

## CHAPTER 2

### LITERATURE REVIEW

The review of the literature and research studies consists of the following topics:

1. Tuberculosis and Its Treatment
2. Directly Observed Treatment (DOT)
3. Role Perception and Role Performance
  - 3.1 Concept of Role
  - 3.2 Role Perception
  - 3.3 Role Performance
4. The Relationship between Role Perception and Role Performance
5. The Role of Family Member-DOT Observers

#### **Tuberculosis and Its Treatment**

Tuberculosis is an infectious disease caused by *Mycobacterium tuberculosis*. *Mycobacterium tuberculosis* is an acid-fast aerobic that grows slowly and is sensitive to heat and ultraviolet light (Smeltzer & Bare, 2000). This disease mainly affects the lungs, but it can also affect other parts of the body such as kidneys, bones and joints (Taylor & Littlewood, 1998). TB is spread from person to person through air borne transmission by droplet nuclei. When people with pulmonary or laryngeal tuberculosis cough, sneeze, speak, laugh or sing, they can send droplet nuclei into the

air and other people who inhale the infectious airborne droplet nuclei can become infected (ATS, 2000).

Tuberculosis infection is different from tuberculosis disease. Although infection always precedes the development of active disease, only about 10% of infections progress to active disease. Tuberculosis infection is characterized by the presence of mycobacteria in the tissue of a host who is free of clinical signs and symptoms and who demonstrates the presence of antibodies against the mycobacteria. Tuberculosis disease is manifest as pathological and functional signs and symptoms indicating destructive activity of mycobacteria in host tissue (Christensen & Kockrow, 1999).

#### 1. Classification of Tuberculosis Cases

It is necessary to classify cases of TB in order to determine the correct patient registration, reporting procedures and prescribing of treatment according to standardized categories. WHO classify cases by the site of disease and bacteriological status (Pio & Chaulet, 1998).

1.1 Pulmonary tuberculosis, sputum smear positive (PTB+) refers to a patient with at least two sputum specimens positive for acid-fast bacilli (AFB) by microscopy, or a patient with only one sputum specimen positive for AFB by microscopy and radiographic chest abnormalities consistent with active pulmonary TB, or a patient with only one sputum specimen positive for AFB by microscopy and a culture positive for *M. tuberculosis*.

1.2 Pulmonary tuberculosis, sputum smear negative (PTB-) refers to a patient with symptoms suggestive of TB, with at least two sputum specimens negative for AFB by microscopy and with radiographic chest abnormalities consistent with

active pulmonary TB (including interstitial or miliary abnormal images), or a patient with at least two sputum specimens negative for AFB by microscopy and a culture positive for *M. tuberculosis*, or a patient with two sets of at least two sputum specimens taken at least two weeks apart negative for AFB by microscopy and radiographic abnormalities consistent with pulmonary TB, and lack of clinical response to one week of broad-spectrum antibiotic and a decision by a clinician to treat with a full course of anti-tuberculosis chemotherapy.

1.3 Extra-pulmonary tuberculosis refers to a patient with tuberculosis of organs other than the lungs: e.g. pleura, lymph nodes, abdomen, genito-urinary tract, skin, joints and bones, and meninges. Diagnosis should be based on one culture positive specimen, or histological or strong clinical evidence consistent with active extra-pulmonary tuberculosis, followed by a decision by a clinician to treat with a full course of anti-tuberculosis chemotherapy.

A patient diagnosed with both pulmonary and extra-pulmonary tuberculosis should be classified as a case of pulmonary tuberculosis.

## 2. Categories of Patients for Registration

At the time of diagnosis every tuberculosis patient must be registered under one of the following 6 categories ( Maher et al., 1997; MoPH, 2002).

2.1 New: A patient who has never had treatment for tuberculosis or who has taken anti-tuberculosis drugs for less than four weeks.

2.2 Relapse: A patient who has been declared cured of any form of tuberculosis in the past by a clinician, after one full course of chemotherapy, and has become sputum smear- positive.

2.3 Failure: A patient who, while on treatment, remained or became again

smear-positive five months or later during the course of treatment. It may also be a patient who was initially smear-negative before starting treatment and became smear-positive after the second month of treatment.

2.4 Treatment after default: A patient who interrupts treatment for two months or more, and returns to treatment with smear-positive sputum (sometimes smear-negative but still with active TB as judged on clinical and radiological assessment).

2.5 Transfer in: A patient who has been transferred from another tuberculosis register to continue treatment.

2.6 Other: All cases which do not fit the above definitions e.g. patient treated more than 4 weeks by a private agency, patient diagnosed with TB and relapsed with sputum negative. This group includes chronic cases: A patient who is sputum positive at the end of a re-treatment regimen.

### 3. Standardized Treatment Regimens

#### 3.1 The Essential Anti-TB Drugs

There are five essential anti-TB drugs for treating TB: Isoniazid (H), Rifampicin (R), Pyrazinamide (Z), Streptomycin (S), and Ethambutol (E). There are three main properties of anti-TB drugs: bactericidal ability, sterilizing ability and the ability to prevent resistance. The anti-TB drugs possess these properties to different extents. Isoniazid and Rifampicin are the most powerful bactericidal drugs, active against all populations of TB bacilli. Pyrazinamide and Streptomycin are also bactericidal against certain populations of TB bacilli. Pyrazinamide is active in an acid environment against TB bacilli inside macrophages while Streptomycin is active against rapidly multiplying extracellular TB bacilli. Ethambutol is a bacteriostatic

drug used in association with more powerful bactericidal drugs to prevent the emergence of resistant bacilli (Maher et al., 1997)

### 3.2 Standard Code for TB Treatment Regimens

A regimen consists of 2 phases. (1) The initial phase and (2) The continuation phase. There is a standard code for TB treatment which uses an abbreviation for each anti-TB drug. The number before a phase is the duration of that phase in months. A number in subscript (e.g. 3) after a letter is the number of doses of that drug per week. If there is no number in subscript after a letter, then treatment with that drug is daily. An alternative drug (or drugs) appears as a letter (or letters) in brackets.

Example: 2HRZE /4HR

The initial phase is 2HRZE. The duration of the phase is 2 months. Drug treatment is daily (no subscript number, e.g. 3 after the letters), with isoniazid (H), rifampicin (R), pyrazinamide (Z) and ethambutol (E).

The continuation phase is 4HR. The duration of the phase is 4 months. Drug treatment is daily, with isoniazid (H) and rifampicin (R).

Example: 2H3R3Z3E3 / 4H3R3

The initial phase is 2H3R3Z3E3. The duration of the phase is 2 months. Drug treatment is three times per week (subscript number 3 after the letter).

The continuation phase is 4H3R3. The duration is 4 months, with isoniazid and rifampicin three times per week (subscript number 3 after the letters) (Maher et al., 1997).

### 3.3 Treatment Regimens

Treatment regimens are divided into the initial phase and the continuation phase. During the initial phase the bactericidal effect of treatment leads to rapid bacteriological sputum conversion and improvement of clinical symptoms. During the continuation phase, consisting usually of fewer drugs given either daily or intermittently, the sterilizing effect of the therapy eliminates remaining bacilli and prevents relapse (Pio & Chaulet, 1998).

