

## **CHAPTER 2**

### **LITERATURE REVIEW**

In this chapter, several relevant aspects to the study are explored and reviewed. Information from this reviews are grouped and presented as follows:

1. Concept of pulmonary tuberculosis and management
  - 1.1 Definition and etiology of pulmonary tuberculosis
  - 1.2 Incidence and risk factors of pulmonary tuberculosis
  - 1.3 Signs and symptoms of pulmonary tuberculosis
  - 1.4 Treatment for pulmonary tuberculosis patients
  - 1.5 Indonesia health care system and management of pulmonary TB patient
2. DOTS program as a treatment of TB patients
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## **1. Concept of pulmonary tuberculosis**

### **1.1 Definition and etiology of pulmonary TB**

Tuberculosis is a chronically infectious and notifiable disease produced by tubercle bacillus, *Mycobacterium tuberculosis* (Crofton et al., 1999). Tuberculosis occurs most often in crowded, inner city, economically disadvantaged environments and among people with others medical risk factors (Monahan & Neighbors, 1998).

TB is spread from person to person through airborne 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 air bone droplet nuclei can become infected (Taylor & Littlewood, 2000).

Ferrara and Meacci (2005), state that the lungs are primarily involved, but the infection can spread to other organs. Close contacts (people with prolonged, frequent, or intense contact) are at the highest risk of becoming infected (typically 22 percent infection rate but studies have reported, even up to 100%). A person with untreated, active tuberculosis can infect an estimated twenty other people per year. Others at risk include foreign-born from areas where TB is common, immunocompromised patients, residents and employees of high-risk congregate settings, health care workers who serve high-risk clients, medically underserved, low-income populations, high-risk racial or ethnic minority populations, and children exposed to adults in high-risk categories. Nettina (2006), transmission can only occur from people with active TB disease not latent TB infection. The probability of transmission depends on infectiousness of the person with TB (quantity expelled), environment of exposure, duration of exposure, and virulence of the organism.

In 1998 Pio and Chaulet, classified TB based on the site of the diseases and bacteriological status : 1) pulmonary tuberculosis, sputum smear positive (PTB+) refers to a patient with at least two sputum specimen positive for acid-fast bacilli (AFB) by microscopy, or a patient with only one sputum specimen positive for AFB by microscopy plus 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 *Mycobacterium tuberculosis* 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, or patient with at least two sputum specimens negative for AFB by microscopy and culture positive for *Mycobacterium 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 decision by a clinician to treat with full course of anti-tuberculosis chemotherapy 3) extra pulmonary tuberculosis, refers to a patient with tuberculosis of organs other than lungs : pleura, lymph nodes, abdomen, genito-urinary tract, skin, joints and bones, and meninges. Diagnosis should be based on one culture positive specimen, or histological evidence 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.

At the time of diagnosis every tuberculosis patient registered under one of the following categories (Fujiwara & Colleagues, 2005) : 1) new case: a patient who has

never had treatment for tuberculosis or who has taken anti-tuberculosis drug for less than four weeks 2) relapsed case: 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 3) failure case: a patient who, while on treatment, remained or became again smear positive five months or later during the course of treatment 4) treatment after default: a patient who interrupts treatment for two months or more, and returns to treatment with smear positive sputum 5) transfer in: a patient who has been transferred from another tuberculosis register to continue treatment and 6) other : all cases which do not fit the above definitions, for example a patient treated more than 4 weeks by a private agency, patient diagnosed with TB and relapsed with negative sputum smear.

WHO (2004) describes TB into 7 types 1) new case: a patient who has never taken anti tuberculosis treatment or has taken it for less than one month, 2) relapsed case: a patient declared cured of TB by a physician but who reports back to the health service and is found to be bacteriologically positive, 3) transferred in case: a patient who has been received into a tuberculosis unit/district hospital after starting treatment in another unit where he has been recorded, 4) default case: a patient who has received antituberculosis treatment for one month from any source and who has interrupted treatment for more than two months, 5) failure case: an initial smear positive patient who remains smear positive at five months or more after starting treatment or an initial smear negative patient who becomes smear positive during the course of treatment, 6) chronic case: a patient who remains smear positive after completing a re-treatment regimen, and 7) other: a patient who does not fit into any of the above categories, e.g. a relapse patient may be smear negative or an extra-

pulmonary TB patient who has not responded to treatment. Such patients are categorized as others and receive category II treatment.

WHO (2004) also described the tuberculosis based on the severity of illness :

1) seriously ill / not seriously ill smear negative pulmonary TB: Smear negative pulmonary TB cases should be clinically ascertained for the severity of illness and 2) seriously ill / not seriously ill extra-pulmonary TB: Seriously ill extra-pulmonary TB includes meningitis, disseminated TB, tuberculosis pericarditis, peritonitis, bilateral or extensive pleurisy, spinal disease with neurological complications, intestinal and genitourinary TB. In this study all of the participants were patients in category I, because the most common category for TB diseases are pulmonary TB.

Depending on the classification of TB, type of TB, severity of illness, history of treatment in the past, history of interruptions in the treatment, the patient will receive category I, category II or category III treatment. The drugs are to be taken on alternate days under direct observation (DOTS-Directly Observed Treatment, Short-course).

