The Effect of Illness Representation Promoting Program on Treatment Adherence Among Patients with End Stage Renal Disease Receiving Hemodialysis

Ali Aminuddin Mohd Rasani

A Thesis Submitted in Partial Fulfillment of the Requirements for the Degree of

Master of Nursing Science (International Program)

Prince of Songkla University

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I hereby certify that this work has not already been accepted in substance for any degree, and is not being concurrently submitted in candidature for any degree.

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ABSTRACT

This quasi-experimental study aimed to examine the effect of the illness representation promoting program on treatment adherence among patients with end stage renal disease (ESRD) receiving hemodialysis (HD) in Kota Bharu, Kelantan, Malaysia. Ninety subjects who met the inclusion criteria were recruited and assigned into two groups according to the day of HD. The experimental group received the illness representation promoting program for 2 weeks while the control group received usual care. Treatment adherence was measured by using the Treatment Adherence Questionnaire (TAQ), a self-report questionnaire composed of four dimensions, modified from previous studies by the researcher. The TAQ was content validated by three experts and internal consistency was tested in 20 patients with ESRD receiving HD who met the same inclusion criteria as the actual sample, yielding Cronbach's alpha coefficient of .83.

Testing assumption showed that the data set of treatment adherence in the experimental group were not normally distributed. Therefore, a Mann-Whitney U Test was conducted to determine the between-group effect of the intervention. A Friedman's Test with post hoc analysis by Wilcoxon Rank Test was used to report the within-group effect of the intervention.

This study had two main results. Firstly, the patients in the experimental group had better treatment adherence than those in the control group at week four ($Z = -2.97$, $p = .00$). Secondly, the treatment adherence mean score at week four was significantly higher than before the intervention for patients in the experimental group ($Z = -5.34$, $p = .00$). According to these results, the illness representation promoting program had been evident in its effectiveness in enhancing treatment adherence among patients with ESRD receiving HD. It is thus recommended that the program should be implemented in nursing practice.

Keywords: Illness representation promoting program, end stage renal disease, hemodialysis

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CHAPTER 1

INTRODUCTION

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

Background and Significance of the Problem

In the past two decades, the incidence and prevalence of end-stage renal disease (ESRD) have increased greatly in Malaysia. There were an estimated 28,590 people living with ESRD in Malaysia at the end of 2012, which shows an increase from a mere 1,396 people in 1993 (Lim, Goh, & Ong, 2013).

ESRD is the final stage of kidney failure, where congenital or inherited diseases have progressively destroyed the normal structure and function of the kidney (Cheema & Singh, 2005). At the end stage of renal insufficiency, kidney function has declined to less than 10% of normal function and renal replacement therapy (RRT) has become a necessity (Cheema & Singh, 2005).

RRT including hemodialysis (HD), peritoneal dialysis (PD), or kidney transplant can be used to replace some of the functions of the non-working kidneys. HD involves the circulation of the body's blood through a machine that cleans the blood of waste products, takes 3-5 hours using a machine and is done three times per week (Bevan, 2000; Starzomski & Hilton, 2000). PD uses the peritoneal cavity as a filter for waste products. A dialysate solution is introduced into the peritoneal cavity. After a time, the dialysate solution containing the wastes is drained, which is called an exchange (Bevan, 2000; Starzomski & Hilton, 2000). Transplantation is the surgical

placement of another person's kidney into the ESRD patient's body. Through a successful transplant, patients no longer have kidney failure and may resume his or her normal life (Lindqvist, Carlsson, & Sjödén, 2000).

This study focused on the patients with ESRD receiving HD since in 2012, the most common form of RRT in Malaysia was HD (92%) and followed by 8% being treated with PD (Lim et al., 2013). This was because of the result of rapid economic growth in Malaysia between 1990 and 2005, HD treatment rates reached a level comparable to rates in developed countries. In spite of the resource constraints that all developing countries face, popular demand in Malaysia, combined with effective stewardship of public funds, resulted in a mix of public and private financing and provision of HD services (Lim, Goh, Lim, Zaher, & Suleiman, 2010).

The lifestyle of persons undergoing HD is greatly affected by the treatment regimen they follow. The treatment regimen is prescribed by the nephrologist and is determined by several factors including the patient's body size, gender, age, race, residual renal function, comorbid conditions, type of dialysis access, blood flow rate, and dialyzer used. Living with ESRD and the complex treatment regimen may result in daily physical symptoms and life uncertainty for these patients (Costantini, 2005). For their survival, patients with ESRD receiving HD need a lifetime commitment to treatment adherence such as enduring regular dialysis treatments to remove toxins and excess fluid from their body, taking multiple medications, limiting their fluid intake, and modifying their diet. For patients with ESRD receiving HD, the treatments must continue routinely until the patient receives a kidney transplant or dies. Discontinuation of HD in patients with ESRD receiving HD results in death on an average of 7 to 10.5 days after the patient has stopped his or her treatment (Rich, Ellershaw, & Ahmad,

2001). Treatment adherence can prevent the progressive worsening of the ESRD and recurrent hospitalization.

The key to the successful management of ESRD and its related treatment relies on patient's continuous adherence to the four dimensions of the therapeutic regimen. Treatment adherence is comprised of adherence to HD, adherence to medications, adherence to fluid restriction, and adherence to dietary restriction (Denhaerynck et al., 2007). Adherence to HD were required to replace a patient's kidney function. Adherence to medications includes phosphate binders with or without vitamin D for secondary hyperparathyroidism, and erythropoietin therapy with or without iron supplementations for anemia. Adherence to fluid restriction is defined as the recommended fluid intake in one day for ESRD patients. Normally, patients were recommended to keep their fluid intake to 1 liter a day (Cvengros, Christensen, & Lawton, 2004). Besides this, patients also required to adhere to dietary restriction on potassium, phosphorus, sodium, calcium, and protein intake (Denhaerynck et al., 2007).

Treatment adherence is important for patients with ESRD receiving HD. Maintaining normal levels of minerals such as potassium and phosphorus between dialysis can improve blood filtration during treatments and overall can provide the patient with a level of good health (Barnett, Li Yoong, Pinikahana, & Si-Yen, 2008). Treatment adherence also is an important factor contributing both to survival and quality of life (Pang, Ip, & Chang, 2001). Patients who demonstrate that they were not following the prescribed fluid restriction and other treatment regimens over time are at much greater risk of developing complications such as cardiovascular disease and hypertension (Barnett et al., 2008). For patients with ESRD receiving HD, failure to

adhere to dietary and fluid restriction, and medication regimes can result in fatal consequences (Kutner, 2001; Tsay, 2003).

Research has shown that treatment adherence rates were still low in regards to adherence to fluid and diet restrictions, medications and attending HD with rates ranging from 9.7% to 49.5%, 9% to 22.1%, 15.4% to 50.2%, and 7.9% to 8.5%, respectively (Saran et al., 2003). In Malaysia, a previous study identified that 80% of the patients undergoing HD in a single center failed to follow adherence to fluid restriction (Barnett et al., 2008). While a study done by Chan, Zalilah, & Hii (2012) found that adherence rates of dietary, fluid, medication and dialysis were 27.7%, 24.5%, 66.5% and 91.0%, respectively, with a high proportion of HD patients in Malaysia had difficulty in adhering to diet and fluid restrictions.

The treatment adherence of patients with ESRD receiving HD is influenced by several factors such as demographic characteristics, the duration of experience in HD, social support, knowledge about the advantages of treatment adherence and illness representation. Therefore, to enhance treatment adherence, these influencing factors need to be controlled and manipulated. Two studies have shown that illness representation contributes to a patient's treatment adherence (Krespi, Bone, Ahmad, Worthington, & Salmon, 2004; Welch, Perkins, Evans, & Bajpai, 2003).

According to Krespi et al. (2004), patients with ESRD receiving HD did not have appropriate representation of their illness and felt that adherence to their treatment was both a physical and emotional burden. Most patients with ESRD receiving HD believed that receiving HD weakened their body and health (Krespi et al., 2004). Moreover, most of them viewed the treatment as dominating them and their lives revolved around this boring activity (Krespi et al., 2004). This evidence indicates that

ESRD can lead to a sense of loss of control, which is known to damage a patient's adjustment to a chronic illness. Therefore, interventions targeted to adjust how persons perceive their illness to result in a desirable outcomes such as treatment adherence when confronting illness, are needed.

Illness representation is a person's thoughts or beliefs or ideas about illness. It is influenced by the patient's external social environment such as health care providers, family or social media (Leventhal, Meyer, & Nerenz, 1980). So that, an illness representation intervention could be effective in patients with chronic illness such as ESRD to enhance his or her treatment adherence (Seyyedrasooli, Parvan, Rahmani, & Rahimi, 2013).

Previous research studies have tried to provide interventions to promote treatment adherence based on the illness representation model (Christensen, Moran, Wiebe, Ehlers, & Lawton, 2002; Karamanidou, Weinman, & Horne, 2008; Seyyedrasooli et al., 2013). Christensen et al. (2002) conducted a study to examine the efficacy of an illness representation intervention designed to increase adherence to fluid-intake restrictions among patients with ESRD receiving HD. While a study done by Karamanidou et al. (2008) evaluated a psycho-educational intervention based on illness representation aimed to improve the understanding of the need for phosphate control, provide a rationale for phosphate-binding medication (PBM) and explain its mode of action. However, the researchers of both of these previous studies only focused on certain aspects of treatment adherence which were fluid restrictions and adherence to medications.

Up until the present time, only one experimental study has been published that has measured the effect of an illness representation based intervention

and all aspects of treatment adherence. A study done by Seyyedrasooli et al. (2013) focused on the effect of illness representation based interventions on treatment adherence in patients with ESRD receiving HD. The researchers focused on all aspect of treatment adherence. The intervention emphasizes the importance of behaviors related to adhering to treatment. They found that the illness representation based interventions led to an improvement in the treatment adherence of the patient. However, the study did not clearly mention the way the researchers shaped the patient's representation in order to get them to adhere to their treatment. The study was also conducted in a cold region as stated in the article which is different this from current study. In Malaysia, fluid restriction is a major problem for patients with ESRD receiving HD since the hot weather can increase the thirst sensation (Barnett et al., 2008; Chan et al., 2012).

As illness representation is related to how people select a coping approach to a health threat and the failure of health education programs to make changes in people's health behaviors, Donovan and Ward (2001) have proposed a representational approach to patient education. This intervention is based on the Common Sense Model (CSM) (Leventhal et al., 1980) and the Conceptual Change Model (CCM) (Posner, Strike, Hewson, & Gertzog, 1982). A representational approach to patient education has been used in several published studies for individuals with physical illness including patients with myocardial infarction (Donovan et al., 2007), breast cancer (Heidrich, Brown, & Egan, 2009) and cancer pain (Ward et al., 2009). Based on previous studies in which the programs were individualized interventions, the results showed that the patients had changed their behavior or their attitude to deal with

their health problem after the intervention (Donovan et al., 2007; Heidrich et al., 2009; Ward et al., 2009).

Up to the present time, there have been no published studies that use a representational approach to treatment adherence for patients with ESRD receiving HD. As this will be conducted for the first time and to ensure that the approach proposed by Donovan and Ward (2001) would effectively shape representation, which will result in treatment adherence behavior among patients with ESRD receiving HD, the program will be developed as an individualized intervention. The previous illness representation studies in Malaysia have only focused on the relationship between illness representation, depression, religious coping and quality of life in patients with ESRD receiving HD (Ibrahim, Desa, & Chiew-Tong, 2011). There was no known study reported using an illness representation promoting program in patients with ESRD receiving HD in Malaysia. Furthermore, Malaysia is a country in which climatic conditions and the prevalence of festive celebrations and other events associated with its multicultural character contribute to a social milieu in which adherence to treatment is especially challenging (Barnett et al., 2008). Therefore, this study proposed to examine the effects of an illness representation promoting program on treatment adherence among patients with ESRD receiving HD in Malaysia.

Objectives of the Study

There were two objectives in this study:

1. To compare treatment adherence mean score in patients with ESRD receiving HD between the experimental group that receives the illness representation promoting program and the control group that receive usual care.

2. To compare treatment adherence mean score in patients with ESRD receiving HD before and after receiving the illness representation promoting program in the experimental group.

Research Questions

There were two research questions:

1. Were there differences in the treatment adherence mean score of patients with ESRD receiving HD before and after received the illness representation promoting program in the experimental group?

2. Were there differences in the treatment adherence mean score of patients with ESRD receiving HD who received the illness representation promoting program in the experimental group and those in the control group who received usual care?

Conceptual Framework

A representational approach to patient education by Donovan and Ward (2001) and treatment adherence dimensions specific to patients with ESRD receiving

HD (Denhaerynck et al., 2007) were used to construct a conceptual framework in this study in order to enhance treatment adherence in the patients with ESRD receiving HD.

The representational approach was developed based on the Common Sense Model (CSM) (Leventhal et al., 1980) and the Conceptual Change Model (CCM) (Posner et al., 1982). The CSM consists of three major constructs: Illness representation (cognitive illness representation and emotion illness representation), coping and appraisal. The cognitive illness representation is regarded as an individual's beliefs (Leventhal et al., 1980). Treatment adherence can be considered as a coping that is influenced by illness representation. While the appraisal component was not included in this conceptual framework since the outcome variable in this study was the treatment adherence.

The primary functions of cognitive illness representation are used as a guide for selecting coping strategies. Representation can be changed by stimuli from the external social environment such as health care providers, family or social media and the current experience with the illness in everyday life (Leventhal et al., 1980).

There are five dimensions in cognitive illness representation which are an individual's idea, including identity, cause, timeline, consequences and cure/controllability of illness (Leventhal et al., 1980). In this study, the identity of illness refers to the belief about the individual's label of his or her ESRD and the symptoms that he or she has experienced. Cause of illness refers to the belief about how the individual gets the ESRD. Timeline of illness refers to the belief about the course of the ESRD and the time scale of ESRD symptoms. Consequences of illness refers to the belief about the impact of the ESRD and HD on the individual's life. Cure or controllability of illness refers to the belief about the efficacy of HD including the

medication, and personal coping to alter the illness. In this study, the researcher focused only on the cognitive representation which has the treatment adherence as the outcome.

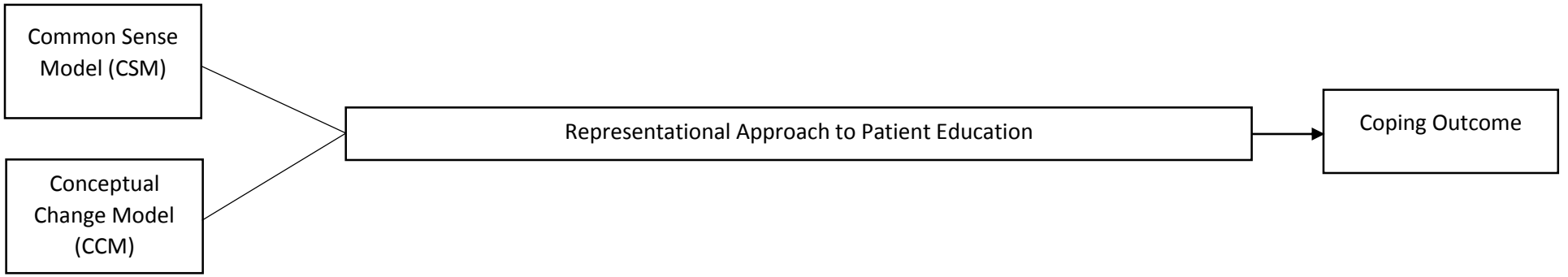
It has been suggested that the key to successful management of ESRD and its related treatment relies on the patient's continuous adherence to the four dimensions of the therapeutic regimen (Denhaerynck et al., 2007). Treatment adherence of patients on HD consists of the following four dimensions: 1) adherence to HD, 2) adherence to medications, 3) adherence to fluid restriction, and 4) adherence to dietary restriction (Denhaerynck et al., 2007).

The CCM is a learning process aimed to restructure current representation (Hewson & Hewson, 1983; Posner et al., 1982). According to Hewson (1992), conceptual change is related to learning and teaching, because learning can happen after the teaching process. The learning process will occur when someone changes their current representation by receiving new representation which are intelligible, plausible, and fruitful (Hewson & Hewson, 1983; Hewson, n.d.; Posner et al., 1982). Intelligible means that the conception is understandable or the individual can understand the conception. Plausible means the conception is reasonable or makes sense. Fruitful means that the conception can be used to solve the current problem. Moreover, learning is related to the idea and availability of evidence that has been experienced (Posner et al., 1982). Conceptual change occurs when individuals become dissatisfied with current representation and the condition of new representation are intelligible, plausible and fruitful (Hewson & Hewson, 1983; Hewson, n.d.; Posner et al., 1982). Dissatisfaction could happen when individuals recognize that their representation has gaps (missing information), misconception (errors) and confusion (unclear or conflated ideas). Furthermore, the health care provider can provide new

information in a specific area, which is appropriate with the individual needs, and allows the individual the chance to accept this new information as intelligible, plausible and fruitful.

Based on both the cognitive illness representation of the CSM and the CCM, Donovan et al. (2007) developed the representational approach to patient education that comprises of seven components. The components that are related to cognitive illness representation, which aims to shape the cognitive illness representation of the patient are as follows: (1) representation assessment, (2) identifying and exploring the gaps, misconceptions and confusion of the illness, (3) creating condition for conceptual change, (4) introducing replacement information, (5) summarizing. While these components support translating the new information into concrete strategies for changing behavior: (6) goal setting and planning, and (7) the follow-up of the goal and the strategies.

The proposed illness representation promoting program in this study was conducted over two weeks in patients with ESRD receiving HD. The program was specifically individualized and directed at enhancing treatment adherence among the patients with ESRD receiving HD by approaching their existing knowledge and beliefs and reorganizing their representation. The program was initiated in the hemodialysis unit while patients were undergoing dialysis sessions. The treatment adherence as the outcome variable in this study will be measured at three time points, before the intervention and during the follow-up sessions at week 2 and week 4.



Illness Representation Promoting Program	
Components	**Activity**
Representation assessment	Encourage patients to describe their illness representation of ESRD, along the five dimensions (identity, cause, timeline, consequences, and controllability).
Exploring the gaps, misconceptions, and confusion	Encourage patients to think and describe their experience of ESRD and HD that lead to misconception, confusion, or error. Ask questions to encourage patients to describe and evaluate the strength of those thoughts.
Creating conditions for conceptual change	Encourage patients to think and explain negative effects of their current representation. Ask for the direct link between the current representation of ESRD and HD, treatment adherence and any consequences that the patient has identified.
Introducing replacement Information	Give information related to patient's needs regarding ESRD and HD along the five dimensions of cognitive illness representation to replace current misconceptions.
Summarizing	Explain the benefit of treatment adherence, how to manage side effects of ESRD and HD.
Goal setting and planning	Encourage patient to think and set his or her goal in order to improve treatment adherence. Set the goal together with patient and write the goal setting and strategies plan form Encourage patient to think the strategies in order to achieve the goal. Develop strategies with the patient to achieve his or her goal.
Follow up of the goal and the strategies	Evaluate whether the goals are achieved or not, whether the strategies worked out or not, and the barriers during implementing the strategies. Develop or maintain the strategies to achieve the goals

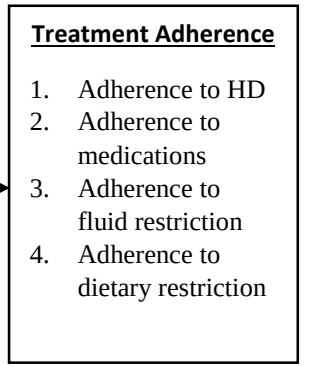


Figure 1

Conceptual Framework of the Study

Hypotheses

The hypotheses of this study were as follows:

1. The treatment adherence mean score in patients that received the illness representation promoting program was higher than the patients that received usual care.