The National Tuberculosis Program (NTP) in Thailand presents four categories of recommended treatment regimens (MoPH, Thailand, 2002).

Category of treatment	Type of patients	Alternative TB treatment regimens	
		Initial phase	Continuation phase
Category 1	New smear-positive PTB New smear negative PTB with extensive parenchymal involvement; new case of severe forms of extra-pulmonary TB	2HRZE or 2HRZS	4HR
Category 2	Sputum smear positive: - Relapse - Treatment failure - Treatment after interruption	2HRZES/ 1HRZE	5HRE

Category of treatment	Type of patients	Alternative TB treatment regimens	
		Initial phase	Continuation phase
Category 3	New smear-negative PTB (other than in category1)  New less severe forms of extra-PTB	2HRZ	4HR
Category 4	Chronic case (still sputum positive after supervised retreatment)	Second line	drugs or INH alone

#### Category 1: 2HRZE(S)/ 4HR

Used in new cases of AFB smear-positive pulmonary TB and new smear-negative pulmonary TB with extensive parenchymal involvement; new cases of severe forms of extrapulmonary TB (such as meningitis, pericarditis, peritonitis, bilateral or extensive pleurisy, spinal disease with neurological complications, intestinal tuberculosis and genito-urinary tuberculosis). This category consists of an intensive phase of daily isoniazide (H), rifampicin (R), pyrazinamide (Z) and ethambutol (E) or streptomycin (S) for 2 months and a continuation phase of daily isoniazide and rifampicin for 4 months.

#### Category 2: 2HRZES/1HRZE/5HRE

The secondary category includes smear-positive relapse, smear-positive treatment failure, and smear- positive patients being treated after default. This category consists of an intensive phase of daily isoniazide (H), rifampicin (R), pyrazinamide (Z) and ethambutol (E), supplemented with streptomycin for the first 2

months, followed by the same drugs without streptomycin for 1 month. The continuation phase is daily isoniazide (H), rifampicin (R), and ethambutol (E) for 5 months.

#### Category 3: 2HRZ/4HR

Used in new cases of AFB smear-negative pulmonary TB and extra pulmonary TB which are not very serious such as TB lymph node. This category consists of an intensive phase of daily isoniazide (H), rifampicin (R) and pyrazinamide (Z) for 2 months followed by a continuation phase of daily isoniazide (H) and rifampicin (R) for 4 months.

#### Category 4: Second line drugs or INH alone

This category includes chronic cases (still sputum-positive after supervised re-treatment). The regimen uses isoniazide alone or at least 3 types of reserved drugs.

### **Directly Observed Treatment (DOT)**

Directly observed treatment or therapy (DOT) is one of the elements of short-course (DOTS) for tuberculosis, the global strategy for effective TB control (Maher et al., 1997; Pio & Chaulet, 1998; WHO, 1999).

Directly observed treatment, short-course (DOTS) has five 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). The government of Thailand adopted the WHO recommended strategy known as DOTS in 1996, with the aim of achieving the global targets for TB control. These are to cure 85% of new infectious cases and detect 70% of the infectious cases estimated to occur each year (MoPH, Thailand & WHO, 1999).

### **Definition of DOT**

Directly observed treatment (DOT) means that a supervisor watches the client swallowing the medication for all doses over the course of treatment. The purpose of DOT is to ensure that a TB patient takes the correct drugs, the correct dose, and at the correct times (Maher et al., 1997).

Directly observed treatment (DOT) is defined as an observation of the patient by a health care provider or other responsible person of the patient's ingestion of anti-tuberculosis medications. DOT can be carried out for daily, twice-weekly, or thrice-weekly administration of medication (ATS, 1994).

### **Recommendations of DOT**

The World Health Organization (WHO) suggests that many patients receiving self-administered treatment do not adhere to treatment and as it is impossible to predict who will or will not comply, Directly Observed Treatment is necessary to ensure adherence, particularly during the initial phase (Maher et al., 1997; Pio & Chaulet, 1998). The United States Center for Disease Control and Prevention (US-CDC) and the American Thoracic Society (ATS) has recommended that DOT should be considered for all patients because of the difficulty in predicting which patients

will adhere to a prescribed treatment regimen (ATS, 1994, 1992; US-CDC, 1994; US-CDC, 1993).

### **Effectiveness of DOT**

Because there have been many studies that have reported the effectiveness of DOT in people with TB, Directly Observed Treatment (DOT) has been recommended as the standard of care and to improve patient adherence to the TB treatment (ATS, 1994; CDC, 1994; Sumartojo, 1993; WHO, 1999). Weis et al. (1994) showed that in a DOT group, the proportion of cases with primary and acquired resistant TB decreased from 13% and 14% to 6.7% and 2.1%. The relapse rate decreased from 20.9% to 5.5% and the multidrug-resistant (MDR) form decreased significantly from 25% to 5%. Chaulk, Moore-Rice, Rizzo, and Chaisson (1995) showed that the implementation of DOT in 1981 in Baltimore city led to a decline of tuberculosis (35.6 cases per 100,000 population, 1981; 17.2 cases per 100,000 population, 1992) and the city ranking for TB (sixth in 1981, 28th in 1992). This occurred despite the fact that the community had risk factors, such as AIDS, unemployment, poverty, and immigration from high-prevalence countries, which were conducive to the presence of the disease. The decline was in contrast to the increased number of cases seen in the five major U.S. cities having the highest incidence of tuberculosis but which did not have comprehensive DOT programs. Furthermore, from 1986 to 1992, the DOT-managed cases in Baltimore had the highest annual sputum conversion rates at 3 months, the highest completion rates for anti-TB therapy, and high bacteriological evidence of cure.

In the China Tuberculosis Control Collaboration (1996) between 1991 and 1994, DOT was used as a strategy with short-course drug therapy to treat 112,842 patients. The results of treatment showed a cure rate of 89.7% among 55,213 new cases with smear-positive tuberculosis and 81.1% among 57,629 previously treated patients and the failure rate dropped from 17.6% to 6.2%. This study represents a success for DOT, as previously only 50% of patients with TB were cured.

In addition, DOT has been shown to be more cost-effective than self-administration (SA). A study shown that the average cost per case cured using DOT was \$ 13,925 compared with \$ 15,003 for SA, and the use of DOT predicted TB relapse (31 vs 133 per 1,000 patients treated) and fewer TB related deaths (3 vs 13 per 1,000 patients treated) (Moore, Chaulk, Griffiths, & Cavalcante, 1996). Similarly, Burman, Dalton, Cohn, Butler, and Reves (1997) reported that the cost per case cured using DOT was \$ 3,999 compared with \$ 12,167 using SA. They suggested that DOT was a more cost-effective strategy than SA because it achieved a higher cure rate after initial therapy, and thereby decreased treatment costs associated with failure of therapy and acquired drug resistance.

In Thailand, Kamolratanakul et al. (1999) conducted a randomized controlled trial of DOT at 8 district hospitals, 3 provincial hospitals and 4 zonal TB centres of the government health system. A total of 836 patients were randomly assigned to be treated either under DOT (N = 414) or self-supervised using monthly drug supplies (SS) (N = 422). The result showed that treatment outcomes were improved compared to pre-study conditions. However, cure and treatment-completion rates were significantly higher in the DOT cohort (76% and 84%) than in the SS group (67% and 76%). The benefits of DOT were more pronounced at district and provincial hospitals

(DOT cure rate 81% vs 69% in the SS group), while differences for patients treated at referral centres were non-significant (DOT cure rate 72% vs 66% in the SS group).

