



**The Effect of a Self-Management with Family Participation Program  
on Medication Adherence among Patients with Schizophrenia  
in Indonesia: A Randomized Controlled Trial**

**Sri Padma Sari**

**A Thesis Submitted in Partial Fulfillment of the Requirements for the Degree of  
Master of Nursing Science (International Program)**

**Prince of Songkla University**

**2013**

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<b>Thesis Title</b>	The Effect of a Self-Management with Family Participation Program on Medication Adherence among Patients with Schizophrenia in Indonesia: A Randomized Controlled Trial
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### ABSTRACT

Medication adherence is essential for patients with schizophrenia to prevent relapse and re-hospitalization. Studies have shown that self-management can enhance medication adherence among them. In addition, the role of the family is very important for treating patients with schizophrenia. Therefore, this study aimed to examine the effect of a self-management with family participation program on medication adherence behavior and attitude toward medication among patients with schizophrenia.

Fifty patients diagnosed with schizophrenia and their families were recruited from the out-patient department (OPD) of a psychiatric hospital in Central Java, Indonesia. Subjects were assigned into either a control group or an experimental group (25 subjects/ group) using block randomization. The subjects in the experimental group received the self-management with a family participation program which involved the patients and their families to perform self-management including an education and counseling session, telephone and face to face follow-ups. A booklet was also used in this study to enhance knowledge on the illness and medication regarding schizophrenia. The pre-test and post-test data were collected using the medication adherence behavior questionnaire and the Drug Attitude Inventory (DAI). Paired t-test was applied to assess changes within the group while independent t-test was used to determine the difference of medication adherence behavior and attitude toward medication between the groups.

The results showed that there were significant differences on medication adherence behavior and attitude toward medication between the experimental and the control group ( $t = 6.08, p < .01$ ; and  $t = 3.05, p < .01$ ,

respectively). In addition, within the experimental group, after receiving self-management with family participation program, the subjects reported significant improvement on medication adherence behavior and positive attitude toward medication than before the program ( $t = -7.76, p < .01$ ; and  $t = -3.78, p < .01$ , respectively).

This study offers an evidence that the self-management with family participation program could be used in nursing practice to enhance medication adherence behavior and attitude toward medication among patients with schizophrenia.

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## CONTENTS

	Page
ABSTRACT .....	v
ACKNOWLEDGEMENTS .....	vii
CONTENTS .....	viii
LIST OF TABLES .....	xii
LIST OF FIGURES .....	xiii
CHAPTER .....	1
1. INTRODUCTION .....	1
Background and Significance of the Problem .....	1
Objectives of the Study .....	8
Research Questions .....	9
Conceptual Framework .....	9
Hypotheses.....	15
Definition of Terms .....	15
Scope of the Study .....	16
Significance of the Study.....	17
2. LITERATURE REVIEW.....	18
Overview of Schizophrenia .....	19
Definition of Schizophrenia .....	19
Causes of Schizophrenia.....	20
Signs and Symptoms of Schizophrenia .....	22
Periods of Schizophrenia .....	24

**CONTENTS (continued)**

	Page
Impacts of Schizophrenia.....	25
Treatment of Schizophrenia .....	26
Schizophrenia Management in Indonesia .....	32
Medication Adherence in Schizophrenia .....	33
Concept of Medication Adherence.....	33
Factors Contributing to Medication Adherence.....	36
The Measurement of Medication Adherence.....	45
Intervention to Enhance Medication Adherence .....	49
Self-Management with Family Participation Program for Patients with Schizophrenia.....	53
Concept of Self-Management .....	53
Self-Management Process.....	55
Family Participation on Self-Management .....	57
Effectiveness of Self-Management Program among Patients with Schizophrenia .....	58
Summary .....	60
3. RESEARCH METHODOLOGY .....	62
Research Design .....	62
Variables .....	63
Setting .....	63
Population and Sample.....	64
Sampling Procedure .....	65

## CONTENTS (continued)

	Page
Instrumentation .....	66
Validity and Reliability of the Instruments .....	72
Data Collection Procedures .....	75
Ethical Considerations .....	78
Data Analysis.....	78
4. RESULTS AND DISCUSSION.....	81
Results .....	81
Subjects' Characteristics.....	81
Clinical Characteristics .....	83
Caregivers' Characteristics .....	86
Prior Knowledge regarding Medication, Medication Adherence Behavior and Attitude toward Medication at the Baseline .....	87
The Effect of a Self-Management with Family Participation Program.....	88
Discussion .....	91
Subjects' Characteristics.....	91
Caregivers' Characteristics .....	92
The Effect of a Self-Management with Family Participation Program .....	93
5. CONCLUSION AND RECOMMENDATIONS .....	103
Conclusion.....	103
Strengths and Limitations of the Study .....	104

**CONTENTS (continued)**

	Page
Implications and Recommendations .....	106
REFERENCES .....	109
APPENDICES.....	120
A. Research Information Sheet .....	121
B. Self-Management with Family Participation Guideline .....	125
C. Teaching Plan for Education and Counseling Session.....	126
D. Booklet .....	128
E. Demographic Data Questionnaire.....	131
F. Brief Psychiatric Rating Scale (BPRS) .....	133
G. Beck Cognitive Insight Scale (BCIS) .....	134
H. Prior Knowledge regarding Medication Questionnaire .....	135
I. Medication Adherence Behavior Questionnaire.....	136
J. Drug Attitude Inventory .....	137
K. List of Experts.....	138
L. Permission of the Instruments .....	139
M. Effect Size Calculation.....	140
VITAE .....	141

## LIST OF TABLES

TABLE	Page
1. Antipsychotic Drugs, Doses and Side Effects .....	28
2. Side Effects of Antipsychotic Drugs and Its Management .....	29
3. Frequencies and Percentages of Subjects' Characteristics of the Experimental Group and the Control Group ( $N = 50$ ) .....	82
4. Frequencies and Percentages of Subjects' Clinical Characteristics of the Experimental Group and the Control Group ( $N = 50$ ).....	84
5. Frequencies and Percentages of Caregivers' Characteristics of the Experimental Group and the Control Group ( $N = 50$ ) .....	86
6. Comparison of the Knowledge regarding Medication, the Pre-test Scores of Medication Adherence Behavior and Attitude toward Medication between Two Groups ( $N = 50$ ).....	88
7. Comparison of the Pre-test and Post-test Scores of Medication Adherence Behavior and Attitude toward Medication within the Experimental Group ( $n = 25$ ) .....	89
8. Comparison of the Post-test Scores of Medication Adherence Behavior and Attitude toward Medication between Two Groups ( $N = 50$ ) .....	89
9. Comparison of the Mean Difference of Medication Adherence Behavior and the Mean Rank Difference of Attitude toward Medication between Two Groups ( $N = 50$ ).....	90

**LIST OF FIGURES**

	Page
<b>FIGURE</b>	
1. Conceptual framework of the study .....	14
2. The implementation phase of the data collection procedures .....	77

## **CHAPTER 1**

### **INTRODUCTION**

This chapter presents the background and significance of the problem, objectives, research questions, conceptual framework, hypotheses, definition of terms, the scope of the study and the significance of the study.

#### **Background and Significance of the Problem**

Schizophrenia is a common mental illness that affects a large number of persons around the world. In 2011 figures showed that 24 million people worldwide were affected by schizophrenia. In developing countries, it is estimated that there are approximately 90% of people suffering from untreated schizophrenia (World Health Organization [WHO], 2011). The prevalence of schizophrenia is increasing in Indonesia and in 2006 compared to 2010 the figure was estimated to have risen from 0.3% to 1% (Arif as cited in Wulansih, 2008). In 2010, according to the Central Statistics Agency, the prevalence of people with schizophrenia was estimated to have increased from 1% to 2% of the population in Indonesia which is around two million people (Sidakaton, 2011).

Schizophrenia is a serious mental disorder characterized by impairments in the thought process which influences behaviors (Thorson, Matson, Rojahn, & Dixon, 2008). Based on Dominguez, Viechtbauer, Simons, van Os, and Krabbendam's study (2009), patients with schizophrenia experienced positive symptoms and negative symptoms. The positive symptoms include hallucinations,

delusions, disorganized speech and behaviors. They also experienced negative symptoms, for instance, flat affect, apathy and social withdrawal. Both types of symptoms can create suffering for patients and their families. For example, patients have difficulty in performing daily living activities that cause a burden on their families (Chan, 2011).

Presently, the central treatment for patients with psychotic disorders, including schizophrenia is pharmacotherapy (Shon & Park, 2002). It is needed at least one year after the first episode and for at least two years after relapse. However, many patients are non-adherent to their medication because they are required to take their medication over a long period of time and also experience the side effects of antipsychotic medication (Gaebel & Riesbeck, 2007). Similarly, according to Roberts and Velligan (2011) many people with schizophrenia are not complying with medication.

The terms, adherence and compliance, have been used interchangeably (Bissonnette, 2008; Horne, 2005). However, adherence is a preferable term. Compliance means the extent of a patient's behavior that matches with the prescriber's recommendation (Bissonnette, 2008; Haynes, Taylor & Sackett as cited in Horne, 2005; Patel & David, 2007). The use of this term has been criticized because it has a negative connotation in the role of the patient who is seen to passively follow the doctor orders (Bissonnette, 2008; Horne, 2005). Therefore, some studies used the term of adherence because it provides better sense since it focuses on the patient's active involvement in taking their medication and having a relationship with the health care provider (Bissonnette, 2008; Horne, 2005; Patel & David, 2007).



In schizophrenia, non-adherence or non-compliance is a major issue since it has several impacts on patients. Patel and David (2007) stated that this causes the patient to relapse, need hospitalization, experience difficulty in achieving remission, and suicide attempts as well as clinical burden and cost. Moreover, Almond, Knapp, Francois, Toumi, and Brugha (2004) found that the relapsed patients showed less global functioning and experienced dissatisfaction in their quality of life. Therefore, medication maintenance is very essential to prevent a relapse and re-hospitalization (Shon & Park, 2002).

Several influencing factors on medication adherence among patients with schizophrenia have been identified. Knowledge regarding medication, skills to manage the side effects of antipsychotic medication and the family support were significant factors that can enhance medication adherence. Therefore, in this study the program includes knowledge regarding medication, skills to manage the side effects of antipsychotic medication and the family support in order to enhance medication adherence, both medication adherence behavior and positive attitude toward medication. Several studies revealed that interventions such as psychoeducation and adherence therapy which aimed to increase knowledge and skills in medication management had a significant effect on positive attitude toward medication (Chaiyajan, Sitthimongkol, Yuttatri, & Klainin, 2009; Maneesokorn, Robson, Gournay, & Gray, 2007; Montes, Maurino, Diez, & Saiz-Ruiz, 2010). Many studies showed that a positive attitude toward medication also significantly correlated with medication adherence (Mutsatsa, Joyce, Hutton, Webb, Gibbins, Paul, & Barnes, 2003; Rungruangsiripan, Sitthimongkol, Maneesriwongul, Talley, &

Vorapongsathorn, 2011; Santone, Rucci, Muratori, Monaci, Ciarafoni, & Borsetti, 2008).

There are several interventions for medication adherence provided to patients with schizophrenia. One of these interventions which can enhance medication adherence is self-management program (Gray, White, Schulz, & Abderhalden, 2010; Shon & Park, 2002). A meta-analysis study conducted by Barkhof, Meijer, Sonnevile, Linszen, and Haan (2012) investigated interventions to improve medication compliance. They found that a patient-tailoring strategy can enhance medication compliance in patients with schizophrenia. According to Lorig and Holman (2003), self-tailoring is based on the principles of learning for behavior change and self-management skills as well as decision-making and problem solving skills. All of these are part of a self-management program.

Self-management is a person's ability to manage the symptoms and the consequences of living with chronic conditions, including treatment, physical, social and lifestyle changes (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002). The aims of self-management are to enhance the patient's participation, engagement and activation in positive health behavior by facilitating knowledge, skills and the ability to enhance self-care ability (Hibbard, Mahoney, Stock, & Tusler, 2007).

Based on the US National Institute of Mental Health (NIMH, 2008), self-management has become a pillar for the individual with severe mental illness. Sterling, von Esenwein, Tucker, Fricks, and Druss (2010) mentioned that self-management for mental illness offers the specific tools to help individuals develop skills and techniques. These aims are to enhance their self-care ability to maintain both physical and mental health. Furthermore, self-management encourages the

individuals with mental illness to participate actively in their recovery process which can lead to a sense of wellness.

Self-management contributes to several significant outcomes for the patients with schizophrenia. Several studies about self-management with this group of patients found that it can enhance a patient's ability to cope with his or her illness. Patients have skills to manage their symptoms (Buccheri, Trygstad, Buffum, Lyttle, & Dowling, 2007; Buffum et al., 2009), adhere to their medication (Hudson, Owen, Thrush, Armitage, & Thapa, 2008; Maneesokorn, Robson, Gourney, & Gray, 2007) and have emotional management skills (Norman et al., 2002). Moreover, the patients also experience a sense of well-being or quality of life including hopefulness and recovery from the illness after receiving the self-management programs (Cook et al., 2010; Salyers, Godfrey, McGuire, Gearhart, Rollins, & Boyle, 2009).

According to Wilkinson and Whitehead (2009), self-management refers to a link with an individual's ability, in conjunction with the family, community and health care professionals to manage symptoms, treatments, lifestyle changes and psychosocial, cultural and spiritual consequences of having a chronic disease. Therefore, self-management not only requires an individual's ability but also needs conjunction with his/her family to control his/her health condition (Richard & Shea, 2011; Wilkinson & Whitehead, 2009). Several studies have found that family participation in the intervention has significant outcomes. The interventions which involve family members resulted in patients showing significant improvement in their symptom status, illness management skills, level of functioning, rates of re-hospitalization (Kapelowicz, Zarate, Smith, Mintz, & Liberman, 2003), developing a positive attitude toward medication (Chaiyajan, Sitthimongkol, Yuttatri, & Klainin,

2009), improving adherence to medication, mental status, and an insight into their illness (Chan, Yip, Tso, Cheng, & Tame, 2009). Therefore, the family has important role in caring for patients with schizophrenia.

Additionally, Shon and Park (2002) who studied medication and symptom management education program for the rehabilitation of psychiatric patients including patients with schizophrenia showed that the intervention produced significant outcomes, i.e., medication compliance, self-efficacy and less relapse warning symptoms. They concluded that educating the family and patient in an active role should be mentioned. Furthermore, educating both of them was very important since the family can identify the patient's own ability in managing medication. A meta-analysis study conducted by Lincoln, Wilhelm, and Nestoriuc (2007) also showed those educational programs which included family members have better outcome in reducing symptoms and preventing relapse than educational programs given only for patients.

In Indonesia, the number of relapses and non-adherence to medication in patients with schizophrenia has also been reported. The percentage of relapses was around 50% in the first year after discharge, 70% relapsed in the second year and 100% relapsed in the fifth year (Keliat as cited in Ryandini, Saraswati, & Meikawati, 2011). This data is supported by another study (Kusumowardhani, 2006) which found that 55 - 75% of schizophrenia patients who stayed in psychiatric hospitals were relapse patients. Another study also found that the ratio between the first episode and relapse of patients who stayed in a psychiatric hospital was approximately 1 : 10 (Purwanto, 2010). The number of relapse patients had a significant correlation with non-adherence to medication. The percentage of medication non-adherence in

schizophrenia patients was around 41.7% (Ryandini et al., 2011) and the majority (64%) of adherence in schizophrenia patients was at a moderate level of adherence (Veranita, 2009).

The common causes of nonadherence to medication among patients with schizophrenia in Indonesia were socio-economic status, attitude, memory problems and family support. Socio-economic problems can influence a patient's non-adherence to medication because the patient with a low income has difficulty to afford relatively costly medication. In addition, the travelling to and from hospital to home can be very costly in terms of transport costs (Mubarak as cited in Tarleli, 2009). The patient's attitude which can include getting bored with a long period of having to take medication can lead to non-adherence to medication. Moreover, they sometimes forget and are reluctant to take their medication (Ashwin, 2009).

The role of the family is important in a patient's medication adherence because patients with schizophrenia usually do not remember to take their medication and may forget the type, time and doses of their medication. The family needs to remind and assist the patients to take their medication continuously (Tarleli, 2009). Some studies on the lack of family support on medication adherence among patients with schizophrenia in Indonesia have been reported. Based on Pratiwi's study (2011), some patients with schizophrenia reported that their families did not remind them to take their medication. In addition, based on Nirmala's study (2012), some family members reported that they were often too busy and did not have time to remind the patient to take his/her medication or accompany the patient to the hospital when need be. Also lack of finances affected whether family members could afford to take the patient to the hospital. Therefore, lack of family support can cause a patient's non-

adherence to medication. Additionally, Davies and Craig (2009) stated that three main factors for medication adherence are understanding, comfortable feelings and collaboration with the family and the health care professionals.

Self-management has been reported as very beneficial for patients with chronic illnesses including schizophrenia. However, in Indonesia, studies have only been conducted with other chronic diseases such as diabetes (Aklima, 2012; Kurniawan, 2011; Primanda, 2011) and hypertension (Ridwan, 2012). Such a study in schizophrenia has not been undertaken in Indonesia. Therefore, this study proposed to examine the effect of a self-management with family participation program on medication adherence among patients with schizophrenia.

### **Objectives of the Study**

There were two objectives in this study:

1. To compare medication adherence behavior and attitude toward medication of patients with schizophrenia before and after receiving self-management with family participation program.
2. To compare medication adherence behavior and attitude toward medication of patients with schizophrenia receiving self-management with family participation program and those receiving the usual care.

## **Research Questions**

There were two research questions as follows:

1. Do patients with schizophrenia receiving self-management with family participation program have higher medication adherence behavior and positive attitude toward medication than before receiving the program?
2. Do patients with schizophrenia receiving self-management with family participation program have higher medication adherence behavior and positive attitude toward medication than those receiving the usual care?

## **Conceptual Framework**

The conceptual framework of this study is based on the self-management method by Kanfer and Gaelick-Buys (1991). Self-management refers to an individual's ability to manage the symptoms, treatments, physical and psychosocial consequences as a result of living with his/her illness or chronic conditions. Self-management assists individuals to change their behavior in order to achieve the health outcomes. Based on Kanfer and Gaelick-Buys, self-management will start when individuals want to change their current problem situations in order to enhance their life conditions. Self-management involves three processes: self-monitoring or self-observation, self-evaluation and self-reinforcement.

In the first process of self-monitoring, an individual carefully observes and pays closer attention on his/her behavior. The individual might have problems related to medication which can make him/her stop the medication and this can

influence his/her condition. Past experiences will influence individuals to carry out certain behavior or his/her desired behavior (performance criteria or standard). The next process is self-evaluation which means that an individual compares the information from self-monitoring and performance criteria that he or she should do. A close match between these will make the individual feel satisfied with his/her self while a large discrepancy might yield dissatisfaction. The last process is self-reinforcement which means that the individual rewards his/her self of what he/she has done in order to achieve his/her goal. Positive self-reinforcement will result in continuing such behavior.

According to Kanfer and Gaelick-Buys (1991), the decision to engage in such behavior can be made in the form of a written statement which is called a therapeutic contract. It can be in the form of action planning and specific goals. A therapeutic contract can be made by an individual with health care providers. Moreover, a behavioral contract can be enhanced if the contract involves commitment from the individual to his/her family.

The framework of this study adds the family participation because from the literature review, it has been found that the family participation can enhance self-management. Hence, the family participation will include in each stages of self-management process in this study: self-monitoring, self-evaluation and self-reinforcement.

The “use of medications” as one of the outcomes of self-management program is usually mentioned instead of the medication adherence. The term of medication adherence implies both medication adherence behavior and medication adherence attitude. Generally, medication adherence is defined as the extent of



patients to take the medication as prescribed which means medication taking behavior. From the literature review, it has been depicted that medication adherence attitude is distinct from adherence behavior. Medication adherence attitude means an explicit statement from the patients regarding overall like or dislike of taking medication. Moreover, attitude toward medication also one of the influencing factors of medication adherence. Therefore, this study uses the term of medication adherence which measures medication adherence behavior and medication adherence attitude.

The intervention program of this study is based on a medication management strategy from the literature review. It aims to educate the patients with schizophrenia in terms of the knowledge and skills in taking medication. Furthermore, several studies on medication management gave the information related to the overview of the illness and medication, side effects of medication, strategies for effective treatment and the management of common side effects (Gray, Tilwykes, Edmonds, Leese, & Gournay, 2004).

Self-management with family participation in this study was conducted over a one-month period. Firstly, in self-monitoring, the researcher assisted patients to reflect on their current behavior related to taking medication, side effects management and the barriers in taking medication. The role of the family in self-monitoring was to identify/ remind the patients of their current taking medication behavior.

Secondly, in the self-evaluation part, the researcher provided an educational and counseling session based on the patients' needs regarding medication. The topics in the educational and counseling session were an overview of schizophrenia, the importance of medication, medication information, the side effects of medication, and the management of common side effects. The educational and

counseling session consisted of a combination of a brief lecture, discussion, and also a booklet for both the patient and family. Then, the researcher assisted the patient to compare whether the patient's behavior was congruent with the desired activity and to identify the current problem related to medication. In this process, the family helped the patient to evaluate his or her behavior and also identify the patient's problem.

Thirdly, in self-reinforcement, the individual was assisted in listing rewards for her/his own self in changing a behavior. Next, the individual was assisted in making a therapeutic contract. Then, the researcher assisted the individual to set the goal and action plans regarding the decision to maintain medication taking and also to assess the individual's confidence to achieve the action (self-efficacy). The role of the family in this process was to participate actively and to be a partner for the patient to make a decision, set a goal and action plan. In this session, the researcher discussed with both the individual and the family to identify the potential barriers in implementing an action plan and sharing some problem solving. The researcher encouraged the family to remind the patient of his or her goal and action plan in maintaining medication adherence.