2. The treatment adherence mean score after receiving illness representation promoting program was higher than before receiving it.

Definition of Terms

Illness Representation Promoting Program

This program was specially designed for patients with ESRD receiving HD based on the representational approach to patient education (Donovan et al., 2007) and knowledge regarding treatment adherence specific to HD. The program was conducted over four weeks in three session. By used this approach, the program was specifically individualized and directed at enhancing treatment adherence for each patient with ESRD receiving HD by approached existing knowledge and beliefs and reorganized his/her representation. The program was initiated at the hemodialysis unit while patients were undergoing dialysis sessions. This program was an individualized intervention consisting of seven process components, i.e. (1) representation assessment of ESRD and HD by using Open Ended Questions (OEQ) and the Modified Brief Illness Perception Questionnaire (BIPQ), (2) identifying and exploring misconceptions, gaps and errors of ESRD and HD, (3) creating conditions for conceptual change about ESRD and HD, (4) introducing

replacement information regarding ESRD and HD, (5) summary, (6) goal setting and planning to increase treatment adherence, and (7) following-up the goal and strategies.

Usual care

Usual care referred to care provided by renal nurses at the Hemodialysis Unit, Hospital Raja Perempuan Zainab 2, Kota Bharu. The usual care from the nurses involved initiated and terminated HD sessions, measured blood pressure and body weight of the patients. The nurses also involved in giving health education regarding HD during receiving HD.

Treatment adherence

Treatment adherence is defined as the behavior of patients with ESRD receiving HD and consists of the following four dimensions; 1) adherence to HD, 2) adherence to medications, 3) adherence to fluid restriction, and 4) adherence to dietary restriction. The Treatment Adherence Questionnaire (TAQ) will be used to assess the treatment adherence of the patients undergoing HD which has been modified from the original tools developed by Kim & Evangelista (2010), Novitayani (2012), and Rushe and Gee (1998). It has 15 items with a 4-point Likert scales. Higher scores on the TAQ denote higher adherence to the treatment.

Scope of the Study

This study was conducted to measure the effect of the illness representation promoting program on treatment adherence among patients with ESRD receiving HD in the Hospital Raja Perempuan Zainab 2, Kota Bharu, in the state of Kelantan, Malaysia. Regular patients with ESRD receiving HD, and who were at least 18 years old, able to speak Malay, had been receiving HD three times per week for at least three months prior to the study. Data was collected from January 2015 until April 2015.

Significance of the Study

Treatment adherence is important for patients with ESRD receiving HD. Treatment adherence is an important factor that contributing both to survival and quality of life of the patients. Therefore, the illness representation promoting program could be used as a solution to help patients with ESRD receiving HD enhance their treatment adherence. Moreover, the finding of this study also could be used as information for future studies that are associated with patients with ESRD receiving HD and treatment adherence.

CHAPTER 2

LITERATURE REVIEW

In this chapter, the knowledge underpinning this study was reviewed and discussed, including the following:

1. Overview of ESRD
    1.1. Dialysis modalities
    1.2. Situation of dialysis in Malaysia
2. Treatment adherence
    2.1. Treatment adherence and ESRD
    2.2. Impact of treatment adherence
    2.3. Dimensions of treatment adherence
    2.4. Prevalence of treatment adherence
    2.5. Factors influencing treatment adherence in patients with ESRD receiving HD
    2.6. Measurement of treatment adherence
3. Common Sense Model (CSM)
    3.1. Illness representation
    3.2. Coping
    3.3. Appraisal
    3.4. Illness representation and treatment adherence
4. Conceptual Change Model (CCM)
5. Interventions for enhancing treatment adherence in patients with ESRD receiving HD
6. Illness representation promoting program

Overview of ESRD

Chronic kidney disease (CKD) has become the standard term to describe the chronic renal dysfunction that occurs prior to ESRD because the term 'kidney' is better appreciated than 'renal' by lay people (Goolsby, 2002). CKD is defined as the presence of either kidney damage or decreased kidney function (as evidenced by a glomerulo-filtration rate (GFR) for 3 or more months (Levey et al., 2003). The CKD trajectory has five stages, based on the calculated GFR (Table 1).

Table 1

Definition and Stages of CKD

Stage	Description	GFR (mL/min/1.73 m^2)
1	Kidney damage with normal or ↑ GFR	> = 90
2	Kidney damage with mild ↓ GFR	60-89
3	Moderate ↓ GFR	30-59
4	Severe ↓ GFR	15-29
5	Kidney failure	< 15 (for dialysis)

Notes: GFR = Glomerulo-filtration rate

This CKD staging system was adapted by the National Kidney Foundation Kidney Disease Outcomes Quality Initiative (NKF-KDOQI) where in stage 5 CKD is synonymous with kidney failure. However, the currently accepted definition of ESRD is confined to the patients with stage 5 CKD who require the RRT (Levey et al., 2003).

Dialysis Modalities

ESRD is a chronic, progressive and debilitating illness. The only treatment modality is RRT, which includes renal transplantation, HD and PD. While renal transplantation is the preferred option, many patients have to undergo HD or PD instead because of the shortage of donor organs (Baid-Agrawal & Frei, 2007). In 2012, there were 28,590 patients receiving dialysis in Malaysia, and this reflects an exponential increase from a mere 1,396 in 1993. While the new intake of dialysis patients was only 358 in 1993, this has shown a steep increase to 5,830 in 2012. The equivalent incidence and prevalence rate of patients on dialysis were 199 and 975 per million of the populations in 2012, respectively. The vast majority (92%) of these patients was on HD, and only 8% were on PD. The increase in the dialysis population has been mainly contributed by the rapid growth in private haemodialysis in the last 20 years (Lim et al., 2013).

HD is the most common form of dialysis. It involves the circulation of the body's blood through a machine that cleans the blood of waste products. The first artificial kidney machine was developed in Holland around the year of 1940 (Bevan, 2000). The early machines could not maintain life for long because repeated treatments were not possible due to the lack of maintaining an access to circulation. The access problem was solved, in 1960, by an American surgeon (Bevan, 2000), and thus, the availability of repeated access of patients to HD commenced. Maintenance HD, as a treatment for patients with ESRD receiving HD, can be traced from this time. HD is usually performed in a health care center and this requires the patient to be away from home approximately three times per week, and several hours per treatment period (Starzomski & Hilton, 2000).

PD is another means of providing dialysis. This therapy is performed by introducing a dialysis solution into the peritoneal cavity. Osmotic pressure causes body wastes to pass from the bloodstream into the dialysate. After a time the dialysate solution containing the wastes is drained. Continuous ambulatory peritoneal dialysis (CAPD) patients always have fluid present in their peritoneal cavity and use only four to five exchanges of fluid per day. CAPD patients manage their treatment at home; thus, do not have to travel to an ESRD facility for treatment. Therefore, CAPD patients have greater freedom of mobility than patients on HD. Intermittent peritoneal dialysis (IPD) is done usually four times a week for a 10-hour period. In the use of PD, the patient will treat her/himself every day, four times a day at home or away from home, which requires some storage of bags of dialysate in the home or in his or her car (Starzomski & Hilton, 2000).

Renal transplantation replaces renal function through a surgical procedure that implants a human kidney from a donor into the right or left groin area of the recipient. The first successful transplant was performed in 1956. As the 21st century begins, transplantation has a decreased risk of rejection, minimal risk of infections, and greater possibility for long-term survival due to the improvement of immunosuppressive drugs (Starzomski & Hilton, 2000). These patients no longer have 'kidney failure' or the ravages of renal failure on all the body's physiological systems. The overall success rates, of renal transplants, were reported to be 95%. But because of the shortage of donor organs (Baid-Agrawal & Frei, 2007), not all patients with ESRD have the opportunity to receive the transplantation.

Situation of Dialysis in Malaysia

Malaysia has a tax-funded public health service same as other former British colonies in the region such as Hong Kong and Sri Lanka. Publicly funded therapy is available for the patients in need of HD, if they meet the criteria for it. Those who can afford to do so can instead get therapy in the for-profit private sector, paying out of pocket or through private health insurance, either their own or insurance provided by an employer. In addition, the not-for-profit private or charity sector made up mostly of nongovernmental organizations (NGOs), raises funds to provide HD for those who were unable to enter the public program or afford private dialysis (Lim et al., 2010).

Until 1990s, very few Malaysians had accessed to HD. Although the country's economy began to improve in 1990, the public sector was unable to meet the demand for the HD. Many patients had to resort to seeking care in the private sector. As a result, by 2000 private spending on HD almost equaled public financing. However, a large number of patients were not eligible for the public program and could not afford to pay for treatment in the private sector. Therefore, The National Kidney Foundation of Malaysia and other NGOs began to raise money and provide dialysis. Funding from NGOs grew from a negligible amount in 1990 to 14 percent of total spending on dialysis by 2000 (Lim et al., 2010).

In the 1990s, in response to growing public demand for HD and advocacy by various NGOs, the government was able to take a series of steps to improve the provision of dialysis (Lim et al., 2010). One of the earliest reforms occurred in 1999, when the Ministry of Health allocated additional funds to develop more public HD facilities and

provided matching capital grants to NGOs. In the same year, the Social Security Organization, a government-run social insurance body that receives mandatory contributions from private-sector employees, agreed to consider HD as a rehabilitation therapy. This change meant that contributors could be reimbursed for HD received in the private sector (Lim et al., 2010).

In 2000, the Baitulmals, state-run Islamic social welfare organizations, began subsidizing HD for poor Muslims. Funded by compulsory but tax-deductible tithes from Muslims, the Baitumals typically pay the full cost of HD. Two additional reforms occurred in 2001. The Ministry of Health began subsidizing HD at private facilities for patients who were eligible for public HD. And the Public Service Department began reimbursing public-sector employees and their dependents for dialysis. Together these changes increased public financing for HD from 2000 onward. In 2005 public money once more accounted for the majority of HD financing. Even then, nonpublic funds from for-profit and nongovernmental organizations combined still accounted for a third of the financing (Lim et al., 2010).

Treatment Adherence

It has been suggested that the key to the successful management of ESRD and its related treatment relies on a patient's continuous adherence to the four dimensions of the therapeutic regimen (Denhaerynck et al., 2007).

Treatment Adherence and ESRD

Treatment adherence is critical to the efficacy of medical recommendations and treatments (Kammerer & Garry, 2007). Most patients with ESRD receiving HD in a dialysis facility three times a week. They must adhere to dietary and fluid prescriptions and must be on medications for their co-morbidities. Because of the commitment required, it is often observed that patients with ESRD receiving HD have a partial or high degree of poor adherence to treatment (Kim, 2009).

A large cross-sectional study in Belgium and Germany measured treatment adherence in 916 HD patients by surveying adherence to diet and fluid with a self-report instrument, the Dialysis Diet and Fluid Adherence Questionnaire (DDFQ), and also the complementary use of laboratory results and interdialytic weight gain (Kugler, Vlaminck, Haverich, & Maes, 2005). The results indicated that as many as 81.4% of HD patients have difficulty following the challenging HD dietary restrictions and 74.6% of the participating patients struggled with HD fluid restrictions.

Impact of Treatment Adherence

A large retrospective study utilizing USRDS data from 12/31/1990 to 12/31/1993 by Leggat et al. (1998) established the criteria for assessing dimensions of treatment adherence to include missing dialysis sessions or shortening at least one dialysis treatment a month by >10 minutes. Results by Leggat et al. (1998) showed that there was 25% higher risk of death in HD patients who skipped HD session than other groups of HD patients. Saran et al. (2003) reported that the risk of death was 30% higher for patients who

skipped one or more treatments per month and the relative risk of mortality was 11% higher for patients who shortened three or more dialysis treatments a month.

Increased time between dialysis, which can occur on weekends or when HD treatments were skipped, results in higher fluid weight gains and metabolic imbalances that have the potential to be especially detrimental to persons with cardiac arrhythmias, congestive heart failure, or coronary artery disease (Bleyer et al., 1999). Poor adherence, particularly by patients with ESRD receiving HD, has significant "medical, social, and economic consequences" (Kammerer & Garry, 2007).

Dimensions of Treatment Adherence

The treatment adherence of patients with ESRD receiving HD consists of four dimensions that include adherence to HD, adherence to medications, adherence to fluid restriction, and adherence to dietary restriction (Denhaerynck et al., 2007).

Adherence to HD. Theoretically, counting the number of skipped dialysis sessions can easily measure adherence to HD. However, investigators have not agreed on an acceptable cut off number for defining adherence. In addition, a shortening of a dialysis session leading to a lower delivered dose of dialysis could be considered as adherence, depending on the cause (Denhaerynck et al., 2007). The prevalence of adherence to dialysis ranged between 0 and 32.3% (Hecking et al., 2004; Kutner et al., 2002; Taskapan et al., 2005). Taskapan et al. (2005) defined as patients missing more than 1 session per month but did not include shortened dialysis sessions in their criteria for adherence. However, the other researchers considered when they shortened a dialysis session for more than 10

minutes, more than once per month, in addition to missing more than one session per month (Hecking et al., 2004; Kutner et al., 2002; Saran et al., 2003). A study done by Gordon, Leon, and Sehgal (2003) revealed five categories of reasons for shortening and skipping, including medical problems, technical problems, life tasks, transportation, and patient decisions with the most common reasons for shortening were medical problems (38%) and life tasks (24%).

Adherence to medications. To treat, correct or prevent concomitant illnesses or symptoms, patients were prescribed with an average daily intake of 10-14 medicines (Lindberg, Lindberg, & Wikström, 2007; Manley et al., 2004). Medications commonly prescribed for these patients are antihypertensive medicines, diuretics for patients with scanty urine output, anti-pruritic medicines, and calcium supplements. Since dialysis alone is insufficient in maintaining calcium and phosphate at a balance level, patients were required to take phosphate-binding agents in addition to the restriction of dietary phosphate intake. In order to achieve optimal medication effects, these phosphate binders have to be taken just before or with meals and the pills should be swallowed whole rather than chewed. Traditionally, adherence to medications has been assessed by self-report questionnaires, compliance ratings by nurses, pill counts or prescription refill history.

Adherence to fluid restriction. The reported adherence rates to fluid restriction using various measures range from 3.4% to 74%. The most common method of assessing adherence to fluid restriction recommendations is to measure interdialytic weight

gain (IDWG). However, there is no standardized way of interpreting IDWG (Denhaerynck et al., 2007).

Adherence to dietary restriction. Patients with ESRD receiving HD were required to follow the dietary prescription on potassium, phosphorus, sodium, calcium, and protein intake (Denhaerynck et al., 2007). Adherence to dietary restriction is usually investigated by using questionnaires or biochemical markers such as serum potassium, phosphate or albumin.

Prevalence of Treatment Adherence

The purpose of this part of the review is to gain an overview of a patient's levels of treatment adherence to the renal therapeutic regimen. Leggat et al. (1998) conducted a large-scale study to investigate the levels of adherence to all four dimensions of the therapeutic regimen among 6,251 patients treated with HD for more than 1 year. It was found that 9% of patients skipped HD, 20% shortened HD, 10% were not adhere to fluid restrictions, and 22% were not adhere to both dietary restrictions and medication prescriptions. In this study, adherence to HD was defined as not skipping any HD sessions in a month, or shortening HD by not more than 10 minutes for HD sessions in a month.

In another large-scale study, Bame et al. (1993) examined the levels of adherence to dietary and fluid restrictions as well as medication prescriptions among 1,230 patients undergoing HD. The patient's pre-dialysis blood urea nitrogen and serum potassium, IDWG, and serum phosphate values were used to determine their adherence to

dietary and fluid restrictions and medication regimens, respectively. Results showed that a patient's adherence to protein and potassium restrictions was 91% and 98%, respectively. However, only half of the patients were adhere to fluid restrictions (50%) and medication prescriptions (50%). In the study by Bame et al. (1993), two criteria, namely blood urea nitrogen and serum potassium, were used to determine the patients adherence to dietary restrictions. However, Leggat et al. (1998) used serum phosphate concentration as a criterion to measure dietary adherence. If different criteria were used to assess one aspect of the therapeutic regimen, it is not surprising that very different adherence rates would be generated. Another question is how each component of the therapeutic regimen should be assessed. In addition to the differences in the number of aspects used to assess a patient's adherence and the inconsistent criteria employed to determine adherence, different cut-off points were set to classify patients as adherence. The use of different calculation formulas adds complexity to the issue.

Pang et al. (2001) reported that among 92 patients undergoing HD, 67% were adherence to fluid restrictions. The patient's IDWG was used as an indicator of fluid adherence. Those with an IDWG of less than 0.9 kg/day were classified as adhere. Lee and Molassiotis (2002) demonstrated a 40% rate of adherence to fluid restrictions among 62 patients undergoing HD. Their adherence parameters were set with reference to the patient's dry weight (the post-dialysis weight when the majority of the excess body fluid has been removed through the ultrafiltration process; the patient is not edematous and the blood pressure is stable). For patients with a dry weight below 50 kg, 0.7 kg/day was the cut-off point for IDWG; for those with a dry weight greater than or equal to 50 kg, the cut-

off value was 1.0 kg/day. Although IDWG is commonly used as an indicator to measure a patient's fluid adherence, Pang et al. (2001) used the absolute value, Lee and Molassiotis (2002) took into account patient's body size, while Leggat et al. (1998) used a patient's percent of weight gain with reference to his or her dry weight. Therefore, it is not difficult to understand the inconsistent results yielded in relation to patients fluid adherence rates.

Results from these studies show that patient adherence can vary from 2% to 60%, highlighting the differences in adherence levels with respect to the various aspects of the therapeutic regimen being investigated. This also suggests that patients may be adherence to one aspect of the therapeutic regimen but no other aspects (Denhaerynck et al., 2007). Even with the same aspect of the therapeutic regimen, different criteria have been utilized to assess patient adherence.

As illustrated by the studies cited above, three phenomena emerged during the review of the relevant literature. Firstly, due to the inconsistency in the definitions of adherence, researchers assessed patients' adherence to a different number of dimensions in the renal therapeutic regimen rather than investigating their adherence to all four dimensions. Secondly, researchers used different criteria to assess the same aspect of the therapeutic regimen. As such, different measurements or instruments were used. Thirdly, different cut-off points were employed to determine adherence even if the same instrument was used.

Factors Influencing Treatment Adherence in Patients with ESRD Receiving HD

Patients' demographic characteristics, duration of dialysis experience, social support, knowledge about the advantages of treatment adherence and illness representation have been examined as determinants of treatment adherence behavior in the literature reviewed.

Demographic characteristics. To identify patients at risk of adherence to treatment, demographic and clinical characteristics such as age, gender, and marital relationship have been studied to examine their relationship with adherence. Previous studies have shown that older patients were more adherence (Bame et al., 1993; Kara, Caglar, & Kilic, 2007; Kugler et al., 2005; Kutner et al., 2002; O'Connor, Jardine, & Millar, 2008). Although younger patients display poorer adherence to all aspects of the prescribed regimen than older patients, the reasons for their poorer adherence have not been explored.