Akksilp (1997) studied the ratio of types of watchers and the feasibility of integration of directly observed therapy, short-course (DOTS) for tuberculosis into routine public health. The study found that DOT could be performed in 292 out of 657 patients (44.44%). The majority of watchers (88%) were family members. The study indicated that patients who used DOT had a statistically significant higher cure rate than those who were self-administered (88.23% and 56.76% respectively).

Kungsaworn, Khunkwa, Ruangsap, and Proybamrung (1997), in their Quasi-experimental study, compared treatment outcomes between DOT and short course chemotherapy (SCC). 61 new TB patients and 8 re-treatment TB patients registered at the 6<sup>th</sup> Zonal Tuberculosis Center Khon Kaen during 1 July - 30 September 1995, were designated to be the control group receiving regular short course therapy, while 51 new TB patients, 15 re-treatment TB patients registered during 1 July - 30 September 1996, were designated to be the experimental group receiving DOT. The results showed that sputum conversion rates at the end of the second month were 92.16% and 80.33% and cure rates were 82.35% and 75.4% among new TB patients in the experimental group and control group respectively.

Siriwat, Aiemtan, and Chaemsanit (1998) conducted a comparative study on the outcomes of the treatment of pulmonary tuberculosis using directly observed treatment and self-administered. The subjects were 172 new smear positive pulmonary tuberculosis patients registered at tuberculosis center region 9, Phitsanulok from September 1996 - October 1997. The researchers randomized patients into 2 groups. 86 cases were treated with DOT while the rest were treated with SA. The

results revealed that the DOT group had a cure rate of 66.3% compared to 52.3% in SA. Additionally the DOT group had better adherence to the treatment.

In Trang Province, Aiemwithiwanich and Phansiwakan (1998) compared treatment outcomes between DOT and Non-DOT groups. 35 new smear positive pulmonary tuberculosis patients and 5 re-treatment smear positive patients in the fiscal year 1996 (1 Oct 1995 – 30 Sep 1996) were treated with DOT by family members. 28 new smear positive pulmonary tuberculosis patients and 4 re-treatment smear positive patients in the fiscal year 1995 were treated by Non-DOT. The results showed that in the DOT group the lost to treatment rate of new smear positive PTB patients decreased from 42.9% to 37.1%, the sputum conversion rate increased from 71.4% to 82.8% and the cure rate increased from 71.4% to 80.0%.

In summary, most of the studies in Thailand comparing self-administered (Non-DOT) and DOT revealed that DOT had more effective outcomes of treatment on cure rate and sputum conversion rate than the self-administered (Non-DOT) group. However, in some settings the success rates with DOT did not reach the WHO global target of an 85% cure rate.

### **DOT Observer**

A person who takes on the responsibility as a DOT observer should always be accessible to the patient, accountable to the health service and be accepted by the patient (MoPH, Thailand, 2002).

#### **1. Qualities of a DOT Observer**

The qualities of a DOT observer taking care of a tuberculosis patient are;  
(Tuberculosis Division, 1998)

1.1 A DOT observer should have a good relationship with the patient. It means an observer should take care of, give love to, assure and encourage a hopeful patient who can spend his life reasonably and correctly.

1.2 A DOT observer should be aware of and accept the actual condition of the patient with tuberculosis without paying attention to his status, disability or any unacceptable behavior.

1.3 A DOT observer must respect the patient's privacy and right to keep his condition secret. An observer should also accept and respect the patient's dignity and listen to his problems. An observer should keep them secret but may consult teammates to solve the problems together.

1.4 A person who is to be a DOT observer should have good intentions toward the patient.

1.5 A person who is to be a DOT observer must have adequate skills in solving problems for the patient. If the patient faces a serious or complex problem, the observer should be an intermediary to compromise the benefit of a patient to the service organization.

## 2. Types of DOT Observer

There are three main types of DOT observers used in Thailand. (MoPH, Thailand, 1998b)

1. DOT by health personnel including staff members of TB clinics, hospital wards, and health centres.
2. DOT by community members including village health volunteers, community leaders, monks, and friends.
3. DOT by family members including spouses, parents, sons, daughters,

brothers, sisters and relatives.

### 3. Recommendations regarding DOT Observers

The national guidelines recommend that the first choice of observer for all patients is DOT by health personnel (Hoondee, Kawkate, & Kasetjaroen, 1997; MoPH, 1998b, 2002). However, DOT by health personnel is not always convenient or accessible to all tuberculosis patients (Akkslip, et al., 1999). When a focus group was conducted in a high human immuno deficiency virus (HIV) prevalence area of Thailand to elicit the perspectives of health staff and clients regarding the feasibility of directly observed treatment (DOT) for tuberculosis, providers and clients expressed different opinions about health centre and home-based DOT. Most participants perceived health centre-based DOT to be impractical for clients due to severe illness, travel inconvenience and interference with employment. Several participants said they did not believe that health centre staff would be able to visit patients' homes daily. They perceived the staff as always busy and providing service only inside the health centre. Most health centre staff perceived home-based DOT to be difficult because of the inconvenience of travel, the inadequate number of health personnel and the high tuberculosis caseload. (Ngamvithayapong, Yanai, Winkvist, Saisorn, & Diwan, 2001).

In a prospective study conducted in 24 districts in Southern Thailand (Pungrassami & Chongsuvivatwong, 2002) health personnel (HP), community members (CM), family members (FM) and self- administration (SA) were initially assigned to be DOT observers for 177, 21, 181, and 32 of the 411 reviewed patients, respectively. However, 212 (56%) of the 379 patients with assigned observers changed their observers. Among the 177 patients assigned to HP, only 17% actually had HP as their main observer. The researcher surmised that HP may not be the best

choice in their setting due to poor sustainability. However, since March 1998, the eleventh Zonal Tuberculosis Center, Nakhon Si Thammarat, Thailand has implemented DOT by assigning people who are not family members of the tuberculosis (TB) patients. Health personnel were the main observers (88.8%) in the study which is different from other studies or reports in Thailand that assigned family members as the main observer. This study demonstrated that DOT without observation by a family member could be a practical model that produced a high cure rate (80.6%). In addition, it demonstrated that the majority of TB patients in urban areas could accept and visit the health service units to take the anti-TB drugs (Rattanasuwan, Yuanlae, & Daewa, 2002).

Of the other options, DOT by family member is controversial. In the context of family, a family member is almost always a potential observer for staying with the patient during taking of the drug especially in regard to the timing of the drug; for example, before bedtime or more than once a day, often making them the only practical observer (Pungrassami, 2001). However, Pozsilk (1993) recommended that it is not desirable to delegate the responsibility of giving medicine to the patient's family members. Because of the emotional ties some family members have with the patient, they may be unwilling to ensure that the patient takes the medication if the patient resists treatment. Moreover, Pio and Chaulet (1998) suggest that family members are less suitable to be responsible for direct observation as they are less accountable to the health service than people outside the family home.