In summary, pulmonary tuberculosis is an infectious disease caused by *Mycobacterium tuberculosis* that may affect almost any tissue or organ of the body. Tuberculosis radiology is used in the diagnosis of TB. It may also include a tuberculin skin test, a serological test, microbiological smears and cultures. Transmission can only occur from people with active TB via airborne spread. The chain of transmission can be stopped by isolating patients with active disease and starting effective anti-tuberculous therapy.

## **1.2 Incidence and risk factors of pulmonary TB**

### **Incidence of pulmonary TB**

By the year 2002, with a population of 217 million people, Indonesia is the fourth largest country in population in the world. It ranks third of countries with the highest (10 %) TB burden following India (30 %) and China (15 %). The WHO global surveillance and monitoring project in 1999, estimated the incidence in Indonesia to be around 583,000 cases and 262,000 new smear positive cases per year. The prevalence of smear positive cases is estimated to be 715,000, with 140,000 patients dying yearly of TB (Ministry of Health, Republic Indonesia, 2004).

### **Risk factors of pulmonary TB**

Tuberculosis can develop after inhaling droplets sprayed into the air from a cough or sneeze by someone infected with *Mycobacterium tuberculosis*. The disease is characterized by the development of granulomas (granular tumors) in the infected tissues. The usual site of the disease is the lungs, but other organs may be involved. The primary stage of the infection is usually asymptomatic. Primary pulmonary TB develops in the minority of people whose immune systems do not successfully contain the primary infection. In this case, the disease may occur within weeks after the primary infection. TB may also lie dormant for years and reappear after the initial infection is contained (Ferrara & Meacci, 2005).

The risk of contracting TB increases with the frequency of contact with people who have the disease, with crowded or unsanitary living conditions and with poor nutrition. Recently, there has been an increase in cases of TB. Factors that may contribute to the increase in tuberculosis infection in a population are: an increase in

the number of homeless individuals (poor environment and poor nutrition), the appearance of drug-resistant strains of TB, incomplete treatment of TB infectious (such as failure to take medications for the prescribed length of time) which can contribute to the emergence of drug-resistant strains of bacteria. Individuals with immune systems damaged by AIDS have a higher risk of developing active tuberculosis, either from new exposure to TB or reactivation of dormant mycobacteria. In addition, without the aid of an active immune system, treatment is more difficult and the disease is more resistant to therapy ( Ferrara & Meacci, 2005).

### **1.3 Signs and symptoms of pulmonary TB**

According to Crofton, Horne and Miller (1999), the signs and symptoms of pulmonary TB are as follows: limited to minor cough and mild fever, if apparent fatigue, unintentional weight loss, coughing up blood, fever and night sweats, phlegm-producing cough, wheezing, excessive sweating, especially at night, chest pain, breathing difficulty. Signs examination of the lungs by stethoscope can reveal crackles, enlarged or tender lymph nodes may be presented in the neck or other areas, fluid may be detectable around a lung, clubbing of the fingers or toes may be present and the tests may include chest x-ray, sputum cultures, tuberculin test, bronchoscopy, thoracentesis, chest CT, rarely, biopsy of the affected tissue (typically lungs, pleura, or lymph nodes), (Ferrara & Meacci 2005).

Furthermore, Nettina (2006), described signs and symptoms of pulmonary TB into two types, 1) constitutional symptoms; fatigue, anorexia, weight loss, low-grade fever, night sweat, indigestion, acute febrile illness, chills, flu like symptom, and 2)

pulmonary signs and symptoms ; cough progressing in frequency and producing mucoid or mucopurulent sputum, hemoptysis, chest pain, dyspnea.

#### **1.4 Treatment for TB patients**

Treatment regimens are divided into the initial or intensive phase and the continuation phase. There is a standard code for TB treatment which uses an abbreviation for each anti-TB drugs.

1) Intensive /initial phase : during the intensive/initial phase the bactericidal effect of treatment leads to rapid bacteriological sputum conversion and improvement of clinical symptoms, the pulmonary TB patient must take the medicines every day for 3-4 months (Pio & Chaulet, 1998).

2) Continuation phase : during the continuation phase, the patient takes the medicines 3 times a week for 5 months, the sterilizing effect of the therapy eliminates remaining bacilli and prevents relapse (Pio & Chaulet, 1998).

There are five essential anti-TB drugs used for treating TB : Isoniazid (H), Rifampicin (R), Pyrazinamide (Z), Streptomycin (S), and Ethambutol (E), and there are three main properties of anti-TB drugs : bactericidal ability, sterilizing ability and the ability to prevent resistance. Isoniazid and Rifampicin are the most powerful bactericidal drugs, active against all types of TB bacilli. Pyrazinamide and Streptomycin are also bactericidal effective against only certain types of TB bacilli. Pyrazinamide is active in an acid environment against TB bacilli inside macrophages while Streptomycin is active against rapidly multiplying TB bacilli (WHO, 2006).

Complying to the drug regimen is critical for success. Directly observed therapy (DOT) is cost-effective for patients at high-risk for non-adherence, and should



be used in all cases, chemotherapy can be successful only within an appropriate health system infrastructure which addresses both the clinical and social management of patients and their contacts (Christopher et al., 2003).

