



**The Effect of the Illness Representation-based Education Program (IREP)  
on Medication Adherence Among Patients with Bipolar Disorder  
in Medan, Indonesia**

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**A Thesis Submitted in Partial Fulfillment of the Requirements for the Degree of  
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**Thesis Title**            The Effect of the Illness Representation-based Education Program (IREP) on Medication Adherence Among Patients with Bipolar Disorder in Medan, Indonesia

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### ABSTRACT

This one-group pretest posttest experimental study aimed to examine the effect of an Illness Representation-based Education Program (IREP) on medication adherence among patients with bipolar disorder. Thirty participants who met the inclusion criteria were recruited from out-patient department (OPD) of a psychiatric hospital in Medan, Indonesia. The IREP is an individualized intervention which consists of 7 major processes including (1) representation assessment, (2) identifying and exploring the gaps, misconceptions and confusion related to bipolar disorder, (3) creating condition for conceptual change, (4) introducing replacement information, (5) summarizing, (6) goal setting and planning regarding enhancing medication adherence, and (7) following-up of the goal and the strategies. Medication adherence was measured by using The Medication Adherence Behavior Questionnaire (MABQ), a self-report questionnaire composed of four subscales, developed by the researcher. The MABQ was content validated by three experts and its reliability was examined using Cronbach's alpha coefficient giving values of .91 for voluntarily, .86 for continuously, .67 for actively, .84 for correctly as prescribed, and .94 for the total scale. Paired t-test was used to analyze changes in medication adherence after intervention.

The result showed that after receiving the IREP, the participants reported significant improvement on medication adherence behavior ( $t = -5.0, p < .01$ ). This study provides empirical evidence on the effectiveness of a representational approach to patient education on the medication adherence behaviors of patients with bipolar disorder. Thus, IREP is highly recommended to be implemented in nursing practice.

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## **CHAPTER 1**

### **INTRODUCTION**

The background and significance of the problem, objectives of the study, research questions, conceptual framework, hypothesis, definition of terms, scope of the study, and significance of the study are presented in this chapter.

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

Bipolar disorder, also called mood disorder, is a chronic mental health disorder with periods of remission and relapse. It involves dramatic swings in affect, cognition, and behavior (Macneil, Hasty, Conus, Berk, & Scottt, 2009). A person with bipolar disorder usually manifests with mania, hypomania, depression, or mixed episodes that can be switched between one mood to another, i.e. from mania to depression (Williams, Ruckert, & Lum, 2011).

The lifetime prevalence of bipolar spectrum disorder is approximately 3% to 7% of the population (Malhi as cited in Williams et al., 2011) and approximately 0.5% to 5% for prevalence in any types of bipolar disorder (Vieta et al., 2011). In addition, the cross-national survey from eleven countries of the World Health Organization (WHO) reported that the lifetime prevalence in each type of bipolar is 2.4% for bipolar spectrum disorder, 0.6% for bipolar I disorder, and 0.4% for bipolar II disorder (Merikangas et al., 2011). The average age at onset is 15 to 30 years old (Stovall as cited in Williams et al., 2011). The prevalence of bipolar disorder, particularly in Indonesia, is unknown yet. However, based on the Global Burden of Disease 2000 survey, the prevalence of bipolar disorder in the sub-region SearB (South-East Asia) in which Indonesia was included,

showed the highest number per population in the 30-44 year age group ranging from 9.0 in males to 9.7 in females per 1000 people (Chisholm, van Ommeren, Ayuso-Mateos, & Saxena, 2005). Even though the prevalence of bipolar disorder was not ranked the first among mental health disorders, bipolar disorder causes a significant burden (Vieta, 2005). Based on Ayuso-Mateos (2001), bipolar disorder was estimated to be the seventh leading cause of non-fatal burden in the world.

Patients with bipolar disorders encounter several disturbances in their moods, cognitions, and behaviours which express differently during mania and depressive episodes. During a mania episode, patients' moods will change to feelings of high, overly happy, and extremely irritable moods. In addition, regarding cognitions and behaviors, patients may be talkative, having racing thoughts, decreased needs for sleep, grandios ideas, inflated self-esteem, or be aggressive. Meanwhile during a depressive episode, a patient usually has a long period of feeling worried, in a depressed mood most of the day including experiencing feelings of worthlessness or guilt, decreased appetite, presence of agitation or slowness, fatigue or loss of energy, has difficulty in concentrating or making decisions, and thoughts of death are recurrent either with or without suicide ideation (American Psychiatric Association [APA], 2000). Nieng (2011) stated that these difficulties can affect a patient's life functionings, especially in regards to social functioning. Similarly, the National Institute of Mental Health (2009) stated that the impacts of mood disorders on people also include difficulty to maintain relationships, and poor job or school performance.

However, bipolar disorder can be treated and the patients can become productive and be able to live meaningfully. One of the management approaches in bipolar disorder is medication (National Institute of Mental Health, 2009). Medication

is an important treatment for bipolar disorder in achieving the treatment goals of the patient and reducing symptom severity (Williams et al., 2011), as well as helping the patient to gain better control of mood swings (Sach as cited in National Institute of Mental Health, 2009). Medications have an important contribution for psychiatric patients to be able to achieve independent living (Dogan & Sabanciogullari, 2003). Therefore, if patients get the proper treatment and their moods as well as other disturbing symptoms are under control, they are able to regain a productive life like others (National Institute of Mental Health, 2009).

However, non-adherence with medication among patients with bipolar disorder is a common problem (Lingam & Scott, 2002). The incidence of non-adherence rate ranges from 20% to 60% (Berk, Berk & Castle, 2004; Colom & Lam, 2005; Lingam & Scott, 2002). Medication non-adherence is associated with elevated rates of relapse, hospitalization, suicidal behavior, greater cost to caring (Adam & Scott, 2000; Colom, Vieta, Tacchi, Sanchez-Moreno, & Scott, 2005; Depp, Lebowits, Patterson, Lacro, & Jeste 2007; Sajatovic, Bauer, Kilbourne, Vertrees, & Williford, 2006; Scott & Tacchi, 2002), and consequently a poor quality of life (Crowe, Wilson, & Inder, 2011).

Several factors contribute to medication non-adherence among patients with bipolar disorder including age (Baldessarini, Perry, & Pike, 2007; Berk et al., 2010; Hou, Cleak, & Peveler, 2010), gender, marital status, substance abuse (Berk et al., 2010; Clatworthy, Bowskill, Rank, Parham, & Horne, 2007; Sajatovic, Bauer, Kilbourne, Vertrees, & Williford, 2006; Sajatovic, Velligan, Weiden, Valenstein, & Ogedegbe, 2010), phase/stage of illness (Berk et al., 2010; Colom et al., 2005), medication knowledge (Berk et al., 2010; Rosa et al., 2009; Seo & Min, 2005), an individual's beliefs and attitude (Adams & Scott, 2000; Clatworthy et al., 2007; Clatworthy et al.,



2009; Lan, Shiau & Lin, 2003; Scott & Pope, 2002), cognitive illness representation (Brown et al., 2001; Hou et al., 2010; Lobban et al., 2003; Sajatovic et al., 2009a), therapeutic alliance (Berk et al., 2004; Lingam & Scott, 2002), social support (Berk et al., 2010; Seo & Min, 2005), and medication side effects (Clatworthy et al., 2009; Patel & David, 2007; Sajatovic et al., 2011).

As medication is important for patients with bipolar disorder, many research studies had been conducted for bipolar disorder aimed to enhance medication adherence. According to a literature review by Berk et al. (2010), in which the reviewed studies were conducted during 1996 to 2008, ten interventions were identified and seven of them were found having positive effects on medication adherence among patients with bipolar disorders. However, despite their effectiveness, it will be difficult to bring into these interventions in to practice, especially when applying them into regular nursing practices because of the cost-effectiveness issue due to the amount of time consumed and the need of an expert.

Among those identified studies, there are 4 of 7 studies that were considered time consuming. For instance, Colom (as cited in Berk et al., 2010) conducted 21 sessions of group psycho-education; Depp et al. (2007) conducted 12 weekly sessions of medication adherence skills training program; Miklowitz (as cited in Berk et al., 2010) conducted 21 sessions of family-focused treatment with assessments every 3-6 months for 2 years; and Lam (as cited in Berket al., 2010) provided 14 sessions of individual cognitive therapy over 6 months. As these interventions provide many sessions and require a long time to complete, they may not be suitable in the real world of psychiatric nursing practice.

Another issue is related to using an expert in cognitive behavior therapy that may not be cost-effective as well. In Berk et al.'s literature review (2010), there were two studies testing cognitive behavioral therapy that required a cognitive behavioral therapist. These included Cochran's study and Lam's study (as cited in Berk et al., 2010) and another one used concordance therapy (Scott & Tacchi, 2002). However, according to the researcher's observation, the nurses who work at the psychiatry hospital in Medan may not be familiar with this kind of intervention, therefore it may be less feasible to bring into regular psychiatric nursing practice specifically in Medan.

Nevertheless, among those effective interventions in Berk et al.'s literature review (2010), another intervention examined by Dogan and Sabaciogullari (2003) seems feasible to bring into nursing practice because it is not time consuming and does not require an expert. However, the validity of its effect is questionable. It is a two-session individual education program about lithium therapy. The result of this study showed an improvement in knowledge about lithium and adherence to medication as measured by lithium serum levels. However, in Dogan and Sabaciogullari's study (2003), prior to conducting the study, the researchers had developed relationships with the subjects during the subjects' hospitalization. As mentioned earlier, therapeutic alliance is one among numerous factors related to medication adherence, a confounding effect of the prior relationship could contribute to the positive outcomes particularly adherence behavior.

Therefore, it is too early to conclude that the effectiveness of a brief individual education program on behavior outcomes would contribute to changed behavior only from gained knowledge. According to a remark by Scott and Tacchi

(2002), it should not be assumed that increasing an individual's knowledge about medication would directly improve the individual's medication adherence. Lee, Wing, and Wong (1992) assured that just giving the information may not be enough to make patients become compliant with medication. Moreover, Donovan and Ward (2001) had criticized the traditional education program designed for only giving information while expecting behavioral outcomes as lacking of theoretical explanatory credits.

Thus, to make an education program theoretically sound, Donovan and Ward (2001) and Donovan et al. (2007) developed a representational approach based on the Common Sense Model (Leventhal, Meyer, & Nerenz, 1980) and learning process of conceptual change (Hewson & Hewson, 1981; Hewson, 1992; Posner, Strike, Hewson & Gertzog, 1982). This educational approach focuses on modifying the existing cognitive illness representation or illness perception into the one that is beneficial for a person to have a healthy response to their illness or health problems. Cognitive illness representation is a central concept in the Common Sense Model and is the key explainer of how people select coping strategies when confronting health threats. Medication adherence can be considered as a coping strategy. Cognitive illness representation is an organized system of beliefs, knowledge, ideas, and information related to illness and it becomes well aware through people's perception of illness along the five components of cognitive illness representation (identity, cause, timeline, consequences, and controllability). Besides, it is dynamic and developed from several sources of information such as individual past experience and current body sensations so that cognitive illness representation varies across individuals and may not be concordant with medical professionals (Leventhal et al., 1980). Even though cognitive illness representation is something that we can change, it is not easy to change through the

traditional education approach. Thus, Donovan and Ward (2001) utilized the learning process of the conceptual change model as a strategy to change cognitive illness representation. This representational approach to patient education not only has theoretical strength but also empirical support. This approach has been applied in a number of education programs and has shown some promising results on behavior outcomes (Donovan & Ward, 2001; Heidrich et al., 2009; Ward et al., 2008; Ward et al., 2009). In sum, this representation approach appears to call for attention from researchers who aim to provide a promising and practicable intervention program to enhance medication adherence.

In the Common Sense Model, Leventhal et al. (1980) stated that information from the external social environment such as culture is one of the basic sources of information influencing cognitive illness representation. Karasz (2005) stated that illness representation can be reflected differently based on different cultural backgrounds. Karasz studied about the illness representation of depression among two diverse cultural groups in the United States of America. European American women and South Asian women had different illness representations of depression. South Asian women were more likely to describe depression as situational stress or a life problem, whereas European women were more likely to describe it as biological problems. In another study by Kabir, Ilyasu, Abubakar and Aliyu (2004) about the perception and beliefs about mental illness among adults in Nigeria, they found that there were seven items perceived as causes of mental illness. These included misuse of drugs (34 %), God's will (18.8 %), accidents/trauma (11.7 %), heredity (10.5 %), family conflict (5.5 %), and financial distress/poverty (1.2 %). People have certain beliefs about mental illness and these beliefs are based on prevailing local culture (Asuni as cited in Kabir et al.,

2004). This is so in Indonesia where there are a number of beliefs related to mental illness. Indonesian people believe that their illness comes from God (Allah), black magic and the misuse of drugs, and this may affect their health behavior, medication adherence in particular. In Medan, generally in North Sumatera, there is no known specific intervention study that can enhance medication adherence, especially in patients with bipolar disorder. Nurses and health care professionals usually use routine care procedures in the hospital to enhance a patient's medication adherence. Usually routine care focuses on the patient's problems, especially problems related to symptom management, providing education about the patient's medication, the frequency of taking medication, and indications and side effects of the medication. Based on the researcher's work experience, patients follow this routine care and take medication because of the order from the nurse or another health care professional. However, as criticized by the founders of the common sense model, sustainability of the changing behaviors is in caution if the behaviors were changed only by external force. Likewise, the external force as such order from health care professional may change the behaviors of medication adherence but is not enough to maintain the behaviors. Therefore, the researcher is interested in conducting Illness Representation-based Education Program (IREP) in Medan, and hopefully, the program of this study can be used as a guideline for taking care of patients with bipolar disorder both at the hospital and home.

### **Objectives of the Study**

1. To compare the medication adherence among patients with bipolar disorder before and after receiving the Illness Representation-based Education Program (IREP).
2. To compare the cognitive illness representation among patients with bipolar disorder before and after receiving the Illness Representation-based Education Program (IREP).

### **Research Questions**

1. Is medication adherence among patients with bipolar disorder after receiving the Illness Representational-based Education Program (IREP) higher than before receiving the Illness Representation-based Education Program?
2. Is cognitive illness representation among patients with bipolar disorder after receiving the Illness Representational-based Education Program (IREP) changed compared to before receiving the Illness Representation-based Education Program?

### **Conceptual Framework**

The Illness Representation-based Education Program (IREP) for bipolar disorder is developed by applying the representational approach to patient education proposed by Donovan et al. (2007), in order to enhance medication adherence among patients with bipolar disorder. Representational approach to patient education refers to understanding the patient's pre-existing representation of illness before giving new information. Basically, the representational approach to patient education is based on

the Common Sense Model (CSM) proposed by Leventhal et al. (1980) and process of the Conceptual Change Model proposed by Hewson and Hewson(1981); and Posner et al. (1982).

Leventhal et al. (1980) asserted that people have their own common sense or representation about their health problems which is not necessary to be concordant with the medical model of illness. The central focus of the CSM is cognitive illness representation. It is an organized system of thoughts/beliefs regarding health problems and is used to organize, analyze and interpret any information including information from internal sources such as body sensations and from external sources such as any educated information. Cognitive illness representation can be explicitly assessed through the patients' perceptions of their illness. Health care providers should use cognitive illness representation to guide nursing intervention as it is proposed to have influences on how people select coping strategies to handle their health problems. According to this assumption, therefore, treatment/medication adherence is hoped for when patients' cognitive illness representations are consistent with the illness conceptions of the medical model. Cognitive illness representation has five dimensions of identity (how a person describes symptoms and labels the illness), cause (beliefs related to the cause of the illness), timeline (beliefs about the course of the illness such as acute, chronic, or cyclic), consequences (beliefs about consequences of a threat), and cure/control (beliefs about curability or controllability of the illness). In Donovan et al.'s representational approach, these five dimensions are used to guide the structure of a patient education program (Donovan et al., 2007)

As cognitive illness representation is not easy to change, instead of using a conventional education approach, Donovan and colleagues (2007) have applied

the learning process of the conceptual change model into their representational approach to patient education. Based on the conceptual change model (Hewson & Hewson, 1981; Posner et al., 1982) the learning process may involve changing a person's conception by the interaction between the new and existing conception. It is the process by which persons' conceptions change under the impact of new conceptions. If the new conception is not contradictive with the individual's existing conceptions, the learning process will go on without any difficulty. However, when the new conception is not compatible, change can occur when a person is dissatisfied with his/her existing conceptions, and the offered alternative conceptions are perceived as intelligible (sounds scientific/logical), plausible (believe it to be true) and beneficial (useful) to him/her.

Taken together this learning process and cognitive illness representation, in the representational approach, Donovan et al. (2007) proposed seven process components; (1) representational assessment, the process where a patient is encouraged to describe cognitive illness representation along five dimensions, (2) exploring misconceptions, such as gaps, errors, and confusions, (3) creating conditions for conceptual change, encouraging the patient to think about the current perceptions that are misconceptions, gaps and confusions, and to recognize the limitations of the current perception (4) introducing replacement information, (5) summary, (6) goal setting and planning, and (7) following-up contact.

Medication adherence has been defined somewhat differently across researchers and health care professionals. Medication adherence refers to (1) a patient's agreement to take medication and continue to use it for a period of time (Velligan et al., 2006), (2) a patient's voluntary behaviors to take their recommendation medication from his/her own commitment, it is more likely that the patient has motivation and



will take action (Vuckovich, 2010), ((3) a patient's choice to take his/her medication under his/her own responsibility and he/she can interpret their medication correctly because of his/her understanding (Patel & David, 2007), (4) patients have their own choice to plan their behavior to take medication and implement their medication by their own motivation and action (Brawley & Culos-Reed, 2000), (5) the patients' attempt to maintain health related to behaviors to take their medication based on their active participation and agreement (Cohen, 2009), (6) adherence is the patients' behavior to take their medication as independent, intelligent, and autonomous people, therefore, the patients are voluntarily and actively participating in their medical treatment (Luthfey & Whisner, 1999), and (7) the patient's behavior matches agreed recommendations from the prescriber (Horne, 2006).

Medication adherence involves quite complex behaviors reflecting an integration of a person's mental state such as a person's willingness as well as external behaviors such as the actual actions of medication taking. In conclusion, for use in this study the construct of medication adherence is considered consisting of the following four attributes; (1) taking medication voluntarily (taking medication by their own commitment/agreement), (2) taking medication continuously, (3) taking medication actively (taking medication from their own responsibility/plan/action/active participation), and (4) taking medication correctly as prescribed (taking medication in the correct dose, time, and type of medication).

The relationship between illness representation of the Common Sense Model, the Conceptual Change Model, and medication adherence is depicted as in Figure 1.

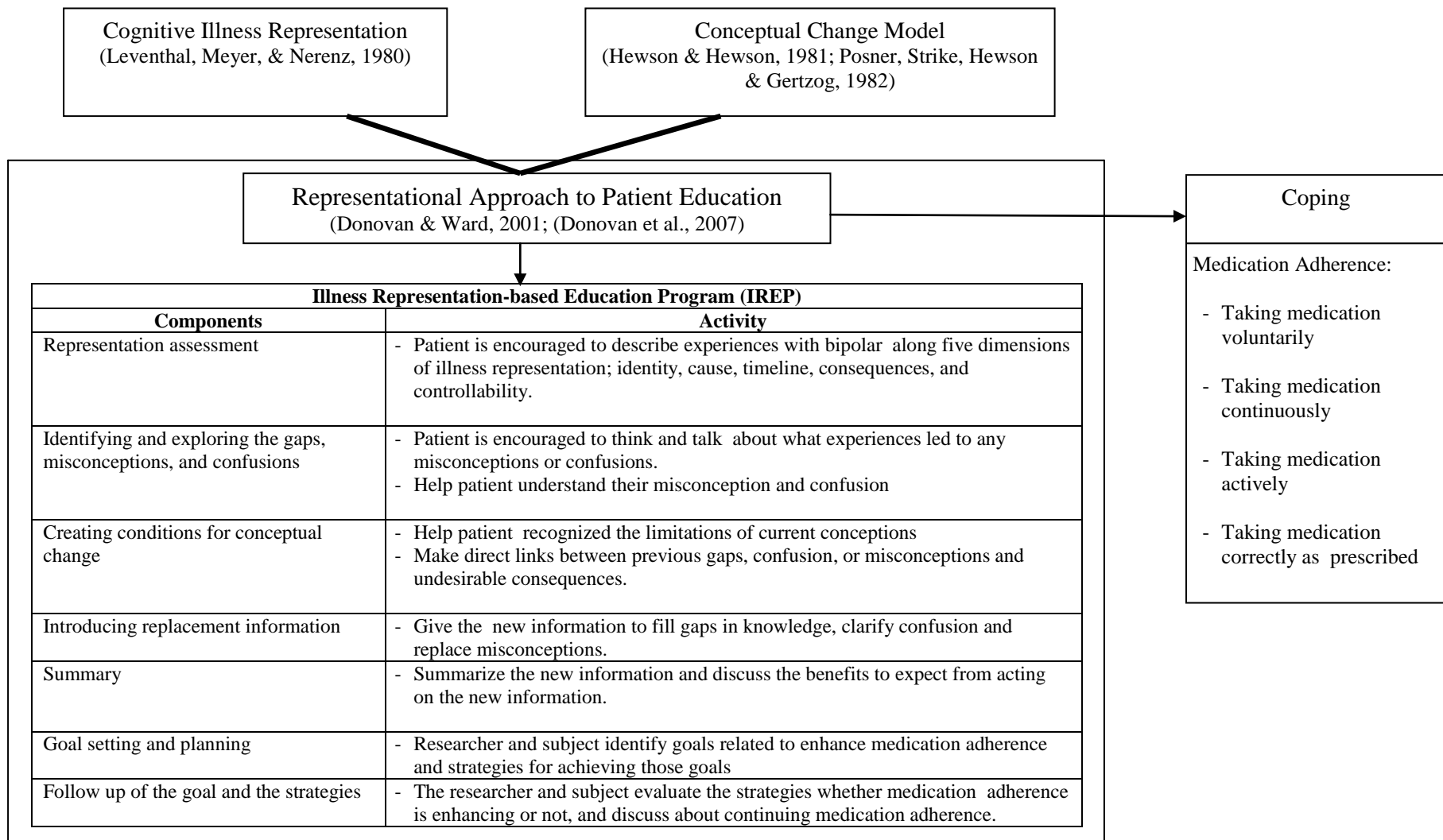


Figure 1. Conceptual framework of

## **Research Hypotheses**

1. Medication adherence among patients with bipolar disorder after receiving the illness representation-based education program is higher than before receiving the illness representation-based education program.
2. Cognitive illness representation among patients with bipolar disorder after receiving the illness representation-based education program is changed compared to before receiving the illness representation-based education program.

## **Definition of Terms**

The Illness Representation-based Education Program (IREP) for bipolar disorder is a tailored education program to improve medication adherence among patients with bipolar disorder by working through individual cognitive illness representations. The essence of this program is to create conditions favored for patients to assimilate the needed and useful information into their illness cognitive framework. The program consists of the following seven process components; (1) representation assessment, (2) identifying and exploring the gaps, misconceptions, and confusions, (3) creating conditions for conceptual change, (4) introducing replacement information, (5) summarizing, (6) goal setting and planning, and (7) following up of the goal and the strategies. It is a two-week program that is conducted in two phases. In the first phase, an individual meeting was undertaken to work on the first to the sixth step of the program. This phase took approximately 70 minutes. The second phase was a telephone follow-up to evaluate whether the goal and strategies were achieved or not. This phase was conducted one week after the first phase.

Medication adherence refers to medication-taking behaviors covering these ranges of behavior attributes including (1) taking medication voluntarily, (2) taking medication continuously, (3) taking medication actively, and (4) taking medication correctly as prescribed. Medication adherence was measured by using the Medication Adherence Behavior Questionnaire (MABQ) developed by the researcher. The MABQ was developed by using the above four categories. This measurement consists of 15 items with positive and negative statements responded to on a Likert-scale.

### **Scope of the Study**

This study was conducted to assess the effects of the Illness Representation-based Education Program (IREP) on medication adherence among patients with Bipolar Disorder. Thirty patients, who were in the Out-Patient Department of the Psychiatric Hospital, Medan, Indonesia, were included in the group. This study was conducted during May to November 2014, at the psychiatric hospital in Medan, North Sumatra Province, Indonesia.

### **Significance of the Study**

The Illness Representation-based Education Program (IREP) for bipolar disorder was developed based on a representational approach which is a theoretical-based approach for patients' education program. This approach aims to enhance patients' responses to health problems through a learning process that would help with the assimilation of information beneficial for healthy responses to their illnesses. Eventually the patients can be active problem solvers so that they become more independent and are less of a burden on their caregivers.