In Thailand in 1992, the Tuberculosis Center Zone 12 Yala studied the feasibility of directly observed treatment (DOT) by family members for the treatment of tuberculosis. They compared treatment outcomes between two groups; 120 cases



took drugs with DOT by family members (DOT group) and 112 cases did without any observers (non-DOT). The study revealed favorable results showing that DOT by family members was feasible, because the completion rate of treatment in the DOT group was significantly higher than in non-DOT (90.8% and 80.4% respectively) (Kasetjaroen et al., 1995). Furthermore, in 1996, a study in Yasothorn province on revised NTP of Thailand explored the options of using supervised family members. The aim of this study was to evaluate the effectiveness of a programme offering the option of direct observation of treatment (DOT) by a supervised family member. The overall cure rate was 80.4% in a program in which trained and supervised family members directly observed the treatment of two-thirds of the sputum smear-positive patients. They suggested that supervised family members may contribute to more widespread effective implementation of the revised tuberculosis strategy in Thailand (Akkslip, Rasmithat, Maher, & Sawert, 1999). A participatory action research in Phayao Province, which studied the feasibility of community participation in DOTS for TB patients and to developing DOTS for TB patients, showed that a suitable form of DOTS for this community was that relatives of the patients should monitor the patients when they take medicines because relatives are close to them and can give encouragement to the patients (Kochang, 2000). Therefore, currently the majority of DOT observers are family members (Akkslip, 1997; Akkslip et al., 1999; Kamolratanakul et al., 1999; Kasetjaroen et al., 1995; Kungsaworn, Khunkwa, Ruangsup, & Proybamrung, 1997; Pungrassami et al., 2002).

#### 4. Research studies related to FM-DOT observer

In Phitsanulok Province, Thailand, Tiptus (2000) studied the roles of family members in caring for tuberculosis patients in terms of medical and nursing care, psychological care and socio-economic care. The results showed that the total mean score of the roles of family members in caring for tuberculosis patients fell into the moderate level (76.9%) as did the roles of family members in medical and nursing care, psychological care and social care (79.7, 76.3, and 71.4% respectively). Economic care fell into the good level (81.4%).

In Bangkok, Thailand, the retrospective study of Kanchanapangka (2002) aimed to examine the effectiveness of DOTS program between health care personnel and family members or health volunteers in the health department of The Bangkok Metropolitan Administration (BMA). Data were collected from TB case records of patients from Jan. 1, 2000 to Dec. 31, 2000. Of the 891 tuberculosis patient cases, 658 cases were successful and 233 cases failed: a success rate of 67.1%. But there was no difference in the success of the DOTS program between health care personnel and family members or health volunteers.

In Malawi, a new TB regimen was introduced from April 1996 in which patients received supervised treatment by either a health worker or a guardian (family member or close relative). Manders et al. (2001) studied adherence rates during the intensive phase. Adherence to the different treatment options was measured by form checks, tablet counts, and tests for detecting isoniazid in the urine. Adherence was measured at 2, 4 and 8 weeks after onset of TB treatment. The results revealed that patients on guardian-based DOT (N = 35) showed 94% adherence, while patients on health center based DOT (N = 40) showed 84% to 89% adherence. The results

suggest that guardians can supervise TB treatment just as well as health workers during the intensive phase of TB treatment.

In Australia, MacIntyre et al. (2003) conducted a randomised, controlled clinical trial of the effectiveness of a family-based programme of directly observed treatment (DOT) for tuberculosis. Of the 173 patients, 87 were allocated to DOT observed by a family member (FDOT) and 86 to standard supervision but non-observed therapy (ST). However, only 58% of the patients allocated to the FDOT group were able to receive FDOT. The rate of non-compliance was 24%, with no significant difference between FDOT and ST. MacIntyre et al. (2003) suggested that FDOT was not feasible for a large proportion of patients in this setting because they lived alone and had no family support. They were unable to demonstrate a benefit of FDOT in an urban, industrialized country setting. FDOT may be more appropriate in developing countries, where extended family support is often available and the burden of TB is much higher.

In Udonthani province, Thailand, Moharmed (2003) conducted a cross-sectional descriptive study of compliance with treatment among tuberculosis patients under a family-based DOTS strategy. The subjects were one hundred and fifty-nine people in various TB categories. The result revealed that 88.6% of the patients had strict compliance with their treatment. There was a significant association between patients' knowledge of TB disease, perception of illness, treatment and the compliance of patient with treatment. A remarkable finding was that the family-based DOTS was the best of all the available DOTS strategies being closer and more appropriate in terms of patient convenience.

In summary, previous studies regarding FM-DOT observers have shown the feasibility of DOT by family members, with levels of compliance and treatment outcomes of health care personnel comparing well to family members. However, there has been no information on the role of FM-DOT observers or role perception of FM-DOT observers, and the relationships between perception and the actual DOT practice of FM-DOT observers.

#### 5. Assignment of DOT observers

The practice guidelines on the assignment of DOT observer and supervision of DOT practice are; (MoPH, Thailand, 2002)

Before starting the patient's treatment, TB clinic staff should explain to the patient about the disease, prescribed treatments, and its complications. The TB clinic staff will explain the importance of completing the course of therapy, the vital importance of DOT, and encourage each patient to accept DOT and select a DOT observer. Patients are given the choice of observation of treatment with either health personnel, a community member or a family member as their observer. The choice of DOT observer is made by the patient in consultation with TB clinic staff, but the most important reason for choosing the DOT observer is for the convenience of the patient. The patient's agreement is recorded by the TB clinic staff on the patient's treatment card. Each patient who opts for a community member or family member receives a DOT card. TB clinic staff give training to the chosen members responsible for DOT on how to observe and record the treatments. The DOT observer who is responsible for DOT marks the card daily after observing each dose of treatment. Jittanaki and Akksilk (2003) studied methods of observer selection in DOTS implementation in 7 provinces of health region 7 Thailand. The study revealed that the percentages of

observer selections at hospitals, health centers and patients' homes were 59.9%, 28.8%, and 10.7% respectively. 62.7 % of the selections were performed on the diagnosis day. The duration of the selection for 64.2% was less than 30 minutes. People who had influence in the selection were patients themselves (35.7%), hospital staff (26.8%), family members (17.7%) and health center staff (16.5%). 93.6% could have an observer while 6.4% could not find any observer. The types of observers were family member (76.9%) health staff (15.9%) and community leader (1.9%). The researchers suggested that the National TB Program should identify the proper criteria for observer selection such as place and duration.

With DOT by community members or family members, health centre staff make a surprise home visit to each patient and DOT observer, usually once a week, during the first two months (initial phase of treatment) and once a month during the continuation phase. The health centre staff ask patients about side effects of the drugs, check the correctness of drug intake including inspecting the DOT card, count the pills and empty drug packets, and test the patient's urine for the presence of anti-TB drugs.

## **Role Perception and Role Performance**

### **Concept of role**

#### 1. Definition of role

Broom and Selznick (1968) defined role as a basic unit of social structure.

It may be defined as a pattern of behavior associated with a distinctive social position, for example, that of father, teacher, employer, or patient.

Clausen, Flook, and Ford (1977) proposed that role refers to the behavior which a person and /or others expect or believe to be appropriate or ideal.

Hardy and Hardy (1988) defined the term role as a set of expectations and actual behavior associated with position.

