CHAPTER 1

INTRODUCTION

Background and Significance of the Problem

Tuberculosis remains one of the major public health problems worldwide. In April 1993, the World Health Organization (WHO) declared tuberculosis "a global health emergency", because tuberculosis was a neglected global health problem and out of control in many parts of the world (Pio & Chaulet, 1998; Raviglione, Snider, & Kochi, 1995). The human immunodeficiency virus (HIV) epidemic was causing an increase in the number of tuberculosis cases, particularly in Africa, although increases were also expected in Southeast Asia (Raviglione et al., 1995). In 2001, 183 of 210 countries reported to WHO a total of 3.8 million cases (62 per 100,000 population) of tuberculosis. 37% of the TB cases in the world were reported from the SouthEast Asia Region. The total number of smear-positive (infectious) cases was 1.6 million (WHO, 2003). There were an estimated 8.0 million new tuberculosis cases in 1997, 8.4 million in 1999 and up to 8.7 million in 2000. It is estimated that by 2005, the incidence of new cases may increase to 10.2 million (WHO, 2001).

Thailand is one of the 22 countries with the highest number of estimated cases of tuberculosis (WHO, 2003). Approximately one third of Thailand's population is infected with TB. There are an estimated 100,000 new cases of TB each year, including 37,000 who have infectious disease and are able to spread the bacteria to the community (Ministry of Public Health, Thailand & WHO, 1999). Various factors

have contributed to the increased incidence of TB in Thailand. The serious tuberculosis situation will be further aggravated by the HIV/ tuberculosis co-epidemic and high burden multi-drug resistant (MDR) TB. Drug resistant TB is caused by inconsistent or partial treatment and affects those who do not complete the course of treatment. (MoPH, Thailand & WHO, 1999). A joint WHO and Thailand government review of the National Tuberculosis Control Program (NTP) of Thailand in 1995 revealed that cure rates for smear-positive tuberculosis patients in various parts of the country were only17-68% and there were high default rates (MoPH, Thailand & WHO, 1995). Following the review of the NTP, the government of Thailand in 1996 adopted the WHO recommended strategy known as Directly Observed Treatment, Short Course (DOTS) for controlling tuberculosis (MoPH, Thailand & WHO, 1999).

Directly Observed Treatment, Short Course (DOTS) has five key elements: 1) government commitment, 2) case detection by sputum smear microscopy among symptomatic patients self-reporting to health services, 3) standardized treatment regimen including directly observed treatment (DOT), 4) a regular, uninterrupted supply of all essential anti-TB drugs, and 5) a standardized recording and reporting system (WHO, 1999). Directly Observed Treatment (DOT), which is one element of the DOTS strategy, is defined as observation of the patient by a health care provider or other responsible person as the patient ingests anti-tuberculosis medications (American Thoracic Society, 1994).

Directly Observed Treatment has been recommended as the standard of care as it improves patient adherence to the TB treatment (American Thoracic Society, 1994; U.S.A.Centers for Disease Control and Prevention, 1994; Sumartojo, 1993; WHO, 1999). DOT also leads to high rates of treatment completion, reduced relapse

rates and drug resistance rates (Chaulk, Moore-Rice, Rizzo, & Chaisson, 1995; Chaulk & Kazandjian, 1998; Chinese Tuberculosis Control Collaboration, 1996; Weis et al., 1994). Furthermore, DOT has been shown to be more cost-effective than self-administered therapy (SAT) (Burman, Dalton, Cohn, Butler, & Reves, 1997; Moore, Chaulk, Griffiths, & Cavalcante, 1996). In Thailand, studies have shown effective outcomes of DOT in terms of higher cure rate and sputum conversion rates than in self-administered groups (Akkslip, 1997; Akkslip et al., 1999; Aiemwithiwanich & Phansiwakan, 1998; Kamolratanakul et al., 1999; Kasetjaroen et al., 1995; Kungsaworn, Khunkwa, Ruangsup, & Proybamrung, 1997; Siriwat, Aiemtan, & Chaemsanit, 1998).