This approach has been empirically tested and demonstrated its positive outcomes on illness reponding behaviors such as pain medication management. The IREP can be an option to apply in regular nursing practice since it does not require special training as such Cognitive Behavioral Therapy (CBT) and the program is not time-consuming. Hopefully, the findings of this study will provide evidence to support a brief-education program for health care providers especially psychiatric nurses. The finding of this study will be used as information for future studies that are related to medication adherence, especially in patients with bipolar disorder.

## **CHAPTER 2**

### **LITERATURE REVIEW**

In this chapter, several aspects relevant to the study are reviewed and presented as follows:

1. Overview of bipolar disorder
  - 1.1 Classification of bipolar disorder
  - 1.2 Signs and symptoms of bipolar disorder
  - 1.3 Causes of bipolar disorder
  - 1.4 Pathophysiology of bipolar disorder
  - 1.5 Course of bipolar disorder
  - 1.6 Consequences of bipolar disorder
  - 1.7 Pharmacological treatment for bipolar disorder
  
2. Medication adherence
  - 2.1 Definition of medication adherence
  - 2.2 The importance of medication adherence for bipolar disorder
  - 2.3 Factors influencing medication non-adherence in patients with bipolar disorder
  - 2.4 Measurement of medication adherence

### 3. The Common Sense Model

3.1 Cognitive illness representation

3.2 Coping

3.3 Appraisal

3.4 Cognitive illness representation and medication adherence

### 4. The Conceptual Change Model

4.1 A model of conceptual change

4.2 Learning process in the conceptual change model

### 5. The Illness Representation-based Education Program

5.1 RIDcancerPain

5.2 RIDPAIN

5.3 IRIS in older breast cancer survivors

5.4 WRITE symptoms

5.5 RIDcancerPAIN+

### 6. Summary

## **Overview of Bipolar Disorder**

Bipolar disorder, known as manic-depressive illness, is a cyclical mood disorder characterised by changes of affect, cognition, and behavior (Macneil, Hasty, Conus, Berk, and Scottt, 2009). Bipolar disorder involves extreme moods swings from episode of mania to episode of depression (Videback, 2011) that can impact on cognitive function (Goodwin, 2009). A person's first episode of bipolar disorder is a depressed phase, he or she might be diagnosed with major depression; a diagnosis of bipolar disorder may not be made until the person experiences a manic episode (Videback, 2011). Bipolar disorder is a brain disorder that causes unusual shifts in moods, energy, activity levels, and the ability to carry out day-to-day-tasks (National Institute of Mental Health, 2009). Moreover, bipolar disorder is defined on the basis of manic symptoms of varying severity (Murray & Johnson, 2010).

### **Classification of bipolar disorder**

The American Psychiatric Association [APA] (2000) has categorized this disorder and introduced Diagnostic and Statistical Manual of Mental Disorder: Fourth Edition – Text Revision (DSM-IV-TR), as follows:

***Bipolar I disorder.*** It presents that a person must have experienced at least one manic episode (Macneil et al., 2009). Patients with bipolar I disorder experience the highest level of severity with respect to elevated moods (Yatham & Maj, 2010).

There are two episodes in bipolar I disorder; major depressive episode and mania episode. A major depressive episode is diagnosed through the presence of a depressed mood or loss of interest or pleasure for most of the day, nearly every day for two weeks or more. Meanwhile for a mania episode, it is diagnosed through



the presence of elevated, expansive, or an irritable mood lasting at least one week, and of three or more from seven additional symptoms (or four or more if the mood is only irritable) (Macneil et al., 2009). In fact, mania represents the primary defining feature of bipolar disorder (Yatham & Maj, 2010).

***Bipolar II disorder.*** This presents as a person having had one or more depressive episodes, and at least one hypomanic episode, with no manic or mixed episode (Macneil et al., 2009). The criteria of bipolar disorder II are essentially the same as for mania, however, the manifestation is less severe (Yatham & Maj, 2010). Hypomania can be seen as a milder form of mania. It draws from the same list of seven symptoms as mania, but the symptoms only need to have been present for four days and cannot include psychotic symptoms. The patient does not require hospitalization during this time or nor does it cause marked impairment in social or occupational function. Moreover, Jamison (as cited in Aubry, Ferrero, Schaad, & Bauer, 2007) stated that in DSM-IV, hypomania episodes can be distinguished from mania essentially by a lesser severity (rarely requiring hospitalization), the absence of psychotic symptoms, a less profound social role dysfunction and a shorter duration.

***Cyclothymic disorder.*** For at least two years, the person has had numerous periods of hypomania and depressive symptoms that do not meet the criteria for a major depressive episode, and has not been without these for more than two months at a time. Cyclothymic, like bipolar disorder II, is characterized by severe impaired symptoms the context of high degree chronicity (Macneil et al., 2009).

### **Sign and symptoms of bipolar disorder**

According to the Diagnostic and Statistical Manual of Mental Disorder, 4<sup>th</sup> edition, text revision (DSM-IV-TR), the symptoms of bipolar disorder are explained based on two episodes of bipolar disorder (mania episode and depressive episode).

For those who are experiencing a mania episode, signs and symptoms are explained as the following:

***Cognition disturbances.*** Attention can be intense but only for short periods. Concentration is poor because of distractibility, so that the patient can not spend more than a few minutes on any task before setting off on another track. Memory is perceived to be good but may actually be poor because of the distraction and lack of focus. The idea and thoughts flow quickly, freely and fast (Hunt, 2005).

***Mood disturbances.*** Patients may exhibit extreme mood swings, with irritability or sudden outbursts of misplaced rage. They also have feelings such as euphoria, grandiosity, and power. Because of these feelings, they may ignore the environmental boundaries. Meanwhile, at the same time, they have little to no insight that their behaviors are inappropriate (Mohr, 2009). Moreover, for mood disorder symptoms in patients with bipolar disorder, the patient has an extreme change in mood. The patient can not tolerate any disagreement but she/he tries to find arguments everywhere. The need for sleep is usually reduced because the patient feels that she/he does not need to sleep as much every day. The patient also has much energy so that she/he looks very active and strong (Hunt, 2005).

***Behavior.*** They usually have sleep disturbances, usually awakening earlier each day and feeling full of energy. Work output is decreased, with the patient feeling distracted or restless. The patient with mania may become a shopaholic and

spend thrift with their money to buy something flamboyant. Patients tend to laugh and talk excessively, and inappropriately (Mohr, 2009). In regards to the patient's speech, the patient may talk non-stop and be difficult to interrupt. Moreover, the patient's appetite may be a little changed though the patient will lose weight (Hunt, 2005).

Meanwhile for those who are in a depressive episode, the symptoms are reversed from the mania episode, as described following:

***Cognition disturbances.*** Patients have negative thoughts because of unpleasant thoughts going round and round in their head so that the only things they can concentrate on are the negative ideas dominating their thinking. During a depressive phase, patients will almost certainly see themselves as a worthless, useless person whether for their family or surrounding people (Hunt, 2005).

***Mood disturbances.*** The basic symptom of depression has to be a change of mood. The mood is usually described as sad, unhappy, down or even just 'depressed'. Some patients experience prominent anxiety rather than feeling down (Hunt, 2005).

***Behavior.*** The patient usually has low energy levels because the patient feels tired all the time, even minor tasks seem too much and some will spend the whole day in the bed and not do anything. The lack of energy may be obvious to others as they see the patient just sitting, doing nothing, and hardly moving. It means that, the patient feels tired and has a lack of energy for no reason. The patient may be very agitated, pacing around wringing his or her hands, not being able to sit down, and not knowing what to do with his or her self. The patient also has the same condition as a mania episode in regards to appetite and sleep in which levels are decreased. In addition, during a depressive episode some patients may have some physical symptoms, such as backache, headaches, stomach pains, and weight loss (Hunt, 2005).

### **Causes of bipolar disorder**

**Genetic theory.** According to Yatam and Maj (2010), who have reviewed many studies related to genetic theory, there are several studies that are concerned with the possibilities of the causes of bipolar disorder. Broadly speaking, these studies are grouped into three parts; family studies, twin studies, and adoption studies. (1) *Family studies.* Bipolar disorder family studies showed that children of parents with bipolar disorder have a 9-fold increase in lifetime bipolar disorder risk. Moreover, a spectrum of mood disorders is found among the first-degree relatives of bipolar disorder: bipolar disorder I, bipolar disorder II with major depression, and schizo-affective disorder. The family studies detected a small increase in risk for a disorder with a base rate of 1-2% in the general population. (2) *Twin studies.* The twin studies showed that monozygotic twins reported significantly higher in concordance rates compared to that for dizygotic twins. (3) *Adoption studies.* The risk for bipolar disorder for a relative of adopted patients (related by law as in adopted) was similar to the risk in relatives of bipolar patients who were not adopted.

**Biological theory.** There are two influences in biological causes of bipolar disorder including neurochemical theories and neuroendocrine theories (Videbeck, 2011). Neurochemical influences of neurotransmitters focus on serotonin and norepinephrine as the two major biogenic amines implicated in mood disorder. Deficits of serotonin found in the blood or cerebrospinal fluid occur in people with depression (Tecot cited in Videbeck, 2011). Also, norepinephrine levels may be deficient in depression and increased in mania. This catecholamine energizes the body

to mobilize during stress and inhibits kindling. Kindling may underlie the cycling of mood disorder as well as addiction (Akiskal as cited in Videbeck, 2011).

Meanwhile, in neuroendocrine theories, hormonal fluctuations are being studied in relation to depression. Mood disturbances have been documented in people with endocrine disorders such as those of the thyroid, adrenal, parathyroid, and pituitary glands. Elevated glucocorticoid activity is associated with the stress response, and evidence of increased cortisol secretion is apparent in about 40 % of clients with depression, with the highest rates found among older clients, and about 5 % to 10 % of people with depression have thyroid dysfunction, notably an elevated thyroid-stimulating hormone (Thase as cited in Videbeck, 2011).

Moreover, biology theories are also related to brain disorder. Some imaging studies show how the brains of people with bipolar disorder were highly different from the brains of healthy people or people with other mental disorders. For instance, in Gogtay's study as cited in the National Institute of Mental Health, using MRI found that the pattern of brain development in children with bipolar disorder was similar to that in children with "multi-dimensional impairment," a disorder that causes symptoms that overlap somewhat with bipolar disorder and schizophrenia. This study result suggested that the common pattern of brain development can be linked to general risk for unstable moods (National Institute of Mental Health, 2009).

***Psychological theory.*** Another cause is psychological causes. Despite the result of a lot of study that strongly proved biological factors and genetics as etiology to bipolar disorder, psychological factors can be another factor of the causes (Scott as cited in Macnail et al., 2009). Manic defense and self esteem are the most common causes. A study that was done by Pardoen (as cited in Macnail et al., 2009) showed

that low self esteem can be a basic component of depression. Another psychological cause is stressful life events (Macneil et al., 2009) including unemployment and divorce which both increased the likelihood of a first admission (Kessing, Agerbo, & Mortensen, 2004).

### **Pathophysiology of bipolar disorder**

*Monoamines and acetylcholine.* Monoaminergic systems are extensively distributed throughout the network of the brain stem, limbic, striatal, and prefrontal cortical neuronal circuits thought to support the behavioral and visceral manifestations of mood disorders (Drevets as cited in Yatham & Maj, 2010). There are three parts of the monoamines which are catecholamine, dopamine, and norepinephrine. These all are synthesized from the amino acids phenylalanine and tyrosine. The monoaminergic hypothesis of mood disorder has been tested using monoamine depletion and has shown that the synthesis of catecholamine critically depends on the action of tyrosine hydroxylase. This step can be reversibly inhibited by the administration of AMPT, which then inhibits the production of norepinephrine and dopamine. Catecholamine depletion results in the attenuation of symptoms of acute mania in patients treated with antipsychotic drugs (Yatham & Maj, 2010).

Meanwhile, cholinergic transmission has long been implicated in the pathophysiology of mood disorder. This has been proven by Janowsky's study (as cited in Yatham & Maj, 2010) that stated that depression represents an over abundance of central acetylcholine, relative to central adrenergic neurochemicals. In Sun's study (as cited in Yatham & Maj, 2010) related to serotonin, it showed that there was increasing serotonin transporter mRNA levels in the frontal cortex of bipolar patients.

***Amino acids and GABA.*** The amino acids glutamate (Glu), gamma-aminobutyric acid (GABA) and glycine (Gly) serve as neurotransmitters in most mammalian central nervous system synapses (Sanacora as cited in Yatham & Maj 2010). Through its action as the major inhibitory neurotransmitter in the brain, GABA modulates an array of behavioral physiological mechanisms related to mood pathology, including sleep, feeding behaviour, pain responsiveness, cardiovascular regulation, thermoregulation and locomotor activity (Paredes as cited in Yatham & Maj, 2010).

Glutamate is the most abundant excitatory neurotransmitter in the brain, with an estimated presence in 60 % of the synapses (Sanacora as cited in Yatham & Maj, 2010). Glutamate in the brain originates from two sources: (1) synthesized *de novo* from glucose via the Krebs cycle and transamination of alpha-ketoglutarate; and (2) from glutamine that is synthesized, transported into nerve terminals, and locally converted into glutamate by glutaminase. Glutamate is released from the nerve terminal by a calcium-dependent exocytosis following cell depolarization (Cooper as cited in Yatham & Maj, 2010). Changes in glutamate levels have been reported in plasma and cerebrospinal fluid of individuals afflicted with bipolar disorder. Altamura's study (as cited in Yatham & Maj, 2010) reported higher glutamate plasma levels in patients with mood disorder, including bipolar disorder, compared to neurological patients with tension headache or patients with schizophrenia, anxiety or an organic mental disorder. Another study by Palomino and colleagues (as cited in Yatham & Maj, 2010) showed that decreased levels of plasma glutamate during the first psychotic episode were part of either bipolar disorder or schizophrenia.

GABA is the most abundant inhibitory neurotransmitter in the mammalian brain. It is estimated approximately 40 % of neurons use GABA as a neurotransmitter

(Hendry as cited in Yatham & Maj, 2010). GABAergic interneurons are abundant in mood-related structures of the forebrain, including anterior cingulate cortex, hippocampus and amygdala. The GABAergic system extensively interacts with the dopaminergic, glutamatergic, and serotonin system as well as the hypothalamo-pituitary-adrenal axis (Jones as cited in Yatham & Maj, 2010). Abnormalities in the GABAergic system have been identified in the GABA level, neuron and transporter density, as well as GABAergic receptor functioning in postmortem brain tissue of bipolar disorder patients. GABAergic interneurons can be classified by their immunoreactivity for the calcium-binding proteins parvalbumin, calbindin, and calretin (Grateron as cited in Yatham & Maj, 2010). Using these markers, the majority of immuno histochemical studies in the post-mortem brains of bipolar patients found a reduced number of calbindin and parvalbumin-positive cells in regions that participate in mood regulation including the anterior cingulate cortex, hippocampus, and dorsolateral prefrontal cortex, suggesting that bipolar disorder might be associated with decreased levels of GABA (Rajkowska as cited in Yatham & Maj, 2010).

### **Course of bipolar disorder**

Macneil et al. (2009) reviewed many articles and studies related to the onset of the illness and concluded that the first symptom of bipolar disorder occurred in young people, and many recent studies found that bipolar disorder generally has its onset in adolescence. This is in line with Hunt (2005) who stated that most patients with bipolar disorder will have had their first major episode of affective illness in their twenties. Hunt also added, later onset is uncommon and most patients who have experienced



the first symptoms in old age, have in fact had the symptoms while they were younger but the symptoms have not become recognizable until the patients have gotten older.

The important question is that does an early onset mean a more severe condition? A severe condition can happen at any age including younger ages, likewise the illness can be chronic or cyclic at any age, depending on how young people deal with the illness and the treatment. This means that how the patients deal with treatment will affect the severity of their illness (Hunt, 2005). Hunt stated that this happens because the treatment of young people with bipolar disorder can be very challenging because of the nature of the teenager. According to Hunt, teenagers are more likely to have complications such as drug misuse and poor adherence to treatment.

As stated earlier, there are two episodes of bipolar disorder, sometimes mania switching into depression unpredictably. Some patients have a regular pattern of switching between these episodes, but others do not. Mostly, a depression episode tends to move from a mild to severe condition because its onset occurs over a few weeks rather than a few days. A depressive episode is more chronic than a manic episode (Hunt, 2005). In addition, most of the literature states that bipolar disorder is a chronic condition that can adversely affect a person's life, has periods of remission and relapse as well as increasing sufferers risk for suicide attempts and suicide deaths, and bipolar disorder is a global burden (Ayuso-Mateos, 2001; Proudfoot et al., 2009; Simon, Hunkeler, Fireman, Lee, & Savarion, 2007; & Ustun, Ayuso-Mateos, Chatterji, Mathers, & Murray, 2004).

In regards to the chronicity of the course of the illness in bipolar disorder, the National Institute of Mental Health Collaborative Depression Study (NIMH CDS) (as cited in Yatham and Maj, 2010) found that people who get bipolar disorder in early

life (around age  $\leq 20$ ) still have this illness during the first 10 years of follow-up after the end of the intake episode. It is very clear that bipolar disorder, both BP-I and BP-II, is intensely chronic with the patients being afflicted from the illness approximately half of the time, of up to 20 years of prospectively observed follow-up.

### **Consequences of bipolar disorder**

Disturbances in the psychosocial functioning in patients with bipolar disorder results in the tasks of daily living becoming difficult for these patients (Levy & Manove, 2012). In addition, self-neglect is recognized as another negative consequence. Self-neglect is the situation where a person ignores or is unaware of who they are or what they have to do. This condition leads them to poor hygiene, poor diet, and non-adherence to their treatment regimen (Nieng, 2011). Another consequence is cognitive impairment. This is mentioned as the strongest predictor of psychosocial disability in patients with bipolar disorder. This cognitive disturbance results in difficulties for bipolar disorder patients in accomplishing tasks of daily living and is a predictor for poor academic performance, low vocational outcome, reduced social adjustment, and diminished quality of life (Levy & Manove, 2012).

### **Pharmacological treatment of bipolar disorder**

#### **Medication classification**

*Antidepressants.* Antidepressants are the most common drugs used to treat bipolar disorder (Schatberg, Cole, & DeBatista, 2007). There are four major categories of antidepressants which are cyclic antidepressants, monoamine oxidase inhibitors (MAOIs), selective serotonin reuptake inhibitors (SSRIs), and atypical

antidepressants. Cyclic antidepressants can relieve symptoms of hopelessness, helplessness, anhedonia, inappropriate guilt, suicidal ideas, and daily mood variation (cranky in the morning and better in the evening). Selective serotonin reuptake inhibitors (SSRIs) are the newest category of antidepressants and are effective for most clients. The drug's action is specific to serotonin reuptake inhibition that can produce few sedating, anticholinergic, and cardiovascular side effects. This drug is also safe to use for older adults. Atypical antidepressants are used when the client has an inadequate response to or side effects from SSRIs. The last, monoamine oxidase inhibitors (MAOIs) are used infrequently because of potentially fatal side effects and interactions with numerous drugs, both prescription and over-the-counter-preparations (Videbeck, 2011).

Contemporary treatment guidelines recommend that antidepressants can be used only in combination with mood stabilizers to lessen the risk of affective switch into mania or hypomania. Bupropion and SSRIs are the most commonly used antidepressants in bipolar disorder because they are thought to have a lower risk of inducing mania. These antidepressants have been associated with mood destabilization by causing switching into mania during the acute treatment of bipolar depression (Kasper, 2003).

*Mood stabilizers.* The first mood stabilizer applied to treat bipolar disorder was Lithium salts and this kind of drug is effective not only in alleviating mania but also as a prophylaxis against both manic and depressive cycles. Lithium is approved by the FDA (Food and Drug Administration) for the treatment of acute mania and as maintenance therapy to prevent or diminish the intensity of subsequent episodes in manic-depressive (Schatberg et al., 2007). Moreover, Lithium salts play a therapeutic and prophylactic role in the treatment of resistant depression (Aubry et al., 2007).

In general, the clinical indications of Lithium can be divided into four main areas; (1) to control rapidly acute, overt psychopathology as in mania or psychotic agitation, (2) to modify milder, ongoing or frequent but episodic clinical symptoms such as chronic depression or episodic irritability, (3) to establish prophylactic maintenance regimen to avert future affective or psychotic episodes, and (4) to enhance the effect of antidepressants in patients with major depressive episodes (Schatberg, Cole, & DeBatista, 2007).

Anticonvulsants are also included in mood stabilizer medication. For examples, carbamazepine and valproate have been widely used in the treatment of bipolar mania. They are commonly used as acute and maintenance treatments for mania. These anticonvulsants may be more effective than lithium in patients experiencing rapid cycling. Carbamazepine was the first agent after lithium to be advocated for long-term treatment of bipolar disorder (Okuma as cited in Goodwin, 2009). Carbamazepine is often used in combination therapy with lithium, particularly for patients with mixed states. For patients who are not responding to a single agent, it may be necessary to combine two mood stabilizers. Lithium–carbamazepine and lithium–divalproex-sodium are the commonly used combinations, resulting in less problematic drug interactions than other possible combinations (Mendlewics, Souery, and Rivelli, 1999).

Another medicine of this group is Lamotrigine. Lamotrigine appears to be a promising new prophylactic treatment for bipolar depression. Lamotrigine was significantly more efficacious than placebos in the treatment of bipolar depression in early clinical studies (Friye as cited in Goodwin, 1999).

*Antipsychotics.* According to the American Psychiatric Association's recommendation, some primarily antipsychotics function as an adjunct to mood

stabilizers in the treatment of severe mania. Thus, a number of atypical antipsychotics are often prescribed for manic symptoms, especially in the presence of psychotic features such as delusions and hallucinations (Kasper, 2003). They are prescribed for some patients in depot formulations, as monotherapy or in combination with other agents. Antipsychotic agents may be appropriate for the long-term management of bipolar patients especially where psychotic features are prominent (Goodwin, 2009).

### **Side effects of medication of bipolar disorder**

*Antidepressants.* Selective serotonin reuptake inhibitors (SSRIs) have the most common side effects in gastrointestinal symptoms including nausea, diarrhea, cramping, heartburn, and other symptoms of gastrointestinal distress. Another common side effect of SSRIs is related to central nervous system (CNS) activation, including insomnia, and agitation in the course of treatment (Schatberg et al., 2007).

Meanwhile, the common side effects of monoamine oxidase inhibitors (MAOIs) include hypotension, hyperpirexia reactions, sexual impotence, insomnia during the night, sedation, muscle cramps, constipation, dry mouth, and weight gain. The most common side effect of MAOIs is dizziness. Dry mouth and weight gain are also common in Cyclic antidepressants side effects (Schatberg et al., 2007).

*Mood stabilizers.* Up to 75% of patients treated with lithium experience some side effects. The most common side effect of Lithium is in renal function. Lithium may cause functional change in the kidneys, which has been reported to be typically benign and reversible (Gitlin as cited in Turan et al, 2001). The common renal side effect of Lithium is polyuria. Lithium induced polyuria is associated with impaired renal concentrating ability, which is possible due to the resistance of the

collecting ducts to the antidiuretic hormone (ADH). The polyuria and polydipsia observed in patients on the maintenance of Lithium treatment are generally considered to be harmless and reversible (Walker as cited in Turan et al, 2001). To support this idea, a study showed that the effect of long-term use of Lithium can induce growth factor production of the human body such as granulocyte megakaryocyte, macrophage, etc (McGrath, Liang, Alberico, Quesenbery, 1987).

Potential long-term complications with lithium therapy are renal impairment, cardiac rhythm disturbances, and hypothyroidism; thus, baseline assessment for pregnancy, potential cardiovascular diseases, renal and thyroid function, and hematology and electrolyte status are recommended (Jibson as cited in Williams et al., 2011). Moreover, Lithium also produces side effects in the neurological system such as tremors and Parkinsonian (Aubry et al., 2007).

The side effects of carbamazepine include gastrointestinal adverse events, sedation, thrombocytopenia, tremors, excessive weight gain and alopecia (Williams et al., 2011). Moreover, the combination of valproate and carbamazepine may increase the risk of toxicity due to competition for protein-binding sites between the two compounds (Mendlewics, Souery, & Rivelli, 1999). In a study by Licht (as cited in Williams et al., 2011) about a clinical practice trial comparing Lamotrigine to Lithium, the results showed that the most commonly reported adverse effects for lamotrigine were headaches, dizziness, acne, and weight gain.

To sum up, the side effects of bipolar disorder medication include (1) central nervous system (CNS) that consists of tremors and Parkinsonian (2) disturbances in renal function, (3) headaches, and (4) weight gain. Therefore, these side effects can influence medication non-adherence among patients with bipolar disorder.

