

CHAPTER 1

INTRODUCTION

In this chapter, the researcher describes the background and significance, the objectives of the study, the research questions, conceptual framework of the research study, definitions of the terms used, the scope of the study and the significance of the study.

Background and significance of the study

According to the World Health Organization (WHO) data, Indonesia has a high number of tuberculosis cases (10%) following India (30%) and China (15%) (USAID, 2005). About 400 people in Indonesia die each day from TB, making it the number one killer among infectious diseases (Sandoz, 2006). Indonesia is ranked third on the World Health Organization list of 22 high-burden countries, which produce 80 percent of the world's new cases of TB every year. This nation of 212 million has an estimated TB incidence of 280 per 100,000 for all forms of TB and 126 per 100,000 for smear positive cases. With 75 percent of the 595,000 cases occurring in the most productive age group of 15 to 54 years of age, proper treatment and prevention would not only reduce morbidity and mortality rates, but also improve Indonesia's economic productivity (Ya Diul, 2006). In Medan, North Sumatra Province, 1750 TB cases occurred among 1,979.720 people (1.13 %) in 2005 (Department of Health, 2006).

Recent Ministry of Health data showed that there were 207,000 cases in 2004, a sharp increase from the 178,000 in 2003 (Ministry of Health, 2006). This condition has forced tuberculosis management to move from an ineffective system and low

patient adherence with treatment regimen to the Directly Observed Therapy Short Course (DOTS) strategy, which has been described as a new paradigm of TB control. Nationwide TB treatment programs include: a) Directly Observed Treatment Short course (DOTS includes six to eight months of the regular treatment method); b) free medication; c) people monitoring the patients; and d) mass media to disseminate TB information and promote public awareness. Government of Indonesia officials say “people monitoring the patients” plays a huge role in the high cure rate at local health centers and in ensuring that medication is taken regularly, preventing a high number of multi-drug resistance cases (Ministry of Health, 2006).

In Indonesia, a lack of education, malnutrition problems, and poor hygiene (Indonesian Nutrition Network, 2002) and an increasing number of HIV/AIDS patients are factors contributing to high numbers of pulmonary TB patients. Some patients fail to follow the complete treatment program because of the long term of the treatment for pulmonary TB. Commitment of family members to giving support to pulmonary TB patients is very important to influence patient compliance to the pulmonary TB treatment (Department of Health and Social Welfare, 2006).

DOTS has been recommended as the standard mode of care as it improves patient compliance to the pulmonary TB treatment (American Thoracic Society 1994). DOTS also leads to high rates of treatment completion, reduced relapse rates and drug resistance rates. DOTS has five key elements : 1) government commitment, 2) case detection by sputum smear microscopy among symptomatic patients self-reporting to health services, 3) a standardized treatment regimen including directly observed treatment (DOT), 4) a regular, uninterrupted supply of all essential anti-

pulmonary TB drugs, and 5) a standardized recording and reporting system (WHO,1999).

DOTS cures active TB, it is remarkably effective. Without treatment, seven in ten people with infectious TB will die of it, on an average within 4-5 years of onset even if they are young when they contract it. Many sufferers remain chronically ill and continue to unknowingly transmit the disease to family, friends and even strangers. DOTS coverage is defined as the population living in areas where DOTS services are available. This indicator serves as a proxy for people with access to DOTS.

Indonesia population access to DOTS increased from 77% at the end of 2003 to over 90% by mid 2005, and the number of patients successful in complying with the DOTS program was 86.7 % and 13.3 % unsuccessful in 2003. Later on in 2005 the number of patients successful in complying with the DOTS program increased to 88 % and unsuccessful decreased to 12 %. (WHO, 2006).

As the DOTS for pulmonary TB requires at least six to eight months, family support is needed to encourage the pulmonary TB patient by showing concern and sympathy, and looking after the patient. Family support involving emotional concern, aid and affirmation will make pulmonary TB patients not feel lonely in facing the situation and family support can empower pulmonary TB patients during the treatment period by supporting the pulmonary TB patient continuously, such as reminding the pulmonary TB patient to taking the medications and being sensitive to pulmonary TB patient if they experience the side effects of the TB medications. Lack of support from family during the period of prolonged sickness and dependency can lower the self confidence and sense of self-worth of the patient, and further demoralize and weaken the patient. Family support is an important factor for success

of the pulmonary TB patient in complying with the DOTS program, because having tuberculosis is a serious situation both physically 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 a patient for at least six to eight months.

Some studies regarding family support and compliance have been reported. In 1990, Ruggiero and colleagues studied the impact of family support and stress on compliance in women with gestational diabetes and found that greater family support was associated with greater compliance. Schlenk and Hart (1994) studied the relationship between health locus of control, health value, and family support and compliance of persons with diabetes mellitus. They found that family support had very good impact on compliance. In the Social Awareness Center in Surkhet, Nepal, a study by Bam and colleagues on the relationship between social support and patient compliance with DOTS in Kathmandu urban areas, Nepal, found that compliance behavior was closely associated with the social support from family and friends and the authors recommended that this aspect of DOTS treatment needed to be examined in detail and strengthened with emphasis of family support for full course compliance. (Bam et al., 2003).