Lastly, the researcher conducted follow-up sessions to evaluate both the patient and the family which included goal achievement during the previous week, self-rewards regarding individual achievement, identifying the barrier to goal achievement and assisting them to identify the possible problems and to find solutions to these problems. Then, the researcher assisted the patient whether he/she wanted to continue, modify or change and develop new goals and action plans. During this session, the researcher also encouraged patients to do self-reinforcement for his/her effort in order to achieve his/her goals. Similarly, the family's role during the follow-

up session was to evaluate the patient's goal achievement, identify the barriers and problem solve. The family can also involve the patient in decision making whether the patient wants to maintain, modify or develop new goals. The researcher then evaluated the program in the fourth week to examine the effect of the self-management program with family participation on medication adherence among patients with schizophrenia. Figure 1 shows the conceptual framework of this study.

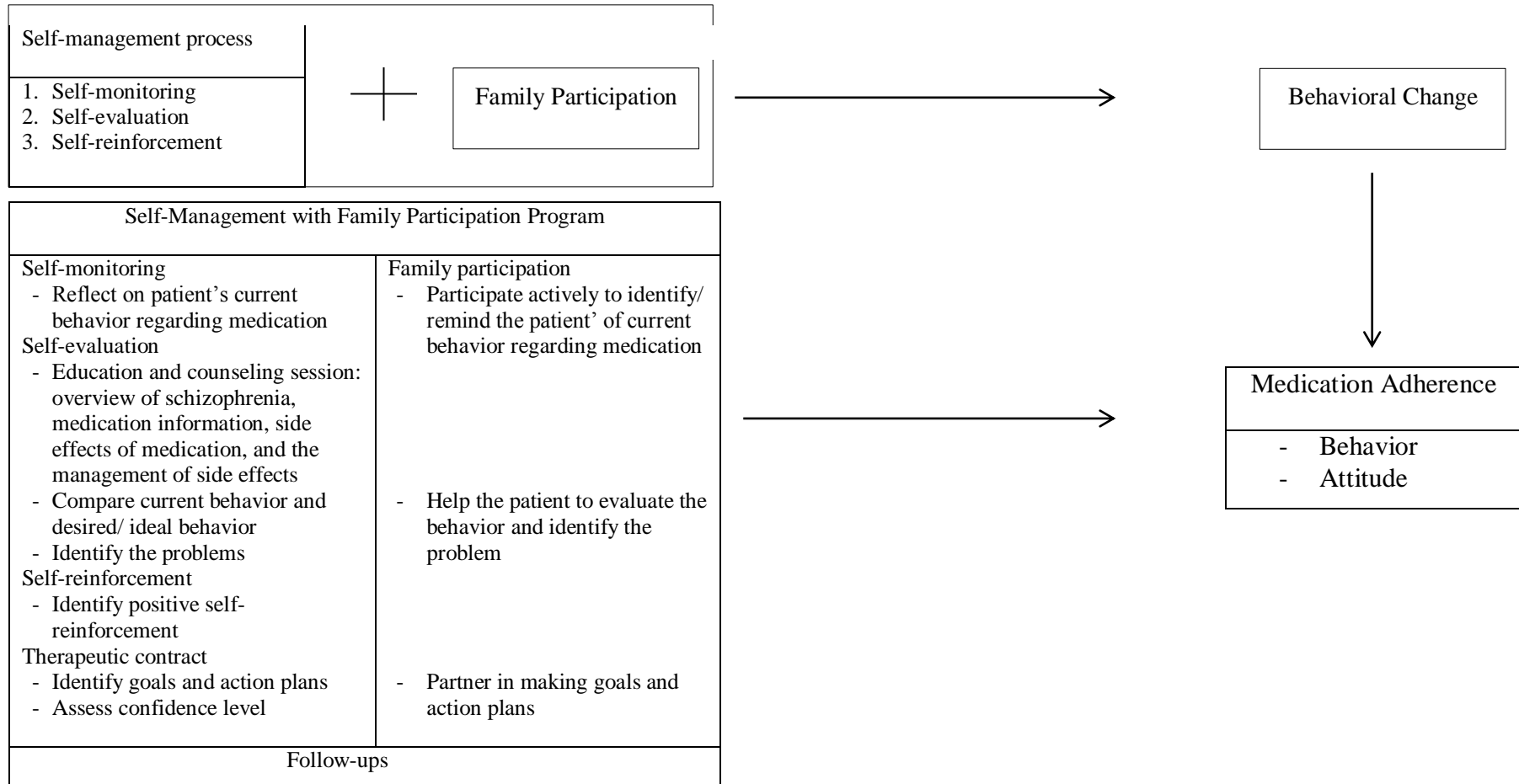


Figure 1. Conceptual framework of the study

## **Hypotheses**

The hypotheses of this study were as follows:

1. The patients with schizophrenia receiving self-management with family participation program would have higher medication adherence behavior and positive attitude toward medication than before completing the program.
2. The patients with schizophrenia receiving self-management with family participation program would have higher medication adherence behavior and positive attitude toward medication than those receiving the usual care.

## **Definition of Terms**

Self-management with family participation program is a one-month program to enhance medication adherence behavior and change the patient's attitude toward medication based on self-management method by Kanfer and Gaelick-Buys (1991) which involves the patient and his/her family in performing self-monitoring, self-evaluation and self-reinforcement. This program assists the patient and his or her family to reflect on the patient's behavior regarding medication management, evaluates the patient's behavior, assists the patient to develop goals and action plans and provides self-reinforcement. The program is conducted weekly and uses telephone and face to face follow-ups.

Usual care means activities/ services provided by health care services/ professionals at the target hospital. In general, the services include regular check-ups,

medication and unstructured health education provided by a nurse or physician which responds to the patient's and the family's needs.

Medication adherence behavior is defined as self-report of the extent of a patient's actions in taking the medication as prescribed. This behavior was measured by the medication adherence behavior questionnaire which has been developed by the researcher. It has 10 items with a Likert-type rating scale (4 = all the time, 3 = usually, 2 = sometimes, 1 = never). The total scale has a range from 10 to 40. A higher score indicates higher medication adherence behavior.

Attitude toward medication refers to the subjective response of a patient in taking medication as prescribed. The Drug Attitude Inventory (DAI) was used to measure attitude toward medication. It was developed by Hogan et al (as cited in Sajatovic, Velligan, Weiden, Valenstein, & Ogedegbe, 2010). It has 30 items with true and false answers (+1 and -1). A higher positive total score indicates positive subjective responses and a negative total score indicates negative subjective responses.

### **Scope of the Study**

This study examined the effect of self-management with family participation program on medication adherence behavior and attitude toward medication among patients with schizophrenia. The study was conducted in the patients' homes in Central Java Province. The subjects were recruited from the OPD of a psychiatric hospital, Central Java, Indonesia from December 2012 to February 2013. The patients who participated in this study were those who were aged between

18-60 years old, in a stable condition, and not co-morbid with depression, had no substance use and cognitive impairment. Moreover, this study also involved the family who lived with the schizophrenia patient and had cared for the patient for at least six months.

### **Significance of the Study**

This study provides empirical evidence of the effect of a self-management program for patients with schizophrenia and their families for improving medication adherence behavior and changing attitudes toward medication. This study is useful not only for the patients in helping them have the ability to self-manage their illness but also their families in participating and caring for the patient regarding medication taking. In addition, this program could be used as evidence based practice for nurses or other health care professionals and also for further research since no studies in this area have been conducted in Indonesia.

## **CHAPTER 2**

### **LITERATURE REVIEW**

In this chapter, several relevant concepts to the study were reviewed.

The outlines of this review are presented as follows:

1. Overview of schizophrenia
2. Medication adherence in schizophrenia
  - 2.1 Concept of medication adherence
  - 2.2 Factors contributing to medication adherence
  - 2.3 The measurement of medication adherence
  - 2.4 Intervention to enhance medication adherence
3. Self-management with family participation program for patients with schizophrenia
  - 3.1 Concept of self-management
  - 3.2 Self-management process
  - 3.3 Family participation on self-management
  - 3.4 Effectiveness of self-management program among patients with schizophrenia
4. Summary



## **Overview of Schizophrenia**

This section presents a review of the definition, causes, signs and symptoms, phases of schizophrenia, impact, treatment and schizophrenia management in Indonesia.

### **Definition of Schizophrenia**

The term of schizophrenia was coined by Eugen Bleuler, the Swiss psychiatrist in 1908. The word schizophrenia is derived from Greek “skhizo” which means split and “phren” which means mind (Townsend, 2003). Schizophrenia is a disconnected mind which involves a lack of coherence in mental functioning (Nasrallah & Smeltzer as cited in Mohr, 2005). McGorry (2004) mentioned that schizophrenia is a descriptive term for clinical features of a heterogeneous group of psychotic disorders. It is a result from disturbances in brain function and in some cases disturbances in brain structure. Recently, schizophrenia refers to a group of disorders characterized by positive psychotic symptoms at some stages of illness where the dominant features are negative and cognitive symptoms which have a relation with the variable level of disability, and where mania and major depression are not dominant or persistent features. Similarly, Austin (2005) also stated that schizophrenia is a complex disorder characterized by psychosis, cognitive dysfunction and negative symptoms.

Based on the American Psychiatric Association (2000), schizophrenia is a disorder that lasts for at least six months and includes at least one-month of active-phase symptoms (i.e., two or more of hallucinations, disorganized speech,

grossly disorganized or catatonic behavior, negative symptoms). Moreover, another definition states that schizophrenia is mixture of positive and negative symptoms that present for a significant portion of a one-month period but with continuous signs of disturbance persisting for at least six months (Diagnostic and Statistical Manual of Mental Disorder IV-text revision (2000)).

In summary, schizophrenia is a mental disorder characterized by psychosis, cognitive dysfunction and negative symptoms which last for at least one-month of an active phase and persist for at least six months.

### **Causes of Schizophrenia**

Based on McGorry (2004), the actual causes of schizophrenia are still unclear. However, it is convincing that it is caused by a combination of multi causal factors including biological factors, psychological factors and sociocultural and environmental factors (Bostrom & Boyd, 2005; Townsend, 2006).

**Biological factors.** These factors include genetics, biochemical influences and physiological influences. In terms of genetic factors, it is well-known that having schizophrenia will make other members in the family at risk of developing schizophrenia. Studies showed that if one twin has schizophrenia, the other twin has the risk of developing schizophrenia at about 40% - 50%. In addition, if both parents suffer from schizophrenia, the risk of schizophrenia in their children is about 40% - 60% and in siblings is 9% - 18% (Tandon, Keshavan, & Nasrallah, 2008). In the biochemical influences, schizophrenia patients have an abnormality in brain chemistry or a chemical disturbance such as a neurotransmitter imbalance. An excess of dopamine in the mesolimbic tract can lead to positive symptoms in schizophrenia and

hypoactivity of mesocortical dopaminergic tract can cause negative symptoms (Bostrom & Boyd, 2005). Several neurotransmitters are also predispositional factors to schizophrenia including abnormalities in norepinephrine, serotonin, acetylcholine and GABA (Townsend, 2006). Based on Pearson (2009), schizophrenia can be caused by the insufficiency of norepinephrine in the brain and also an imbalance between dopamine and norepinephrine which can lead to an abnormality in the process of sensory information. In the physiological factors, schizophrenia can be caused by a viral infection and a neuroanatomical abnormality in the brain such as cerebral ventricular enlargement, a decrease of various portions in the limbic system which has the role to control emotion, a reduced volume in basal ganglia and brain injury (Pearson, 2009).

**Psychological factors.** Schizophrenia probably occurs by poor parent-child relationship and family dysfunction (Townsend, 2006). Furthermore, the illness can be caused partly by the family and partly by some individual characters, marital conflict, communication in double message or “double bind” communication and the failure to accomplish an early stage of psychosocial development. In addition, the schizophrenic person is seen as an example of a person who cannot cope with stress (Moller, 2009). Based on the stress-vulnerability model, vulnerable people may be predisposed to break down (Pearson, 2009).

**Sociocultural and environmental factors.** Schizophrenia is shown in greater number of individuals from lower socioeconomic backgrounds, and those experiencing social and cultural disharmony, major life changes and substance abuse. These factors can accumulate as risk factors (stressors). However, this may contribute to the severity and the course of the illness. Stress may precipitate symptoms in an

individual who is vulnerable (Pearson, 2009; Townsend, 2006). In addition, social theories determine that schizophrenia correlates with “express emotion”. The family which has high levels of expressed emotion including making negative comments such as connote criticism, hostility and negativity about the patient and also being overprotective may increase symptoms and relapse in the patients with schizophrenia (Bostrom & Boyd, 2005).

To sum up, there are several causes that might be related to schizophrenia such as the biological factors, psychological factors, sociocultural factors and environmental factors.

### **Signs and Symptoms of Schizophrenia**

There are three core symptoms in schizophrenia including positive symptoms, negative symptoms, and cognitive symptoms (National Institute of Mental Health [NIMH], 2009).

**Positive symptoms.** Positive symptoms are the distortion of normal functions such as psychotic disorders of thinking and disorganized speech and behavior. Psychotic disorders can manifest as delusions (fixed false belief: paranoid, somatic, grandiose, religious, nihilistic, thought broadcasting) and hallucinations (perceptual experience which is not shared by others and may affect the 5 senses: auditory, visual, tactile, gustatory, and olfactory) (Austin, 2005; Moller, 2009). Disorganization of speech and behavior can manifest as a thought disorder (incoherence, word salad, loose association, pressure of speech, distractible speech, illogically, derailment, tangentiality) and bizarre behavior such as catatonia, movement disorders, deterioration of social behavior including clothing, appearance,

and sexual behavior (Moller, 2009; Pearson, 2009). Positive symptoms present in schizophrenic persons are usually responsive to traditional antipsychotic drugs.

**Negative symptoms.** Negative symptoms are diminution or loss of normal function (Moller, 2009). It is an experience or behavior that usually presents in the general population (Austin, 2005). Negative symptoms include avolition or apathy such as a lack of motivation to pursue goals or activities, lethargy, sleepiness, impaired grooming and hygiene; alogia (poverty of speech), which is clinically identified by poverty of speech and content of speech, blocking and increased response latency; anhedonia means an individual is experiencing little or no pleasure from activities that they would typically enjoy such as few recreational interests, little sexual interest, impaired intimacy and few relationships; and blunted affect means limited of emotional expression where expressiveness of the face, body language, and voice is reduced. Negative symptoms are usually unresponsive to traditional antipsychotic drugs and more responsive to atypical antipsychotics drugs (Austin, 2005; Moller, 2009; Pearson, 2009).

**Cognitive symptoms.** Schizophrenia patients have dysfunctions in cognition which is important to the process of knowing such as a dysfunction in attention (poor concentration), learning, memory (impaired short-term/long-term memory), concentration, abstract thinking, problem solving and decision making (lack of insight, impaired judgment). At illness onset most patients experience a decline in cognition but the functioning of their cognitive level tends to remain stable (Austin, 2005; Moller, 2009).

In conclusion, the symptoms in schizophrenia have three categories including positive symptoms, negative symptoms and cognitive symptoms. These

symptoms cause the patients to have difficulty in performing their daily living activities.

### **Periods of Schizophrenia**

According to Bostrom and Boyd (2005), the clinical features in schizophrenia are complex which describe three periods namely the acute illness period, the stabilization period and the maintenance and recovery period.

**Acute period.** In the acute period, individuals might have most of the symptoms seen in schizophrenia such as intense hallucinations, incoherent conversation or aggressive actions. Moreover, they lack self-care ability such as eating, sleeping and bathing and also can show impairment in school or work. They become dependent on their family. In this phase, schizophrenic patients have a high risk of suicide and need hospitalization to protect themselves or others (Bostrom & Boyd, 2005).

**Stabilization period.** In this period, the symptoms become less acute but are still present. The patients still need treatment and medication. They begin to socialize with others and rehabilitation begins (Bostrom & Boyd, 2005).

**Maintenance and recovery period.** In this period, the patients focus on regaining their previous level of functioning and enhancing their quality of life. Medication management is needed in order to reduce impairment functioning and to diminish extreme behavior that may occur in the patients. Moreover, the involvement and support of the family are very important in this period to anticipate a relapse and how to cope with it (Bostrom & Boyd, 2005).

**Relapses.** Relapses can happen anytime during treatment and recovery. The biggest factor for relapse is non-adherence to the medication regimen. Stopping the use of medication certainly leads to relapse. The other factors which can trigger relapses are lack of coping in dealing with a stressor, the accessibility of community resources, stigmatization in the community and lack of support from family, friends or the health care provider. The combination of medication and psychosocial treatment can diminish the severity and frequency of recurrent relapses (Bostrom & Boyd, 2005). The early warning signs of relapse include a change in sleep patterns and behavior, social withdrawal, deterioration in activities of daily living and functioning, loss of motivation, strange ideas, poverty of speech, irritability, restlessness, agitation and aggressive acts (Spaniel et al., 2008).

To sum up, schizophrenia fluctuates within acute, stable, recovery and relapse phases. From this fluctuation various impacts occur on the schizophrenia patients and their families.

### **Impacts of Schizophrenia**

Schizophrenia not only impacts the individual as a patient but also impacts on the family and society. Patients with schizophrenia have several symptoms which can lead to social and occupational dysfunction such as impairment in work or activities, lack of interpersonal relationships, impairment in self-care ability and also mortality or morbidity (Moller, 2009). These impacts cause schizophrenia patients to become dependent on their family. Caring for the patients for a long time can impact on their families psychologically and economically. Families may experience psychological distress, for instance, being angry and feeling shameful because of

having a person with a mental illness in their family. Furthermore, the family also can experience economic burden because they need to take care of the patient and also the cost of treatment (Chan, 2011). Individuals who suffer from mental illness also might have a secondary illness from social environment reaction and stigma associated with the disorder. The impact of stigmatization will lead to social isolation, a lack of chances in life such as employment and also social discrimination (Horrison & Gill, 2010).

### **Treatment of Schizophrenia**

There are two treatments for schizophrenia which include pharmacological treatment and psychosocial treatment (Tandon, Nasrallah, & Keshavan, 2010).

**Pharmacological treatment of schizophrenia.** Antipsychotic drugs or neuroleptic or major tranquilizers are effective in treating acute and chronic symptoms of schizophrenia and also in maintaining therapy to prevent schizophrenic symptoms (Townsend, 2006). The target symptoms of these drugs include hallucinations, delusions, disorganized speech and behavior, flat or inappropriate affect and catatonia (Moller, 2009).

The mechanism of the action of antipsychotic drugs is blocking postsynaptic dopamine receptors in the brain which can lead to blocking dopamine transmission. It results in a desirable antipsychotic effect, however it also creates undesirable side effects (Bostrom & Boyd, 2005).

Antipsychotic drugs are contraindicated in clients with hypersensitivity, depression in the cerebral nervous system (CNS), blood dyscrasias,



Parkinson's disease, and clients with liver, renal or cardiac insufficiency. Moreover, these drugs are cautioned in be given to the following clients including the elderly, diabetic clients, clients with respiratory insufficiency, prostatic hypertrophy or intestinal obstruction (Townsend, 2006).

It is also important to be concerned with the drug interaction of antipsychotic drugs. Anticholinergic effects will be enhanced when antipsychotic drugs are taken with other drugs that produce anticholinergic effect such as antihistamine, antidepressants and antiparkinsonian drugs. When taken with beta-adrenergic blocking agents (propranolol and metoprolol), it can induce additive hypotensive. Antacids and antidiarrheal medication may reduce the absorption of antipsychotic drugs and barbiturates may enhance metabolism and decrease the effectiveness of antipsychotics. Using alcohol, antihistamine, antidepressants, sedative-hypnotics and anxiolytics may induce additive CNS depression (Townsend, 2006).

There are two categories of antipsychotic drugs for treating schizophrenia: traditional and atypical drugs (Pearson, 2009). The usual drugs in the category of traditional drugs are haloperidol, perphenazine and chlorpromazine. Atypical or novel drugs include risperidone, aripiprazole, clozapine, and olanzapine. Table 1 shows the summary of medication frequently used for schizophrenia patients and the side effects of each medication.

Table 1

*Antipsychotic Drugs, Doses and Side Effects*

<b>Generic/brand names</b>	<b>Usual dose (PO) in adult/ day</b>	<b>Side effects</b>
<b>Typical/ traditional antipsychotics</b>		
fluphenazine (Prolixin)	0.5-10.0 mg	Drowsiness, pseudoparkinsonism, dystonia, akathisia, cardiac arrest
chlorpromazine (Thorazine)	25-50 mg	Drowsiness, insomnia, vertigo, EPS, dry mouth, salivation, nausea, vomiting, anorexia, constipation, hypotension, anemia, photophobia, blurred vision, urticarial
thioridazine (Mellaril)	50-100 mg	Drowsiness, pseudoparkinsonism, dystonia, akathisia, NMS, photophobia, blurred vision, dry mouth, salivation, nausea
trifluoperazine (Stelazine)	2-5 mg	Drowsiness, pseudoparkinsonism, dystonia, akathisia, NMS, photophobia, blurred vision, dry mouth, salivation, nausea
haloperidol (Haldol)	0.5-2 mg	Drowsiness, pseudoparkinsonism, dystonia, akathisia, NMS,
<b>Atypical antipsychotics</b>		
clozapine (Clorazil )	25 mg	Weight gain, sedation, salivation, seizure, danger in agranulocytosis. Require monthly testing of WBC
risperidone (Risperdal)	0.25-1 mg to 9-12 mg	Insomnia, agitation, anxiety, headache, nausea, vomiting, NMS
olanzapine (Zyprexa)	5-10 mg	Excessive weight gain, somnolence, dizziness, NMS, constipation, fever
aripiprazole (Abilify)	2-30 mg	Headache, anxiety, insomnia, tremor, nausea, vomiting, hypotension, constipation, diarrhea, NMS

*Note.* Adapted from "Side effects of antipsychotic drugs" by M. D. Moller in W. K. Mohr, 2009, *Psychiatric-mental health nursing: Evidence-based concepts, skills and practices*, 7, pp. 291-294.