The person conducting DOT needs to be someone who is accessible to the patient, accountable to the health service and acceptable to the patients (MoPH, Thailand, 2002). Currently, there are three main types of DOT observers used in Thailand: 1) DOT by health personnel; 2) DOT by community members; and 3) DOT by family members FM-DOT (Ministry of Public Health, 1998). In Thailand the majority of DOT observers are assigned family member (Akkslip, 1997; Akkslip et al., 1999; Kamolratanakul et al., 1999; Kasetjaroen et al., 1995; Kungsaworn, Khunkwa, Ruangsup, & Proybamrung, 1997; Pungrassami, Johnsen, Chongsuvivatwong, Olsen, & Sorensen, 2002), especially, in the lower southern part of Thailand where the highest proportion (74.8%) of family members were assigned as DOT observers (Rattanasuwan, 2002). Some studies regarding FM-DOT observers have been reported. Siangsung & Nokyongthong (2000), based on their research findings, found that having an observer was advantageous to a patient because the supervision and encouragement received from observers meant better compliance by the patients. In a case control study of 500 patients with TB in China, Wan (1993) found that 250 patients with TB self-administering drugs under family supervision was as effective as 250 patients taking drugs under the strict supervision of a health worker. In Thailand, Kaseijaroen et al. (1995) conducted a clinical trial of DOT by family members. The study showed that the completion rates were higher in DOT by family members when compared to not having any observers (90.8% and 80.4%, respectively). Moreover, Akkslip et al. (1999) revealed a cure rate of 85.2% for DOT by family members compared with 70.9% for self-administration (SA) among new sputum smear-positive patients. Kanchanapangka (2002) found that there was no difference in the success of DOTS program between health care personnel and family members or health volunteers in the health department of The Bangkok Metropolitan Administration (BMA). Tiptus (2000) also studied the roles of family members in caring for tuberculosis patients. The results showed that the total mean score of role performance of family members fell into the moderate level (76.9%). In addition, one participatory action research in Phayao Province found that their community considered that relatives of the patients should monitor when they take medicines because the relatives are close to them and can encourage them (Kochang, 2000). Some studies regarding FM-DOT observers have shown the feasibility of DOT by family members (Akkslip, 1997; Kamolratanakul et al., 1999; Kasetjaroen et al., 1995), with treatment outcomes of self administered comparing well to family members, however, in some settings the success rates with FM-DOT observers did not reach the WHO global target of an 85% cure rate and the study did not shown data on the practical observers.

Furthermore, Pungrassami et al. (2002) found that among health personnel, community members, and family member observers, the proportions who did not actually practice DOT were 11%, 23%, and 35% respectively. The FM-DOT observers had the highest risk of not practicing DOT. In addition, Siripanichgon, Lubis, Sujirarat, and Vathanophas (1999) indicated that a factor associated with an unsuccessful DOTS program of pulmonary tuberculosis in West Kalimantan, Indonesia was that patients received drugs from family members. The reason could be that in the study the observation was inadequate or irregular, but Arkaravichien, Usawamethapun, Soonthornpas and Teerasut (2003) found that the main reason given to explain why patients did not comply with DOTS was that the observers of DOTS did not really do their jobs (56.3%). As report in previous studies, the reason for the FM-DOT observers did not practice DOT may be partly due to lack of information and a misunderstanding or lack of perception of the role of observer.

Perception, the first stage of role performance (Roy & Robert, 1981), influences individuals behavior (King, 1981) and guides their actions (Huse & Bowditch, 1977). Some research studies have reported the role perception and role performance in several groups, such as in fathers with their first child, fathers with preschool children, health volunteers and public health center personnel (Arunyapoom, 1999; Nirach, 2000; Runggeatikul, 1998; Wanachatisara, 1994). They showed that role perception is positively related to role performance. Therefore, the perception of FM-DOT observers could influence their behavior. Some previous studies regarding FM-DOT observers have shown effective treatment outcomes, but there has been no information on role perception, or the relationship between perception and the actual DOT practice of FM-DOT observers. Furthermore, previous

studies on care received as perceived by care providers and care recipients demonstrated that there were different perceptions of both care providers and care recipients of the care the patient received (Thongpat, 1997). Thus, to ensure the delivery of the most effective care by FM-DOT observers, there is a need to identify, understand, and rectify the role perception and role performance of FM-DOT observers. Therefore, the researcher will study the role perception and role performance of FM-DOT observers as perceived by themselves and by the people with pulmonary tuberculosis (PTB) that they are observing. The comparison focuses on the role performance of FM-DOT observers but additional data will be collected to identify possible reasons that may cause any differences in the perception of care between the observer and the patient. The results of this study could provide a clearer understanding of the connection between role perception and role performance of FM-DOT observers that would be helpful for nurses and other health care providers to support FM-DOT observers in performing their roles more effectively.

Objectives of the Study

- 1. To describe the levels of role perception and role performance of family member-DOT observers (FM-DOT observers) as perceived by FM-DOT observers
- 2. To examine the relationships between the role perception and role performance of FM-DOT observers as perceived by FM-DOT observers
- 3. To describe the levels of role perception and role performance of FM-DOT observers perceived by people with PTB
 - 4. To examine the differences of FM-DOT observers'role performance as

perceived by FM-DOT observers and people with PTB

Research Questions

- 1. What are the levels of role perception and role performance of FM-DOT observers as perceived by FM-DOT observers?
- 2. Are there any relationships between role perception and role performance of FM-DOT observers as perceived by FM-DOT observers?
- 3. What are the levels of role perception and role performance of FM-DOT observers as perceived by people with PTB?
- 4. Are there any differences of the FM-DOT observers'role performance as perceived by FM-DOT observers and people with PTB?