Roy and Roberts (1981) stated that a role is a functioning unit of our society. It defines the expected behaviors that a person should perform to maintain a title. Role always occurs in interaction with another person, that is, in a dyadic relationship.

In summary, role is a functioning unit of social structure which defines a pattern of behavior associated with expected and actual behaviors that a person should perform to maintain a specific position or situation.

## 2. The categories of role

Broom and Selnic (1973) proposed 3 components of role:

1. Prescribed role (society prescribed role or ideal role) is the role that others within the society expect or prescribe a person to do something.
2. Perceived role is the role that individuals prescribe to themselves to perform or have expectations on how they should behave in a particular position.
3. Performed role is the role that the individual actually does relevant to a specific position and responsibility.

## **Role Perception**

### 1. Definition of perception

Mosby's dictionary (1994:1188) defined perception as "the conscious recognition and interpretation of sensory stimuli that serves as a basis for

understanding, learning, and knowing or for the motivation of a particular action or reaction”

The definition provided by King (1981:24) stated that “perception is a process of organizing, interpreting, and transforming information from sense data and memory. Perception is a process of human transactions with environment. It gives meaning to one’s experience, represents one’s image of reality, and influences one’s behavior”

Roy (1991:166) defined perception as “the interpretation of a stimulus and the conscious appreciation of its result of activity of cells in the cortex”

Berger and Williams (1999) proposed that perception is the ability of the mind to interpret and analyze input from the senses in order to understand the internal and external environment.

In conclusion, perception refers to a process of organizing, interpreting, and transforming information from sense data and memory. Perception gives meaning to one’s experience, represents one’s image of reality, and influences one’s behavior.

## 2. Characteristics of perception

Imogene King is a nursing theorist who developed a conceptual model for nursing. In King’s theory (1981), she viewed perception as the most important variable because perception influences individual behavior. King summarized the characteristics of perception in four perspectives.

2.1 Perception is universal. All people perceive other individuals and objects in the environment, and these experiences provide information about the world. Through these experiences, individuals form categories of the concrete world, and these abstractions are called concepts.

## 2.2 Perception is subjective, personal, and selective for each person.

Perceptions are selective as each person permits only some stimuli to enter from the environment. Experiences in each person vary in spatial- temporal relationships, in the integrity of the nervous system and/or disturbance in it, in the level of the person's development and in the context or situation in which perceptions are experienced. Therefore, one cannot assume that each person in a situation perceives the events similarly. Perceptions are based on each person's background of experiences, which make them uniquely personal until communicated to others.

2.3 Perception is action oriented in the present. One views the world from the information that is available. Perceptions are influenced by current interests, needs, and future goals. Human beings are in a continuous state of active participation in a perceptual milieu. Awareness of past events, values, and needs serve as organizing factors in one's perceptions. Role and status in the family, in the world of work, and in recreation influence perceptions of individuals. Perception and learning are interrelated concepts.

2.4 Perception is transactions. All individuals enter a situation as active participants, and their existence in the interaction will affect their identity.

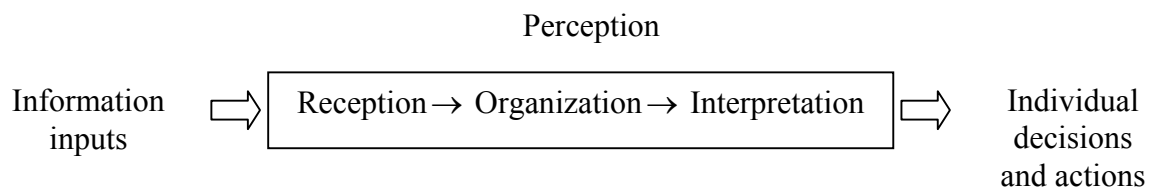
## 3. The Perception process

Perception is an event which occur inside a person and is not able to be observed directly. The perception process of each individual consists of many factors according to psychologists and educators.

Schermerhorn, Hunt, and Osborn (1982) who stated that perception is the process through which people receive, organize, and interpret information from their environment. Through perception, people process the information inputs into



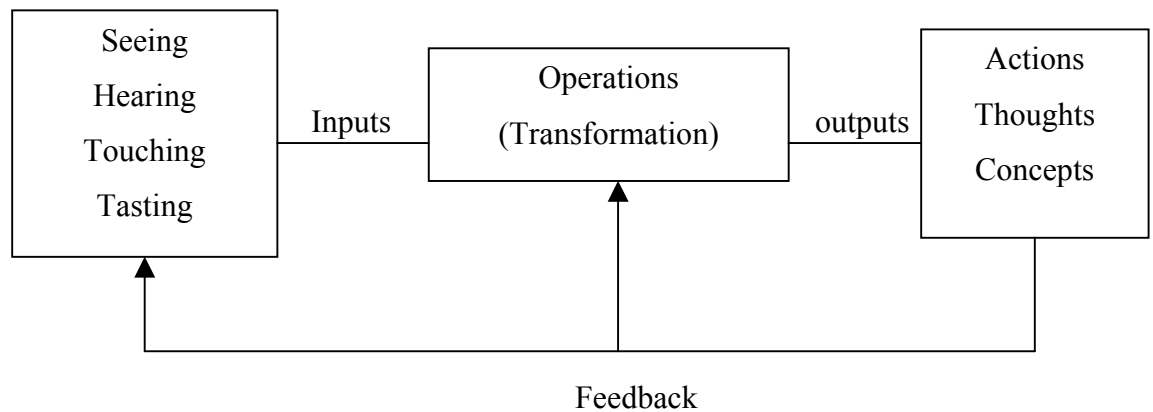
decisions and actions. It is a way of forming impressions about yourself, other people, and daily life experiences. Perception is a screen or filter through which information must pass to achieve impact on human thought processes and behaviors. People can perceive the same situation quite differently. This tendency for perceptions to vary among people is most important for managers to recognize, anticipate, and understand. (Figure 2)



**Figure 2** Perception process of Schermerhorn, Hunt, and Osborn

Note. From *Managing organizational behavior* (p.409-410), by J.R. Schermerhorn, J.G. Hunt, & R.N. Osborn, 1982, New York: John Wiley & Sons.

Huse and Bowdich (1977) stated that each individual is an open system, receiving information inputs, transforming them from sensations to perceptions, which then become modified outputs. These outputs may be modified still further as a result of the feedback loop. This perception process is shown in figure 3.