Even antipsychotic medication can treat symptoms of schizophrenia; these drugs can create some side effects and lead to medication adherence problems. Extrapyramidal symptoms (EPS) are common side effects of antipsychotic medication. They include acute dystonic reactions which means severe muscle spasms; dyskinesias which is an abnormality of muscle movement but not severe as in causing spasms; Parkinsonian reactions and akathisia which means nearly continual muscle activity. Schizophrenia patients should know the side effects of antipsychotic drugs and their management. Table 2 shows the side effects of antipsychotic drugs and their management.

Table 2

*Side Effects of Antipsychotic Drugs and Its Management*

<b>Side effects</b>	<b>Management</b>
Nausea, GI upset	- Tablet can be diluted and administer with fruit juice or other liquid
Sedation	- Administer at bedtime - Decrease dose
Orthostatic hypotension	- Instruct to rise slowly from a lying or sitting position - Monitor blood pressure
Photosensitivity	- Use sun glasses when spending time out-doors
Hormonal effect	
- Decreased libido	- Explain the side effect and possible reversibility
- Weight gain	- Encourage physical exercise, and diet
Agranulocytosis	- Observe for symptoms of sore throat, fever, malaise and complete blood count
Extrapyramidal symptoms	- Observe for symptoms - Administer anti parkinsonian drug as ordered such as Trihexyphenidyl (Artane)

Table 2 (continued)

Side effects	Management
Tardive dyskinesia (bizarre facial and tongue movement, stiff neck and swallowing difficulty)	- Stop the drug at the first sign
Neuroleptic malignant syndrome (NMS)	- Observe symptoms including severe parkinsonian muscle rigidity, hyperpyrexia, tachycardia, fluctuation in blood pressure, diaphoresis, stupor and coma. - Stop medication immediately - Monitor vital signs, intake and output, and level of consciousness

*Note.* Adapted from “Side effects of antipsychotic drugs” by M. C. Townsend, 2006, *Psychiatric mental health nursing: Concepts of care in evidence-based practice*, 5, pp. 304-306.

**Psychosocial treatment of schizophrenia.** Psychosocial treatments in schizophrenia patients include psychoeducation, cognitive behavior therapy (CBT), social skills training, family therapy and assertive community treatment (ACT) (Tandon, Nasrallah, & Keshavan, 2010).

Psychoeducation is a systematic psychotherapeutic intervention which is designed to give information related to the disorder and promote coping for the patients and their relatives (Wiedenmann as cited in Lincoln, Wilhelm, & Nestoriuc, 2007). Most studies of psychoeducation showed positive improvement for schizophrenia patients in their attitude toward medication (Chaiyajan, Sitthimongkol, Yuttatri, & Klainin, 2009), insight and physical and mental health (Chan, Lee, & Chan, 2007), and the level of functioning (Kapelowicz, Zarate, Smith, Mintz, & Liberman, 2003). However, a meta-analysis study showed that psychoeducation had no effect on symptoms, functioning and medication adherence (Lincoln et al., 2007).

Cognitive behavior therapy (CBT) is psychotherapy to help the patient regarding psychotic symptoms such as delusions and hallucinations which come from misinterpretation and irrational attribution (Tandon, Nasrallah, & Keshavan, 2010). A study found that the CBT can be effective for negative symptoms (Zimmermann, Favrod, & Trieu, 2005). However, meta-analysis studies showed that CBT was ineffective for symptoms in schizophrenia and for relapse prevention (Lynch, Laws, & McKenna, 2010).

Social skills training (SST) is needed because schizophrenia patients have a deficit in social skills. The aim of SST is to enhance living skills by focusing on components of social competence such as self-care, basic conversation, vocational skills, and recreation which are mostly practiced in a group setting based on the operant and social learning theory (Tandon, Nasrallah, & Keshavan, 2010). Meta-analysis studies showed that SST can enhance psychosocial functioning in schizophrenia (Kurtz & Mueser, 2008).

Family therapy is useful because the family plays a vital role for patients with schizophrenia. Family therapy aims to alter the interactions within the family or caregivers to reduce relapse (Turkington, Dudley, Warman, & Beck, 2004). The family intervention can be in the form of psychoeducation to provide information regarding the illness of schizophrenia and strategies to help the patient. The study showed that psychoeducation for the family can improve their knowledge on the illness (Kulhara, Chakrabarti, Avasthi, Sharma, & Sharma, 2009).

Assertive community treatment (ACT) is a strategy to integrate the clinical services in the community by using a multidisciplinary approach and a high frequency of family contact (Tandon, Nasrallah, & Keshavan, 2010). ACT aims for

maintaining contact with the patients, reducing symptoms and relapse and improving social functioning and quality of life (Turkington, Dudley, Warman, & Beck, 2004).

In conclusion, psychosocial treatments are varied such as psychoeducation, cognitive behavior therapy (CBT), social skills training, family therapy and assertive community treatment (ACT). The goal of the treatments is to enhance the quality of life for the patients with schizophrenia.

### **Schizophrenia Management in Indonesia**

The prevalence of schizophrenia is increasing in Indonesia. It was estimated to affect 0.3% - 1% of the population in 2006 (Arif as cited in Wulansih 2008). In 2010, according to the Central Statistics Agency, the prevalence of people with schizophrenia was estimated at 1% - 2% of the population of Indonesia which is around two million people (Sidakaton, 2011).

In Indonesia, the mental health hospitals have general guidelines for schizophrenia management especially in regards to nursing interventions. Mostly, nurses give an intervention based on the common problems of the schizophrenia patient including hallucinations, delusions, social isolation, violent behavior, low self-esteem, risk of self-harm and a deficit of self-care. The nurse assists the patient, gives educational information and trains the patient in skills in regards to solving the patient's problem. Moreover, the hospitals provide health education especially regarding medication for both the patient and his or her family before the patient is discharged from the psychiatric hospital.

After discharge from the psychiatric hospital, the patient usually receives medication for 2 - 4 weeks. In the community, there is no self-help group for

patient. While at home the family needs to take care of the patient. The family should take the patient to the out-patient department (OPD) for regular check-ups on the patient's condition and also to get medication. The usual care for the patient at the OPD includes a nursing assessment, doctor's examination, and education for the family.

The first time when the patient comes to the OPD, the nurses will assess the patient's condition. The nursing assessment includes both physical and psychological aspects such as vital signs, complaints, positive and negative symptoms, and the patient's activity while at home. The next step is having an examination by doctor and the doctor will prescribe some medication for the patient. Some patients sometimes also need therapy such as drug injections. Then, after the doctor's examination, the patient gets the medication the doctor has prescribed. Unstructured health education sometimes will be given by the nurse or the physician to respond to the patient and family needs (nurse of the OPD of RSJP Prof. dr. Soeroyo Magelang, personal communication, June 19, 2012).

## **Medication Adherence in Schizophrenia**

### **Concept of Medication Adherence**

The term of adherence is sometimes used interchangeably with compliance and concordance. Compliance means the extent of the patient's behavior that matches with the prescriber's recommendation (Bissonnette, 2008; Patel & David, 2007). This term has been criticized because it has a negative meaning in the role of the patient who seems to passively follow the doctor's orders. Therefore, this

sometimes places blame on the patients when they do not take their medication (Bissonnette, 2008; Horne, 2005).

Concordance is a complex concept which involves negotiation between the patient and the health care professional with respect to the beliefs and wishes of the patients in determining when and how medication will be taken (Bissonnette, 2008; Horne, 2005; Patel & David, 2007). The essential components of concordance are knowledge both from the patient and the practitioners, the partnership and supportive relationship. Thus, concordance is not concerned with actual medication taking but is concerned in the dynamics of the interaction between the health-care professionals (Lehane & McCarthy, 2009).

The term of compliance is similar with the term of adherence, which means the patients' act based on the health care provider's recommendation with respect to the time, dose and frequency of medication taking (Cramer et al., 2008). Adherence to medication means the process of the patient taking the medication as prescribed which includes the process of initiation, implementation and discontinuation (Vrijens et al., 2012). Actually, adherence is an extension of compliance in terms of the need of agreement between the patient and prescribers. It emphasizes the patients' freedom to decide whether they follow the prescriber's recommendation or not (Bissonnette, 2008; Horne, 2005; Patel & David, 2007). Adherence is concerned with active patient involvement in taking medication and the relationship with the health care provider. Moreover, many studies in medication taking used the term of adherence which reflects the extent to which the patient is taking the medication as prescribed (Masand & Narasimhan, 2006; Patel & David, 2007). Furthermore, Hearnshaw and Lindenmeyer as cited in Lehane and McCarthy



(2009), define adherence in five categories which are (i) coincidence of patient behavior with professional advice, (ii) relationship as part of the process of care, (iii) outcome and process targets, (iv) taking medication as prescribed, and (v) other factors influencing behavior. Adherence as a concept focuses on the attributes which facilitate the description of medication-taking behavior and person-centered interactions (Lehane & McCarthy, 2009). It implies both medication adherence behavior and medication adherence attitude. Medication adherence is an observable behavior which can be observed continually, can be recorded by pills taken and can be compared to the prescribed regimen (Sajatovic, Velligan, Weiden, Valenstein, & Ogedegbe, 2010).

The term of medication adherence implies both medication adherence behavior and medication adherence attitude. However, adherence attitude is distinct from adherence behavior. The difference is one's behavior is not always the same as one's attitude toward medication. It is an important reason for the need of attitudes' assessment. Adherence attitude means an explicit statement from the patient regarding overall like or dislike of taking medication. The patient may have favorable and unfavorable attitudes in taking medication at the same time (Sajatovic, Velligan, Weiden, Valenstein, & Ogedegbe, 2010).

In summary, an adherence attitude is different from adherence behaviors such as medication-taking behavior. In this study, medication adherence includes not only medication adherence behaviors but also medication adherence attitude.

## **Factors Contributing to Medication Adherence**

A review of the literature informs that there are some factors contributing to adherence in patients with schizophrenia which are patient-related factors, illness-related factors, treatment-related factors, environmental factors and health care system factors.

**Patient related factors.** These factors are related to the characteristics and socio-economic status of patients. Age is one of the variables in demographic factors. Numerous studies have examined the correlation between age and medication adherence in patients with schizophrenia. Some studies showed that age had no correlation with medication adherence (Adewuya et al., 2009; Kamali et al., 2006; Liu-Seifert, Osuntokun, & Feldman, 2012; Mullins, Obeidat, Cuffel, Naradzay, & Loebel, 2008; Ritchie, Harrigan, Mastwyk, Macfarlane, Cheesman, & Ames, 2010; Sapra, Vahia, Reyes, Ramirez, & Cohen, 2008). Conversely, some studies showed that older aged patients were likely to be adherent to medication (McCann, Boardman, Clark, & Lu, 2008; Novick, Haro, Suarez, Perez, Dittmann, & Haddad, 2010). An older age is associated with maturity and life experience to maintain adherence. However, a study conducted by McCann et al. (2008) reported an inconsistent relationship between these factors.

Education is one of demographic factors that can influence medication adherence among patients with schizophrenia. The patient who has a higher education level is expected to have better knowledge about disease therapy which can influence him or her to be more adherent (Jin, Sklar, Edward, Sen Oh, & Li, 2008). However, some studies revealed that the education level did not influence medication adherence

in patients with schizophrenia (Adewuya et al., 2009; Dassa, Boyer, Benoit, Bourcet, Raymondet, & Bottai, 2010; Sapra, Vahia, Reyes, Ramirez, & Cohen, 2008).

Employment, in one study showed that it had no association to medication adherence (Dassa, Boyer, Benoit, Bourcet, Raymondet, & Bottai, 2010). On the other hand, a study in Nigeria found that the working status was a predictor with medication adherence. This study found that the employed population had a higher rate of non-adherence. It is possible that employed patients may view their side effects of medication as influencing their functioning at work. They were more likely to be free of symptoms and may stop their medication when they felt better (Adewuya et al., 2009).

Income, in some studies revealed that it correlated to medication adherence in schizophrenia. The patients with a low income were more likely to be non-adherent (Adewuya et al., 2009; Robinson, Woerner, Alvir, Bilder, Hinrichsen, & Lieberman, 2002). Conversely, a study from Dassa, Boyer, Benoit, Bourcet, Raymondet, and Bottai (2010) showed that income did not influence medication adherence in patients with schizophrenia.

Attitude toward medication has an important role in medication adherence (Santone, Rucci, Muratori, Monaci, Ciarafoni, & Borsetti, 2008). Attitude toward medication is a subjective response of the patient regarding his/ her medication (Lambert et al., 2004). Several studies revealed that antipsychotic side effects can influence a patient's attitude and lead to medication adherence. Many studies showed that attitude toward medication significantly correlated with medication adherence. Positive attitudes toward medication can influence adherence to medication and has a significant correlation with medication adherence among

patients with schizophrenia (Mutsatsa, Joyce, Hutton, Webb, Gibbins, Paul & Barnes, 2003; Rungruangsiripan, Sitthimongkol, Maneesriwongul, Talley, & Vorapongsathorn, 2011). However, one study showed that there was no correlation between attitude toward medication and medication adherence (Tsang, Fung, & Corrigan, 2009). In addition, a patient's beliefs can influence his or her attitude toward medication and lead to medication adherence in schizophrenia. The patients were more likely to be adherent, if they believes that medication can help them during hospitalization. On the other hand, patients who believe that their illness is because of supernatural powers were also found to have poor adherence (Buchanan as cited in Lan, Shiau, & Lin, 2003). Furthermore, a previous study found that beliefs were a predictor for medication adherence. Patients and caregivers who believe in the spiritual realm may believe in a spiritual solution to solve the mental health problems of the patients (Adewuya et al., 2009). However, a study in Taiwan revealed that there was no correlation between those factors (Lan et al., 2003).

Knowledge about disease and treatment is an important factor in medication adherence. Psychoeducation intervention which gives knowledge to a patient about his or her illness including treatment side effects has shown to have an effect on medication adherence (Chan, Yip, Tso, Cheng, & Tame, 2009; Pitszel-Walz, Bauml, Bender, Engel, Wagner, & Kissling, 2006, Shon & Park, 2002). However, a study conducted by Lan, Shiau and Lin (2003) found that knowledge of drug effects had a negative influence on adherence to medication.

Self-efficacy is the cornerstone of medication adherence (McCann, Clark, & Lu, 2008). Self-efficacy is an individuals' belief or their confidence in performing a specific task or activity (Bandura as cited in Lorig & Holman, 2003).

The patients who have strong self-efficacy are better in coping with the problems related to medication taking (McCann et al., 2008). The study revealed that the intervention which is based on self-efficacy has positive effects on medication adherence. Higher self-efficacy can contribute to a patient in managing their problem in regards to medication taking (Shon & Park, 2002).

**Illness-related factors.** The illness-related factors to medication adherence in schizophrenia are illness history, severity of illness, insight, cognition, co-morbid substance use, and depressive symptoms. The illness history of schizophrenia includes age at onset of schizophrenia, duration of illness and the number of hospitalizations. Some studies revealed that there was no correlation between medication adherence and age (Dassa, Boyer, Benoit, Bourcet, Raymondet, & Bottai, 2010) and the length of the illness (Adewuya et al., 2009; Dassa et al., 2010; Mutsatsa, Joyce, Hutton, Webb, Gibbins, Paul, & Barnes, 2003) and also the number of hospitalizations (Adewuya et al., 2009; Mullins, Obeidat, Cuffel, Naradzay, & Loebel, 2008). However, one study revealed that a high number of hospitalizations correlated with non-adherence to medication (Dassa et al., 2010).

Illness severity can influence medication adherence in schizophrenia patients. The patients who have a high score of positive symptoms were more likely to be non-adherent (Dassa, Boyer, Benoit, Bourcet, Raymondet, & Bottai, 2010; Liu-Seifert, Osuntokun, & Feldman, 2012; Novick, Haro, Suarez, Perez, Dittmann, Haddad, 2010; Staring, Mulder, Duivenvoorden, De Haan, & Van der Gaag, 2009). Conversely, some studies also revealed that there was no correlation between those factors (Mutsatsa, Joyce, Hutton, Webb, Gibbins, Paul, & Barnes, 2003; Sapra, Vahia, Reyes, Ramirez, & Cohen, 2008).

Insight has been reported as an important factor to medication adherence in schizophrenia. Most of the studies revealed that insight is a predictor for medication adherence. Poor insight correlated with non-adherence to medication (Adewuya et al., 2009; Dassa, Boyer, Benoit, Bourcet, Raymondet, & Bottai, 2010; Tsang, Fung, & Corrigan, 2009). Moreover, some studies indicated that insight was the best predictor for non-adherence to medication (Kamali et al., 2005, Tsang, Fung & Corrigan, 2009). On the other hand, some studies also found that those factors did not correlate significantly (McCann, Boardman, Clark, & Lu, S, 2008; Mutsatsa, Joyce, Hutton, Webb, Gibbins, Paul, & Barnes, 2003).

Cognition impairment can contribute to medication adherence among patients with schizophrenia. A study from Robinson, Woerner, Alvir, Bilder, Hinrichsen, and Lieberman (2002) showed that during one year after discharge, the discontinuation of medication was associated with cognitive impairment. This finding supported the results from a survey in Korea showed that cognitive impairment was less in the patients with adherence to medication (Kim et al., 2008).

Substance use such as alcohol misuse and drug misuse are predictors of non-adherence to medication (Kamali et al., 2006). However, most of the studies showed that substance use in patients with schizophrenia was not associated with medication adherence (Dassa, Boyer, Benoit, Bourcet, Raymondet, & Bottai, 2010; McCann, Boardman, Clark, & Lu, 2008; Mutsatsa, Joyce, Hutton, Webb, Gibbins, Paul, & Barnes, 2003; Robinson, Woerner, Alvir, Bilder, Hinrichsen, & Lieberman, 2002).

Depressive symptoms appeared to predict medication adherence in patients with schizophrenia. Greater severity of depressive symptoms may predict

non-adherence to medication (Liu-Seifert, Osuntokun, & Feldman, 2012; Robinson, Woerner, Alvir, Bilder, Hinrichsen, & Lieberman, 2002). However, a study also found that there was no correlation between those factors (Sapra, Vahia, Reyes, Ramirez, & Cohen, 2008).

**Treatment-related factors.** The type of antipsychotic and the side effects of medication are included in the treatment-related factors. It is well-known that the typical antipsychotic drugs have more negative side effects than atypical antipsychotic drugs. The previous study showed that the patients who use typical antipsychotic drugs were more likely to be non-adherent to medication (Dassa, Boyer, Benoit, Bourcet, Raymondet, & Bottai, 2010). Some studies also revealed that the patients who use atypical olanzapine drugs have better adherence than the patients who use other atypical drugs because Olanzapine was associated with a greater improvement in symptom severity (Liu-Seifert, Osuntokun, & Feldman, 2012; Mullins, Obeidat, Cuffel, Naradzay, & Loebel, 2008; Ritchie, Harrigan, Mastwyk, Macfarlane, Cheesman, & Ames, 2010).

The side effects of medication can influence the patient to be adherent with medication. The studies showed that medication side effects predict medication adherence in patients with schizophrenia especially for patients who have experienced Parkinson side effects (Liu-Seifert, Osuntokun, & Feldman, 2012; McCann, Boardman, Clark, & Lu, 2008; Sapra, Vahia, Reyes, Ramirez, & Cohen, 2008; Staring, Mulder, Duivenvoorden, De Haan, & Van der Gaag, 2009). Conversely, some studies showed an inconsistent relationship between those factors (Adewuya et al., 2009; McCann, Clark, & Lu, 2009; Mutsatsa, Joyce, Hutton, Webb, Gibbins, Paul,

& Barnes, 2003; Ritchie, Harrigan, Mastwyk, Macfarlane, Cheesman, & Ames, 2010).

**Environmental factors.** Environmental factors include family support, culture and stigma. Family support can influence medication adherence among patients with schizophrenia. Previous studies conducted in Africa (Adewuya et al., 2009) and Korea (Kim et al., 2008) revealed that perceived social support influences the patient to take his or her medication. The patients reported that they need their family to remind them to take their medication. Therefore, for maintaining medication consumption, the role of the family is very important (Kim et al., 2006). However, some studies revealed that family support has no correlation with medication adherence (Dassa, Boyer, Benoit, Bourcet, Raymondet, & Bottai, 2010; McCann, Boardman, Clark, & Lu, 2008; McCann, & Lu, 2009; Robinson, Woerner, Alvir, Bilder, Hinrichsen, & Lieberman, 2002; Rungruangsiripan, Sitthimongkol, Maneesriwongul, Talley, & Vorapongsathorn, 2011). Based on McCann et al.'s study (2008), there were several reasons might contribute to this findings. First, the relationship between the significant others' support and medication adherence is moderated by beliefs about the control over one's illness. The patients with high of internal locus of control will perceive non-significance of family support. Second, there could be a difference in the early subjective response to antipsychotics among the patients, with or without the significant others' support. Third, the level of Expressed Emotion (EE) of the significant others has been linked to adherence. The possible discrepancy in the EE of the significant others in the current study might lead to the insignificance of the significant others' support, as previous research has shown that the individuals living with family members with low levels of EE are less



adherent than the individuals living with family members with high EE. The findings related to the inconsistent relationship between family support and medication adherence emphasize the importance of treating medication adherence as a multidimensional phenomenon. Moreover, a living situation can contribute to medication adherence. Some studies showed that those patients who were living alone were more likely to be non-adherent (Novick, Haro, Suarez, Perez, Dittmann, & Haddad, 2010; Tsang, Fung, & Corrigan, 2009). However, most studies showed that there was no relationship between medication adherence and patients' living situations (Adewuya et al., 2009; Dassa et al., 2010; McCann et al., 2008; Sapra, Vahia, Reyes, Ramirez, & Cohen, 2008).