Leggat et al. (1998) and Kimmel et al. (2000) failed to identify any gender difference in adherence to the dialysis regimen among patients undergoing HD. In contrast, an earlier study conducted by Kimmel et al. (1995) found that women were more adherence to the dialysis regimen. For fluid restriction, women were more adherence than men (Bame et al., 1993; Kugler et al., 2005; Vlaminck, Maes, Jacobs, Reyntjens, & Evers, 2001). In other words, women seem to be more adherence than men only to fluid restrictions, but not to other aspects of the therapeutic regimen. It would be interesting to understand the circumstances leading to men's adherence to fluid restrictions.

Marital relationship is another demographic variable used to correlate with patient adherence. Bame et al. (1993) demonstrated that single patients were more likely to not adhere to dietary restrictions. Conversely, Kara et al. (2007) evaluated 160 patients' adherence behavior, and revealed that being married was an important factor for adherence to dietary and fluid restrictions. The study conducted by Mai, Busby and Bell (1999) among 48 patients undergoing HD showed no significant relationship between marital relationship and adherence measures. Kimmel (2000) suggested that marital conflict can affect a patient's representation of illness and interfere with his or her ability to adhere to the dialysis regimen. This implies that a patient's marital relationship, rather than marital relationship, influences adherence. Whether a patient's spouse has a positive or negative influence on patient's adherence, and how the influence is exercised remain uncertain and unexplored.

Duration of dialysis experience. Inconclusive findings have been generated in relation to adherence and the duration of a patient's experience in HD. Vlaminck et al. (2001) studied the prevalence of adherence to dietary and fluid restrictions among 564 patients who had been receiving HD for an average of 45.8 months. Results showed that there was no significant correlation between adherence behavior and the length of time a patient had been receiving dialysis. In a study by Kugler et al. (2005) on 916 patients undergoing HD for a mean duration of 47 months, patients with a longer experience of dialysis were found to have low levels of adherence to dietary and fluid restrictions. Both studies used the self-report DDFQ to assess the adherence of patients utilizing the same treatment modality who had been on dialysis for a similar duration,

however different results were generated. The authors of these two studies did not offer any possible explanation for the phenomenon they had identified because the study design did not allow any explanation from the patient's perspective.

Social support. Social support, especially support from the family, is believed to be an important factor affecting a patient's adherence. A number of authors have attempted to identify the relationship between social support and a patient's adherence to his or her therapeutic regimen, but with inconsistent results. Christensen et al. (1992) conducted a study on 78 patients undergoing HD, and suggested that family support positively correlated with fluid restrictions but had no association with dietary restrictions. Family support was measured by the Family Relationship Index from the Family Environment Scale, whereas IDWG and serum potassium levels were used to monitor a patient's adherence to fluid and dietary restrictions, respectively. If family support is a factor positively influencing a patient's adherence to fluid restrictions, the reason why this important variable has no effect on dietary adherence has yet to be explored. When the number of family members living with the patient increased, the patient's ability to resist tempting eating situations decreased (Zrinyi et al., 2003). It is important to understand how family members influence a patient's adherence to fluid and dietary restrictions, especially the kind of temptations patients have to face in relation to their diet and their abilities to resist such temptations.

Oka and Chaboyer (1999) investigated dietary behavior and sources of support among 325 patients receiving HD, and revealed that informal support from family members and formal support from physicians, nurses and technicians were significantly

related to a patient's dietary adherence. The authors went on to report that the patients who were 65 years and older received more support from family members, doctors, nurses and technicians than the younger patients. Their study results also indicated that patients who had been on HD for fewer than 3 years received more support from healthcare professionals than those who had been on dialysis for longer periods of time. When interpreting the results, it is worthwhile to note that the validity of the Dietary Behavioral Scale employed to evaluate a patient's dietary behaviors appears to be questionable. This scale classifies a patient's daily dietary intake into two subscales, namely nutritive elements and food. Patients were asked to rate the frequency of their intake of the listed nutritive elements and food from never to always. It seems that the questionnaire not only assesses the patient's adherence behavior, but also their knowledge about the nutritive components of foods. Without thoroughly understanding the nutritive elements of the different kinds of foods, patients may not be able to respond to the questions accurately. Another issue worth considering is that the assessment items on the sources of support focused on identifying the supporter's provision of psychological support, his or her belief in the patient's ability, and his or her participation in teaching, providing physical assistance and interacting with the patient. Patients were only asked to rate the availability of such support from various personnel. Although the sources and types of support were important to an individual's adherence, the critical issue should be the patient's satisfaction with the support they receive. However, this factor was not investigated in the study.

Knowledge about the advantages of treatment adherence. Another factor believed to influence patients' adherence is their knowledge about the advantages of

adherence to their therapeutic regimen. Thomas, Sargent, and Michels (2001) showed that knowledge related to dietary restrictions was significantly associated with adherence. Patients who followed special diets more closely were found to have a higher knowledge level. Dietary knowledge was also measured around the restrictions of the three major electrolytes in a renal patient's diet, namely potassium, phosphorus and sodium. However, instead of using physiological and biochemical markers, patients were asked to report the number of times a particular food was consumed per week or per month to indicate their adherence. The inconsistent findings between studies may be explained by the different assessment criteria used to determine adherence. Another factor that needs to be considered is that one of the inclusion criteria in the study by Thomas et al. (2001) was the age group of 50 and older, which was not specified in other studies. As mentioned above, studies have unanimously demonstrated that age is the only demographic variable that is highly and persistently correlated with patient adherence. In the study by Thomas et al. (2001), 56% of patients were aged 65 years or below, and the rest were over 65. The results showed that patients classified as adherence were generally 65 years or older (53%). It remains uncertain whether knowledge or age actually influences an individual's adherence.

A number of educational programs, sometimes supplemented with other strategies such as individualized attention, supervision and encouragement, have been developed to enhance patients' knowledge to improve their adherence. Barnett et al. (2008) examined the effectiveness of patient education on fluid adherence among 26 patients undergoing HD with an IDWG above 2.5 kg. One of the participant selection criteria was adherence. It was a one-group design with measurements taken before and after an

educational intervention. The results showed that the patients' mean IDWG decreased from 2.6 to 2.2 kg. It is possible that the selected patients were aware of the label attached to them, and may have attempted to get rid of the unwanted label and behave themselves regardless of whether or not they took part in the education program. Furthermore, attention provided to the patients during the intervention might also lead to a change in their behavior. Therefore, without a control group, it is difficult to tell whether the decrease in IDWG is truly because of the effectiveness of the education program.

In the study conducted by Casey, Johnson, and McClelland (2002), a program including verbal and written reinforcement of fluid balance advice was provided to 21 patients treated with HD. The same group of patients received three types of interventions during three separate 6-week periods, each followed by a 2-week period. The only outcome measure was the patient's mean IDWG. The results indicated that 48% of the patients had an overall improvement in mean IDWG, but this was not statistically significant. Due to the accumulation effect of one patient receiving three types of interventions at three different time periods, the authors were unable to identify which type of intervention was more effective in enhancing the patient's adherence. As patient adherence is a multifaceted and complex issue (De Geest & Sabaté, 2003) that is not totally dependent on staff intervention, it is necessary to understand the factors contributing to difficulties patients encounter in the process of adhering to fluid restrictions.

Dietary knowledge is necessary for patients to follow their dietary regimen (Parmenter, Waller, & Wardle, 2000). Despite the number of educational programs that have been developed (Baraz, Parvardeh, Mohammadi, & Broumand, 2010; Cummings,

Becker, Kirscht, & Levin, 1981; Shaw-Stuart & Stuart, 2000) to enhance patients' knowledge and improve their adherence, a meta-analysis has revealed the futility of generalizing any results and the impossibility of identifying which intervention influences patient adherence outcomes (McDonald, Garg, & Haynes, 2002). As suggested by Baraz et al. (2010) and Cummings et al. (1981), any interventions implemented could improve patient adherence. Although some authors claimed that their interventions were effective (Baraz et al., 2010; Cummings et al., 1981), they also admitted that when the inducements for behavioral change were removed, patient behavior reverted to pre-intervention levels (Cummings et al., 1981). This further reinforces the message that knowledge is a necessary factor contributing to improved adherence, but is insufficient in fostering long-term behavioral change in isolation (White, 2001).

If patients failed to follow treatment adherence despite understanding the therapeutic regimen, the measures to be taken to adhere, and the benefits of adherence, it is possible that there are other factors leading to their behavior. The majority of educational programs have been developed based on healthcare professionals' representation of patient needs. Based on this representation, healthcare professionals provide information about the therapeutic regimen and advise patients to adhere to it. Although it is assumed that adherence is good for patients, it is the patients themselves who have to implement the items included in the regimen. As suggested by McDonald et al. (2002), "such regimens fulfill theoretical, physiological, and empirical considerations about optimal care, while ignoring practical patient-centered concerns, such as nature, nurture, culture, and

stereotyping of the patient, and the inconvenience, cost, and adverse effects of the treatment."

Illness representation. Although there is a considerable amount of research investigating the prevalence of adherence and factors influencing a patient's adherence, the majority of the studies were conducted from the perspectives of healthcare professionals, and objective measures were frequently used to assess patient adherence. Studies exploring adherence from a patient's perspective were limited.

Measurement of Treatment Adherence

Treatment adherence in patients with ESRD receiving HD is measured by a variety of methods (Denhaerynck et al., 2007; Loghman-Adham, 2003). Biological measures such as IDWG and biochemical markers were the clinical measures that used to evaluate treatment adherence in patients with ESRD receiving HD (Durose et al., 2004; Hecking et al., 2004; Kutner et al., 2002; Lee & Molassiotis, 2002). In general, biological and biochemical markers can be regarded as objective measurement instruments; however, the lack of a universally accepted cut off value for each marker raises the question of whether these measurements were reliable tools to assess adherence rates in the patients with ESRD receiving HD. These measurements have been used not only to assess treatment adherence but to also evaluate the clinical outcomes in the patients with ESRD receiving HD. Although these biological and biochemical markers maybe more effective or reliable measures of clinical outcomes, the measures may not necessarily be adequate for measuring adherence (Durose et al., 2004; Hecking et al., 2004; Kutner et al., 2002; Lee & Molassiotis, 2002).

Direct questioning of patients is frequently used to measure adherence, however few adherence scales have been developed and tested for use with patients with ESRD receiving HD (Gordon et al., 2003; Lee & Molassiotis, 2002). Self-report instruments such as questionnaires are valuable for measuring adherence if they are well validated and reliable. In fact, they might be the best measure with regard to cost-effectiveness. However, the wide variations in the reported adherence rates are mainly due to the lack of reliable measurement tools that address the four classical dimensions of treatment adherence behavior of patients with ESRD receiving HD: adherence to HD, adherence to medications, and adherence to fluid and dietary restrictions (Kim, Evangelista, Phillips, Pavlish, & Kopple, 2011). One of the few instruments with established validity and reliability to evaluate treatment adherence in the patients with ESRD receiving HD is the Dialysis Diet and Fluid Non-Adherence Questionnaire (DDFQ) (Vlaminck et al., 2001). The DDFQ consists of four questions assessing adherence to fluid restriction and to dietary guidelines in terms of frequency and degree over the past 14 days. However, the DDFQ is limited in that it does not address some of the important dimensions of adherence (i.e. attendance to HD sessions and adherence to prescribed medications) (Vlaminck et al., 2001). Therefore, a valid and reliable instrument is needed to determine the degree of adherence to treatment and to identify adherence patients who would benefit from interventions to prevent adverse events.

Kim et al. (2011) created the 46-item ESRD-Adherence Questionnaire (ESRD-AQ). The ESRD-AQ is the first self-report instrument to address all dimensions of adherence behaviors of patients with ESRD receiving HD. The instrument is reliable and

valid, and is easy to administer (Kim et al., 2011). The ESRD-AQ for patients requiring in-center HD was designed to measure treatment adherence behaviors in four dimensions: HD attendance, medication use, fluid restrictions, and diet recommendations. Items were initially generated based on in-depth literature reviews and in consultation with clinical experts, such as nephrologists and nephrology researchers, HD nurses, and renal dieticians. The ESRD-AQ consists of 46 questions/items divided into five sections. The first section pursues general information about the patient's ESRD and RRT-related history (5 items), and the remaining four sections ask about adherence to HD (14 items), adherence to medications (9 items), adherence to fluid restrictions (10 items), and adherence to dietary recommendation (8 items). The ESRD-AQ is easy to administer with acceptable validity and reliability. Furthermore, the ESRD-AQ is the first self-report instrument to address all the dimensions of adherence behaviors of patients with ESRD receiving HD. The ESRD-AQ also provides researchers and clinicians with comprehensive information, such as the patient's clinical history related to his or her ESRD, and the patient's representation and level of understanding about his or her medical recommendations.

Common Sense Model (CSM)

The CSM was developed by Leventhal et al. (1980). The CSM consists of illness representation, coping, and appraisal. The illness representation is composed of cognitive illness representation and emotional illness representation.

Illness Representation

Leventhal et al. (1980) found that individuals formulate their illness representation based on information that gives sense of their problem and can be used to overcome the problem. Leventhal and colleagues stated that the information comes from the following three resource stimuli; past experience with illness, information from influential others, and current experience with illness.

There are two levels of illness representation that are formulated from these stimuli which are cognitive illness representation and emotional illness representation (Leventhal et al., 1980). Cognitive illness representation involves identity, cause, consequences, timeline, and cure or controllability dimensions. Identity refers to statements regarding beliefs about the illness, label, and knowledge about its symptoms. Cause refers to beliefs regarding the factors that are responsible for causing the illness. Consequences refer to beliefs regarding the impact of the illness on the quality of life of functional capacity. Timeline refers to beliefs about the course of the illness, such as chronic, acute, etc., and the time scale of the illness symptoms, such as persistence, temporary, etc. Cure refers to beliefs about the efficacy of treatment and personal coping that may alter the illness.

Emotional illness representation is associated with the individual's fear about the illness (Leventhal et al., 1980). It is necessary for the individual to receive information about a health threat (such as medication) and information regarding the action in order to face the fear. How the individual copes with the stress when he or she gets an illness is affected by his or her fear of the illness. It means fear influences the individual to choose coping in order to deal with the problem or illness.

Coping

Both cognitive and emotional illness representation affect the coping strategies of individuals in order to face their problem regarding their illness. According to this, CMS has a fear control process that is associated with emotion and a danger control process that is associated with representation based on cognition (Leventhal et al., 1980). The fear control process refers to what is the reason that makes the patient feel fear and what the patient does in order to face his or her fear. The danger control process refers to how the patients perceived the threat of their illness and what they do to overcome the illness.

There are three principles in order to set up the behavior as coping (Leventhal et al., 1980). First, the events and the individual's emotion define the goals to cope with the problem that is caused by the events. Second, setting the behavior needs to specify the goals based on the cognitive illness representation and making the plan about what one should do. Third, information has a role to formulate the illness representation and planning for the behavior. The individual 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).

Appraisal

Appraisal is evaluating the effectiveness of coping activities. In order to evaluate the effectiveness of coping, the individual needs to trial and error the coping strategies to face the problem in reality (Leventhal et al., 1980). While individuals apply their coping, they do not put high expectations on the effectiveness of their coping. Moreover, individuals need to anticipate coping if the coping is not successful in achieving the individual's goal or if there are any barriers that the individual faces when he or she uses coping.

Illness Representation and Treatment Adherence

The current conceptual view of adherence emphasizes the client's self-care autonomy in collaboration with the health care personnel. Thus, addressing the issue of adherence behavior from the perspective of a self-regulation theory, CSM, is an ideal and suitable approach. The key constructs within the CSM are how lay people perceive illness representation and how the individual acts as an active problem solver based on how the individual perceives illness representation (Leventhal, Leventhal, & Cameron, 2001). The CSM also provides a theoretical background that illustrates how illness representation may determine how patients cope with their illness, either being adherence to their therapeutic recommendations, according to their illness representation. When patients are

overwhelmed by their illnesses at either the cognitive or emotional level, they may opt to be more adherence.

Conceptual Change Model (CCM)

Conceptual change is the changing of current conception in order to overcome problems in the phenomenon (Hewson & Hewson, 1983). There are four ways to change conception; (1) add a new conception from experiences and interaction with others, (2) differentiate and clarify current conceptions from external or internal resources as the result of the thought process, (3) reorganize the current conceptions that come from external and internal resources (4) reject some current conceptions by replacing with some new conceptions (Hewson & Hewson, 1983). The conceptual change model is a model of the learning process in order to change an individual's conceptions that are already there by adding new knowledge (Hewson, n.d.; Posner et al., 1982).

Conceptual change is associated with the status condition of conception, which is divided into four statuses, namely no status, status I (intelligible), status IP (intelligible and plausible) and status IPF (intelligible, plausible and fruitful) (Hewson & Hewson, 1983; Hewson, n.d.; Posner et al., 1982). Intelligible means the individual knows and understands the meaning of conception and can construct a coherent representation of it. Plausible means the individual believes that the conception is true and it is reconcilable with other existing conceptions. Fruitfulness means the individual sees the effectiveness of

the conception. Therefore, in order to make conceptual change occur, the status condition of the conception needs to be met.

Conceptual change consists of assimilation and accommodation phases. In the assimilation phase, an individual uses current concepts to face new phenomena by defining problems, setting strategies to face the problems, and identifying criteria for the solution (Posner et al., 1982). It means current concept will be used if it is suitable, and relates to and supports the new phenomenon. The accommodation phase occurs when a current conception cannot deal with the new phenomenon, and so, needs to be modified or restructured (Posner et al., 1982).

In order to change the current conception, in the beginning, the individual needs to be dissatisfied with the current conception, and then, the new conception is intelligible, plausible, and fruitful (Hewson & Hewson, 1983; Hewson, n.d.; Posner et al., 1982). For the individual to be dissatisfied with the current conception, the current conception must have no status of being intelligible, plausible, and fruitful. It means the individual's current conception has lost the ability to overcome the problems. Thus, the individual will likely change his or her current conception.

In the conceptual change model, there needs to be a learning process in order to change the concepts. The learning process is associated with teaching and education. According to Posner et al. (1982), in the learning process, the implication of education consists of teaching, fundamental conceptual change, individuals resisting to make such changes and conceptual ecology. Teaching involves providing a rational basis

for a conceptual change. According to Posner et al. (1982), in order to accommodate new conception on a rational basis, there are four important ways that the educator can follow, namely (1) curricular objectives, (2) intelligible, plausible and fruitful content of the new conception, (3) teaching strategies and (4) teacher role in order to facilitate and accommodate.

In curricular objectives, the educator has the aim to recognize the current conception, the consistency of the individual's belief with the phenomenon and the new conception, and make sense that the new conception is fruitful. The educator's role is helping the individual to develop scientific thinking and help the individual confront his or her problem to receive a new conception. In the accommodation phase, five teaching strategies are recommended (Posner et al., 1982). The first is developing lectures to create cognitive conflict. The second is organizing instruction to identify errors in the individual's thinking in order to resist accommodation. The third is developing the strategies to overcome the individual errors. The fourth is helping the individual to recognize and sense the new conception and to translate from one representation to another. The fifth is developing evaluation techniques to be used in order to see the process of conceptual change in the individual. Strategy teaching for assimilation also has five steps; clarifying the content presented in the text, explaining solutions to problems, demonstrating principles, providing laboratory exercises and testing for the recall of facts and the ability to apply knowledge to problems.