## **Medication Adherence**

Medication adherence is important for patient with bipolar disorder, to prevent relapse and re-hospitalization, to reduce symptoms severity, to gain a better control of mood swings and to improve functioning and quality of life. However, in fact, non-adherence to medication is a common problem in the psychiatric area including patients with bipolar disorder (Lingam & Scott, 2002) with the incidence ranging from 20% to 60% (Berk, Berk & Castle, 2004; Colom & Lam, 2005; Lingam & Scott, 2002). Prior to helping to enhance medication adherence in patients, health care providers indeed need to understand the phenomenon of medication adherence. This section provides a review regarding the definition of medication adherence, the importance of medication adherence for patients with bipolar disorders, and the factors influencing medication adherence in patients with bipolar disorder.

### **Definition of medication adherence**

In the literature review, there are three terms related to a patient's medication taking behavior; compliance, adherence, and concordance. In terms of compliance and adherence, these terms reflect different meanings in a patient's action in taking medication. However, some authors have often used compliance and adherence interchangeably because they want to shift away from negative connotation of compliance which is coercion. Even though they used adherence to replace compliance, however, they may use the same measurement. For instance, in Berk's literature review (as cited in Berk et al., 2010), some studies used adherence and the others used compliance. However, among those studies, the same measurement to measure variables of taking medication was used.

Currently, since compliance and adherence have different meanings, some authors have defined these two terms. In terms of compliance, Vukovich (2010) defined that compliance is a patient's acceptance of medication and other psychiatric treatment because he/she is forced, persuaded, or pressured to take his/her medication. In compliance, patients yield to or obey to physicians' instructions. It implies conformity to medical defined goals only. Based on Seo and Min (2005), compliance is more likely a person's behavior of taking medication in the correct dose, and time as prescribed by the doctor. Based on Mullen (as cited in Cohen, 2009), compliance implies obedience and the expectation that patients will passively follow the order. It refers to behavior characterized by the extent to which people obey, follow the instructions, or use the prescriptions assigned by a health-care provider (Brawley & Culos-Reed, 2000). Meanwhile, Patel and David (2007) defined compliance is the extent to which a person's behavior coincides with medical advice. From these definitions, it shows that compliance occurs because of control or force by other people to follow the prescriptions (external control), therefore, in this condition, the patient is a passive patient.

Adherence, on the other hand, refers to patients' voluntary behaviors to take their recommended medication from their own commitment (Vukovich, 2010). Adherence is the patients' choice to take their medication under their own responsibility and they can interpret their medication correctly because of their understanding (Patel & David, 2007). It implies that patients have their own choice to plan their behavior to take medication and implement their medication by their own motivation and action (Brawley & Culos-Reed, 2000). Adherence is the patient's agreement to take medication and continue to use it for a period of time (Velligan et al., 2006). Patients' attempts to maintain health behavior related to behaviors to take their medication are based on



their active participation and agreement (Cohen, 2009). Based on Lutfey and Whisner (1999), adherence is the patients' behavior to take their medication as independent, intelligent, and autonomous people, therefore, the patients are voluntary and become active participants in their medical treatment. Furthermore, Horne (2006) defined adherence as “the extent to which the patient’s behavior matches agreed recommendations from the prescriber” (p. 66S).

Nevertheless, to achieve adherence, adherence needs concordance that is emphasized on patient decision-making and patient agreement. Vukovich (2010) defined concordance as the agreement between the patient and the treatment team on the goals and means of the treatment. It implies that concordance is a necessary way to achieve adherence.

Finally, medication adherence for this study refers to patients’ behavior in taking their medication by their own commitment/agreement (voluntarily), taking medication from their own responsibility/plan/action/active participation as a result of their understanding (actively), taking medication continuously for a period of time (continuously), and taking medication matching the recommendation (taking medication correctly as prescribed).

### **The importance of medication adherence for patients with bipolar disorder**

The importance of medication adherence among patients with bipolar disorder is to prevent relapse and re-hospitalization, to reduce symptoms severity, to gain a better control of mood swings and to improve functioning and quality of life. These are evidenced by some studies as outlined below.

***Relapse prevention.*** Taking medication as prescribed can prevent a symptomatic relapse of bipolar disorder (Tohen, Chengappa, Suppes, Baker, Zarate, et al., 20014), therefore, not taking medication as correctly prescribed became one of the predictor factors of relapse (Degenhardt, Gatz, Jacob, & Tohen, 2011). For instance, patients with bipolar disorder who are on maintenance medication, especially Lithium, but discontinue their medication, almost always result in relapse, usually in weeks to months after stopping (Peet & Harvey, 1991). This was supported by a study by Adam and Scott (2000) that showed that patients who are partially adherent are more likely to be relapsing compared than those who are highly adherent.

***Hospitalization prevention.*** Likewise, high adherence to medication among patients with bipolar disorder is more likely to result in a smaller number of hospitalizations (Lage & Hassan, 2009; Sajatovic et al., 2006). A study by Scott and Pope (2002) about self-reported adherence in which psychiatric hospitalization was one of the outcomes among bipolar disorder patients showed that patients who were partially adherent to medication had had a higher number of psychiatric hospitalizations compared to those who were fully adherent.

***Reducing of symptoms severity.*** Being more severely mentally ill was included as one of factors associated with treatment of non-adherence among patients with bipolar disorder (Baldessarini, Perry, & Pike, 2007). Therefore, taking medication as prescribed can reduce symptoms severity which was supported by a few studies. For instance, a study by Adam and Scott (2002) in which the result showed that patients with stronger beliefs about the benefits of treatment were highly adherent compared with the partially adherent subjects who had higher perceived severity of illness scores.

Moreover, individuals who were non-adherent with prescribed medication experienced more severe symptoms. (Sajatovic et al, 2009).

### **Factors influencing medication adherence in patients with bipolar disorder**

Influencing factors of medication adherence consist of age, gender, marital status, substance abuse, phase/stage of illness, medication knowledge, individual's beliefs, attitude, illness representation, therapeutic alliance, social support, and medication side effects.

*Age.* Adherence problems can be linked to age. Hou et al. (2010) assessed treatment and illness beliefs related to medication adherence among patients with bipolar disorder (range age 18-60 years). They found that younger aged patients were more non-adherent than older patients. Hou and colleagues concluded that this could be because younger patients have more negative views of medicines, they perceive that their medicines can harm them, and they perceive that they have more personal control over managing themselves in relation to their illness. This fact was also supported by other studies. A survey study of 429 patients with bipolar disorder related to treatment adherence (Baldessarini et al., 2007) showed that younger patients were more non-adherent. In another study by Sajatovic (as cited by Berk et al., 2010), patients who received either lithium or anticonvulsant medication were more likely to be younger in non-adherence to medication. To sum up, younger aged patients are more non-adherent than older aged patients.

*Gender.* In patients with bipolar disorder, females are more likely to be non-adherent than males. Sajatovic et al. (2010) in their study about illness experience

and reason for non adherence showed that females were more likely to be non-adherent. Similarly, Clatworthy et al. (2007) also reported higher numbers of females for non adherence. In addition, Kessing (as cited in Berk et al., 2010) reported that females were significantly more likely to have poorer adherence to lithium in a naturalistic study in Denmark. To sum up, females are more non adherent than males. According to Parial (2015) bipolar disorder in women is a challenging disorder to treat because it differs with male in various aspects, such as; women reproductive cycle particularly postpartum, premenstrual phase of menstrual cycle, peri-menopause, and menopause.

***Marital status.*** Related to marriage status, there are some studies that showed a difference in results in regards to marital status. In assessing a patient's understanding about medication non adherence among patients with bipolar disorder, Clatworthy et al. (2007) reported that there were no significant differences in marital status for non adherence or adherence. Meanwhile, based on Connely as cited in Berk et al., (2010) it appears that marital status is a protective factor that increases adherence. Similarly with Connely's study, Sajatovic (as cited in Berk et al., 2010) showed the results that non-adherent patients were more likely to be in the single status group. To sum up, patients in the marital status group are more adherent to medication than those who are single. According to Aubry et al. (2007), individuals who get married are less frequent to suffer bipolar disorder than those who have divorced or never been married.

***Substance abuse.*** Individuals with bipolar disorder who have any current substance abuse disorder will be more likely to be non-adherent and individuals who have any past substance use disorder showed no significant difference between the adherence and non-adherence group. The most common substance abuse was alcohol (Sajatovic et al., 2006). Moreover, Sajatovic, et al. (2010) reported that a high number

(65 % of 13 participants with bipolar disorder) of substance use dependents are non-adherent in regards to prescribed medication. In a study by Manwani (as cited in Berk et al., 2010), people with bipolar disorder who had substance use disorders are more likely to be non-adherent compared to those without substance use disorders.

***Phase/Stage of illness.*** Adherence problems also can happen in different phases and stages of the illness. For example, people who have an increasing severity of manic symptoms are at risk for adherence problems (Keck as cited in Berk et al., 2010). Related to this problem, Colom et al. (2005) stated that adherence problems may be prevalent at specific stages in the course of the illness, for example late adherence and late non-adherence. In late adherence, patients were in adherence after experiencing repeated relapses. Meanwhile in late non-adherence, patients will be in non-adherence in long-term treatment and they will feel that their treatment is not working well.

***Medication knowledge.*** Having a good level of knowledge about their illness and treatment is one of important factors among patients with bipolar disorder. This condition can help patients in making decisions about illness management and negative beliefs about medications (Berk et al., 2010). The example studies supported this idea. For instance, good knowledge about medication was found to directly improve medication compliance (Seo & Min, 2005). Moreover, a correlation study by Rosa et al. (2009) that assessed medication adherence and its related factors in patients with bipolar disorder showed that patients' knowledge about their disorder and medication positively correlated with treatment adherence to lithium prophylaxis. A large Gamian-Europe/Beam survey in people with bipolar disorder undertaken by Morselli (as cited in Berk et al., 2010), found that there was an improvement in quality of life when patients got more information about their illness and its treatment.

***Individuals' attitude.*** Attitude toward medication had a significant positive effect on medication compliance (Lan, Shiao & Lin, 2003). A study of Clatworthy et al. (2009) focused on patients' attitudes to medication showed that about 30% of patients were reported with low adherence because of greater doubts about personal need for treatment and stronger concern about potential negative effects. According to Scott and Pope (2002), not easy to accept the illness may also influence medication non adherence.

***Individual's beliefs and cognitive illness representation.*** Adams and Scott (2000) reported that highly adherent and partially adherent subjects are significantly different in their perception of illness severity, their beliefs about themselves and their control over the disorder, and their concerns about future hospitalization. Moreover, Clatworthy et al. (2007) assumed that patients can make decisions about taking medication or not based on their perceptions of the illness and treatment.

Since Leventhal, Meyer, and Nerenz (1980) proposed a cognitive illness representation along five dimensions related to patient's beliefs, there now are some study findings and literature reviews that show how these dimensions of cognitive illness representation can be linked to medication adherence. For instance, a study by Hou et al. (2010) showed that participants who were in the non-adherence group believed that their illness caused more negative effects on their life (consequences) and would have a longer-term impact (timeline). In a preliminary investigation by Brown et al. (2001), Brown stated that a patient's illness cognition (i.g. timeline, consequences, and cause) were associated with medication adherence. In their study, they also found that poor adherence associated with interpersonal difficulties was a cause of depressive symptoms.

Budd (as cited in Lobban, Barrowclough & Jones, 2003) found that some individuals perceived that their consequences of symptoms severity and their treatment (cure) was associated with medication adherence. In addition, patients who perceived their illness as a mental health identity, with negative consequences, and high levels of belief in treatment to control symptoms were more likely to take medication as prescribed (Lobban, Barrowclough & Jones, 2003). Furthermore, an individual's perception of risks and benefits of medication treatment were more likely to affect treatment adherence in bipolar populations (Scott as cited in Sajatovic et al., 2009b).

***Therapeutic alliance.*** One of the treatment variables that may have an effect on medication adherence is therapeutic alliance. Therapeutic alliance is important for affective disorder patients (Lingam & Scott, 2002). Lingam and Scott reported that poor interaction between the clinician and patient was four times more common with non-adherent patients compared to those who were adherent. Moreover, in Zeber's study (as cited in Berk et al., 2010) among veteran patients with bipolar disorder, it showed that therapeutic alliance was positively connected to medication adherence.

***Social support.*** Social support has been identified as a factor to medication adherence. Seo and Min study (2005) found that social support is the strongest direct effect on medication compliance. This social support can come from family, friends and health care professionals. Family members will also influence the patient's attitudes and beliefs about the illness and its treatment, and it also can affect adherence (Cochran as cited in Berk et al., 2009). High expressed emotions and particularly over involvement in the family is considered being associated with poorer adherence and poorer overall outcomes in bipolar patients (Miklowitz as cited in Berk et al., 2010).

***Medication side effects.*** Medication side effects are a common reason for non-adherence in psychiatric patients (Scott as cited in Patel & David, 2007). There are several studies to support this, for instance, Clatworthy et al. (2009) reported that about 30% of the participants that were in low adherence was predicted by greater doubts about personal need for treatment and stronger concern about potential negative effects. Then, Sajatovic et al. (2011) reported that the side effects of a drug were main reason for deciding not to take the medication.

### **Measurement of medication adherence**

There are two kinds of measurement to measure medication outcome. Since many studies have used adherence and compliance interchangeability that reflect different meanings, however, in measuring the medication variable, the two kinds of measurement usually used both compliance and adherence. These measurements include direct method (objective method) and indirect method (subjective method). They will be presented as follows:

***Direct method (objective method).*** Velligan, Lam, Glahn, Barret, Maples, Ereshefsky, and Miller (2006) mentioned an objective method for a direct method and a subjective method for an indirect method of those medication measurements. For the direct method, this includes pill count, blood or urine analysis, electronic monitoring, and electronic refill records. This is the same as Velligan, as in another review by Sajatovic et al. (2010), who stated that the direct method of medication measurement includes pharmacy records, pill counts, electronic monitoring, and blood plasma levels.

Even though the direct or objective method has several advantages, such as no missing data due to patient non-adherence to the adherence assessment, it does



have limitations in terms of cost, particularly when there is the use of electronic monitoring. Therefore, because of this reason, the researcher will not use this kind of measurement in this study.

***Indirect method (subjective method).*** Indirect or subjective method includes self-report, provider report, significant other report and chart review. The most common measurement tools used in self-report include Rating of Medication Influences (ROMI), Treatment Compliance Interview (TCI), Drug Attitude Inventory (DAI), the medication compliance item from the Multnomah Community Ability Scale (MCAS), Medication Adherence Rating Scale (MARS), Brief Evaluation of Medication Influences and Beliefs (BEMIB), Morisky Adherence Scale, and Tablet Routine Questionnaire (TRQ), and Brief Adherence Rating Scale (BARS) (Sajatovic et al., 2010; Velligan et al., 2006). Furthermore, Sajatovic et al. (2010) categorized the indirect or subjective methods into two categories: adherence attitude and adherence behavior. A detailed explanation of each of the measurements is shown in Table 1.

In the review of Velligan et al. (2006) that included 161 studies, they found that less than 23% of the studies used the direct or objective method in their assessment compared to those which used the indirect or subjective method (77%). It means that the most common method used was the indirect or subjective method.

Table 1

*Indirect Method Tools Used to Measure Medication Adherence*

Tools	Category of tools	Description
The Rating of Medication Influences (ROMI)	Adherence attitude	ROMI was developed based on the Health Belief Model and is divided into two subscales (reason for adherence and reason for non-adherence)
Drug Attitude Inventory (DAI)	Adherence attitude	DAI is a 30-item self-report scale evaluating subjective effects of antipsychotics and insight into illness
Morisky Adherence Scale	Adherence behavior	Morisky Adherence Scale is a four-item self-report measure of treatment adherence. Originally, this measurement was developed for populations with hypertension, however, recently, this tool has been used to evaluate adherence in the mentally ill population
Medication Adherence Rating Scale (MARS)	Adherence attitude	MARS is a 10-item tool using dichotomous scale (yes/no). This tool was developed from Drug Attitude Inventory (DAI) and Morisky Adherence Scale
Brief Adherence Rating Scale (BARS)	Adherence behavior	BARS is a tool to measure adherence behavior. There is a four-item patient-report scale

Table 1 (continued)

Tools	Category of tools	Description
Brief Evaluation of Medication Influences and Beliefs (BEMIB)	Adherence attitude	BEMIB is an 8-item scale measuring costs and benefits of medication use based on Health Belief Model
Tablet Routine Questionnaire (TRQ)	Adherence behavior	TRQ was developed to evaluate treatment adherence in populations with bipolar disorder. TRQ consists of two general questions regarding any difficulties taking or coping with medication and four questions regarding number of missed doses in the past week and past month
Adherence Barrier Survey	Adherence attitude	Adherence Barrier Survey was developed to measure barriers to medication adherence. This tool consists of 20 items that represent multiple factors known to affect treatment adherence

As shown in Table 1, there are two categories of the indirect method which are attitude and behavior, however, for this study, the researcher only used the behavior related to medication adherence because behavior is strongly assured to maintain a patient's adherence to medication compared to attitude measurement (adherence attitude). In adherence behavior measurement, it seems that the items of the questionnaire are very similar to the meaning of compliance. For instance, the Tablet Routine Questionnaire (TRQ) assesses daily routine for taking medication and proportion

of medication an individual has missed in the previous week and previous month. While in Morisky Adherence Scale and Brief Adherence Rating Scale (BARS), the four domains in medication outcome, as presented in Chapter 1, are not shown. Especially in relation to BARS, which only provides the question items related to compliance such as the number of prescribed doses of medication per day, and the number of days in the past month when the patient did not take/took less than the prescribed doses.

Therefore, the researcher has developed a new measurement that represents the four domains of medication outcome (taking medication voluntarily, continuously, actively, and correctly as prescribed). The developed questionnaire is called the Medication Adherence Behavior Questionnaire (MABQ).

### **The Common Sense Model**

The Common Sense Model (CSM) consists of three primary stages in the model: representation, coping, and appraisal. The illness representation is divided into cognitive illness representation and emotional illness representation (Leventhal, Meyer, & Nerenz, 1980). However, this study only uses cognitive illness representation in order to see any change in individuals' perceptions along the five dimensions of cognitive illness representation.

### **Cognitive illness representation**

Cognitive illness representation is an organized system of beliefs, knowledge, ideas, and information related to illness and it becomes well aware through people's perception of illness along five components of cognitive illness representation (Leventhal, Meyer, & Nerenz, 1980). Leventhal and colleagues described three main

sources of information which are used to construct illness representation; past experience with the illness, current experience with the illness, and other people such as health care providers, family, or social media. The five components that have been defined and identified as being keys to guide individual responses are described as following (Hagger & Orbell, 2003):

***Identity.*** Identity is considered by the symptoms and labeling of the illness. When an individual is labelled (diagnosed) as having an illness, the individual might look for and search for some consistent symptoms with the label.

***Cause.*** Cause represents the beliefs regarding the factors that are responsible for causing the illness or disease. Cause can be used to assess what the individual thinks has caused his or her illness.

***Timeline.*** Timeline refers to the individual's beliefs about the course of the illness such as acute, chronic, and/or cyclic. This component can be used to assess a patient's belief about how long are the experiences of his or her illness.

***Consequences.*** Consequences refers to beliefs regarding the impact of the illness on quality of life or how it may affect functional capacity. This component can be used to assess what the individual believes will be the consequences of having the health problem on their lives.

***Control/cure.*** Control/cure is the extent to which the individual believes the illness is curable or controllable. Cure control component beliefs can be divided into perceptions about how much treatment, such as medication, is likely to help their condition and how the patient's own behavior can influence the course of the illness. This component can be used to assess beliefs about how the problems can be controlled (Moss-Morris et al., 2002).

## **Coping**

The next stage after illness representation in the CSM is coping.

According to Leventah et al. (1980), individuals' representation of illness (both cognitive and emotional) can construct coping procedures. The coping strategies they select, for example, whether or not to take medication, are guided by their interpretation and evaluation of their illness.

How could coping be a part of the Common Sense Model? When Leventhal et al. developed the model, they set questions related to what makes individuals fearful and what individuals do to cope with the fear, and how the individuals perceive and interpret the threat and how they cope with it. Taking those two processes together, Leventhal and colleagues labeled the model as the 'Parallel Model' and divided the process into two parts; the fear control process that is associated with emotion (later referred to as emotional illness representation) and danger control process (later referred to cognitive illness representation). Both emotional illness representation and cognitive illness representation lead the individual to set the coping. However, since this study only focused on cognitive illness representation, it discusses only about how the individuals perceived and interpreted the threat, their representation of danger, and how they cope with the danger, in order to deal with the threat (Leventah et al., 1980).

In the danger control associated with cognitive perception, there are 10 important principles about the ways that patients regulate their illness behaviour, and these are; (1) the individual attempts to understand and regulate his/her treatment, in the case of the passive subject, the individual needs to be pushed into making actions to make him or her be active, (2) symptoms define illness and illness defines symptoms so that it will have a symmetry of relationship between symptoms and illness, (3) symptomatic

representations facilitate attributional analysis, which means that the more intense the symptoms, the more intense the illness and the less intense the symptoms, the less intense the illness, (4) a patient's symptoms are organized by his/her own thought and beliefs, a patient's beliefs about his/her illness are formed by his/her thoughts and may be implicit, thus those beliefs are the basic thoughts that firstly created the patient's illness representation, (5) there are three basic sources of information which are bodily experience, information from the external social environment, and information based on past experience with illness, (6) the purpose of illness representation is people can create an appropriate coping strategy, (7) the real picture of illness representation can provide a specific goal setting or action, (8) the patient uses his/her symptomatic representation of disease to evaluate and regulate the utilization of treatment, (9) the representation of illness guides coping that is an adjunct to medical treatment, (10) unpredictable and uncontrollable effects of treatment can induce high levels of distress and hopelessness (Leventhal et al., 1980).

There are three principles in order to set up the behavior as coping and these are (1) the events and the individual's emotion define the goals to cope with the problem that is caused by the events, (2) setting behavior needs to specify the goals based on the cognitive illness representation and making the plan about what one should do, (3), information has a role to formulate the illness representation and planning for behavior. It needs to have concrete information about the threat of the illness and coping strategies in order to provide planning behavior for dealing with the illness or preventing the illness and for decreasing the fear (Leventhal et al., 1980).

Since this study will focus on the danger control process, the coping of this study is the behavior toward medication adherence.

### **Appraisal**

The last stage of the CSM is appraisal. Appraisal refers to personality differences and formulation of coping plans. In this stage, individuals will evaluate the effectiveness of their coping. The coping strategies related to behaviors will attempt to correlate their perceptions between their current health and a future goal state (Leventhal et al., 1980).

### **Cognitive illness representation and medication adherence**

In this study, medication adherence is as an outcome toward the behaviors in taking medication voluntarily, continuously, actively, and correctly as prescribed (as presented in chapter 1). There are several studies and literature reviews that have proven that medication adherence was strongly influenced by individuals' cognitive illness representation. For instance, individuals who had high levels of belief in treatment to control their symptoms (Lobban, Barrowlough, & Jones, 2003), and perceived the benefits of medication treatment (Scott as cited in Sajatovic et al., 2009) were more likely to adhere to their medication. Unlike, the individuals who believed that their illness caused more negative effects on their life (Hou et al., 10), thus the perceived negative causes of the illness (Brown et al., 2001) were associated with poor adherence to medication.

In cognitive illness representation of the Common Sense Model, individuals construct coping in order to deal with the threat and danger of the illness, and the behavior of taking medication is a coping strategy in the danger control process (Leventhal et al., 1980). In the ten principles of danger control that have been proposed by Leventhal and colleagues as described previously, it is stated that individuals



adherence to medication is a set of actions to deal with the illness. The success of appropriate behavior to take medication is dependent on the concrete information given by the health care providers. The more the patients know about their illness, the more they can generate a good plan and action for dealing with their illness. The purpose of the given information is to produce an applicable and credible cognitive illness representation and effective coping to deal with any problems. In order to understand how communication of health care providers might affect an individual, it may be necessary to understand what the patient's cognitive illness representation is, how he/she develops his/her cognitive illness representation, and how he/she develops his or her behaviors to overcome the problems in these cognitive illness representations.

### **The Conceptual Change Model**

#### **A model of conceptual change**

Conceptual change is the change of existing conceptions in order to overcome problem(s) in the phenomenon. This change could happen through any of the following four ways; (1) the addition of a new conception through experience, personal development by the individual concerned, and interaction with others, (2) differentiation and clarification of existing conceptions from external or internal resources, (3) reorganization of existing conceptions that come from both external and internal resources (4) rejection of some existing conceptions by some new conceptions (Hewson & Hewson, 1981). These ways lead to the learning process that may involve a change in an individual's conception in addition to adding new knowledge to what is already there (Hewson, 1992; Posner et al., 1982).