Cultural context can influence the medication adherence of the patients with schizophrenia. African caregivers are more likely to live with their mentally ill family member and thus, providing a higher degree of support which influences medication adherence for patients (Adewuya et al., 2009). Similarly, Shon and Park (2002) reported that patients with schizophrenia who lived together with their family had needed support from them. These examples might be different from western countries where most patients with schizophrenia lived separately from their family.

Stigma was a predictor for medication adherence in schizophrenia. Self-stigma has been known to be a large barrier to medication adherence among mentally ill patients (Adewuya et al., 2009). Lack of global awareness about the side effects of antipsychotic drugs and how they affect a patient outwardly, as well as the social stigma attached to the mentally ill can influence a patient to discontinue taking his or her medication as well as the patient denying that he or she has a mental illness. Therefore, patients try to deny the illness and discontinue taking medication (Lee,

Chiu, Tsang, Chui, & Kleinman, 2006). However, some studies showed that there was no correlation between those factors (McCann, Boardman, Clark, & Lu, 2008; Tsang, Fung, & Corrigan, 2009).

**Health care system.** The physician-patient relationship can contribute to medication adherence. The information exchanged from patients and health care providers can initiate the comparison between initial perception and reference values which can develop medication adherence (Laventhal as cited in Rungruangsiripan, Sitthimongkol, Maneesriwongul, Talley, & Vorapongsathorn, 2011). Moreover, poor therapeutic alliance between patients and health care providers was associated with poor adherence (Dassa, Boyer, Benoit, Bourcet, Raymondet, & Bottai, 2010; McCann, Boardman, Clark, & Lu, 2008). However, some studies mentioned that the physician-patient relationship is not associated with medication adherence (Rungruangsiripan et al., 2011; Sapra, Vahia, Reyes, Ramirez, & Cohen, 2008).

Access to health care services such as access to psychiatrists or medication can influence medication adherence. A study revealed that access to a psychiatrist can predict adherence to medication. Patients who have poor access were more likely to be non-adherent. Therefore, the knowledge and expertise of a psychiatrist can contribute to greater adherence (McCann, Boardman, Clark, & Lu, 2008). Some patients are non-adherent to medication because they lack access to medication and they feel that getting to a pharmacy to get their medication is costly and difficult (Lacro, 2006).

In conclusion, patient-related factors, illness-related factors, treatment-related factors, environmental factors and the health care system are contributing factors for medication adherence among patients with schizophrenia. Of those factors,

some factors (age, level of education, employment, income, access to health care services, age of disease onset, length of illness, number of hospitalizations, type of medication, side effects of medication, insight and family characteristics) are collected in the demographic data that will be analyzed as to whether these factors influence the outcomes in this study. Co-morbidity such as depression, cognition problems and substance use are excluded in this study. Moreover, knowledge, self-efficacy, a patient's attitude and beliefs, stigma, and family involvement are included in the developed program.

### **The Measurement of Medication Adherence**

From the literature review, there are two kinds of medication adherence measurements which are used in schizophrenia studies: (1) objective indicators of medication-taking such as pill counts, electronic monitoring, pharmacy records, and blood plasma levels, and (2) subjective measures of medication use via patient-report or interviewer ratings which can be divided into adherence behavior measurement and adherence attitude measurement.

**Objective measurement.** Pill counts, electronic monitoring, pharmacy records, and blood plasma levels are included in the objective measurement of medication-taking. Pill counts determine how many pills are missing compared to the number of pills that should have been taken within a period of time which results in an estimated percentage of adherence to medication. This method does not require expensive equipment or trained personnel. However, some issues are raised such as the pill count should take place at a patient's home, and it should be unannounced and

randomly scheduled visits (Sajatovic, Velligan, Weiden, Valenstein, & Ogedegbe, 2010).

Electronic monitoring is often known to be a “gold standard” for adherence measurements such as MEMS caps, Med-eMonitor, eCaps and Medsignals. These devices are used to capture when the pill containers are opened and closed to estimate the specific timing of doses, to identify patterns of medication use, and to calculate adherence rates. However, obtaining these devices is expensive. Moreover, electronic monitoring needs trained personnel to use the software (Sajatovic, Velligan, Weiden, Valenstein, & Ogedegbe, 2010).

Pharmacy records are an objective method to determine adherence levels such as medication possession ratios, gaps in medication use, medication consistency and persistence. The advantages of these records are no missing data because of a patient’s non adherence and no assessment reactivity. However, electronic records should not be assumed to be accurate or complete such as if the clinician changes the patient’s dose but does not change the prescribed dose, and refill rates may also become inaccurate (Sajatovic, Velligan, Weiden, Valenstein, & Ogedegbe, 2010).

Blood plasma levels include the measurement of a drug or its metabolite in the serum, urine, and saliva. These measures are objective and vary related to utility, degree of intrusiveness, cost, and availability. Moreover, it is only useful to determine whether medication has been taken or not rather than how much of the medication has been taken because of individual medication differences in metabolism and half-life of medication (Sajatovic, Velligan, Weiden, Valenstein, & Ogedegbe, 2010).

**Subjective measurement.** Subjective measurement can be divided into adherence attitude measurement such as the Rating of Medication Influences (ROMI), the Drug Attitude Inventory (DAI) and the Medication Adherence Rating Scale (MARS) and adherence behavior measurement such as the Brief Adherence Rating Scale (BARS) and the Morisky Medication Adherence Scale (MMAS).

The Rating of Medication Influences (ROMI) was designed based on the health belief model to measure adherence attitude to medication by Weiden et al in 1994. It is a self-reported attitude measurement for assessing reasons for and against adherence to medication. It consists of 20 items: 7 items for reasons of adherence and 13 items for reasons of non-adherence. Inter-rater reliability showed that the ROMI has good reliability ( $Kappa > .60$ ). The reasons for adherence items have a Kappa range from .75 to 1.00 and for the reasons for non-adherence items, the Kappa range is from .63 to 1.0. In terms of validity, this scale uses internal consistency in which the Cronbach alpha ranges from .41 to .57 for adherence reasons items and from .54 to .55 for non-adherence reasons (Sajatovic, Velligan, Weiden, Valenstein, & Ogedegbe, 2010; Welden, Rapkin, Mott, Zygmunt, Goldman, Horvitz-Lennon, et al, 1994).

The Drug Attitude Inventory (DAI) was developed by Hogan et al in 1983. It is a self-reported questionnaire to evaluate the subjective effects of antipsychotic drugs and insight among schizophrenia patients. The items consist of 30 items with true and false answers (+1 and -1). The higher positive total scores indicate positive subjective responses (compliant) and negative scores indicate negative subjective responses (non-compliant). The internal consistency was .93 and test-retest

reliability was .82 (Sajatovic, Velligan, Weiden, Valenstein, & Ogedegbe, 2010; Thompson, Kulkarni, & Sergejew, 2000).

The Medication Adherence Rating Scale (MARS) was developed from the DAI and the MAQ by Thompson in 2000. It assesses both attitude toward medication and medication taking behavior. It consists of 10 items with two answer options: yes and no where a “yes” response does not indicate a positive attitude or behavior for all questions. A response consistent with non-adherence is coded as 0, while a response consistent with adherence is coded as 1. The total score ranges from 0 - 10, with higher score indicating better adherence. The internal consistency of this scale using Cronbach’s alpha was .75 and the test-retest following a two week interval was .72 and at 12 months was .52 (Pomykacz, Mao, Weiss, & Teter, 2007; Sajatovic, Velligan, Weiden, Valenstein, & Ogedegbe, 2010; Thompson, Kulkarni, & Sergejew, 2000).

The Brief Adherence Rating Scale (BARS) is a brief clinician-administered adherence assessment instrument which was developed by Byerly, et al in 2008. It consists of 4 items: 3 questions and an overall visual analog rating scale (VAS) to assess the proportion of doses taken by the patient in the past month (0% – 100%). The internal consistency by using Cronbach alpha was high at .92 and test-retest reliability ranged from .46 to .86. It also showed good sensitivity at 73% and specificity at 71% (Byerly, Thompson, Carmody, Bugno, Erwin, Kashner, & Rush, 2007; Sajatovic, Velligan, Weiden, Valenstein, & Ogedegbe, 2010).

The Morisky Medication Adherence Scale (MMAS) is an eight items self-reported instrument to measure treatment adherence behavior. It was developed by Morisky et al in 1986. Recently, the MMAS has been developed to include eight

items. The 7 items has answers yes (0) and no (1) and 1 item is rated on four points (0 – 4) with a Likert-type rating scale (0 = all the time, 1 = usually, 2 = sometimes, 3 = once in a while, 4 = never/rarely) which is then converted to 0 - 1. The total scale has a range of 0 to 8. The score can be interpreted into three levels: low adherence (< 6), medium adherence (6 to < 8), and high adherence (= 8). The eight-item adherence scale had an alpha reliability of .83 (Morisky, Ang, Krousel-Wood, & Ward, 2008).

In conclusion, the Drug Attitude Inventory (DAI) questionnaire is used in this study to measure attitude toward medication because this questionnaire has high validity and reliability and is also easy to use. There was no measurement regarding medication adherence behavior which is feasible to use in this study, because for objective measurements such as pill counts, this needs to take place at the patient's home by an unannounced and random visit, and electronic monitoring requires expensive devices. In regards to other subjective measurements, the BARS needs to assess the medication taking of the patient in the past month which will take a longer time to measure patient adherence in this study. The MMAS, even though it fits with this study, requires an expensive charge for the use of this questionnaire so will not be used. Therefore, the measurement of the medication adherence behavior will be developed by the researcher based on the literature review.

### **Intervention to Enhance Medication Adherence**

Several strategies were conducted to improve medication adherence among patients with schizophrenia. These strategies were conducted in different

settings, populations, with different teaching strategies, facilitators, content and material of an educational session, duration and also follow-up strategies.

The settings of the studies include the patients in the hospital and in community mental health care. The target population was mostly patients who were diagnosed as schizophrenia patients by using DSM. The age of patients ranged from 18-65 years old. Some studies excluded the patients with co-morbid organic disorders/ disabilities, substance and or alcohol dependency (Anderson, Ford, Robson, Cassis, Rodrigues, & Gray, 2010; Maneekorn, Robson, Gournay, & Gray, 2009). One study also excluded patients who had to travel > 150 km from their home to the hospital, who had no regular contact with their relatives, were pregnant, had an IQ < 80, and also had no remission in the last two years (Pitszel-Walz, Bauml, Bender, Engel, Wagner, & Kissling, 2006).

Some studies involved the family member or caregivers in the intervention (Chan, Yip, Tso, Cheng, & Tame, 2009; Pitszel-Walz, Bauml, Bender, Engel, Wagner, & Kissling, 2006). Moreover, review studies which involved family members showed that patients had significant improvement in positive attitudes toward their medication (Chaiyajana, Sitthimongkol, Yuttatri, & Klainin, 2009), improved in adherence to medication, mental status, and insight into their illness (Chan et al., 2009). These findings were also supported by a meta-analysis study which showed that an educational program which included the family members had better outcomes than if it was given only for the patients (Lincoln, Wilhelm, & Nestoriuc, 2007).

Most of the review studies provided the intervention as an individual or a group base with varied strategies including adherence therapy which combines



cognitive behavior therapy, motivational interviewing, counseling, psychoeducation, patient-tailoring, telephone-based therapy, goal setting, problem-solving, behavioral training, telephone-coaching, instructional videos, group discussion, and a brochure or module. The facilitators of these interventions were mostly nurses, especially psychiatric nurses. One study provided training for the facilitator (Anderson, Ford, Robson, Cassis, Rodrigues, & Gray, 2010). Moreover, based on the literature review from Barkhof, Meijer, Sonnevile, Linszen, and Haan (2012), it was found that the significant effect to improve medication adherence was focusing on the facilitator such as a training case-manager for the nurse and tailoring strategies (Gray, Tilwykes, Edmonds, Leese, & Gournay, 2004; Hudson, Owen, Trush, Armitage, & Thapa, 2008).

Patient's assessment before an education session was needed in order to provide the appropriate content for the educational program which can be knowledge regarding medication, illness, attitudes toward medication, insight, barriers in taking medication and coping strategies (Shon & Park, 2002). Another study also assessed the patient's problems, experience of side effects, beliefs and attitudes toward medication (Maneesokorn, Robson, Gournay, & Gray, 2007).

The content of the educational session varied depending on the strategy of the program. Some studies not only focused on medication management but also combined other topics related to schizophrenia such as knowledge about schizophrenia, causes, symptoms, coping strategies and stress management. There were no studies that clearly mentioned educational standard guidelines for their intervention. However, there are five evidence-based elements to effective adherence intervention which are (1) collaborative working with a service user consistently; (2)

giving of information about the illness and treatment; (3) suited medication regimens-patient; (4) consistent use of motivational interviewing and cognitive behavioral techniques and (5) assessment of patient's beliefs and experiences related to antipsychotic medication (Gray & Robson as cited in Anderson, Ford, Robson, Cassis, Rodrigues, & Gray, 2010). Moreover, most studies which focused on medication adherence had topics which covered an overview of schizophrenia, medication information, side effects of medication, and the management of side effects.

The duration of the studies varied from one month interventions (Pitszel-Walz, Bauml, Bender, Engel, Wagner, & Kissling, 2006) to 12 months (Chan, Yip, Tso, Cheng, & Tame, 2009). In each session, the duration also varied from 15 minutes (Chaiyajan, Sitthimongkol, Yuttatri, & Klainin, 2009) to 90 minutes (Pitszel-Walz et al., 2006). However, most of the studies conducted each session for approximately 60 - 70 minutes.

Most of the studies in medication adherence used follow-up strategies to evaluate and monitor a patient's condition. Most of them used telephone follow-ups (Hudson, Owen, Thrush, Armitage, & Thapa, 2008; Montes, Maurino, Diez, & Saiz-Ruiz, 2010; Shon & Park, 2002) and also face to face follow-up (Maneesokorn, Robson, Gournay, & Gray, 2007). Furthermore, the literature review showed that most of the researches in motivational interviewing were found to have a small significance in enhancing medication adherence because of a lack of monitoring during the intervention (Drymalski & Campbell, 2009).

## **Self-Management with Family Participation Program for Patients with Schizophrenia**

This section presents a review of the concept of self-management, the self-management process, family participation on self-management and the effectiveness of a self-management program.

### **Concept of Self-Management**

Self-management is early developed in chronic illness. Based on Lorig and Holman (2003), the individual has the responsibility for day-to-day management to engage in health promoting activities. The main concept of self-management is the individuals' decision to be active in controlling or managing their illness rather than being controlled by their illness.

Self-management is concerned with encouraging people to be active by being engaged in such activity. Its aims are to promote health and reduce risk, monitor and manage symptoms and signs of illness; manage the impacts of illness on functioning, emotions, and interpersonal relationships; make decisions; be adherent to appropriate treatment which includes following the care plan and medication management; and collaborating with other health care providers in order to gain the best care (Alfred Workforce Development Team as cited in Sterling, Esenwein, Tucker, Fricks, & Druss, 2008). Hibbard, Mahoney, Stock, and Tusler (2007) mentioned that the aims of self-management are to enhance the patient's participation, engagement and activation in positive health behavior by facilitating knowledge, skills and the ability to enhance self-care ability.

Several studies related to self-management have been found in the chronic illness population. Self-management is an individual's ability to manage the symptoms, medication and the consequential condition of the illness such as physical, psychological and life style changes (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002). In their review of relevant literature, Barlow et al. (2002) stated that self-management trains the individual in skills to self-manage their condition. Similarly, other authors mentioned that self-management is an individual's ability in conjunction with the family, community and health care professionals in managing symptoms, treatment, lifestyle changes and psychosocial, cultural and spiritual consequences of having a chronic disease (Richard & Shea, 2011; Wilkinson & Whitehead, 2009).

Based on the National Institute of Mental Health, USA (NIMH, 2008), self-management has become the pillar for the individual with severe mental illness. Sterling, Esenwein, Tucker, Fricks, and Druss (2010) mentioned that self-management for mental illness offers the specific tools to help individuals develop skills and techniques. These aims are to enhance their self-care ability to maintain both physical and mental health. Furthermore, self-management encourages the individuals with mental illness to participate actively in the recovery process which can lead to a sense of wellness.

Based on Kanfer and Gaelick-Buys (1991), the self-management method was defined as a treatment which provides a therapeutic environment and encourages an individual's responsibility for his/her behavior in effort to change his or her current problem situation and deal with his or her chronic disease. Self-management helps individuals to have skills in self-monitoring, to establish specific

rules or a contract with oneself or others, to seek support from the environment for fulfillment, and to self-evaluate and self-reinforce as a consequence for engaging behavior or achieving a goal. According to Ryan and Sawin (2009), self-management programs refer to the interventions that are created by health care providers to prepare the patients in order to manage their illness or to engage in health promotion activities.

The outcomes of self-management programs are associated with the increase of knowledge, use of medications, self-efficacy, self-management behavior, patient's satisfaction, health behavior change, quality of life or well-being and a decrease in health care costs (Richard & Shea, 2011; Ryan & Sawin, 2009).

### **Self-Management Process**

The process of self-management involves self-regulation skills which have several activities including goal setting, self-monitoring and reflective thinking, decision making, planning for engaging in specific behaviors, self-evaluation and management of physical, emotional and cognitive responses related to health behavior change (Ryan & Sawin, 2009). Similarly, this process also includes monitoring perceived health and implementing strategies to manage treatment and medication, safety, symptoms and other consequences of having chronic disease.

According to Kanfer and Gaelick-Buys (1991), there are three processes in self-management: self-monitoring or self-observation, self-evaluation and self-reinforcement. In self-monitoring, an individual carefully observes and pays close attention on his/her behavior. Based on Richard and Shea (2011), self-monitoring means monitoring the symptoms or specific physiological parameters of a

health condition. There are two components of self-monitoring: (1) awareness of body symptoms, sensations, cognitive process and daily activities and (2) information, measurements, and recording (Wilde & Garvin, 2007). Self-evaluation means that the individual compares the information from self-monitoring and performance criteria that he/she should do. The closer the match the more satisfied the individual will feel with his/ herself while a large discrepancy might yield dissatisfaction. The last process is self-reinforcement which means that the individual rewards his/herself for what he/she has done in order to achieve his/her goal. Positive self-reinforcement will result in continuing such behavior (Kanfer & Gaelick-Buys, 1991).

In self-reinforcement, when individuals decide to take action, modify or change a behavior, building a contract is needed in order to facilitate the self-management process. A good contract should have short range goals, details and should be written. There are seven elements which should be provided in the contract including: (1) a clear and detailed description of the required behavior, (2) a time or frequency limitation, (3) positive reinforcement related to the fulfillment, (4) provision for aversive consequences, (5) additional positive reinforcement if the individual can perform more than the minimal demand, (6) being specified, observed, measured and recorded and (7) a time arrangement for reinforcement which is as soon as possible following the responses (Kanfer & Gaelick-Buys, 1991). The term contract by Kanfer and Gaelick-Buys is known as goal-setting and action planning (MacGregor et al., 2006).

Goal-setting and action planning are the agreement of the patient and the health care professional to decide on a concrete behavior change. The patient sets a goal for a desired behavior and the health care professional engages the patient in

discussing an action plan that can help the patient fulfill the goal (MacGregor et al., 2006). The action plan should be short-term, specific and realistic (Lorig & Holman, 2003). The purpose of the action plan is to give the patient confidence in managing his or her disease, confidence that fuels internal motivation (Bodenheimer, Lorig, Holman, & Grumbach, 2006). When, a specific action plan has been chosen by the patient, the health care professional should assess the patient's confidence to achieve the action (self-efficacy). This confidence can be measured on a scale ranging from 0 (totally unconfident) to 10 (totally confident). If the patient's confidence level was less than 7, then there is a need to discuss problem solving to make the plan more realistic and avoid failure (Lorig et al., 2003; MacGregor et al., 2006).

### **Family Participation on Self-Management**

Managing chronic illness is difficult for patients and health care providers. Many of the patients and health care providers feel that family members can be a source of support in chronic illness care. Moreover, the family has the potential to support patient self-management and medical care because of several reasons including (1) family members provide the daily setting for the patient, (2) family members take an active role in self-management and medical care, (3) family members give support in relation to better the patient's self-management and outcomes (Rosland, 2009).

According to Wilkinson and Whitehead (2009), self-management is linked to an individual's ability, in conjunction with the family, community and health care professionals to manage symptoms, treatments, lifestyle changes and psychosocial, cultural and spiritual consequences of having chronic disease.

Therefore, self-management not only requires the individual's ability but also needs conjunction with his/her family to control his or her health condition (Richard & Shea, 2011; Wilkinson & Whitehead, 2009). The patient needs to seek support from the environment to accomplish the self-management task (Kanfer & Gaelick-Buys, 1991). In the patient's self-management, the role of the family is to support by facilitating, reminding and motivating the patient to perform self-management tasks, be a partner in problem solving and decision making and also help the patient to cope with emotional stress because of having chronic illness (Rosland, 2009).