### Treatment for pulmonary TB patient

(WHO, 2006)

Treatment category	Type of TB Patient	Intensive Phase	Continuation Phase
I	<ol style="list-style-type: none"> <li>1. New smear positive pulmonary TB</li> <li>2. New smear negative pulmonary TB seriously ill</li> <li>3. New extra-pulmonary TB seriously ill</li> </ol>	2(EHRZ) 3(24 doses)	4(HR) 3(54 doses)
II	<ol style="list-style-type: none"> <li>1. Sputum smear positive relapses</li> <li>2. Sputum smear positive treatment failure cases</li> <li>3. Sputum smear positive cases, treatment after default</li> <li>4. New smear negative pulmonary TB not seriously ill</li> </ol>	2(SEHRZ) 3+ I (EHRZ) 3(24+12 doses)	5(HRE)3 (66 doses)
III	<ol style="list-style-type: none"> <li>1. New smear negative, extra-pulmonary TB, not seriously ill</li> </ol>	2(HRZ)3 (24 doses)	4(HR)3 (54 doses)

Note: Prefix is number of months and suffix is number of doses in a week H-Isoniazid  
E-Ethambutol R-Rifampicin S-Streptomycin Z-Pyrazinamide.

Ethambutol is a bacteriostatic drug used in association with more powerful bactericidal drugs to prevent the emergence of resistant bacilli (WHO, 2003). The major principles for TB treatment are as follows : drug treatment is an individual and a public health measure, regimens must contain multiple drugs to which organisms

are susceptible, and drug must be given for a sufficient period of time, (Nettina, 2006).

Some pulmonary TB patients do not complete taking the anti TB medications because they feel better, but many pulmonary TB patients fail to follow the treatment medications because they can not tolerate the side effects of the medications. Lee et al., (2002) studied the risk factors for hepatotoxicity associated with rifampin and pyrazinamide for the treatment of latent tuberculosis infection: in three public health tuberculosis clinics and they found that of 148 patients prescribed 2RZ, 85 patients (57.4%) completed therapy, and grade 3 or 4 hepatotoxicity occurred in 14 patients.

**Side effects of TB medications  
(WHO, 2005)**

TB drugs	Side effects
Isoniazid (INH)	tingling or pain in hands and feet (neuropathy), nausea and vomiting, skin rash, fever, may cause liver problems (hepatitis), psychosis
Ethambutol (E)	skin rashes, eye problems such as blurred vision nausea and vomiting, headaches, dizziness joint pain
Rifampicin (R)	nausea and vomiting, diarrhea, skin rash, anemia, liver problems (jaundice), fever, flu like symptoms, body fluids orange
Streptomycin (S)	vestibular and auditory nerve damage, renal damage, coetaneous hypersensitivity, pain, skin rash, indurations at injection site
Pyrazimamide (Z)	joint pain, arthralgia, hepatitis, coetaneous reactions sideroblastic anemia, gastrointestinal problem

### **1.5 Management of pulmonary TB patient: Indonesia context**

In Indonesia pulmonary TB is a national problem that makes the Indonesia government concerned very much to solve the problem. Treatment for TB focused on Community Health Center, Medan Health Service, 2007 stated that 70 % pulmonary TB patients visited a community health center and 30 % visited a hospital to seek treatment for TB. When the patient come to the community health center and complains of cough, the following questions will ask: how long have the patient been coughing, if reply suggests less than 3 weeks, the health workers will ask: has he/she recently had a cough before this, and if yes, ask for how long, what other symptoms does the patient have, does he/she cough up sputum, what color, is it stained with blood, does he/she have fever, if yes, for how long, is it more by day or night, how is his/her weight and appetite, what drugs the patient already taking, does he/she smoke, if so, for how long, does any of close contact/family member suffer from TB, is there any history of previous TB, after that the health worker will do the physical examinations includes: count the pulse, take the blood pressure, take the temperature, count the respiratory rate, good general clinical examination, and listen with stethoscope for wheeze or crackles.

The health worker will advise and treat suspect TB if any of these present: cough more than 3 weeks, or cough less than 3 weeks or of uncertain duration, PLUS either blood stained sputum or fever at night or weight loss, or previous TB in the patient, family or other close contact, continued to sputum smear examination and x-ray if needed (has signs and symptoms of pulmonary TB but sputum smear negative).

The patient who diagnosed pulmonary TB, would asked by the community health center staff to come to the community health center with a family member and

the pulmonary TB patients and family would receive health education about pulmonary TB from the community health center staff. And the last step is the pulmonary TB patient and family would receive the medications based on their TB type and they would also receive explanation related to the medications, such as time, dose and possible side effects of the medications (Ministry of Health, 2007).

Community health center staff also inform the pulmonary TB patients and families that they must come to community health center weekly to take the TB medications and consult with health team about side effects of the TB medications.

Pulmonary TB patients can access any community health center and government hospital if they are in bad condition or in an emergency situation. After the condition is better or not in crisis anymore the community health center or the government hospital will refer the pulmonary TB patient to the community health center which is closed to the pulmonary TB patients house and the pulmonary TB patient need not pay for the treatment regimen, all of that is covered by the government.