Moreover, Hewson and Hewson (1981) explained that individuals have their own conception (existing conception), however, sometimes in daily life, individuals meet with a new phenomenon that collides with what is their perceived conception and they are faced with the new conceptions. The following questions about new conceptions are of interest to examine.

Firstly, what could happen to the new conceptions? They can be rejected by individuals, they can be replaced and be reconciled with the remaining conceptions (conceptual exchange), or, they can be reconciled with existing conceptions, including the new conception (conceptual capture). Both conceptual exchange and conceptual capture depend on the reconciliation between the conceptions. In this process, the individual makes sense of the new conception then tries to see if it fits with her/his present knowledge and understanding.

Secondly, what conditions determine what will happen to new conceptions? There are three conditions that can explain what will happen to the new conceptions; intelligible, plausible, and fruitful. Intelligible is knowing what it means, plausible is believing it to be true, and fruitful is useful. These conditions are divided into four statuses; no status (not intelligible, plausible or fruitful), status I (intelligible, but not plausible or fruitful), status IP (intelligible and plausible, but not fruitful), and status IPF (intelligible, plausible and fruitful). Therefore, in order for conceptual change to occur, a person needs to meet the status condition of the conceptions.

Thirdly, how does the status of a conception change? Obviously, status (existing conception) cannot change spontaneously. It must be faced with the dissatisfaction and at the same time the individual gains the advantage of the new conception. Dissatisfaction with the existing conception can occur if the individual thinks that the

existing conception is no longer necessary, or the individual sees that the existing conception is irreconcilable with the new knowledge which cannot be ignored (Hewson et al., 1981).

According to Posner, Strike, Hewson, and Gertzog (1982), there are two phases of conceptual change namely assimilation and accommodation. In the assimilation phase, an individual uses existing concepts to deal with new phenomena by defining problems, indicating strategies for dealing with the problems, and finding specific solutions. Meanwhile, the accommodation phase occurs when a current conception cannot deal with the new phenomenon successfully, so that the individual must replace or reorganize his/her existing concepts. However, there are several important conditions that must be fulfilled before an accommodation occurs, as described in the following.

***Dissatisfaction with existing conceptions.*** In this part, individuals must first view their existing conceptions with some dissatisfaction before they take the new one. Posner et al., (1982) stated that anomaly is one major source of dissatisfaction. An anomaly exists when an individual fails to assimilate a new conception into his/her existing conception. It means that this individual cannot make sense with the new conception. The anomaly will produce dissatisfaction only if the individual believes that it is necessary to reconcile between the new and existing conceptions, and attempts to assimilate the new conceptions into his/her existing conceptions which are seen not to work. So that accommodation can occur if dissatisfaction with existing conceptions does not seem to make sense because they are intelligible, then the new conception may be plausible.

***Intelligibility of a new conception.*** Intelligible is knowing what something means, in this case a new conception. In considering the new conception, the individual

must find it intelligible. The individual must understand, for example, about component terms, symbols used, and the syntax of the mode of expression.

***Plausibility of a new conception.*** Plausible is believing it to be true.

Plausibility can be thought of as the anticipated degree of fit of a new conception into an existing conception. There are five ways for the new conception to become initially plausible and these are; 1) the individual finds it consistent with the existing conceptions, 2) the individual finds the new conception to be consistent with other theories or knowledge (3) the individual finds the new conception to be consistent with past experience, (4) the individual finds or can create an image for the new conception in which it matches the individual's sense of what it could be like, and (5) the individual finds the new conception capable of solving problems of which the individual is aware of (Posner et al., 1982).

***Fruitfulness of a new conception.*** Fruitful is useful. Fruitfulness occurs when an individual is fully aware of an intelligible, plausible conception which leads to a new insight and discoveries for the individual.

### **Learning process in the conceptual change model**

In the conceptual change model, teaching is one process that can provide a rational basis about knowledge in order to change the existing conceptions. The learning process is associated with teaching and education. In the learning process, there are four important points that should be considered for both the learner (someone with the existing conceptions) and the educator/teacher (someone as a change agent who introduces the new conceptions), as explained below in detail (Posner et al., 1982).

**Curricular objectives.** This part is aimed to establish an awareness of the individual who has his/her own assumptions about the world and of those implicit in scientific theory, as well as establishing a demand for consistency among the individual's beliefs, and some sense of the fruitfulness of a new conception. The educator's role is to help the individual to have scientific thinking and encourage him/her to confront the problem before receiving the new conceptions.

**Content.** The content of a learning process should be intelligible, plausible and fruitful. However, there must be some necessary conditions that should be considered by the individual in order to change existing conceptions, which are; the individual's emphasis to assimilate and accommodate the sufficient observation conception, and using models and analogies to make a new conception more intelligible and plausible.

**Teaching strategies.** Teaching strategies that have been proposed by Posner et al. were actually in part of both the accommodation and assimilation phase. For the accommodation phase, there are five teaching strategies; a) developing lectures, demonstrations, problems, and labs, to create cognitive conflict, b) organizing instruction to diagnose errors in an individual's thinking and identify defensive moves used by the individual in order to resist accommodation, c) developing the strategies to overcome individual errors, d) helping the individual to make sense of new conception content by many ways and helping the individual to translate from one representation to another, and e) developing evaluation techniques to track the process of conceptual change in the individual. For the assimilation phase there are five steps of teaching strategies which are; clarifying content presented in a text, explaining solutions to problems, demonstrating principles, providing laboratory exercises, and testing for recall of facts and the ability to apply knowledge to problems.

**Teacher Role.** The teacher has two roles in order to facilitate student accommodation which are; 1) an adversary in the sense of a Socratic tutor, in which the teacher confronts the students in relation to their problem arising during the assimilation of new conceptions, 2) a model of scientific thinking, in which the teacher must be consistent between theory and empirical evidence.

### **Illness Representation-based Education Program**

Illness Representation-based Education Program (IREP) for Bipolar Disorder is developed based on a representational approach to patient education (which is based on the cognitive illness representation of common sense model) and the process of conceptual change model. Representational approach to patient education was developed by Donovan and Ward (2001), while the process of the conceptual change model was proposed by Hewson and Hewson (1981), Hewson (1992), and Posner et al.(1982).

The Common Sense Model is used as a guide to develop a representation approach to patient education in order to introduce the knowledge after assessing an individual's existing perceptions. Moreover, the process of the conceptual change model is the way to change an individual's existing conceptions that may have misconceptions, confusions and/or gaps, through giving the new information which is intelligible, plausible and fruitful. In this conceptual change model it is also required that before giving new information, it is important to firstly understand the individual's existing representation.

In the representational approach to patient education, there are five steps that have been developed by Donovan and Ward (2001). Firstly, the representation

assessment which includes the five dimensions of illness representation as proposed by Leventhatl et al. (1980). Individuals are encouraged to describe their illness along the five dimension of cognitive illness representation. Secondly, exploring misconceptions and encouraging individuals to think about the experiences that have led to any gaps and/or confusion of their illness representation. Thirdly, creating conditions for conceptual change, the individual and the nurse discuss any problems regarding his/her current representations that are misconceptions, gaps and/or confusion, and the consequences of those current illness representations for his/her coping behavior. Thus, the individual can recognize the limitation of his or her current illness representation. Fourthly, introducing replacement information, the nurse provides information to fill gaps, replace misconceptions and/or clarify confusion. Fifthly, summarizing, the nurse summarizes the information as the new conception and discusses the benefits of the new conception in order to show the expected outcomes from acting on the new information.

Donovan et al. (2007) stated that although the steps of the representational approach are described as linear, however in reality, these can move back and forth between steps in order to maximize the opportunities of the individual on what he/she thinks or what ideas he/she has. At the same time, Donovan and colleagues also suggested to add two elements in the representational approach to patient education. The first element is goal setting and planning, which the individual identifies the important goals regarding his/her health problems and strategies with the nurse in order to achieve the goals. The second element is follow-up, which the individual evaluates his/her strategies, which he/she used and revises or modifies the strategies for continuing on. Then by the overall of the representational approach steps, Thus in relation to the added two elements to the representational approach steps, the first and the second steps suggested by

Donovan and colleagues automatically become the sixth and seventh steps of the representational approach.

From the result of the literature searched, it was quite difficult to find any studies related to the representational approach to patient education, especially in the psychiatric area; however, there were several studies in the adult area. There are two studies associated with the representational approach to patient education using five steps; (1) Representational Intervention to Decrease Cancer Pain (RIDcancerPain) (Ward et al., 2008) and (2) a Representational Intervention to Decrease Pain (RIDPAIN) (Donovan & Ward, 2001). Furthermore, there are three studies using seven elements of the representation approach to patient education, which are (1) an Individual Representation Intervention to Improve Symptoms Management (IRIS) in older breast cancer survivors (Heidrich et al., 2009), (2) a written representational intervention to ease symptoms (WRITE symptoms) (Donovan et al., 2007), and (3) RIDcancerPain intervention (RIDcancerPain+) (Ward et al., 2009).

### **RIDcancerPain**

The RIDcancerPain stands for Representational Intervention to Decrease Cancer Pain. It was tested in a randomized study conducted by Ward et al. (2008), among adult patients with pain related to metastatic cancer. As the name implies representational intervention, therefore the basic theory used for this study was based on theories regarding cognitive illness representations and processes of conceptual change. The content of this program involves beliefs about analgesic use, adequacy of analgesic use as coping, pain severity, pain interference and well-being. This program was designed in order to overcome barriers to cancer pain management. The program



provided an educational intervention (individual and face-to-face psycho-educational sessions) which included five steps of the representational approach.

In the first step which is the representational assessment, the subject was asked to describe his/her beliefs about their cancer pain along the five dimensions of cognitive illness representation. The next step is exploring and identifying misconceptions about the subject's reporting of pain and using analgesics. The third step is creating conditions for the conceptual change where the researcher and the subject discussed the limitations and losses of consequences of these misconceptions that have been identified. The fourth step is providing the information to replace the misconceptions that have been identified. And in the last step which is clarification and summary, the researcher and the subject discussed the benefits of applying the new information. All of these steps were provided in one session that lasted from 20 minutes to one hour.

This study had two groups, an experimental group for the participants who were receiving the RIDcancerPain and the control group for participants who were receiving standard education information (SEI). The measures were taken at different three times, involving the baseline (T1), one month later (T2) and two months later (T3).

The result of this study showed that the subjects in the RIDcancerPain group had greater changes in beliefs about analgesic use and some measures of pain severity after the intervention than those in the SEI group. The RIDcancerPain intervention did not have an effect on coping, pain severity and pain interference or well-being. From T1 to T2 and from T1 to T3, subjects in the RIDcancerPain showed greater decreased levels in beliefs about analgesic use that were measured by the Barriers Questionnaire-II (BQ) than those of the control group. From T2 to T3, the subjects in

the RIDcancerPain group showed greater decreased levels in pain severity than those of the control group.

### **RIDPAIN**

The RIDPAIN was developed by a group of advanced practice nurses (APNs) and is aimed to improve pain management outcomes (Donovan & Ward, 2001). As the RIDcancerPain, the RIDPAIN also consists of five steps of the representational approach to patient education. The duration for the intervention for each individual was different. It took around 20 to 75 minutes, depending on the number of misconceptions that were elicited in the first step.

The outcomes of this study were measured at two times; the first was immediately done after the intervention and the second was two months after the intervention. For the first measurement result, it showed that 98% of participants stated that both the length of discussion and the level of the difficulty of the information were appropriate, 94% of participants said the information would be helpful to them, and 49% of participants said they had learned something new.

The result two months after the intervention showed that 83% of participants had changed the way they think about pain medication, 85% of participants were more confident using pain medication, 80% of participants indicated more confidence talking with their physician or nurse about pain, 68% of participants were better in managing their pain, 57% of participants were better able to manage the side effects of pain medication, and 57% of participants were making changes in the way they managed their pain.

In conclusion, the RIDPAIN is an effective intervention to replace the misconceptions of pain among patients who were experiencing cancer pain, which in turn affected the way they managed their pain. Moreover, the patients reported that the RIDPAIN was meaningful and useful for them.

### **IRIS in older breast cancer survivors**

IRIS stands for Individualized Representational Intervention to Improve Symptom Management which was developed by Heidrich et al. (2009), for use among older breast cancer survivors. They conducted three pilot studies aimed to test the feasibility and acceptability of the IRIS among older breast cancer survivors and tested the short-term effects of the IRIS on symptom distress, symptoms management and quality of life. The IRIS is a counseling interview conducted by advanced practice nurses focused on an individual approach. The duration of the IRIS was around 30 to 75 minutes depending on an individual's need. Unlike the previous two studies about a representational approach, the IRIS consists of seven elements of representational approach with the details of the results as described below.

In the first pilot study, subjects were randomized to the IRIS group or the usual care group. The measures were taken three times, at the baseline, 6 weeks after the intervention (post-test) and 10 weeks after the intervention (follow up). The result showed that distress decreased significantly from the baseline to the follow up, symptoms management more likely changed in the IRIS group, and QOL had no significant differences by group.

In the second pilot study, subjects were randomized to the IRIS group or the delayed IRIS (waiting list) control. The result reported that symptoms duration

was significantly lower in the IRIS group than the control group at eight weeks.

Moreover, the IRIS group was more likely to talk with a health care provider, begin new medical treatment for their symptoms and change their self-care of symptoms.

In the third pilot study, all subjects received the IRIS by telephone. The measures were taken at the baseline, and 2, 4, 6, 8, and 16 weeks after the intervention. The third pilot study was similar to the second pilot study. The result showed that target symptoms distress decreased significantly. This showed through symptoms interference and negative moods from symptoms which decreased significantly from the baseline to the eight week follow-up.

These pilot studies showed the effectiveness of the IRIS in older breast cancer survivors because the women's symptoms management behavior changed and symptoms distress was reduced.

### **WRITE Symptoms**

The WRITE Symptoms (as cited in Donovan et al., 2007) was conducted among women with recurrent ovarian cancer through a secure internet messaging services to measure the differentiation of changes in symptoms representations, symptoms interference with life activities, and quality of life between women who received the WRITE Symptoms and those who received usual care from the health care providers. This intervention consists of seven elements of the representation approach to patient education which was conducted over 3 to 4 weeks. The outcomes were measured at three times, at the baseline (T1), 5 weeks after the intervention (T2), and 9 weeks after the intervention (T3).

Despite using the seven process component of representational approach, this study was quite unique among five studies using the representational approach because it was not a face-to-face intervention; instead, the intervention was conducted over the internet. This way was easier than a conventional intervention which requires a set of meetings between the researcher(s) and one-on-one with the participants in some places. The delivery of this intervention is suitable to be applied in the current period where the internet has been rapidly growing and is used by almost everyone. Further research could use this kind of intervention.

### **RIDcancerPAIN+**

The RIDcancerPAIN+ was conducted by Ward et al. (2009) among cancer patients who had experienced moderate or severe pain in the past two weeks and their significant others. This study was modified from the representational approach (Donovan et al., 2007) and the RIDcancerPain intervention (Ward et al., 2008).

The purposes of the RIDcancerPAIN+ were: (1) to compare the effect of the RIDcancerPAIN+ on attitudes about analgesic use between the subjects in Dyad condition and the subjects in Solo condition, and (2) to compare the attitude about analgesic use between subjects in the experimental groups (Dyad condition and Solo condition) and those in the control group. In Dyad condition, the patients and the significant others (SOs) received the educational intervention; in Solo condition, only the patients received the intervention; and in the control group, the patients only received usual care.

The RIDcancerPAIN+ has seven elements of the representational approach to patient education in which six elements were covered in a single session

that lasted from 20 to 80 minutes, and the seventh element was a follow-up by phone call, and was conducted twice (after 2 and 4 weeks of the first session) with each of the follow-up sessions approximately 5 to 10 minutes long. The measures were taken three times consisting of at the baseline (T1), 5 weeks after the baseline (T2), and 9 weeks after the baseline (T3). The result showed that there was no significant difference in attitudes about analgesic use between the three groups at T2 after the intervention had occurred in the experimental groups. At T3, there was a significant difference in attitudes about analgesic use in both Dyad condition and Solo condition, and in the control group, however, there was no significant differences in attitudes about analgesic use between the subjects in Dyad condition and those in Solo condition. The findings showed that the barrier score of attitudes about analgesic use was decreased in the experimental groups at T3.

In conclusion, these findings showed that the RIDcancerPAIN+ effectively changed attitudes to analgesic use in patients with cancer in order to overcome their pain. But the intervention did not make a difference on the attitude to analgesic use between the SOs included in the intervention and those not included. Therefore, the subjects' attitude about analgesic use in this study was not influenced by others, but it was influenced by their own thinking or beliefs.

These five studies using the representational approach to patient education are focused on an individual approach and are based on the seven process elements of the representation approach to patient education. The researcher has used the seven process elements because it seems to be more useful in changing behavior rather than using the five process elements as in previous studies. The seven process elements are conducted in two phases with a duration time that depended on the participant's needs.

The maximal time duration for the first phase was 70 minutes. For the second phase, the researcher provided the follow-up by phone call. The study was conducted over two weeks for each individual. This study is called the Illness Representation-based Education Program (IREP) in which the outcome is medication adherence.

### **Summary**

To sum up, the literature review of this study provided information associated with the concept of bipolar disorder, medication adherence, the common sense model, the conceptual change model, and Illness Representation-based Education Program (IREP) for bipolar disorder. Pharmacological treatment is the main approach for relieving and preventing the symptoms. Therefore, patients with bipolar disorder need to take their medication.

According to several resources, medication adherence refers to taking medication voluntarily, taking medication actively, taking medication continuously, and taking medication correctly as prescribed. Moreover, several factors were found influencing medication adherence including age, gender, marital status, substance abuse, phase/stage of illness, medication knowledge, an individual's beliefs and attitude, illness representation, therapeutic alliance, social support, and medication side effects.

The representational approach to patient education is based on the common sense model and the conceptual change model in patient education. Evidence showed that this approach has proven to be strongly effective in changing a patient's behavior. Several studies have shown the effectiveness of this program and have provided some advantages. These advantages include no need to provide a long session and no need to have expertise to do the intervention. However, in Indonesia, this approach may

not be well-known and has not been applied yet. Thus, this is the reason why the researcher needs to conduct a study to examine the effect of the illness representation based-education program on medication adherence among patients with bipolar disorder in the Psychiatric Hospital in Medan, North Sumatra.



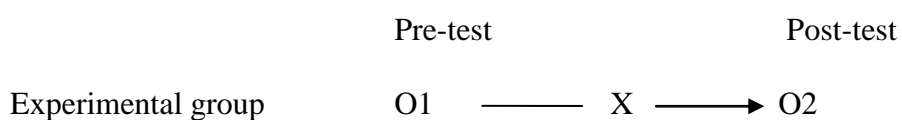
## CHAPTER 3

### RESEARCH METHODOLOGY

This chapter presents the details of the methodology of research design, setting, population and sample, research instruments, validity and reliability of instruments, ethical consideration, data collection methods, and data analysis.

#### Research Design

This study is a quasi-experimental study using a one-group, pre and post-test design. The participants were recruited from the Out Patient Department (OPD) in a psychiatric hospital, Medan, Indonesia. It was conducted to test the effect of the Illness Representation-based Education Program on medication adherence among patients with bipolar disorder in Medan, Indonesia. The research design is as follows:



O1 : Pre-test of medication adherence among patients with bipolar disorder

O2 : Post-test of medication adherence among patients with bipolar disorder

X : The Illness Representation-based Education Program (IREP) for patients with Bipolar Disorder

## **Setting**

This study was conducted at the Out Patient Department (OPD) of the Psychiatric Hospital Medan (North Sumatera Province) and at the participant's house in the community. In Medan (the capital city of North Sumatera Province), there is only one psychiatric hospital of which everyone in every district of North Sumatera Province who suffers from mental illness will be referred to, the Medan Psychiatric Hospital. This hospital is located in Jamin Ginting Street, Medan, near the center of the city.

This hospital is a teaching hospital. Medical students, nursing students, and students of other allied health professionals are placed here during their practicum courses. At the OPD, medical and nursing students are rotated to practice here also.

Daily, there are two physicians, one psychiatrist and five nurses. There are approximately 70-100 patients who visit the OPD. The hospital has rules for patients in the OPD; (1) for a patient coming for in follow-up, she/he is directly transferred to meet a psychiatrist, and (2) for a new patient, she/he meets with the physician at the first appointment. Moreover, if the patient comes with the family member(s), the family is also involved together with the patient to meet the physician or the psychiatrist.

The health care services for psychiatric patients in the OPD are provided by the students, the nurses who work in the hospital, the physician, and the psychiatrist. The nursing students usually help with the patients' admission process including the physical examination, patient's weight, and checking blood pressure. The medical students usually do the assessment (asking for the patient's data, the history of the illness, the recent and current symptoms) before transferring the patient to the physician or the psychiatrist, sometimes they also give some simple advice to the patients related to the information of their illness. Nurses who work in the OPD sometimes also do the general assessment,

give any injections if needed (there is one room provided for giving injections in the OPD), and help the physician or the psychiatrist in assessing the patient's problems and responding to the patient or the family member's questions. Mostly, the nurses do the nursing documentations.

Meanwhile, the physician or the psychiatrist provide health care services based on the patient's need/problem. For the new patients, the physician (sometimes helped by a nurse) usually does the first assessment including health information and neurological examination, asking the patient about her/his problem and giving advice to the patient and family member related to the information of the patient's illness and what the family should do in the home related to the patient's illness. For those who are follow-up patients, she/he will be asked some questions related to his/her previous/recent symptoms, medication, and other problems that she/he has in the home or in the environment.

To sum up, the health care services provided for patients in the OPD were only the daily routine services. Based on the researcher's observation, there was no psycho-education service provided.

## **Population and Sample**

### **Population**

The target population for this study were patients who have been diagnosed with bipolar disorder and have currently attended care at the OPD of this hospital. For diagnosing bipolar disorder, the psychiatrists use PPDGJ (*Pedoman Penggolongan dan Diagnosis Gangguan Jiwa di Indonesia*) or Guidelines for Classification and Diagnosis of Mental Disorders in Indonesia. The guideline is based on DSM IV-TR.

### **Sample and sample size**

Based on Ward et al.'s study findings (2008), the participants who completed baseline data only had a decrease in barriers related to beliefs about analgesic use compared with those who had completed baseline and at least one post measure, with the effect size ( $d$ ) of 0.34. According to Polit and Beck (2008), to achieve alpha = .05, power = .80, and  $d = .34$ , at least 174 subjects are required.

This study was conducted as Phase I clinical trial to examine whether implementing this representational approach of patient education in the local context of Medan, Indonesia, with a group of patients with bipolar disorder is feasible. Thus, at least 30 subjects were included in this study.

### **Inclusion criteria**

The inclusion criteria used to recruit participants in this study were as follows: (1), the age is no more than 60 years old, (2) is diagnosed with bipolar disorder by psychiatrists of the Psychiatric Hospital, Medan, North Sumatera, (3) the Score of Brief Psychiatric Rating Scale (BPRS) is less than 40 (considered as normal to mildly ill, according to Leucht, Kane, Kissling, Hamann, Etschel, & Engel, 2005), (4) is able to communicate well with the researcher, (5) is able to read, (6) is able to participate in this study from the beginning to the end, and (7) has phone access.

### **Instrumentations**

There are three parts of the instruments that were used in this study; (1) The Illness Representation based-Education Program (IREP) for bipolar disorder,

(2) instrument for screening, and (3) instruments for data collection. The following explanation presents each instrument in detail.

### **The Illness Representation-based Education Program (IREP) for bipolar disorder**

The Illness Representation-based Education Program (IREP) for bipolar disorder was developed in this study. This is an individual program consisting of seven steps of the representational approach. It took two weeks from the beginning of the IREP to the post-test. The protocol for conducting the IREP is presented in Appendix B.

The practice of the IREP was conducted in two phases. Before that, the researcher provided an introduction before going to the first phase which took around 5 minutes.

*The introduction phase.* This introduction was done in the first meeting with the participants in the OPD. In this phase, the researcher and the research assistant identified the participants who were diagnosed with bipolar disorder and met the inclusion criteria. Then, the research assistant asked the participant if she/he was willing to meet with the researcher. After the participants agreed, the research assistant introduced the participant to the researcher to establish trust and help the participant to understand the program.