The family can have an active role in the self-management process. In self-monitoring when the patient reflects on his or her current behavior, family members often have detailed and intimate knowledge of how the patient manages his or her disease. In the self-evaluation process when the patient compares his/her behavior and desired behavior, educating on the illness and its management is not only used for the patient but also the family in order to gain better knowledge since they want to have an active role in caring for the patient. In self-reinforcement, the family also can provide support and positive reinforcement after the patient accomplishes the action plan (Rosland, 2009). Moreover, a behavioral contract or action plan can be enhanced if the contract involves commitment from the individual to his/her family (Kanfer & Gaelick-Buys, 1991).

### **Effectiveness of Self-Management Program**

Several studies about self-management among schizophrenia patients have found that it can enhance patients' abilities to cope with their illness. The



patients have skills for managing their symptoms (Buccheri, Trygstad, Buffum, Lyttle, & Dowling, 2010; Buffum et al., 2007; Tsai & Ku, 2005), can promote medication compliance (Hudson, Owen, Thrush, Armitage, & Thapa, 2008; Maneesokorn, Robson, Gourney, & Gray, 2007) and can have skills in emotional management (Norman et al., 2002). Moreover, the patients also have a sense of well-being or quality of life including hopefulness and recovery after following self-management programs (Cook et al., 2010; Salyers, Godfrey, McGuire, Gearhart, Rollins, & Boyle, 2009).

Additionally, a previous study about medication and symptoms management education in psychiatric patients including schizophrenia patients in Korea showed that the intervention has positive outcomes on medication compliance, self-efficacy and less relapse warning signs but did not show a positive outcome on family support. The study concluded that educating the family and the patient to take an active role should be emphasized. Furthermore, educating both of them was very important so that they can identify the patient's own ability in managing the medication (Shon & Park, 2002). Another study also showed that schizophrenia patients reported the need of their family to remind them about their medication. Therefore, in maintaining medication, the role of the family is very important (Kim et al., 2006).

Several studies include family participation in programs among schizophrenia patients (Chan, Yip, Tso, Cheng, & Tame, 2009; Pitszel-Walz, Bauml, Bender, Engel, Wagner, & Kissling, 2006). Moreover, review studies which involved family members had significant improvement for the patients in terms of symptoms, illness management skills, level of functioning, rates of re-hospitalization

(Kapelowicz, Zarate, Smith, Mintz, & Liberman, 2003), improvement in positive attitudes toward medication (Chaiyajan, Sitthimongkol, Yuttatri, & Klainin, 2009), improvement in adherence to medication (Chan et al., 2009; Pitszel-Walz et al., 2006), mental status, and insight into illness (Chan et al., 2009). These findings were also supported by a meta-analysis study which showed that educational programs which involved the family members had better outcome than if it was given only for patients (Lincoln, Wilhelm, & Nestoriuc, 2007).

### **Summary**

In summary, the literature review provides fundamental knowledge for the development of a self-management with family participation program to enhance medication adherence among patients with schizophrenia in Indonesia. Schizophrenia is a mental disorder which is characterized by positive symptoms, negative symptoms and cognitive symptoms. The treatment of schizophrenia can be divided into pharmacological treatment and psychosocial treatment. Adherence to medication is useful for treating schizophrenia to reduce the symptoms and prevent the relapse phase. Several factors including patient-related factors, illness-related factors, treatment-related factors, the health care system and socioeconomic factors contribute to medication adherence among patients with schizophrenia.

From the literature review, several interventions have been found to be able to enhance the medication adherence in schizophrenia including patient tailoring which is actually a part of a self-management intervention. A self-management program can enhance patients' ability to cope with their illness including promoting

medication adherence. Moreover, self-management not only requires an individual's ability but also needs conjunction with his/her family to control his or her health condition. The meta-analysis study showed that educational programs which involved family members had better outcomes than if they were given only for patients to enhance medication adherence. Therefore, it is important to examine the effect of a self-management with family participation program on medication adherence among patients with schizophrenia.

## CHAPTER 3

### RESEARCH METHODOLOGY

This chapter describes the research methodology of this study which covers the following topics: research design, variables, setting, population and sample, sampling procedures, instrumentation, ethical considerations, data collection procedures and data analysis.

#### Research Design

This study was a randomized controlled trial with two groups, pre-test and post-test design aimed to examine the effect of a self-management with family participation program on medication adherence among patients with schizophrenia. The control group received the usual care and the experimental group received the self-management with family participation program. This study design was as

follows:	pre-test	post-test
Control group	O <sub>1a</sub> O <sub>1b</sub>	O <sub>2a</sub> O <sub>2b</sub>
Experimental group	O <sub>3a</sub> O <sub>3b</sub>	X O <sub>4a</sub> O <sub>4b</sub>

Where:

O<sub>1a</sub>, O<sub>3a</sub> refers to the baseline data (pre-test score) of medication adherence behavior

O<sub>1b</sub>, O<sub>3b</sub> refers to the baseline data (pre-test score) of attitude toward medication

X refers to the self-management with family participation program

O<sub>2a</sub>, O<sub>4a</sub> refers to post-test score of medication adherence behavior

O<sub>2b</sub>, O<sub>4b</sub> refers to post-test score of attitude toward medication

## **Variables**

The independent variable in this study was the self-management with family participation program while the dependent variables were medication adherence behavior and attitude toward medication. The factors that might influence dependent variables were controlled by using a statistical approach. Data regarding patient-related factors, illness-related factors, treatment-related factors, the health care system and socioeconomic factors were collected and taken into account for statistical control. In addition, some factors were restricted through the exclusion criteria such as co-morbidity with depression, cognitive impairment and substance use.

## **Setting**

This study was conducted in the patient's home. The patient's data were obtained from the out-patient department (OPD) of the mental health hospital RSJP Prof. dr. Soeroyo Magelang, Indonesia. It is the biggest public mental health hospital and the top referral center in Central Java province. The OPD provides services for new patients and patients after discharge to control their disease. Generally, every month the patients will come to the hospital for follow-up and also renew their prescribed medications. The usual routine services include regular check-ups, taking medication and sometimes unstructured health education is provided by a nurse or physician to respond to the patient's and the family's needs. There are approximately 1,200 patients every month with different mental illness diagnoses but

mostly they are diagnosed with schizophrenia (medical records from OPD of RSJP Prof. dr. Soeroyo Magelang, January - February, 2013).

### **Population and Sample**

The population of this study was patients with schizophrenia. Samples in this study were patients with schizophrenia who attended the OPD in the mental health hospital of RSJP Prof. dr. Soeroyo Magelang, Indonesia during the study period and their family caregivers.

### **Inclusion Criteria**

The inclusion criteria of the samples in this study were patients with; (1) aged 18-60 years old, (2) being diagnosed of schizophrenia, (3) being clinically stable (BPRS < 36), (5) being able to communicate verbally, (6) being able to be contacted by phone, (7) consenting to participate in the study and (8) having a family member or relative who can be involved in the program.

The inclusion criteria of the family member who were; (1) spouse, parent, sibling or other family member, (2) responsible for caring for the patient for at least six months, (3) living together with the patient, (4) being able to communicate verbally and (5) willing to participate in the study.

### **Exclusion Criteria**

The exclusion criteria were (1) patients who developed severe complications that may cause them to be unable to participate in the study, (2) being

hospitalized during the study period, (3) comorbid organic disorder/ disability, (4) comorbid depressive disorder, (5) current substance dependence and (6) cognition problems. During the study period, 79 subjects were assessed for eligibility, 27 patients were unable to participate because of several reasons such as no telephone contact, being in an unstable condition or having comorbid depression, current substance dependence and cognitive problems.

### **Sample Size**

The sample size estimation of the study was based on a previous study (Shon & Park, 2002) which examined the effects of a medication and symptom management program on medication compliance. The effect size calculation of that study was .98. Since this study was conducted individually, involving family members and also using a different conceptual framework, this study used the effect size of .80 as a large effect size to calculate the sample size. Based on Cohen (1988) sample size for a significant level of  $\alpha = .05$ , power = .80 and  $d = 0.80$ , 26 subjects per group were needed. Therefore, 52 subjects were employed in this study. During the study, two subjects were withdrawn from the study; one subject in the control group was re-hospitalized whereas the other in the experimental group did not have permission from the other family member. Totally, 50 subjects completed the study and their data were used in the statistical analysis.

### **Sampling Procedure**

The nurse who works at the OPD introduced the researcher to the eligible subjects. They were approached and the researcher explained the details of the study: purpose, benefits, the program, the right to participate and to withdraw and the confidentiality issue. Subjects who were interested in joining the study provided verbal and written informed consent. The eligible subjects who came on the first day of data collection were assigned either into the experimental or control group by using the block randomization method. It was used to ensure that the sample sizes across groups over time are balanced (Kang, Ragan & Park, 2008). There were 26 subjects assigned into either the experimental or the control group. The randomized block procedure in this study was as follows: (1) a block size of 4 was chosen, (2) possible balanced combinations with 2 C (control) and 2 T (treatment) subjects were calculated as 6 (TTCC, TCTC, TCCT, CTTC, CTCT, CCTT), and (3) blocks were randomly chosen to determine the assignment of all 52 subjects with one random sequence which the results were TCCT / CTTC / CTTC / TCTC / CCTT / TCCT / TCTC / TCTC / TTCC / CTCT / TTCC / TCCT / CTCT. This procedure results in 26 subjects in both the experimental and the control group.

### **Instrumentation**

There were two sets of instruments used in this study namely the self-management with family participation program and data collection instruments including the Demographic Data Questionnaire, the Brief Psychiatric Rating Scale



(BPRS), the Beck Cognitive Insight Scale (BCIS), the Prior Knowledge Medication Questionnaire, the Medication Adherence Behavior Questionnaire and the Drug Attitude Inventory (DAI). Each instrument is described as follows:

### **Self-Management with Family Participation Program**

The self-management with family participation program was a one-month program developed by the researcher to enhance medication adherence behavior and to change the patient's attitude toward medication. This program involved patients and their families to reflect on the patient's behavior regarding medication management, provide educational sessions, evaluate the patient's behavior, assist patients to develop goals and action plans, assist patients to perform self-reinforcement, and to conduct weekly telephone follow-ups and face to face follow-up (Appendix B). The description of the program is as follows:

**The first week intervention.** The intervention was conducted in the patient's home. In this week, the researcher assisted the patient and his or her family to reflect on the patient's current behavior regarding medication adherence by using open-ended questions. An educational and counseling session was given by the researcher based on the patient's condition regarding an overview of schizophrenia, medication information, side effects of medication, and the management of side effects (Appendix C). During this session, the patient and his or her family received a medication management booklet with the topics covering general information of schizophrenia, the importance of medication management, the types of medication, the side effects of medication and the management of side effects and the goal setting and action plan form (Appendix D). Then, the researcher clarified the patient's and

family's understanding/ misperceptions regarding medication adherence based on prior knowledge assessment, medication adherence behavior, and their attitude toward medication.

Then, the researcher assisted the patient and family to conduct self-evaluation by comparing the patient's current behavior and the desired behavior regarding medication and also discussed and identified the problems. The patient and family were asked to identify the patient's current behaviors which needed to be maintained, modified or changed. Then, the researcher assisted the patient and family together to set the patient's goal and action plan to overcome the identified problems and identify rewards for his/her self when achieving his/her goal and action plan. Then, the researcher assessed the patient's confidence in achieving the action by using confidence level from 0 (no confidence at all) to 10 (totally confidence). There were two subjects who had a confidence level less than 7, therefore the researcher discussed their problems/ barriers and discussed the solutions together with the patients and their families. After that, the researcher encouraged the family to remind the patient to follow the written plan to achieve the goal and help problem solve if the patient encountered a problem. At the end of this session, the researcher made a contract with the patient and family about an available time for a telephone follow-up. The duration was 90 minutes.

**The second and the third week intervention.** The researcher conducted a telephone follow-up to evaluate the implementation of the goal and action plan and to facilitate the subject to self-reward based on goal achievement. The researcher also discussed whether the patient could achieve the goal and discussed with the patient and the family to identify factors/ barriers and helped them to find

alternative strategies to overcome them. The researcher also assisted whether the patient wanted to maintain or develop a new goal and action plan. The duration of this session was around 10 - 15 minutes.

**The fourth week intervention.** In the fourth week, the researcher met the patient and family in the patient's home to evaluate the implementation of the goals and action plan by a face to face follow-up. The researcher also discussed whether the patient could achieve the goal and self-reward. Then, the researcher discussed with the patient and family to identify factors/ barriers and helped them to find alternative strategies to overcome them. Then, the researcher also discussed further plans to maintain the medication adherence and made a closing session. The duration for this session was around 30 minutes.

### **Data Collection Instruments**

**Demographic Data Questionnaire (DDQ).** The DDQ was developed by the researcher to obtain the data of the subjects' and clinical characteristics and the family caregivers' characteristics. The subjects' characteristics are age, gender, religion, marital status, educational level, occupation, income, distance from hospital, and type of transportation and clinical characteristics are age of onset, length of illness, number of hospitalizations, type of medication, medication taken, barriers in taking medication and side effect, BPRS score, and insight. The caregivers' characteristics are age, gender, education level, occupation, family relationship and duration of caring (Appendix E).

**Brief Psychiatric Rating Scale (BPRS).** The BPRS was a widely used instrument for assessing the positive, negative and affective symptoms of psychotic

people especially those with schizophrenia. It was developed by Overall and Gorham (as cited in Leucht, Kane, Kissling, Hamann, Etschel, & Engel, 2005). It consists of 18 symptoms, with a score ranging from 1 (not present) to 7 (extremely severe) (Appendix F). The total score was the sum score from 18 items in which a higher total score indicates severe problems. Inter-rater reliabilities for the BPRS between .87 and .97 were reported (Collegium Internationale Psychiatricum Academicum as cited in Leucht et al., 2005).

**Beck Cognitive Insight Scale (BCIS).** The BCIS was used to measure cognitive insight since psychosis patients often have a reduced capacity to reflect rationally on their anomalous experiences and to recognize that their conclusions are incorrect. It is a 15-item self-report instrument with two subscales: 9 items of self-reflectiveness (1, 3, 4, 5, 6, 8, 12, 14, 15) and 6 items of self-certainty (2, 7, 9, 10, 11, 13) (Appendix G). The response was a Likert scale ranging from 0 (do not agree at all) to 3 (agree completely). The total score was the sum of the scores of self-reflectiveness minus the sum of the scores of self-certainty. A lower total score means poorer cognitive insight (Beck as cited in Engh et al., 2007).

**Prior Knowledge regarding Medication Questionnaire.** This questionnaire is used to assess the subject's prior knowledge on medication which includes the effect of medication, side effects and patient's care regarding medication. This questionnaire was developed by the researcher and the result of this questionnaire was used to guide the researcher in designing the content of educational session. The questionnaire consists of 10 items with 7 positive statements and 3 negative statements (2, 4, 8) (Appendix H). The format of this questionnaire is true (1) and false (0) answers. The score of negative statements were reversed. The

possible score ranges from 0 to 10, in which a higher score indicates better prior knowledge.

**Medication Adherence Behavior Questionnaire (MABQ).** The MABQ was used to measure medication adherence behavior which developed by the researcher. It is 10-items with 3 positive statements (1, 9, 10) and 7 negative statements (Appendix I). The answer was rated on a four-point Likert scale (4 = all the time, 3 = usually, 2 = sometimes, 1 = never). The score of negative statements were reversed. The total score ranges from 10 to 40. The higher score indicates higher medication adherence behavior.

**Drug Attitude Inventory (DAI).** The DAI is a self-reported questionnaire to evaluate the subjective affect of antipsychotic drugs among schizophrenia patients. It was developed by Hogan et al (as cited in Sajatovic, Velligan, Weiden, Valenstein, & Ogedegbe, 2010). The internal consistency was .93 and test-retest reliability was .82 (Sajatovic et al., 2010; Thompson, Kulkarni, & Sergejew, 2000). It is a 30- item questionnaire with true and false answers (+1 and -1). The scale has 15 items scored as true (2, 4, 6, 7, 8, 9, 15, 18, 21, 22, 23, 24, 26, 29, 30) and 15 items (1, 3, 5, 10, 11, 12, 13, 14, 16, 17, 19, 20, 25, 27, 28) scored as false (Appendix J). The correct answers were scored as +1 and incorrect answers were scored as -1. The final score was the sum of the total of the pluses and minuses. A positive total score indicates positive subjective responses (compliant). A negative total score means a negative subjective response (non-compliant). The higher positive total score indicates higher compliance and the higher negative total score indicates lower non-compliance.

## **Validity and Reliability of the Instruments**

### **Validity of the Instruments**

The content validity of the instruments including the intervention program, teaching plan and the booklet, the Prior Knowledge regarding Medication Questionnaire and the Medication Adherence Behavior Questionnaire (MABQ) were validated by three experts. They were two experts from the Faculty of Nursing, Prince of Songkla University, and the other expert was from the Indonesia University, Indonesia. They are lecturers in psychiatric nursing. The instruments of the Prior Knowledge regarding Medication Questionnaire and the MABQ had a good content validity index (.90 and 1.00, respectively). The instruments were also revised based on the experts' comments and recommendations. The experts suggested the following: 1) to delete the instruments of Schizophrenia Cognition Rating Scale (SCoRS); 2) to add particular contents in the interventions (i.e. side effects of each antipsychotic medication, medication in fasting time, and antipsychotic injections); and 3) to provide an example in the evaluation record form.

### **Reliability of the Instruments**

The Prior Knowledge regarding Medication Questionnaire, the MABQ and the Indonesian version of the Beck Cognitive Insight Scale (BCIS), and the Drug Attitude Inventory (DAI) were examined for their reliability in 20 patients with schizophrenia. The reliability was tested for internal consistency and stability. The Cronbach's alpha coefficient was used to determine the internal consistency reliability of the BCIS, the MABQ and the DAI questionnaire. For the Prior Knowledge

regarding Medication Questionnaire, Kuder-Richardson formula ( $KR20$ ) was used to determine the internal consistency. The internal consistencies of the Prior Knowledge regarding Medication Questionnaire, BCIS, MABQ, DAI were .36, .67, .70, and .77, respectively. The Intraclass Correlation Coefficient (ICC) reliability (retest after one week) of the instruments of the Prior Knowledge regarding Medication Questionnaire, BCIS, MABQ, DAI yielded results of .69, .74, .79, and .86, respectively.

### **Translation of the Instruments**

The Drug Attitude Inventory (DAI), and the Beck Cognitive Insight Scale (BCIS) were originally developed in the English language. To ensure the equivalence of the content, the instruments were translated using the back-translation technique (Hilton & Skrutkowski, 2002). The instrument was translated from the original English version to an Indonesian version for conceptual equivalence across the languages by using three translators. The first translator translated the original English version to an Indonesian version and the second translator translated back from the Indonesian version to an English version. Then, the third translator compared both the English versions and discussed the discrepancies. The discrepancies between the two versions were found on the DAI questionnaire: item no 8 “my own free choice” and item no 14 “slow-acting poisons”. Based on the discussion from the experts, the researcher revised the Indonesian version and the discrepancies were resolved.

## **Pilot Study**

The pilot study is a small-scale version as a trial or preparation before the major study. The purpose of a pilot study is to test the feasibility of the studies (Polit & Beck, 2008). The pilot study was done with 12 subjects (six patients and their families in the experimental group and six patients and their families in the control group) who met the inclusion criteria. The subjects in the experimental group received one-month of the self-management and family participation intervention, with two telephone follow-ups and one face to face follow-up session.

The researcher also collected the data before and after implementing the program. The results showed that the subjects receiving self-management with family participation reported significant improvement in medication adherence behavior ( $Z = -2.48, p = .01$ ) and positive attitude toward medication ( $Z = -2.21, p = .02$ ) compared to those receiving the usual care. This result showed that the self-management with family participation program can work and have a significant effect on patients with schizophrenia.

Generally, the program was applicable in this study. There was no problem in understanding and applying the intervention as well as the booklet. However, the difficulties were found in terms of patient's concentration and telephone follow-up. During the education and counseling session, some patients had a lack of concentration especially when the family was dominant in the discussion. Therefore, the researcher needed to motivate the patients during the discussion. During the telephone follow-up when the researcher evaluated the goal and action plan some patients did not write in the evaluation form. Therefore, the researcher's notes were important during the telephone follow-up.



## **Data Collection Procedures**

There were two phases of data collection; preparation phase and implementation phase.

### **Preparation Phase**

In the preparation phase, the researcher did the following steps:

1) obtained research approval from the Faculty of Nursing, Prince of Songkla University; 2) obtained official permission from the psychiatric hospital Prof. dr. Soerojo Magelang; 3) prepared the education session material, the questionnaire package and an informed consent form, 4) recruited two research assistants who had experience in psychiatric practice, 5) trained the research assistants and 6) conducted a pilot study.

In this study, the researcher employed two research assistants (RAs) who were responsible for data collection. They collected pre and post-test data. They explained to the subjects how to properly fill in the questionnaire. There were three steps for the RAs' training. Firstly, the researcher explained the objective, protocol, their role and responsibility for collecting data. Secondly, the researcher explained the instruments used in the study and reviewed each item in the instruments with the RAs and also discussed and clarified any unclear matters. Lastly, the researcher trained them to collect the data during the pilot study both in the OPD and in the community (patient's home) and also discussed and clarified any problems.