To promote patients' compliance and maximize the success rate, the Indonesia government also have collaboration with community organizations such as housewives organization and religious organization to increase community participation. The community organization helps the community health center to visit the pulmonary TB patients' house to ensure that the patient continues taking the TB medications. This collaboration has a positive impact on pulmonary TB patients, because sometimes the people who come to their house is someone whom they respect very much, such as a religious man (Ustadz), head of ethnic or someone their believe in very much, it can stimulate the pulmonary TB patients to comply with the

treatment regimen, because people in Indonesia especially in Medan will believe and follow, if the information received from an important person.

## **2. DOTS program as a treatment of TB patients**

### **2.1 Definition of DOTS program**

Directly observed treatment or therapy (DOT) is an integral and essential component of DOTS for tuberculosis, the global strategy for effective TB control (WHO, 1999). Directly Observe Treatment (DOT), defined as observation of the patient by a health care personal or other responsible person as the patient ingests anti-tuberculosis medications. Directly Observed Treatment has been recommended as the standard of care as it improves patient compliance to the TB treatment, and DOT also reduced relapse rates, drug resistance rates and leads to high rates of treatment compliance (American Thoracic Society, 1994).

Directly observed treatment, short course (DOTS) the internationally recommended approach to TB control, which forms the core of the stop TB strategy. DOTS has five elements :1) government commitment to ensuring sustained, comprehensive tuberculosis control activity 2) case detection by sputum smear microscopy among symptomatic patients self reporting to health services 3) a standardized treatment regimen of 6-8 months, for at less confirm smear positive cases including directly observed treatment (DOT) 4) a regular uninterrupted supply of all essential anti TB drugs, and 5) a standardized recording and reporting system that allows assessment of case detection and treatment results for each patient and of the tuberculosis control programmed overall performance (WHO,1999)

Directly observed treatment, short course (DOTS) means that a supervisor watches the client swallowing the medication for all doses over the course of treatment. The purpose of DOTS is to ensure that a TB patient takes correct drugs, the correct dose, and at the correct times (WHO, 1999).

In 1940, sixty years after the basil tuberculosis was found, WHO offered anti-tuberculosis drug (Streptomysin), followed by Pyrazinamide (1947), Isoniazid (1952), and Ripampicin (1967), with the number of cure rate 65%, latter on WHO recommended DOTS as an effective way out from tuberculosis (cure rate more than 85%), and have someone as an observer of the patient in taking the TB medication, because the patient must take the TB medicines for six to eight months without any interruption, the person can be a health care provider or the person responsible for the patients ingestion of anti TB medication. because the patient must take the TB medicines for six to eight months without any interruption.

## **2.2 Indicators of compliance to the DOTS program**

According to Nevins (2002) indicators of compliance are regularity with which patients keep clinic appointments, make telephone contacts, and obtain blood tests or other necessary examinations to evaluate the patients condition following the treatment. In addition, scientifically compliance can be expressed as the ratio between an observed treatment behavior and treatment standards (Fleischacker, 2002).

In the case of compliance to the DOTS program the indicators are that the patient takes the medicine regularly. Health staff will know through support from the people who observed the patient take the medicine, from the amount of the drug left and from the sputum smear. If the patient completes the medication regimen correctly the laboratory finding will be a negative sputum smear (Tonsing, 2006). If the patient

takes the medications with any interruption and sputum smear remaining positive or becomes positive again it means unsuccessful compliance (WHO, 1999).

### **2.3 Effectiveness of DOTS**

DOTS has been shown to be effective in curing pulmonary TB in many studies already completed. In 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. 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 (Moore et al.,1996).

Mac et al., (1999) studied about evaluation of the effectiveness of DOTS Program in Vietnamese tuberculosis patients and they found that completion of therapy rate was higher in the DOTS group than in the non-DOTS group, the relapse rate was lower in the DOTS group than in the non-DOTS group, and sputum conversion occurred more rapidly in the DOTS group than in the non-DOTS group. That means to treat TB is more effective with DOTS than non DOTS.

In Thailand, Kamolratanakul et al., (as cited in Tengtrisorn, 2001) conducted a randomized controlled trial of DOTS at 8 district hospitals, 3 provincial hospitals and 4 zonal TB centers of the government health system. A total of 836 patients were randomly assigned to be treated either under DOT (N = 414) or were selfsupervised (SS) using monthly drug supplies (N = 422). The results showed that treatment outcomes were improved compared to pre-study conditions. However, cure and treatment-completion rates were significantly higher in the DOT cohort (84%) than in

the SS group (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 centers was non-significant (DOT cure rate 72% vs 66% in the SS group). In Indonesia the DOTS related cure was 86.7 % in 2003, and increased to 88.8 % in 2004. DOTS is very important to TB patients, because having TB not only physical problem but also social, therefore TB patient needs they family to strengthen them and to motivate them to follow the treatment regimen by direct observe them in taking the medications.

#### **2.4 DOTS guidelines for patient family**

Practice DOT guidelines for patient family : role of caregiver proposed by WHO (1998). This guidelines consists of four dimensions: 1) treatment regimen, 2) psychological support, 3) financial support, and 4) case finding.

