sharing eating utensils 3. From ancestor to next generation 4. From mother to baby 5. Eating with patients 6. Do not know 7. Others(Please specify)	
	Could you tell me if the following statements are true or false:		
17	Family members need to be screened for TB	1. True 2. False 3. Unsure	
18	TB patient should not eat together with other family members	1. True 2. False 3. Unsure	
19	TB is not curable within proper treatment	1. True 2. False 3. Unsure	
20	TB can be cured with a 4 weeks course of treatment	1. True 2. False 3. Unsure	
21	As soon as TB symptoms have gone, TB patient is cured from the disease	1. True 2. False 3. Unsure	
22	How long should the treatment of TB be?	1. Number of	

		months..... 2. Don't know	
23	What type of people are most vulnerable to TB Record all answer provided	1. Poor people in rural areas 2. Poor people in slum areas 3. People living on streets 4. Husband/wife of PLW/TB 5. People living with AIDS 6. Don't know 7. Others (please specify).....	
24	Why do you think this?	Record all answer provided	
25	How is TB prevented? Record all answer provided	1. Vaccination against TB 2. Have BCG vaccination 3. Have good nutrition 4. Maintain good health 5. Don't talk with TB patient 6. Don't Know 7. Others (please specify).....	
26	Where should a TB patient find TB treatment	1. Private provider 2. <i>Kru Khmer</i> 3. NGO clinic 4. Health Centre 5. Referral hospital 6. National hospital 7. Pharmacy 8. Don't know 9. Other.....	
27	Why do you think like this		
Section 3: Attitudes toward TB patients			
	Imagine a situation where a PLW/TB is under treatment for TB who is healthy with a stable health condition		
28	Should TB patient under treatment live as normal with their family in the same house?	1. Yes  2. No 3. Don't Know	Q30
29	If no, should they be kept isolated?	1. All time during treatment 2. Before receiving treatment 3. Only first one month of treatment 4. Don't know 5. Others (please specify).....	
30	Should a TB patient eat with their family members?		
31	TB patient should take leave from their job during treatment	1. Strongly disagree 2. Disagree 3. Neutral/DK 4. Agree	

		5. Strongly agree	
32	TB patient have the same rights as other people	1. Strongly disagree 2. Disagree 3. Neutral/DK 4. Agree 5. Strongly agree	
33	I should not worry about my risk of getting TB	1. Strongly disagree 2. Disagree 3. Neutral/DK 4. Agree 5. Strongly agree	
34	TB is a curse to patient	1. Strongly disagree 2. Disagree 3. Neutral/DK 4. Agree 5. Strongly agree	
35	If I live with TB, it is shameful	1. Strongly disagree 2. Disagree 3. Neutral/DK 4. Agree 5. Strongly agree	
36	If my family member is living with TB, I want to keep it a secret	1. Strongly disagree 2. Disagree 3. Neutral/DK 4. Agree 5. Strongly agree	
37	If my relatives had TB, I would not allow them to come to my house	1. Strongly disagree 2. Disagree 3. Neutral/DK 4. Agree 5. Strongly agree	
38	I would not provide financial support to my relative who has TB	1. Strongly disagree 2. Disagree 3. Neutral/DK 4. Agree 5. Strongly agree	
Section 4: Perceptions and practices related to TB			
	Now I would like to ask you question related to TB		
39	Based on what you know about TB, do you think to have chance of getting TB	1. Yes 2. No 3. Don't know	
40	If yes, what are the chances of you getting TB?	1. Very high chance 2. Medium chance 3. Don't Know 4. Low chance 5. No chance	

41	Why do you think this? Record all answer provided	1. I never contacted with TB patient 2. I'm strong and healthy 3. I'm vaccinated with BCG 4. None of my family members have ever had TB 5. Don't know 6. Others (please specify).....	
42	What do you fear the most about TB? Record all answer provided	1. Transmission of the disease 2. Long treatment 3. Shame for family 4. Poor health status caused by TB 5. Don't know 6. Others (please specify).....	
43	What do you think about TB disease? Record all answer provided	1. TB is a dirty disease 2. TB is a disease of poverty 3. TB is associated with HIV 4. Women would have less chance of getting married 5. Don't know 6. Others (please specify)	
44	How do you feel to TB patient Record all answer provided	1. Compassion 2. Support rewards to TB patient 3. Scared of patient 4. It s their "Karma" 5. Don't know 6. Others (please specify)	
45	Have you ever known TB patient in your village or workplace in the past year?	1. Yes 2. No 3. Not sure	
46	How many of them?	
47	How are they related to you?	1. A family member 2. Relative 3. Friends 4. People in the same village 5. Others (please specify)	
48	What did you do to prevent infection of TB from them? Record all answers provided	1. I never talk to them 2. I always wear a mask while talking to them 3. I asked them to wear a mask while talking to me 4. I never eat with them 5. I never share any equipment 6. Others (please specify).....	