In addition, if the researcher observed that a participant felt uncomfortable receiving the program while he or she was waiting for the full process of admission in the OPD, including updating medical records and going to the pharmacy to take their medication, the researcher initiated asking the participants whether they wanted to do the intervention in their home or not. If the participants came with the family member(s), the researcher also asked the family members about their agreement to come to their

house. When everything had been agreed, the researcher made an appointment with the participant and family. This means that the researcher did a home visit to do the intervention. This home visit was done in the day after the first meeting in the hospital. All of the participants of this study agreed to allow the researcher came to their home.

*The first phase.* The first phase was conducted to cover the first to the sixth process components of the IREP. This phase was done at the first meeting when the researcher met the participant at the OPD. The duration of time for each step is presented in the protocol of the IREP (Appendix B). This phase took around 70 minutes. The program activity in first phase according to each component is described as following:

*The first process component.* It was the representational assessment. The goal of this step is to understand the participant's ideas/perceptions about bipolar disorder. The program activities included discussion to encourage the participant to describe his/her illness along the five dimensions of cognitive representation, including identity, cause, timeline, consequences, and cure/controllability.

*The second process component.* It was identifying and exploring the gaps, misconceptions, and confusions. It was done after the participant describe his or her beliefs and experiences with bipolar disorder along the five dimensions of illness representation. It took about 5 minutes. The goals of this process component were to understand how any identified misconceptions/confusion developed and how comitted the participant is to those beliefs or ideas. The researcher provided a discussion in the way of activities to encourage the participant to think and talk about the experiences that led to any misconceptions, or confusion since developing bipolar disorder. Then, the participant was asked to evaluate the strength or the importance of those perceptions that influenced his/her medication behavior. During this phase, several misconceptions,

confusions, and/or gaps were indicated and reflected on by the participants. These misconceptions, confusions, and/or gaps are shown in the following table.

Table 2

*The Common Current Perceptions Which Were Misconceptions, Gaps, and/or Confusion of the Participants (n=30)*

No	Common Misconceptions, Gaps, and/or Confusion of the Perceptions
1.	My illness is part of God's plan.
2.	I'm not suffering from mental illness, I was just exhausted, that's why I became like this.
3.	I know there is something wrong in my mind and body, but I do not know about the illness. I do not know what bipolar disorder is.
4.	I do not know that bipolar disorder is such a severe illness, so I must have had it for years and have been taking medication for a long time.
5.	I sometimes feel complicated with this illness, in which certain moments I feel fine and at the other times I feel sick, while the doctor said I had not healed completely.
6.	My illness is caused by black magi
7.	This illness is a punishment from Allah because once when I was young, I did not obey the commandments of Allah.
8.	My illness as a result of demonic influence.
9.	I got a labeling of illness as a mad person.
10.	The course of my illness is short-term.
11.	I experienced symptoms of illness at this time and have before but it does not mean I suffer from mental illness.
12.	I have had negative consequences since I have had this illness, such as no one to marry with me, no have chance to get a permanent job, often to be excommunicated, and most people do not respect me.

Table 2 (continued)

No	Common Misconceptions, Gaps, and/or Confusion of the Perceptions
13.	I have suffered from this illness for a long time, so I feel that the medicine from the hospital would not be useful for me. I never really recovered despite many years of taking medication.
14.	The most beneficial treatment for my illness is spiritual treatment or alternative treatment.
15.	My treatment will not be as effective as treatment given by experts from alternative treatment or treatment from ustadz. Treatment from ustadz can control my illness more than drugs given by the doctor.
16.	Drugs that doctors prescribe have more bad effects on me because I often feel the side effects of the drugs and feel uncomfortable with the drugs.
17.	Because sometimes I do not experience the symptoms of my illness, so I just have to take my drugs when I feel the symptoms of the illness course

*The third process component.* It was creating conditions for conceptual change. This process took a maximum of 10 minutes. The goal is to help the participants to recognize the limitation of their current conception, i.e., ways in which misconceptions or confusions may be having negative effects. To accomplish this goal as an activity, the researcher discussed with the participant about any problems related to the participant's current representations, coping strategies, and any consequence that the participant has identified. After that, the researcher helped the participant to recognize how their current conceptions affect their coping strategies and the consequences.

*The fourth process component.* It was introducing replacement information. This process took a maximum of 15 minutes. The goal of this process is to provide new information to fill gaps in knowledge, to clarify confusions and to replace misconceptions. The activities included giving new information to fill gaps in knowledge, clarifying confusions and replacing misconceptions. The information refers to knowledge



of bipolar disorder according to the five dimensions of representation related to bipolar disorder. It consisted of an explanation of the knowledge about the identity of bipolar disorder, cause, timeline, consequences, and cure/treatment.

*The fifth process component.* It was the summary. This process took a maximum of 10 minutes. The goal of this process is to ensure the participants' assimilation of the new information. In this process, the researcher explained the benefits of the medication, how to manage the side effects, and asked the participant if he/she understood his or her illness. The researcher also summarized the new information, asked the participant to summarize the information given by the researcher first, and encouraged them to discuss the benefits expected from acting on the new information.

*The sixth process component.* It was goal setting and planning. This process took time around 15 minutes. The aim of this process was to develop goals related to improving medication adherence and strategies to achieve the goals. The researcher and the participant discussed setting the goal and the strategies regarding medication adherence.

*The second phase of the IREP.* The second phase (follow-up contact) was done after the first phase. The goal of this phase is to evaluate whether the goal was achieved and that the strategies are working, to discuss the continuing of same strategies or making modifications, and to encourage the subject to continue implementing the new pattern, evaluating, and modifying strategies to manage medication adherence. For this second phase, the researcher only provided the activity through telephone contact. Specifically, the participant was asked if the goal was achieved, to evaluate whether the strategies worked or not, to identify any problems or barriers during the implementation of the strategies, and to develop strategies for continuing medication adherence.

The researcher also encouraged the participant to reflect on his/her behaviors regarding medication adherence over the past week.

### **Data collection instruments**

***Instrument for screening.*** The instrument that was used for screening is the Brief Psychiatric Rating Scale (BPRS). The BPRS was used to measure the participants' condition according to their symptoms. This questionnaire was only used for screening whether the participants met the study's inclusion criteria. According to Leucht, Kane, Kissling, Hamann, Etschel, and Engel (2005), the BPRS consists of 18 items. The format of the BPRS is a 7-point Likert scale (1 = not present, 2 = very mild, 3 = mild, 4 = moderate, 5 = moderately severe, 6 = severe, 7 = extremely severe). The category of BPRS consists of normal/not ill at all (with score 18), borderline mentally ill (19-31), mildly ill (32-40), moderately ill (with score 41-52), markedly ill (with score 53-66), severely ill (with score 67-85), and extremely ill (with score 86-126). Only the participants whose scores were normal to mildly ill range (less than 40) would be included.

***The Demographic Data Questionnaire (DDQ).*** This questionnaire was developed by the researcher. It consists of the following items: initials of the participants' name, age, gender, marital status, ethnicity, religion, education level, occupation, income, previous hospitalization, current medication, and experiences of the side effects of medication. The format of this questionnaire is a combination between dichotomous and fill in the blank questions.

***The Cognitive Illness Representation Questionnaire for Bipolar Disorder (CIRQBD).*** The Cognitive Illness Representation Questionnaire for Bipolar Disorder

(CIRQBD) was modified by the researcher based on the Illness Perception Questionnaire for Schizophrenia (IPQS) developed by Lobban, Barroclough, and Jones (2005). The IPQS was developed and modified from the Revised Illness Perception Questionnaire (IPQ-R) which IPQ-R was originally developed for physical illness population.

The researcher got permission from the author to use and modify the measurement based on the five components of bipolar disorder (identity, cause, timeline, consequences, and control/cure). The IPQS consists of five domains of cognitive illness representation, personal control, personal blame, illness coherence, and emotional representation. However, since the researcher only assessed the participants' cognitive illness representation, therefore from the IPQS, the researcher only included the five domains of cognitive illness representation with modification in some parts. Particularly, in the part of identity, the researcher modified all of the question items related to symptoms/experience of bipolar disorder. In addition, in terms of identity, the researcher also modified the items in labeling. In the cause and consequences domain, the researcher left in some existing items and added more items related to those domains.

The CIRQBD consists of identity (symptoms have 20 items while labeling has 4 items and fill in the blanks), causes (13 items and fill in the blanks), timeline (10 items), consequences (13 items), and cure/control/treatment (5 items). This questionnaire consists of 65 total items. The format of the CIRQBD is a combination between dichotomous, the Likert scale and fill in the blanks.

For identity, there are two parts of this domain: symptoms and labeling of bipolar disorder. In the symptoms part, there are two statements including participants' experiences since they have had mental health problems (bipolar disorder) and those experiences that are related to their mental health problems or due to other factors. For

the statements of symptoms that the participant has had the experience since his/her mental health problem, the items statement are scored from 0 to 1 with 0 = no and 1 = yes. For the attribution of the experience of symptoms due to part of their mental health problems or other factors are scored by 0 = no symptoms, 1 = due to others factors, and 2 = part of the illness. Meanwhile, the format in the labeling is a 5-point Likert scale (1 = strongly disagree, 2 = disagree, 3 = neither agree nor disagree, 4= agree, and 5 = strongly agree).

The cause domain has 13 items with a 5-point Likert-scale and is scored from 1 to 5. The timeline dimension has two sub-domains which are acute/chronic and cyclic. Acute/chronic sub-domain has 3 positive statements (no. 2, no. 3, no. 5) and 3 negative statements (no. 1, no. 4, and no. 6) with a-5 point Likert scale, while cyclic sub-domain has all positive statements (no.7 to no.10). The consequences domain has 11 positive statements (no. 1, no. 3 – no. 9, and no. 11 – no. 12) and 3 negative statements (no. 2, no. 10 and no. 13). And the controlability/curability consists of 3 positive statements (no. 2 – no. 4) and 2 negative statements (no.1 and no. 5). The interpretation of each dimension is summarized in Table 3.

Table 3

*The Interpretation of Cognitive Illness Representation Questionnaire for Bipolar Disorder*

No	Dimensions	Response Format	Possible Range	Interpretation
1.	Identity			
	- Symptoms subjects experienced since their illness (20 items)	Yes/No	1 – 20	- The higher score is the more number of symptoms participants had experienced
	- Label (4 items)	5-point Likert scale	4 – 20	- The higher score indicates the strong perception that the symptoms are labeled as the illness
2.	Causes (13 items) (calculated for each cause)	5-point Likert scale	1 – 5	The higher score indicates the strong perception about the causes of the illness
3.	Timeline			
	- Chronic/ acute (6 items)	5-point Likert scale	6 – 30	- The higher score indicates the strong perception about the nature of the illness as chronic
	- Cyclic (4 items)	5-point Likert scale	4 – 20	- The higher score indicates the strong perception about the nature of the illness as cyclic
4.	Consequences (13 items)	5-point Likert scale	13 – 65	The higher score indicates the strong perception of the negative consequences of the illness
5.	Controllability (5 items)	5-point Likert scale	5 – 20	The higher score indicates the strong perception that the treatment/cure will be helpful in managing subjects' illness.

*The Medication Adherence Behavior Questionnaire (MABQ).* The Medication Adherence Behavior Questionnaire (MABQ) was developed by the researcher based on the literature reviews. The MABQ is used to assess behavior of taking medication. It consists of four sub-scale including taking medication voluntarily which involves 2 positive statements (no. 1 and no. 2) and 1 negative statement (no.3), taking medication continuously which involves 3 positive statements (no. 6, No. 7, and no. 9) and 3 negative statements (no. 4, No. 5, and no. 8), taking medication actively which involves 1 positive statement (no. 11), and 2 negative statements (no. 10 and no. 12), and taking medication correctly as prescribed which involves 1 positive statement (no. 15) and 2 negative statements (no. 13 and no. 14). The instrument yields a total of 15 items. The format of this questionnaire is 5-point Likert scale. For positive statements, the score ranges from 1 to 5 in which 1 = never, 2 = rarely, 3 = sometimes, 4 = most of the times, and 5 = always. For negative statements, it is reverse scored. The total score is the sum from the 15 items in which the possible range is from 15 to 75. The higher score of MABQ indicates higher medication adherence behavior.

### **Translation of the instrument**

The CIRQBD and the MABQ were originally developed in the English version. After the instruments were validated by three experts, the instruments then were translated by using the back-translation process (Brislin as cited in Aklima, 2012). In the beginning, the instruments were translated from the original English version to an Indonesian version by an Indonesian bilingual translator from the Language Center of Syiah Kuala University, Banda Aceh. This Indonesian version was then translated back to an English version without seeing the original version by another person from

the same institution as in the beginning. Finally, both English versions were clarified and any discrepancies were identified between the two versions. This process showed that there were no significant differences between the original version and the back-translation version. The differences were only in wording but the meanings were verified as being the same.

### **Validity and reliability of the instruments**

*Validity of the instruments.* The content validity of the instruments including the intervention program, goal setting and planning strategies form, the DDQ, the CIRQBD, and the MABQ were examined by three experts. Two experts were psychiatric nurses, one is from Prince of Songkla University, Thailand, and the other is from Indonesia. The third expert is an expert in illness representation from Prince of Songkla University. These experts were approached to validate the content of the instruments. Then the researcher revised the instruments based on the suggestions from the experts.

Based on the calculation of content validity index (CVI) for both the CIRQBD and the MABQ, it showed that the score of CVI is good (the CIRQBD = 0.98 and the MABQ = 0.99). However, there were some parts of the questionnaires that need to be revised or deleted. One expert gave “not relevant” for two items in the causes of the CIRQBD “Unbalanced emotion” and “Low self-esteem. The expert suggested taking out these two items because they had a similar meaning with items in the identity section. While for the MABQ, one expert gave “somewhat relevant” for item no. 4 (“I did the follow up on my medication” was changed to “I skip my medication when I feel better”) in which the question was changed from a positive statement to a negative statement.

Another expert asked about item no. 12 (“I prepare my medication by myself”) because it was repeated in item no. 11 (“I took my medication by myself without help from anyone”), therefore the statement of “I prepare my medication by myself” was changed to “My family prepared my medication” in which the question changed from a positive statement to a negative statement. One expert also gave “somewhat relevant” for item no. 14 (“I know how much dosage for each kind of my medication which I have to take in the morning, afternoon, or before bed”) so this was changed to negative statement “I forget how much dosage for each kind of my medication which I have to take in the morning, afternoon, or before bed”.

***Reliability of the instruments.*** The instruments of this study were tested for reliability using Kappa Coefficient for a test-retest evaluation of symptoms questions with dichotomous and Cronbach’s alpha coefficient for the Likert scale questions. The researcher examined 20 participants with bipolar disorder who met the inclusion criteria. The participants were recruited from the psychiatric hospital in Medan, North Sumatera Province. For identity (symptoms) of CIRQBD, this is a one-week test re-test. These were accepted if the value for the reliability of this instrument is .70. The reliability coefficients are shown in Table 4.



Table 4

*Reliability of the Questionnaires*

No	The Questionnaires	Reliability test	Results
1.	CIRQBD		
	- Identity (symptoms)	Kappa coefficient	.77 – 1.00
	- Cause	Cronbrach's alpha coefficient	.51
	- Timeline acute/chronic	Cronbrach's alpha coefficient	.54
	- Timeline Cyclic	Cronbrach's alpha coefficient	.67
	- Consequence	Cronbrach's alpha coefficient	.67
	- Controllability	Cronbrach's alpha coefficient	.81
2.	MABQ	Cronbrach's alpha coefficient	.94 (total)
	- Voluntarily		.91
	- Continuously		.86
	- Actively		.67
	- Correctly as prescribed		.84

The MABQ were accepted due to the value of the reliability being greater than .70. Among the CIRQBD, there was only one dimension (controllability) that showed that it was greater than .70 (.81), however, the rest of those dimensions were lower than the acceptable value. For the symptoms, the kappa value of 0.77-1 was in a substantial agreement range between the first test and second test (test-retest) and was accepted, because the reliability value of the Kappa coefficient was greater than 0.4 (Sim & Wright, 2005).

### **Pilot study**

The purpose of the pilot study was to establish that the CIRQBD and the MABQ were well understood by the participants, and that the proposed program was feasible. Three participants who met the same inclusion criteria for participants in this study were recruited for this pilot study. They received the planned intervention.

In the pilot study, the participants were willing to accept the IREP with full attention. The total time to complete the intervention from the first phase to second phase depended on the participants since they have different gaps, confusions or misconceptions. The time spent for each participant; the first participant 50 minutes, the second 60 minutes and the last participant 65 minutes to finish the first phase. For the follow up, they spent approximately 15 – 20 minutes.

All the participants were able to follow all process components provided by the researcher. Patients said that they understood the explanation of the program and that it was appropriate for them.

However, based on the researcher's observation during this pilot study, it was difficult to provide the intervention in the hospital because of the service system in the OPD. When the participants arrived at the hospital and brought their medical record form, they were asked to wait to have their weight and blood pressure checked. Two participants were bored because they and their families began to think about going back home.

Based on the situation described above, the researcher decided to change the intervention plan for this study by delivering it in the participant's home. In addition, the researcher did not change the time spent for each process component, because the

time spent depended on the subject's needs or problems, especially in regards to the subject's misconceptions, gaps, or confusion.

### **Ethical Consideration**

This study was approved by the Research Ethics Committee, Faculty of Nursing, Prince of Songkhla University, Thailand. This study was conducted in a Psychiatric Hospital, Medan, Indonesia. The participants included in this study were diagnosed with bipolar disorder, not in an acute phase, so that the researcher can communicate well with them. Even though the participants in this study are mentally ill persons, the researcher must still apply ethical principles to the participants. To conduct the research, the study plan and protection of human rights of the participants were assured.

The researcher gave a full explanation of this study to the participants regarding the purposes of the study, the procedures, the possible benefits, and some risks. Related to the possible risks, the participants may feel inconvenience of time in the intervention delivery, and feeling of discomfort or sadness. The researcher also applied confidentiality in which each participant's name was labeled with initials only. Of course, the initials were only known by the researcher. The explanation was given in the Indonesian language.

In cases when the participants had psychological discomfort, the researcher stopped the intervention and provided assessment and psychological first aid. If the participant still felt out of control and needed more intensive care, the researcher referred them to an expert.

## **Data Collection Procedures**

The data collection was conducted at the Out-Patient Department (OPD) of the Psychiatric Hospital Medan, Indonesia, and at the participants' homes. There are two phases of the data collection as follows:

### **Preparation phase**

In the preparation phase, the researcher provided this in several steps:

1) obtaining the official approval from the Faculty of Nursing, Prince of Songkla University, Hatyai, Thailand, 2) obtaining permission for the data collection from the Psychiatric Hospital in Medan, North Sumatera Province, 3) preparing all materials and instruments including informed consent, 4) testing validity and the reliability of the instruments, 5) recruiting and training the research assistants (RA) to assist the researcher in collecting data, and 6) conducting the pilot study.

In this study, two research assistants were recruited. One of them was a nurse who is working in the Psychiatric Hospital in Medan. The other was a nurse who is working in a private hospital in Medan. In order to assist the researcher in collecting data, the researcher conducted a simple training for the research assistants related to the study. They received a detailed explanation about the objectives of the study, how to use the instruments, and ethical considerations. These two research assistants had the following responsibilities; (1) the first research assistant who is working in the psychiatric hospital helped the researcher when doing pre-test data collection at the OPD, and (2) the second research assistant who is a nursing graduate helped the researcher when conducting post-test data collection in the participants' homes in the community.

### **Implementation phase**

The implementation phase was conducted sequentially as follows:

1. *Identifying the eligible subjects.* The research assistant identified the participants who are diagnosed with bipolar disorder and meet all the inclusion criteria of age, being able to read, being able to communicate well, being able to participate in the study, and having phone access. Then, the research assistant asked the participant if he/she was willing to meet the researcher. When they agreed, the researcher assistant introduced the participants to the researcher. After that, the researcher conducted the BPRS test for screening.
2. *Getting consent form.* After the eligible participants were identified, they were approached and asked to participate to this study based on their interest and willingness. The participants received a detailed explanation about the study and were asked to fulfill the informed consent.
3. *Pre-test data collection.* After the participants sign the informed consent form, the research assistant collected the data of DDQ, ICRQBD and MABQ as a pre-test score.
4. *Implementation of the program.* The process component of this phase included the representation assessment, identifying and exploring the gaps, misconceptions, and confusions. This phase was done at the participants' homes. Approximately 70 minutes was spent on this. After finishing the first phase, the researcher and the participants made an appointment to continue the second phase of the intervention (follow-up) by phone contact, in the following week.

5. *Post-test data collection.* The post-test data collection was conducted one week after the intervention. It also was done at the participant's home. The detail of the program is clearly explained in the following figure:

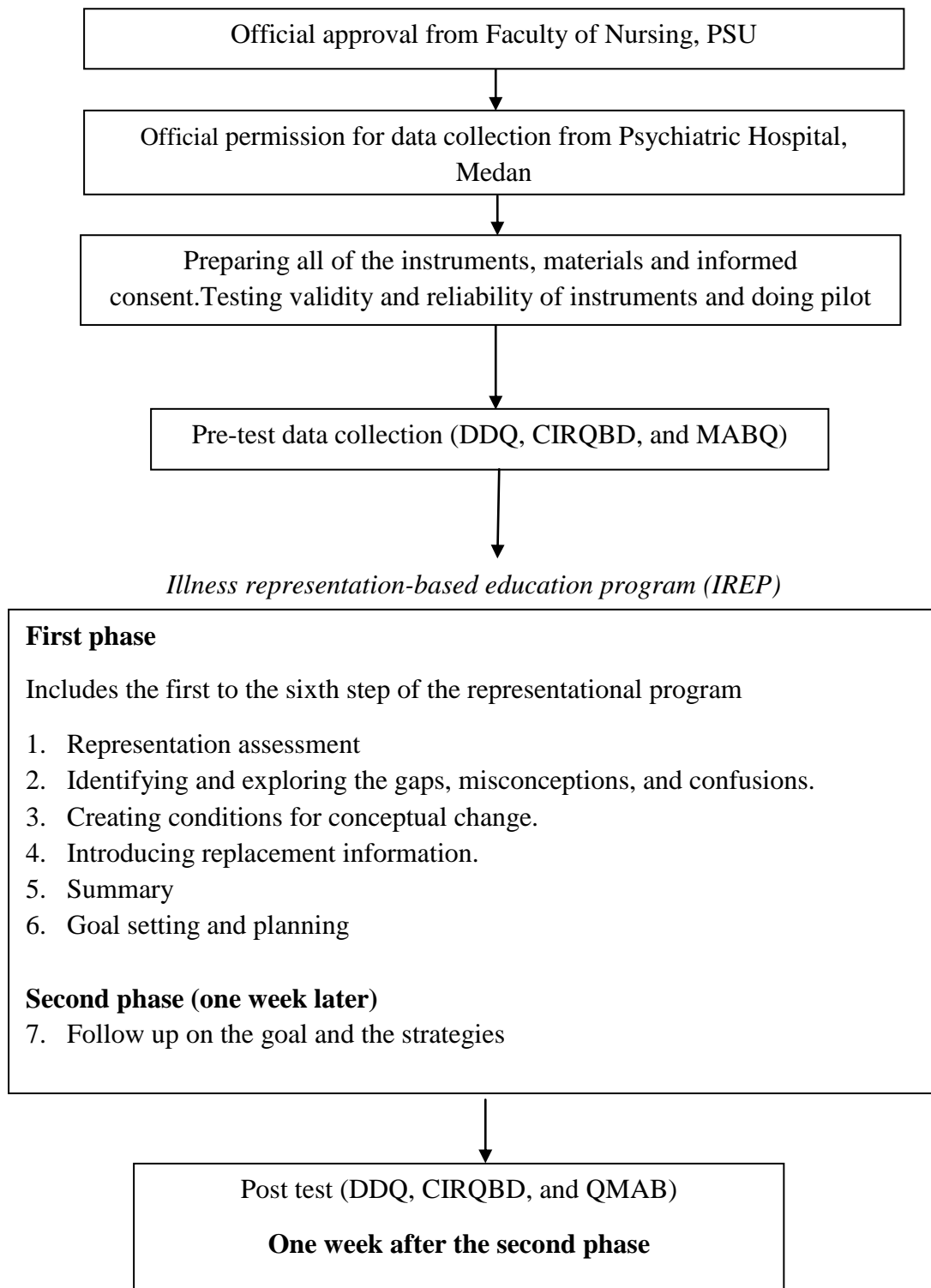


Figure 2. The data collection procedure

## **Data Analysis**

Descriptive statistics and inferential statistics were used for the data analysis in this study. The descriptive statistics were used to describe the subject's demographic characteristics and health information. Frequency, percentage, mean (M) and standard deviation (SD) were used.