### **Implementation Phase**

The researcher and the research assistants worked collaboratively to collect the data both in the OPD and in the patient's home. The eligible subjects were approached and asked about their interest and willingness to participate in this study in the OPD. The signed or verbal informed consent was provided if the subjects agreed to participate in this study. Then, the subjects were introduced to the RAs to complete the pre-test questionnaire (DDQ, BCIS, Prior Knowledge Medication Questionnaire, Medication Adherence Behavior Questionnaire and Drug Attitude Inventory) and that took around 15 – 20 minutes depending on the patients' capability. Some patients who had not completed the questionnaire in OPD asked permission to complete it at their home. The reasons for them not being able to complete the questionnaire were time limitation, having a headache or feeling uncomfortable with the OPD situation. The subjects were assigned into either the experimental or the control group by the block randomization method. In addition, they were asked about their time for a home visit. Next, the subjects in the experimental group received the self-management with family participation program that lasted around 90 minutes in their home, two telephone follow-ups and a face to face follow-up. In the fourth week, the researcher conducted a face to face follow-up in the patient's home to evaluate his or her goal and action plan and also discussed further plans in taking medication. Finally, the patients were asked to complete the post-test questionnaire (the Medication Adherence Behavior Questionnaire and Drug Attitude Inventory).

The data of the subjects in the control group were collected similarly with the subjects in the experimental group. However, after completing the pre-test

questionnaire, they were told that the researcher would come to their home after the fourth week. In this week, the subjects were asked to complete the post-test questionnaire and received the educational and counseling session as well as a booklet.

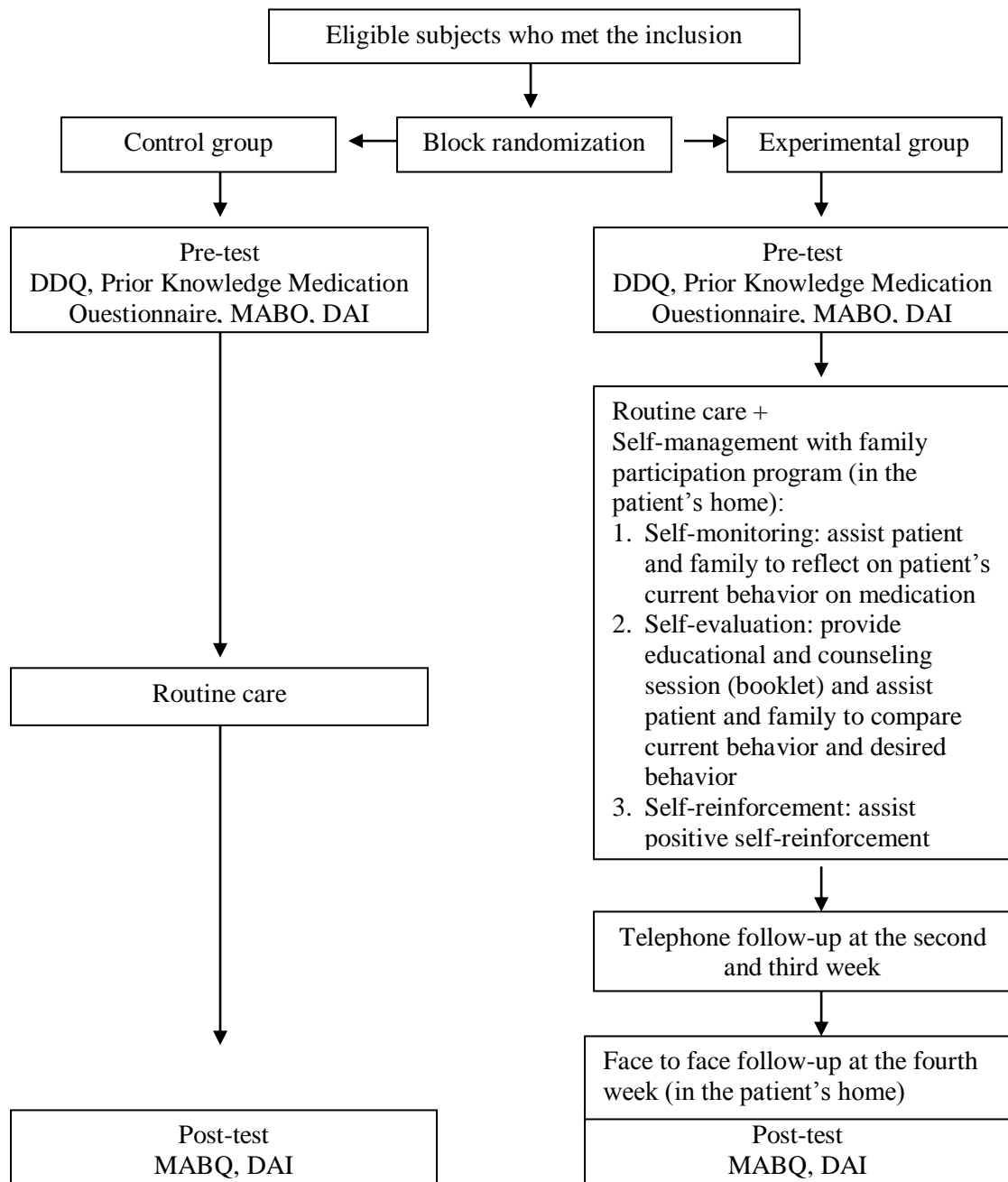


Figure 2. The implementation phase of the data collection procedures

### **Ethical Considerations**

In respect to the human rights of the participants of this study, the data was collected after obtaining approval from the Ethics Committee of the Faculty of Nursing, Prince of Songkla University and permission was obtained from the psychiatric hospital Prof. dr. Soerojo Magelang. The researcher explained clearly about the purpose of the study, the procedure, the possible benefits and risks of the study to the participants (Appendix A). They were informed that they had the right to choose whether to participate or not in the study and they could withdraw at any time during the study even after they had signed the consent form and had agreed to participate in the study. The researcher explained in Indonesian language. Agreement to participate was marked verbally. Then participants were asked to sign the informed consent and returned it to the researcher. Moreover, the subjects in the control group were put on a waiting list. The researcher gave the education and counseling session for all subjects in the control group regarding their prior knowledge, medication adherence behavior and attitude toward medication as well as giving a booklet to them after the study period.

### **Data Analysis**

Data were analyzed using descriptive statistics and inferential statistics. The subjects' characteristics, clinical information and caregivers' characteristics were described using frequency, percentage, mean, standard deviation as well as median and quartile deviation for data that was not normally distributed.

The Chi-square, Fisher's exact test, and Likelihood Ratio were used to examine the comparison of the equivalence of the proportion of the demographic data between the experimental group and the control group.

The researcher examined the assumption of the normality distribution which is determined by kurtosis and skewness value less than  $\pm 3$  as an accepted value for the normality distribution and examined the assumption of homogeneity of variance which is determined by the non-significance of the Levene's test of the data sets. The independent t-test was used to detect the significant differences for patient's age, age of onset, BPRS, BCIS and caregiver's age while Mann-Whitney U test was used to detect the significant differences for distance, length of illness, and duration of caring.

The prior knowledge of medication and pre-test and post-test medication adherence behavior and pre-test attitude toward medication data of both the experimental and the control groups met these assumptions. The dependent t-test was employed to test the mean differences of pre-test and post-test of medication adherence behavior and attitude toward medication within the experimental group. The independent t-test was employed to test the mean differences of the data for prior knowledge medication, pre-test and post-test medication adherence behavior and pre-test attitude toward medication between the experimental and the control groups as well as the mean difference between the pre-test and post-test of medication adherence behavior. The Mann-Whitney U test was used to detect the significant differences for the mean rank difference between the pre-test and post-test data of attitude toward medication because the data was not normally distributed. The data of the post-test attitude toward medication was distributed normally but did not meet the

assumption of homogeneity of variance. Therefore, the  $F_{\max}$  statistic was used instead of Levene's test by using the maximum variance divided by the smallest variance.

The  $F_{\max}$  value yielded 4.39 which can be an accepted value to use parametric statistic with a reduction in the level of significance of  $p < .01$  (Keppel, 1991).

## **CHAPTER 4**

### **RESULTS AND DISCUSSION**

This chapter presents the results and discussion of the study's findings. The subjects' characteristics and clinical characteristics are described, followed by the caregivers' characteristics. The differences in the data in the experimental group and the control group are illustrated as well as the effect of a self-management with family participation.

#### **Results**

##### **Subjects' Characteristics**

The mean ages of the subjects in the experimental and the control group were 32.20 years ( $SD = 8.68$ ) and 35.52 years ( $SD = 8.05$ ), respectively. Most of the subjects in both groups were male and Moslem. Half of the subjects in the experimental group (48%) had junior high school education and one-third of the subjects in the control group had elementary school (32%) and senior high school (36%) education. More than half of the subjects in both groups were single. The subjects in the experimental and the control group were employed (64% and 60%, respectively). More than half of the subjects in both groups did have an income but they felt their income was sufficient. More than half of the subjects in the experimental group (52%) used private transportation whereas subjects in the control group (60%) used public transportation to go to the psychiatric hospital. Table 3

showed that there were no significant differences in the subjects' characteristics between both groups.

Table 3

*Frequencies and Percentages of Subjects' Characteristics of the Experimental Group and the Control Group (N = 50)*

Patient's characteristics	Experimental group (n = 25)		Control group (n = 25)		Statistics	p
	n	%	n	%		
Age	M (SD) 32.20 (8.68)		M (SD) 35.52 (8.05)		-0.98 <sup>a</sup>	.33
Gender						
Male	18	72	15	60	0.80 <sup>b</sup>	.37
Female	7	28	10	40		
Religion						
Islam	25	100	24	96	1.02 <sup>c</sup>	1.00
Christian			1	4		
Level of education						
Elementary school	6	24	8	32	5.44 <sup>d</sup>	.15
Junior high school	12	48	7	28		
Senior high school	7	28	8	32		
Bachelor/ higher			2	8		
Marital status						
Single	17	68	14	56	2.22 <sup>d</sup>	.53
Married	6	24	6	24		
Widowed	1	4	4	16		
Separated	1	4	1	4		
Occupation						
No occupation	9	36	10	40	0.57 <sup>d</sup>	.97
Had occupation	16	64	15	60		
- Private employee	8	50.00	7	46.67		
- House wife	2	12.50	2	13.33		
- Farmer	4	25.00	5	33.33		
- Other	2	12.50	1	6.67		
Income (IDR)						
None	13	52	13	52	1.43 <sup>d</sup>	.70
< 500.000	1	4	0	0		
500.000 - 1.000.000	10	40	11	44		
>1.000.000	1	4	1	4		



Table 3 (continued)

Patient's characteristics	Experimental group ( <i>n</i> = 25)		Control group ( <i>n</i> = 25)		Statistics	<i>p</i>
	<i>n</i>	%	<i>n</i>	%		
Income sufficient						
Enough	15	60	15	60	0.00 <sup>b</sup>	1.00
Not enough	10	40	10	40		
Distance from hospital	<i>M (SD)</i>		<i>M (SD)</i>		-1.00 <sup>e</sup>	.32
	26.78 (29.42)		28.58 (16.83)			
	<i>Mdn (QD)</i>		<i>Mdn (QD)</i>			
	19.40 (5.40)		28.20 (14.55)			
Transportation						
Public	12	48	15	60	0.73 <sup>b</sup>	.40
Private	13	52	10	40		

*Note.* <sup>a</sup> = Independent t-test, <sup>b</sup> = Chi-square, <sup>c</sup> = Fisher's exact test, <sup>d</sup> = Likelihood Ratio, <sup>e</sup> = Mann-Whitney U test, *M* = Mean, *SD* = Standard Deviation, *Mdn* = Median, *QD* = Quartile Deviation.

### Clinical Characteristics

Eight clinical characteristics were examined and there were no significant differences between the experimental group and the control group, except for barriers in taking medication (Table 4). The mean age of disease onset of the subjects in the experimental and the control group were 24.08 years (*SD* = 7.02) and 25.96 years (*SD* = 7.37), respectively. The length of time being diagnosed with schizophrenia of the subjects in both groups was around 9 years with around two times of hospitalization. Most of the subjects in the experimental group (68%) and control group (88%) received typical or traditional antipsychotics.

Regarding barriers in taking medication, the majority of the subjects reported having memory problems (72% in the experimental group and 64% in the control group). The subjects in the experimental group reported forgetfulness as the most frequent barrier in taking medication followed by the side effects of

antipsychotic medications, and the distance to travel to the hospital. Additionally, the barrier in taking medication: perceived as a far distance to travel to hospital was significantly different between the two groups ( $p = .02$ ). More than half of the subjects in both groups had drowsiness as the most common side effects of antipsychotic medication followed by weight gain, headaches and dry mouth. Additionally, the mean of BPRS score and insight (BCIS) score of the subjects in the experimental group and the control group were not significantly different.

Table 4

*Frequencies and Percentages of Subjects' Clinical Characteristics of the Experimental Group and the Control Group (N = 50)*

Patient's information	Experimental group (n = 25)		Control group (n = 25)		Statistics	p
	n	%	n	%		
Age of onset	M (SD) 24.08 (7.02)		M (SD) 25.96 (7.37)		-0.93 <sup>a</sup>	.36
Length of illness	M (SD) 9.04 (6.48) Mdn (QD) 8.00 (4.75)		M (SD) 9.44 (7.50) Mdn (QD) 8.00 (3.75)		-0.06 <sup>b</sup>	.95
Number of hospitalizations	M (SD) 2.12 (1.79)		M (SD) 2.32 (1.84)		-0.39 <sup>a</sup>	.70
Type of medications						
1. Typical antipsychotics	17	68	22	88	4.16 <sup>c</sup>	.25
2. Atypical antipsychotics	4	16	1	4		
3. Typical + Amitriptyline	3	12	2	8		
4. Atypical + Amitriptyline	1	4	0	0		

Table 4 (continued)

Patient's information	Experimental group ( <i>n</i> = 25)		Control group ( <i>n</i> = 25)		Statistics	<i>p</i>
	<i>n</i>	%	<i>n</i>	%		
<b>Barriers in taking medication</b>						
1. Memory	18	72	16	64	0.37 <sup>d</sup>	.54
2. Problem with side effects	11	44	5	20	3.31 <sup>d</sup>	.07
3. Afraid	2	8	2	8	0.00 <sup>e</sup>	1.00
4. Distance from hospital	4	16	12	48	5.88 <sup>d</sup>	.02
5. Budgets	5	20	9	36	0.94 <sup>d</sup>	.33
6. Lack of support	3	8	8	36	2.90 <sup>d</sup>	.09
7. Bored	0	0	1	4	0.00 <sup>e</sup>	1.00
8. Feel better	1	4	1	4	1.02 <sup>e</sup>	1.00
<b>Problems/side effects</b>						
1. None	0	0	2	8	2.08 <sup>e</sup>	.49
2. Drowsiness	17	68	18	72	0.10 <sup>d</sup>	.76
3. Insomnia	1	4	2	8	0.36 <sup>e</sup>	1.00
4. Headache	10	40	10	40	0.00 <sup>d</sup>	1.00
5. Dry mouth	8	32	12	48	1.33 <sup>e</sup>	.25
6. Nausea	6	24	8	32	0.40 <sup>d</sup>	.53
7. Weight gain	14	56	17	68	0.76 <sup>d</sup>	.38
8. Diarrhea	3	12	3	12	0.00 <sup>e</sup>	1.00
9. Movement problem	4	16	3	12	0.17 <sup>e</sup>	1.00
10. Spasm	2	8	3	12	0.22 <sup>e</sup>	1.00
11. Fatigue	11	44	5	20	3.31 <sup>d</sup>	.07
12. Salivation	5	20	5	20	0.00 <sup>d</sup>	1.00
BPRS	<i>M (SD)</i> 20.80 (1.76)		<i>M (SD)</i> 20.68 (2.08)		0.22 <sup>a</sup>	.83
BCIS	<i>M (SD)</i> 5.32 (4.36)		<i>M (SD)</i> 6.68 (3.77)		-1.32 <sup>a</sup>	.19

*Note.* <sup>a</sup> = Independent t-test, <sup>b</sup> = Mann-Whitney U test, <sup>c</sup> = Likelihood Ratio, <sup>d</sup> = Chi-square, <sup>e</sup> = Fisher's exact test, *M* = Mean, *SD* = Standard Deviation, *Mdn* = Median, *QD* = Quartile Deviation, BPRS = Brief Psychiatric Rating Scale, BCIS = Beck Cognitive Insight Scale.

### Caregivers' Characteristics

Caregivers' characteristics are presented in Table 5. The mean ages of the caregivers in the experimental group and the control group were 45.96 years ( $SD = 12.36$ ) and 48.68 years ( $SD = 11.89$ ), respectively. Most of caregivers in both groups were female. More than half of the caregivers in both groups worked as private employees. The majority of the caregivers in both groups had studied to the level of elementary school. More than half of them, 56% in the experimental group and 60% in the control group were the patient's parent. In addition, the duration of caring for the patients in both groups was around 8 years. All caregivers' characteristics between the two groups showed no significant difference.

Table 5

*Frequencies and Percentages of Caregivers' Characteristics of the Experimental Group and the Control Group (N = 50)*

Caregiver's information	Experimental group (n = 25)		Control group (n = 25)		Statistics	p
	n	%	n	%		
Age	M (SD) 45.96 (12.36)		M (SD) 48.68 (11.89)		-0.79 <sup>a</sup>	.43
Gender						
Male	10	40	7	28	0.80 <sup>b</sup>	.37
Female	15	60	18	72		
Occupation						
None	0	0	1	4	6.23 <sup>c</sup>	.29
Government employee	1	4	2	8		
Private employee	15	60	13	52		
House wife	5	20	2	8		
Farmer	3	12	7	28		
Other	1	4	0	0		
Level of education						
None	2	8	1	4	4.23 <sup>c</sup>	.38
Elementary school	10	40	16	64		
Junior high school	5	20	3	12		

Table 5 (continued)

Caregiver's information	Experimental group ( <i>n</i> = 25)		Control group ( <i>n</i> = 25)		Statistics	<i>p</i>
	<i>n</i>	%	<i>n</i>	%		
Senior high school	7	28	3	12		
Bachelor/higher	1	4	2	8		
Family relationship						
Spouse	3	12	5	20	1.28 <sup>c</sup>	.73
Parent	14	56	15	60		
Sibling	6	24	4	16		
Other family member	2	8	1	4		
Duration of caring	<i>M</i> ( <i>SD</i> )		<i>M</i> ( <i>SD</i> )		-0.30 <sup>d</sup>	.76
	8.40 (5.49)		8.00 (5.10)			
	<i>Mdn</i> ( <i>QD</i> )		<i>Mdn</i> ( <i>QD</i> )			
	8.00 (4.75)		8.00 (3.00)			

Note. <sup>a</sup> = Independent t-test, <sup>b</sup> = Chi-square, <sup>c</sup> = Likelihood Ratio, <sup>d</sup> = Mann-Whitney U test.

### **Prior Knowledge regarding Medication, Medication Adherence Behaviors and Attitude toward Medication at the Baseline**

At the baseline, there were no significant differences of prior knowledge regarding medication, medication adherence behavior and attitude toward medication between the experimental and the control group (Table 6). The mean score of prior knowledge regarding medication in the experimental group and the control group were 6.28 (*SD* = 1.31) and 6.56 (*SD* = 1.12), respectively. The mean for pre-test score of medication adherence behavior in the experimental group was 30.08 (*SD* = 4.02) and 31.88 (*SD* = 3.30) in the control group. Additionally, the mean for pre-test score of attitude toward medication in the experimental group and the control group were 15.44 (*SD* = 7.20) and 16.00 (*SD* = 7.64), respectively. Independent t-test showed that there were no significant differences between the experimental group and the control group.

Table 6

*Comparison of the Knowledge regarding Medication, the Pre-test Scores of Medication Adherence Behavior and Attitude toward Medication between Two Groups (N=50)*

	Experimental group ( <i>n</i> = 25)	Control group ( <i>n</i> = 25)	<i>t</i>	<i>p</i>
	<i>M</i> ( <i>SD</i> )	<i>M</i> ( <i>SD</i> )		
Prior knowledge regarding medication	6.28 (1.31)	6.56 (1.12)	-0.81	.42
Medication adherence behavior	30.08 (4.02)	31.88 (3.30)	-1.73	.09
Attitude toward medication	15.44 (7.20)	16.00 (7.64)	-0.27	.79

### **The Effect of a Self-Management with Family Participation Program**

#### **Medication adherence behavior and attitude toward medication**

**comparing within the experimental group.** The mean of the medication adherence behavior pre-test and post-test scores in the experimental group were 30.08 (*SD* = 4.02) and 37.24 (*SD* = 2.70), respectively (Table 7). Additionally, the mean of the attitude toward medication pre-test and post-test scores in the experimental group were 15.44 (*SD* = 7.20) and 21.52 (*SD* = 4.09), respectively. The dependent t-test showed that the mean of post-test score of medication adherence behavior and attitude toward medication of the subjects in the experimental group were significantly higher than the mean of pre-test score ( $t = -7.76, p < .01$  and  $t = -3.78, p < .01$ ). This result completely supported hypothesis 1.

Table 7

*Comparison of the Pre-test and Post-test Scores of Medication Adherence Behavior and Attitude toward Medication within the Experimental Group (n = 25)*

	Experimental group (n = 25)		t	p
	M (SD)			
Medication adherence behavior				
Pre-test	30.08 (4.02)		-7.76	.00
Post-test	37.24 (2.70)			
Attitude toward medication				
Pre-test	15.44 (7.20)		-3.78	.00
Post-test	21.52 (4.09)			

### Medication adherence behavior and attitude toward medication

**comparing between groups.** In order to examine the effect of the self-management with family participation program, the pre-test and post-test scores of medication adherence behavior and attitude toward medication were examined by using independent t-test (Table 8). The mean of post-test score of medication adherence behavior and attitude toward medication in the experimental group were significantly higher than the medication adherence behavior ( $t = 6.08, p < .01$ ) and attitude toward medication ( $t = 3.05, p < .01$ ) in the control group.