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

The family plays a vital role in caring for the people with TB by ensuring they;

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

The caregiver 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 caregiver is responsible for making  $\checkmark$  on the correct day on the DOT card each time after observing the dose of the antituberculosis drug is taken. The DOT card will help the caregiver ensure that he/she gives the patient the right TB drugs at the correct time (WHO, 2002). The caregiver carefully monitor for possible side effects of TB medications, because often a reason the TB patient fails to comply to the



treatment regimen. If the patient experience the side effects of the medication, the caregiver should consult to the community health center.

### 1.2 Prevent disease transmission

The caregiver has 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 caregiver reminds the patient of the importance of covering their mouth and nose with a tissue or handkerchief when sneezing or coughing. Furthermore, the caregiver 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, because direct sunlight can kill TB bacilli in 5 minutes (Crofton et al., 1999), the caregiver should ventilate the patient's room with open windows and doors allowing sunlight and fresh air into the room.

### 1.4 Have adequate nutrition

Impaired nutritional status, anorexia, weight loss, and malnutrition are the common problems in TB patient (Indonesia Nutrition Network, 2002). Malnutrition will reduced resistance to the diseases, therefore caregiver should provide a balanced diet, which includes all five nutrients. Because most of the TB patient have copious secretions, which can obstruct the airways and interfere with adequate gas exchange, increase fluids intake promotes systemic hydration, serves as an effective expectorant and helps keep the airways clear. The caregiver can promote the importance of an adequate fluid intake, maintaining daily fluid intake of at least 8-10 glasses per day.

### 1.5 Have adequate sleep

The caregiver should encourage the TB patient to take rest and sleep at least 8 hours per day to alleviate fatigue and to promote the healing process (Crofton et al., 1999), and the caregiver should provide a quiet environment to support the TB patient for have a good sleep.

### 1.6 Have appropriate and adequate physical activity

Regular physical activity is a factor that contributes to physical fitness, because can improves muscle strength, endurance, and flexibility, increase lung capacity, reduce anxiety and reduce muscle tension, and maintenance of normal body weight (Ferrara & Meacci, 2005). The caregiver should encourage the TB patient to do daily activities to increase activity tolerance involves careful assessment of the physiologic response to activity.

### 1.7 Avoid smoking and alcohol use

Smoking and high alcohol intakes are important in reducing the body's defense. Most antituberculosis medications have some degree of or risk for hepatotoxicity. Therefore, the caregiver should suggest that the patient avoids alcohol while taking antituberculosis drugs and also avoids exposure to other potentially toxic chemicals that may be dangerous to the liver (Crofton et al., 1999).

## 2. Psychosocial support

Having tuberculosis is a serious condition both psychologically and socially (Karyadi et al., 2002). 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 the patient for at least six to eight months.

Patients need psychosocial support and understanding, caregiver 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 caregiver needs to establish a trust relationship with the patient to give the patient opportunity to express their grief over impaired functioning.

### 2.2 Family support

As the treatment for TB requires at least six to eight months, the caregiver needs to encourage all the family member to give concern, sympathy, look after the TB patient. The caregiver should encourage the patient to practice leisure activities, such as watching TV, listening to music, cooking, cleaning, and participating in family recreational activities for fun, and participating in social and neighborhood activities.

### 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 treatment for TB disease also take long periods of time. Most of the TB patients encountered financial problems during their illnesses. Financial problems were due to the patients being unable to attend to their jobs because of their health problem. The caregiver needs to provide financial support, to help the patient and not let them be alone.

#### 4. Case finding

Evaluation of contacts with cases of infectious TB is one of the most productive methods of finding people with the diseases. Contacts of people with infectious TB are at high risk of infection and diseases. In the same household with infectious tuberculosis patients whose sputum is smear positive have a high risk of becoming infected by mycobacterium tuberculosis and developing active TB later on (Ferrara & Meacci, 2005). The role of caregiver in case finding activities were:

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

4.2 The caregiver should advise and motivate all of the family members living in the same household with the patient to be checked with x-ray and sputum examination at the community health center.

4.3 The caregiver 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.

#### **2.5 Factors influencing compliance to the DOTS program**

Noncompliance to the anti tuberculosis regimen is well known to be a most common cause of treatment failure. Many studies have been done to explore the factors influencing compliance. The common causes influencing compliance are as follows:

1. The severity of the disease. According to Nevins (2002), factors influencing compliance include the severity of the disease and associated complexity of the regimen, education, motivation, and convenience are also factors in determining

compliance. Stromberg and colleagues in 1999 stated that compliance was influenced by the disease condition. Some patients felt uncertainty with their disease, causing them to have low motivation to comply with the treatment, because they felt no hope to recover or they felt that the condition was already bad with no possibility to recover, so the medications would not work and what for their follow the treatment regimen.

2. Treatment regimen and the side effects. Fujiwara, Simone and Munsiff (2003), found that compliance to TB treatment depends on the characteristic of the treatment. The characteristics of TB treatment that can cause a decrease in compliance include its length and the need to take several medications. Furthermore Gonzales & colleagues (2005) reported that common reasons for medication noncompliance in primary care settings are medication side effect, negative attitude toward medication, marked improvement in symptoms, and insufficient response to the medication. Vlasnick, Aliotta, and De lor (2005) stated that poor adherence involves patient, medication, and prescriber factors. Medication factors include complexity of dosing regimen, pill burden, side effects, and cost. Some patients stop taking the medications because their feel better after take the medications for one month. Kaona & colleagues (2004) in their study about an assessment of factors contributing to treatment adherence and knowledge of TB transmission among patients on TB treatment, found that 29.8% of TB patients failed to comply with TB drug taking regimen once they started feeling better. Meanwhile some patients stop taking the medications because of the side effects of the TB medications.