Interventions for Enhancing Treatment Adherence in Patients with ESRD Receiving HD

Several interventions were conducted to enhance treatment adherence in patients with ESRD receiving HD. Tsay (2003) conducted a RCT of 62 chronic HD patients to examine the effectiveness of self-efficacy training on fluid intake adherence. While Nozaki et al. (2005) conducted a quasi-experimental study to compare the effects of a standard patient education program (SPE) with a cognitive behavioral therapy (CBT) intervention on sodium intake and fluid gains in a sample of 22 Japanese HD patients. Three previous research studies also have tried to provide interventions to promote treatment adherence based on the illness representation since it is one of the factors that can be manipulated to increase treatment adherence in patients with ESRD receiving HD. Christensen et al. (2002) examined the efficacy of a group administered behavioral intervention to increase adherence to fluid intake restrictions in a sample of 40 HD patients. While the study done by Karamanidou et al. (2008) focused on the evaluation of a psycho-educational intervention aimed to improve the understanding of the need for phosphate control, to provide a rationale for phosphate-binding medication (PBM) and to explain its mode of action. Finally, the study done by Seyyedrasooli et al. (2013) focused on illness representation interventions in order to determine the effect of the interventions on treatment adherence in patients with ESRD receiving HD.

Tsay (2003) did a study in Northern Taiwan over a six month period. The experimental group received 12 sessions of structured self-efficacy training and the control group received routine care. The intervention included an educational component, self-

monitoring of dietary and fluid intakes, performance mastery, experience sharing and stress management. Patients recorded daily food and fluid intake which were reviewed during each HD treatment. The experimental group was found to have decreased IDWG and decreased fluid intake for up to six months following the intervention as compared to the control group. Limitations of the study included lack of generalizability as the study was conducted in Taiwan.

Nozaki et al. (2005) conducted a quasi-experimental study to compare the effects of a standard patient education program (SPE) with a cognitive behavioral therapy (CBT) intervention on sodium intake and fluid gains in a sample of 22 Japanese HD patients. The CBT intervention consisted of a self-monitoring component, a shaping method and assertion training and response prevention. The self-monitoring component consisted of having patients monitor and record behaviors related to salt and fluid intake and record associated attitudes, emotions and thoughts. The shaping method divided the target achievement process into several steps and identified behaviors in each step to finally achieve the target behaviors. In the response prevention, patients were encouraged to discuss ways they could control impulsive behavior induced by a stress reaction by doing something other than ingesting fluid and salt. They found that CBT intervention appeared to have a longer effect.

For the illness representation based study, Christensen et al. (2002) examined the efficacy of a group administered behavioral intervention to increase adherence to fluid intake restrictions in a sample of 40 HD patients. The intervention was administered to groups of four to six participants meeting for seven one hour long weekly

sessions. The participants were guided by a psychologist to develop behavioral goals related to fluid restriction, to generate plans to reach their goals, and to establish criteria to monitor their responses. No significant differences in IDWG were found between the treatment and control groups immediately post intervention, however a significant reduction in IDWG was found between the two groups two months after the intervention. However, the findings highlight the importance of goal setting to the process of behavior change.

The other study that has been based on illness representation was the study done by Karamanidou et al. (2008). The study focused on the evaluation of a psycho-educational intervention aimed to improve the understanding of the need for phosphate control, to provide a rationale for phosphate-binding medication (PBM) and to explain its mode of action. The study was done on 39 adult patients with ESRD receiving HD for at least 6 months and on phosphate-binding medication. The results show that this brief intervention had an immediate effect on the patients' treatment beliefs and knowledge but not all of these were maintained at the follow-up. The demonstration helped patients to develop a concrete representation of the mode of action of the treatment, which should result in a more enduring understanding of the treatment. The key theoretical and practical relevance of the findings are that it is possible to change treatment beliefs through a simple psycho-educational intervention but that more comprehensive approaches are necessary for sustained change in treatment-related cognitions and behaviors. However, the researchers did not mention the duration for each session. Furthermore, their intervention needs a preparation phase of the equipment to show the demonstration to the patients.

The study done by Seyyedrasooli et al. (2013) focused on illness representation interventions in order to determine the effect of the interventions on treatment adherence in patients with ESRD receiving HD. The interventions were based on the CSM, which emphasizes the importance of behaviors related to adhering to the treatment. The researchers performed the data collection by using a questionnaire with two parts that consisted of social-demographic information and the End Stage Renal Disease Adherence Questionnaire (ESRD-AQ). This questionnaire consists of 41 items that is divided into 4 areas: regular attendance at HD sessions (14 items), consuming prescribed drugs (9items), and limitation of liquid consumption (10 items) and limitation of diet consumption (8 items). Most of the questions have been graded in the form of a Likert scale.

The findings of the study showed that illness representation promoting interventions led to the improvement of treatment adherence of the patient adherence to medication regimen, adherence to diet regimen, adherence to liquid limitation and the shortening of dialysis sessions dimensions. It is interesting to note that illness representation interventions are also effective in patients with chronic illness that failed to follow treatment adherence. According to CSM, illness representation can be effective in patients coping with illness and their adherence or lack of adherence to treatment and prescribed recommendations. When people have adequate knowledge about different aspects of their illness and are able to manage different aspects of their illness, then they are able to have better coping with illness and treatment and in this way, they have better adherence to treatments and recommendations of treatment from staff.

The researchers did not assess the illness representation of the patients. This study used an appropriate period of time for each session which was 45 minutes but each session needed a skilled advisor and the study did not provide details on how the advisor was trained. The researchers followed up the patients after 8 weeks of the interventions by using the ESRD-AQ. However, the study did not clearly mention the way the patients' representation were shaped to make them adhere to the treatment. The study was also conducted in a cold region, thus the weather and cultural aspects are quite different from Malaysia.

Illness Representation Promoting Program

The illness representation promoting program is based on the representational approach to patient education, which is based on CSM and CCM. Representational approach to patient education was developed by Donovan and Ward (2001). The CSM was used to develop a representational approach to patient education. Moreover, the process of the CCM was used to shape current misconceptions, confusion and/or gaps through giving information, which is intelligible, plausible and fruitful. Before giving information, the individual's current representation about his or her illness needs to be understood. Thus, the information provided can be specific and appropriate with the individual's needs in order to fill the gaps, clarify the confusion, and replace the misconceptions.

At the beginning, the representational approach to patient education has five steps (Donovan & Ward, 2001). First, representation assessment, the individual describes his or her illness along the five dimensions of cognitive illness representation. The five

dimensions of cognitive illness representation are identity, cause, timeline, consequences and cure/controllability (Leventhal et al., 1980). Second, identifying and exploring the gaps, misconception and confusion, the individual thinks and describes his or her experiences that could cause any gaps, misconceptions and/or confusion of his or her illness representation. Third, creating conditions for conceptual change, the individual and the nurse discuss any problems regarding her or his current representation that are misconceptions, gaps and/or confusion, and the consequences of those current illness representation for her or his coping behavior. Thus, the individual can recognize the limitation of his or her current illness representation. Fourth, introducing replacement information, the nurse provides information to fill gaps, replace misconceptions and/or clarify confusion. Fifth, summary, the nurse summarizes the information as the new conception and discusses the benefits of new conception in order to outline the expected outcomes from acting on the new information.

Moreover, Donovan et al. (2007) suggested that, the steps of the representational approach to patient education change to elements because the steps move back and forth between steps in reality. Thus, the individual has opportunities for reflecting and commenting moving back and forth between the steps. This is shown in the study by Ward, Donovan, and Gunnarsdottir (2008). Furthermore, Donovan et al. (2007) also suggested to add two more elements in the representational approach to patient education. The first element, goal setting and planning, the individual identifies important goals regarding his or her health problems and strategies with the nurse in order to achieve the goals. The second element, follow-up reinforcement, the individual evaluates his or her

strategies, which he or she used and makes revision or modification of the strategies for continuing.

From the review, the representational approach to patient education in renal area was not found. However, there were several studies in the adult area that applied this approach. There was one study associated with representational approach to patient education using five steps, the Representational Intervention to Decrease Cancer Pain (RIDcancerPain). Furthermore, there were two studies used seven elements of the representation approach to patient education, including the Individual Representation Intervention to Improve Symptoms Management (IRIS) in older breast cancer survivors, and the Illness Representation Based Education Program (IRBEP) on medication adherence in schizophrenia patients.

The RIDcancerPain was provided by (Ward et al., 2008). This study was conducted in adults with pain related to metastatic cancer. 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 RIDcancerPain provided focus on the individual and face-to-face psycho-educational sessions.

The RIDcancerPain has five steps. Firstly, the representational assessment step, the participant described his/her beliefs about cancer pain along the five dimensions of cognitive illness representation. Secondly, the exploration of the misconception step, the misconceptions were about reporting pain and using analgesics. Thirdly, creating

conditions for the conceptual change step, the researcher and patients discussed the limitations and losses of consequences of these misconceptions that have been identified. Fourthly, the replacement information step, the researcher provided information to replace the misconception. Fifthly, clarification and summary step, they 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.

The study had two groups, an experimental group for the patients who were receiving the RIDcancerPain and the control group for patients who were receiving standard education information (SEI). The measures were taken three times, involving at the baseline (T1), one month later (T2) and two months later (T3). Patients received $10.00 for each set of measures.

The results of the study reported that patients in the RIDcancerPain group had greater changes in their beliefs and some measures of pain severity from before to after the intervention than those in SEI group. Moreover, the RIDcancerPain intervention did not have an effect on coping, pain interference and overall well-being. Furthermore, beliefs mediated the long-term effects on usual pain severity but not the short-term effects, suggesting that patients needed more than one month to integrate the new knowledge into their mental representation. Then, the composition of the sample at time 3 could have been different enough to reveal the relationships that were not seen at time 2. In conclusion, from T1 toT2 and from T1 to T3, patients in the RIDcancerPain showed greater decreases in beliefs about analgesic use as measured by the Barriers Questionnaire-II (BQ) than those

in the control. From T2 to T3, patients in the RIDcancerPain showed that greater decrease in pain severity than those in the control.

For the limitations of the study, the intervention does not provide the step of setting the strategies for the patients in order to achieve their goal and the step of evaluating the strategies. According to teaching strategies in order to change the conception (Posner et al., 1982), the researchers need to provide the practice and test of the new conception and an evaluation whether it is successful or not. It could be adequate to incorporate changes in belief into action and thereby impact on pain-related outcomes. To sum up, it is evident that the intervention could be strengthened in a number of ways, such as by providing additional sessions to support the patient while making changes in their pain management practices.

The IRIS in older breast cancer survivors was provided by Heidrich et al. (2009). These were three pilot studies with the aim to test the feasibility and acceptability of the intervention and test the short-term effects on symptom distress. The outcome is symptoms distress, symptoms management and quality of life. The IRIS is a counseling interview conducted by advanced practice nurses, which focused on individualized sessions. The duration time of the IRIS was different for each individual, which was influenced by the individual's needs. A session was around 30 to 75 minutes. The IRIS consists of seven elements.

In the first pilot study, patients were randomized to the IRIS group as either the experimental group or the usual care group as the control group. Measures were taken

three times; at the baseline, 6 weeks after the intervention (post-test) and 10 weeks after the intervention (follow-up).The results showed that distress decreased significantly from the baseline to the follow-up, the self-care of symptoms more likely changed in the IRIS group, and QOL showed no significant differences by group.

In the second pilot study, patients were randomized to the IRIS group or a delayed IRIS group. The measures were taken six times; at the baseline, 2, 4, 6, 8, and 16 weeks after the intervention. The results reported showed that the symptoms duration was significantly lower in the IRIS group than the control group at eight weeks. Moreover, the patients in the IRIS group were more likely to talk with their health care provider, begin new medical treatment to treat their symptoms and change their self-care of symptoms at 16 weeks. However, QOL had showed no significant difference between the IRIS group and the control group.

In the third pilot study, all patients received the IRIS intervention by telephone. The measures were taken at the baseline, 2, 4, 6, 8, and 16 weeks after the intervention. The results showed that target symptoms distress decreased significantly. It can be shown through symptoms interference and negative moods from symptoms which decreased significantly from the baseline to eight weeks. Moreover, symptoms duration, symptoms interference and negative moods from symptoms decreased significantly from the baseline to 16 weeks. For symptoms management, the result reported that most patients had a change in symptoms management behavior. However, there were no significant changes in QOL. From the third pilot study, it showed that IRIS could be successfully delivered by telephone.

From the three pilot studies, the findings showed that the IRIS intervention is needed for older breast cancer survivors, it has feasibility, the symptoms distress is sensitive to change, and the IRIS can change women's symptoms management behavior and reduce symptoms distress.

The IRBEP was conducted in schizophrenia patients with the objective to examine the effect of the program on medication adherence among Muslim patients with schizophrenia in the Psychiatric Hospital Banda Aceh, Indonesia. The program was developed by Novitayani (2012). Forty patients who met the inclusion criteria were recruited and assigned into two groups using covariate adaptive randomization. The two controlled covariates were family support and dosage frequency. The experimental group received an individualized intervention, the IRBEP. The major processes of the program included (1) representation assessment, (2) identifying and exploring the gaps, misconceptions and confusion related to schizophrenia, (3) creating conditions for conceptual change, (4) introducing replacement information, (5) summarizing, (6) goal setting and planning regarding enhancing medication adherence, and (7) follow-up of the goal and the strategies.

During the program implementation, patients in both groups did not receive other therapy programs. Medication adherence was measured by using the Behavior of Medication Adherence Questionnaire (BMAQ), a self-report questionnaire composed of four subscales, developed by the researcher. The results showed that patients in the experimental group significantly improved their medication adherence behavior after receiving the IRBEP. The medication adherence behavior of the patients in the

experimental group was significantly higher than the patients in the control group at post-test. This study provides empirical evidence on the effectiveness of a representational approach to patient education on the medication adherence behaviors of Muslim patients with schizophrenia.

From these studies outlined, the previous studies that implemented seven process elements and had added setting goals and a strategy element and follow-up element showed that patients had changed their cognitive illness representation and had improved their outcomes. All of the studies had conducted the intervention program for more than two months for each individual except for IRBEP which was conducted over two weeks for each individual.

According to the studies, which used seven elements of a representational approach to patient education, the findings showed the intervention effects on changing behavior and attitude in order to overcome health problems. In the study using the IRIS intervention, the outcomes were measured several times, and the results showed that patient behavior was significantly different after eight weeks. Moreover, the patients were likely to ask the researcher or nurse to visit them many times.

Therefore, this illness representation promoting program was focused on individuality and based on the seven process elements of the representational approach to patient education. The researcher used the seven process elements because it seems to be more useful in changing behavior as seen from previous studies. The study was conducted for four weeks for each patients. The outcome of the program was treatment adherence.

The outcome was measured in pre-test, two weeks after the intervention, and four weeks after the intervention.

Summary

To sum up, the literature review of this study provides information associated with the overview of the ESRD, treatment adherence, CSM, CCM, the interventions for enhancing treatment adherence in patients with ESRD receiving HD, and the illness representation promoting program.

ESRD is a chronic, progressive and debilitating illness. The number of patients with ESRD receiving HD in Malaysia increases from year to year. Treatment adherence is critical to the efficacy of medical recommendations and treatments for patients with ESRD receiving HD. Patients with ESRD receiving HD must adhere to HD, medications, fluid restriction, and dietary restriction. Research has shown that treatment adherence rates were still low.

According to CSM, behavior of adherence can be influenced by cognitive illness representation along the five dimensions of identity, cause, timeline, consequences, and cure/controllability. If there is any misconception, gaps or confusion in the illness representation of the patient, the process of conceptual change can be used to change or replace the misconception, gaps or confusion.

The CCM is a learning process that can change an individual's representation, beliefs or thoughts. The representation approach to patient education is

based on CSM and CCM in which the structure of knowledge and the processes of knowledge change by receiving new information. From the evidence, it has been proven that a representation approach to patient education is effective in changing behavior. In Malaysia, this concept is not well-known and has not yet been applied. Thus, it is necessary to conduct a study to examine the effect of the illness representation promoting program on treatment adherence among patients with ESRD receiving HD in Malaysia.

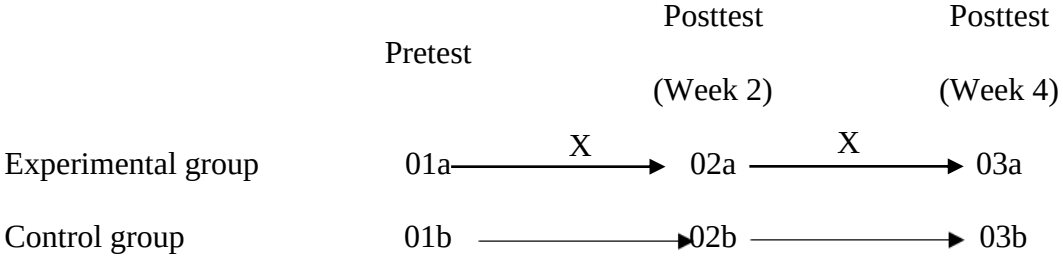
CHAPTER 3

RESEARCH METHODOLOGY

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

Research Design

This study used a quasi-experimental design, pre and posttest with a control group. The objective of this study was to examine the effect of the illness representation promoting program on treatment adherence among patients with ESRD receiving HD. Treatment adherence was measured before and two times after the intervention. Then, the scores were compared between the two groups. In this study, the research design was as follows:



O1a refers to the pretest score on treatment adherence of patients with ESRD receiving HD who received the program

O1b refers to the pretest score on treatment adherence of patients with ESRD receiving HD who received the usual care

X refers to the illness representation promoting program for patients with ESRD receiving HD

O2a refers to the posttest score on treatment adherence of patients with ESRD receiving HD who received the program that measured in the week two

O2b refers to the posttest score on treatment adherence of patients with ESRD receiving HD who received the usual care that measured in the week two

O3a refers to the posttest score on treatment adherence of patients with ESRD receiving HD who received the program that measured in the week four

O3b refers to the posttest score on treatment adherence of patients with ESRD receiving HD who received the usual care that measured in the week four

Variables

The independent variable in this study was the illness representation promoting program. There were two groups: those receiving the illness representation promoting program (the experimental group) and those not receiving the intervention (the control group, receiving usual care). The treatment adherence in patients with ESRD receiving HD was the dependent variables.

Setting

The study was conducted in an outpatient HD unit in Hospital Raja Perempuan Zainab II, Kota Bharu, in the state of Kelantan. This hospital is one of the primary hospital in Kelantan. This hospital is also an educational, medical and health science research hospital. The HD unit of this hospital consists of 20 HD stations which can dialyze 60 patients in one day. Patients were scheduled for three days a week for HD. In the usual practice, the patients were receiving health education regarding HD from the nurses during receiving HD. Sometimes, the patients shortened their dialysis session for various reasons including medical problems, technical problems, life tasks, transportation, and patient decisions with the most common reasons for shortening were medical problems and life tasks.