Table 8

*Comparison of the Post-test Scores of Medication Adherence Behavior and Attitude toward Medication between Two Groups (N = 50)*

	Experimental group	Control group	t	p
	(n = 25)	(n = 25)		
	M (SD)	M (SD)		
Medication adherence behavior				
Post-test	37.24 (2.70)	31.96 (3.40)	6.08	.00
Attitude toward medication				
Post-test	21.52 (4.09)	15.76 (8.51)	3.05	.00

Additionally, the mean difference between the pre-test and post-test scores of the medication adherence behavior and the mean rank differences of attitude toward medication was examined (Table 9). The mean difference of medication adherence behavior and the mean rank difference of attitude toward medication in the experimental group were significantly higher than the medication adherence behavior ( $t = 6.35, p < .01$ ) and attitude toward medication ( $U = 147.5, p < .01$ ) in the control group.

Table 9

*Comparison of the Mean Difference of Medication Adherence Behavior and the Mean Rank Difference of Attitude toward Medication between Two Groups (N = 50)*

	Experimental group (n = 25)			Control group (n = 25)			Statistics	p
	M (SD)	MR	SR	M (SD)	MR	SR		
Medication adherence behavior	7.16 (4.62)			0.08 (3.12)			6.35 <sup>a</sup>	.00
Attitude toward medication		32.10	802.50	18.90	472.50		147.50 <sup>b</sup>	.00

Note. <sup>a</sup> = Independent t-test, <sup>b</sup> = Mann-Whitney U test, MR = Mean Rank, SR = Sum of Rank



## Discussion

Discussion of the study consists of subjects' characteristic, caregivers' characteristics and the effect of a self-management with family participation program.

### Subjects' Characteristics

There were no significant differences in the demographic characteristics between the experimental group and the control group. The average age of the patients in both groups was around 30 years which is similar to a previous study in Indonesia conducted by Rafiyah (2011). Some studies found that older ages were more likely to adhere to medication (McCann, Boardman, Clark, & Lu, 2008; Novick, Haro, Suarez, Perez, Dittmann, & Haddad, 2010). The majority of subjects were male. The evidence showed that males have 30% to 40% higher lifetime risk of developing schizophrenia (Aleman as cited in Messias, Chen, & Eaton, 2007). Moreover, a review study revealed that the male to female rate ratio of schizophrenia estimated to be 1.4 : 1 (McGrath, 2005). Similarly, previous studies in Indonesia and other countries also found that the majority of patients were male (Adewuya et al., 2009; Dassa, Boyer, Benoit, Bourcet, Raymondet, & Bottai, 2010; Novick et al., 2011; Rafiyah, 2011). Most of the subjects were Muslim, and one subject was Christian which is similar to the general population in Indonesia in that Muslim is the biggest sector of the total population. More than half of the subjects in both groups had lower education levels (elementary and junior high school). In Indonesia, the minimum education level is junior high school level. Patients with higher education levels are expected to have better knowledge about disease therapy which can

influence more adherent to medication (Jin, Sklar, Edward, Sen Oh, & Li, 2008). The majority of subjects in both groups did not report having an income. Some studies revealed that patients with a low income were more likely to be non-adherent (Adewuya et al., 2009; Robinson, Woerner, Alvir, Bilder, Hinrichsen, & Lieberman, 2002).

There were no significant differences between the experimental and the control groups, except in barriers in taking medication. The mean onset of the subjects in both groups was more than 24 years which was longer than the usual onset of schizophrenia in the population. The average number of hospitalization times was 2 times during the illness. Most of the subjects in both groups used typical antipsychotics. Study has shown that patients who used typical antipsychotic drug were more likely to be non-adherent to medication (Dassa, Boyer, Benoit, Bourcet, Raymondet, & Bottai, 2010). It is well-known that typical antipsychotic drugs have more negative side effects than atypical antipsychotic drugs. In this study, most of the subjects in both groups experience drowsiness and weight gain as the common side effects. The subjects who suffered from uncomfortable side effects are most likely to be non-adherent to medication. There was a significant difference between the two groups on problems in taking medication: the distance from a subject's home to the hospital which may have influenced the results of this study.

### **Caregivers' Characteristics**

More than half of the caregivers in both groups were parents and female. This finding is similar with the previous studies conducted by Rafiyah (2011) and Chan, Yip, Tso, Cheng, and Tame (2009) which found that most caregivers of

schizophrenia patients were mothers. Considering the cultural context, a mother's responsibility is the household tasks and to care for both the home and children. Both groups also had a duration of caring of around 8 years. All caregivers' characteristics between the two groups showed no significant differences.

### **The Effect of a Self-Management with Family Participation Program**

Self-management is an individual's ability to manage his or her symptoms, medication and the consequences of the condition of his or her illness which is in conjunction with the family, community and health care professionals (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002; Richard & Shea, 2011; Wilkinson & Whitehead, 2009). The self-management program is associated with many outcomes, such as an increased use of medications, self-efficacy, self-management behavior, and enhancing health behavior change (Richard & Shea, 2011; Ryan & Sawin, 2009). The present study revealed that the subjects receiving self-management with family participation had higher levels of medication adherence behavior and attitude toward medication than subjects in the control group. There are several reasons underpinning the positive outcomes of this study.

A self-management method was used in this study which involves three processes: self-monitoring or self-observation, self-evaluation and self-reinforcement. In this study, patients were assisted in these processes. In self-monitoring, the patient and family were asked to share and reflect on the patient's behavior in taking medication. Self-evaluation was done by giving education and counseling session based on the patient's condition for both the patient and his or her family and they were assisted to decide whether the patient's current behavior was

congruent with the ideal behavior or not. In self-reinforcement, the patient was assisted to make self-rewards if he/she can change his/her behavior. During the program, patients and families were active to share their experiences and also active in the discussion. All of these processes were based on the self-management method (Kanfer & Gaelick-Buys, 1991). Using this method, the subjects had active involvement in their medication taking.

This study used a patient-tailoring strategy in the intervention. Similar to the self-management method, the patients discussed actively regarding their experiences and barriers in taking medication as well as strategies to overcome the barriers. In this study, the barriers which were commonly found in the patients were listed in the questionnaire and also discussed in the first week of the intervention. The result showed that the patients' common problems in taking medication in the experimental group were memory problems followed by the side effects of antipsychotic medication.

Actually, self-tailoring is based on the principles of learning for behavior changes and self-management skills as well as decision-making and problem solving skills which is part of a self-management program (Lorig & Holman, 2003). Using this strategy, the patients were allowed to discuss their problems in medication taking. The patients in this study reported that they sometimes forgot to take their medication especially the time and the dose. Therefore, the researcher facilitated the patients to solve this problem by giving them strategies for remembering to take their medication and letting them choose their preference. Most of the patients selected the strategy of setting the time, for example, taking morning medication at 8.00 am or

after breakfast time and also asking their family to remind them (the time and the dose).

In the present study, the patients also reported drowsiness and weight gain as side effects of antipsychotic medication. The patients were given education related to the management of side effects. Hence, the patients could understand that the drug can reduce their symptoms but at the same time resulting in side effects. They selected the strategies to overcome these side effects by doing such activities to reduce their sleeping time and controlling their food intake. These kinds of strategy could enhance the patients' medication adherence. The findings in this study were consistent with previous studies which found that a patient-tailoring strategy can enhance medication compliance in schizophrenia patients (Barkhof, Meijer, Sonnevile, Linszen, & Haan, 2012; Hudson, Owen, Trush, Armitage, & Thapa, 2008).

The researcher and subject's relationship can contribute to medication adherence. In this study, the researcher acted as a facilitator who gave information to the patients and their family. During the intervention, the subjects had a facilitator who could evaluate their progress, their barriers and gave additional information if needed. Culturally, in Asia, patients and their families have more respect for professional health care providers (nurses) especially when the health care providers show concern in their conditions. This program was conducted at the patient's home which can strengthen the relationship between the researcher and subjects. Therefore, this condition can improve the subject's motivation to perform the behaviors and achieve the goal like the health care provider expects. Exchanging information between the researcher as a health care provider and the patients can initiate the

difference between the patients' initial perceptions and reference values which in turn can develop medication adherence (Laventhal as cited in Rungruangsiripan, Sitthimongkol, Maneesriwongul, Talley, & Vorapongsathorn, 2011).

This present study involved the family in the intervention (family participation) since the family can encourage and facilitate the patients in medication taking. During the program, the family gave support to the patient to perform self-management tasks. The family took an active role in self-monitoring by giving additional information regarding the patient's behavior in taking medication. In the self-evaluation, they also took part in helping the patient to identify the patient's problems and as a partner for patients in helping to make decisions and problem solve. Additionally, most of the patients reported that they received encouragement and facilitation from their family by reminding, motivating and helping them in taking medication. Moreover, during the intervention, the family were also involved and worked as a partner with the patient in making a behavioral contract or action plan which can enhance the commitment from an individual to his/her family to perform the goal and action plan. The results of this study were consistent with previous studies involving the family member or a patient's care giver in the intervention which had a significant improvement in positive attitudes toward medication (Chaiyajan, Sitthimongkol, Yuttatri, & Klainin, 2009) and improved adherence to medication (Adewuya et al., 2009; Chan, Yip, Tso, Cheng, & Tame, 2009, Kim et al., 2008).

Patient's assessments during the program were also employed in this study such as prior knowledge of medication, barriers in taking medication, perceived side effects of antipsychotic medication and attitude toward medication. This

information was needed before the education and counseling session in order to provide appropriate content for the educational and counseling program. There were eight problems reported by the subjects in this study: memory problems, perceived side effects of antipsychotic medication, fear, the travelling distance to the hospital, budget, lack of support, boredom and feeling better. These problems and strategies to overcome the barriers were discussed. During this study, some subjects reported difficulty to get health insurance (JAMKESMAS) and the long distance to travel from their home to the hospital. The researcher discussed with the subjects how to process health insurance and how to get antipsychotic medication from near their homes since some of them did not know that they can get the medication from the community health center as well.

Moreover, this study also identified the side effects of antipsychotic medication perceived by schizophrenia patients such as drowsiness, weight gain, headaches, fatigue, dry mouth, nausea, movement problems, diarrhea, spasms, and insomnia which were also discussed during the intervention. This study had a similar strategy with previous studies conducted by Shon and Park (2002) which assessed prior knowledge of medication to guide the content of the program as well as the assessment of illness, attitude and the problems. Similarly, the study conducted by Maneesokorn, Robson, Gournay, and Gray (2007) also assessed patient problems, experience of side effects, beliefs & attitude toward medication. This finding of this study supported the previous study that patients' assessment can increase medication adherence (Hudson, Owen, Trush, Armitage, & Thapa, 2008; Shon & Park, 2002) and attitude toward medication (Maneesokorn et al., 2007).

Giving education about disease and treatment was also included in this study since it is one of the important factors in medication adherence. This study provide an educational and discussion session regarding disease and medication for both the patients and their family. During the program, the knowledge about illness and medication may help the patients and their families to understand how medication can control the symptoms and behaviors, thus, changing their attitudes and improving their adherence to medication. These findings are consistent with other studies providing a psychoeducation intervention which showed a significant effect on medication adherence (Chan, Yip, Tso, Cheng, & Tame, 2009; Pitszel-Walz, Bauml, Bender, Engel, Wagner, & Kissling, 2006, Shon & Park, 2002).

In addition, this study also provided a booklet which contains information regarding illness and antipsychotic medication for schizophrenia patients so the patients and their families can understand more about the patient's illness and medication as well as how to manage the side effects of antipsychotics. Providing the booklet allowed the patients and their families to re-read the information to remind and strengthen the knowledge gained after the education and counseling session. A previous study also reported that this strategy can enhance medication management skills for patients (Kapelowicz, Zarate, Smith, Mintz, & Liberman, 2003).

Follow-up sessions by a phone call and face to face follow-up is also one important method for achieving the outcome. The researcher evaluated the implementation of goals, action planning and self-reward by a phone call follow-up in the second and third week and a face to face follow-up in the fourth week. The researcher also discussed any factors/ barriers each week and helped the subject to find alternative strategies to overcome a patient's problems as well as motivating



patients to achieve their goal on medication adherence. The result of the present study was consistent with previous studies that showed a significant effect on medication adherence when using a follow-up strategy (Hudson, Owen, Thrush, Armitage, & Thapa, 2008; Maneesokorn, Robson, Gournay, & Gray, 2007; Shon & Park, 2002) as well as a significant effect on attitude toward medication (Montes, Maurino, Diez & Saiz-Ruiz, 2010).

Goal-setting and action planning strategy which is called a therapeutic contract in this study could help the patients to decide their goal for their desired behavior. During the program, the researcher as a health care professional discussed with the patients and their families an action plan that can help the patient fulfill his or her goal. Moreover, in this written contract should also be a short term goal which will include how the goal will be achieved. During this study, after the subjects set their goal and action plan in taking medication, the researcher assessed the patients confidence to achieve the action (self-efficacy) which can be measured on a scale ranging from 0 (totally not confident) to 10 (totally confident) (Lorig & Holman, 2003; MacGregor et al., 2006). In the first week of the intervention, two subjects had a confidence level less than 7, therefore, the researcher discussed their problems/ barriers and discussed a solution together with the patients and their families to enhance the confidence level to at least 7. Other weeks later, none of the subjects had confidence level less than 7.

However, there were some concerns in this study: patient's cognition and patient's cooperation in recording. During the telephone follow-up, when the researcher evaluated the goal and action plan from the previous week, most of the subjects (20 subjects) stated that they would remain on implementing same goal, and

action plan, therefore, there was no change in the goal set or the patient's confidence level from the previous week. Additionally, when the researcher asked the subjects to write their goal and action plans on the evaluation form, some subjects reported they cannot write by themselves or forget what they should do. During the face to face follow-up, only eight subjects can fill in the evaluation form by their self every week. Even these problems did not influence the outcomes but they can influence the therapeutic contract where a good contract should be written (Kanfer & Gaelick-Buys, 1991). This can be a consideration as well since schizophrenia patients have limitations of cognitive problems such as a dysfunction in attention, learning and memory (Austin, 2005; Moller, 2009).

In this study, the mean of pre-test medication adherence behavior in the subjects in the experimental group and the control group shows quite high (30.08 and 31.88, respectively) out of 40. There were some reasons related to this result. Firstly, the measurement which was used in this study was a self-report questionnaire. This measurement has been criticized to measure medication adherence since adherence is an observable behavior compared to an objective measurement such as a pill count or electronic monitoring like Medication Event Monitoring (MEMS) caps and smart pill boxes that are often presented as a "gold standard" for medication adherence measurement (Sajatovic, Velligan, Weiden, Valenstein, & Ogedegbe, 2010). In order to reduce the outcome measures and to maintain the subject's response, this study used the research assistant as the person who collected the data and who was trained before data collection. Moreover, the research assistant also did not know which subjects were in the experimental group or in the control group.

Secondly, the patients were approached in the OPD as this is the place that monitors their condition and prescribes their medication. These kinds of patients have better medication adherence than the patients who do not come to the OPD. The result might be different if this study approaches the patients in the community.

Thirdly, the timing of the measurement in medication adherence behavior using a self-report questionnaire did not allow the researcher to know the sustainability of the behavior. Even though the score of medication adherence behavior was quite high, the patients reported that they had problems in medication taking as well as side effects of antipsychotic medication which can influence their adherence to medication.

Therefore, the researcher still needed to give the intervention for them by using the self-management with family participation program to help them solve the problems as well as to enhance their medication adherence and positive attitude toward medication.

There might be some co-intervention during the program that can influence the result of this study such as the patients receive health education from the nurses in the OPD or in the community. The patients who come to the OPD might receive health education from the nurse or the doctor especially when they reported that they did not adhere to their medication. However, this unstructured health education is the usual care for the patients at the OPD and both patients in the experimental group and the control group may have the same chance since this study used block randomization as random assignment. In terms of co-intervention in the community, the researcher was assured that even though this study setting has community health centers but they do not provide the intervention for patients with schizophrenia in the community as well as do not have community mental health

nursing (CMHN). Therefore, this co-intervention had no effect on the result of this study.

In addition, the researcher could give the intervention to more than one subject on the same day that can influence the intervention and might be different from one subject to another. In order to reduce this matter, the researcher tried to maximize the protocol consistency by using the intervention guideline when giving the intervention to the subjects. The researcher tried out this guideline in the pilot study and checked the consistency. Therefore, the subjects received the same intervention from the researcher.

In conclusion, this one-month self-management and family participation program by using a combination of strategies effectively enhances the medication adherence behavior and attitude toward medication among patients with schizophrenia. The result indicated that this program is feasible to be implemented. Moreover, all subjects both the patients and their families were satisfied and gained benefits after receiving the program.

## CHAPTER 5

### CONCLUSION AND RECOMMENDATIONS

The conclusion of this study composes of a summary of the study based on the research findings, the strengths and limitations as well as the implications and recommendations.

#### Conclusion

This study is a randomized controlled trial that was under taken to evaluate the effectiveness of self-management with family participation program in patients with schizophrenia in Indonesia. Fifty patients and their families recruited from the OPD of a psychiatric hospital in Central Java based on an inclusion criteria and block randomization completely participated. The subjects in the experimental group received self-management with family participation program based on self-management methods for four weeks with two telephone follow-ups and one face to face follow-up which was conducted in the patient's home, whereas the subjects in the control group received the usual care.

Both the patients and their family members were asked to fill in a form for the baseline data which consists of the patients' characteristics and caregivers' characteristics as well as prior knowledge regarding medication, medication adherence behavior and attitude toward medication. The patients' characteristics were described using frequency, percentage, mean, standard deviation and median as well as quartile deviation for not normal distribution data. The Chi-square, Fisher's exact

test, Independent t-test and Mann-Whitney U test were used to examine the characteristics between the experimental group and control group. Additionally, the dependent t-test and independent t-test were employed to test mean score differences as well as answering the first and second research questions on medication adherence behavior and attitude towards medication. The subjects who received self-management with family participation program had significantly higher score on medication adherence behavior and attitude toward medication than before receiving the program ( $t = -7.76, p < .01$  and  $t = -3.78, p < .01$ , respectively). Moreover, there were significant differences in medication adherence behavior and attitude toward medication between the subjects in the experimental group and the control group ( $t = 6.08, p < .01$  and  $t = 3.05, p < .01$ , respectively).

To conclude, these findings show that self-management with family participation program had a significantly positive effect on medication adherence behavior and attitude toward medication among patients with schizophrenia.

### **Strengths and Limitations of the Study**

The present study has several strengths including the study design, patients' selection and the programs. This study was a randomized controlled trial with pre and post-test measures. It is a powerful design for testing the hypothesis of a cause-effect relationship. Block randomization was used to assign the subjects into either the experimental or the control group in order to minimize the selection bias and yielded equal sample size. The program in this study included the strategies which showed significant results from previous studies including family involvement,

patient-tailoring, providing psychoeducation and counseling as well as providing a booklet and follow-up sessions.

Despite the strengths, there were some limitations in this study. In the selection of the subjects, there was a significant difference between the two groups on confounding variable: the perceived of a far distance to travel to hospital that may influence the results on medication adherence. It is supported by a study which reported that living far away from the hospital, lack of access to the hospital, and high cost of accommodation to get to the hospital would cause the non-adherent to medication (Lacro, 2006).

The generalizability of the study findings is limited to only those who are in a stable condition, taking oral medication and not having comorbid diseases. Moreover, the patients also had quite good insight. Applying this program in schizophrenia patients who do not meet the criteria as set in this study, for example, subjects with poor insight and comorbid diseases may be more challenging and may yield different results.

During the study, two subjects dropped out. One subject from the control group was hospitalized whereas the other subject was in the experimental group and did not have permission from other family members. It might be difficult to control the condition of patients since schizophrenia patients have different periods in the clinical feature such as acute, stable and relapse. In some cases, the primary care givers sometimes do not accompany patients to the hospital.

Additionally, even the Intraclass Correlation Coefficient (ICC) of the instruments in this study revealed good reliability; those measurements had low internal consistency especially for the prior knowledge regarding the medication

questionnaire. In addition, the measurement of medication adherence behavior in this study was a self-report measurement which cannot truly measure the behavior of medication taking compared to the objective measurements.

## **Implications and Recommendations**

### **Implications for Practice**

This study provides evidence on the effect of a self-management with family participation program on enhancing medication adherence behavior and attitude toward medication in patients with schizophrenia. The program contains clear intervention guidelines and methods to be applied by nurses to promote medication adherence and could be used for nurses or other health professional either in the hospital or community setting. The health professionals could use this program to encourage patients' goals and action planning as well as encouraging family members to be involved. It will be helpful for patients and their family by providing education as well as providing a booklet regarding the illness, medication and how to manage the side effects of antipsychotic medication.

This study also reveals that the distance to access a psychiatric hospital is one of barriers for patients with schizophrenia to adhere to medication. In Indonesia, there are only a few community health centers which stock and provide the psychiatric medications. Therefore, the distribution of antipsychotic medication in the community is very important, especially in places where there are many psychiatric patients. Furthermore, it is useful for psychiatric hospitals or health professionals to



provide information regarding the community health centers near patients' homes which do supply psychiatric medications to patients in the community.

Adherence to medication is important for patients with schizophrenia to prevent relapse and re-hospitalization. Involving family members in this study is similar to another method to improve medication adherence in TB patients which used directly observed treatment (DOT). Not only family members, but also DOT supporters who are trained to observe patients swallowing their medication can be a health care provider and/or a community health volunteer. This method might be useful for some schizophrenia patients who are reluctant in taking medication even though they have family support and encouragement.