3. Environment and support. Fleischnacker (2002) described factors influencing compliance related to the patient, such as the patients' environment,

including social activities, social relationships, and health care professionals. The American Thoracic Society (2003) described factors that interfere with compliance to TB treatment regimen including cultural and linguistic barriers to cooperation, lifestyle differences, homelessness, substance abuse, and a large number of other conditions and circumstances that, for the patient are priorities that compete with taking treatment for tuberculosis.

Abel and Painter (2003), found that patients who perceived themselves as being actively engaged in their care with their provider reported greater adherence to treatment and provider advice. Perception of engagement was conceptualized as access to the health care provider, information sharing, involvement of patient in the decision making related to self-care activities, and respect and support by the provider of patient's choices. They have also linked psychological well being to engagement activities, such as adherence to treatment, appointments, and provider advice. Quality provider patient relationships have been found to promote treatment adherence. Race, marital status, current substance abuse, low literacy, poor understanding of the need for treatment, insufficient confidence in the clinician or medication, psychological problems, low motivation to change behavior, and low socioeconomic status are prominent patient factors that have a negative impact on adherence.

According to WHO (2003), a comprehensive framework for possible interventions helpful for increasing compliance includes education about disease and medicines, multidisciplinary care by trained professionals, assessment of social needs, treatment of psychiatric co-morbidity, simplification of drug regimens and management of side effects.

Dodor and Afentadu (2005) in their study found that noncompliance to the treatment was significantly associated with income per month, ability to afford supplementary drugs, availability of family support and problems relating with others while on treatment. A cordial relationship between patients and health staff was the main motivating factor for completion of treatment, whilst financial difficulty was the main reason for noncompliance to the treatment.

Many studies related to compliance already run, but no study about compliance related family support for pulmonary TB patients. Hadjis et al., in 2002, studied the role of family social support in first-stroke recovery process, and found that higher levels of family support, both instrumental and emotional was associated with progressive improvement of functional status, mainly in severely impaired patients. Family support is factor for pulmonary TB patients in complying with the DOTS program, because the length of the treatment process and the side effects of the TB drugs can lower pulmonary TB motivation to comply with the treatment regimen.

In summary, factors influencing compliance are severity of the disease, the treatment regimen and the side effects and environment and support. Intervention to improve medication compliance includes self-management programs, educational and behavioral strategies. Patients who are educated can communicate well with their physicians and can understand side effects or details of therapy. Tailoring the therapy to the patients needs, and effective management in chronic disease can be potentially brought about by a combination of patient education, good provider patient relationships, and collaborative efforts from healthcare professionals to improve medication compliance.

### **3. Concept of family support**

#### **3.1 Definition and dimensions of family support**

Family support can be defined terminologically or syntactically as social support from the family. According to Cobb (1982), family support is similar to social support, except the source of support is specified as family. Cobb mentioned that social support involves sharing information leading the person to believe that he is cared for and loved, esteemed, and a member of a network with mutual obligations. Another definition of social support uses the four key words of love, esteem, security, and appraisal, to describe four different types of support potentially available from others (Cobb 1988).

In defining family support, various conceptualizations have been presented in the literature. House (1981) conceptualized family support into four supportive behavioral categories that reflect four types of support : emotional, instrumental, informational and appraisal support. The emotional type of support is the provision of empathy and demonstration of love, trust, and caring. Instrumental support allows access to the individual for help in time of need. Informational support occurs through the provision of information that the person can use in coping with personal and environmental problems. Appraisal support is the transmission of information relevant to self-evaluation.

Procidano and Heller (1983) defined family support as the perceived needs for moral and emotional support as well as the need for information, and feedback fulfilled by family. The family support is social support from family members.

Furthermore, Medalie (1985) defined family support as a reciprocal relationship with others that assists individuals and groups in mobilizing resources



and interacting effectively with the environment. Types of family support include emotional support, esteem support, informational support, instrumental support, and material support (Medalie,1995).

According to Albrecht and Adelman (1987), family support refers to verbal and nonverbal communication between recipients and providers that reduces uncertainty about the situation, the self, the other, or the relationship, and functions to enhance a perception of personal control in one's life experience.

Pender (1987) described family support as the subjective feeling of belonging, of being accepted, loved, esteemed, valued, and needed for oneself, not for what one can do for others. Family, in order to provide appropriate support, must be sensitive to the needs of family members, establish effective communication, respect the unique needs of its members, and establish expectations of mutual assistance. In 2002, Pender described family support as an interpersonal transaction involving emotional concern (expressions of caring, encouragement, empathy), aid (service, money, or information), and affirmation (constructive feedback, acknowledgement).