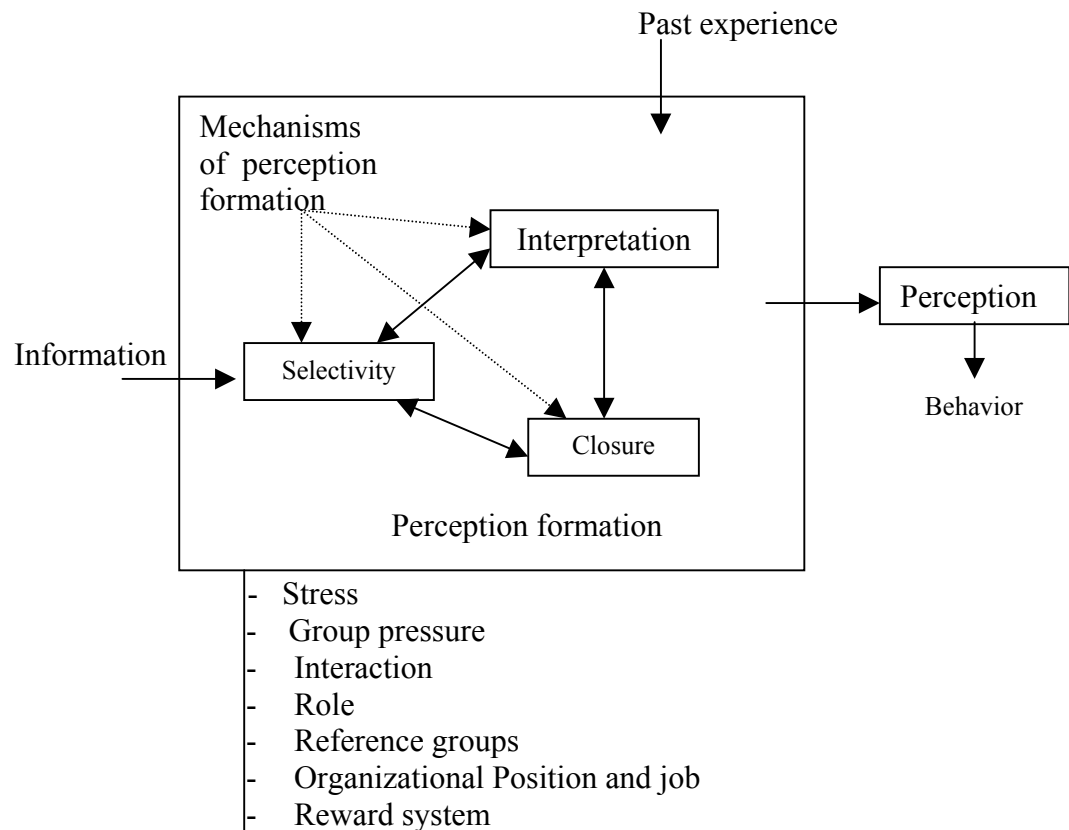


**Figure 3** Perception process of Huse and Bowditch

Note. From Behavior in organizations: A systems approach to managing (p.127), by B.F. Huse & J.L. Bowditch, 1977, Sydney: Addison Wesley.

Kast and Rosenzweig (1985) stated that perception is basic to understanding behavior because it is the means by which stimuli affect an organism or individual. A stimulus that is not perceived has no effect on behavior.

Figure 4 is a model of the way perceptions are formed and hence influence individual behavior. Numerous external forces such as the stress of the situation, group pressure, and reward systems are involved. Past experience has a direct influence on interpretation of stimuli. Basic processes (mechanisms) of perception formation of Kast and Rosenzweig (1985) can be identified as selectivity, closure, and interpretation.



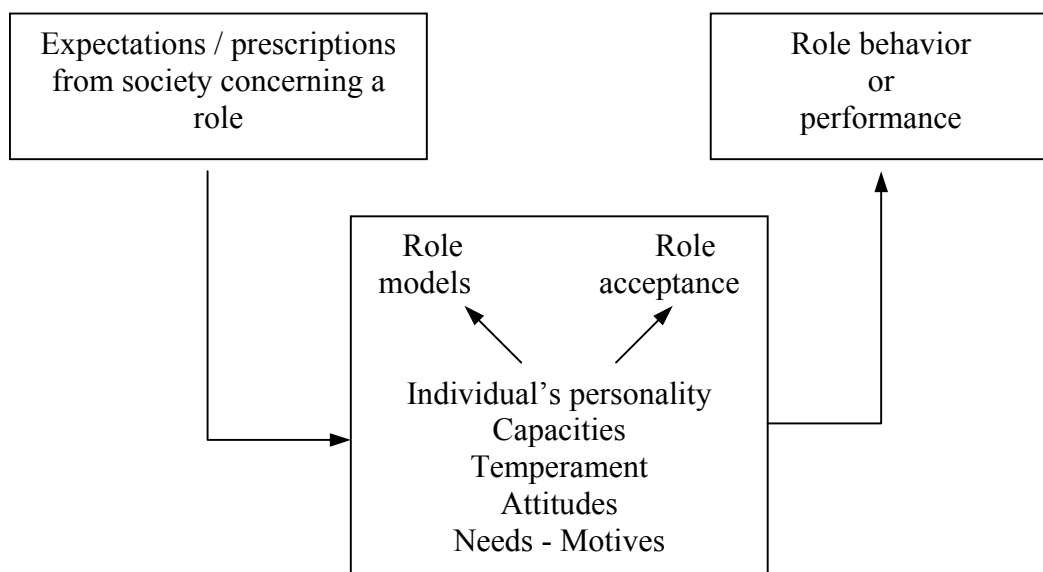
**Figure 4** Perception process of Kast and Rosenzweig

Note. From *Organizations management: A system and contingency approach* (p.283-285), by F.E. Kast & J.E. Rosenzweig, 1985, Singapore: Mc Grow-Hill.

### **Role Performance**

Role performance is what a person actually does within a position in response to role expectation. Expectations and/or prescriptions for the sets of behavior appropriate for the basic social positions and their associated roles (family roles, occupational roles) evolve and are developed by society. These expectations are modified in some cases by particular reference groups (Friedman, 1998). Many of the

roles associated with our basic social positions are learned within the family context. Societal role expectations are modified or refined as a result of an individual's exposure to role models and the person's individual personality, that is, his or her capacities, temperament, attitudes, and interests. An individual accepts particular roles based on societal expectations and as modified by his or her identification with role models and individual personality characteristics. The outcome of an individual's role modification is the person's actual role behavior or performance (Friedman, 1998). Figure 5 illustrates the process by which role behavior actually develops.



**Figure 5** Development of role behavior

Note. From Family nursing: Research, theory, and practice (p.294-295), by M.M.Friedman, 1998, Connecticut: Appleton & Lange.

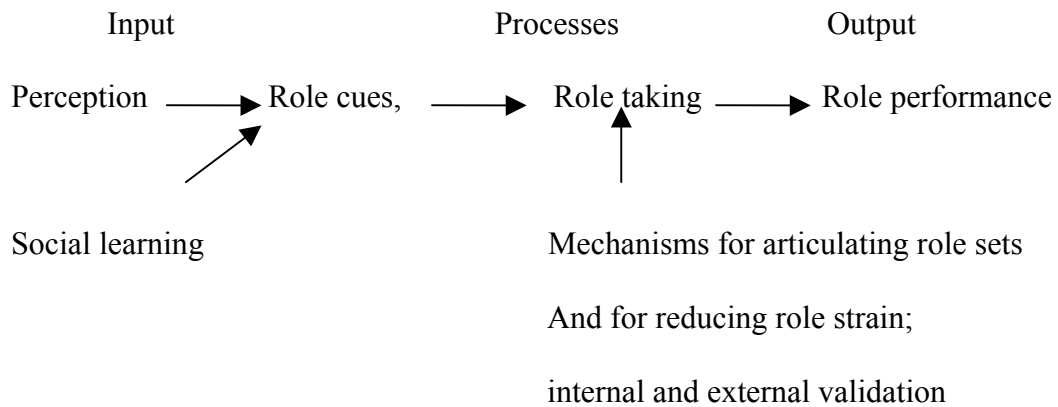
### **Factors influencing role performance**

Factors facilitating the role performance of an individual can be classified into 4 types. (Allport, 1968 cited in Phuphaibul, 1998: 76)

1. Role expectation corresponds with the situation the individual is in.
2. Role conception or role perception corresponds with the tasks society expects the individual to execute.
3. Role acceptance arises when an individual sees the importance of the role he must take. It minimizes conflict with expectations of the society.
4. Role performance can result only when there are factors concerning role expectation by society, perceiving and understanding the roles, and accepting the roles.