Population and Sample

Target Population

In this study, the target population was the patients with ESRD receiving HD for at least three months prior to this study at the Hemodialysis Unit, Hospital Raja Perempuan Zainab II, Kota Bharu, Kelantan.

Sample Size

The number of samples in this study was estimated based on power analysis by using the effect size (*d*) from the study of Seyyedrasooli et al. (2013) which examined the effect of illness representation promoting interventions on treatment adherence in

patients with ESRD receiving HD in Iran. The effect size calculation of that study was 0.56 (Appendix G). Based on Polit and Beck (2012), the sample size for a significant level of alpha = .05, power = .80, and effect size (*d*) = .56, 44 patients per group were required to comprise adequate samples. The number of patients were rounded up to 90 patients (45 patients per group) that were recruited in this study in order to ensure that the number of patients is large enough to be a representative of the population.

Inclusion Criteria

The potential patients have been approached if they met the following inclusion criteria: 1) aged 18 and above, 2) able to speak Malay, 3) have been receiving HD three times per week for at least three months prior to the study since it is the appropriate time for the patients to develop their illness representation (Kim, 2009), and 4) willingly participated in the study throughout the course of the study.

Sampling and Group Assignment Procedure

HD centers are a highly social context, and patients at a given dialysis center typically have physically close, sustained, social contact with each other several times a week for years (Christensen et al., 2002). Given the nature of the hemodialysis setting, diffusion of treatment across patients at a given center is a major barrier to utilizing a randomized control-group design. Thus, in the present quasi-experimental design study, patients were divided into groups using the day they receive HD in order to avoid contamination across groups. The patients of the control group were those coming on Saturday, Monday, and Wednesday, whereas the patients of the intervention group were

those who come on Sunday, Tuesday, and Thursday. If there were any patients that change the day of receiving HD, they will remain in their original group.

Instrumentation

Two sets of instruments were used in this study: Illness representation promoting program and data collection instruments. Details are presented sequentially to cover descriptions of the instruments, validity and reliability, and a pilot study.

Illness Representation Promoting Program

The program was an individualized intervention using representational approach to patient education. The goal of this program was to enhance treatment adherence among patients with ESRD receiving HD. The program has seven process components. It took four weeks in three sessions from the beginning of the program implementation to the post-test (Appendix B).

The patients received the illness representation promoting program in the first week, received the follow up session in the second week, and being evaluated at the fourth week. Potential patients were approached by the head nurse and the researcher was introduced to the patients. The purpose of the study was explained to them and those who agreed to participate was given a consent form to sign. The data was collected by the research assistant (RA) within the first 2 hours after the initiation of HD in order to ensure that patients were not suffering from any dialysis-related discomfort (Baraz et al., 2010). The program was given during their dialysis session.

The first session. In the first session during the first week, the researcher worked on the first to the sixth process components. The first session took about 55 minutes to complete. The researcher provided an introduction in order to build rapport with the patients and to help them understand the program. Firstly, representation assessment was conducted by using the OEQ and the Modified BIPQ. The researcher asked the patients to describe their representation and experiences with ESRD based on the five dimensions of cognitive illness representation. The goal of this process component was to understand the patient's representation of illness and to identify gaps, misconceptions and confusion of the patient's cognitive illness representation. It took about 15 minutes to perform the representation assessment.

Secondly, the researcher identified and explored the gaps, misconceptions, and/or confusion with the patients. Two goals need to be achieved; (1) understanding how the patient's experience contributed to the development of his/her misconceptions, confusion, and/or gaps in ESRD, and (2) evaluating the strength of those representation in the patient's life. The researcher identified any issues, such as gaps, confusion, and/or misconceptions, in the patient's representation. In doing so, the patient was asked to think and talk about his or her experiences since getting ESRD that led to any representation that were misconceptions, confusion, and/or gaps along the five dimensions of cognitive illness representation. This process component took about 5 minutes.

Thirdly, the researcher facilitated to the point of creating conditions for conceptual change. The goal was to help the patients to identify and recognize the limitation of their current representation in order to make them dissatisfied with their

current representation. During this process component, the researcher discussed with the patients any problems related to their current representation and the consequences of the representation for their coping behavior. This process component took about 10 minutes.

After that, the researcher introduced replacement information to accommodate the patient's current representation to fill the gaps, correct misconceptions, and clarify and lessen confusion by giving new information using a flipchart. The information included ESRD according to the five dimensions of cognitive illness representation and the treatment. The patient accommodated his or her current representation with the new representation, because the new representation were more intelligible, plausible and fruitful to the patient than his or her current conceptions or representation. This took about 10 minutes.

Subsequently, the researcher summarized and discussed the expected benefits of the new representation from acting on the new information that the patient has received. The goal of this process component was to ensure the patient's understanding of the benefit of the new representation in his or her life if their actions were based on the new representation. This took about 5 minutes. Finally, the researcher and the patient discussed and set goals, and then set the planning strategies for achieving the goals in regards to enhancing the patient's treatment adherence. The aim was to set goals associated with enhancing treatment adherence and the strategies to achieve the goals. This took about 10 minutes.

The second session. The second session was in the second week. In the second session, the researcher followed-up on the goal and the planning strategies set by the patients in the first session. The aim was to evaluate whether the goal has been achieved and that the strategies work in order to enhance treatment adherence. If the strategies did not work, the researcher and the patient evaluated and discussed the barriers and how to overcome the barriers in order to continue fulfilling the patient's goal. The researcher focused on the evaluation of the effectiveness of previous strategies and suggest other strategies if needed in order to achieve the patient's goal for enhancing treatment adherence. The outcome measure which was the treatment adherence measured. This session took about 10 to 30 minutes depended on the patients.

The third session. The third session was the final session that was done in the fourth week. The researcher informed the patients that the program has finished. The treatment adherence was measured again in this session. This sessions took about 10 minutes.

Data Collection Instruments

The following instruments were used in this study: the Demographic Data Questionnaire (DDQ), the Open-Ended Questionnaire (OEQ), the Modified Brief Illness Perception Questionnaire (BIPQ), and the Treatment Adherence Questionnaire (TAQ). The explanation of each instrument was as follows:

The Demographic Data Questionnaire (DDQ). The DDQ was used to collect the patient's demographic data. Data about the patient's age, gender, marital

relationship, religion, educational level, occupation, total monthly income, comorbid diseases and the duration of having ESRD and receiving HD were collected from the questionnaire (Appendix C).

The Open-Ended Questionnaire (OEQ). The open-ended questions consisted of eight questions related to the patient's beliefs about health and illness. The questions were constructed based on the five dimensions of the CSM and were specific to ESRD. The questions were: (a) Do you have a name for your condition? Can you tell me what it is? (b) Do you think your condition will go away or you will have it forever? (c) What do you think your condition does to you? (d) How severe is your condition? (e) What do you think has caused your condition? (f) Do you think you have control over your condition? (g) What do you think about HD? (h) Do you think HD can help your condition? (Appendix D).

There were two purposes of using the OEQ in this intervention: 1) to capture and assess whether the patient's representation was already correct or was incorrect and 2) the finding from the questionnaires were used to guide the illness representation promoting program to shape illness representation in patients with ESRD receiving HD.

The Modified Brief Illness Perception Questionnaire (BIPQ). The Modified BIPQ was used for pre-test and post-test to assess the patient's illness representation along with the dimension of identity of the illness, causal, timeline, control and consequences. The questionnaire has been adapted from Broadbent, Petrie, Main, and Weinman (2006). The original BIPQ consisted of eight items plus part of the causal scale.

Three items were excluded in this study as they measure emotional representation and comprehensibility which were not the focus of this study. The five of the remaining items assessed four dimension of cognitive illness representation which were identity (Item 5), timeline (Item 2), consequences (Item 1), and cure / controllability (Item 3 and 4), rated using a 0 to 10 response scale with 0 indicating inappropriate representation and 10 indicating appropriate representation. The causal representation was assessed by an open-ended question (Item 6) which asked patients to list the three most important causal factors of their illness. To compute the total score, the reversed score items 1 and 5 were added to the scores of items 2, 3, and 4. The total possible scores ranged from 0 – 50. Higher scores reflects a more appropriate illness representation. Regarding the causal representation, patients' answers were grouped into categories (Appendix E).

The purposes of using the Modified BIPQ in this intervention were same as OEQ: 1) to capture and assess whether the patient's representation was already correct or was incorrect and 2) the finding from the questionnaires were used to guide the illness representation promoting program to shape illness representation in patients with ESRD receiving HD.

The Treatment Adherence Questionnaire (TAQ). The TAQ was developed by the researcher based on previous questionnaires regarding adherence from Kim et al. (2011), Novitayani (2012), and Rushe and Gee (1998). The TAQ was used to assess treatment adherence which was the outcome of this study. The TAQ consists of four dimensions of treatment adherence in patients with ESRD receiving HD which were adherence to HD, adherence to medication, adherence to fluid restriction, and adherence to

diet restriction. The adherence to HD dimension has 2 statements which were 1 positive statement (no. 1) and 1 negative statement (no. 2). The adherence to medication dimension has 4 statements with 2 positive statements (no. 4 and no. 5) and 2 negative statements (no. 3 and no. 6). For the adherence to fluid restriction dimension, there were 4 statements with 2 positive statements (no. 7 and no. 9) and 2 negative statements (no. 8 and no. 10). The final dimension was adherence to diet restriction which has 5 statements consisting of 3 positive statements (no. 11, no. 12, and no. 13) and 2 negative statements (no. 14 and no. 15). The response option range for this questionnaire is a 4-point Likert scale from 1 to 4 (1 = never, 2 = sometimes, 3 = most of the time, 4 = all the time). For negative statements, the scores were reversed. The total possible scores range from 15 to 60. A higher score of TAQ indicates higher treatment adherence (Appendix F)

Translation of the Instruments

The OEQ, the Modified BIPQ, and the TAQ were originally developed in English. The instruments were translated from English into Malay language using the back translation technique (Polit & Beck, 2012). Two bilingual experts who have an ability in both English and Malay language and work as English lecturer were translated the instruments. The first bilingual translator translated the instruments from the English version into Malay language. Then, the second bilingual translator translated again the instruments from the Malay version into an English version. Finally, the third bilingual expert, who is a nursing lecturer compared and solved any discrepancies and adjusted the identified disagreements between the original version and the back-translated version.

Validity and Reliability of the Instruments

Validity of the instruments. The content of the instruments including the program, the DDQ, the OEQ, the Modified BIPQ, and the TAQ were validated by three experts. The first expert was a lecturer from the Faculty of Nursing, Prince of Songkla University, who has expertise in ESRD and HD. The second expert was a nephrologist from Songkhlanagarind Hospital. The third expert was a nephrologist from Malaysia. The experts gave suggestions for the instruments, and then the researcher revised the instruments based on the suggestions (Appendix H).

Reliability of the instruments. Since this study was conducted in Malaysia, the researcher used the Malay version in 20 patients with ESRD receiving HD who met the same inclusion criteria as the actual sample to meet statistical assumptions for testing the reliability of the instruments. The test-retest reliability was tested for the stability of the Modified BIPQ. The retest was conducted 2 days after the first test. A correlation coefficient of 0.9 was obtained and this was considered reliable. The TAQ was tested for internal consistency with the acceptable Cronbach's alpha coefficient of 0.83.

Pilot Study

A pilot study is a small-scale version or trial conducted before the major study to see the plausibility of the study (Polit & Beck, 2012). The researcher conducted a pilot study in order to examine the feasibility of the planned intervention procedure. The researcher recruited three patients with ESRD receiving HD who met the inclusion criteria of the present study from those 20 patients involved in reliability testing to receive the illness representation promoting program.

From the pilot study, the three patients had the same times for finishing the first session in the first week. The actions of the researcher and the patients also has been observed during the pilot study. All of the actions of the researcher during the intervention were appropriate and understood by the patients. All of the patients also could follow the instructions from the researcher. Based on this pilot study, the researcher did not change the time spent for each process components. The researcher also did not change any activities since all of the patients satisfied with the intervention process.

Data Collection Procedures

Data collection was conducted in the Hemodialysis Unit, Hospital Raja Perempuan Zainab 2, at Kota Bharu in the state of Kelantan, Malaysia. Data collection was carried out through the following procedures:

Preparation Phase

The preparation phase consisted of the following steps: (1) obtained the official approval from the Research Ethics Committee of the Faculty of Nursing, Prince of Songkla University (PSU), 2) obtained official permission for data collection from the Medical Research and Ethics Committee (MREC), Ministry of Health, Malaysia, 3) prepared all instruments and materials including informed consent, 4) tested validity and reliability of the instruments, 5) conducted the pilot study, and 6) recruited a research assistant (RA).

In this study, a research assistant (RA) was recruited for collecting the pre-test and post-test data. The RA was a nurse who has graduated with a Bachelor's Degree

in Nursing and did not worked in the unit. There were three steps of training the RA. Firstly, the researcher explained the objective of the study, the protocol and the instruments used in this study. Secondly, the researcher provided an explanation about the RA roles and responsibilities. Lastly, the researcher and the RA reviewed the questionnaires. The RA asked about any confusion and the researcher clarified the RA during this process to ensure that she was able to answer any questions from the patients during data collection. This training process took about 5 hours. In this study, the researcher was the only person who implemented the intervention and the RA was the person who collected the data and was not informed if the patient was in the control or the experimental group.

Implementation Phase

The implementation phase started from the selection of the patients. The patients with ESRD receiving HD who met the inclusion criteria were introduced to the researcher by the head nurse. The patients received a letter of informed consent from the researcher. They signed it to state that they agreed to participate in this study. Before that, the researcher provided an explanation of the study including the purpose, benefits, confidentiality, and the procedures to the patients. The researcher also informed the patients that they had the right to withdraw from this study at any time without any negative consequences.

After the patient signed the informed consent form, the RA collected the data using the DDQ and the TAQ. Then, the patients in the experimental group received the illness representation promoting program from the researcher. The posttest data of the

TAQ was collected by the RA in the second and fourth week. For the patients in the control group, they received the same intervention if they were interested after the second posttest.

After collected the data, coding was used to maintain the patient's anonymity. Name and other information from the patients were only for the researcher and all of the data will be destroyed at the end of the study. The details of the implementation of data collection procedure of this study were presented in Figure 2.

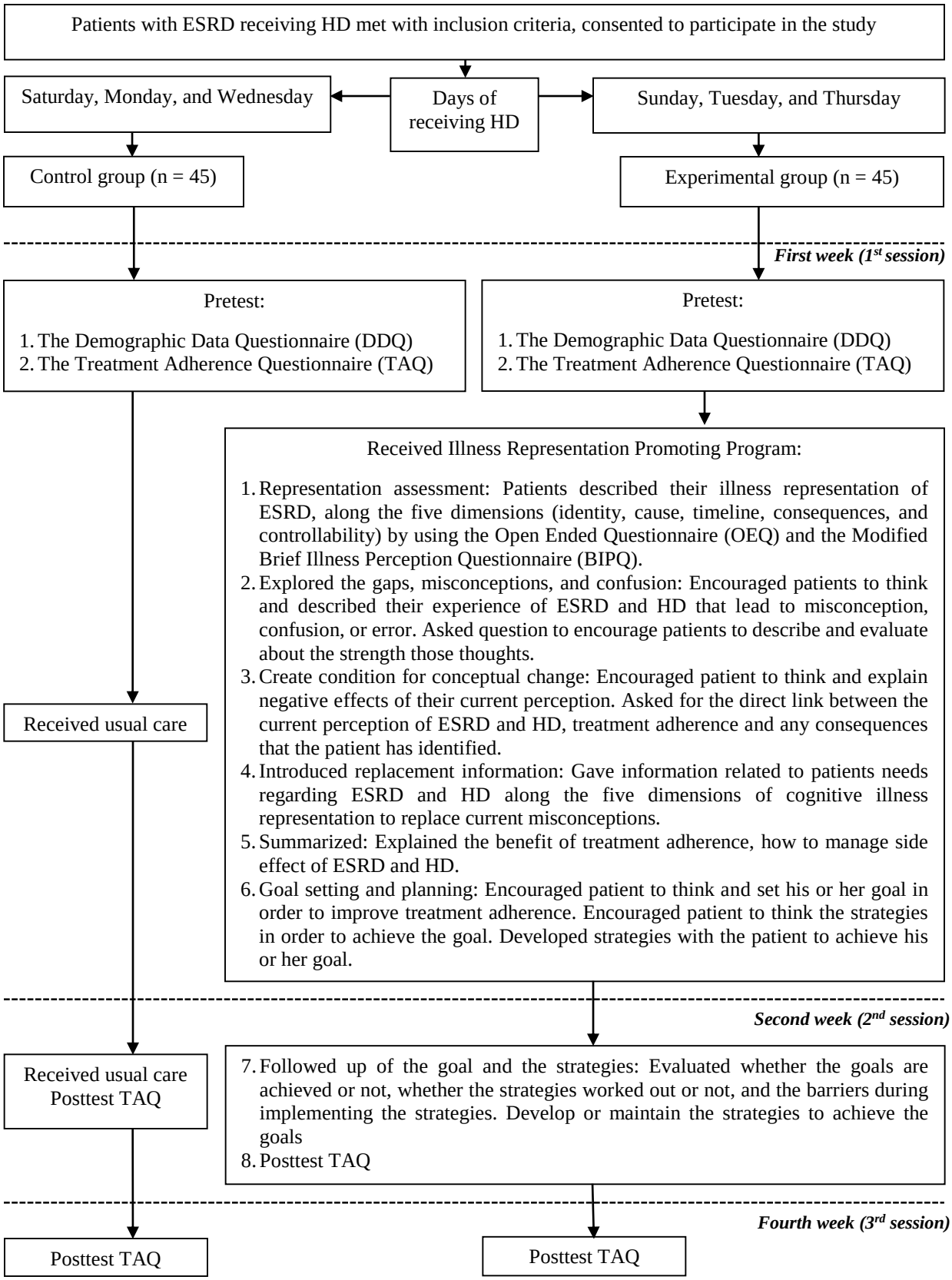


Figure 1. *Data Collection Procedures*

Ethical Consideration

The researcher obtained permission for data collection from the Research Ethics Committee of the Faculty of Nursing, Prince of Songkla University, Thailand, and from the Medical Research and Ethics Committee (MREC), Ministry of Health, Malaysia. The head nurse asked the potential patients with ESRD receiving HD who met the inclusion criteria to participate in this study and if the patients agreed, the head nurse introduced the researcher to the patients. The researcher explained to the patients that they had the right to participate or not to participate. Moreover, the researcher also gave information about their right to withdraw at any time during the study without any negative consequences. The researcher explained the purpose of the study, procedures, risk and comfort, and the benefit of the study. The patients who agreed to participate in this study were given written informed consent (Appendix A). For the patients in the experimental group, the researcher explained the procedures of the illness representation promoting program. The patients in the control group received the intervention without follow-up after the second posttest in fourth week, if the patients interested. All of the information from the patients and the identity of the patients were kept confidential. The researcher used a coding system to identify the patients to maintain anonymity.

Data Analysis

The researcher used descriptive and inferential statistics to analyze the data to answer the research questions. Descriptive statistics were used to analyze and describe the demographic and clinical characteristics of the patients by using frequencies, percentages, mean, range, median, interquartile range, and standard deviation. The equivalence of the proportion of demographic and clinical characteristics data between the control group and the experimental group was tested using Independent t-test, Chi-Square, and Likelihood Ratio. In addition, the Fisher's exact test was used as an alternative statistical analysis to test the equivalence of the proportion of demographic and clinical characteristics data between the control group and the experimental group for two by two contingency table when expected frequencies were too small.