In addition, even though this program uses family participation, the patients who are living alone or do not have family member can use this program as well. The family participation can be replaced by using DOT supporters such as a health care provider and/or a community health volunteer as the one who encourages and facilitates the patients in their medication taking. Although the supporter cannot observe as well as a patient's family since the DOT supporters live separately from the patients.

In terms of cost effectiveness in the follow-ups strategy, the patients might have a chance to contact the nurse by phone if they face any problems with their medication/ illness. The nurse can provide consultation or counseling based on the patient's problems. Moreover, this strategy can enhance the patients' involvement in taking responsibility of their medication intake.

### **Implications for Future Research**

Further study is needed to test the effectiveness of the program on enhancing medication adherence among patients with schizophrenia. Firstly, future studies are needed to determine whether the results can be generalized to the patients with schizophrenia in the Indonesian population. Since this study uses family participation, applying other strategies by combining other methods such as using DOT supporters for the patients who are living alone or do not have family members may need to be explored in a further study. Secondly, this study used self-report measurements and measured medication adherence directly after the face to face follow-up, future research could use an objective measurement and measure the medication adherence after the program has finished or has a longer follow-up periods. Thirdly, since block randomization might have unequal confounding variables, applying other techniques such as stratified random sampling is recommended. Lastly, studies in a larger sample size, in different settings such as in the OPD or the community health centers are also recommended.

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**APPENDICES**

## **APPENDIX A**

### **Research Information Sheet**

#### Informed Consent

My name is Sri Padma Sari. I am a lecturer of Nursing Program, Faculty of Medicine, Diponegoro University, Indonesia who is doing my master degree in the Faculty of Nursing, Prince of Songkla University, Thailand. I am conducting a research study entitled “The effect of a self-management with family participation program on medication adherence among patients with schizophrenia”. This study will be held for four weeks and the findings of this study will be a good resource for others who want to help patients with schizophrenia like you. This study has been approved by the Institutional Review Board of Faculty of Nursing, Prince of Songkla University, Thailand and RSJP Prof. dr. Soeroyo Magelang, Indonesia. You are asked to participate in this research project. If you decide to participate in this study voluntarily, you will be asked about your personal information and health history as well as other information through some questionnaire.

#### Procedures Explanation

1. You will be assigned to either the experimental group or the control group
2. If you are in the experimental group, you will receive the self-management with family participation program
3. If you are in the control group, you will not receive the program. You will receive the usual care in psychiatric hospital as you usually get. However, if you want to receive the similar intervention, you will receive it after the end of the study.

#### Evaluation and Forms

1. You will be asked to fill the forms about personal data and health information.
2. You also will be asked to fill the questionnaire asking you about how well you adhere with prescribe medications in the first week and fourth week of the intervention.

### Risk and Comforts

There is no evidence shown risk related to participating in this study. However, this program may make you spend more time with me. Moreover, there is neither cost nor payment to you for participating in this study.

### Benefits

The finding of this study will be beneficial specifically for persons like you as well as for the nurse and other health care providers in order for them to help patients with schizophrenia to increase their adherence to the medications. The data from this research will be used to write a research paper and provide useful information for further research in this area.

### Confidentiality

All information and your responses in this study will be kept confidential and anonymous. Only the researcher and the advisors are eligible accessing the data. Neither your name nor any identifying information will be used in the reports of the study.

### Participation and withdrawal

Your participation in this study is voluntary. Signing the informed consent or agreeing verbally to participate indicates that you understand what is involved and you consent to participate in this study. You have the right to withdraw from participation anytime without any problems prior to completion of data collection.

Thank you for expressing interest in this study. If you have questions, suggestion or cannot participate in this study you can contact me (the researcher) at my mobile phone 085225197321. If you agree to participate in this study, please sign your name on the consent form.

Thank you for your cooperation.

Researcher  
(Sri Padma Sari)



Research Information Sheet  
Self-Management with Family Participation Program

You are in the experimental group, attending this program, you will be involve in the following procedures:

1. The first week of intervention
  - a. Initially, you will be asked to fill some forms including the demographic data, prior knowledge regarding medication questionnaire, drug attitude inventory and medication adherence behavior questionnaire. My assistant will help you to complete the forms.
  - b. You will join the session discussing about medication management to help you be able to take medication properly.
  - c. You will receive a booklet that has contents of medication management in schizophrenia to facilitate your further learning. You will be asked about the time for telephone follow-up that that must convenient to you.
2. The second and third week of intervention

In this period, I will make telephone follow-up to evaluate your current progress in implementing this program. During this activity, you will be asked to report your progress regarding how will you take your medication, your goals and action plans. You will also allow sharing any difficulties during implementation or asking question or giving suggestion to me in order to help medication you adhere with your medication. In addition, I will guide you to maintain or to make it even better.
3. The fourth week of intervention

In the last week of the study, you will be followed up by me at your home in order to review your progress in taking your medication. You will be asked to fill the questionnaires that you did before once again. This will take around 15 minutes. My assistant will help you to complete the questionnaires.

### Informed Consent Form

Title : The Effect of a Self-Management with Family Participation Program on Medication Adherence among Patients with Schizophrenia in Indonesia

Researcher : Sri Padma Sari (Master student at Faculty of Nursing, Prince of Songkla University, Thailand)

Patient's Name : \_\_\_\_\_ Age: \_\_\_\_\_

#### **Patient's Consent**

I, \_\_\_\_\_, was informed of the details of the research entitled "The Effect of a Self-Management with Family Participation Program on Medication Adherence among Patients with Schizophrenia in Indonesia" and was ensured that all information related to personal information, health history and research results will be kept confidential. If any further problem or issues arise, I can discuss with the researcher. I have the right to withdraw from the study at any time without any effect on any nursing/medical services and treatment that I currently receive from this hospital. I am willing to participate in this research study voluntarily without any threat and force. Hereby, I endorse my signature.

Given by: \_\_\_\_\_ (Consenter) Date: \_\_\_\_\_

#### **Researcher's note**

I gave the detailed information of the research entitled "The Effect of a Self-Management with Family Participation Program on Medication Adherence among Patients with Schizophrenia in Indonesia" to the patients. The signature and the returned forms indicate that you understand what is involved and that you consent to participate in this study voluntarily. You have been given an opportunity to ask question.

Signature: \_\_\_\_\_ (Researcher) Date: \_\_\_\_\_

## APPENDIX B

### Self-Management with Family Participation Guideline

Step	Time	Objectives	Method	Duration	Activities		
					Researcher	Patient	Family
1	Week 1	To establish relationship with patient and family	Discussion	10 minutes	a. Explain the purpose of the study b. Make agreement for available time of patient and family to conduct the program	Actively participate in this activity	Actively participate in this activity
2	Week 1	To share and reflect the patient's current behavior	Discussion	10 minutes	a. Ask the patient and the family related to patient's current behavior in medication b. List the answer of patient and family	Answer the researcher question by describing his/her current behavior in medication	Add information to patient and researcher
3	Week 1	Provide education and counseling session based on patient's condition	Discussion	40 minutes	a. Provide the information related to schizophrenia and medication in patient with schizophrenia b. Clarify any misunderstanding/ misperception c. Give the booklet	Patient participate actively in the discussion	Family participate actively in the discussion
.	.....	.....	.....	.....	.....	.....	.....
9	Week 4 (face to face)	Evaluate the goal and action planning	Discussion	30 minutes	a. Ask the patient whether he/she accomplish the goal and action planning. b. .... c. Summary and evaluation of the program.	Patient participate actively in the discussion and answer question	Patient participate actively in the discussion and answer question



No	Topic	Objectives	Content	Method & Time	Activities											
					Researcher	Patients and family										
4.	The type of medication	.....	There are two categories of antipsychotic drugs for treating schizophrenia: traditional and atypical drugs (Pearson, 2009). Similar with most medication, antipsychotic medication also has side effects	Discussion 5minutes	.....	Active in discussion										
5.	The management of side effect	.....	a. The management of common side effects	Discussion Lecture Counseling Booklet 8minutes	a. Explain the importance of side effects management b. Ask the patients and family related to the topics c. Clarify any unclear explanation	Active in discussion Ask the question related to unclear explanation										
			<table border="1"> <thead> <tr> <th>Side effects</th> <th>Management</th> </tr> </thead> <tbody> <tr> <td>Anticholinergic effect: - Dry mouth - Constipation</td> <td>Eat sugarless candy, gum, Eat food which has high fiber increase physical activity and fluid</td> </tr> <tr> <td>Hormonal effect - Decreased libido - Weight gain</td> <td>Do physical exercise and diet</td> </tr> <tr> <td>Involuntary movement</td> <td>Trihexyphenidyl (Artane)</td> </tr> <tr> <td>.....</td> <td>.....</td> </tr> </tbody> </table>				Side effects	Management	Anticholinergic effect: - Dry mouth - Constipation	Eat sugarless candy, gum, Eat food which has high fiber increase physical activity and fluid	Hormonal effect - Decreased libido - Weight gain	Do physical exercise and diet	Involuntary movement	Trihexyphenidyl (Artane)	.....	.....
			Side effects				Management									
			Anticholinergic effect: - Dry mouth - Constipation				Eat sugarless candy, gum, Eat food which has high fiber increase physical activity and fluid									
			Hormonal effect - Decreased libido - Weight gain				Do physical exercise and diet									
Involuntary movement	Trihexyphenidyl (Artane)															
.....	.....															
.....	.....	.....														
.....	.....	.....														
.....	.....	.....														
7.	The strategies to manage the medication	To explain the strategies to manage the medication	The strategies for adherence to medication: <ul style="list-style-type: none"> <li>• Take medication with the right name, dose and time</li> <li>• The strategy for remembering the medication <ul style="list-style-type: none"> <li>- Using alarm/ mobile phone</li> <li>- .....</li> <li>- Ask family member to remind</li> </ul> </li> </ul>	Discussion Lecture Counseling Booklet 5minutes	.....	.....										

**APPENDIX D**  
**Booklet**  
**MEDICATION MANAGEMENT**  
**FOR SCHIZOPHRENIA**



**Sri Padma Sari**

**Master Student of Psychiatric Nursing  
Prince of Songkla University, Thailand  
2012**

Name of patient :  
Address :  
Phone number :

**Introduction**

This booklet aims to help in medication management among patients with schizophrenia. It helps remind both patient and family about medication management. It consists of six main components: 1) general information about schizophrenia, 2) why schizophrenia patients have to manage the medication, 3) the type of medication, 4) common side effects, 5) management of side effects, and 6) goal setting and action plan form. Please read the booklet carefully and fill the action plan as explained.

### The goal and action plan form

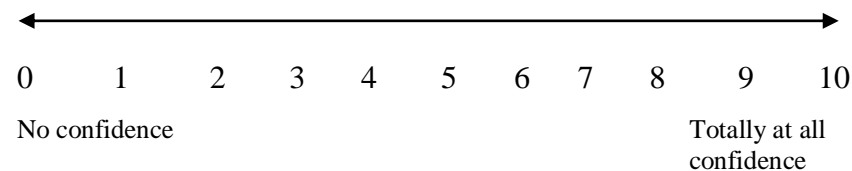
This forms use to plan your goal and action plans regarding medication management. The researcher will assist you and your family to fulfill the form.

1. Decide your goals every week in medication management
2. Give in detail your action plans (what, when, frequency and how)
3. Write the self-reward if you could accomplish the goal and action plan
4. Write your confidence level in achieving the goals and action plans
5. Write the possible barriers to achieve the goals and action plans
6. Write the possible solution

### Goal and action plan in the first week

Goal: 1. Taking medication regularly	Action plans (in detail) - Morning time (8 am): Haloperidol 1 tab & THP 1 tab - Bedtime (8 pm): Haloperidol 1 tab, THP 1 tab & CPZ 1 tab -
Goal: 2.	Action plans (in detail) - -
Self-reward	Plan of activities - -

Confidence level (0 – 10)



Possible barriers to perform action plans:

.....

Possible problem solving:

.....





## APPENDIX E

### Demographic Data Questionnaire

Code:

Date:

**Direction:** Below is the form to obtain information about your current demographic data and health information.

#### I. Patient's demographic data

1. Age: .....years
2. Gender :
3. Religion
4. ....

#### II. Clinical information (Filled by Research Assistant)

1. Age of onset:.....
2. Length of illness: .....years
3. Number of hospitalization: .....
4. Type of current medication and doses (...times/day):
  - a. ....
  - b. ....
  - c. ....
5. Lists of barriers to medication adherence (can answer more than 1 item)
  - 1 Memory problem/ forgetfulness
  - 2 Problem with the medication regimen
  - 3 .....
  - Others, please identify.....
6. Lists of problems/side effects after taking medication (can answer more than 1 item)
  - 1 Drowsiness
  - .....
  - 8 Movement problem
  - Others, specify.....

7. BPRS score: .... (It will be measured by Brief Psychiatric Rating Scale)
8. Insight score:..... (It will be measured by Beck Cognitive Insight Scale)

### III. Care giver's demographic data

1. Age: .....years
2. Gender:
3. Family relationship
4. Duration for caring the patient..... ..years
5. Education level
6. Occupation

## APPENDIX F

### Brief Psychiatric Rating Scale (BPRS)

**Direction:** Please fill the statement by mark (√) in the column which indicates patient's condition.

1 = not present, 2 = very mild, 3 = mild, 4 = moderate, 5 = moderately severe, 6 = severe, 7 = extremely severe

No.	Patient's condition	Score							
		1	2	3	4	5	6	7	
1.	Somatic concern (complaints of physical health)								
2.	Anxiety								
3.	Emotional withdrawal								
4.	Conceptual disorganization								
5.	Guilt feeling								
6.	Tension								
7.	Mannerism and posturing								
8.	Grandiosity								
9.	Depressive mood								
10	Hostility								
11	Suspiciousness								
12	Hallucinatory behavior								
13	Motor retardation								
14	Uncooperativeness								
15	Unusual thought content								
16	Blunted affect								
17	Excitement								
18	Disorientation								
<b>Total score</b>									

## APPENDIX G

### Beck Cognitive Insight Scale (BCIS)

<b>Instructions:</b> Below is a list of sentences about how people think and feel. Please read each sentence in the list carefully. Indicate how much you agree with each statement by placing an <b>X</b> in the corresponding space in the column next to each statement.				
	Do Not Agree at All	Agree Slightly	Agree a Lot	Agree Completely
1. At times, I have misunderstood other people's attitudes towards me.	0	1	2	3
2. My interpretations of my experiences are definitely right.	0	1	2	3
3. .... .....	0	1	2	3
4. .... .....	0	1	2	3
..... .....	0	1	2	3
11. I cannot trust other people's opinion about my experiences.	0	1	2	3
..... .....	0	1	2	3
15. My unusual experiences may be due to my being extremely upset or stressed.				

## APPENDIX H

### Prior Knowledge regarding Medication Questionnaire

Code:

Date:

Direction: Please fill the statement by mark (√) in the column which indicates your understanding about the statements.

No.	Questions	True=1	False=0
1.	Antipsychotic medications do not work when it is taken irregularly.	1	0
2.	.....	0	1
3.	.....	1	0
4.	.....	0	1
5.	The doses of antipsychotic medication depend on doctor prescription.	1	0
6.	.....	1	0
7.	Drowsiness, nausea, vomiting, diarrhea and weight gain are side effects of antipsychotic medication.	1	0
8.	.....	0	1
9.	.....	1	0
10.	Physical exercise and diet can manage the side effects of antipsychotic medication.	1	0

## APPENDIX I

### Medication Adherence Behavior Questionnaire (MABQ)

Direction:

You indicated that you are taking antipsychotic medication(s) for your schizophrenia. Individuals have identified several issues regarding their medication-taking behavior and we are interested in your experiences. There is no right or wrong answer. Please select one of four choices (all the time, usually, sometimes, never) based on your personal experience with your antipsychotic medication.

No	Statement	All the time	Usually	Some Times	Never
1.	I take antipsychotic medication regularly	4	3	2	1
2.	I ever forget to take my antipsychotic medication	1	2	3	4
3.	I am difficult remembering to take antipsychotic medication	1	2	3	4
4.	I stop taking antipsychotic medication when I feel better	1	2	3	4
5.	..... ...	1	2	3	4
6.	..... ...	1	2	3	4
7.	..... ...	1	2	3	4
8.	..... ...	1	2	3	4
9.	..... ...	4	3	2	1
10	I go to the doctor before my pill finish	4	3	2	1

**APPENDIX J**  
**Drug Attitude Inventory (DAI)**

Direction:

Please read each statement below and decide whether it is **true as applied to you** or **false as applied to you**. If the statement is **TRUE** or **MOSTLY TRUE**, circle the **T** following the statement. If a statement is **FALSE** or **NOT USUALLY TRUE**, circle the **F** following the statement. If you want to change an answer, mark an **X** over the incorrect answer and circle the correct answer.

Please answer every question. If a statement is worded not quite the way you would express it yourself, decide whether it is **MOSTLY TRUE**, or **MOSTLY FALSE**.

Remember to give **YOUR OWN OPINION** – there is no right or wrong answer. Do not spend too much time on any one item.

No.	Statements	True	False
1.	I don't need to take medication once I feel better	T	F
2.	For me, the good things about medication outweigh the bad	T	F
3.	I feel strange, "doped up", on medication	T	F
4.	Even when I am not in hospital I need medication regularly	T	F
5.	If I take medication, it's only because of pressure from other people	T	F
	.....		
	.....		
28.	I can't relax on medication	T	F
29.	I am in better control of myself when taking medication	T	F
30.	By staying on medications I can prevent myself getting sick	T	F

## **APPENDIX K**

### **List of Experts**

Three experts examined the content validity of the instruments of intervention program, teaching plan and booklet, prior knowledge medication questionnaire and medication adherence behavior questionnaire, they were:

1. Dr. Vineekarn Kongsuwan

Nursing Lecturer, Prince of Songkla University, Thailand

2. Assist. Prof. Dr. Orawan Nukaew

Nursing Lecturer, Prince of Songkla University, Thailand

3. Prof. Dr. Budi Anna Keliat, S.Kp, MAppSc

Nursing lecturer, University of Indonesia



## APPENDIX L

### Permission of the Instruments

#### **Drug Attitude Inventory (DAI)**

Thank you for your interest in our DAI. I am pleased to authorize the use of the DAI in your study, free of charge. Enclosed please find a copy of the DAI.

Good luck,

Dr. A.G. Awad  
 Professor Emeritus, University of Toronto  
 Chief of Psychiatry, Humber River Regional Hospital  
 2175 Keele Street, Suite 243A  
 Toronto, Ontario M6M 3Z4  
 Tel: (416) 658-2012  
 Fax: (416) 658-2015

#### **Beck Cognitive Insight Scale (BCIS)**

Pada Rab, 19/9/12, Kelly Devinney <[devinney@mail.med.upenn.edu](mailto:devinney@mail.med.upenn.edu)> menulis:

Dari: Kelly Devinney <[devinney@mail.med.upenn.edu](mailto:devinney@mail.med.upenn.edu)>  
 Judul: Re: asking permission  
 Kepada: ners\_45@yahoo.com  
 Tanggal: Rabu, 19 September, 2012, 8:24 PM

Dear Padma,

I am responding on behalf of Dr. Aaron T. Beck.

You have my permission to use and reproduce the BCIS, only for the designated research project that you described in your letter. There is no charge for this permission.

I am attaching a copy of the BCIS, as well as the scoring key and instructions. However, in exchange for this permission, I would appreciate it if you could send me a copy of your results once you have completed your study. Any reports, reprints, or publications you prepare in which our materials are used would also be greatly appreciated, as these are catalogued in our central library as a resource for other researchers and clinicians.

Best of luck with your project,

ATB  
 Kelly Devinney

--

University of Pennsylvania

## APPENDIX M

### Effect Size Calculation

The sample size of the study will calculate by the formula power analysis of variance as follow (Cohen, 1988).

$$\text{Effect size} = \frac{M_1 - M_2}{\text{pooled } SD}$$

$$\text{Pooled SD} = \sqrt{\frac{SD_1^2 + SD_2^2}{2}}$$

Where M1 : Mean of medication compliance in the experiment group

M2 : Mean of medication compliance in the control group

Pooled SD : Standard deviation

$$M1 = 95.555 \quad SD1 = 7.838$$

$$M2 = 86.5 \quad SD2 = 10.4$$

$$\begin{aligned} \text{Pooled SD} &= \sqrt{(SD1^2 + SD2^2)/2} \\ &= \sqrt{(7.838^2 + 10.4^2)/2} \\ &= \sqrt{61.434244 + 108.16/2} \\ &= \sqrt{169.59424/2} \\ &= \sqrt{84.79712} = 9.2085 \end{aligned}$$

$$\begin{aligned} \text{Effect size} &= M1 - M2/ \text{pooled SD} \\ &= 95.555 - 86.5/9.2 \\ &= 9.055/ 9.2 = 0.978 \approx 0.98 \end{aligned}$$

**VITAE**

**Name** Sri Padma Sari

**Student ID** 5410420042

**Educational Attainment**

<b>Degree</b>	<b>Name of Institution</b>	<b>Year of Graduation</b>
Bachelor of Nursing	Diponegoro University	2006

**Scholarship Awards during Enrolment**

Directorate of Higher Education, Ministry of National Education, Republic of Indonesia.

**Work - Position and Address**

Lecturer at Nursing School, Faculty of Medicine, Diponegoro University

Jl. Prof. Soedarto, Tembalang, Semarang, Central Java Indonesia

Mobile : +62852 251 97321

Email : ners\_45@yahoo.com