49	What support have you given to the patient?	1. Money 2. Food 3. Remind to take medicine 4. Advice to seek treatment 5. Did not help anything 6. Don't know, don't remember 7. Nothing 8. Other.....	
	Practices related to utilization of health services		
50	In this year, have you ever coughed for 2-3 weeks?	1. Yes 2. No 3. Don't remember	
51	What did you do to cure the cough	1. Don't do anything 2. Buy medicines from pharmacy 3. Go to health centre 4. Go to private	
52	If you go to health centre or private provider what did they do to treat your cough?		
53	How far from your home to the nearest health centre?metres	
54	Where would you like to go as your first choice when you are sick with any illness?	1. At health centre 2. At referral hospital 3. NGO's clinic 4. Private clinics 5. Kru Khmer 6. Don't know 7. Others	
55	Why would you choose that place?		
56	If you disease persists or worsen, where would you like to seek health care?	1. At health centre 2. At referral hospital 3. NGO's clinic 4. Private clinics 5. <i>Kru Khmer</i> 6. Don't know 7. Others	
57	Why would you choose that place?		
58	Have you ever used health centre?	1- Yes 2- No	
59	What do you describe health centre services?	1. Peet did not pay attention 2. Service fee is expensive 3. High transportaion cost	

		4. Health staff are friendly 5. Have good medicine 6. Good services 7. No medicines 8. Cheap services 9. Long waiting 10. Health staff absent 11. Don't know 12. Other	
	Health information related to TB		
60	Have you ever received health information on TB	3- Yes 4- No 5- Don't remember	
61	How do you learn health information about TB? Record all answers provided	1. From school 2. From media 3. From health workers 4. From friends/relatives 5. From health volunteers 6. Others (please specify) 7. Never get health information on TB	
62	What did the health information on TB inform you about? Record all answers provided	1. Transmission of TB 2. Prevention of TB 3. Vaccination of TB 4. DOTS 5. Don't know 6. Others (please specify)	
63	What do you think about health information on TB you have received? Record all answers provided	1. I can't understand it 2. It's very difficult to understand 3. There's very little information on TB in my community 4. It's hard to get information about TB 5. Others	
64	How often do you hear health information on TB?		
65	Would you like to learn more about TB?	1. Yes 2. No Not sure	
66	What would you like to learn more about TB?	1. Prevention of TB 2. Transmission of TB 3. Vaccination of TB 4. DOTS 5. Don't know 6. Others (please specify).....	

Thank you very much

Appendix 7: Publication related to the thesis



ORIGINAL RESEARCH

Health worker effectiveness and retention in rural Cambodia

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Health worker effectiveness and retention in rural Cambodia

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Available from: <http://www.rrh.org.au>

ABSTRACT

Introduction: A decade after health sector reform, public health services in rural Cambodia remain under-utilised for multiple reasons related to financial, structural and personnel factors. Ineffectiveness of rural public health services has led to a significant increase in private providers, often the same people who staff public facilities. Public health clinics are often portrayed as low quality, with long waiting times and unexpected costs; in contrast, private clinics are seen to provide more convenient health care. Several strategies, including contract management and health equity funds, have been introduced to improve public sector performance and encourage utilization; these efforts are ongoing. However, the feasibility of these strategies remains in question, particularly in terms of cost-effectiveness and sustainability.

Methods: In this article the strategies of and barriers met by health workers who remain in rural areas and deliver public health services are elucidated. Ethnographic research conducted in 2008 with health providers involved in treating tuberculosis patients in Kampong Speu Province, Cambodia is drawn on. Participants were recruited from the provincial health department, provincial hospital and four health centres. Data collection involved in-depth interviews, participation in meetings and workshops aimed at health workers, and observation of daily activities at the health facilities. Data were transcribed verbatim, imported into NVivo software (www.qsrinternational.com) for management, and analysed using a grounded theory approach.

Results: Primary healthcare service delivery in rural Cambodia was reliant on the retention of mid-level of health staff, primarily midwives and nurses. Its performance was influenced by institutional characteristics relating to the structure of the health system. Personal factors were impacted on by these structural issues and affected the performance of health staff. Institutional factors worked against the provision of high-quality public health services, and included the fragmentation of service delivery and