### **The Relationship Between Role Perception and Role Performance**

Roy and Roberts (1981) stated that perception and social learning provide the basis for role cues and cultural norms which act as input for the role taking process. Mechanisms for articulating role set and for reducing role strain act as self-regulation while internal and external validation provide feedback. All this leads to the system output of role performance. Conceptualization of the role function system as seen in figure 6.



**Figure 6.** Role function system.

Note. From Theory construction in nursing: An adaptation model. (p.265), by C. Roy & S.L. Roberts, 1981, London: Prentice Hall.

Roy and Robert's concept indicated that there are many factors related to role performance. However, this study will focus on only one of these factors, role perception.

Some researchers have studied the relationship between role perception and role performance. Wanachatisara (1994) studied the role perception and role performance of fathers in the rearing of their first child from birth to 2 months old . She found that 78% of the sample (N = 220) had a moderate score of role perception in child rearing and 65% of the subjects had moderate score of role's performance in child rearing. These findings showed a significant positive correlation between the father's role performance in child rearing and his role perception. Another study examined the perception of fathers' roles and the relation between the selected factors and the roles fathers performed in childcare and child rearing of preschool child. The results showed that the 64% of the fathers with preschool children (N = 200) had a moderate score of role perception in child rearing and 64.5% of the sample had a

moderate score of role performance in child care and child rearing (Arunyapoon, 1999). In a similar study, Nirach (2000), in a sample consisting of 400 fathers with preschool child studied the relationship between knowledge on preschool child development, the father's roles perception and roles performance in preschool child care. The results showed that the sample (N = 400) had a high score of knowledge on preschool child development and father's roles perception but had a moderate score of role performance in preschool childcare. Knowledge on preschool child development and father's role perception were positively correlated with father's roles performance in preschool childcare ( $P < .05$ ). Rungeatikul (1998) examined the relationships between role performance and public health center personnel's and health volunteers' perceptions of the health volunteer roles in a sample consisting of 215 health volunteers and 40 public health center personnel. The findings revealed a positive correlation between both health volunteer experience and supervision by public health center personnel and role performance.

In summary, according to review literature related to role perception and role performance in several groups. However, no information could be found about the relationship between role perception and role performance in DOT observers including in family member-DOT observers. Therefore, the researcher wanted to study role perception and role performance of FM-DOT observers as perceived by FM-DOT Observers and people with PTB. The study is also aim to explore the difference of perceived role performance between and FM-DOT observers and people with PTB.

## **The Role of Family Member -DOT Observers**

In this study, the role of a FM-DOT observer is based on the role of a DOT observer as described by the practice guideline for DOT observers proposed by the Tuberculosis Division (1998). The role of a FM-DOT observer consists of four dimensions: 1) treatment regimen support, 2) psychological support, 3) financial support, and 4) case finding.

### **1. Treatment regimen support**

The FM-DOT observer plays a vital role in caring for the people with TB by ensuring they;

#### **1.1 Take the anti-tuberculosis medication**

The FM-DOT observer should prepare the drug packets, checking the drugs for correctness and watch the patient swallow all the drugs. This role is to make sure that the patient takes the TB drugs regularly, on schedule, and for the full duration of the treatment. The FM-DOT observer is responsible for marking ✓ on the correct day on the DOT card each time after observing the dose of the antituberculosis drugs is taken. The DOT card will help the FM-DOT observer ensure that he/she gives the patient the right TB drugs at the correct time (WHO, 2002). It is important to assess for medication side effects because they are often a reason the patient fails to adhere to the prescribed medication plan (Smeltzer & Bare, 2000). The FM-DOT observer carefully monitor for possible side effects of TB medications, including hepatitis, neurologic changes (hearing loss, neuritis), and rash. If side effects continue, the FM-DOT observer should refer the patient to the health facility and report any changes in the patient's status to the health care provider. The FM-DOT observer



needs to go with the patient to the health facility each month to collect a fresh supply of TB drugs, show the patient's DOT cards, review the patient's progress and discuss any problems (WHO, 2002).

### 1.2 Prevent disease transmission

The FM-DOT observer has a responsibility to instruct the patient in ways of protecting others from possible infection. Knowing how to reduce the number of droplet nuclei will significantly decrease the spread of infection. The FM-DOT observer reminds the patient of the importance of covering their mouth and nose with a tissue or handkerchief when sneezing or coughing. If the patient coughs up any sputum, he must be instructed to expectorate it into a tissue, use it only once and then dispose of it by flushing it down the toilet, or burn it as soon as possible after use (Crofton et al., 1999). Furthermore, the FM-DOT observer should be discouraged from spitting secretion or saliva in public places and should only spit into a closed container.

### 1.3 Manage environmental hygiene

Good ventilation lessens the danger of spreading the disease to someone else as the likelihood of inhaling TB bacilli is reduced if the room is well ventilated. (Lyneh, 1983). As direct sunlight can kill TB bacilli in 5 minutes (Crofton et al., 1999), the FM-DOT observer should ventilate the patient's room with open windows and doors allowing sunlight and fresh air into the room.

### 1.4 Have adequate nutrition

People with TB are often debilitated from a prolonged chronic illness and impaired nutritional status, so, anorexia, weight loss, and malnutrition are common people (Smeltzen & Bare, 2000). Starvation or malnutrition reduces

resistance to the disease (Crofton et al., 1999), therefore, the FM-DOT observer should provide a well balanced diet, which includes all five nutrients. Because most people with TB have copious secretions, which can obstruct the airways and interfere with adequate gas exchange (Smeltzen & Bare, 2000), increasing fluid intake promotes systemic hydration, serves as an effective expectorant and helps keep the airways clear. The FM-DOT observer can promote the importance of an adequate fluid intake, maintaining a daily fluid intake of at least 2,000 to 3,000 ml or 8-10 glasses per day.

#### 1.5 Have adequate sleep

TB patients are encouraged to rest as fatigue is common during the active phase of infection and beginning of medication treatment (Dewit, 1998). People with TB require increased periods of rest to promote healing and alleviate fatigue (Phipps et al., 2003). The FM-DOT observer should provide a quiet environment to afford the maximum amount of rest.

#### 1.6 Have appropriate and adequate physical activity

Physical activity is a factor that contributes to physical fitness. Regular exercise improves muscle strength, endurance, and flexibility, increases lung capacity, reduces anxiety and muscle tension, and assists in maintenance of normal weight and body composition (Sorenson & Poh, 1989 cited by Tamer, 1991). The FM-DOT observer needs to explain to patients the benefits of physical activity in dealing with their tuberculosis disease. During the acute phase of the illness, people with TB experience fatigue and have difficulty completing activities of daily living (ADLs) (Phipps et al., 2003). The FM-DOT observer should encourage activities of daily living to increase activity tolerance and build muscle strength. Increasing activity tolerance involves careful assessment of the physiologic response to activity.