Brillhart (1988) stated that family support included four aspects: physical care, economic support, emotional support, and social support. According to Enskar et al., (1997) family, in order to provide appropriate support, must be sensitive to the needs of family members. Family must establish effective communication, respect the unique needs of members, and establish expectations of mutual help and assistance. Family relationships were frequent sources of support, enabling young adults to manage different aspects of the family as it increased. The greatest support came from the family, especially from the mother. Cameron and Vanderwoerd (1997) define family supports as instrumental, educational, social, and psychological forms of

assistance classified into four functional components: concrete/tangible help; support through education, information and/or referral; emotional support; and social integration. Sarafino (1994) added that family support is perceived as the comfort, caring, and help individuals receive from others. Family support raises esteem and reduces the vulnerability to stress (cited in Manji, Maiter & Palmer, 2005).

In 1999, Taylor stated that three or four categories of family support can be distinguished: emotional support (warmth and nurturance expressing commitment, reassuring the person that he or she is a valuable individual who is cared for, including approval or appreciation for the patient's behavior), appraisal support (helping a person understand a stressful event better and what resources and coping strategies may be mastered to deal with it) or informational support (giving advice and information), and tangible assistance or practical-instrumental support (material or other practical help such as services, financial assistance, or goods). Furthermore, Gardner (2003) reported that family support is a generic term covering an enormous number and diversity of activities meeting a comparable diversity of needs.

In 2004, the Association of South East Asia Nations Institute for Health Development, Mahidol University, Thailand, classified family support into three aspects : emotional support, informational support, and logistical support. Park (2004) described family support as having four characteristics : instrumental support, which includes some one who provides labor, materials, or some other direct service ; informational support, which includes someone who provides information that you need to act, make decisions, or who provides access to that information; appraisal support, which includes someone who will give you useful, accurate feedback about your performance, and behavior, and how you compares to expectations ; emotional

support, which includes someone who will give reassurance, who will express concern, care, or love, and who expresses understanding of you. Wright and Leahey (2005) divided family support into nine parts : emotional communication, verbal communication, nonverbal communication, circular communication, problem solving, roles, influence and power, beliefs, and alliance and coalition from family member to other family members.

Family support is another important factor in illness management. Family support has been assessed in various ways, including different types and sources of family support. The types of family support include emotional, instrumental, informational, and appraisal support, as well as the extent of social network. The source of family support may include family, friends, work, and community. Regardless of the type and source of social support, an important aspect of social support is the level of satisfaction perceived by the recipient (Heaney & Israel, 2002, Gallant, 2003).

In summary, family support is regarded as an aspect of social support. The perceived social support from family can be called family support. Even though the literature described family support as a multidimensional concept, the area of family support includes three aspects: emotional concern (expression of caring, encouragement, empathy), aid (service, money, information), and affirmation (constructive feedback, acknowledgement).

In this study, family support is understood based on Pender's (2002) definition of family support, because this definition covered all the functional components and properties of family support such as mental and material support.

### **3.2 Family support for pulmonary TB patients in complying with the DOTS program**

Pulmonary TB patients have not only medical but also social problems related to their illness, which may influence their motivation for the completion of treatment. Most TB patients have poor nutritional status and live in crowded environments. They face joblessness and negative attitudes from their neighbors and relatives (Karyadi et al., 2002).

Some studies have been conducted to show the significance of family support. Family support appears to protect people in crisis from a wide range of health problems including arthritis, tuberculosis, cancer, depression and so on. Loss of supportive family relationships can increase the risk of mortality and morbidity (Kumento; cited in Zeng Hui, 2000). Harley and Eskenazi, (2006) studied family support and health behaviors during pregnancy among women of Mexican descent; they found that higher social support was associated with better quality of diet, increased likelihood of using prenatal vitamins, and decreased likelihood of smoking during pregnancy. High social support also appeared to prevent the negative impact of life in the US on diet quality.

The study of Newel and colleagues (2006), focused on family member DOTS and community DOTS for tuberculosis control in Nepal. They found that community DOTS and family member DOTS achieved success rates of 85% and 89%, respectively. Estimated case-finding rates were 63% with the community strategy and 44% with family member DOTS. In 2006, Barnhoorn and Adriaanse studied factors responsible for noncompliance among tuberculosis patients in Wardha District, India and reported that higher levels of family support were associated with lower levels of

caregiver depressive symptomatology and higher levels of well-being and general health, independent of family problem solving. A greater negative problem orientation was associated with higher levels of depressive symptomatology and lower levels of well-being. A more positive problem orientation was associated with greater increases in general health. The strength or slope of this positive relation lessened over time.

### **3.3 Family support and compliance**

As the treatment for TB requires at least six to eight months, family support is needed to encourage the family member to compliance to the treatment. Lack of support and strength from family members during the treatment period prolongs sickness and lower self-confidence and the sense of worth of patients, and further demoralizes and weakens the pulmonary TB patient. Support from the family is very important in motivating the patient to complete the treatment, prevent disease transmission, manage environmental hygiene, have adequate nutrition, have adequate sleep, have appropriate and adequate physical activity, avoid smoking and alcohol use, and live normally (Utama, 2004). Family support for pulmonary TB patients goals is to motivate the patients to follow the treatment regimen or motivate the patients complying with the DOTS program, because having pulmonary TB is not only a physical problem but also a psychosocial problem, therefore family must consider the treatment regimen and psychosocial factor of the patient.