Inferential statistics were used to compare the significant differences of medication adherence behavior and cognitive illness representation before and after the intervention. Before that, the researcher examined the assumptions of normality of medication adherence and cognitive illness representation. The normality testing showed that the medication adherence behavior scores were normally distributed as presented by skewness and kurtosis ratios less than  $\pm 3$  (Appendix H), thus the paired t-test was used. The cognitive illness representation scores were normally distributed as well, except for labeling (sub-domain of the identity) that did not meet the normality assumption. Thus, the paired t-test was used to test causes, timeline, consequences, and controllability, while Wilcoxon signed-rank test was used to test the labeling.



## **CHAPTER 4**

### **RESULTS AND DISCUSSION**

This chapter presents and discusses the findings of the study. The results are presented in three parts as follows: the demographic characteristics and medical related data, the cognitive illness representation along five domains, and effect of the Illness Representation-based Education Program on medication adherence. The data was collected during May to November 2014, at the psychiatric hospital in Medan, North Sumatra Province, Indonesia.

#### **Results**

##### **Subject's characteristics**

Data related to the demographic characteristics of the participants is shown in Table 5. The results showed that the mean age of the participants was 35.83 years (SD = 11.29). Most of the participants were single (53.3%) and female (57.7%). Interestingly, both religions, Islam and Christianity were at the same percentage (Islam 50% and Christian 50%). Most of the participants had senior high school education (63.3%). Most of the participants (50%) had no job. For monthly income, half of the participants did not have any income (50.0%). And more than half of the participants (66.7%) had family members currently taking care of them.

Table 5

*Frequency, Percentage, Means and Standard Deviation of Demographic Data of the Participant (N = 30)*

Characteristics	Frequency (n)	Percentage (%)
Age (year)	<i>M (SD) = 35.83 (11.29)</i>	
(Range = 20 - 60)		
Gender		
Male	13	43.3
Female	17	56.7
Marital Status		
Single	16	53.3
Married	10	33.3
Divorced/Widowed	4	13.3
Religion		
Islam	15	50.0
Christianity	15	50.0
Level of education		
Junior High School	4	13.3
Senior High School	19	63.3
College/University	7	23.3
Occupation		
Unemployed	15	50.0
Non-Government Employed	13	43.3
Government Employed	2	6.7
Income per month (IDR)		
No income	15	50.0
≤ 1.000.000	7	23.3
>1.000.000	8	26.7
Caring from family members		
No	10	33.3
Yes	20	66.7

### **Clinical characteristics**

Data related to the clinical characteristics and medical history of the participants is shown in Table 6. This data consists of hospitalization, length of illness, alcohol intake, drug abuse, how the participants received the medication at the hospital (by him/herself or accompanied by family members), type of medication, and the participant's experience of any side effects of medication. The mean score of the hospitalization was .97 times ( $SD = 1.33$ ). The participants have been diagnosed with bipolar disorder on average of 5.87 years ( $SD = 4.95$ ). Most of the subjects did not drink alcohol (90.0%) and did not misuse drugs (96.7%). Most of the participants (70.0%) in this study came to take the medication at the hospital without family members' accompaniment.

Related to the side effects of medication, all of the participants stated that they had side effects from medication. The common side effects they had experienced were weight gain (43.3%) and insomnia (43.3%). Other side effects that subjects had experience were headache, dry mouth, sleepy, laziness, agitation, nausea, and dizziness. Among the three types of the medications, antidepressants were the most commonly used (90%).

Table 6

*Frequency, Percentage, Means and Standard Deviation of Clinical Characteristics of the Participants (N = 30)*

Characteristics	Frequency (n)	Percentage (%)
Hospitalization (Range = never – 5 times)	$M (SD) = 0.97 (1.33)$	
Length of Illness (Range = 1 year – 20 years)	$M (SD) = 5.87 (4.95)$	
Drinking alcohol		
No	27	90.0
Yes	3	10.0
Drug abuse		
No	29	96.7
Yes	1	3.3
Getting medication in the hospital		
By her/himself	21	70.0
Accompanied by family member(s)	9	30.0
Type of medication		
Antidepressant	27	90.0
Mood Stabilizer	24	80.0
Antipsychotic	24	80.0
Type of medication		
Antidepressant	27	90.0
Mood Stabilizer	24	80.0
Antipsychotic	24	80.0

Table 6 (continued)

Characteristics	Frequency (n)	Percentage (%)
Experiencing side effects		
Weight gain	13	43.3
Insomnia	13	43.3
Headache	6	20.0
Dry mouth	4	13.3.
Sleepy	3	10.0
Laziness	6	20.0
Agitation	3	10.0
Nausea	3	10.0
Dizziness	5	16.7
BPRS Score	M ( <i>SD</i> ) = 19.93 (3.29)	

### **The Effect of the Illness Representation-based Education Program on Medication Adherence**

This part was conducted to determine the effect of the Illness Representation-based Education Program (IREP) on medication adherence. The mean score of medication adherence for pre-test and post-test were examined. A paired *t*-test was used. The findings are presented in Table 7.

Hypothesis: Medication adherence among patients with bipolar disorder after receiving the illness representation-based education program is higher than before receiving the illness representation-based education program. By focusing on the mean score of total medication adherence and the subscales of medication adherence, this hypothesis was completely supported by the result of the analyses, except for taking medication correctly as prescribed subscale. The mean score of medication adherence

pre-test and post-test were 54.47 ( $SD = 11.34$ ) and 59.60 ( $SD = 10.01$ ), respectively. The dependent  $t$ -test showed that the mean post-test scores of medication adherence were significantly higher than the mean of pre-test scores ( $t = -5.04, p < .01$ ). In addition, the mean scores of the subscales of medication adherence pre-test and post-test were 10.83 ( $SD = 2.78$ ) and 12.10 ( $SD = 2.47$ ) for taking medication voluntarily, 20.07 ( $SD = 4.89$ ) and 22.33 ( $SD = 4.33$ ) for taking medication continuously, 11.40 ( $SD = 2.57$ ) and 12.40 ( $SD = 2.43$ ) for taking medication actively, and 12.17 ( $SD = 2.49$ ) and 12.77 ( $SD = 2.46$ ) for taking medication correctly as prescribed.

Table 7

*Comparison of Mean Scores of Medication Adherence of the Participants (N = 30)*

Medication Adherence	Before Intervention		After Intervention		$T$	$P$
	$M$	$SD$	$M$	$SD$		
Total	54.47	11.34	59.60	10.01	-5.04	.000
Voluntarily	10.83	2.78	12.10	2.47	-4.75	.000
Continuously	20.07	4.89	22.33	4.33	-5.19	.000
Actively	11.40	2.57	12.40	2.43	-3.53	.001
As prescribed	12.17	2.49	12.77	2.46	-1.31	.201

### **The Effect of the illness representation-based education program on cognitive illness representation**

This part is to determine the effect of the Illness Representation-based Education Program (IREP) on cognitive illness representation. The mean score for each dimension of cognitive illness representation for pre-test and post-test were examined. A paired *t*-test and Wilcoxon signed Ranks Test were used. The findings are presented in table 8 – 13.

Hypothesis cognitive illness representation among patients with bipolar disorder after receiving the illness representation-based education program is changed compared to before receiving the illness representation-based education program.

Identity dimension of cognitive illness representation is presented in Table 8. The frequency and percentage of experiencing symptoms for the pre-test and post-test are shown. The highest scores of the symptoms that the participants had experienced were for: ‘Sometimes I cannot concentrate well’ symptom (96.6), followed by ‘My self-esteem fluctuates; sometimes it is high, sometimes it is low’ symptom (93.3%), ‘Sometimes I feel unhappy and sad for no reason’ symptom (90.0%), and ‘I have a big appetite’ symptom (90.0%).

Table 8

*Frequency and Percentage of Experiencing Symptoms of the Participants (N = 30)*

Symptoms of the illness	Before Intervention	After Intervention
	Yes <i>n</i> (%)	Yes <i>n</i> (%)
Get tired easily	23 (76.6)	23 (76.6)
Full of energy	13 (43.3)	12 (40.0)
Talkative and can not help myself to stop talking	11 (36.6)	13 (43.3)
Sometimes I laugh too much because I feel happy for no reason	14 (46.6)	16 (53.3)
I sleep too much	15 (50.0)	16 (53.3)
I can not sleep well	26 (86.6)	24 (80.0)
I feel very confident	17 (56.6)	18 (60.0)
My self-esteem fluctuates; sometimes is high, sometimes is low	28 (93.3)	27 (90.0)
Sometimes I feel very happy for no reason	21 (70.0)	24 (80.0)
Sometimes I feel unhappy and sad for no reason	27 (90.0)	27 (90.0)
My thoughts flow quickly, freely and fast	21 (70.0)	23 (76.6)
I feel depressed most of the day	19 (63.3)	20 (66.6)
I feel no spirit to do activities	25 (83.3)	27 (90.0)
My weight gain is much	12 (40.0)	12 (40.0)
I have a big appetite	27 (90.0)	27 (90.0)
Sometimes I feel fatigue and have a loss of energy	24 (80.0)	25 (83.3)



Table 8 (continued)

Symptoms of the illness	Before Intervention	After Intervention
	Yes <i>n</i> (%)	Yes <i>n</i> (%)
Sometimes I feel guilty and worthless	24 (80.0)	23 (76.6)
Sometimes I cannot concentrate well	29 (96.6)	29 (96.6)
Sometimes I think about the idea of death	8 (26.6)	8 (26.6)
I am easily irritated	26 (86.6)	27 (90.0)

Table 9 shows the mean rank of the label of illness of the symptoms that the participants had experienced. The score shows the increasing mean rank before to after the intervention (6.31 to 6.88), however, there was no significant difference of the label of illness after the intervention.

Table 9

*Comparison of Label of Illness of the Participants (N = 30)*

	Before Intervention		After Intervention		<i>Z</i>	<i>p</i>
	Mean	Sum	Mean	Sum		
	Rank	Rank	Rank	Rank		
Label of Illness	6.31	50.50	6.88	27.50	-.96	.334

The cause dimension of cognitive illness representation is presented in Table 10. Among the mean score of all of the causes below, the highest score of causes held by the participants before the intervention were thinking about things too much

( $M = 4.10$ ,  $SD = 0.71$ ), lack of sleep ( $M = 3.93$ ,  $SD = 0.98$ ), stress or worry ( $M = 3.83$ ,  $SD = 1.05$ ), over work or non-work ( $M = 3.83$ ,  $SD = 0.99$ ), and their mental attitude related to thinking negatively about life ( $M = 3.77$ ,  $SD = 1.01$ ). After the intervention, the mean score of those causes were higher except for over work or non-work cause. The mean scores of the other four causes were thinking about things too much ( $M = 4.27$ ,  $SD = 0.79$ ), stress or worry ( $M = 4.07$ ,  $SD = 1.14$ ), lack of sleep ( $M = 3.97$ ,  $SD = 1.09$ ), and their mental attitude related to thinking negatively about life ( $M = 3.83$ ,  $SD = 1.15$ ). The dependent  $t$ -test showed that stress or worry ( $t = -2.97$ ,  $p < .05$ ) and taking illicit drugs ( $t = 2.41$ ,  $p < .05$ ) were significantly different after the intervention.

Table 10

*Comparison of Mean Scores of Cause Dimension of the Participants (N = 30)*

	Before Intervention		After Intervention		$t$	$p$
	$M$	$SD$	$M$	$SD$		
Stress or worry	3.83	1.05	4.07	1.14	-2.97	.006
Hereditary - it runs in my family	1.83	.46	1.80	.61	.273	.787
My own behavior	3.30	1.21	3.40	1.25	-1.79	.083
My mental attitude e.g. thinking about life negatively	3.77	1.01	3.83	1.15	-.81	.423
Stressful life	3.23	1.17	3.37	1.25	-1.44	.161
Trauma	2.50	1.14	2.37	1.33	1.68	.103
Overwork or non-work	3.83	.99	3.57	1.38	1.25	.223
Alcohol Use	1.73	.79	1.73	1.02	.00	1.00
Taking illicit drugs	1.73	.64	1.57	.68	2.41	.023

Table 10 (continued)

	Before Intervention		After Intervention		<i>t</i>	<i>p</i>
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>		
Brain damage or abnormality	2.77	1.38	2.80	1.52	-.154	.879
Lack of sleep	3.93	.98	3.97	1.09	-.23	.823
Thinking about things too much	4.10	.71	4.27	.79	-1.98	.057
Lack of friends or people who care about me	3.27	1.17	3.30	1.34	-.33	.745

Table 11 shows the mean scores of the timeline domain (both acute/chronic and cyclic sub-domain). There was no significantly different in acute/chronic condition before and after receiving the intervention, however, there was a significant difference in the cyclic condition before and after receiving the intervention ( $t = -2.06, p < .05$ ).

Table 11

*Comparison of Mean Scores of Timeline Dimension of the Participants (N = 30)*

	Before Intervention		After Intervention		<i>T</i>	<i>p</i>
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>		
Acute/chronic	12.77	4.68	12.07	4.86	1.45	.159
Cyclic	14.80	3.63	15.70	4.02	-2.06	.049

The consequences dimension and controllability dimension of cognitive illness representation are presented together in Table 12. The mean scores of consequences pre-test and post-test were 44.20 ( $SD = 8.18$ ) and 44.60 ( $SD = 8.29$ ). The mean scores of controllability pre-test and post-test were 17.53 ( $SD = 2.47$ ) and 18.30 ( $SD = 3.23$ ). The dependent  $t$ -test showed there was no significant difference in consequences before and after receiving the intervention. However, the controllability dimension shows that there was a significant difference before and after receiving the intervention ( $t = -2.64$ ,  $p < .05$ ).

Table 12

*Comparison of Mean Scores of Consequences Dimension and Controllability Dimension of the Participants (N = 30)*

	Before Intervention		After Intervention		$t$	$p$
	$M$	$SD$	$M$	$SD$		
Consequences	44.20	8.18	44.60	8.29	-.82	.419
Controllability	17.53	2.47	18.30	3.23	-2.64	.013

## Discussion

The discussion of the study consists of the participants' characteristics and the effects of the Illness Representation-based Education Program (IREP).

### Subjects' characteristics

The average age of the participants was around 35 years old. This result is similar to a previous study conducted by Colom et al. (2009) and a study by Savas, Unal, and Virit (2011), which the results of those studies showed that the average age

was very close to the result of this study (36-37 years old). However, globally, there is no official data in the World Health Organization (WHO) related to the average age of patients. Mostly, the report gives information about the age of the onset of the illness which showed that the onset of bipolar disorder is most common in the adolescent to young adult years (Ayuso-Mateos, 2001; Macneil et al., 2009; Merikangas et al., 2011).

More than half of the participants were female (57.7%). In the Psychiatric Hospital in Medan, based on the researcher's observations during the data collection, most of the out-patients who are diagnosed with bipolar disorder were female (Psychiatric Hospital Medan, 2013). According to Global Burden in the year 2000 reviewed by Ustun et al. (2004), females with bipolar disorder were twice more than males. This was almost similar with the previous studies about medication adherence among patients with bipolar disorder (Aikens, Nease, Nau, Klinkman, & Schwenk, 2005; Baldessarini et al., 2007; Bowskill, Clatworthy, Parham, Rank, & Horne, 2007; Clatworthy, 2007; Clatworthy, 2009; Hou, 2010; Rosa et al., 2009; Sajatovic, 2011). In addition, other studies showed contrary results in which there was no significant difference between female and male, and some showed that males numbered higher than females (Aubry et al., 2007; Ferrari, Baxter, Somerville, Scheurer, & Whiteford, 2011; Hirschfeld & Weissman, 2002).

Most of the participants were single (53.3%) rather than married or divorced/widowed status. The ECA (Epidemiologic Catchment Area) study and NCS (National Comorbidity Survey) conducted in the United States and reviewed by Hirschfeld and Weissman (2002) showed that bipolar disorder was much less frequent among married people compared with divorced or never-married people. Marriage appears to be a protective factor that increases adherence to medication (Connelly as cited in

Sajatovic, 2009). However, the result of this study was contrary to the result of many studies with the medication adherence outcome among patients with bipolar disorder which showed most of patients were married. The result of this study was only similar to one study proposed by Sajatovic et al., (2011).

Both religions, Islam and Christianity, were at the same percentage (Islam 50% and Christianity 50%). In the North Sumatra Province, the religious affiliation of the population is more diverse than Aceh Province (the place where the researcher lives). Moslems remain the dominant group, and the second is Christians.

Most of the participants (63.3%) had senior high school education. The NCS (National Comorbidity Survey) that was conducted in the United States and reviewed by Hirschfeld and Weissman (2002) showed that bipolar disorder was more frequent among poorly educated people. In Indonesia, graduation from high school is not considered low education. Since 2003, the Indonesian government enacted legislation stating that all Indonesians are required to attend *Wajib Belajar Sembilan Tahun* (Nine-Year Compulsory Education); six years of elementary school and three years of junior high school. It means that for those who graduate from high school, they are not included in low education, as the result of this study. Most of the subjects (33.3%) have no job and did not have any income (50.0%). Patients with bipolar disorder were more likely to have small incomes (Hirschfeld & Weissman, 2002) as the impact of having no job.

More than half of the participants (66.7%) reported that their family members were taking care of them. A high level of support from family member(s) has been identified as a factor to better behavior in medication adherence. A high level of attention and a good relationship between a patient and family member(s) may help some individuals to overcome the barriers to adherence and living a functional life

(Horne, Weinmann, Barber, Elliot, & Morgan, 2006; Price & Marzani-Nissen, 2012). This was similar with the previous studies (Johnson, Winnet, Meyer, Greenhouse, & Miller, 1999; Michalak, Yatham, Kolesar, & Lam, 2006; Simoneau, Miklowitz, Richards, Saleem, & George, 1999).

In conclusion, the subjects' demographic characteristics in this study were similar with other studies, except for marital status.

### **Clinical characteristics**

This study found that the average hospitalization was 0.97 times (rounded to be 1 time). Patients who adhere to their prescribed medication have strong beliefs that their medication was necessary to avoid being hospitalized (Clatworthy et al., 2007). In addition, fear of future hospitalization was strongly proved as one of the factors influencing a patients' behavior in taking their medication (Adam & Scoot, 2000). According to the average number of hospitalizations that showed only as 1 time, with 6 years as the average length of having bipolar disorder, it was a small number of hospitalizations. According to the literature review, most of the patients with bipolar disorder who are non-adherent were associated with a high number of hospital admissions (Suppes et al. as cited in Clatworthy, 2007).

Most of the participants showed a small average in drinking alcohol and drug abuse. From the 30 participants, there were only 3 participants who were alcoholics and 1 participant was a drug addict. These numbers were contrary with many of the previous studies and literature that showed that many patients with bipolar disorder had substance abuse disorders and became non-adherent (Berk et al., 2010; Sajatovic et al., 2006; Sajatovic et al., 2010).

It should be noted that in regards to the medication the participants received during this study, the participants had been prescribed several kinds of medications. Thus the researcher categorized the medications into three categories of drugs; antidepressants, mood stabilizers, and antipsychotics. 90% of the subjects were prescribed antidepressants and 80% received both mood stabilizers and antipsychotic drugs. This was not surprising when looking at the same number of the percentage of mood stabilizer and antipsychotic. According to literature review, many patients who had been prescribed mood stabilizers usually also received antipsychotic drugs, since this category of drugs was often adjusted to the mood stabilizer prescribed to control episodes of mania (Kasper, 2003). A few of the studies showed the condition of the combination of the medication related to medication adherence and the patient's admission. For instance, in a one-year study about hospitalization by Woo et al. (2014), patients who got valproate (mood stabilizer) and an atypical antipsychotic were more likely to be adherent to medication than those who were prescribed lithium and an atypical antipsychotic. This is similar to the result of Woo et al.'s study conducted by Patel (2005) in that patients receiving a mood stabilizer plus a typical antipsychotic were more likely to be non-adherent compared with those receiving a mood stabilizer plus an atypical antipsychotic.

All of the participants stated they had experienced the side effects of medication. Medication side effects are a common reason for non-adherence in psychiatric patients (Scott as cited in Patel & David, 2007). Some studies strongly proved this condition (Clatworthy et al., 2009; Sajatovic et al., 2010). In this study, the most common side effects reported by the participants were weight gain and insomnia. Both these



side effects were the most experienced by patients with bipolar disorder (Schatberg et al., 2007; Williams et al., 2011).

**Effect of the illness representation-based education program on medication adherence among patients with bipolar disorder**

The hypotheses statement is; medication adherence among patients with bipolar disorder after receiving the illness representation-based education program is higher than before receiving the illness representation-based education program.

As presented earlier in the results of this study, the hypothesis is supported which shows that the mean scores of medication adherence among patients with bipolar disorder were significantly higher after receiving the intervention (Table 7).

Some of the studies reveal strong evidence to support the theory in the Common Sense Model (CSM) that emphasized on how changing an individual's perception about the illness (cognitive illness representation) can impact on behavior change towards dealing with the disease (Leventhal et al., 1980). This means that changes in the perception of the disease will lead to changes in behaviors. This is concordant with the theory of process of conceptual change which states that changes can only occur under the impact of new conceptions, of course, followed by three important factors; intelligible (sounds scientific/logic), plausible (believe it to be true) and beneficial (useful) (Posner et al., 1982).

Since this study showed positive results in medication adherence (refers to an individual's behavior to take his/her medication), this can be concluded that the participants in this study had changed their existing perception about their illness into a new perception after going through the process as in the process of

conceptual change. The new conception they got during the intervention, might not be easy for them to accept, especially if those new conceptions were contrary with their existing perceptions. However, since the researcher gave much encouragement in the part of the intervention to change the individual's existing perception about the illness, as at this time conflict occurs between existing perceptions and new conceptions. On one hand, participants faced new information which seems to be logical about the illness, and on the other hand, participants recognized the limitations or negative consequences of their current perceptions. When the participants felt dissatisfied with their existing perceptions, they tried to deal with the new conceptions before accepting them into their own thoughts. And when the new conceptions are believable (plausible) and beneficial (useful), it is then the time to be ready for those new perceptions.

In this study, the participants were assisted to work on the seven process components of the IREP. For the first process component, the participants were encouraged to describe their illness, bipolar disorder, in terms of identity, cause, timeline, consequence, and controllability. From the participants' information, the researcher knew which part of the participant's perception was a misconceptions, gaps and/or confusion. So the researcher focused the discussion on what makes their misconceptions, gaps and/or confusion. Moving onto the second process component, at the beginning, the researcher asked the questions in order to encourage the participant to think and describe about the experience that led the participant to have any thoughts that are misconceptions, confusion, or an error about bipolar disorder. Experience is one of the stimuli for the development of illness perception besides knowledge from others, culture or social thought (Leventhal et al., 1980). For example, the participants had an unpleasant experience with the medicine, whether because of the side effects from the

medications or other factors, so this influenced the participant's perception that medications are not good in dealing with their health problem. This belief led the participants to stop their medication even though the participants had known that medication is important to manage their symptoms. Then the participants were encouraged to think that those perceptions that could contribute to their taking medication behavior and ultimately affect the cure/control process of the disease. Then after that the researcher recognized the strength of the participant's ideas.

In the third process component, the researcher helped the participant to recognize the limitation of their current conception, i.e., ways in which misconceptions, gaps, or confusion that maybe having negative effects then make links between those misconceptions, gaps, or confusion and consequences of them. At this stage, then contrary occurs between existing perceptions and new conceptions. Since the participant got encouragement as mentioned above, the participant faced the new information which seems to be logical about the illness compared to his/her current perceptions. As proposed in the theory of conceptual change (Posner et al., 1982), in which when the person felt dissatisfied with his or her existing perceptions, he/she tried to deal with the new conceptions before accepting it into his/her own thoughts. In this line, the participant asked more questions related to his or her illness and the way to overcome the health problem. It means that he or she was ready to receive the new information by asking many questions. Finally, it was the time for the researcher to provide new information related to the questions asked in order to change the current perceptions.

In the fourth process component, the aim was of replacing the misconceptions, gaps, and/or confusion and introducing replacement information by giving information related to bipolar disorder. The researcher gave the information

related to what the participant's needed along the five dimensions of cognitive illness representation until the participant understood the new information. Understanding of the information or knowledge can require intelligibility for the participants, as outlined in the theory proposed by Posner et al. (1982). The new information given by the researcher should be consistent with the concept of bipolar disorder, past experience, and the participant's ability to solve mental health problems, in which medication adherence is the most effective way to deal with bipolar disorder. And in order to make the given information appear plausible, the information must be consistent with the individual's beliefs, theories or knowledge, past experience, the individual must be able to create an image for the new conception, and have the capability of solving problems. Lastly, the participants' awareness of those new conceptions must be intelligible and plausible which will finally lead to new insight and discoveries; the new perception. These steps in the fourth process component are consistent with the description of the Conceptual Change Model proposed by Posner et al. (1982).