For the inferential statistics, the researcher planned for Independent *t*-test for the between-group effect of the intervention. Before the appropriate statistical analysis was performed, the researcher examined the assumptions of normality and homogeneity of variance of the variables. The assumption of normality was examined using skewness and kurtosis divided by its standard error values. Testing assumption showed that the data set of treatment adherence in the experimental group were not normally distributed, determined by the values were not in the range of ± 3. The homogeneity of variance was examined using Levene's test. The variables met the assumption, determined by the significance score of Levene's test ($p > .05$). Therefore, a Mann-Whitney U Test was conducted to determine the between-group effect of the intervention.

While for the within-group effect of the intervention, the researcher planned for One Way Repeated Measure ANOVA. Since the data violated the assumption of normality, the Friedman's Test with post hoc analysis by Wilcoxon signed-rank tests was conducted to determine the within-group effect of the intervention.

CHAPTER 4

RESULTS AND DISCUSSION

This chapter presents the results of the study and discussion of the findings as follows: 1) patients' characteristics, 2) the cognitive illness representation, and 3) the effect of illness representation promoting program on treatment adherence.

Results

Patients' Characteristics

The demographic characteristics data of the patients are presented in Table 2. Between the experimental and control group, all demographic characteristics of the subjects were not significantly different. The majority of the patients from both groups were aged less than 59 years old (84% in the experimental group and 82% in the control group). More than half of the participants were female in the experimental group (53%) while in control group, the majority were male (67%). Most of the patients in both groups were married (71% in the experimental group and 73% in the control group). The majority of the patients were unemployed in both groups (60% in the experimental group and 53% in the control group). This factor contributed to their monthly income, which shows that more than half of the patients in the experimental group, 58% and 47% patients in the control group had an income of less than 1,500 Malaysia Ringgit (RM). This was equal to about 14,000 Thai Baht. More than half of the patients in both groups were living together with 3 to 4 family members (58% in the experimental group and 53% in the control group). More than half of the patients in

both groups also had family members who prepared their diet (60% in the experimental group and 67% in the control group).

Table 2

Frequency, Percentage, Means, and Standard Deviations of the Patients in the Experimental and the Control Groups Classified by Demographic Characteristics (N = 90)

Characteristics	Experimental Group (*n* = 45)		Control Group (*n* = 45)		Statistic test value	*p*
	n	%	*n*	%		
Age (Year) (*M = 47.69, SD = 12.76, Min - Max = 20-77 years)*					.08[a]	.78
Less than 59	38	84	37	82		
60 and above	7	16	8	18		
Gender					3.67[b]	.06
Male	21	47	30	67		
Female	24	53	15	33		
Marital status					1.66[c]	.64
Single	9	20	10	22		
Married	32	71	33	73		
Divorced / Separated / Widow / Widower	4	9	2	5		
Educational level					1.86[c]	.60
No formal education	1	2	1	2		
Primary school	7	16	3	7		
Secondary school	25	57	28	62		
Tertiary school or above	12	27	13	29		
Occupation					3.51[c]	.48
Full-time	14	31	19	42		
Part-time	1	2	0	0		
Retired	3	7	2	5		
Unemployed	27	60	24	53		

Note. [a] = Independent *t*-test, [b] = Fisher's Exact Test, [c] = Likelihood Ratio, *M* = Mean, *SD* = Standard Deviation

Table 2 (continued)

Characteristics	Experimental Group (n = 45)		Control Group (n = 45)		Statistic test value	*P*
	n	%	*n*	%		
Monthly income					8.76[d]	.07
< RM1,500	26	58	21	47		
RM1,501 – RM2,500	8	18	8	18		
RM2,501 – RM3,500	3	7	0	0		
RM3,501 – RM4,500	3	7	10	22		
> RM4,501	5	10	6	13		
Family living together					1.76[d]	.42
1 to 2 persons	11	24	8	18		
3 to 4 persons	26	58	24	53		
> 5 persons	8	18	13	29		
Diet prepared by					2.05[d]	.36
Patient	18	40	14	31		
Family members	27	60	30	67		
Maid	0	0	1	2		

Note. [d] = Likelihood Ratio, *M* = Mean, *SD* = Standard Deviation, RM = Malaysia Ringgit

Table 3 presents the clinical characteristics of the patients in this study. All the clinical characteristics of the patients between the experimental and control group were not significantly different. More than half of the patients in the experimental group (55%) and the control group (53%) had been diagnosed with renal disease for more than 5 years. Almost half of the patients in both groups also had been receiving HD treatment for more than 5 years (47% in the experimental group and 44% in the control group). The majority of the patients in both groups were not receiving other renal replacement therapies (71% in the experimental group and 82% in the control group). In the experimental group, 49% of the patients had hypertension while 52% of the patients in control group had hypertension.

Table 3

Clinical Characteristics of the Patients in the Experimental and the Control Groups (N = 90)

Characteristics	Experimental Group (*n* = 45)		Control Group (*n* = 45)		Statistic test value	*p*
	n	%	*n*	%		
Length of diagnosed with renal disease (*M = 89.28, SD = 66.19, Min - Max = 7-288)*					.71[a]	.87
Less than 1 year	4	9	3	7		
1 – 3 years	8	18	7	16		
4 – 5 years	8	18	11	24		
More than 5 years	25	55	24	53		
Length of receiving HD (*M = 74.00, SD = 60.48, Min-Max = 4-276)*					1.23[a]	.75
Less than 1 year	5	11	7	16		
1 – 3 years	8	18	5	11		
4 – 5 years	11	24	13	29		
More than 5 years	21	47	20	44		
Other renal replacement therapies					2.55[a]	.28
No	32	71	37	82		
Peritoneal dialysis	12	27	8	18		
Kidney transplant	1	23	0	0		
Comorbidities					3.47[a]	.33
No	7	16	2	4		
Diabetes mellitus	16	35	20	44		
Hypertension	22	49	23	52		

Note. [a] = Likelihood Ratio

The Cognitive Illness Representation

The OEQ and the Modified BIPQ were used to examine illness representation and guide the illness representation promoting program, particularly to shape illness representation in patients with ESRD receiving HD in the experimental group. The Modified BIPQ scores of patients in the experimental group are summarized in Table 4. Mean scores were higher in the dimension of timeline and cure / controllability than scores from other dimension. The high mean scores on the

dimension of timeline and cure / controllability indicate that most of the patients understood their ESRD as permanent illness rather than temporary illness and believed they could control the illness. The total illness representation mean score was 37.02 (SD = 4.17). For the causal dimension, the most common answers were hypertension, diabetes mellitus and foods.

In addition, the patients also were asked to answer the OEQ. Result revealed that for the identity dimension, the common answers from the patients regarding the symptoms that they experienced and related to ESRD were breathlessness, edema, and fatigue. For those who experienced breathlessness, the symptoms were the major cause of seeking a medical opinion and a diagnosis was quickly given by one of the patient:

> *"I think when I felt hard to breath, it was the sign of fluid overload and it was related to my illness."*

Regarding the treatment that they received, all of them answered that the HD were very helpful for them to continue their lives. Identification with the symptoms and the treatment indicated that identification with the illness had been made.

For the timeline representation, all of the patients thought that the illness was long term and will be with them forever. The answers from the OEQ were consistent with the score in the Modified BIPQ. The long-term course was usually explained in absolute terms of years since diagnosis or since started HD. One of the patient stated:

"I have suffered from ESRD for 5 years and has been on HD for 3 years. It will last forever with me, until I die or receive kidney transplant from others."

Regarding the consequences dimension of ESRD in the OEQ, more than half of the patients said they did not have energy or fatigue either before receiving HD or after receiving HD. Patients described symptoms of fatigue that decreased their mobility and affected the ability to socialize. Responses also combined the effects of ESRD and side effect of HD. One patient commented:

"I always feel tired and no energy to do anything. Therefore, my activity also limited."

One patient mentioned that the ESRD was very severe because he felt pain, could not work, felt fatigue after HD, and need to receive HD forever:

"I always feel pain in my body and joint. Sometimes I feel very itchy and cannot sleep."

Other patient commented:

"Because of ESRD and receiving HD, I cannot work because no employer want to hire me since I need to come to hospital three times every week."

All of the patients answered for the cure / controllability dimension that they believed they can control their illness. One patient stated:

"I believed that I have control over my illness because I can control the amount of water to drink."

All of them also answered that HD really helpful to them and help them to live. One patient commented:

> *"I am very thankful that HD can help me to continue my life."*

Regarding the causal dimension, most of the patients in the experimental group said that their comorbidities were the cause of ESRD. Variations included hypertension and diabetes mellitus. Six patients related the causes to eating behavior including eating too much, eating the wrong foods, eating foods high in fat, eating too much meat, or eating on an irregular schedule. Three of the patients related the cause of the ESRD to the medications that they took for their comorbidities. Some of them were very clear about their perceptions of the etiology, as mentioned by one patient:

> *"The reasons for having ESRD according to my point of view are: Number one, old age, which means that the inner organs become weak. Plus, I like to eat foods high in fat and eating on irregular schedule."*

Table 4

Possible Scores, Min – Max, Mean, and Standard Deviations of the Modified BIPQ in the Experimental group (n = 45)

Dimension	Possible Score	Min - Max	M	SD
Total	0 – 50	29 - 47	37.02	4.17
Identity	0 – 10	3 – 10	6.41	1.59
Timeline	0 – 10	10 - 10	10.00	0.00
Consequences	0 – 10	0 - 9	3.73	2.63
Cure / controllability	0 – 20	13 - 20	16.88	1.38

The Effect of Illness Representation Promoting Program on Treatment Adherence

Between group effect. Since the assumptions were violated, the Mann-Whitney U Test was conducted to determine the between-group effect of the Illness Representation Promoting Program on treatment adherence.

Hypothesis 1: The treatment adherence mean scores in patients that received the illness representation promoting program were higher than the patients that received usual care. This hypothesis was supported.

As shown in Table 5, the total score of treatment adherence in the experimental group was higher (*Mdn = 54, IQR = 6*) than the control group (*Mdn = 52, IQR = 5*) at fourth week after received the intervention. There were no statistically significant differences found in total score of treatment adherence at before receiving the intervention ($Z = -0.34$, $p = .73$) and second week after received the intervention

(*Z = -0.35, p = .72*) between patients in the experimental group and the control group. There was a statistically significant difference in total score of treatment adherence at fourth week after received the program among patients in the experimental group and the control group (*Z = -2.97, p = .00*).

Regarding the dimensions of treatment adherence, no statistically significant differences were found in adherence to HD, adherence to medications, adherence to fluid restriction, and adherence to dietary restriction at before intervention (*Z = -1.07, p = .29, Z = -0.70, p = .95, Z = -0.16, p = .87,* and *Z = -0.40, p = .69,* respectively) and second week after receiving the intervention (*Z = -0.92, p = .36, Z = -0.04, p = .97, Z = -1.12, p = .26,* and *Z = -0.64, p = .53,* respectively). At fourth week after the intervention, there were no statistically significant differences were found in adherence to HD, adherence to medications, and adherence to fluid restriction (*Z = -0.30, p = .76, Z = -1.83, p = .07,* and *Z = -1.53, p = .13,* respectively). There was a statistically significant difference in adherence to dietary restriction at fourth week after receiving the program among patients in the experimental group and the control group (*Z = -3.12, p = .00*).

Table 5

Min –Max, Median, Interquartile Range, Mean Rank, and Sum Rank of Treatment Adherence of Patients in the Experimental and the Control Groups Before Intervention, 2nd Week After Intervention, and 4th Week After Intervention Using Mann-Whitney U Test (N = 90)

	Experimental Group (n = 45)					Control Group (n = 45)					*Z*	*p*
	Min-Max	Mdn	IQR	Mean Rank	Sum Rank	Min-Max	Mdn	IQR	Mean Rank	Sum Rank		
Before intervention												
Total	28 – 56	48	7	44.56	2005.0	42 – 59	49	6	46.44	2090.0	-0.34	.73
Adherence to HD	5 - 8	7	1	42.89	1930.0	5 – 8	7	1	48.11	2165.0	-1.07	.29
Adherence to Medications	6 - 16	15	1	45.67	2055.0	10 - 16	15	1	45.33	2040.0	-0.70	.95
Adherence to Fluid Restriction	5 - 16	13	4	45.94	2067.5	8 - 15	13	3	45.06	2027.5	-0.16	.87
Adherence to Dietary Restriction	10 - 18	15	3	44.42	1999.0	10 - 20	15	3	46.58	2096.0	-0.40	.69

Table 5 (continued)

	Experimental Group (n = 45)					Control Group (n = 45)					*Z*	*p*
	Min-Max	Mdn	IQR	Mean Rank	Sum Rank	Min-Max	Mdn	IQR	Mean Rank	Sum Rank		
After intervention (2nd week)												
Total	33 – 56	52	5	46.47	2091	43 - 59	52	5	44.53	2004	-0.35	.72
Adherence to HD	7 - 8	7	1	43.29	1948.0	6 – 8	8	1	47.71	2147.0	-0.92	.36
Adherence to Medications	11 - 16	15	1	45.59	2051.5	12 - 16	15	1	45.41	2043.5	-0.04	.97
Adherence to Fluid Restriction	5 - 16	14	3	48.52	2183.5	8 - 15	13	2	42.48	1911.5	-1.12	.26
Adherence to Dietary Restriction	10 - 19	15	3	43.78	1970.0	10 - 20	16	3	47.22	2125.0	-0.64	.53

Table 5 (continued)

	Experimental Group (n = 45)					Control Group (n = 45)					*Z*	*p*
	Min-Max	Mdn	IQR	Mean Rank	Sum Rank	Min-Max	Mdn	IQR	Mean Rank	Sum Rank		
After intervention (4th week)												
Total	39 – 58	54	6	53.64	2414	43 - 59	52	5	37.36	1681	-2.97	.00
Adherence to HD	7 - 8	8	1	46.22	2080.0	6 – 8	8	1	44.78	2015.0	-0.30	.76
Adherence to Medications	11 - 16	15	1	49.97	2248.5	12 - 16	15	1	41.03	1846.5	-1.83	.07
Adherence to Fluid Restriction	9 - 16	14	3	49.64	2234.0	8 - 15	13	2	41.36	1861.0	-1.53	.13
Adherence to Dietary Restriction	12 - 20	17	3	53.99	2429.5	10 - 20	16	3	37.01	1665.5	-3.12	.00

Within-group effect. A Friedman's Test was conducted in order to determine the within-group effect of the Illness Representation Promoting Program on treatment adherence in the experimental group. The score of treatment adherence before the intervention, second week after the intervention and fourth week after the intervention of experimental group were examined with post hoc analysis by Wilcoxon signed-rank tests.

Hypothesis 2: The treatment adherence mean scores after received illness representation promoting program were higher than before received it in the experimental group. This hypothesis was supported.

As shown in Table 6, the treatment adherence total score of the patients in the experimental group fourth week after the intervention (*Mdn = 54, IQR = 6*) were significantly higher than before the intervention (*Mdn = 48, IQR = 7*) and second week after the intervention (*Mdn = 52, IQR = 5*), $\chi^2 = 83.04$, $p = .000$. There was statistically significant difference of treatment adherence total score ($\chi^2 = 83.04$, $p = .000$) across the time. Regarding the dimensions of treatment adherence, statistically significant differences also were found in adherence to HD ($\chi^2 = 27.04$, $p = .000$), adherence to medications ($\chi^2 = 32.90$, $p = .000$), adherence to fluid restriction ($\chi^2 = 39.20$, $p = .000$), and adherence to dietary restriction ($\chi^2 = 71.36$, $p = .000$) across the time. Post hoc analysis by Wilcoxon Signed-Rank Tests was conducted with a Bonferroni correction applied. A Bonferroni correction was applied when run multiple tests to establish a more conservative alpha level (Polit & Beck, 2012). In this study, the alpha level was set at .05 and there were three separate tests. Therefore corrected alpha needed to reject the null hypothesis for all tests would be .017.

A Wilcoxon Signed-Rank Test indicated that treatment adherence total scores at second week after intervention were statistically significant higher than before intervention (*Z = -5.34, p = .000*). The treatment adherence total scores at fourth week after intervention were also statistically significant higher than before intervention (*Z = -5.86, p = .000*) and second week after intervention (*Z = -5.48, p = .000*). (Appendix J)

Regarding the dimensions of treatment adherence, only adherence to dietary restrictions at fourth week after intervention were statistically significant higher than before intervention (*Z = -5.68, p = .000*) and second week after intervention (*Z = -5.16, p = .000*). The adherence to dietary restriction at second week after intervention also statistically significant higher than before intervention (*Z = -4.34, p = .000*). The other dimensions of treatment adherence; adherence to HD, adherence to medications, and adherence to fluid restriction were statistically significant equal between all of the time (Appendix J).

Table 6

Comparison of the Treatment Adherence Before Intervention, 2nd Week After Intervention, and 4th Week After Intervention Using Friedman's' Test (N = 90)

	Before Intervention			After intervention (2nd week)			After intervention (4th week)			χ^2	*p*
	Mdn	IQR	Mean Rank	Mdn	IQR	Mean Rank	Mdn	IQR	Mean Rank		
Experimental Group (n = 45)											
Total	48	7	1.09	52	5	1.98	54	6	2.93	83.04	.000
Adherence to HD	7	1	1.68	7	1	2.07	8	1	2.26	27.04	.000
Adherence to Medications	15	1	1.60	15	1	2.04	15	1	2.36	32.90	.000
Adherence to Fluid Restriction	13	4	1.53	14	3	2.16	14	3	2.31	39.20	.000
Adherence to Dietary Restriction	15	3	1.27	15	3	1.90	15	3	2.83	71.36	.000

Table 6 (continued)

	Before Intervention			After intervention (2nd week)			After intervention (4th week)			χ^2	*p*
	Mdn	IQR	Mean Rank	Mdn	IQR	Mean Rank	Mdn	IQR	Mean Rank		
Control Group (n = 45)											
Total	49	6	1.16	52	5	2.42	52	5	2.42	68.76	.000
Adherence to HD	7	1	1.78	8	1	2.11	8	1	2.11	14.29	.001
Adherence to Medications	15	1	1.71	15	1	2.14	15	1	2.14	22.53	.000
Adherence to Fluid Restriction	13	3	1.76	13	2	2.12	13	2	2.12	18.62	.000
Adherence to Dietary Restriction	15	3	1.36	16	3	2.32	16	3	2.32	50.97	.000

Discussion

The discussion focuses on two parts based on the results and the hypotheses testing of this study, involving the patients' characteristics and the hypotheses testing of the effects of the illness representation promoting program on treatment adherence among patients with ESRD receiving HD.