The level of activity should be considered within the given limitations of individual circumstances. Physical activity also should be stressed if it appears that the patient is overexerting himself either by working or by indulging in a debilitating social life (Dewit, 1998).

### 1.7 Avoid smoking and alcohol use

Tobacco smoking and high alcohol intakes are important in reducing the body's defenses (Crofton et al., 1999). Most antituberculosis medications have some degree of or risk for hepatotoxicity. Therefore, the FM-DOT observer should suggest that the patient avoids alcohol while taking antituberculosis drugs and also avoids exposure to other potentially toxic chemicals that may be harmful to the liver. Smoking is a risk factor for tuberculosis. Ariyothai (2002) reported that the active smoker who started smoking at age 15-20 years, or who had a duration of smoking >10 years had a higher risk of pulmonary TB compared to others. Moreover, Altet et al.(1996) reported that passive smoking was a risk factor for pulmonary TB.

## 2. Psychosocial support

Having tuberculosis is a serious situation both psychologically and socially. The patient is required to have medical treatment regularly, manage the various problems that emerge due to the disease, maintain confidence and hope and accept the dependent role of a patient for at least six to eight months (Hemraj, 1992). Patients need a great deal of psychosocial support and understanding. The FM-DOT observer plays a vital role in caring for a person with tuberculosis and must provide;

### 2.1 Emotional support

When a person learns for the first time that they have tuberculosis,

they will need reassurance and understanding. Newly diagnosed patients should not be left alone. The FM-DOT observer needs to establish a relationship of trust with the patient to give the patient an opportunity to express any feelings of fear, anger, and guilt. The patient also may express grief over impaired functioning. It is important to provide them a supportive space in which to sort out their feelings.

## 2.2 Family support

As the treatment for TB requires at least 6-8 months, the FM-DOT observer needs to encourage family members to give concern, sympathy, look after and support the sick patient. Lack of support and strength from family members during the period of prolonged sickness and dependency can lower the self confidence and sense of worth of the patient, and further demoralize and weaken them. Family support also helps in sustaining the effort of the patient in taking prolonged treatment and observing other precautions. The FM-DOT observer may encourage the patient to practice leisure activities, such as watching TV, listening to music, cooking, cleaning as a family project and participating in family recreational activities for fun. Moreover, the FM-DOT observer should encourage visits from friends and family and social outings through neighborhood and church activities.

## 2.3 Social response

Tuberculosis is an infectious disease and the ensuing segregation of the patient can lead to various unfortunate consequences. Relatives and other people become wary of the patient and even of the patient's entire family. Myths rather than knowledge start dictating interpersonal relationships (Hemraj, 1992).

Some people are ashamed of the tuberculosis disease. They feel

that it is a disgrace to the family, and can lead to ostracism of the patient and family. In order to escape the humility of this social malpractice, patients and their family members often attempt to conceal the disease. This secrecy is an additional source of psychological stress upon the patient's mind, and possibly aggravates his condition. In many cultures people think that tuberculosis is hereditary, so, if a daughter gets tuberculosis the family may be afraid that they will never find her a husband. This idea may remain even after she is obviously cured (Crofton et al., 1999). However, facing adverse social response is one problem with which patients have to live. Social attitudes and fear about tuberculosis seem to remain encapsulated (Hemraj, 1992).

A focus group discussion study in Pakistan has been carried out to gain a better understanding of the impact of social stigmatization. The study shows that TB is perceived as a very dangerous, infectious and incurable disease. This perception has many social consequences such as stigmatization and social isolation of TB patients and their families, diminished marriage prospects for young TB patients, and even for their family members, and TB in one of the partners may lead to divorce. Divorce and broken engagements occur more often in female patients. Due to fear, patients often deny the diagnosis and reject the treatment. ( Liefoghe, Michiels, Habib, Moran, & Muynck, 1995). Focus groups were conducted in Thailand to elicit perspectives of health staff and clients regarding the feasibility of DOT for tuberculosis. The result showed that over half of HIV- negative TB females strongly rejected home-based DOT due to unease and fear of the stigma of TB (Ngamvithayapong et al., 2001).

Social rejection can create depression, anxiety, and loneliness and can lower the sense of worth of the patient. Conversely, the warm social response of neighbors, friends, and relatives is emotionally supportive and comforting. The FM-DOT

observer needs to discuss openly with the patient and help them devise a plan in which the patient's needs for companionship, diversion, and support are recognized and met. The FM-DOT observer needs to encourage activities to help the patient, such as, encouraging family communication, expressing sympathy to the patient, creating pleasant surroundings with shared meals, company, and music, and involving other family member with specific tasks to increase confidence and feelings of usefulness.

### 3. Financial support

Illness is an important cause affecting the financial state of the family, especially in chronic illness which needs a long treatment time and expensive treatment costs. The treatments for TB disease also necessitate long periods of time. Most the patients encountered financial problems during their illnesses. Financial problems were due to the patients being unable to attend to their jobs and to other miscellaneous expenditure due to the illness which added to the financial worries of the patients (Hemraj, 1992). The FM-DOT observer needs to provide support, to help the patient and not let them be alone. If the FM-DOT observer cannot help the patient when they have financial problems, the FM-DOT observer can contact social work organizations or related organizations for help. Kamolratanakul et al. (1999b) studied the economic impact of tuberculosis at the household level. The subjects were 673 adult tuberculosis patients who completed treatment at 16 randomly selected government health care facilities in Thailand. The financial statuses were stratified for three levels of patient household income: above national average, below national average but above the poverty line, and below the poverty line. Illness-related costs particularly affected patients with incomes below the poverty line (153 patients). In this group, average out-of-pocket expenditures for the disease amounted to more than

15% of annual household income, while incomes were reduced by 5% due to illness-related effects. Expenditures were most frequently financed from household savings or transfer payments from community members and relatives. However, 11.8% of patient households took out bank loans, and 15.9% sold part of their property to pay for the illness related expenditure. After diagnosis, more than 80% of all patients had out-of-pocket expenditure for travel to hospital and more than 35% had the same for food when going to hospital.

#### 4. Case finding

Evaluation of contacts with cases of infectious TB is one of the most productive methods of finding people with the disease (and infection). Contacts of people with infectious TB are at high risk of infection and disease. Household contacts living in the same household with infectious tuberculosis patients whose sputum is smear positive have a high risk of becoming infected by mycobacterium tuberculosis and of developing active TB later on (Suggaravetsiri, 2003). Sukhapesna, Nateniyom, and Rientrairat (2001) reported that the household contacts of smear positive tuberculosis patients have a very high risk of developing tuberculosis. Contacts investigations usually use methods of acid fast staining, culture, chest x-rays, and tuberculin skin test for case finding.

According to the practice guidelines for DOT observer proposed by the Tuberculosis Division, Thailand (1998), the role of DOT observer in case finding activities were:

1. The observer should advise and motivate neighbors or others suspected of having TB to be checked with chest x-ray and sputum examination at a health care center.

2. The observer should advise and motivate family members living in the same household with the patient to be checked with chest x-ray and sputum examination at a health care center.

3. The observer should advise and motivate children in the contact household who are aged below five years and have never received a BCG vaccination, to be vaccinated.