For the fifth process component with the aim of ensuring participants assimilate the new information so that the participants understand the new information and can see the benefit of it in their life, the researcher and the participant made a summary. Both the researcher and the participant discussed the new conception if the participant decided to adopt it to deal with his/her mental health problem, including medication adherence problem. This part is important to know and to ensure whether the benefit of the new conception influences individuals to change their current perceptions or not. It can create a powerful motivation of the participant to accommodate the new perception.

For the sixth process component, the participant developed the goals and created the strategies to achieve those goals related to enhancing medication

adherence. Goal setting and strategies planning play an important role in medication adherence. This process component was provided with the aim of encouraging participants to set the goal related to medication adherence and discuss strategies appropriate and visible for each individual so as to facilitate transition from their perception to the behavior in taking medication. The new perception, which has been perceived by the participant, would be applied in the participant's behavior that focuses on medication adherence through this process. In order to help the participants to remember their goal setting and planning, the researcher encouraged the participants to write those goals down. This way is the easy way to remember, it was also easy to implement the strategies based on their own writing. Writing about life goals has been strongly proved to be an easy way to do the fulfil the tasks (Harrist, Carlozzi, McGovern, & Harrist, 2007). It means that an individual needs to set goal(s) and action/strategies planning(s) for successful behavior change for the better.

In the seventh process component, with the aim of evaluating the goal and the strategies (whether achieved/worked or not), identifying the problem or barrier during the implementation of the strategies, and maintaining or developing strategies for continuing medication adherence, the researcher assisted the participant to reflect on his/her behavior regarding medication adherence during the previous week, the researcher also set the strategies for continuing medication adherence. If the participant did not have any barrier or problem with the previous strategies to achieve the goal related to enhancing medication adherence, the participant can still use the previous strategies for maintaining his/her behaviors. But, if the participants have any barrier with the strategies, or if they said that they cannot use the same strategies from the previous week to enhance their medication adherence, they were encouraged to add another

strategy to deal with the barriers. Follow-up is an important method for achieving the goals. It has been previously proven that an educational intervention together with the follow-up home visit for patients with bipolar disorder who took Lithium resulted in not only gained knowledge for the patient about his/her medication, it also stimulated the patients to achieve their life goal (Peet & Harvey, 1991). However, in this study, the researcher used the phone call method in the follow-up. In this time, the researcher asked the participants about their goals and strategies that they had set. Only a few of the participants reported that they had some barriers to implement the strategies. Then, the researcher discussed with the participants how to overcome the barrier and added new strategies to overcome the barrier if the participant needed it. The researcher also motivated the participants to take their medication as in the planning strategies if they did not follow the planning strategies because of any reason.

### **Effect of the illness representation-based education program on cognitive illness representation among patients with bipolar disorder**

The hypotheses statement; medication adherence among patients with bipolar disorder after receiving the illness representation-based education program is changed compared to before receiving the illness representation-based education program.

In this study, after the participants had received the intervention, it showed that there were changes in several dimension of the perceptions in regards to two causes, cyclic of timeline, and controllability which were misconceptions, gaps, and/or confusion. The participants' perceptions of the cause domain before the intervention were 'thinking about things too much' ranked first as the cause of bipolar

disorder, followed by 'lack of sleep', and 'stress or worry and 'over or non-work'. After the intervention, 'stress or worry' as the cause of bipolar was significantly different. In addition, 'taking illicit drugs' was also significantly different after the intervention (Table 11).

Another finding about the participants' perception after receiving the intervention in this study was the participants' perception about the natural cycle condition of the illness was higher than before receiving the intervention. They perceived that they will have the symptoms of the illness all the time in particular cases, such as; sometimes they feel worse and at another time they feel better, or, the symptoms come and go alternately during their life. These perceptions may form the beliefs that continuously taking medication as prescribed while they have an illness in their life is needed even though their condition is sometime getting worse or better.

The last finding of the participants' perception about controllability after receiving the intervention was that the participants had a more positive perception of the controllability of medication to manage their illness than before the intervention (Table 13). According to a review article about severe mental illness by Lobban et al. (2003), patients were more adherent to their medication when they have a high level of perception in the treatment for controlling their symptoms. Beliefs about the benefits of medication treatment were more likely to affect treatment adherence among the bipolar disorder population (Scott as cited in Sajatovic et al., 2009). The participants would be more adherent to medication if they believe in the benefits of the medication in managing their symptoms.

As a matter of fact, the data analysis of this study proved the evidence that cognitive illness representation had influenced the participants' behavior to adhere

to their medication, especially the perceptions about stress or worry and taking illicit drugs as the causes of their illness, bipolar disorder as a cyclic illness, and the positive controllability of bipolar disorder. How the program could link to the change of those perceptions are described in detail below.

During the intervention, especially in the second process component, the researcher encouraged the participants to think and to describe their experience that led the participants to have any thoughts that are gaps, misconceptions, or confusions. During this process component, most of the participants talked about their own experience(s) that were of concern and had developed their existing perceptions. For instance, when they were asked about ‘what makes you think about the causes of your illness’, the most common answers for the cause of their illness are stress, or pressure of life, or economic problems, which can be included in ‘Stress or worry’ list causes (Appendix E). When they were asked ‘How do you come to be concerned about those perceptions’, they answered that because they had experienced those causes while they had had the illness. To see the second process component of the intervention which is identifying and exploring the gaps/misconceptions/confusion, therefore based on this, their answer should be part of gaps/misconceptions/confusion. However, in fact, not always all of participants’ existing perceptions could be interpreted as an error. In this case, when the participants’ answers are stressor pressure of life, or economic problem; these are in line with what the theory says that the causes of bipolar disorder are, especially in the part of psychological causes, which are unbalanced emotions, stressful life events, or low self-esteem (Macneil et al., 2009). In addition, negative life events and perceived stress appear to be related to depression in life (Kraaij, Arensman, Spinhoven, 2002). Those existing perceptions about stress were supported by the



participants own experience. It seems that their experiences of the causes of the illness are in accordance with what was presented by the researcher during the fourth process component (introducing replacement information). According to Posner et al. (1982), one of the five ways of the conceptions becoming initially plausibility (believing it to be true) is the participant finds the new conception to be consistent with his/her past experience. In this case, their experiences are consistent with the theory. Therefore, stress or worry is on the second rank among the most causes held by the participants. The mean score of stress or worry was also higher than before the intervention.

When asked about ‘What do you think about the course of bipolar disorder’, most of the perceptions in this regard were included in the cyclical timeline dimension, such as most of the participants perceived that ‘sometimes they are well and sometimes they are not well’, or ‘Sometimes they have the symptoms and sometimes not’. Such answers essentially illustrate the term of cyclical condition. Of course, these perceptions are also true if seeing the theory of bipolar disorder that states that patients with bipolar disorder usually manifest by the elevated moods from mania to depression (Macneil et al., 2009). It means that during the mania which the symptoms seem not to be in the ‘severe conditions’, some patients may think that they are not sick. That was what the participants perceived when they were asked about the timeline of their illness. In this case, the participants found the new conceptions presented by the researcher were consistent with their existing conceptions. According to Posner et al. (1982), one of the ways of the new conception to become initially plausibility is the individual finds the new conceptions consistent with the existing conceptions.

The controllability dimension was also significantly different after the intervention. However, during the intervention, the researcher found there were

misconceptions when the participants perceived about how the treatment can control their illness. They perceived that there is no medication that can help them to manage their illness, or they did not have much hope in the medication that was prescribed by the doctor. They thought that since they have had the illness, they have been treated but the medication does not seem to work well. Therefore, when conducting the intervention, the researcher asked the participants; what are the negative effects of their current conceptions? Or what will happen in the future if they still maintain their current conceptions? These questions helped the participants think deeply and they were then able to recognize the limitation of their current conceptions. The researcher tried to lead the participants to see the beautiful life they could have in the future if they are cured or if they recover which would lead to the advantages of taking medication, for instance; to stabilize switching moods (Kasper, 2003), to relieve daily mood variation symptoms (Videbeck, 2011), to prevent the intensity of subsequent episodes of mania and depression (Aubry et al., 2007). When the individuals eventually think that the existing conceptions are no longer necessary, the individuals will be faced with the dissatisfied of their existing conceptions (Hewson et al., 1981). Therefore, the result of controllability was significantly different after the intervention.

However, there were some dimensions of cognitive illness representation that showed there were no significant differences before and after the intervention. These were the label of the identity, causes (except for stress or worry and taking illicit drugs), acute/chronic timeline, and the consequences dimension. The result of these did not change probably because of several reasons. Firstly, this can be seen from the results of the reliability of cognitive illness representation that showed less than .70, only controllability had a reliability greater than .70 (.81). The lowest scores are cause

and timeline of acute/chronic domain which are .51 and .54. Secondly, the intervention was done only with one time of follow up. Since the follow up is an important method for achieving the goals (Peet & Harvey, 1991), some participants might need more than one follow up to instill in them confidence in dealing with their illness. The previous representational study conducted by Ward et al. (2009) provided two follow up sessions and showed how this representational intervention effectively changed attitudes about analgesic use.

Nevertheless, even though some participants still had the same perceptions in some dimensions of their cognitive illness representation before and after receiving the intervention, it does not mean that the subjects' behavior in taking medication cannot be changed for the better. Providing the information that the subjects asked for during the intervention could actually create new perceptions as to what is good and what is not in terms of their concern for their current treatment while they had the illness. The participants actively asked what they wanted to know about their illness and their treatment. Thus, the analysis of the data in this study proved the evidence that cognitive illness representation affected the participants to adhere to their medication, especially the perception about the causes of the illness (stress or worry and taking illicit drugs), timeline (perceived as cycle illness), and the positive controllability. The results of this study also proved that the IREP can change the individuals' perceptions. They understand what they should do if they want to achieve the goal. The important point in this case is the participants absorbed all the information provided by their questions and could hold it strongly in their minds. This seems to be linear with what was stated by Posner et al. (1982) in that the participants' awareness about the new perception must be intelligible, plausible, and fruitful. When the participants grabbed those three

points in the end, they were ready to accept the new insight to change their behavior in relation to the main goals for their life; being an adherent patient to their medication, and ultimately, to achieve better levels of functioning in daily life.

In conclusion, this two-week Illness Representation-based Education Program (IREP) was significantly effective to enhance the medication adherence among patients with bipolar disorder. Since all the participants were able to follow each phase of the intervention and the results are also good, it is evidenced that IREP is feasible to be implemented for patients with bipolar disorder in particular, and for general other psychiatric patients.

## CHAPTER 5

### CONCLUSION AND RECOMMENDATIONS

#### Conclusion

This quasi-experimental study aims to examine the effect of the Illness Representation-based Education Program (IREP) on medication adherence among patients with bipolar disorder in the Psychiatric Hospital Medan, Indonesia. This study used a one-group, pre and post-test design. Thirty patients with bipolar disorder who met the inclusion criteria were recruited for this study. IREP is a 2-week individualized intervention. The subjects had received the IREP which offered (1) representation assessment, (2) identifying and exploring the gaps, misconceptions, and/or confusion, (3) creating conditions for conceptual change, (4) introducing replacement information, (5) summarizing, (6) goal setting and strategy planning, and (7) following up on the goal and the strategy planning.

In the beginning, all the participants were asked to respond to the Demographic Data Questionnaire (DDQ), The Cognitive Illness Representation Questionnaire for Bipolar Disorder (CIRQBD), and the Medication Adherence Behavior Questionnaire (MABQ) to provide pre-test data. Then the participants were asked again to answer the CIRQBD, and the MABQ to provide post-test data.

The instruments in this study were validated by 3 experts. Reliability testing was only provided for the CIRQBD and the MABQ. These instruments were tested for reliability using Kappa Coefficient for test-retest of symptoms questions with dichotomous scale and Cronbach's alpha coefficient for the Likert scale questions. The Cronbach's alpha coefficient of the MABQ gained the result of .94 and a less

acceptable score for the CIRQBD except for the controllability dimension which gained .81. Meanwhile, the Kappa coefficient of CIRQBD of the symptoms dimension gained the result of 0.77-1.00.

Descriptive statistics and inferential statistics were used for data analysis in this study. Descriptive statistics was used to describe the subject's demographic characteristics and health information using frequency, percentage, mean, and standard deviation (SD), while inferential statistics (paired *t*-test) was used to analyze and describe the medication adherence behaviors.

Overall, the result of this study showed the effectiveness of the IREP before and after the intervention. The total mean score of medication adherence was significantly higher after receiving the IREP ( $p < .01$ ). According to this finding, the IREP had been evident in its effectiveness in enhancing medication adherence behavior among patients with bipolar disorder.

### **Strengths and Limitations**

This study offers evidence to support that the IREP effectively influenced medication adherence among patients with bipolar disorder. The strengths of this study are, firstly, this intervention was developed based on the theory support which are the cognitive illness representation of the Common Sense Model (Leventhal, Meyer, & Nerenz, 1980) and the learning process of the Conceptual Change Model (Hewson & Hewson, 1981; Hewson, 1992; Posner, Strike, Hewson & Gertzog, 1982). This representational approach has been strongly evident in changing an individual's behavior when dealing with his/her illness by changing perceptions/beliefs (Donovan & Ward, 2001; Donovan et al., 2007; Heidrich et al., 2009; Ward et al. 2008; Ward et al., 2009).

Secondly, this study measured the cognitive illness representation before measuring the behavior of the medication adherence in which Leventhal et al. stated that when the perceptions change then the behaviors change.

In spite of the strengths, a one-group pre and post-test design certainly has limitations. The limitations of this study are, firstly, related to the internal validity because the effectiveness of this program was based on pre and post-test only and cannot compare the effective result to another group. The second limitation was the measurement used for the first time especially in Indonesia. Some results of the reliability value, in particular most dimensions of cognitive illness representation, were lower than the acceptable value. The third limitation was that the findings of this study cannot be generalized to all populations of patients with bipolar disorder, but only for those who were in the stable condition.

### **Implications and Recommendations**

This study provides evidence that the Illness Representation-based Education Program (IREP) is effective in enhancing medication adherence behavior among patients with bipolar disorder. Through the IREP, new insight could be created that individuals perceive as intelligible, plausible and fruitful, along the five dimensions of cognitive illness representation, and thus, eventually can change behavior. According to the findings of this study, there are several recommendations for nursing practice and for future research study.

### **Nursing Practice**

The findings of this study have important implications for the nursing profession and health care professionals in order to enhance medication adherence. Nurses can combine the practice of Illness Representation-based Education Program with pharmacological management to help the patients who are non-adherent to their medication to change their behavior to be adherent to medication. IREP should be included in the nursing practice because this program is easy and an applicably practical to apply to all psychiatric patients with any diagnosis of the disease. The nurses do not need to provide or to set up any equipment in applying this practice. However, for the nurses who will apply this program into nursing practice they should understand the program in detail from the representation assessment to the patient's follow-up. A simple training session before applying the intervention to the patients is necessary. In addition, the nurses also need to understand about the new conceptions that will be given to the patients that are related to the perceptions in which a patient might have misconceptions, gaps, and/or confusion. The nurses also should know how to ensure the patients' assimilation of the new information to help the subjects fully understand in order to change to a better behavior.

### **Further research study**

This study provides evidence of the effect of IREP on medication adherence among patients with bipolar disorder that have experienced non-adherent behavior to medication. However, there are several entries if any further research would be conducted in the future. The first, the results of this study cannot be extended to all patients because the numbers of subjects studied were too small. Any future research



using IREP should be conducted with more subjects and thus reducing the occurrence of bias. The second, any further research should consider providing more than one follow-up in order to see whether or not the medication adherence behavior is still effective. The third point is since this study was only a one-group pre and post-test, it would be better to conduct a two-group for the further study. Fourthly, this study has been proven to be an effective program, therefore the researcher recommends further research to conduct the IREP in a ward setting for patients with bipolar disorder who will be discharged. The follow-up session could be provided at the patients' homes.

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**APPENDICES**

**APPENDIX A**

## Informed Consent

**RESEARCH INFORMATION SHEET**

My name is Fardelin Hacky Irawani. I am a lecturer at the School of Nursing, Faculty of Medicine, Syiah Kuala University, Indonesia who is doing my master degree of nursing at the Faculty of Nursing, Prince of Songkla University, Thailand. I am conducting a research study as one of the requirements entitled “Effect of Illness Representation-based Education Program on Medication Adherence among Patients with Bipolar Disorder in Medan, Indonesia”.

This study and its procedures have been approved by the Research Ethics Committee of the Faculty of Nursing, Prince of Songkla University, Thailand and has been granted permission by the Director of the Psychiatric Hospital, Medan, Indonesia. You are asked to participate in this research study because you are diagnosed with bipolar disorder by a psychiatrist and have a history in medication non-adherence, and are able to communicate. Your participation will be beneficial to improve the quality of nursing care provided in the future.

If you voluntarily decide to participate in this study, I will initiate the following procedure:

***Explanation Procedures***

- a. You will be involved in this study because you are eligible. You will receive the Illness Representation-based Education Program (IREP) individually.

b. Evaluation and forms

1. You will be asked to fill in the forms about your personal information and health information (demographics and questionnaire) before the program. It will take around 15 minutes.
2. You also will be asked to answer the questionnaires. The first questionnaire is CIRQBD to ask what you think about your illness, and the second questionnaire is MABQ to ask you about taking your medication. These questionnaires will take another 10 minutes to complete.

***Risk and Comfort***

There is no known risk or harm to you to join this study. There is no payment for you to participate in this study. But asking you some questions may make you feel upset or uncomfortable. If you feel like that, the researcher will stop and help you until you feel better.

***Benefit***

This study is expected to be beneficial for you in order to make you clearly understand about your illness and how you can face your illness. The finding of this study can be used as a protocol for nurses and other health care professionals to help people like you to understand their illness and adherence to their medication. The data from this study will be used to write a research paper. It also will provide useful information for future research related to this area.

***Confidentiality***

All information and your responses in this study will remain confidential. Only the researcher and the researcher's advisors are eligible to access the data. Neither your name nor identifying personal information will be used in the report of the study.

***Participation and Withdrawal from Participation***

Your participation in this study is voluntary. Signing the informed consent or agreeing verbally to participate in the provided session with the researcher and returning the form given indicate that you understand what is involved and you consent to participate in this study program. At any time of this study, you have the right to withdraw from participation. No punishment will be incurred if you decide to withdraw and it will not influence your medical service or medical treatment.

If you have any questions, suggestions or cannot participate in this study, you can directly contact the researcher (me) on her mobile phone (+6281360338747). Finally, if you agree to participate in this study, please kindly sign your name on the consent form or verbally state your agreement to participate in the study.

Thank you for your cooperation

(Fardelin Hacky Irawani)

Researcher

## INFORMED CONSENT FORM

Study Title : Effect of the Illness Representation-based Education Program on Medication Adherence among Patients with Bipolar Disorder in Medan, Indonesia.

Researcher : Fardelin Hacky Irwani  
Master Student Faculty of Nursing, Prince of Songkla University

Patients' Name : \_\_\_\_\_ Age: \_\_\_\_\_

*Patients' Consent*

I, \_\_\_\_\_, was informed of the details of the research entitled "Effect of Illness Representation-based Education Program on Medication Adherence among Patients with Bipolar Disorder in Medan, Indonesia" and was ensured that all information related to my personal information and health history will be kept confidential. I will attend an individual education session with the researcher and she will follow up with me 2 times, within 2 weeks. If any problems or issues arise, I can discuss them with the researcher. I have the right to withdraw from the study at any time without any effect on my medical services and medical treatment. I am willing to participate in this research study voluntarily, without any threat and force. Hereby, I endorse my signature.

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

*Researchers' Note*

I have given the detailed information of the research article entitled “Effect of Illness Representation-based education Program on Medication Adherence among Patients with Bipolar Disorder in Medan, Indonesia”. The signature and returning the form indicate that you understand what is involved and that you consent to participate in this study voluntarily. You have been given the opportunity to ask questions and were satisfied with the answers given.

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

Date: \_\_\_\_\_



## APPENDIX B

### Protocol of Illness Representation-based Education Program (IREP)

Phases	Process Components	Objectives	Method and duration	Action	
				Researcher	Participant
Introduction(at the OPD)		Participant is able to: a. Get to know the researcher b. Establish rapport and trust with researcher c. Know and understand the program.	Introducing face to face  10 minutes	<ul style="list-style-type: none"> <li>- Introducing researcher to participant</li> <li>- Explain the objective and benefits of the study</li> <li>- Make a contract time with the participant and explain about time allocation of the program.</li> </ul>	<ul style="list-style-type: none"> <li>- Listening to what researcher said.</li> <li>- Asking questions if participant does not understand.</li> <li>- Negotiating if participant does not agree in some parts.</li> </ul>
First phase of intervention (it was undertaken at participants' homes with approximately 70 minutes)	1. Representation assessment	The researcher is able to: Encourage subject to describe his or her illness along five dimensions of representation, including identity, cause, timeline, consequences, and control/cure/treatment a. Understand subject's idea/perceptions about bipolar disorder  b. To identify any	Method: Open interviews face to face  10 minutes.	<ul style="list-style-type: none"> <li>- Researcher will provide questions about participant's illness representation along five dimensions as presented in the Cognitive Illness Representation Questionnaire for Bipolar Disorder (CIRQBD)</li> <li>a. Identity (symptoms)               <ul style="list-style-type: none"> <li>- Can you tell me about your symptoms you experience since you have had bipolar disorder?</li> <li>- What makes you come up with the idea of the symptoms?</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>- Participant describes his/her belief and experiences with bipolar disorder through answering the questions from researcher along five dimensions of illness representation.</li> </ul>

Phases	Process Components	Objectives	Method and duration	Action	
				Researcher	Participant
		misconception, gaps and/or confusions.		<ul style="list-style-type: none"> <li>b. Identity (label) <ul style="list-style-type: none"> <li>- What makes you think of the label of your illness?</li> <li>- What makes you come up with the idea you use to describe your illness?</li> </ul> </li> <li>c. Cause <ul style="list-style-type: none"> <li>- What makes you think about the causes of your illness</li> </ul> </li> <li>d. Timeline <ul style="list-style-type: none"> <li>- What do you think about the course of bipolar disorder?</li> <li>- What makes you come up with the idea of your illness timeline?</li> </ul> </li> <li>e. Consequences <ul style="list-style-type: none"> <li>- I would like to hear your ideas about the consequences of bipolar disorder.</li> <li>- What makes you think that?</li> </ul> </li> <li>f. Cure or control <ul style="list-style-type: none"> <li>- What do you think about the medication for your illness? What makes you think that?</li> <li>- What do you think about the side effects that occur while you take your medication?</li> </ul> </li> </ul>	

Phases	Process Components	Objectives	Method and duration	Action	
				Researcher	Participant
				- What do you do to overcome the side effects?	
	2. Identifying and exploring the gaps, misconceptions and confusions	<p>The researcher is able to:</p> <ul style="list-style-type: none"> <li>- Understand how any identified misconception/confusion developed and how committed the subject is to those beliefs or ideas</li> <li>- To encourage participant to think about what experiences that led to any beliefs that met with the misconceptions, confusion or gaps.</li> </ul> <p>To evaluate the strength or importance of those beliefs or ideas.</p>	<p>Discussion</p> <p>5 minutes</p>	<p>Asking questions in order to encourage participant to think and describe about his/her experience that led subject to have any thoughts that are misconception, confusion, or error.</p> <ul style="list-style-type: none"> <li>- Can you think about how you came to be concerned about “A” (his/her statement of misconception, gaps or confusion)?</li> <li>- Do you have any personal experience with “A” (his/her statement of misconception, gaps or confusion)?</li> <li>- Can you tell me how “A” developed?</li> </ul>	<ul style="list-style-type: none"> <li>- Participant states about the experience that led to any beliefs that are misconceptions, gaps or confusion.</li> <li>- Participant evaluates the strength or importance of those beliefs.</li> </ul>
	3. Creating condition for conceptual change	<p>Researcher is able to:</p> <p>a. Help participant to recognize the limitation of their</p>	<p>Discussion face to face.</p> <p>10 minutes</p>	<p>Encouraging participant to think and explain negative effects of participant’s current perception that are misconception, gaps and confusions by</p>	<ul style="list-style-type: none"> <li>- Explain the negative effect of current conception</li> <li>- Answer what the</li> </ul>