Patients' Characteristics

Demographic characteristics. This study found that the majority of patients from both groups were men and were aged less than 59 years old. This data is supported by Lim et al. (2013) who reported that the majority of patients with ESRD receiving HD in Malaysia were in the age group less than 59 years old and most of the patients were males. This data is also supported by the earlier studies (Ibrahim et al., 2011; Kim & Evangelista, 2010; Seyyedrasooli et al., 2013). The earlier studies also found that most of the patients from both groups were married which is the same as this study with 71% from experimental group and 73% from control group being married. In this study, more than half of the patients from both groups had a secondary school background (57% in the experimental group and 62% in the control group) with more than half of them being unemployed (60% in the experimental group and 53% in the control group). The findings are similar with previous studies (Chan et al., 2012; Ibrahim et al., 2011; Kim & Evangelista, 2010; Seyyedrasooli et al., 2013). Based on the demographic findings, the majority of the patients had poor socioeconomic status as reflected in high levels of unemployment, low monthly incomes, and low educational levels. In conclusion, the patient's demographic characteristics in this study were similar with other studies. In this

study, there were no significant differences in the demographic characteristics between the patients in the experimental group and control group.

Clinical characteristics. The majority of the patients in this study had been diagnosed with renal disease and had been receiving HD for more than 5 years. These findings are congruent with a previous study of Chan et al. (2012). The majority of the patients in both groups were not receiving other renal replacement therapies (71% in the experimental group and 82% in the control group). In the experimental group, 49% of the patients have hypertension while 52% of the patients in control group have hypertension. These findings are supported by the study done by Lim et al. (2013). In this study, there was no significant difference in the clinical characteristics between the patients in the experimental group and control group.

The Effect of the Illness Representation Promoting Program on Treatment Adherence

The first hypothesis, the treatment adherence mean score in patients that received the illness representation promoting program was higher than the patients that received usual care was supported (Table 5). There was no significant differences found in total score of treatment adherence at second week after received the intervention between patients in the experimental group and the control group. This finding is comparable with the study by Ward et al. (2008). In their study, they found that the patients needed more time to integrate the new representation after receiving the illness representation promoting program. Therefore, in this present study, the significant difference only can be seen at week four after the intervention.

Regarding the dimension of treatment adherence, only adherence to dietary restriction showed statistically significant difference at week four after intervention in the experimental group. The other dimensions of treatment adherence; adherence to HD, adherence to medications, and adherence to fluid restriction showed no statistically significant differences at week 2 and week 4 after intervention in the experimental group. Results of this study were different from previous study done by Seyyedrasooli et al. (2013). They focused on illness representation interventions in order to determine the effect of the interventions on treatment adherence in patients with ESRD receiving HD. They found the improvement of treatment adherence of the patient adherence to medication regimen, adherence to diet regimen, adherence to liquid limitation and the shortening of dialysis sessions dimensions. Findings from the current study are different might be because the patients were from a different geographical location, different study setting and different measurement instruments of the treatment adherence. These results also might be related to the difficulty in following the treatment recommendations for fluid and dietary since this required more willpower from the patients (Kim & Evangelista, 2010).

The second hypothesis, the score of treatment adherence was significantly higher after receiving the illness representation promoting program than before receiving the intervention in the experimental group also was supported (Table 6). This proved the importance of addressing patients' illness representation in order to improve treatment adherence. It seemed that representation assessment, explored the gaps, misconception, and confusion were useful to identify issues pertinent to the patient, thereby setting the stage for addressing concerns in a highly contextual manner. The program was highly

individualized to the patient needs and requires an active involvement of the patient. However, the significant difference also can be found in the control group. This was because patients in the control group also still received usual care from the nurses, which was including health education from time to time. Furthermore, the hemodialysis unit is highly integrated nature and the frequent and prolonged interaction between patients. Therefore, there might be the possibility that some information of the program have been told by the patients in the experimental group to the patients in the control group.

The results of this study provide empirical evidence to support the representational approach to patient education, which was based on CSM and CCM. According to Leventhal et al. (1980), the cognitive illness representation can influence the individual's behavior to deal with an illness. In this current study, the patients changed their adherence behavior when their representation about their illness changed. Regarding the CCM, in order to successfully change a patient's conception, a linear process was required. The process started from dissatisfaction with the current representation, followed by finding intelligible and plausible information for the new representation, and then applying the new representation to overcome the problem which resulted in a fruitful outcome (Posner et al., 1982).

In this study, the patients received an individualized intervention using the representational approach to patient education. The patients were assisted by the researcher to work on seven process components of illness representation promoting program in order to enhance their treatment adherence. From the patients responds, the researcher would

understand their representation of illness and could identify gaps, misconceptions and confusion of the patient's cognitive illness representation.

The researcher identified and explored the patients' experience that contributed to the development of his/her misconceptions, confusion, and/or gaps in ESRD. Experience is one of the stimuli that involved in the development of illness representation (Leventhal et al., 1980). The patients were asked to think and talk about his or her experiences since getting ESRD that may have led to any representation that are misconceptions, confusion, and/or gaps.

Posner et al. (1982) mentioned that the individuals will be dissatisfied or refused their current representation if they recognized the negative effect of it. Therefore, they would like to change the current representation to a new one. In this current study, the patients asked more regarding their health problem and the way to overcome it. According to Donovan et al. (2007), this was the right time for the researcher to introduce a new representation to the patients. The patients accommodated his or her current representation with new representation, because the new representation was more intelligible, plausible and fruitful to the patient than his or her current conceptions or representation (Posner et al., 1982).

Summarized and discussed the expected benefits of the new representation from acting on the new information was done to ensure the patient's understanding of the benefits of the new representation in his or her life if his or her actions were based on the new representation. Finally, the researcher and the patient discussed and set goals, and

planned the strategies for achieving the goals in regards to enhancing the treatment adherence of the patient. The new representation that already been perceived by the patients would encourage them to adhere to the treatment. According to Leventhal et al. (1980), in order to set an individual's behavior to overcome a health problem, the individual needs specific goal setting and action planning. In this current study, the researcher had to understand the patient's goal before being able to help the patient to set and choose the strategies that would be useful for him or her to achieve his or her goals. The patients would implement the strategies without any force from others because they set the goals and the strategies themselves (Novitayani, 2012).

The researcher evaluated and followed-up on the goal and the strategies set by the patients. If the strategies did not work, the researcher and the patient evaluated and discussed the barrier and the way to overcome the barrier in order to continue fulfilling the patient's goal. The researcher focused on the evaluation of the effectiveness of previous strategies and suggested other strategies if needed in order to achieve the patient's goal for enhancing treatment adherence.

This illness representation promoting program which was based on a representational approach to patient education was significantly effective to enhance treatment adherence among patients with ESRD receiving HD. The findings of this study also showed that this intervention was feasible to patients with ESRD receiving HD in order to overcome the problem of adherence in this population.

CHAPTER 5

CONCLUSION AND RECOMMENDATIONS

Conclusion

This quasi-experimental study aimed to examine the effect of the illness representation promoting program on treatment adherence among patients with ESRD receiving HD in Kota Bharu, Kelantan, Malaysia. The patients were divided into groups using the day they received HD in order to avoid contamination across groups. The patients of the control group were those coming on Saturday, Monday, and Wednesday, whereas the patients of the intervention group were those who came on Sunday, Tuesday, and Thursday. Ninety patients with ESRD receiving HD who met the inclusion criteria were recruited for this study. The Illness Representation Promoting Program was an individualized intervention using a representational approach to patient education. The goal of this program was to enhance treatment adherence. The patients in the experimental group had received the intervention which consists of seven process components.

Before implemented the intervention, each patient was asked to respond to the Demographic Data Questionnaire (DDQ), the Open-Ended Questionnaire (OEQ), the Modified Brief Illness Perception Questionnaire (B-IPQ), and the Treatment Adherence Questionnaire (TAQ) to provide pre-test data. After that, the intervention was given to the subjects in the experimental group. At second week, the patients in the control and experimental groups were asked to answer the TAQ for the first posttest data collection.

The patients also were asked to respond to the TAQ at fourth week after intervention for the second posttest data.

The instruments in this study were validated by 3 experts in ESRD. Test-retest reliability was done for the Malay version of the Modified BIPQ. A correlation coefficient of about 0.9 was obtained and this was considered reliable. For TAQ, internal consistency was tested in 20 patients with ESRD receiving HD who met the same inclusion criteria as the actual sample to meet statistical assumption. Cronbach's alpha coefficient revealed a reliability score of 0.83.

Descriptive and inferential statistics were used to analyze and describe the data in this study. Descriptive statistical analysis which included frequencies, percentages, means, and standard deviations were used to describe the demographic and clinical characteristics. The assumptions of normality and homogeneity were checked. Independent *t*-test, Chi square test, Fisher's Exact Test, and Likelihood Ratio were used to examine the equivalence of the demographic and clinical characteristics between the experimental group and control group. For the inferential statistics, a Mann-Whitney U Test was conducted to determine the between-group effect of the intervention while the Friedman's Test with post hoc analysis by Wilcoxon signed-rank tests was used to determine the within-group effect of the intervention.

This study had two main results. Firstly, the patients in the experimental group had better treatment adherence than those in the control group at week four ($Z = -2.97$, $p = .00$). Secondly, the treatment adherence mean score at week four was

significantly higher than before the intervention for patients in the experimental group ($Z = -5.34, p = .00$). According to these results, the illness representation promoting program had been evident in its effectiveness in enhancing treatment adherence among patients with ESRD receiving HD.

Strengths and Limitations

The present study was a quasi-experimental with pretest – posttest design. There were some strengths in this study. This study was a single-blind design. The RA who collected the data at pre-test and post-test did not know whether each patient was in the experimental group or control group. The intervention for the experimental group was given by one researcher only. The intervention also has been tailored for each patient according to the variation of their illness representation.

Despite the strengths, there were also some limitations. Findings from the current study are limited because the patients were from a specific geographical location. Due to the hemodialysis unit setting, the intervention was done while the patients received HD. Therefore, the patients were easily distracted by nursing procedures, doctor's assessment and the other patients. Finally, the TAQ is a newly generated self-report questionnaire used for this study. Although its validity and reliability were supported, it may require further modification depending on future studies, such as its application to a more diverse population in different experimental settings.

Implications and Recommendations

The research findings have clearly supported that the illness representation promoting program does have an effect on enhancing treatment adherence among patients with ESRD receiving HD. There are several recommendations for nursing practice and future research study.

Nursing Practice

The illness representation promoting program has several process components that can be applied to nursing practice to improve adherence behavior. It is a simple nursing practice because the nurses only need to explore and understand a patient's representation about the illness and the treatment, change the misconception, gaps, and/or confusion, and motivate the patient to accept the new representation in order to enhance the adherence behavior of the patient.

Further Research Study

Although this study has positive findings, further research should conduct follow-ups over a longer period of time in order to see whether the treatment adherence of the patient still increases or not.

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APPENDICES

APPENDIX A

Informed Consent Form

Research Information Sheet

My name is Ali Aminuddin Mohd Rasani. I am a lecturer at Kulliyyah (Faculty) of Nursing, International Islamic University Malaysia. Now, I am student of master degree at Faculty of Nursing, Prince of Songkla University, Thailand. As a master student, I am conducting a research study as one of requirements of my study in Thailand. The title of my research study is "The Effect of Illness Representation Promoting Program on Treatment Adherence among Patients with End Stage Renal Disease (ESRD) Receiving Hemodialysis (HD).

This study has been approved by the Research Ethics Committee of Prince Songkla University, Thailand and got permission from Ministry of Health, Malaysia. You are asked to participate in this research study because you have ESRD that diagnosed by physician and history of treatment non-adherence. Your participation will be beneficial to improve the quality of nursing care provided for ESRD patients who do not adhere to their treatment like you in the future.

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

Explanation Procedures

a. Grouping
    1. You will be designed to either the control group or the experimental group according to the day you receiving your HD.
    2. If you are in the control group, you will receive the intervention without follow up after post-test if you willing to receive the intervention.
    3. If you are in the experimental group, you will receive the intervention as individual.
b. Evaluation and forms
    1. You will be asked to fill up the forms about your personal information and health information before the program started.
    2. You will be asked to answer the questionnaire of the Brief Illness Perception Questionnaire (BIPQ) to measure your illness representation.
    3. You also will be asked to answer the questionnaire of the Treatment Adherence Questionnaire (TAQ) to measure your behavior of treatment adherence.
    4. You will be asked to answer the BIPQ and TAQ for three times, which are pre, 2 weeks after the intervention and 4 weeks after the intervention.

Risk and Comfort

There are no known in risk or harm to you to join this study. There is no payment for you to participate in this study.

Benefit

This study will be benefit 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 nurse and other health care professionals to provide the illness representation promoting program in order to enhance treatment adherence in patients with ESRD receiving HD. The data from this research 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 be kept strictly confidential and will be destroyed after completion of the study. Only the researcher and the researcher's advisor are eligible to access the data. Neither your name nor identifying personal information will be used in the report of the study. It will be presented as an oral report during an academic conference and information of the study will be presented in an overview without identifying data of individual.

Participation and Withdrawal from Participation

Your participation in this study is voluntary. Signing the informed consent or agreeing verbally to participate and returning the form given indicate that you understand what is involved and you consent to participate in this study program. In any time of this study, you have right to withdraw from participation. No punishment will be incurred if you decide to withdraw and no any influence to your medical service or medical treatment.

If you have any question, suggestion or cannot participate in this study, you can directly contact the researcher at mobile phone (+60199831107). 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

(Ali Aminuddin Mohd Rasani)

Researcher

RESEARCH INFORMATION SHEET: ILLNESS REPRESENTATION PROMOTING PROGRAM (FOR INTERVENTION GROUP)

If you are in the illness representation promoting program group, you will receive following procedures:

1. At the beginning, you will be asked to fill the forms of the Demographic Data Questionnaire (DDQ), the Modified Brief Illness Perception Questionnaire (BIPQ) and the Treatment Adherence Questionnaire (TAQ). The researcher will help you to complete these three forms.
2. In the next step, after all of the questionnaires complete, you will receive individually intervention of the illness representation promoting program by researcher. The intervention consists of:
    a. Representation assessment
    b. Identifying and exploring the gaps, misconceptions and confusions
    c. Creating condition for conceptual change
    d. Introducing replacement information
    e. Summary
    f. Goal setting and planning
    g. Follow up of the goal and the strategies
3. After you get individually intervention from first process component (a) to sixth process component (f), you will receive a goal setting form that you will use to record your treatment adherence for one week. The goal setting and planning will set up by you and researcher according to your problem.
4. You will receive two times follow up of the goal and the strategies on the second and fourth week after the intervention. The follow up will be conducted by face to face during your HD session. The follow up will be done by researcher.
5. During the follow up, you will be asked to fill the Modified BIPQ and the TAQ again. The researcher will help you to complete it.
6. You have right to withdraw from the program anytime without any punishment.
7. There are no foreseeable risks or harm to you to join in this study.

INFORMED CONSENT FORM

Study Title : The Effect of Illness Representation Promoting Program on Treatment Adherence Among Patients with ESRD Receiving HD

Researcher : Ali Aminuddin Mohd Rasani (Master Student, Faculty of Nursing, Prince of Songkla University, Hatyai, Thailand)

Patient's Name: _____ Age:_____

Patient's Consent

I, _____, was informed of the details of the research entitled as above and was ensured that all of information related to personal information, health history and research design will be kept confidential. If any problem 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 to 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: _____

Researcher's Note

I had given the detailed information of the research article entitled as above to the patient. 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 question and were satisfied with the answer.

Signature: _____ (Researcher) Date: _____

APPENDIX B

Protocol of the Illness Representation Promoting Program

Process Components	Objectives	Method	Actions	
			Researcher	Patient
Introduction	Before patient participates in the program, patient a. knows researcher b. has relationship and trusts the researcher c. knows and understands the program	Introduce self-face to face.	- Introduce self. - Explain the objective, the benefit and the procedure of the program - Make contract with the patient about time allocation of the program.	- Listen to the researcher. - Ask questions if patient does not understand. - Negotiate if patient does not agree with some parts.
Representation assessment	The researcher is able: a. To clearly understand patient's representation related to ESRD along the five dimensions of cognitive illness representation b. To identify any misconception, gaps and/or confusions of patient's representation along the five dimensions of cognitive illness representation.	Ask open ended questions face to face.	- Ask about patient's illness representation along the five dimensions: a. Identity b. Cause c. Timeline d. Consequences e. Cure or controllability	- Patient describes his or her thoughts and experiences with ESRD by answering the questions from researcher along the five dimensions of cognitive illness representation.

Process Components	Objectives	Method	Actions	
			Researcher	Patient
Identifying and exploring the gaps, misconceptions and confusions	The researcher is able: - To understand how any misconception, gaps and confusion were developed. - To recognize the strength or importance of those ideas in patient's life.	Discussion face to face.	- Ask questions in order to encourage patient to think and describe patient's experience leading the patient to misconception, confusion, or error: • Can you think about how you came to be concerned about "A" (the key of misconception, gaps or confusion)? ▪ Example for misconception: My illness comes from God ▪ Example for gaps: There is nothing that can be used to reduce these symptoms of ESRD. HD cannot reduce my symptoms. ▪ Example for confusion: My symptoms have been relieved after HD. So that, I did not continue HD until the symptoms occurred again. • Do you have any personal experience with "A"? • Can you tell me how "A" developed? - Ask questions to encourage patient to describe and evaluate the strength of those thoughts	- Patient explains his or her experience leading to any representation that are misconceptions, gaps or confusion and thoughts regarding misconceptions, gaps or confusion. - Patient evaluates the strength or importance of those representation in his or her life.

Process Components	Objectives	Method	Actions	
			Researcher	Patient
Creating conditions for conceptual change	Patient is able: a. To recognize the limitation of his or her current representation (misconception, gaps and/ or confusions). b. To be dissatisfied with the current representation.	Discussion face to face.	- Encourage patient to think and explain negative effects of patient's current representation that are misconception, gaps and confusions by asking questions as follows: • What are the negative effects of your current representation that you experience? • What will happen if you still maintain your current representation in the future? - Ask for the direct link between the current representation, treatment adherence and any consequences that the patient has identified. - If the patient cannot explain the direct link, the researcher will explain it.	- Explain the negative effect of current representation. - Answer what the consequences that might happen if the patient still maintains his or her current representation. - Explain the link between current representation, taking medication and any consequences that patient has identified.
Introducing replacement information	The researcher is able to replace the current representation, which are	Teaching face to face	- Give information related to patient's needs along the five	- Listen - Pay attention - Provide comment

Process Components	Objectives	Method	Actions	
			Researcher	Patient
	misconception, gaps and/or confusion by giving information that is intelligible, plausible and fruitful. Patient is able to accommodate the representation to fill gaps in knowledge, clarify confusions and replace misconception.		dimensions of cognitive illness representation.	- Ask further explanation if the patient was not clear about the information given by researcher.
Summarizing	Patient is able to understand the benefit of new conception or representation if he or she used it to solve his or her problem in the future.	Discussion face to face.	- Explaining the benefit of treatment adherence - Explain how to manage side effects of HD if it occurs - Ask the patient if he or she understands about his or her illness and wants to enhance treatment adherence	- Describe the benefit of treatment adherence - Describe how to manage side effects of HD - Give statement to motivate him or her to enhance treatment adherence
Goal setting and planning	Patient is able: a. To develop related goals to enhance treatment adherence	Discussion face to face.	a. The goal - Encourage patient to think and set his or her goal in order to improve treatment adherence by asking the question:	a. The goal - Set the goal with researcher in order to enhance treatment adherence and write it in

Process Components	Objectives	Method	Actions	
			Researcher	**Patient**
	b. To develop strategies for achieving those goals		• What is your goal related to your treatment? - Set the goal together with patient and write the goal setting and strategies plan form b. The strategies - Encourage patient to think about the strategies in order to achieve patient's goal by asking the question: • What kind of strategies will you use to achieve your goal (to enhance treatment adherence)? - Develop strategies with the patient to achieve his or her goal. - Write the strategies and list them to help the patient implement the strategies easily by using the goal setting and strategies plan form.	the goal setting and strategies plan form. b. The strategies - Think what kind of strategies will be useful in order to achieve his or her goal. - Develop the strategies with researcher to achieve his or her goal and write it in the goal setting and strategies plan form. - Understand about the strategies
Follow-up of the goal and the strategies	Patient is able: a. To evaluate whether the goal is achieved or not. b. To evaluate whether the strategies work or not. c. To identify the problem or barrier when	Discussion face to face.	- Assist patient to reflect on his or her behavior regarding treatment adherence during one week through the goal setting and strategies plan form. - Ask these questions: a. The goals	- Answering the questions: a. The goal - Reflect on the goal's progress using the goal setting. - Answer the questions from the researcher.