In Indonesia especially in Medan, there is no study about compliance of pulmonary TB patients, therefore the researcher wants to study the influence of family support for pulmonary TB patients and compliance with the DOTS program, because the number of pulmonary TB still high and the success rate was 88.8% (Ministry of Health, 2006). This data motivate the researcher to explore whether the family support influenced patients compliance to the treatment regimen or not.

Objectives of the study

The objectives of this study were as follows :

1. To identify the level of family support perceived by pulmonary TB patients who are successful in complying with the DOTS program in Medan, Indonesia.
2. To identify the level of family support perceived by pulmonary TB patients who are unsuccessful in complying with the DOTS program in Medan, Indonesia.
3. To examine the differences of perceived family support between pulmonary TB patients who are successful and those who are unsuccessful in complying with the DOTS program in Medan, Indonesia.

Research questions of this study

This study aimed to answer the following research questions :

1. What is the level of family support perceived by pulmonary TB patients who are successful in complying with the DOTS program in Medan, Indonesia ?
2. What is the level of family support perceived by pulmonary TB patients who are unsuccessful in complying with the DOTS program in Medan, Indonesia ?
3. Is there a difference of perceived family support between pulmonary TB patients who are successful compared to those who are unsuccessful in complying with the DOTS program in Medan, Indonesia ?

Research framework to study family support perceived by pulmonary TB patients in complying with the DOTS program

This study aims to identify the level of family support for pulmonary TB patients who are successful and unsuccessful in complying with the DOTS program and to examine the difference of family support between pulmonary TB patients who are successful and those who are unsuccessful in complying with the DOTS program. Family support is very important for pulmonary TB patients in complying with the DOTS program. Family support was found to be closely associated with compliance (Bam et al., 2005). Drageset and Lindstrom (2005) also stated that family support had been treated as a positive coping resource in the diagnostic phase of disease.

In this study family support is based on Pender's (2002) definition of family support and DOTS guidelines for patient family will be used as role of caregivers in support the pulmonary TB patients.

Family support based on Pender (2002) defined as an interpersonal transaction involving 1) emotional concern, consists of expression of caring, encouragement, and empathy 2) Aid, consists of service, money, and information, and 3) affirmation, consists of constructive feedback and acknowledgement.

Emotional concern support may help the patient in a crisis circumstance, whereas informational support may be more useful in assisting individuals to understand how to relate effectively with their peers. Aid provides help with special tasks, such as the preparation of nutritious meals or transport of the patient. Affirmation helps individuals to realize their own strengths and potential.

Practice DOTS guidelines for patient family : role of caregiver proposed by WHO (2005). This guidelines consists of four dimensions: 1) treatment regimen:

ensuring the pulmonary TB patient take the anti-tuberculosis medication, prevent disease transmission, manage environmental hygiene, help the pulmonary TB patient to have adequate nutrition and have adequate sleep, have appropriate and adequate physical activity, avoid smoking and alcohol use, 2) psychological support: provide emotional support to the pulmonary TB patient, 3) financial support: provide all of the patient need during the long time treatment, and 4) case finding: 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 and advise and motivate children in the contact household who are aged below five years and have never received a BCG vaccination, to be vaccinated.

Operational Definition

Family support refers to pulmonary TB patient's perception of receiving attention and help from their family. Family support consists of emotional concern, aid and affirmation. These family supports were measured by a Family Support Questionnaire developed by the researcher based on the definition of family support by Pender (2002), combined with DOTS guideline for family members (WHO, 2005) to measure the level of family support perceived by pulmonary TB patients who are successful and those who are unsuccessful in complying with the DOTS program.

Success in complying with DOTS program refers to the pulmonary TB patient who completes taking TB medications for six to eight months and based on the following criteria: 1) keeps clinic appointments, 2) takes the medicine regularly, 3) has the appropriate amount of the drug left, 4) and has a negative sputum smear for

TB on at least two occasions, one of which is at completion of treatment (WHO, 2005).

Being unsuccessful in complying with DOTS program refers to the pulmonary TB patient who does not fulfill any of the above criteria, or who takes the medicines with any interruption or where sputum microscopy becomes positive for TB again at five months or later during treatment (WHO, 2005).

Scope of the Study

This descriptive study examines family support perceived by pulmonary TB patients in complying with the DOTS program. The subjects were pulmonary TB patients who were successful and who were unsuccessful in complying with the DOTS program in Medan, Indonesia.

Significance of the study

This study will provide contributions to nursing practice, nursing education, and the development of nursing research.

1. For nursing practice, the research findings will be useful for better understanding by nursing practitioners especially in a community health center, who can apply the knowledge to promote how family support influences patient compliance to the DOTS program.
2. For nursing education, the study can be used by nurse educators to focus the content in teaching community and family nursing, especially related to promoting compliance for pulmonary TB patients.

3. For development of further research, the study can be used as baseline data for further research related to family support and compliance.