Hypotheses

- 1. There are positive relationships between the role perception and role performance of FM-DOT observers.
- 2. There are differences between the perception of people with PTB and FM-DOT observers regarding the role performance of FM-DOT observers.

Conceptual Framework

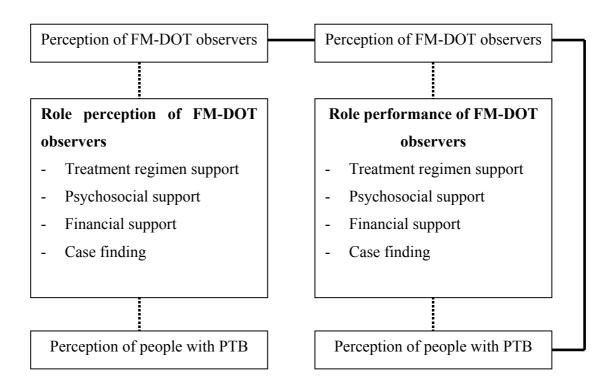
The conceptual framework for this study on the role perception and role performance of FM-DOT observers as perceived by FM-DOT observers and people with pulmonary tuberculosis is based on the concept of perception, Roy and Robert's

concept of role function system (Roy & Robert, 1981), and DOT observers' roles outlined in The Practice Guidelines for DOT Observers purposed by the tuberculosis division (Tuberculosis Division, Thailand, 1998).

Role is the pattern of behavior associated with expected and actual behaviors that a person should perform to maintain a specific position or situation. Role performance by the individual results when the individual perceives their role, because perception is the first stage of role performance, (Roy & Robert, 1981) and perception influences individual behavior (King, 1981). Moreover, perception is the basis of behavior and a guideline to action (Huse & Bowditch, 1977). Therefore, an individual's perception influences their behavior.

The main role of a DOT observer is to make sure that the patient takes the TB drugs regularly, on schedule, and for the full duration of the treatment. The DOT observer also needs to provide reassurance, listen to and encourage the patient (WHO, 2002). The Thai Tuberculosis Division has outlined the role of the DOT observer in The Practice Guideline for DOT observers and includes treatment regimen support, psychosocial support, financial support, and case finding (Tuberculosis Division, Thailand, 1998). These roles are expected to overcome any problems encountered by the patient and the observer. If the FM-DOT observers perceive and understand their roles they will be able to carry out their roles in a suitable and effective manner.

The conceptual framework for the present study can be summarized as shown in figure1:



Dot in the model implies extension of concept specific to respondent

Figure 1 Conceptual framework of the study

Definition of Terms

1. Role Perception of Family Member- DOT Observers

Role perception of FM- DOT observers refers to perceiving and understanding the actions that FM-DOT observers need to perform when caring for people with PTB in four dimensions; treatment regimen support, psychosocial support, financial support, and case finding. Role perception of FM-DOT observers will be measured by the questionnaires developed by the researcher based on DOT

observers' roles purposed by the Thai tuberculosis Division (1998) and the literature review.

2. Role Performance of Family Member-DOT Observers

Role performance of family member-DOT observers refers to the perceived role obligations that have been performed by FM-DOT observers during the initial phase of treatment consisting of four dimensions: treatment regimen support, psychosocial support, financial support and case finding. Perceived role performance of family member-DOT observers will be measured by questionnaires modified by the researcher based on Tiptus (2000) and the DOT observers' roles purposed by the Thai tuberculosis Division (1998).

3. Family Member-DOT Observers

Family member-DOT observer refers to a parent, spouse, son, daughter, or relative who is assigned to care for the patient and is recorded as the DOT observer in the patient's TB treatment cards or the DOT cards.

4. People with Pulmonary Tuberculosis (PTB)

People with pulmonary tuberculosis refer to patients newly diagnosed with pulmonary tuberculosis by a physician and who have been receiving TB medication for at least two months but no longer than four months.

Expected Outcomes

The results of this study will provide a clearer understanding of the roles of FM-DOT observers and of the perceptions of people with PTB of the care they are given. This information will be of value to nurses and health care providers who work

with people with PTB to gain a deeper understanding of the role and value of FM-DOT observers. In addition, the finding of this study will help to understand the behavior of FM-DOT observer in performing their role for people with PTB. Furthermore, the results could be used as baseline information for further studies with DOT observers.