Process Components	Objectives	Method	Actions	
			Researcher	**Patient**
	implementing the strategies. d. To maintain or develop strategies for continuing treatment adherence.		- Did you apply the strategies that we developed together the previous time? - Can you achieve your goal using these strategies? If not, what makes you think that? What are the barriers, such as the strategies that do not fit with patient's home, the strategies that are difficult to apply, etc.? - Give reinforcement for patients' achievement b. The strategies - Were you able to implement the strategies? - Give reinforcement for patient's action in implementation of the strategies. - Did the strategies work in achieving your goal (to enhance treatment adherence)? If not, what makes you think that? What are the barriers? - What are problems that you experienced since you used the strategies?	b. The strategies - Reflect on the behavior using the goal setting. - Answer the questions t provided by researcher about the strategies. c. The strategies for continuing treatment adherence - Set up or modify the strategies with the researcher.

Process Components	Objectives	Method	Actions	
			Researcher	**Patient**
			- What did you do to face the problems? Did it work? c. The strategies for continuing treatment adherence - Is it important for you to continue treatment as prescribed? - Give recommendation for the future - Can you use the same past strategies to enhance your treatment adherence? - Do you need to modify the strategies to enhance treatment adherence? If yes, which strategies need to be modified? Please describe them.	
Termination	In follow-up of the goal and planning, patient is able: a. To evaluate whether the goal has been achieved or not. b. To evaluate whether the strategies work or not. c. To identify the problem or barrier when	Discussion face to face.	- Assist patient to reflect on his or her behavior regarding treatment adherence over one week by using the goal setting form. - Ask these questions: a. The goals • Did you apply the strategies that we developed together? • Can you achieve your goal using these strategies? If not, what makes you think that?	- Answer the questions: a. The goal • Reflect on the goal's progress using the goal setting. • Answer the questions from the researcher. b. The strategies

Process Components	Objectives	Method	Actions	
			Researcher	**Patient**
	implementing the strategies. d. To maintain or develop strategies for continuing treatment adherence. In follow-up of the program, patient is able: a. To evaluate the program. b. To terminate with the researcher.		What are the barriers, such the strategies that do not fit with patient's home, the strategies are difficult to apply, etc.? • Give reinforcement for patient's achievement b. The strategies • Were you able to implement the strategies? • Give reinforcement for patient's action in implementation of the strategies. • Did the strategies work in achieving your goal (to enhance treatment adherence)? If not, what makes you think that? What are the barriers? • What are problems that you experienced since you used the strategies? • What did you do to face the problems? Did it work? c. The strategies for continuing treatment adherence • Is it important to you to continue treatment as prescribed?	• Reflect on the behavior using the goal setting. • Answer the questions that were provided by the researcher about the strategies. c. The strategies for continuing treatment adherence d. Set up or modify the strategies with the researcher.

Process Components	Objectives	Method	Actions	
			Researcher	**Patient**
			• Give recommendations for the future • Can you use the same past strategies to enhance your treatment adherence? • Do you need to modify the strategies to enhance treatment adherence? If yes, which strategies need to be modified? Please describe them.	
		Evaluating the program and informing of terminating with the researcher	- Ask the following questions about the program: a. How do you feel after finishing this program? b. What do you think about this program? - Inform the patient that the researcher will terminate the program.	- Answer the questions - Accept the information and the termination with the researcher.

APPENDIX C

The Demographic Data Questionnaire (DDQ)

This questionnaire consists of two main sections. Please answer all the questions in each section.

Section A: Demographic data

1. Age: _____

2. Gender:

□ Male

□ Female

3. Marital status:

□ Single

□ Married

□ Divorced / Separated

□ Widowed

4. Education:

□ No formal education

□ Primary school

□ Secondary school

□ Tertiary education or above

5. Employment status:

□ Full time Job title: _____

□ Part time Job title: _____

□ Retired

□ Unemployed

□ Housewife

6. Monthly family income:

□ < RM1500

□ RM1501 – RM2500

□ RM2501 – RM3500

□ RM3501 – RM4500

□ ≥ RM4501

7. No. of family members living together (excluding patient): _____

8. Daily diet prepared by:

□ Patient

□ Family members. Please specify: _____

□ Maid

□ Other Please specify: _____

Section B: Clinical data

1. Month(s) diagnosed with renal disease: _____.

2. Length of receiving hemodialysis: _____ year(s) _____ month(s).

3. Other renal replacement therapy received:

□ No

□ Peritoneal Dialysis

□ Renal Transplant

6. Co-morbidities:

□ No

□ Diabetes mellitus

□ Hypertension

□ Heart disease

□ Other. Please specify:_____

□ Hyperparathyroidism

APPENDIX D
The Open-Ended Questionnaire (OEQ)

Please answer all of the questions:

(a) What is the sign or symptom that you have and think that it is related to your illness? (Identity)

……..……

(b) How long do you think your illness will last? (Timeline)

……..……

(c) How severe do you think about your illness? Why? (Identity)

……..……

(d) What are the consequences of your illness? (Consequences)

……..……

(e) What is/are the cause(s) of your illness? (Causal)

……..……

(f) Do you think that you have the control over your illness? (Control)

……..……

(g) What do you think about your hemodialysis? (Identity)

……..……

(h) Do you think that the hemodialysis can help with your condition? (Control)

……..……

APPENDIX E

The Modified Brief Illness Perception Questionnaire (BIPQ)

For the following questions, please circle the number that best corresponds to your view:

1. How much does your illness affect your life?

0	1	2	3	4	5	6	7	8	9	10
no affect at all										severely affects my life

2. How long do you think your illness will continue?

0	1	2	3	4	5	6	7	8	9	10
a very short time										forever

3. How much control do you feel you have over your illness?

0	1	2	3	4	5	6	7	8	9	10
absolutely no control										extreme amount of control

4. How much do you think your treatment can help your illness?

0	1	2	3	4	5	6	7	8	9	10
not at all										extremely helpful

5. How much do you experience symptoms from your illness?

0	1	2	3	4	5	6	7	8	9	10
no symptoms at all										many severe symptoms

6. Please list in rank order the three most important factors that you believe caused your illness.

   i. …….
   ii. …….
   iii. …….

APPENDIX F

The Treatment Adherence Questionnaire (TAQ)

This survey asks for your opinion about how well you follow your dialysis treatment schedule and about medical recommendations related to medication, diet, and fluid intake. This information will help us to understand if you have difficulty following your dialysis treatment, medication regimen, fluid restriction, and recommended diet. This questionnaire consists of four main sections. Please answer every question by marking the appropriate box.

No	Statement	Never	Sometimes	Most of the times	All of the times
Section A: Adherence to Hemodialysis					
1	I attended my dialysis treatment regularly.				
2	I have shortened my dialysis time.				
Section B: Adherence to Medication					
3	I missed the prescribed medications.				
4	I took my medications even though I have problem due to side effect of the medications.				
5	I took my prescribed medications even though I do not have any symptoms.				
6	I stopped taking medication.				
Section C: Adherence to Fluid Restriction					
7	I followed the fluid restriction recommendation.				
8	I took water as much as I want.				
9	I managed my thirst, for example by staying in cool place, sipping my beverage, or using the ice cube.				
10	I took food with hidden fluids, for example soup or ice creams.				
Section D: Adherence to Diet Restriction					
11	I followed the diet recommendation.				
12	I took high protein foods, for example 2 matchbox size of meats, fish, or 1 drumstick of chicken every day.				
13	I avoid foods containing salt.				
14	I took high phosphate foods, for example beans, dried vegetables or fruits, or chocolate.				
15	I took high potassium foods, for example bananas, papayas or oranges.				

APPENDIX G

Effect Size Calculation

$$ES = \frac{M2 - M1}{Pooled\ SD}$$

$$Pooled\ SD = \sqrt{\frac{(SD1)^2 + (SD2)^2}{2}}$$

Note:

ES	= Effect size
M1	= Mean of treatment adherence post test score of the control group
M2	= Mean of treatment adherence post test score of the experimental group
Pooled SD	= Pooled standard deviation
SD1	= Standard deviation of treatment adherence post test score in the control group
SD2	= Standard deviation of treatment adherence post test score in the experimental group

$$Pooled\ SD = \sqrt{\frac{(SD1)^2 + (SD2)^2}{2}} = \sqrt{\frac{(183)^2 + (108)^2}{2}} = 150$$

$$ES = \frac{M2 - M1}{Pooled\ SD} = \frac{989.1 - 904.5}{150} = 0.56$$

APPENDIX H

List of Experts

Three experts who validated the content of the instruments including the illness representation promoting program, the DDQ, the OEQ, the Modified BIPQ, and the TAQ were:

1. Asst. Prof. Dr. Tippamas Chinnawong
   Faculty of Nursing, Prince of Songkla University, Thailand

2. Asst. Prof. Dr. Phongsak Dandecha, M.D.
   Department of Nephrology, Faculty of Medicine, Prince of Songkla University, Thailand

3. Asst. Prof. Dr. Che Rosle Deraman, M.D.
   Department of Internal Medicine, Kulliyyah of Medicine, International Islamic University Malaysia, Malaysia

APPENDIX I

Testing Assumptions

1. Normal Distribution

The assumption of normality was examined using skewness divided by its standard error values. Testing assumption showed that the data set of treatment adherence in the experimental group were not normally distributed, determined by the values were not in the range of ± 3.

		Statistic (a)	Standard Error (b)	Z value= a / b
Before intervention				
Experimental Group	Skewness	-1.36	0.35	-3.8
Control Group	Skewness	0.21	0.35	0.60
2 weeks after intervention				
Experimental Group	Skewness	-1.92	0.35	-5.42
Control Group	Skewness	-0.17	0.35	-0.49
4 weeks after intervention				
Experimental Group	Skewness	-1.17	0.35	-3.30
Control Group	Skewness	-0.17	0.35	-0.49

2. Homogeneity of Variance

The homogeneity of variance was examined using Levene's test. The variables not met the assumption, determined by the significance score of Levene's test ($p > .05$).

	Levene's Test for Equality of Variances	
	F	*p*
Before Intervention	.88	.35
2 weeks after intervention	.16	.70
4 weeks after intervention	.22	.64

APPENDIX J

Wilcoxon Signed-Rank Tests

1. Treatment adherence total score

Ranks

		N	Mean Rank	Sum of Ranks
total score taq post 2 weeks - total score pre taq	Negative Ranks	0[a]	.00	.00
	Positive Ranks	37[b]	19.00	703.00
	Ties	8[c]		
	Total	45		
total score taq post 4 weeks - total score pre taq	Negative Ranks	0[d]	.00	.00
	Positive Ranks	45[e]	23.00	1035.00
	Ties	0[f]		
	Total	45		
total score taq post 4 weeks - total score taq post 2 weeks	Negative Ranks	0[g]	.00	.00
	Positive Ranks	39[h]	20.00	780.00
	Ties	6[i]		
	Total	45		

a. total score taq post 2 weeks < total score pre taq

b. total score taq post 2 weeks > total score pre taq

c. total score taq post 2 weeks = total score pre taq

d. total score taq post 4 weeks < total score pre taq

e. total score taq post 4 weeks > total score pre taq

f. total score taq post 4 weeks = total score pre taq

g. total score taq post 4 weeks < total score taq post 2 weeks

h. total score taq post 4 weeks > total score taq post 2 weeks

i. total score taq post 4 weeks = total score taq post 2 weeks

Test Statistics[a]

	total score taq post 2 weeks - total score pre taq	total score taq post 4 weeks - total score pre taq	total score taq post 4 weeks - total score taq post 2 weeks
Z	-5.335[b]	-5.861[b]	-5.482[b]
Asymp. Sig. (2-tailed)	.000	.000	.000

a. Wilcoxon Signed Ranks Test

b. Based on negative ranks.

2. Adherence to HD

Ranks

		N	Mean Rank	Sum of Ranks
total taq hd post 2 weeks - total pre taq hd	Negative Ranks	0[a]	.00	.00
	Positive Ranks	12[b]	6.50	78.00
	Ties	33[c]		
	Total	45		
total taq hd post 4 weeks - total pre taq hd	Negative Ranks	0[d]	.00	.00
	Positive Ranks	17[e]	9.00	153.00
	Ties	28[f]		
	Total	45		
total taq hd post 4 weeks - total taq hd post 2 weeks	Negative Ranks	0[g]	.00	.00
	Positive Ranks	6[h]	3.50	21.00
	Ties	39[i]		
	Total	45		

a. total taq hd post 2 weeks < total pre taq hd

b. total taq hd post 2 weeks > total pre taq hd

c. total taq hd post 2 weeks = total pre taq hd

d. total taq hd post 4 weeks < total pre taq hd

e. total taq hd post 4 weeks > total pre taq hd

f. total taq hd post 4 weeks = total pre taq hd

g. total taq hd post 4 weeks < total taq hd post 2 weeks

h. total taq hd post 4 weeks > total taq hd post 2 weeks

i. total taq hd post 4 weeks = total taq hd post 2 weeks

Test Statistics[a]

	total taq hd post 2 weeks - total pre taq hd	total taq hd post 4 weeks - total pre taq hd	total taq hd post 4 weeks - total taq hd post 2 weeks
Z	-3.357[b]	-3.945[b]	-2.449[b]
Asymp. Sig. (2-tailed)	.001	.000	.014

a. Wilcoxon Signed Ranks Test

b. Based on negative ranks.

3. Adherence to medications

Ranks

		N	Mean Rank	Sum of Ranks
total taq med post 2 weeks - total pre taq med	Negative Ranks	1[a]	5.50	5.50
	Positive Ranks	15[b]	8.70	130.50
	Ties	29[c]		
	Total	45		
total taq med post 4 weeks - total pre taq med	Negative Ranks	0[d]	.00	.00
	Positive Ranks	22[e]	11.50	253.00
	Ties	23[f]		
	Total	45		
total taq med post 4 weeks - total taq med post 2 weeks	Negative Ranks	0[g]	.00	.00
	Positive Ranks	10[h]	5.50	55.00
	Ties	35[i]		
	Total	45		

a. total taq med post 2 weeks < total pre taq med

b. total taq med post 2 weeks > total pre taq med

c. total taq med post 2 weeks = total pre taq med

d. total taq med post 4 weeks < total pre taq med

e. total taq med post 4 weeks > total pre taq med

f. total taq med post 4 weeks = total pre taq med

g. total taq med post 4 weeks < total taq med post 2 weeks

h. total taq med post 4 weeks > total taq med post 2 weeks

i. total taq med post 4 weeks = total taq med post 2 weeks

Test Statistics[a]

	total taq med post 2 weeks - total pre taq med	total taq med post 4 weeks - total pre taq med	total taq med post 4 weeks - total taq med post 2 weeks
Z	-3.328[b]	-4.239[b]	-2.970[b]
Asymp. Sig. (2-tailed)	.001	.000	.003

a. Wilcoxon Signed Ranks Test

b. Based on negative ranks.

4. Adherence to fluid restriction

Ranks

		N	Mean Rank	Sum of Ranks
total taq fluid post 2 weeks - total pre taq fluid	Negative Ranks	0[a]	.00	.00
	Positive Ranks	20[b]	10.50	210.00
	Ties	25[c]		
	Total	45		
total taq fluid post 4 weeks - total pre taq fluid	Negative Ranks	0[d]	.00	.00
	Positive Ranks	22[e]	11.50	253.00
	Ties	23[f]		
	Total	45		
total taq fluid post 4 weeks - total taq fluid post 2 weeks	Negative Ranks	0[g]	.00	.00
	Positive Ranks	6[h]	3.50	21.00
	Ties	39[i]		
	Total	45		

a. total taq fluid post 2 weeks < total pre taq fluid

b. total taq fluid post 2 weeks > total pre taq fluid

c. total taq fluid post 2 weeks = total pre taq fluid

d. total taq fluid post 4 weeks < total pre taq fluid

e. total taq fluid post 4 weeks > total pre taq fluid

f. total taq fluid post 4 weeks = total pre taq fluid

g. total taq fluid post 4 weeks < total taq fluid post 2 weeks

h. total taq fluid post 4 weeks > total taq fluid post 2 weeks

i. total taq fluid post 4 weeks = total taq fluid post 2 weeks

Test Statistics[a]

	total taq fluid post 2 weeks - total pre taq fluid	total taq fluid post 4 weeks - total pre taq fluid	total taq fluid post 4 weeks - total taq fluid post 2 weeks
Z	-4.008[b]	-4.177[b]	-2.333[b]
Asymp. Sig. (2-tailed)	.000	.000	.020

a. Wilcoxon Signed Ranks Test

b. Based on negative ranks.

5. Adherence to dietary restriction

Ranks

		N	Mean Rank	Sum of Ranks
total taq diet post 2 weeks - total pre taq diet	Negative Ranks	0[a]	.00	.00
	Positive Ranks	24[b]	12.50	300.00
	Ties	21[c]		
	Total	45		
total taq diet post 4 weeks - total pre taq diet	Negative Ranks	0[d]	.00	.00
	Positive Ranks	42[e]	21.50	903.00
	Ties	3[f]		
	Total	45		
total taq diet post 4 weeks - total taq diet post 2 weeks	Negative Ranks	0[g]	.00	.00
	Positive Ranks	33[h]	17.00	561.00
	Ties	12[i]		
	Total	45		

a. total taq diet post 2 weeks < total pre taq diet

b. total taq diet post 2 weeks > total pre taq diet

c. total taq diet post 2 weeks = total pre taq diet

d. total taq diet post 4 weeks < total pre taq diet

e. total taq diet post 4 weeks > total pre taq diet

f. total taq diet post 4 weeks = total pre taq diet

g. total taq diet post 4 weeks < total taq diet post 2 weeks

h. total taq diet post 4 weeks > total taq diet post 2 weeks

i. total taq diet post 4 weeks = total taq diet post 2 weeks

Test Statistics[a]

	total taq diet post 2 weeks - total pre taq diet	total taq diet post 4 weeks - total pre taq diet	total taq diet post 4 weeks - total taq diet post 2 weeks
Z	-4.336[b]	-5.682[b]	-5.157[b]
Asymp. Sig. (2-tailed)	.000	.000	.000

a. Wilcoxon Signed Ranks Test

b. Based on negative ranks.

VITAE

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