1. Emotional concern is the provision of empathy and demonstration of love, trust, and caring (House,1981). Emotional concern consists of a) expression of caring: helping the pulmonary TB patient to prepare the medicines, watching him/her swallowing the medicines, marking (√) on the correct day on the DOTS card each time after observing the pulmonary TB taking the medicines, accompanying

him/her on scheduled appointments to the community health center, and being with him/her at the time of consultation with the health care team; b) encouragement: reminding the pulmonary TB patient to take the anti TB medicines, being with him/her and eating together at meal times, encouraging him/her to sleep and have adequate rest, at least 8 hours per day, encouraging him/her to participate in social and community activities such as religious practice, motivating him/her to have social interaction with friends and neighbors ; c) empathy: telling the patient that the family loves him/her very much even though he/she has TB, asking him/her about his/her feelings after taking the anti TB medicines, asking him/her about his/her feelings related to the change in signs and symptoms, asking him/her about his/her feelings related to the side effects of the medicines, and because having TB is not only a physical but also a social problem, being sensitive to the patients emotional change.

2. Aid is a tangible assistance or practical instrumental support for the pulmonary TB patient such as a) service: keeping the house clean, helping the pulmonary TB patient to prepare clean clothes and exposing the linen to sunlight, helping the pulmonary TB patient in the activity of daily living, opening doors and windows to ventilate the room, and providing the pulmonary TB patient with nutritious food which includes the five nutrients, such as rice, meat, eggs, vegetables, and fruits; b) money: providing the pulmonary TB patient with everything he/she uses in daily living, providing support in transportation when the pulmonary TB patient want to visit the community health center, asking the pulmonary TB patient if anything is needed, taking care of things the patient needs in the treatment process, and saving some money for the patient to use in case of emergency; c) information: giving information to the pulmonary TB patient about the cause of pulmonary TB,

how the disease transmitted, how pulmonary TB is cured, suggesting that the patient cough and sneeze into tissue to prevent disease transmission, and asking if the patient experiences any side effects of the TB drugs such as nausea, vomiting and dizziness.

3. Affirmation means showing the pulmonary TB patient that the family will give the patient useful and accurate feedback and help them in the treatment process. Affirmation may include a) constructive feedback: providing warm response and showing concern when the patient has abnormal signs and symptoms such as fatigue, cough and dyspnea, coming to the patient, touching when the patient coughs, suggesting covering the mouth and nose when coughing, suggesting the pulmonary TB patient watch television as a recreation and suggesting doing physical exercise such as walking regularly; b) acknowledgement: allowing the pulmonary TB patient to participate in decision making about his/her treatment regimen, being open about what the family thinks about things, being happy to hear about what the patient thinks, asking about problems and giving the patient opportunity to express feelings, and telling to the pulmonary TB that she/he is good at helping the family to solve problems.

### **3.4 Family support measurement**

Since family support is considered as social support from family the instrument for measurement of social support is often used to measure family support. There are various instruments for measurement of family support. The perceived social support from family scale (PSS-Fa) was developed by Procidano & Heller (1983) to measure family support in 222 undergraduates studying at Indiana University. Later on function social support index (FSSI) developed by Fink in 1995, to measure social support from relatives, friends and community. It consists a 35-

item, four-point scale, both of these questionnaires could be used in this study because items did not fit with the subjects of this study.

Based on literature review, many studies about family support had already done, such as 1) family support and self-care ability among stroke survivors, but the questionnaire could not be used in this study because of focuses more on physical support, 2) family support and quality of life among hemodialysis patients but the questionnaire was too general, and 3) family support and self-care behavior among chronic obstructive pulmonary diseases patients but the questionnaire could not be used in this study because of the items were not sensitive to measure family support perceived by pulmonary TB patients. Studies about family support for pulmonary TB patients could not be found, so the instrument in this study was developed by the researcher based on the definition of family support by Pender 2002 and family member DOTS guidelines (WHO, 2005). The instrument consists of three dimensions of family support 1) emotional concern such as expression of caring (five items questions number 1 to 5), encouragement (five items questions number 6 to 10) and empathy (five items questions number 11 to 15), 2) aid such as service, (five items questions number 16 to 20), money (five items questions number 21 to 25), information (seventh items questions number 26 to 31), and 3) affirmation such as constructive feedback (five items questions number 32 to 36) and affirmation (five items questions number 37 to 41). Each item has four scales of 1-4: 1 for never, 2 for sometimes, 3 for most of the time, and 4 four all the time. The instrument, which consists of 41 items was used to measure the family support received by pulmonary TB patients who were successful and those who were unsuccessful in complying with the DOTS program.



In summary pulmonary TB is an infectious and chronically diseases, TB in Indonesia is a national problem because high number of pulmonary TB (ranking third in the world). DOTS program is the method offered by WHO to increase the cure rate of TB treatment. Some patients do not complete taking the TB medications because they feel better after taking the medication for two or three weeks, but many patients stop taking the TB medications because of they can not tolerate the side effects of the drugs. The ways that the family supports the patient are very important to motivate the pulmonary TB patients to complying with the DOTS program.