Phases	Process Components	Objectives	Method and duration	Action	
				Researcher	Participant
		<p>current conception, i.e., ways in which misconception or confusions maybe having negative effects.</p> <p>Participant is able to:</p> <p>b. Recognize the limitation of current conception, i.e., ways in which misconception or confusions maybe having negative effects.</p> <p>c. Make links between misconception and consequences of them</p>		<p>asking questions as follows:</p> <ul style="list-style-type: none"> <li>- What are the negative effects of your current conception that you experience?</li> <li>- Do you think your concern about current conceptions affect how you use your medication?</li> <li>- What will be happen if you still maintain your current conception in the future?</li> <li>- Making direct link between current conception (representation), coping strategies and any consequences that the participant has identified.</li> </ul> <p>For example: less energy (researcher will give say that this medication will help you to be able to build relationships with others and then help him/her to cope with the strategies that he/she used</p>	<p>consequences might be if the participant still maintains his/her current conception.</p> <ul style="list-style-type: none"> <li>- Explain the link between current conception or perception, taking medication, and any consequences that participant has identified.</li> </ul>
	4. Introducing replacement information	The researcher is able to:	Teaching face to face  15 minutes	<ul style="list-style-type: none"> <li>- Giving information related to participant's need along five dimensions of illness representation.</li> </ul> <p>a. Identity</p> <ul style="list-style-type: none"> <li>- Mania episode symptoms</li> </ul>	<ul style="list-style-type: none"> <li>- Listening</li> <li>- Pays attention</li> <li>- Provides comment</li> <li>- Asks for further explanation if the</li> </ul>

Phases	Process Components	Objectives	Method and duration	Action	
				Researcher	Participant
		<p>confusions, or gaps</p> <p>Participant is able to:</p> <p>b. Assimilate the conception or perception to fill gaps in knowledge, clarify confusions and replace misconception.</p>		<p>involve extreme mood swings (extreme change in mood), reduced sleeping, full of energy, poor concentration (because of distraction and lack of focus), the ideas and thoughts flow quickly, freely and fast, grandiosity, euphoria, laugh and talk excessively, but inappropriately and difficult to interrupt, appetite.</p> <p>- Depressed episode symptoms involve changing of mood to be sad, unhappy, down or even just 'depressed', lack of energy, easily feel tired all the time,</p> <p>- Label of symptoms</p> <p>b. Cause</p> <p>- Genetic</p> <p>- Disturbances of neurotransmitters</p> <p>- Psychological cause (low self esteem, stressful life events, unbalanced, emotional.</p> <p>c. Timeline</p> <p>- Pathophysiology of bipolar</p>	<p>participant does not understand about the information that is given by researcher.</p>

Phases	Process Components	Objectives	Method and duration	Action	
				Researcher	Participant
				disorder - The course of bipolar disorder is chronic - Time scale of bipolar disorder symptoms are persistence d. Consequences - The impact of bipolar disorder in functioning e. Cure/controllability - Medication for bipolar disorder. - Efficacy of medication - The side effects of medication - Managing the side effects of medication	
	5.Summary	Researcher is able to: a. Ensure participant assimilates the new information  Participant is able to: b. Understand new information and the	Discussion face to face. 10 minutes	- Explain the benefit of medication adherence - Explain how to manage side effects of medication if they occurs - Ask the participant if he/she understands about his or her illness and wants to enhance medication adherence	- Describe the benefit of medication adherence - Describe how to manage side effects - Give statement that he/she has motivation in improving medication adherence

Phases	Process Components	Objectives	Method and duration	Action	
				Researcher	Participant
		benefit of it in his or her life if the subject's believes in the new information			
	6.Goal setting and planning	<p>Researcher is able to:</p> <p>a. Encourage participants to set the goal related to medication adherence and discuss strategies appropriate and visible for each individual</p> <p>Participant is able to</p> <p>b. Develop goals related to enhance medication adherence</p> <p>c. Develop strategies for achieving those goals</p>	Discussion 15 minutes	<p>a. The goal Encourage participant to think and set his/her goal in order to improve medication adherence by asking question.</p> <ul style="list-style-type: none"> <li>- What is your goal related to your medication?</li> <li>- Set the goal together with participant and write the goal setting and strategies plan form</li> </ul> <p>b. The strategies</p> <ul style="list-style-type: none"> <li>- What kind of strategies will you use to improve your medication adherence?</li> <li>- Developing the strategies to achieve his/her goals.</li> <li>- Writing the strategies and making a list in order to help participant to easily remember and implement</li> </ul>	<p>a. The goal</p> <ul style="list-style-type: none"> <li>- Set the goal with researcher in order to enhance medication adherence</li> </ul> <p>b. The strategies</p> <ul style="list-style-type: none"> <li>- Thinking what kind of strategies will be useful in order to achieve the goal.</li> <li>- Develop the strategies with researcher to achieve the goal.</li> <li>- Understand about the strategies</li> </ul>

Phases	Process Components	Objectives	Method and duration	Action	
				Researcher	Participant
				the strategies.	
Second phase of intervention (30 minutes)	7. Follow up of the goal and the strategies	Participant is able to: a. Evaluate whether the goal has been achieved or not. b. Evaluate whether the strategies work or not. c. Identify the problem or barrier during implementing the strategies. d. Maintain or develop strategies for continuing medication adherence.	Discussion  30 minutes	<ul style="list-style-type: none"> <li>- Assist participant to reflect his/her behavior regarding medication adherence during the last two weeks by using the goal setting form.</li> <li>- Ask these following questions:               <ul style="list-style-type: none"> <li>a. The goals                   <ul style="list-style-type: none"> <li>- Did you apply the strategies that we developed together at the previous time?</li> <li>- Could you achieve your goal by using these strategies?</li> <li>- Give reinforcement for subject's achievement</li> </ul> </li> <li>b. The strategies                   <ul style="list-style-type: none"> <li>- Were you able to implement the strategies?</li> <li>- Did the strategies work to achieve your goal (to enhance medication adherence)?</li> <li>- What were barriers/problems you experienced since you used the strategies?</li> <li>- What do you do to face the problems? Did it work?</li> </ul> </li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>- Answer the questions:               <ul style="list-style-type: none"> <li>a. The goal                   <ul style="list-style-type: none"> <li>- Reflect on the participant's goal progress by using the goal setting.</li> <li>- Answer the questions from the researcher.</li> </ul> </li> <li>b. The strategies                   <ul style="list-style-type: none"> <li>- Reflect the behavior by using the goal setting.</li> <li>- Answer the questions provided by researcher about the strategies.</li> </ul> </li> <li>c. The strategies for continuing medication adherence                   <ul style="list-style-type: none"> <li>- Receive recommendation from researcher regarding to</li> </ul> </li> </ul> </li> </ul>



Phases	Process Components	Objectives	Method and duration	Action	
				Researcher	Participant
				<ul style="list-style-type: none"> <li>c. The strategies for continuing medication adherence               <ul style="list-style-type: none"> <li>- Are the strategies important for you to continue taking medication as prescribed?</li> <li>- Can you use the same strategies from the previous time to enhance your medication adherence?</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>enhance or maintain the medication adherence.</li> </ul>
Termination	-	a. To evaluate the program.	10 minutes	<ul style="list-style-type: none"> <li>- Asking questions about the program as follows:               <ul style="list-style-type: none"> <li>a. How do you feel after doing this program?</li> <li>b. What do you think about this program?</li> </ul> </li> <li>- Informing the participant that the researcher will terminate with the participant and the program has finished.</li> </ul>	<ul style="list-style-type: none"> <li>- Answering the questions</li> <li>- Receiving the information and accepting the termination with the researcher.</li> </ul>

**APPENDIX C**

Code:
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**Goal Setting and Strategies Plan Form**

*Instruction:* This form is used to monitor your goals within a week. You can write any goals and strategies or action plan that you want to do to enhance your medication adherence.

No (1)	Goal planned		Implementation and grade		Barriers (7)
	Goal (2)	Action (3)	Action done (5)	Achievement (6)	
1.	Voluntary in actively taking medication			<input type="checkbox"/> Completely done <input type="checkbox"/> Partially done <input type="checkbox"/> Not done at all	
2.	Taking correct type of medication			<input type="checkbox"/> Completely done <input type="checkbox"/> Partially done <input type="checkbox"/> Not done at all	
3.	Taking medication in correct doses			<input type="checkbox"/> Completely done <input type="checkbox"/> Partially done <input type="checkbox"/> Not done at all	
4.	Taking medication in correct frequency			<input type="checkbox"/> Completely done <input type="checkbox"/> Partially done <input type="checkbox"/> Not done at all	
5.	Taking medication everyday			<input type="checkbox"/> Completely done <input type="checkbox"/> Partially done <input type="checkbox"/> Not done at all	
6.	Others ....			<input type="checkbox"/> Completely done <input type="checkbox"/> Partially done <input type="checkbox"/> Not done at all	

**APPENDIX D**

**The Brief Psychiatric Rating Scale (BPRS)**

Code :

No	Statement	Not present (1)	Very mild (2)	Mild (3)	Moderate (4)	Moderately severe (5)	Severe (6)	Extremely severe (7)
1.	<p>Somatic Concern Degree of concern over present bodily health: ✓ Rate the degree to which physical health is perceived as a problem by the patient, whether complaints have a realistic basis or not.</p>							
2.	<p>Anxiety Worry, fear, or over-concern for present or future. ✓ Rate solely on the basis of verbal report of patient's own subjective experiences. Do not infer anxiety from physical signs or from neurotic defense mechanisms.</p>							
3.	<p>Emotional Withdrawal Deficiency in relating to the interviewer and to the interview situation. ✓ Rate only the degree to which the patient gives the impression of failing to be in emotional contact with other people in the interview situation.</p>							
4.	<p>Conceptual Disorganization Degree to which the thought processes are confused, disconnected, or disorganized. ✓ Rate on the basis of integration of the verbal products of the patient; do not rate on the basis of patient's subjective impression of his own level of functioning.</p>							

No	Statement	Not present (1)	Very mild (2)	Mild (3)	Moderate (4)	Moderately severe (5)	Severe (6)	Extremely severe (7)
5.	<p>Guilt Feelings Over-concern or remorse for past behavior.</p> <p>✓ Rate on the basis of the patient's subjective experiences of guilt as evidenced by verbal report with appropriate affect; do not infer guilt feelings from depression, anxiety, or neurotic defenses.</p>							
6.	<p>Tension Physical and motor manifestations of tension "nervousness", and heightened activation level.</p> <p>✓ Tension should be rated solely on the basis of physical signs and motor behavior and not on the basis of subjective experiences of tension reported by the patient.</p>							
7	<p>Mannerisms and Posturing Unusual and unnatural motor behavior, the type of motor behavior which causes certain mental patients to stand out in a crowd of normal people.</p> <p>✓ Rate only abnormality of movements; do not rate simple heightened motor activity here.</p>							
8.	<p>Grandiosity Exaggerated self-opinion, conviction of unusual ability or powers.</p> <p>✓ Rate only on the basis of patient's statements about himself or self-in-relation-to-others, not on the basis of his demeanor in the interview situation.</p>							
9.	<p>Depressive Mood Despondency in mood, sadness.</p> <p>✓ Rate only degree of despondency; do not rate on the basis of</p>							

No	Statement	Not present (1)	Very mild (2)	Mild (3)	Moderate (4)	Moderately severe (5)	Severe (6)	Extremely severe (7)
	interferences concerning depression based upon general retardation and somatic complaints.							
10.	<p>Hostility Animosity, contempt, belligerence, disdain for other people outside the interview situation.</p> <p>✓ Rate solely on the basis of the verbal report of feelings and actions of the patient toward others; do not infer hostility from neurotic defenses, anxiety, nor somatic complaints.</p> <p>✓ Rate attitude toward interviewer under "uncooperativeness".</p>							
11.	<p>Suspiciousness Belief (delusional or otherwise) that others have now, or have had in the past, malicious or discriminatory intent toward the patient.</p> <p>✓ On the basis of verbal report, rate only those suspicions which are currently held whether they concern past or present circumstances.</p>							
12.	<p>Hallucinatory Behavior Perceptions without normal external stimulus correspondence.</p> <p>✓ Rate only those experiences which are reported to have occurred within the last week and which are described as distinctly different from the thought and imagery processes of normal people.</p>							
13.	<p>Motor Retardation. Reduction in energy level evidenced in slowed moments.</p> <p>✓ Rate on the basis of observed behavior of the patient only; do not rate on the basis of patient's subjective impression of own energy level.</p>							

No	Statement	Not present (1)	Very mild (2)	Mild (3)	Moderate (4)	Moderately severe (5)	Severe (6)	Extremely severe (7)
14.	<p>Uncooperativeness Evidence of resistance, unfriendliness, resentment, and lack of readiness to cooperate with the interviewer.</p> <p>✓ Rate only on the basis of the patient's attitude and responses to the interviewer and the interview situation; do not rate on basis of reported resentment or uncooperativeness outside the interview situation.</p>							
15.	<p>Unusual Thought Content Unusual, odd, strange, or bizarre thought content.</p> <p>✓ Rate here the degree of unusualness, not the degree of disorganization of thought processes.</p>							
16.	<p>Blunted Affect Reduced emotional tone, apparent lack of normal feeling or involvement.</p>							
17.	<p>Excitement Heightened emotional tone, agitation, increased, reactivity</p>							
18.	<p>Disorientation Confusion or lack of proper association for person, place, or time.</p>							

(Leucht., Kane., Kissling., Hamann., Etschel., & Engel., 2005)

Code	: _____
Date	: _____

## APPENDIX E

### Demographic Data Questionnaire (DDQ)

**Instruction:** This form aims to obtain information about your current demographic data and health information. Please fill in the blank and mark (√) in the column which indicates your data.

#### *Demographic data*

1. Initial of Name :
2. Age :
3. Gender : 1[ ] Male 2[ ] Female
4. Marital Status : 1[ ] Single 2[ ] Married  
3[ ] Widower/widow 4[ ] Divorce
5. Religion : 1[ ] Islam 2[ ] Christian  
3[ ] Hindu 4[ ] Buddhism
6. Educational level : 1[ ] Never School 4[ ] Senior high school  
2[ ] Elementary School 5[ ] Diploma  
3[ ] Junior high school 6[ ] University
7. Occupation : 1[ ] Government employee 4[ ] Farmer  
2[ ] Private employee 5[ ] No occupation  
3[ ] Housewife 6[ ] Others
8. Income : 1[ ] no income (who give money for your living? (\_\_\_\_\_))  
2[ ] < Rp. 500.000  
3[ ] Rp. 500.000 – Rp. 1.000.000  
4[ ] > Rp. 1.000.000

9. Living in environment of disaster (earthquake, tsunami, etc) : 1  yes 2  no

10. Drinking alcohol : 1  yes 2  no

11. Drug abuse : 1  yes 2  no Please specify (\_\_\_\_\_)

12. Do your family member take care you : 1  yes 2  no

13. Hospitalization : \_\_\_\_\_ times (the last one year)

14. How long you have been diagnosed with bipolar disorder?

---

15. How do you get your medicine in the hospital?

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16. Type and frequency of your medication: (from the hospital record)

---

---

---

---

17. Experiencing of side effect :

---

---

---

18. Experience on joining therapy program :

---

---



Code	: _____
Date	: _____

## APPENDIX F

### The Cognitive Illness Representation Questionnaire for Bipolar Disorder

#### (CIRQBD)

The questionnaire is using to measure your perception about your illness. The questionnaire has five dimensions as following:

1. *Identity (symptoms)*

List below are a number of symptom experiences that you may or may not not have had since your bipolar disorder began. Please indicate by filling mark (√) in YES or NO whether or not you have had each of these experiences since your bipolar disorder began. In the next column, please indicate whether you think that this experience is part of your mental health problems, or due to other factors.

No	Statements of symptoms	I have had this experiences since my mental health problem		This experience is/was:	
		Yes	No	Part of my illness	Due to others factors
1.	Get tired easily			2	1
2.	Full of energy				
3.	Talkative and can not help myself stop talking				
4.	Sometimes I laugh too much because I feel happy for no reason				
5.	I sleep too much				
6.	I can not sleep well				
7.	I feel very confidence				
8.	My self-esteem is fluctuation; sometimes is high, sometimes is low				
9.	Sometimes I feel very happy for no reason				

No	Statements of symptoms	I have had this experiences since my mental health problem			This experience is/was:	
		Yes	No		Part of my illness	Due to others factors
10	Sometimes I feel unhappy and sad for no reason					
11	My thoughts flow quickly, freely and fast					
12	I feel depressed most of the day					
13	I feel no spirit to do activities					
14.	My weigh is gain much					
15	I feel appetite					
16	Sometimes I feel fatigue and loss of energy					
17	Sometime I feel guilty and worthlessness					
18	Sometime I cannot concentrate well					
19	Sometime I think about the idea of death					
20	I easy get irritated mood					

## 2. Identity (labelling)

Please tick any of following terms that have been used to describe your mental health, and add any other terms that may have been used. For each term, please indicate the extent to which you would agree that this label describes the experiences you have had.

No	Label/term	Tick if been used	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
1.	Depression						
2.	Mood disturbance						
3.	Extremely mood						
6.	Other .....						

Please write the term/label that you feel best describes your illness:

---

## 3. Causes

Below is a list of possible causes for your illness regarding to your own view. Please indicate how much you agree or disagree about with the following statements by filling mark (√) in the appropriate box. As people are very different, there is no correct answer for this question.

No	Statement	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
1.	Stress or worry					
2	Hereditary - it runs in my family					
3.	My own behavior					

4.	My mental attitude e.g. thinking about life negatively					
5.	Stressfull life					
6.	Trauma					
7.	Overwork or non-work					
8.	Alcohol Use					
9.	Taking illicit drug					
10.	Brain damage or abnormality					
11.	Lack of sleep					
12.	Thinking about things too much					
13.	Lack of friends or people who cared about me					

Below, please list in rank order the three most important factors that you now believed caused your illness. You may use any of the items from the box above, or **YOU MAY HAVE ADDITIONAL IDEAS OF YOUR OWN.**

The most important causes for me:

1. \_\_\_\_\_

2. \_\_\_\_\_

3. \_\_\_\_\_

#### 4. Timeline

Below is a list of possible timeline for your illness regarding to your own views.

Please indicate how much you agree or disagree with the following statements by filling mark (√) in the appropriate box.

No	Statement	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
<b>Acute/chronic</b>						
1.	My illness will last a short time					
2.	My illness is likely to be permanent rather than temporary					
3.	My illness will last for a long time					
4.	This illness will pass quickly					
5.	I expect to have this illness for the rest of my life					
6.	My illness will improve in time					
<b>Cyclical</b>						
7.	Sometimes I have more symptoms than other times					
8.	I have times when I am well and times when I am not so well					
9.	Sometimes the symptoms of my illness is worse than other times					
10.	Some of my symptoms will be there all the time but others will					

	come and go					
--	-------------	--	--	--	--	--

### 5. Consequences

Below is a list of possible consequences for your illness regarding to your views.

Please indicate how much you agree or disagree with the following statements by filling mark (√) in the appropriate box.

No	Statement	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
1.	My illness is a serious condition in term of work or study					
2.	My illness does not have much effect on my life					
3.	My illness has financial consequences for me					
4.	I cannot take care myself because of my illness					
5.	My illness causes difficulties for those who are close to me					
6.	My illness have messed up my social life					
7.	I am valued less because of my illness					
8.	My illness make working very difficult for me					
9.	I have lost important relationships as a result of my illness					
10.	My illness has had some positive effects on my life					
11.	My medication make me feel bored					

12.	My medication affect negatively in my life					
13.	My medication make my life better					

#### 6. Controlability

Below is a list of possible of cure/control for your illness regarding to your own views. Please indicate how much you agree or disagree with the following statements by filling mark (√) in the appropriate box.

No	Statement	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
1.	There is a little treatment available that can improve my illness					
2.	My medication will be effective in managing my illness					
3.	The negative effects of illness can be prevented by medication					
4.	My medication can control my illness					
5.	There is no medication that can help with my condition					

## APPENDIX G

### Medication Adherence Behavior Questionnaire (QMAB)

*Instruction:*

Please select one of four choices and put a mark (√) next to the item you have selected that you performed your medication treatment. The questionnaire is measuring your behavior of taking medication **during the past two weeks**. Please do not skip any items and respond to each item accurately.

Always : everyday

Most of the time : 10-13 days

Sometime : 5-9 days

Rarely : 1-4 days

Never : not done at all

No	Statement	Never	Rarely	Sometimes	Most of the time	Always
<b>Taking medication voluntarily</b>						
1.	I was willing to take my medication.					
2.	I took medication because of my own motivation					
3.	I did not take my medication even though other tried to encourage me to take it.					
<b>Taking medication continuously</b>						
4.	I skip my medication when I feel better					
5.	I missed my medication that I should take.					
6.	I took my medication even though the symptoms have gone.					
7.	I still took my medication after even though I feel better or worse					
8.	I stopped taking medication because my symptom did not relief					
9.	I was still taking medication even though I have another problem due to the side effect of my medication					



Taking medication actively						
10.	I took my medication after other people remind me					
11.	I took my medication by myself without helping from anyone					
12.	My family prepared my medication					
Taking medication correctly as prescribed						
13.	I missed some medications I should take in the morning, afternoon, or before bed.					
14.	I forgot how much dosage for each kind of my medication which I have to take in the morning, afternoon, or before bed					
15.	I took my medication timely as doctor's order.					

**APPENDIX H**

## Normal Distribution

## 1. Total score Pre-test of Medication Adherence

- S value;  $.164/.427 = .38$
- K value;  $-1.089/.833 = -1.31$

## 2. Total score Post-test of Medication Adherence

- S value;  $-.252/.427 = -.59$
- K value;  $-1.220/.833 = -1.46$

## **APPENDIX I**

### List of Expert

Three experts examined the construct validity for the Illness Representation Based Education Program (IRBEP), Behavior of Medication Adherence Questionnaire, they were:

1. Assist. Prof. Dr. Orawan Nukaew

Nursing Lecture, Prince of Songkla University, Thailand

2. Jenny Marlindawany

Nursing Lecture, Sumatera Utara University, Medan, Indonesia

3. Dr. Charuwan Kritpracha

Nursing Lecture, Prince of Songkla University, Thailand

## APPENDIX I

### Permission of The Instrument

**From:** Hacky Irawani [mailto:fhacky\_irawani@yahoo.com]  
**Sent:** 28 January 2013 12:55  
**To:** Lobban, Fiona  
**Subject:** Asking permission for IPQ-P

Dear Mrs. Fiona Lobban,

Firstly, I would like to introduce myself. My name is Fardelin Hacky Irawani. I am a student in Faculty of Nursing, Prince of Songkla University, Thailand.

I am doing my thesis with the title: "Effect of Illness Representation Based Education Program on Medication Adherence Among Patients With Bipolar Disorder in Aceh, Indonesia." Now, I am in process developing my thesis article with an experimental study. This study is aimed to change illness representation/perception. In doing this intervention, I will use your developing questionnaire 'The revised Illness Perception for Psychosis (IPQ-P)' for this study.

Now, I review your developing questionnaire. However, I need asking permission to you to use your measurement in my study and make it modify to use in bipolar disorder patients. Previously, my friend also sent email to you and asked permission to use this questionnaire. Her name is Sri Novitayani. We are in the same faculty in Thailand and we have the same title of the thesis, however, in the different population. I will do intervention for Bipolar Disorder. Event hough she already got permission from you, however, I need your permission as well, as Sri Novitayani.

If you allow me to use IPQ-P in my study, I also need permission to modify a

some part of this measurement, particularly the questions items. For example, in identity, my advisor suggest that I have to modify the symptom items become a specific symptoms of bipolar disorder. Moreover, I will only use the items including in illness representation (identity, cause, timeline, consequence, and cure/control), and will not use emotion representation part.

Finally, I would like to say thank you very much for your permission.

Regards,

Fardelin Hacky Irawani

Student of Master of Psychiatric Nursing

Faculty of Nursing, Prince of Songkla University

Hatyai, Thailand

Email: [fhacky\\_irawani@yahoo.com](mailto:fhacky_irawani@yahoo.com)

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**Lobban, Fiona**

To

Hacky Irawani

Jan 29, 2013

Dear Fardelin

You have my permission and good luck with your research

Best wishes

Fi

## VITAE

**Name** : Mrs. Fardelin Hacky Irawani

**Student ID** : 5410420034

### **Educational Attainment**

<b>Degree</b>	<b>Name of Institution</b>	<b>Year of Graduation</b>
Diploma of Nursing	Health Department of Indonesia	2002
Bachelor of Nursing	Syiah Kuala University	2009

### **Scholarship Awards during Enrolment**

2011-2013                      Aceh Scholarship Commission, Indonesia

### **Work – Position and Address**

**Work position**              Nursing Lecturer of Faculty of Nursing, Syiah Kuala  
University, Aceh, Indonesia

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